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Title:

Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records:

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Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

ABSTRACT

Objective To accomplish a comparative study of the perceptions of electronic personal health records (PHRs) between consumers who reported having a chronic illness or disability and those who reported being well.

Materials and methods A national survey was conducted with an Internet panel recruited across Canada. Data were collected from 800 individuals 18 years or older. Half reported having a chronic illness or disability and half reported being well. Analyses were done with Structural Equation Modeling techniques.

Results A total of 389 valid answers from chronically ill and 383 from well participants were collected. We found Perceived Usefulness to be the key explanation of the intention to use PHRs for both ill and well people (total effect of .601 and .565, respectively) followed by Security, Privacy, and Trust in PHRs (total effect of .377 and .479, respectively). Conversely, Computer Anxiety was perceived as a significant barrier (total effect of -.327 for ill individuals and -.212 for well individuals).

Discussion Key motivators and barriers for user adoption of electronic PHRs that were identified are broadly in concordance with previous knowledge in behavioral research. We found little difference in perceptions of electronic PHRs between chronically ill and well individuals, although self-reporting their health status might have influenced the results.

Conclusions To increase the adoption rate of electronic PHRs among both chronically ill and well consumers it is necessary to reinforce people perceptions on the usefulness of and trust in these eHealth technologies while mitigating consumer anxieties about computer use in general.

Strengths and limitations of this study

- This research compared empirically the perceptions of chronically ill and well consumers about electronic PHRs using a rigorous theoretical approach.
- The health condition of study participants was self-reported and not diagnosed by practitioners.

OBJECTIVE

Given the current shortage of medical resources available for managing the growing numbers of patients with chronic illnesses, it is becoming apparent that patient self-management is key to managing such illnesses.[1] If health self-management is to function successfully, care plans and goals must be developed jointly by patients and their physicians, to move towards improved health and quality of life.[2] But to manage this process effectively, as in every management system, it is important to keep up-to-date records that can assist the patient and the patient's healthcare provider to monitor the patient's progress towards meeting the established self-care goals. It is also important to make these records readily accessible to both patients and their providers, in order that integration of care and sharing of information can occur both within and across services.[1, 3] An online health self-management system that is grounded in the chronic care model[4] and utilizes the patient's health record as a repository can support a system with self-management functionalities for assisting in improved patient-centerd care.[5-8]

When health records are maintained and accessible by individual patients, these records are referred to as Personal Health Records (PHRs). Although they can be recorded and maintained in paper form, a fast emerging trend with the advent of digital data and the Internet is to keep them in an electronic format. Therefore, we will assume throughout this paper that PHRs refer to electronic records on digital media. A PHR can be defined as "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment".[9] This is in contrast with EHR/EMRs (Electronic Health Records/Electronic Medical Records) which contain patient data gathered during the course of patient visits to healthcare providers, and are managed solely by healthcare providers or healthcare institutions. Also, most EHR/EMR data are based on acute care episodes[10] since people are more likely to see their doctors when they have an acute problem.

An ideal form of a PHR is one that exchanges data freely, as authorized by the patient and physician, between the physician's EHR/EMR and the patient's records, as needed.[11] Types of data that may be available in this way to a PHR include, but are not limited to: patient problem lists, procedures, major illnesses, provider list, allergies, home monitored data (e.g., blood pressure, glucose level, weight, exercise schedule, etc.), family history, lifestyle, immunizations, medications, and lab tests.[10]

In theory, PHRs can be of great use to patients in the self-management of chronic diseases and disabilities, but there are significant obstacles to their sustainability, which refers to their adoption and continued use. Trials of eHealth implementations tend to be prone to participant dropouts, or attrition.[12] Reported attrition rates from the use of PHRs for health self-management vary widely, from as low as 3% for an interactive web-based intervention that included telephone counseling to 65% in a smoking cessation program, and to an enormous rate of 99% in a panic disorder self-help program.[13, 14] Although factors affecting attrition tend to be complex,[15] they must be addressed effectively if the benefits of self-management interventions are to be maximized.

The goal of better health may not be sufficient to motivate people to use PHRs, although there are techniques to predict in advance whether patients will adopt and continue with beneficial healthcare behaviors.[16] If patient motivation to adopt PHR innovations were better understood, resulting reductions in attrition rates would lead to improved outcomes from health self-management interventions.

Accordingly, the objective of this study is to help determine the motivation of individuals to adopt PHRs, for the purpose of self-management of chronic ailments and disabilities. There are indications that people with serious chronic ailments and disabilities are more likely to be favorable to the adoption of PHRs than people who are well.[9] Therefore, in our study we compare these two groups of people empirically to determine the factors by which chronically ill or disabled people are more motivated to adopt PHRs than well individuals. Finally, we discuss the results and their significance to further sustainable development and implementation of PHRs, and consumer motivation to adopt and use them.

BACKGROUND AND SIGNIFICANCE

Personal Health Records background

Studies done in various parts of the world have indicated a great deal of public interest in PHRs. For instance, a major motivation for over 70% of U.S. consumers is that they believe having access to PHRs would improve the quality of their healthcare,[17] although as yet there is no convincing evidence that this is the case. Field studies report the greatest interest in PHRs is manifested by the chronically ill, frequent users of healthcare, and caregivers for elderly parents.[9,18] The same studies show that among American consumers saying they were not interested in using PHRs more than 55% indicated that worries about privacy and confidentiality affected their reluctance. Moreover, about 90% of consumers surveyed felt that the provision of privacy, record access, and user remedies would be significant factors affecting their agreement to use an online PHR service.[17] Conversely, some barriers to maintaining and accessing PHRs include cost and loss of interest over time.[19]

Through online and decision support for patient-centerd care, changes in healthcare practice can often help to meet practice and patient goals. For example, research has demonstrated improvements in diabetes outcomes and chronic illness self-management when behavioral support is forthcoming from relevant technologies, improving dietary practices, physical activity, and adherence to medication regimens.[20] Other studies indicate that social activities are particularly important for older people, with health benefits that may include less chance of mortality, disability, and depression, and better cognitive and health-related behaviors.[21] Empirical studies have shown that relative advantage, ease of use, trialability, perceptions of privacy and security, age, and computer experience were positive predictors of the value of PHRs for supporting communications with the doctor’s office.[22] Therefore, it is important to understand the key motivators and deterrents for PHR adoption with the target of improving the adoption rate and sustainability of these systems.

Theoretical model and hypotheses

In the following, we develop a theoretical model that takes into account the above considerations for chronically ill and disabled consumers on the one hand with consumers who feel that they are relatively healthy on the other hand, in order to compare their perceptions of PHRs. For that we use a number of key constructs validated by previous research in information systems and healthcare, and propose hypotheses regarding their relationships, based on empirical findings and theoretical reasoning.

Information Seeking. Although patients may prefer not to make all their own decisions about their healthcare, they do want to be kept informed. Reportedly, over 40 percent of patients with chronic conditions prefer to receive more information from their healthcare providers than they actually received.[23] It seems, therefore, that patients with higher information seeking preferences are more likely to feel that PHRs are useful in accessing information on their health status than those who do not. Therefore, we propose the following hypothesis:

H1: Consumers with higher information-seeking preferences will tend to believe that PHRs would be more useful.

Personal Information Technology Innovativeness. This construct captures the willingness of an individual to try out an information technology, as it relates to the concept of technology acceptance.[24] This indicates that people exhibiting high levels of information technology innovativeness will be more interested in accepting PHRs than those who do not. This leads to the hypothesis:

H2: Individuals with higher levels of IT innovativeness will exhibit higher levels of perceived usefulness for PHRs.

Computer Anxiety. This construct expresses an individual's apprehension or fear when faced with the possibility of using a computer.[25] Previous research has found a negative relationship between computer anxiety and perceived usefulness of new technology, as well as to intention to use a new technology.[26, 27] This results in the following propositions:

H3: Level of computer anxiety will be negatively related to the perceived usefulness of PHRs.

H4: Level of computer anxiety will be negatively related to the intention to use PHRs.

Privacy, Security, and Trust. These concepts have been consistently found in large scale studies to have an impact on consumer interest in online PHR adoption.[28] While some surveys showed two-thirds of adult consumers were concerned about security and privacy of their health data,[17] other market studies found that consumers actually using a PHR did not worry too much about its privacy implications.[29] The chronically and acutely ill and others who often require healthcare appear to have fewer concerns about privacy than do health professionals.[30, 31] Consequently, we propose the following hypotheses:

H5: Consumer perceptions of security, privacy, and trust in PHR providers will positively affect their perceptions of PHR usefulness.

H6: Consumer perceptions of security, privacy, and trust in PHR providers will positively affect their intention to adopt PHRs.

Perceived Usefulness. This construct is a widely known and strong extrinsic motivator of technology use. It expresses “the degree to which a person believes that using a particular system would enhance his or her job performance”.[32] In the case of PHR use, job performance (expectancy) would refer to being able to self-monitor accurately certain health parameters. Thus, it is logical to formulate the hypothesis below:

H7: Higher perceived usefulness for PHRs leads to a higher level of intention to adopt this technology.

The proposed constructs and their related hypotheses are shown in Figure 1 in the form of a theoretical model of PHR adoption. The final endogenous construct of this model is Behavioral Intention to adopt PHRs that measures potential user intentions regarding this eHealth support tool.

*** Insert Figure 1 here. ***

Figure 1 Theoretical Model of PHR Adoption

MATERIALS AND METHODS

Participant recruitment and data collection

The theoretical model proposed by this study was tested with empirical data collected through an online survey of Canadian consumers. Both French and English versions were prepared and pre-tested with graduate students and practitioners in a Canadian university. The full scale survey was approved by the Research Ethics Board of the university and subsequently conducted with a Canadian Internet panel of consumers through a market research company.

Participants were required to be at least 18 years old and willing to report their health condition. 800 of the participants who had pre-registered with the market research company participated in the experiment: the sample was stratified to select exactly 400 who reported a chronic illness or disability at various levels of severity, and exactly 400 who did not report such a condition. These two strata will be indicated in the remainder of this study as ‘Ill’ and ‘Well’.

All participants were presented a detailed description of an electronic Patient Health Record system and then asked to answer an online questionnaire. This comprised questions meant to measure the latent variables in the theoretical model described in Figure 1, together with relevant demographic characteristics of the participants surveyed. Most of the survey questions were adapted from those validated by previous research in healthcare[33] and information systems.[24, 27, 32] Measures for the only formative construct in the model, Security, Privacy and Trust, although initially sourced from relevant information systems literature, were designed and validated by this research. All responses were collected on 7-point Likert scales ranging from Strongly Disagree (1) to Strongly Agree (7), with an additional Not Applicable option.

Theoretical model evaluation

As this research was intended mainly for exploratory purposes, data analysis was done with Partial Least Squares (PLS) due to the suitability of this Structural Equation Modeling methodology for complex exploratory models,[34] using formative indicators[35] such as the Security, Privacy and Trust construct used in this research. PLS analysis was carried out with the SmartPLS software tool[36] and included two successive model assessments: measurement tests followed by structural tests.[37] Each analysis for the two samples (Ill and Well) was done separately using the same model.

Assessment of differences between ill and well individuals

Results of theoretical model tests for the two sub-samples were compared through differences in terms of the values of the path coefficients.[38] The degree of difference was assessed with the *t*-statistic with $N1+N2-2$ degrees of freedom,[39-41] where:

$$t = (Path1 - Path2)/[Spooled*sqrt(1/N1+1/N2)]$$

Here, *Path1*, *Path2* are the corresponding path coefficients in the model results and *N1*, *N2* are the respective sub-sample sizes.

Spooled represents the pooled estimator for the variance and is calculated from:

$$Spooled = sqrt\{[square\ of\ (N1-1)/(N1+N2-2)]*square\ of\ SE1 + [square\ of\ (N2-1)/(N1+N2-2)]*square\ of\ SE2\}$$

Here *SE1*, *SE2* are the standard errors of the corresponding path coefficients in the two sub-sample model results.

RESULTS

Characteristics of study participants

After removing the cases with more than 10% missing answers, 389 Ill cases and 383 Well cases remained and were used in further statistical analyses. Raw data analyzed in this study were part of a larger project conducted in this setting. Table 1 shows comparative demographic characteristics, summarized for the two strata.

Table 1 Participant characteristics

		Ill Participants	**Well Participants**
Sample size		389	383
Age (years, average)		52.5	46.5
Gender			
	Female	248 (63.7%)	221 (57.7%)
	Male	141 (36.3%)	162 (42.3%)
Subject maintains up-to-date PHRs on paper			
	Yes	132 (34.0%)	74 (19.2%)
	No	257 (66.0%)	309 (80.8%)
Subject maintains up-to-date electronic PHRs			
	Yes	46 (11.7%)	22 (5.8%)
	No	343 (88.3%)	361 (94.2%)
Number of visits with a doctor during past 6 months (average)		5.0	2.3
Number of doctors seen during past 6 months (average)		2.3	1.4
Number of children 12 years old or younger for whom they have main care responsibility at home (average)		0.2	0.3
Subject (or someone for whom they are responsible) has a chronic disease that requires continuing medical attention			
	Yes	308 (79.2%)	81 (21.2%)
	No	81 (20.8%)	302 (78.8%)
Subject (or someone for whom they are responsible) has a disability that requires continuing care			
	Yes	205 (52.7%)	42 (11.0%)
	No	184 (47.3%)	341 (89.0%)
Subject is caring for elderly person(s)			
	Yes	49 (12.6%)	21 (5.5%)
	No	340 (87.4%)	362 (94.5%)
Subject is interested in regularly maintaining records about health			
	Yes	323 (83.0%)	247 (64.4%)
	No	66 (17.0%)	136 (35.6%)
Average amount of time spent using the Internet at home daily (largest two categories out of five)			
	31 - 60 minutes	263 (67.7%)	222 (58.0%)
	11 - 30 minutes	99 (25.5%)	111 (29.0%)

Theoretical model evaluation

An initial evaluation of the measurement model that comprised 22 items indicated the necessity to drop 2 items when running it with the Ill data sample and 3 items when running it with the Well data sample, because of unsatisfactory significance and loading values of these items. After re-running SmartPLS for the remaining items, all reflective constructs for both samples displayed Cronbach's alpha and composite reliability values above 0.7, Average Variance Extracted (AVE) values above 0.5, and item loadings above 0.7, while the remaining items of the formative construct Security, Privacy and Trust in PHR were significant and had loadings above 0.5. Thus, the measurement model was considered to have acceptable reliability and convergent validity for both sub-samples.[38 ,42, 43]

A visual inspection of a matrix having the square root of AVEs on the diagonal and the correlations between all reflective constructs in the off diagonal cells showed diagonal numbers to be larger than all numbers on the corresponding rows and columns for both sub-samples (Table 2). This led to the conclusion that the model's reflective constructs had sufficient discriminant validity for both sub-samples.[37] Consequently, the measurement tests of the model for both sub-samples indicated adequate reliability and construct validity. This allowed the second step of the PLS process, which was to perform the structural analysis of the model.

Table 2 Reflective construct correlations and square root of AVEs (Ill sample numbers off parentheses and Well sample numbers in parentheses)

	Computer	Behavioral	Information	Perceived	Personal IT

	Anxiety	Intention	Seeking	Usefulness	Innovativeness
Computer Anxiety	**0.89 (0.91)**				
Behavioral Intention	-0.51 (-0.38)	**0.87 (0.93)**			
Information Seeking	-0.13 (-0.13)	0.27 (0.24)	**0.86 (0.88)**		
Perceived Usefulness	-0.47 (-0.31)	0.76 (0.75)	0.33 (0.34)	**0.92 (0.92)**	
Personal IT Innovativeness	-0.33 (-0.17)	0.46 (0.38)	0.07 (0.03)	0.39 (0.42)	**0.92 (0.94)**

Evaluation of the structural model involved running SmartPLS with a bootstrap of 200 re-samples. Results for path coefficients, their significance levels, and the values of R^2 are compared in Figure 2 for both sub-samples.

*** Insert Figure 2 here. ***

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

SmartPLS results also provided the total effects of the factors in the theoretical model on behavioral intention to use PHRs, for the two categories of participants (Table 3).

Table 3 Total effects and their significance levels on behavioral intention to adopt PHRs

	Ill Sample		**Well Sample**	
Antecedent Construct	**Coefficient**	***P*-value**	**Coefficient**	***P*-value**
Computer Anxiety	-.327	<.001	-.212	.01
Information Seeking	.118	.01	.141	.01
Perceived Usefulness	.601	<.001	.565	<.001
Personal IT Innovativeness	.100	.08	.162	.01
Security, Privacy, and Trust	.377	<.001	.479	<.001

All characteristics in Table 1 were tested as potential control variables. In the case of the PHR Ill sub-sample the only influence came from the factor '*subject is interested in regularly maintaining records about health*'. This factor influenced positively the Perceived Usefulness construct (path coefficient of .234 at a P =.02 significance level) and increased the variance explained by this construct from $R^2 = 0.473$ to $R^2 = 0.521$). In the case of the PHR Well sub-sample the same interest in regularly maintaining records about health influenced positively the Perceived Usefulness construct (path coefficient of .171 at a $P = .04$ significance level and increased the variance explained from $R^2 = 0.474$ to $R^2 = 0.499$). In addition for this sub-sample, the factor increased Behavioral Intention (path coefficient of .154 at a $P = .03$ significance level and increase of variance explained from $R^2 = 0.620$ to $R^2 = 0.640$). So, the results for the control variable '*subject is interested in regularly maintaining records about health*' played a significant role in both sub-samples.

Assessment of differences between ill and well individuals

The results of the differences between the path coefficients of the model for the two sub-samples are presented jointly in Table 4. No P-values were calculated since the lack of statistical significance, at a level of probability $P < .05$, of the difference between the results from the two sub-samples (indicated by the low absolute t-value of the difference) is very clear.

Table 4 Statistical analysis of differences between Ill and Well consumer sub-samples

Path	Ill Sub-sample Path Coefficient	Well Sub-sample Path Coefficient	Absolute *t*-value of Difference
Computer Anxiety → Behavioral Intention	-.177	-.142	0.348
Computer Anxiety → Perceived Usefulness	-.249	-.123	1.021
Information Seeking → Perceived Usefulness	.196	.249	0.479
Perceived Usefulness → Behavioral Intention	.601	.565	0.255
Personal IT Innovativeness → Perceived Usefulness	.167	.287	0.982
Security, Privacy, and Trust → Behavioral Intention	.140	.244	0.717
Security, Privacy, and Trust → Perceived Usefulness	.393	.416	0.161

DISCUSSION

Principal findings and comparison with prior work

The objective of this study was to determine the key motivators for individuals to adopt electronic Personal Health Records, through a theoretical behavioral model. As previous research and theoretical reasoning indicated that people with chronic illnesses may be more likely to be favorable to the adoption of PHRs than people who are well,[9] in our study we compared two sub-samples drawn in Canada from these two populations in order to assess empirically the possible behavioral differences and their determinants.

Our study (Table 3 and Figure 2) confirms the findings of an overwhelming body of research in information systems according to which Perceived Usefulness is the key explanation of the behavioral intention to use an information technology application.[44] Therefore individuals, either chronically ill or well, would use PHRs only if they see the usefulness of these artifacts.

This is concordant with findings on other empirical studies on PHRs that showed relative advantage[22] or perception of empowerment[45] as key motivators of adoption.

As expected from previous research,[17] the perception of Security, Privacy, and Trust in PHRs is a significant motivator for use in both categories of individuals surveyed. Table 3 shows this factor is second in terms of total effect to Perceived Usefulness only, being significant at $P < .001$ for both sub-samples. Interestingly, Security, Privacy, and Trust in PHRs has a non-significant direct influence on Behavioral Intention to use PHRs for the Ill sub-sample (coefficient = .140, $P = .15$). This means security, privacy and trust mean less for ill people – the association of these features with usefulness is more important in the adoption equation. This is confirmed by previous research showing that benefits of access to medical records online may outweigh privacy risk perceptions.[46]

Study results confirm that Information Seeking and Personal IT Innovativeness are motivators of PHR use for both categories of potential users while exerting their influence through Perceived Usefulness (Table 3 and Figure 2). However, the total effect of Personal IT Innovativeness over adoption intention is not significant for the Ill sub-sample, but it is for the Well sub-sample (Table 3). This suggests that technical innovativeness means less for ill people than it does for well people, indicating that ill people are less interested in adopting a PHR just because it is innovative, but for other reasons, including the value it can provide in managing their disease(s).

As hypothesized, Computer Anxiety is the only deterrent on PHR adoption in the theoretical model proposed by this study. It has a negative total influence significant at $P < .001$ for the Ill sub-sample and at $P = .01$ for the Well sub-sample (Table 3). Results in Figure 2 confirm that the influence of Anxiety is less apparent for the Well sub-sample compared to the Ill sub-sample.

Therefore ill individuals, who, presumably, might be attracted to using PHRs, would be more concerned about the skills necessary to access computer-based PHRs. Their concerns would clearly have to be addressed in order to increase PHR adoption.

All demographic characteristics measured and reported in Table 1 were tested as control variables but had no effect for either sample with the exception of participant interest in regularly maintaining records about health. This factor was positive for both sub-samples but more so for the Well one. Therefore, individual interest in self-monitoring health makes them better able to perceive PHR usefulness and to want to use these systems.

Overall, the original model proposed by this study to explain the adoption of PHRs had moderately high variance explained values for all the endogenous constructs, for both sub-samples (R^2 of 0.473/0.474 for Perceived Usefulness and 0.620/0.626 for Behavioral Intention) and 6 out of 7 significant paths in both cases (Figure 2). Therefore, from the statistical point of view, this model could be considered to be reasonably good.[47]

Assessment of differences between ill and well individuals

The key outcomes from the study are in Table 4, which shows that there were no significant differences between the Ill and Well sub-samples for any of the paths in Figure 2. On the surface, these outcomes appear to contradict what we had expected – that people with chronic illnesses or disabilities are more interested in PHR adoption than are well people. We suspect that the differences are masked by the fact that many of the people in the Ill sample were, in fact, not seriously ill. The low rate of current PHR use in the both sub-samples could be another explanation for the non-significant differences in perceptions between them. Findings from consumers, especially those with serious chronic illnesses, who had a considerable amount of experience with well-designed PHRs, might be more conclusive than the results from this comparative survey.

Limitations

As virtually any empirical research, this study has also some limitations. First, it is likely that the functionalities that accompany PHR systems would have a strong influence on their adoption. This aspect was not measured in this study. Second, the participants were all Internet users, so it excluded many, particularly older, consumers who were not. In fact more than 60% of the survey participants overall claimed to use the Internet for from 30 to 60 minutes per day. On the other hand, the proportion of Internet and portable device users falls off rapidly with age beyond 65 years,[48] especially for lower income seniors. Therefore, “those who can benefit the most from a PHR system may be the least able to use it”.[49] In addition to all these limitations, the most important for a comparative study such as this, participant health conditions were self-reported and not diagnosed by practitioners. Therefore, it is possible that the difference we found in overall perceptions between the two sub-samples was not significant because the difference in participant self-reported health condition between the two sub-samples was weak.

CONCLUSIONS

Despite the inherent limitations of an exploratory study, this research has the merit of investigating individual perceptions about electronic PHRs, using a rigorous theoretical approach that considers the perspectives of ill and well people separately. To maximize the chances of adoption for PHR support in self-management initiatives, it appears necessary to enhance the motivators, especially the perceptions of usefulness as well as that of security, privacy and trust in PHRs, while mitigating anxieties associated with computer use.

A first exposure to PHRs did not reveal significantly different perceptions of this tool between individuals who reported having a chronic illness and those who reported being well. Therefore it appears that both categories of potential users should be addressed by promoters of PHRs in much the same way in terms of motivating and demotivating factors. However, caution is advised regarding assumptions of equivalence between individuals who report being chronically ill and those who have been diagnosed accordingly. Thus, future studies should attempt to survey chronically ill patients recruited through the healthcare system, after having a specified experience with self-managing their conditions with the aid of PHRs. A comparison of their perceptions of PHRs with those of well individuals would help to improve our understanding of how the adoption of PHRs could be increased overall.

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Ethics approval Research Ethics Board of a Canadian university.

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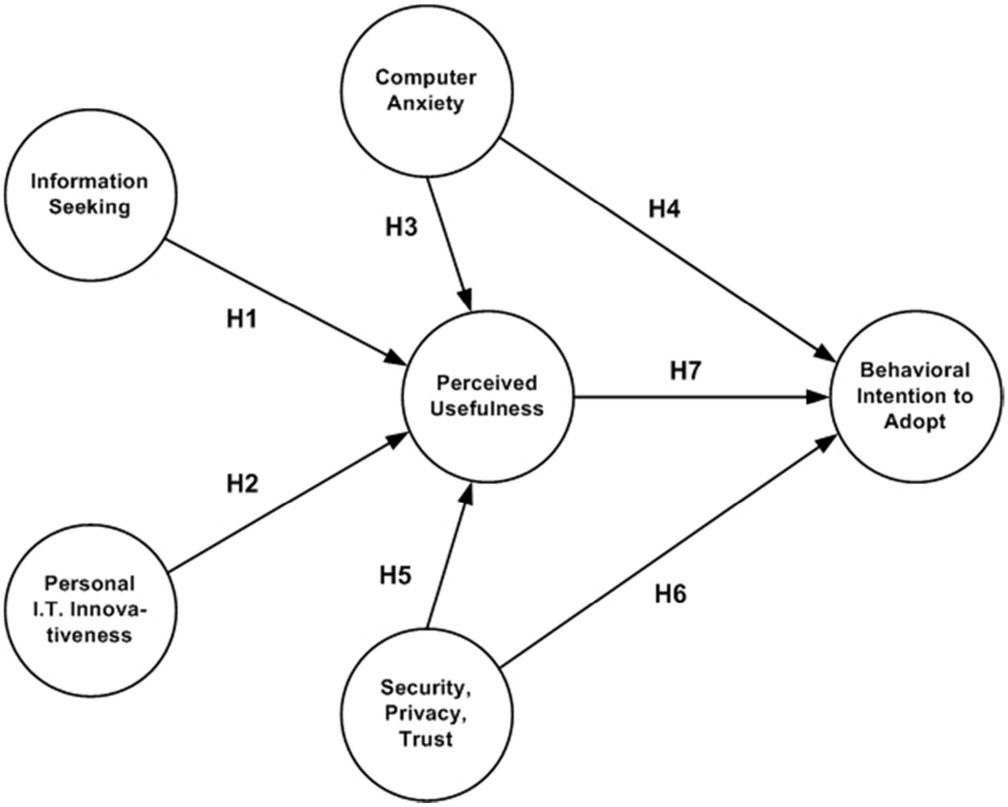

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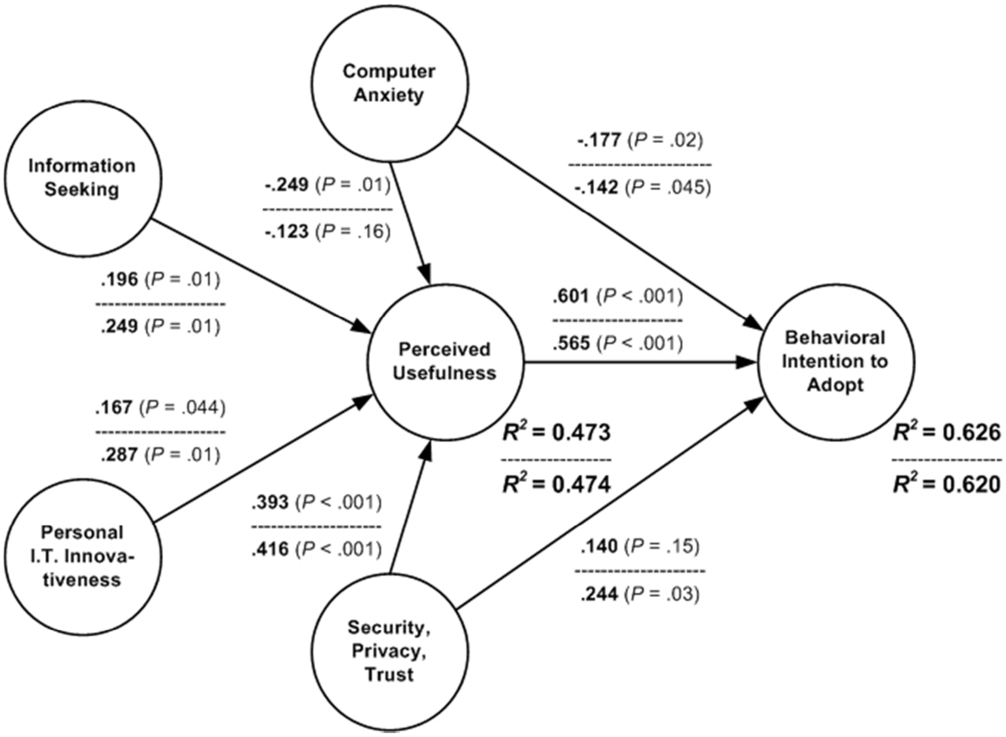

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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1, 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6-9
Methods			
Study design	4	Present key elements of study design early in the paper	9, 10
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	9, 10
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	9
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	10
Bias	9	Describe any efforts to address potential sources of bias	9
Study size	10	Explain how the study size was arrived at	9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10, 11
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10, 11
		(*b*) Describe any methods used to examine subgroups and interactions	10,11
		(*c*) Explain how missing data were addressed	11
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	12
		(b) Indicate number of participants with missing data for each variable of interest	11
Outcome data	15*	Report numbers of outcome events or summary measures	12
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	14, 15
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	15, 16
Discussion			
Key results	18	Summarise key results with reference to study objectives	16-19
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20
Generalisability	21	Discuss the generalisability (external validity) of the study results	20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records:

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Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

ABSTRACT

Objective To develop a model of consumer perceptions of electronic personal health records (PHRs) and validate it in a comparative study between consumers who report having a chronic illness and those who report being well.

Materials and methods A model of PHR use motivators and barriers was built and tested through a national survey across Canada. Data were collected from 800 individuals 18 years or older. Half reported having a chronic illness or disability and half reported being well. Analyses were done with Structural Equation Modeling techniques.

Results A total of 389 answers from chronically ill and 383 from well participants were collected. Perceived Usefulness was the key explanation of the intention to use PHRs for both ill and well people (total effect of .601 and .565, respectively) followed by Security, Privacy, and Trust in PHRs (total effect of .377 and .479, respectively). Conversely, Computer Anxiety was perceived as a significant barrier (total effect of -.327 for ill individuals and -.212 for well individuals).

Discussion The model proposed was appropriate in explaining key consumer positive and negative perceptions on electronic PHR use. We found little difference in perceptions of

electronic PHRs between chronically ill and well individuals, although self-reporting their health status might have influenced the results.

Conclusions To increase the adoption rate of electronic PHRs among both chronically ill and well consumers it is necessary to reinforce consumer perceptions of the usefulness of and trust in these eHealth technologies while mitigating their anxieties about computer use in general.

Strengths and limitations of this study

- This study developed an unbiased theoretical model of consumer perceptions of electronic personal health records (PHRs).
- The model was validated through empirical research comparing the perceptions of chronically ill and well consumers about electronic PHRs.
- The health condition of study participants was self-reported and not diagnosed by practitioners.

OBJECTIVE

Given the current shortage of medical resources available for managing the growing numbers of patients with chronic illnesses, it is becoming apparent that patient self-management is key to managing such illnesses and improving health and quality of life.[1, 2] To manage this process effectively it is important for patients to maintain up-to-date and readily accessible health records.[1, 3] An online health self-management system that is grounded in the chronic care model[4] and that utilizes the patient's health record as a repository can support a system with self-management functionalities for assisting in improved patient-centerd care.[5-8]

Health records maintained and accessible by individual consumers are referred to as Personal Health Records (PHRs). Although they can be recorded and maintained in paper form, a fast emerging trend with the advent of digital data and the Internet is to keep them in an electronic format. Therefore, we will assume throughout this paper that PHRs refer to electronic records on digital media. A PHR can be defined as "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment".[9] This is in contrast with EHR/EMRs (Electronic Health Records/Electronic Medical Records) which contain patient data gathered during the course of patient visits to healthcare providers, and are managed solely by healthcare providers or healthcare institutions. Also, most EHR/EMR data are based on acute care episodes[10] since people are more likely to see their doctors when they have an acute problem.

An ideal form of a PHR is one that exchanges data freely, as authorized by the patient and physician, between the physician's EHR/EMR and the patient's records, as needed.[11]

In theory, PHRs can be of great use to patients in the self-management of chronic diseases and disabilities, but there are significant obstacles to their sustainability, which refers to their adoption and continued use. Trials of eHealth implementations tend to be prone to participant dropouts (attrition).[12] Reported attrition rates from the use of PHRs for health self-management vary widely, from as low as 3% for an interactive web-based intervention that included telephone counseling, to 65% in a smoking cessation program, and to an enormous rate of 99% in a panic disorder self-help program.[13, 14] Although factors affecting attrition tend to be complex,[15] they must be addressed effectively if the benefits of self-management interventions are to be maximized.

The goal of better health may not be sufficient to motivate people to use PHRs, although there are techniques to predict in advance whether patients will adopt and continue with beneficial healthcare behaviors.[16] If patient motivation to adopt PHR innovations were better understood, resulting reductions in attrition rates would lead to improved outcomes from health self-management interventions.

Accordingly, the objective of this study is to determine the key motivators and barriers for individuals to adopt PHRs. As there are indications that people with serious chronic ailments and disabilities are more likely to be favorable to the adoption of PHRs than people who are well,[9] we compared these two groups of people empirically to determine possible differences between adoption factors. Finally, we discuss the results and their significance to further sustainable development and implementation of PHRs, and consumer motivation to adopt and use them.

BACKGROUND AND SIGNIFICANCE

Personal Health Records background

Studies done in various parts of the world have indicated a great deal of public interest in PHRs. For instance, a major motivation for over 70% of U.S. consumers is that they believe having access to PHRs would improve the quality of their healthcare,[17] although as yet there is no convincing evidence that this is the case. Field studies report the greatest interest in PHRs is manifested by the chronically ill, frequent users of healthcare, and caregivers for elderly parents.[9,18] The same studies show that among American consumers saying they were not interested in using PHRs more than 55% indicated that worries about privacy and confidentiality affected their reluctance. Moreover, about 90% of consumers surveyed felt that the provision of privacy, record access, and user remedies would be significant factors affecting their agreement to use an online PHR service.[17] Conversely, some barriers to maintaining and accessing PHRs include cost and loss of interest over time.[19]

Through online and decision support for patient-centerd care, changes in healthcare practice can often help to meet practice and patient goals. For example, research has demonstrated improvements in diabetes outcomes and chronic illness self-management when behavioral support is forthcoming from relevant technologies, improving dietary practices, physical activity, and adherence to medication regimens.[20] Other studies indicate that social activities are particularly important for older people, with health benefits that may include less chance of mortality, disability, and depression, and better cognitive and health-related behaviors.[21] Empirical studies have shown that relative advantage, ease of use, trialability, perceptions of privacy and security, age, and computer experience were positive predictors of the value of

PHRs for supporting communications with the doctor's office.[22] Therefore it is important to understand the key motivators and deterrents for PHR adoption, with the target of improving the adoption rate and sustainability of these systems.

Theoretical model and hypotheses

In the following, we develop a theoretical model that takes into account the above considerations and test it for chronically ill and disabled consumers on the one hand and with consumers who feel that they are relatively healthy on the other hand, in order to compare their perceptions of PHRs. For this purpose we use a number of key constructs validated by previous research in information systems and healthcare, and propose hypotheses regarding their relationships, based on empirical findings and theoretical reasoning.

Information Seeking. Although patients may prefer not to make all their own decisions about their healthcare, they do want to be kept informed. Reportedly, over 40 percent of patients with chronic conditions prefer to receive more information from their healthcare providers than they actually receive.[23] It seems, therefore, that patients with higher information seeking preferences are more likely to feel that PHRs are useful in accessing information on their health status than those who do not. Therefore, we propose the following hypothesis:

H1: Consumers with higher information-seeking preferences will tend to believe that PHRs would be more useful.

Personal Information Technology Innovativeness. This construct captures the willingness of an individual to try out an information technology, as it relates to the concept of technology

acceptance.[24] This indicates that people exhibiting high levels of information technology innovativeness will be more interested in accepting PHRs than those who do not. This leads to the hypothesis:

H2: Individuals with higher levels of IT innovativeness will exhibit higher levels of perceived usefulness for PHRs.

Computer Anxiety. This construct expresses an individual's apprehension or fear when faced with the possibility of using a computer.[25] Previous research has found a negative relationship between computer anxiety and perceived usefulness of new technology, as well as to intention to use a new technology.[26, 27] This results in the following propositions:

H3: Level of computer anxiety will be negatively related to the perceived usefulness of PHRs.

H4: Level of computer anxiety will be negatively related to the intention to use PHRs.

Privacy, Security, and Trust. These concepts have been consistently found in large scale studies to have an impact on consumer interest in online PHR adoption.[28] While some surveys showed two-thirds of adult consumers were concerned about security and privacy of their health data,[17] other market studies found that consumers actually using a PHR did not worry too much about its privacy implications.[29] The chronically and acutely ill and others who often require healthcare appear to have fewer concerns about privacy than do health professionals.[30, 31] Consequently, we propose the following hypotheses:

H5: Consumer perceptions of appropriate security and privacy of PHRs, and trust in PHR providers will positively affect their perceptions of PHR usefulness.

H6: Consumer perceptions of appropriate security and privacy of PHRs, and trust in PHR providers will positively affect their intention to adopt PHRs.

Perceived Usefulness. This construct is a widely known and strong extrinsic motivator of technology use. It expresses “the degree to which a person believes that using a particular system would enhance his or her job performance”.[32] In the case of PHR use, job performance (expectancy) would refer to being able to self-monitor accurately certain health parameters. Thus, it is logical to formulate the hypothesis below:

H7: Higher perceived usefulness for PHRs leads to a higher level of intention to adopt this technology.

The proposed constructs and their related hypotheses are shown in Figure 1 in the form of a theoretical model of PHR adoption. The final endogenous construct of this model is Behavioral Intention to adopt PHRs that measures potential user intentions regarding this eHealth support tool.

*** Insert Figure 1 here. ***

Figure 1 Theoretical model of PHR adoption

MATERIALS AND METHODS

Participant recruitment and data collection

The theoretical model proposed by this study was tested with empirical data collected through an online survey of Canadian consumers. Both French and English versions were prepared and pre-

tested with graduate students and practitioners in a Canadian university. The full scale survey was approved by the Research Ethics Board of the university and subsequently conducted with a Canadian Internet panel of consumers through a market research company. There is no relationship between the researchers and this company, and the company was not allowed to analyze nor retain any copies of the data collected during the survey.

Participants were required to be at least 18 years old and willing to report their health condition. Participants were provided detailed descriptions of a chronic illness condition and of its typical degrees of severity: mild, moderate and severe. 800 of the participants who had pre-registered with the market research company participated in the experiment: the sample was stratified to select exactly 400 who reported a chronic illness or disability at various levels of severity, and exactly 400 who did not report such a condition. These two strata will be indicated in the remainder of this study as ‘Ill’ and ‘Well’.

All participants were presented a detailed description of an electronic Patient Health Record system and then asked to answer an online questionnaire. The questions it contained were meant to measure the multi-item latent variables in the theoretical model described in Figure 1, together with relevant demographic characteristics of the participants surveyed. Most of the survey questions were adapted from those validated by previous research in healthcare (e.g., *Information Seeking*)[33] and information systems (e.g., *Personal Information Technology Innovativeness*, *Computer Anxiety*, *Perceived Usefulness* and *Behavioral Intention*).[24, 27, 32] Measures for the only formative construct in the model, *Security, Privacy and Trust*, although initially sourced from separate constructs in relevant information systems literature, were designed and validated as describing a single variable for this research. Measurement scales are

included in Appendix A. All responses were collected on 7-point Likert scales ranging from Strongly Disagree (1) to Strongly Agree (7), with an additional Not Applicable option. Cases with more than 10% missing answers were deemed invalid and removed from the data analysis.

Theoretical model evaluation

As this research was intended mainly for exploratory purposes, data analysis was done with Partial Least Squares (PLS) due to the suitability of this Structural Equation Modeling methodology for complex exploratory models,[34] using formative indicators[35] such as the Security, Privacy and Trust construct used in this research. PLS analysis was carried out with the SmartPLS software tool[36] and included two successive model assessments: measurement tests (assessing the reliability and validity of the construct measures), followed by structural tests (evaluating the relationships between model constructs).[37] Each analysis for the two sub-samples (Ill and Well) was done separately using the same model.

Use of the PLS tool for analysis determined the minimum study sample size. As the study involves a complex formative construct (i.e., Security, Privacy and Trust), the sample size should be at least ten times the number of its indicators.[38] Furthermore, sample size should account for possible high non-response rates or invalid cases in health-related studies. These considerations led to the target of 400 respondents in each of the two sub-samples.

Assessment of differences between ill and well individuals

Results of theoretical model tests for the two sub-samples were compared through differences in terms of the values of the path coefficients determined by PLS analysis.[38] The degree of difference was assessed with the t-statistic with $N1+N2-2$ degrees of freedom,[39-41] where:

$t = (Path1 - Path2)/[Spooled*sqrt(1/N1+1/N2)]$

Here, $Path1$, $Path2$ are the corresponding path coefficients in the model results and $N1$, $N2$ are the respective sub-sample sizes.

$Spooled$ represents the pooled estimator for the variance and is calculated from:

$Spooled = sqrt\{[square\ of\ (N1-1)/(N1+ N2-2)]*square\ of\ SE1 + [square\ of\ (N2-1)/(N1+ N2-2)]*square\ of\ SE2\}$

Here $SE1$, $SE2$ are the standard errors of the corresponding path coefficients in the two sub-sample model results.

RESULTS

Characteristics of study participants

After removing the invalid cases, a total of 389 Ill cases and 383 Well cases remained and were used in further statistical analyses. Raw data analyzed in this study were part of a larger project conducted in this setting. Table 1 shows comparative demographic characteristics, summarized for the two strata.

Table 1 Participant characteristics

		Ill Participants	**Well Participants**
Sample size		389	383
Age (years, average)		52.5	46.5
Gender			
	Female	248 (63.7%)	221 (57.7%)
	Male	141 (36.3%)	162 (42.3%)
Subject maintains up-to-date PHRs on paper			
	Yes	132 (34.0%)	74 (19.2%)
	No	257 (66.0%)	309 (80.8%)
Subject maintains up-to-date electronic PHRs			
	Yes	46 (11.7%)	22 (5.8%)
	No	343 (88.3%)	361 (94.2%)
Number of visits with a doctor during past 6 months (average)		5.0	2.3
Number of doctors seen during past 6 months (average)		2.3	1.4
Number of children 12 years old or younger for whom they have main care responsibility at home (average)		0.2	0.3
Subject (or someone for whom they are responsible) has a chronic disease that requires continuing medical attention			
	Yes	308 (79.2%)	81 (21.2%)
	No	81 (20.8%)	302 (78.8%)
Subject (or someone for whom they are responsible) has a disability that requires continuing care			
	Yes	205 (52.7%)	42 (11.0%)
	No	184 (47.3%)	341 (89.0%)
Subject is caring for elderly person(s)			
	Yes	49 (12.6%)	21 (5.5%)
	No	340 (87.4%)	362 (94.5%)
Subject is interested in regularly maintaining records about health			
	Yes	323 (83.0%)	247 (64.4%)
	No	66 (17.0%)	136 (35.6%)
Average amount of time spent using the Internet at home daily (largest two categories out of five)			
	31 - 60 minutes	263 (67.7%)	222 (58.0%)
	11 - 30 minutes	99 (25.5%)	111 (29.0%)

Theoretical model evaluation

An initial evaluation of the *measurement model* that comprised 22 items indicated the necessity of dropping 2 items when running it with the Ill data sample and 3 items when running it with the Well data sample, because of unsatisfactory significance and loading values of these items. After re-running SmartPLS for the remaining items, all reflective constructs for both samples displayed Cronbach's alpha and composite reliability values above 0.7, Average Variance Extracted (AVE) values above 0.5, and item loadings above 0.7, while the remaining items of the formative construct Security, Privacy and Trust in PHR were significant and had loadings above 0.5. Thus, the measurement model was considered to have acceptable reliability and convergent validity for both sub-samples.[38 ,42, 43]

A visual inspection of a matrix having the square root of AVEs on the diagonal and the correlations between all reflective constructs in the off diagonal cells showed diagonal numbers to be larger than all numbers on the corresponding rows and columns for both sub-samples (Table 2). This led to the conclusion that the model's reflective constructs had sufficient discriminant validity for both sub-samples.[37] Consequently, the measurement tests of the model for both sub-samples indicated adequate reliability and construct validity for all measurement instruments, either adapted from previous research or developed by this study. This allowed the second step of the PLS process, which was to perform the structural analysis of the model.

Table 2 Reflective construct correlations and square root of AVEs (Ill sample numbers off parentheses and Well sample numbers in parentheses)

	Computer Anxiety	Behavioral Intention	Information Seeking	Perceived Usefulness	Personal IT Innovativeness
Computer Anxiety	**0.89 (0.91)**				
Behavioral Intention	-0.51 (-0.38)	**0.87 (0.93)**			
Information Seeking	-0.13 (-0.13)	0.27 (0.24)	**0.86 (0.88)**		
Perceived Usefulness	-0.47 (-0.31)	0.76 (0.75)	0.33 (0.34)	**0.92 (0.92)**	
Personal IT Innovativeness	-0.33 (-0.17)	0.46 (0.38)	0.07 (0.03)	0.39 (0.42)	**0.92 (0.94)**

Evaluation of the *structural model* involved running SmartPLS with a bootstrap of 200 re-samples. Results for path coefficients, their significance levels, and the values of R^2 are compared in Figure 2 for both sub-samples.

*** Insert Figure 2 here. ***

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

SmartPLS results also provided the total effects of the factors in the theoretical model on behavioral intention to use PHRs, for the two categories of participants (Table 3).

Table 3 Total effects and their significance levels on behavioral intention to adopt PHRs

	Ill Sample		Well Sample	
Antecedent Construct	**Coefficient**	***P*-value**	**Coefficient**	***P*-value**

Computer Anxiety	-.327	<.001	-.212	.01
Information Seeking	.118	.01	.141	.01
Perceived Usefulness	.601	<.001	.565	<.001
Personal IT Innovativeness	.100	.08	.162	.01
Security, Privacy, and Trust	.377	<.001	.479	<.001

All characteristics in Table 1 were tested as potential control variables. In the case of the PHR Ill sub-sample the only influence came from the factor '*subject is interested in regularly maintaining records about health*'. This factor influenced positively the Perceived Usefulness construct (path coefficient of .234 at a P =.02 significance level) and increased the variance explained by this construct from R^2 = 0.473 to R^2 = 0.521). In the case of the PHR Well sub-sample the same interest in regularly maintaining records about health influenced positively the Perceived Usefulness construct (path coefficient of .171 at a P = .04 significance level and increased the variance explained from R^2 = 0.474 to R^2 = 0.499). In addition for this sub-sample, the factor increased Behavioral Intention (path coefficient of .154 at a P = .03 significance level and increase of variance explained from R^2 = 0.620 to R^2 = 0.640). So, the results for the control variable '*subject is interested in regularly maintaining records about health*' played a significant role in both sub-samples.

The self-reported degree of severity of the chronic illness or condition (i.e., mild, moderate or severe) was tested as a possible control variable for the Ill sub-sample. No statistically significant effects on the theoretical model were noticed.

Assessment of differences between ill and well individuals

The results of the differences between the path coefficients of the model for the two sub-samples are presented jointly in Table 4. No *P*-values were calculated since the lack of statistical significance, at a level of probability $P < .05$, of the difference between the results from the two sub-samples (indicated by the low absolute *t*-value of the difference) is very clear.

Table 4 Statistical analysis of differences between Ill and Well consumer sub-samples

Path	Ill Sub-sample Path Coefficient	Well Sub-sample Path Coefficient	Absolute *t*-value of Difference
Computer Anxiety → Behavioral Intention	-.177	-.142	0.348
Computer Anxiety → Perceived Usefulness	-.249	-.123	1.021
Information Seeking → Perceived Usefulness	.196	.249	0.479
Perceived Usefulness → Behavioral Intention	.601	.565	0.255
Personal IT Innovativeness → Perceived Usefulness	.167	.287	0.982
Security, Privacy, and Trust → Behavioral Intention	.140	.244	0.717
Security, Privacy, and Trust → Perceived Usefulness	.393	.416	0.161

DISCUSSION

Principal findings and comparison with prior work

The objective of this study was to determine the key motivators for individuals to adopt electronic Personal Health Records, through a theoretical behavioral model developed here. Furthermore, as previous research and theoretical reasoning indicated that people with chronic illnesses may be more likely to be favorable to the adoption of PHRs than people who are well,[9] in our study we use the model we developed to compare two sub-samples drawn in

Canada from these two populations in order to assess empirically the possible behavioral differences and their determinants.

Our study (Table 3 and Figure 2) confirms largely the findings of research in information systems according to which Perceived Usefulness is the key explanation of the behavioral intention to use an information technology application.[44] Therefore individuals, either chronically ill or well, would use PHRs only if they see the usefulness of these artifacts. This is concordant with findings on other empirical studies on PHRs that showed relative advantage[22] or perception of empowerment[45] as key motivators of adoption.

As expected from previous research,[17] the perception of Security, Privacy, and Trust in PHRs is a significant motivator for use in both categories of individuals surveyed. Table 3 shows this factor is second in terms of total effect to Perceived Usefulness only, being significant at $P < .001$ for both sub-samples. Interestingly, Security, Privacy, and Trust in PHRs has a non-significant direct influence on Behavioral Intention to use PHRs for the Ill sub-sample (coefficient = .140, $P = .15$). This means security, privacy and trust mean less for ill people – the association of these features with usefulness is more important in the adoption equation. This is confirmed by previous research showing that benefits of access to medical records online may outweigh privacy risk perceptions.[46]

Study results confirm that Information Seeking and Personal IT Innovativeness are motivators of PHR use for both categories of potential users while exerting their influence through Perceived Usefulness (Table 3 and Figure 2). However, the total effect of Personal IT Innovativeness over adoption intention is not significant for the Ill sub-sample, but it is for the Well sub-sample (Table 3). This suggests that technical innovativeness means less for ill people than it does for well people, indicating that ill people are less interested in adopting a PHR just because it is innovative, but for other reasons, including the value it can provide in managing their disease(s).

As hypothesized, Computer Anxiety is the only deterrent on PHR adoption in the theoretical model proposed by this study. It has a negative total influence significant at $P < .001$ for the Ill sub-sample and at $P = .01$ for the Well sub-sample (Table 3). Results in Figure 2 confirm that the influence of Anxiety is less apparent for the Well sub-sample compared to the Ill sub-sample. Therefore ill individuals, who presumably might be attracted to using PHRs, would be more concerned about the skills necessary to access computer-based PHRs. Their concerns would clearly have to be addressed in order to increase PHR adoption.

All demographic characteristics measured and reported in Table 1 were tested as control variables but had no effect for either sample with the exception of participant interest in regularly maintaining records about health. This factor was positive for both sub-samples but more so for the Well one. Therefore, individual interest in self-monitoring health makes them better able to perceive PHR usefulness and to want to use these systems.

Overall, the original model proposed by this study to explain the adoption of PHRs had moderately high variance explained values for all the endogenous constructs, for both sub-samples (R^2 of 0.473/0.474 for Perceived Usefulness and 0.620/0.626 for Behavioral Intention) and 6 out of 7 significant paths in both cases (Figure 2). Therefore, from the statistical point of view, this model could be considered to be reasonably good.[47]

Assessment of differences between ill and well individuals

The key outcomes from the study of perceptions on PHRs of Ill and Well individuals in Table 4 show that there were no statistically significant differences (at a level $P<.05$) between the two sub-samples for any of the paths in Figure 2. On the surface, these outcomes appear to contradict what we had expected – that people with chronic illnesses or disabilities are more interested in PHR adoption than are well people. We suspect that the differences are masked by the fact that many of the people in the Ill sample were, in fact, not seriously ill. The low rate of current PHR use in the both sub-samples could be another explanation for the non-significant differences in perceptions between them. Findings from consumers, especially those with serious chronic illnesses, who had a considerable amount of experience with well-designed PHRs, might be more conclusive than the results from this comparative survey.

Limitations

As in virtually any empirical research, this study has some limitations. First, it is likely that the functionalities that accompany PHR systems would have a strong influence on their adoption. This aspect was not measured in this study. Second, the participants were all Internet users, so it excluded many, particularly older, consumers who were not. In fact more than 60% of the survey participants overall claimed to use the Internet for from 30 to 60 minutes per day. On the other hand, the proportion of Internet and portable device users falls off rapidly with age beyond 65 years,[48] especially for lower income seniors. Therefore, “those who can benefit the most from a PHR system may be the least able to use it”.[49] In addition to all these limitations, the most important for a comparative study such as this, participant health conditions were self-reported and not diagnosed by practitioners. Therefore, it is possible that the difference we found in overall perceptions between the two sub-samples was not significant because the difference in participant self-reported health condition between the two sub-samples was weak.

CONCLUSIONS

Despite the inherent limitations of an exploratory study, this research has the merit of investigating individual perceptions about electronic PHRs, using a rigorous theoretical approach that considers the perspectives of ill and well people separately. While remaining parsimonious, the theoretical model developed by this research has the merit of explaining a reasonably high percent of the consumer intention to use electronic PHRs and thus could be a starting point for researchers examining more complex models of eHealth adoption.

According to the findings of this research, to maximize the chances of adoption for PHR support in self-management initiatives, it appears necessary to enhance the motivators, especially the perceptions of usefulness as well as that of security, privacy and trust in PHRs, while mitigating anxieties associated with computer use. Developers and implementers of electronic PHRs should try to enhance the perceptions of positive factors among consumers, and focus on the benefits of using these systems in particular, since favourable factors are far more important than deterrents in the overall adoption equation.

A first exposure to PHRs did not reveal significantly different perceptions of this tool between individuals who reported having a chronic illness and those who reported being well. Therefore it appears that both categories of potential users should be addressed by promoters of PHRs in much the same way in terms of motivating and demotivating factors. However, caution is advised regarding assumptions of equivalence between individuals who report being chronically ill and those who have been diagnosed accordingly. Thus, future studies should attempt to survey chronically ill patients recruited through the healthcare system, after having a specified experience with self-managing their conditions with the aid of PHRs. A comparison of their perceptions of PHRs with those of well individuals would help to improve our understanding of how the adoption of PHRs could be increased overall.

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2) contributed to drafting the article or revising it critically for important intellectual content; and

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Figure legends

Figure 1 Theoretical model of PHR adoption

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

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Research Article

Title:

Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

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Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

ABSTRACT

Objective To develop a model of consumer perceptions of electronic personal health records (PHRs) and ~~accomplish~~ validate it in a comparative study ~~of the perceptions of electronic personal health records (PHRs)~~ between consumers who report~~ed~~ having a chronic illness ~~or disability~~ and those who report~~ed~~ being well.

Materials and methods A model of PHR use motivators and barriers was built and tested through a national survey ~~was conducted~~ ~~with an Internet panel recruited~~ across Canada. Data were collected from 800 individuals 18 years or older. Half reported having a chronic illness or disability and half reported being well. Analyses were done with Structural Equation Modeling techniques.

Results A total of 389 ~~valid~~ answers from chronically ill and 383 from well participants were collected. ~~We found~~ Perceived Usefulness ~~to be~~was the key explanation of the intention to use PHRs for both ill and well people (total effect of .601 and .565, respectively) followed by Security, Privacy, and Trust in PHRs (total effect of .377 and .479, respectively). Conversely, Computer Anxiety was perceived as a significant barrier (total effect of -.327 for ill individuals and -.212 for well individuals).

Discussion The model proposed was appropriate in explaining key consumer positive and negative perceptions ~~Key motivators and barriers for user adoption of~~ on electronic PHR use~~s that were identified are broadly in concordance with previous knowledge in behavioral research~~. We found little difference in perceptions of electronic PHRs between chronically ill and well individuals, although self-reporting their health status might have influenced the results.

Conclusions To increase the adoption rate of electronic PHRs among both chronically ill and well consumers it is necessary to reinforce consumer~~people~~ perceptions of~~n~~ the usefulness of and trust in these eHealth technologies while mitigating their~~consumer~~ anxieties about computer use in general.

Strengths and limitations of this study

- This study developed an unbiased theoretical model of consumer perceptions of electronic personal health records (PHRs).
- The model was validated through~~in an~~ empirical ~~is~~ research comparing~~ed empirically~~ the perceptions of chronically ill and well consumers about electronic PHRs~~ using a rigorous theoretical approach~~.
- The health condition of study participants was self-reported and not diagnosed by practitioners.

OBJECTIVE

Given the current shortage of medical resources available for managing the growing numbers of patients with chronic illnesses, it is becoming apparent that patient self-management is key to managing such illnesses and improv~~e~~ing health and quality of life.[1, 2] ~~If health self-management is to function successfully, care plans and goals must be developed jointly by patients and their physicians, to move towards improved health and quality of life.[2] But t~~To manage this process effectively~~, as in every management system,~~ it is important for patients to maintain~~keep patient~~ up-to-date and readily accessible health records~~ that can assist the patient and the patient's healthcare provider to monitor the patient's progress towards meeting the established self-care goals. It is also important to make these records readily accessible to both patients and their providers, in order that integration of care and sharing of information can occur both within and across services~~.[1, 3] An online health self-management system that is grounded in the chronic care model[4] and that utilizes the patient's health record as a repository can support a system with self-management functionalities for assisting in improved patient-centerd care.[5-8]

~~When h~~Health records ~~are~~ maintained and accessible by individual ~~patients, these records~~ consumers are referred to as Personal Health Records (PHRs). Although they can be recorded and maintained in paper form, a fast emerging trend with the advent of digital data and the Internet is to keep them in an electronic format. Therefore, we will assume throughout this paper that PHRs refer to electronic records on digital media. A PHR can be defined as "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment".[9] This is in contrast with EHR/EMRs (Electronic Health Records/Electronic Medical Records) which contain patient data gathered during the course of patient visits to healthcare providers, and are managed solely by healthcare providers or healthcare institutions. Also, most EHR/EMR data are based on acute care episodes[10] since people are more likely to see their doctors when they have an acute problem.

An ideal form of a PHR is one that exchanges data freely, as authorized by the patient and physician, between the physician's EHR/EMR and the patient's records, as needed.[11] ~~Types of data that may be available in this way to a PHR include, but are not limited to: patient problem lists, procedures, major illnesses, provider list, allergies, home monitored data (e.g., blood pressure, glucose level, weight, exercise schedule, etc.), family history, lifestyle, immunizations, medications, and lab tests.[10]~~

In theory, PHRs can be of great use to patients in the self-management of chronic diseases and disabilities, but there are significant obstacles to their sustainability, which refers to their adoption and continued use. Trials of eHealth implementations tend to be prone to participant dropouts~~, or~~ (attrition).[12] Reported attrition rates from the use of PHRs for health self-management vary widely, from as low as 3% for an interactive web-based intervention that included telephone counseling, to 65% in a smoking cessation program, and to an enormous rate of 99% in a panic disorder self-help program.[13, 14] Although factors affecting attrition tend to be complex,[15] they must be addressed effectively if the benefits of self-management interventions are to be maximized.

The goal of better health may not be sufficient to motivate people to use PHRs, although there are techniques to predict in advance whether patients will adopt and continue with beneficial healthcare behaviors.[16] If patient motivation to adopt PHR innovations were better understood, resulting reductions in attrition rates would lead to improved outcomes from health self-management interventions.

Accordingly, the objective of this study is to ~~help~~ determine ~~the~~ the key motivators and barriers~~ion of~~ for individuals to adopt PHRs~~, for the purpose of self-management of chronic ailments and disabilities~~. As ~~T~~there are indications that people with serious chronic ailments and disabilities are more likely to be favorable to the adoption of PHRs than people who are well,~~.~~[9] ~~Therefore, in our study~~ we ~~then~~ compared these two groups of people empirically to determine possible differences between adoption factors. ~~the factors by which chronically ill or disabled people are more motivated to adopt PHRs than well individuals.~~ Finally, we discuss the results and their significance to further sustainable development and implementation of PHRs, and consumer motivation to adopt and use them.

BACKGROUND AND SIGNIFICANCE

Personal Health Records background

Studies done in various parts of the world have indicated a great deal of public interest in PHRs. For instance, a major motivation for over 70% of U.S. consumers is that they believe having access to PHRs would improve the quality of their healthcare,[17] although as yet there is no convincing evidence that this is the case. Field studies report the greatest interest in PHRs is manifested by the chronically ill, frequent users of healthcare, and caregivers for elderly parents.[9,18] The same studies show that, among American consumers saying they were not interested in using PHRs, more than 55% indicated that worries about privacy and confidentiality affected their reluctance. Moreover, about 90% of consumers surveyed felt that the provision of privacy, record access, and user remedies would be significant factors affecting their agreement to use an online PHR service.[17] Conversely, some barriers to maintaining and accessing PHRs include cost and loss of interest over time.[19]

Through online and decision support for patient-centerd care, changes in healthcare practice can often help to meet practice and patient goals. For example, research has demonstrated improvements in diabetes outcomes and chronic illness self-management when behavioral support is forthcoming from relevant technologies, improving dietary practices, physical activity, and adherence to medication regimens.[20] Other studies indicate that social activities are particularly important for older people, with health benefits that may include less chance of mortality, disability, and depression, and better cognitive and health-related behaviors.[21] Empirical studies have shown that relative advantage, ease of use, trialability, perceptions of privacy and security, age, and computer experience were positive predictors of the value of PHRs for supporting communications with the doctor’s office.[22] Therefore, it is important to understand the key motivators and deterrents for PHR adoption, with the target of improving the adoption rate and sustainability of these systems.

Theoretical model and hypotheses

In the following, we develop a theoretical model that takes into account the above considerations and test it for chronically ill and disabled consumers on the one hand and with consumers who feel that they are relatively healthy on the other hand, in order to compare their perceptions of PHRs. For this purpose~~at~~ we use a number of key constructs validated by previous research in information systems and healthcare, and propose hypotheses regarding their relationships, based on empirical findings and theoretical reasoning.

Information Seeking. Although patients may prefer not to make all their own decisions about their healthcare, they do want to be kept informed. Reportedly, over 40 percent of patients with chronic conditions prefer to receive more information from their healthcare providers than they actually receive~~d~~.[23] It seems, therefore, that patients with higher information seeking preferences are more likely to feel that PHRs are useful in accessing information on their health status than those who do not. Therefore, we propose the following hypothesis:

H1: Consumers with higher information-seeking preferences will tend to believe that PHRs would be more useful.

Personal Information Technology Innovativeness. This construct captures the willingness of an individual to try out an information technology, as it relates to the concept of technology acceptance.[24] This indicates that people exhibiting high levels of information technology innovativeness will be more interested in accepting PHRs than those who do not. This leads to the hypothesis:

H2: Individuals with higher levels of IT innovativeness will exhibit higher levels of perceived usefulness for PHRs.

Computer Anxiety. This construct expresses an individual's apprehension or fear when faced with the possibility of using a computer.[25] Previous research has found a negative relationship between computer anxiety and perceived usefulness of new technology, as well as to intention to use a new technology.[26, 27] This results in the following propositions:

H3: Level of computer anxiety will be negatively related to the perceived usefulness of PHRs.

H4: Level of computer anxiety will be negatively related to the intention to use PHRs.

Privacy, Security, and Trust. These concepts have been consistently found in large scale studies to have an impact on consumer interest in online PHR adoption.[28] While some surveys showed two-thirds of adult consumers were concerned about security and privacy of their health data,[17] other market studies found that consumers actually using a PHR did not worry too much about its privacy implications.[29] The chronically and acutely ill and others who often require healthcare appear to have fewer concerns about privacy than do health professionals.[30, 31] Consequently, we propose the following hypotheses:

H5: Consumer perceptions of appropriate security and~~,~~ privacy of PHRs, and trust in PHR providers will positively affect their perceptions of PHR usefulness.

H6: Consumer perceptions of appropriate security and~~,~~ privacy of PHRs, and trust in PHR providers will positively affect their intention to adopt PHRs.

Perceived Usefulness. This construct is a widely known and strong extrinsic motivator of technology use. It expresses "the degree to which a person believes that using a particular system would enhance his or her job performance".[32] In the case of PHR use, job performance (expectancy) would refer to being able to self-monitor accurately certain health parameters. Thus, it is logical to formulate the hypothesis below:

H7: Higher perceived usefulness for PHRs leads to a higher level of intention to adopt this technology.

The proposed constructs and their related hypotheses are shown in Figure 1 in the form of a theoretical model of PHR adoption. The final endogenous construct of this model is Behavioral Intention to adopt PHRs that measures potential user intentions regarding this eHealth support tool.

*** Insert Figure 1 here. ***

Figure 1 Theoretical Model of PHR Adoption

MATERIALS AND METHODS

Participant recruitment and data collection

The theoretical model proposed by this study was tested with empirical data collected through an online survey of Canadian consumers. Both French and English versions were prepared and pre-tested with graduate students and practitioners in a Canadian university. The full scale survey was approved by the Research Ethics Board of the university and subsequently conducted with a Canadian Internet panel of consumers through a market research company. There is no relationship between the researchers and this company, and the company was not allowed to analyze nor retain any copies of the data collected during the survey.

Participants were required to be at least 18 years old and willing to report their health condition. Participants were provided detailed descriptions of a chronic illness condition and of its typical degrees of severity: mild, moderate and severe. 800 of the participants who had pre-registered with the market research company participated in the experiment: the sample was stratified to select exactly 400 who reported a chronic illness or disability at various levels of severity, and exactly 400 who did not report such a condition. These two strata will be indicated in the remainder of this study as 'Ill' and 'Well'.

All participants were presented a detailed description of an electronic Patient Health Record system and then asked to answer an online questionnaire. ~~This~~ The ~~comprised~~ questions it contained were meant to measure the multi-item latent variables in the theoretical model described in Figure 1, together with relevant demographic characteristics of the participants surveyed. Most of the survey questions were adapted from those validated by previous research in healthcare (e.g., *Information Seeking*)[33] and information systems (e.g., *Personal Information Technology Innovativeness*, *Computer Anxiety*, *Perceived Usefulness* and *Behavioral Intention*).[24, 27, 32] Measures for the only formative construct in the model, *Security, Privacy and Trust*, although initially sourced from separate constructs in relevant information systems literature, were designed and validated as describing a single variable for~~by~~ this research. Measurement scales are included in Appendix A. All responses were collected on 7-point Likert scales ranging from Strongly Disagree (1) to Strongly Agree (7), with an additional Not Applicable option. Cases with more than 10% missing answers were deemed ~~as~~ invalid and removed from the data analysis.

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Theoretical model evaluation

As this research was intended mainly for exploratory purposes, data analysis was done with Partial Least Squares (PLS) due to the suitability of this Structural Equation Modeling methodology for complex exploratory models,[34] using formative indicators[35] such as the Security, Privacy and Trust construct used in this research. PLS analysis was carried out with the SmartPLS software tool[36] and included two successive model assessments: measurement tests (assessing the reliability and validity of the construct measures), followed by structural tests (evaluating the relationships between model constructs).[37] Each analysis for the two sub-samples (Ill and Well) was done separately using the same model.

Use of the PLS tool for analysis determined ~~imposed~~ the minimum study sample size. As the study involves a complex formative construct (i.e., Security, Privacy and Trust), the sample size should be at least ten times the number of its indicators.[38] Furthermore, sample size should account for possible high non-response rates or invalid cases in health-related studies. These considerations led to the target ~~number~~ of 400 respondents ~~targeted~~ in each of the two sub-samples.

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Assessment of differences between ill and well individuals

Results of theoretical model tests for the two sub-samples were compared through differences in terms of the values of the path coefficients determined~~provided~~ by PLS analysis.[38] The degree of difference was assessed with the t-statistic with $N1+N2-2$ degrees of freedom,[39-41] where:

$$t = (Path1 - Path2)/[Spooled*sqrt(1/N1+1/N2)]$$

Here, *Path1*, *Path2* are the corresponding path coefficients in the model results and *N1*, *N2* are the respective sub-sample sizes.

Spooled represents the pooled estimator for the variance and is calculated from:

*Spooled = sqrt{[square of (N1-1)/(N1+ N2-2)]*square of SE1 + [square of (N2-1)/(N1+ N2-2)]*square of SE2}*

Here *SE1*, *SE2* are the standard errors of the corresponding path coefficients in the two sub-sample model results.

RESULTS

Characteristics of study participants

After removing the invalid cases~~ with more than 10% missing answers~~, a total of 389 Ill cases and 383 Well cases remained and were used in further statistical analyses. Raw data analyzed in this study were part of a larger project conducted in this setting. Table 1 shows comparative demographic characteristics, summarized for the two strata.

Table 1 Participant characteristics

		Ill Participants	Well Participants
Sample size		389	383
Age (years, average)		52.5	46.5
Gender			
	Female	248 (63.7%)	221 (57.7%)
	Male	141 (36.3%)	162 (42.3%)

Subject maintains up-to-date PHRs on paper			
	Yes	132 (34.0%)	74 (19.2%)
	No	257 (66.0%)	309 (80.8%)
Subject maintains up-to-date electronic PHRs			
	Yes	46 (11.7%)	22 (5.8%)
	No	343 (88.3%)	361 (94.2%)
Number of visits with a doctor during past 6 months (average)		5.0	2.3
Number of doctors seen during past 6 months (average)		2.3	1.4
Number of children 12 years old or younger for whom they have main care responsibility at home (average)		0.2	0.3
Subject (or someone for whom they are responsible) has a chronic disease that requires continuing medical attention			
	Yes	308 (79.2%)	81 (21.2%)
	No	81 (20.8%)	302 (78.8%)
Subject (or someone for whom they are responsible) has a disability that requires continuing care			
	Yes	205 (52.7%)	42 (11.0%)
	No	184 (47.3%)	341 (89.0%)
Subject is caring for elderly person(s)			
	Yes	49 (12.6%)	21 (5.5%)
	No	340 (87.4%)	362 (94.5%)
Subject is interested in regularly maintaining records about health			
	Yes	323 (83.0%)	247 (64.4%)
	No	66 (17.0%)	136 (35.6%)
Average amount of time spent using the Internet at home daily (largest two categories out of five)			
	31 - 60 minutes	263 (67.7%)	222 (58.0%)
	11 - 30 minutes	99 (25.5%)	111 (29.0%)

Theoretical model evaluation

An initial evaluation of the *measurement model* that comprised 22 items indicated the necessity of~~to~~ dropping 2 items when running it with the Ill data sample and 3 items when running it with

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the Well data sample, because of unsatisfactory significance and loading values of these items. After re-running SmartPLS for the remaining items, all reflective constructs for both samples displayed Cronbach's alpha and composite reliability values above 0.7, Average Variance Extracted (AVE) values above 0.5, and item loadings above 0.7, while the remaining items of the formative construct Security, Privacy and Trust in PHR were significant and had loadings above 0.5. Thus, the measurement model was considered to have acceptable reliability and convergent validity for both sub-samples.[38 ,42, 43]

A visual inspection of a matrix having the square root of AVEs on the diagonal and the correlations between all reflective constructs in the off diagonal cells showed diagonal numbers to be larger than all numbers on the corresponding rows and columns for both sub-samples (Table 2). This led to the conclusion that the model's reflective constructs had sufficient discriminant validity for both sub-samples.[37] Consequently, the measurement tests of the model for both sub-samples indicated adequate reliability and construct validity for all measurement instruments, either adapted from previous research or developed by this study. This allowed the second step of the PLS process, which was to perform the structural analysis of the model.

Table 2 Reflective construct correlations and square root of AVEs (Ill sample numbers off parentheses and Well sample numbers in parentheses)

	Computer Anxiety	**Behavioral Intention**	**Information Seeking**	**Perceived Usefulness**	**Personal IT Innovativeness**
Computer Anxiety	**0.89 (0.91)**				
Behavioral Intention	-0.51 (-0.38)	**0.87 (0.93)**			
Information Seeking	-0.13 (-0.13)	0.27 (0.24)	**0.86 (0.88)**		

Perceived Usefulness	-0.47 (-0.31)	0.76 (0.75)	0.33 (0.34)	**0.92 (0.92)**	
Personal IT Innovativeness	-0.33 (-0.17)	0.46 (0.38)	0.07 (0.03)	0.39 (0.42)	**0.92 (0.94)**

Evaluation of the *structural model* involved running SmartPLS with a bootstrap of 200 re-samples. Results for path coefficients, their significance levels, and the values of R^2 are compared in Figure 2 for both sub-samples.

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*** Insert Figure 2 here. ***

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

SmartPLS results also provided the total effects of the factors in the theoretical model on behavioral intention to use PHRs, for the two categories of participants (Table 3).

Table 3 Total effects and their significance levels on behavioral intention to adopt PHRs

	Ill Sample		**Well Sample**	
Antecedent Construct	**Coefficient**	***P*-value**	**Coefficient**	***P*-value**
Computer Anxiety	-.327	<.001	-.212	.01
Information Seeking	.118	.01	.141	.01
Perceived Usefulness	.601	<.001	.565	<.001
Personal IT Innovativeness	.100	.08	.162	.01
Security, Privacy, and Trust	.377	<.001	.479	<.001

All characteristics in Table 1 were tested as potential control variables. In the case of the PHR Ill sub-sample the only influence came from the factor '*subject is interested in regularly maintaining records about health*'. This factor influenced positively the Perceived Usefulness construct (path coefficient of .234 at a P =.02 significance level) and increased the variance explained by this construct from $R^2 = 0.473$ to $R^2 = 0.521$). In the case of the PHR Well sub-sample the same interest in regularly maintaining records about health influenced positively the Perceived Usefulness construct (path coefficient of .171 at a $P = .04$ significance level and increased the variance explained from $R^2 = 0.474$ to $R^2 = 0.499$). In addition for this sub-sample, the factor increased Behavioral Intention (path coefficient of .154 at a $P = .03$ significance level and increase of variance explained from $R^2 = 0.620$ to $R^2 = 0.640$). So, the results for the control variable '*subject is interested in regularly maintaining records about health*' played a significant role in both sub-samples.

The self-reported degree of severity of the chronic illness or condition (i.e., mild, moderate or severe) was tested as a possible control variable for the Ill sub-sample. No statistically significant effects on the theoretical model were noticed.

Assessment of differences between ill and well individuals

The results of the differences between the path coefficients of the model for the two sub-samples are presented jointly in Table 4. No P-values were calculated since the lack of statistical significance, at a level of probability $P < .05$, of the difference between the results from the two sub-samples (indicated by the low absolute t-value of the difference) is very clear.

Table 4 Statistical analysis of differences between Ill and Well consumer sub-samples

Path	Ill Sub-sample Path Coefficient	Well Sub-sample Path Coefficient	Absolute *t*-value of Difference
Computer Anxiety → Behavioral Intention	-.177	-.142	0.348
Computer Anxiety → Perceived Usefulness	-.249	-.123	1.021
Information Seeking → Perceived Usefulness	.196	.249	0.479
Perceived Usefulness → Behavioral Intention	.601	.565	0.255
Personal IT Innovativeness → Perceived Usefulness	.167	.287	0.982
Security, Privacy, and Trust → Behavioral Intention	.140	.244	0.717
Security, Privacy, and Trust → Perceived Usefulness	.393	.416	0.161

DISCUSSION

Principal findings and comparison with prior work

The objective of this study was to determine the key motivators for individuals to adopt electronic Personal Health Records, through a theoretical behavioral model developed here. Furthermore, ~~A~~as previous research and theoretical reasoning indicated that people with chronic illnesses may be more likely to be favorable to the adoption of PHRs than people who are well,[9] in our study we use the model we developed to compare~~d~~ two sub-samples drawn in Canada from these two populations in order to assess empirically the possible behavioral differences and their determinants.

Our study (Table 3 and Figure 2) confirms largely the findings ~~of an overwhelming body~~ of research in information systems according to which Perceived Usefulness is the key explanation of the behavioral intention to use an information technology application.[44] Therefore individuals, either chronically ill or well, would use PHRs only if they see the usefulness of these artifacts. This is concordant with findings on other empirical studies on PHRs that showed relative advantage[22] or perception of empowerment[45] as key motivators of adoption.

As expected from previous research,[17] the perception of Security, Privacy, and Trust in PHRs is a significant motivator for use in both categories of individuals surveyed. Table 3 shows this factor is second in terms of total effect to Perceived Usefulness only, being significant at $P < .001$ for both sub-samples. Interestingly, Security, Privacy, and Trust in PHRs has a non-significant direct influence on Behavioral Intention to use PHRs for the Ill sub-sample (coefficient = .140, $P = .15$). This means security, privacy and trust mean less for ill people – the association of these features with usefulness is more important in the adoption equation. This is confirmed by previous research showing that benefits of access to medical records online may outweigh privacy risk perceptions.[46]

Study results confirm that Information Seeking and Personal IT Innovativeness are motivators of PHR use for both categories of potential users while exerting their influence through Perceived Usefulness (Table 3 and Figure 2). However, the total effect of Personal IT Innovativeness over adoption intention is not significant for the Ill sub-sample, but it is for the Well sub-sample (Table 3). This suggests that technical innovativeness means less for ill people than it does for well people, indicating that ill people are less interested in adopting a PHR just because it is innovative, but for other reasons, including the value it can provide in managing their disease(s).

As hypothesized, Computer Anxiety is the only deterrent on PHR adoption in the theoretical model proposed by this study. It has a negative total influence significant at $P < .001$ for the Ill sub-sample and at $P = .01$ for the Well sub-sample (Table 3). Results in Figure 2 confirm that the influence of Anxiety is less apparent for the Well sub-sample compared to the Ill sub-sample. Therefore ill individuals, who~~,~~ presumably~~,~~ might be attracted to using PHRs, would be more concerned about the skills necessary to access computer-based PHRs. Their concerns would clearly have to be addressed in order to increase PHR adoption.

All demographic characteristics measured and reported in Table 1 were tested as control variables but had no effect for either sample with the exception of participant interest in regularly maintaining records about health. This factor was positive for both sub-samples but more so for the Well one. Therefore, individual interest in self-monitoring health makes them better able to perceive PHR usefulness and to want to use these systems.

Overall, the original model proposed by this study to explain the adoption of PHRs had moderately high variance explained values for all the endogenous constructs, for both sub-samples (R^2 of 0.473/0.474 for Perceived Usefulness and 0.620/0.626 for Behavioral Intention) and 6 out of 7 significant paths in both cases (Figure 2). Therefore, from the statistical point of view, this model could be considered to be reasonably good.[47]

Assessment of differences between ill and well individuals

The key outcomes from the study of perceptions on PHRs of Ill and Well individuals ~~are~~ in Table 4~~, which~~ show~~s~~ that there were no statistically significant differences (at a level $P<.05$) between the two ~~Ill and Well~~ sub-samples for any of the paths in Figure 2. On the surface, these outcomes appear to contradict what we had expected – that people with chronic illnesses or disabilities are more interested in PHR adoption than are well people. We suspect that the differences are masked by the fact that many of the people in the Ill sample were, in fact, not seriously ill. The low rate of current PHR use in the both sub-samples could be another explanation for the non-significant differences in perceptions between them. Findings from consumers, especially those with serious chronic illnesses, who had a considerable amount of experience with well-designed PHRs, might be more conclusive than the results from this comparative survey.

Limitations

As in virtually any empirical research, this study has ~~also~~ some limitations. First, it is likely that the functionalities that accompany PHR systems would have a strong influence on their adoption. This aspect was not measured in this study. Second, the participants were all Internet users, so it excluded many, particularly older, consumers who were not. In fact more than 60% of the survey participants overall claimed to use the Internet for from 30 to 60 minutes per day. On the other hand, the proportion of Internet and portable device users falls off rapidly with age beyond 65 years,[48] especially for lower income seniors. Therefore, “those who can benefit the most from a PHR system may be the least able to use it”.[49] In addition to all these limitations, the most important for a comparative study such as this, participant health conditions were self-reported and not diagnosed by practitioners. Therefore, it is possible that the difference we found in overall perceptions between the two sub-samples was not significant because the difference in participant self-reported health condition between the two sub-samples was weak.

CONCLUSIONS

Despite the inherent limitations of an exploratory study, this research has the merit of investigating individual perceptions about electronic PHRs, using a rigorous theoretical approach that considers the perspectives of ill and well people separately. While remaining parsimonious, the theoretical model developed by this research has the merit of explaining a reasonably high percent of the consumer intention to use electronic PHRs and~~,~~ thus~~,~~ could be a starting point for researchers examining more complex models of eHealth adoption.

According to the findings of this research, ~~T~~to maximize the chances of adoption for PHR support in self-management initiatives, it appears necessary to enhance the motivators, especially the perceptions of usefulness as well as that of security, privacy and trust in PHRs, while mitigating anxieties associated with computer use. Developers and implementers of electronic PHRs should try to enhance the perceptions of ~~the~~ positive factors among consumers, and focus on the benefits of using these systems in particular, since ~~the~~ favourable~~ing~~ factors are far more important than ~~the~~ deterrents in the overall adoption equation.

A first exposure to PHRs did not reveal significantly different perceptions of this tool between individuals who reported having a chronic illness and those who reported being well. Therefore it appears that both categories of potential users should be addressed by promoters of PHRs in much the same way in terms of motivating and demotivating factors. However, caution is advised regarding assumptions of equivalence between individuals who report being chronically ill and those who have been diagnosed accordingly. Thus, future studies should attempt to survey chronically ill patients recruited through the healthcare system, after having a specified experience with self-managing their conditions with the aid of PHRs. A comparison of their perceptions of PHRs with those of well individuals would help to improve our understanding of how the adoption of PHRs could be increased overall.

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Ethics approval Research Ethics Board of a Canadian university.

Data sharing statement No additional data available.

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APPENDIX A

Measurement scales

Information Seeking

I believe that doctors should explain the purpose of laboratory and other tests.

I believe that the results of laboratory and other tests should be made available to patients.

I believe that people should know all the important side effects of their medications.

Personal Information Technology Innovativeness

If I hear about a new information technology I look for ways to experiment with it.

Among my friends I am usually the first to try out new information technologies.

In general, I am eager to try out new information technologies.

Computer Anxiety

I would feel apprehensive about using an Electronic Personal Health Record system.

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It scares me to think that I could lose a lot of information using an Electronic Personal Health Record system by hitting the wrong key.

Using an Electronic Personal Health Record system would make me nervous.

Security, Privacy and Trust

From a security and privacy perspective I would prefer to maintain up-to-date electronic personal health records on a system that:

Ran strictly on my own personal computer.

Ran strictly on my own personal computer, with provision to take the records with me on a secure memory device, such as a smart card, as needed.

Is accessible through a secure Internet web site that is maintained by the provincial government's health authority.

Is accessible through a secure Internet web site that is maintained by my own family doctor.

Is accessible through a secure Internet web site that is maintained by a private company.

Perceived Usefulness

Using my own Electronic Personal Health Records would help to support critical aspects of my health care such as scheduling appointments, recording my health status, etc.

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Using my own Electronic Personal Health Records would enhance my effectiveness in managing my own health care, such as managing medications, reviewing my progress, etc.

Using my own Electronic Personal Health Records would make me more effective in providing up-to-date health information about myself when interacting with my physician.

Using my own Electronic Personal Health Records would help to improve my health.

Overall, having my own Electronic Personal Health Record system would be useful in managing my health care.

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Behavioural Intention to Adopt an ePHR

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If an Electronic Personal Health Record system is made available for me, I intend to use it.

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If an Electronic Personal Health Record system is made available for me, I predict that I would use it.

If an Electronic Personal Health Record system is made available for me, I intend to work together with my spouse or other caregiver(s) to use it on my behalf.

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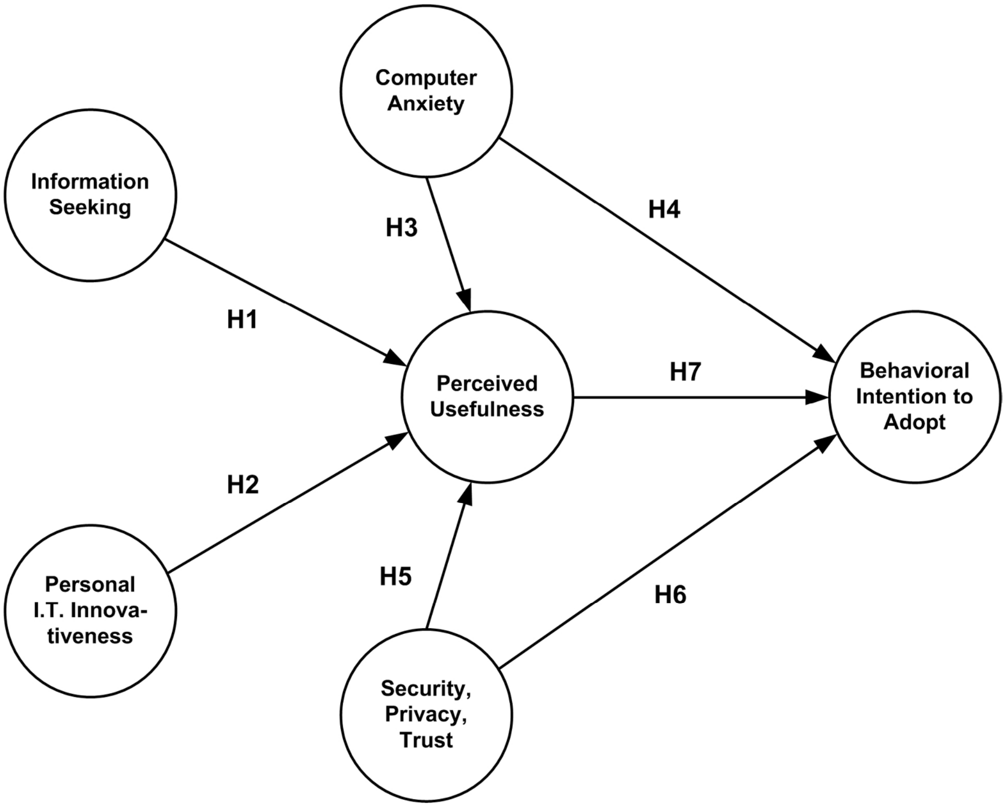

Figure 1 Theoretical model of PHR adoption
163x130mm (300 x 300 DPI)

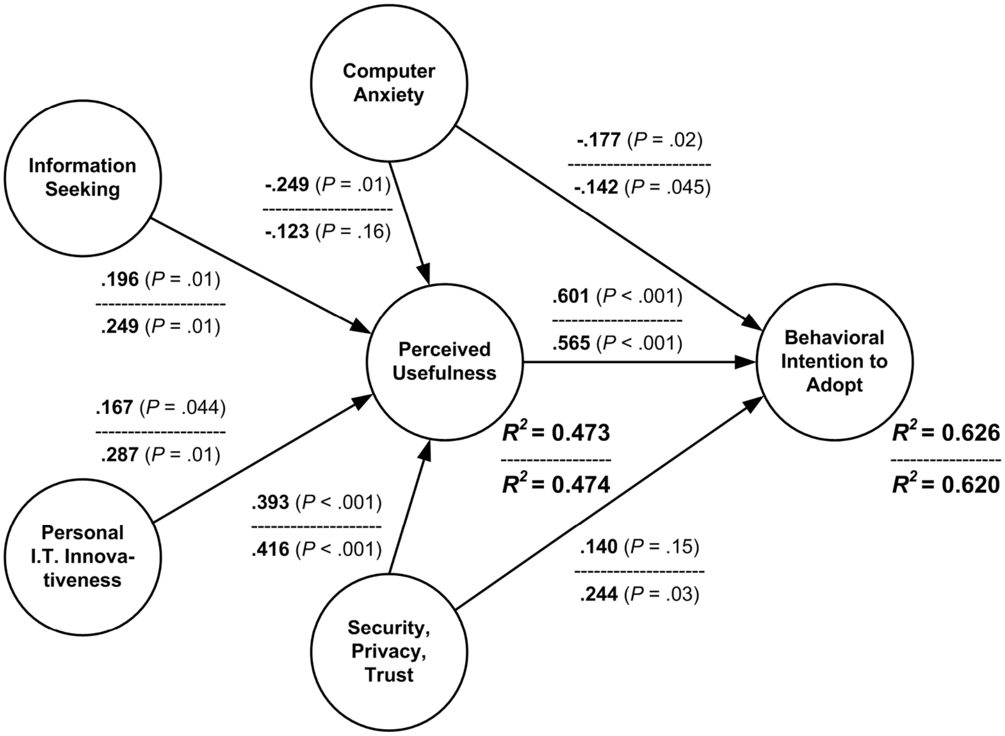

Figure 2 Path coefficients, significance levels and R2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)
179x130mm (300 x 300 DPI)

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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1, 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6-9
Methods			
Study design	4	Present key elements of study design early in the paper	9, 10
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	9, 10
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	9
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	10
Bias	9	Describe any efforts to address potential sources of bias	9
Study size	10	Explain how the study size was arrived at	9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10, 11
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10, 11
		(*b*) Describe any methods used to examine subgroups and interactions	10,11
		(*c*) Explain how missing data were addressed	11
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	12
		(b) Indicate number of participants with missing data for each variable of interest	11
Outcome data	15*	Report numbers of outcome events or summary measures	12
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	14, 15
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	15, 16
Discussion			
Key results	18	Summarise key results with reference to study objectives	16-19
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20
Generalisability	21	Discuss the generalisability (external validity) of the study results	20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

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Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

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Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

ABSTRACT

Objective To develop a model of consumer perceptions of electronic personal health records (PHRs) and validate it in a comparative study between consumers who report having a chronic illness and those who report being well.

Materials and methods A model of PHR use motivators and barriers was built and tested through a national survey across Canada. Data were collected from 800 individuals 18 years or older. Half reported having a chronic illness or disability and half reported being well. Analyses were done with Structural Equation Modeling techniques.

Results A total of 389 answers from chronically ill and 383 from well participants were collected. Perceived Usefulness was the key explanation of the intention to use PHRs for both ill and well people (total effect of .601 and .565, respectively) followed by Security, Privacy, and Trust in PHRs (total effect of .377 and .479, respectively). Conversely, Computer Anxiety was perceived as a significant barrier (total effect of -.327 for ill individuals and -.212 for well individuals).

Discussion The model proposed was appropriate in explaining key consumer positive and negative perceptions on electronic PHR use. We found little difference in perceptions of

electronic PHRs between chronically ill and well individuals, although self-reporting their health status might have influenced the results.

Conclusions To increase the adoption rate of electronic PHRs among both chronically ill and well consumers it is necessary to reinforce consumer perceptions of the usefulness of and trust in these eHealth technologies while mitigating their anxieties about computer use in general.

Strengths and limitations of this study

- This study developed an unbiased theoretical model of consumer perceptions of electronic personal health records (PHRs).
- The model was validated through empirical research comparing the perceptions of chronically ill and well consumers about electronic PHRs.
- The health condition of study participants was self-reported and not diagnosed by practitioners.

OBJECTIVE

Given the current shortage of medical resources available for managing the growing numbers of patients with chronic illnesses, it is becoming apparent that patient self-management is key to managing such illnesses and improving health and quality of life.[1, 2] To manage this process effectively it is important for patients to maintain up-to-date and readily accessible health records.[1, 3] An online health self-management system that is grounded in the chronic care model[4] and that utilizes the patient's health record as a repository can support a system with self-management functionalities for assisting in improved patient-centerd care.[5-8]

Health records maintained and accessible by individual consumers are referred to as Personal Health Records (PHRs). Although they can be recorded and maintained in paper form, a fast emerging trend with the advent of digital data and the Internet is to keep them in an electronic format. Therefore, we will assume throughout this paper that PHRs refer to electronic records on digital media. A PHR can be defined as "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment".[9] This is in contrast with EHR/EMRs (Electronic Health Records/Electronic Medical Records) which contain patient data gathered during the course of patient visits to healthcare providers, and are managed solely by healthcare providers or healthcare institutions. Also, most EHR/EMR data are based on acute care episodes[10] since people are more likely to see their doctors when they have an acute problem.

An ideal form of a PHR is one that exchanges data freely, as authorized by the patient and physician, between the physician's EHR/EMR and the patient's records, as needed.[11]

In theory, PHRs can be of great use to patients in the self-management of chronic diseases and disabilities, but there are significant obstacles to their sustainability, which refers to their adoption and continued use. Trials of eHealth implementations tend to be prone to participant dropouts (attrition).[12] Reported attrition rates from the use of PHRs for health self-management vary widely, from as low as 3% for an interactive web-based intervention that included telephone counseling, to 65% in a smoking cessation program, and to an enormous rate of 99% in a panic disorder self-help program.[13, 14] Although factors affecting attrition tend to be complex,[15] they must be addressed effectively if the benefits of self-management interventions are to be maximized.

The goal of better health may not be sufficient to motivate people to use PHRs, although there are techniques to predict in advance whether patients will adopt and continue with beneficial healthcare behaviors.[16] If patient motivation to adopt PHR innovations were better understood, resulting reductions in attrition rates would lead to improved outcomes from health self-management interventions.

Accordingly, the objective of this study is to determine the key motivators and barriers for individuals to adopt PHRs. As there are indications that people with serious chronic ailments and disabilities are more likely to be favorable to the adoption of PHRs than people who are well,[9] we compared these two groups of people empirically to determine possible differences between adoption factors. Finally, we discuss the results and their significance to further sustainable development and implementation of PHRs, and consumer motivation to adopt and use them.

BACKGROUND AND SIGNIFICANCE

Personal Health Records background

Studies done in various parts of the world have indicated a great deal of public interest in PHRs. For instance, a major motivation for over 70% of U.S. consumers is that they believe having access to PHRs would improve the quality of their healthcare,[17] although as yet there is no convincing evidence that this is the case. Field studies report the greatest interest in PHRs is manifested by the chronically ill, frequent users of healthcare, and caregivers for elderly parents.[9,18] The same studies show that among American consumers saying they were not interested in using PHRs more than 55% indicated that worries about privacy and confidentiality affected their reluctance. Moreover, about 90% of consumers surveyed felt that the provision of privacy, record access, and user remedies would be significant factors affecting their agreement to use an online PHR service.[17] Conversely, some barriers to maintaining and accessing PHRs include cost and loss of interest over time.[19]

Through online and decision support for patient-centerd care, changes in healthcare practice can often help to meet practice and patient goals. For example, research has demonstrated improvements in diabetes outcomes and chronic illness self-management when behavioral support is forthcoming from relevant technologies, improving dietary practices, physical activity, and adherence to medication regimens.[20] Other studies indicate that social activities are particularly important for older people, with health benefits that may include less chance of mortality, disability, and depression, and better cognitive and health-related behaviors.[21] Empirical studies have shown that relative advantage, ease of use, trialability, perceptions of privacy and security, age, and computer experience were positive predictors of the value of

PHRs for supporting communications with the doctor's office.[22] Therefore it is important to understand the key motivators and deterrents for PHR adoption, with the target of improving the adoption rate and sustainability of these systems.

Theoretical model and hypotheses

In the following, we develop a theoretical model that takes into account the above considerations and test it for chronically ill and disabled consumers on the one hand and with consumers who feel that they are relatively healthy on the other hand, in order to compare their perceptions of PHRs. For this purpose we use a number of key constructs validated by previous research in information systems and healthcare, and propose hypotheses regarding their relationships, based on empirical findings and theoretical reasoning.

Information Seeking. Although patients may prefer not to make all their own decisions about their healthcare, they do want to be kept informed. Reportedly, over 40 percent of patients with chronic conditions prefer to receive more information from their healthcare providers than they actually receive.[23] It seems, therefore, that patients with higher information seeking preferences are more likely to feel that PHRs are useful in accessing information on their health status than those who do not. Therefore, we propose the following hypothesis:

H1: Consumers with higher information-seeking preferences will tend to believe that PHRs would be more useful.

Personal Information Technology Innovativeness. This construct captures the willingness of an individual to try out an information technology, as it relates to the concept of technology

acceptance.[24] This indicates that people exhibiting high levels of information technology innovativeness will be more interested in accepting PHRs than those who do not. This leads to the hypothesis:

H2: Individuals with higher levels of IT innovativeness will exhibit higher levels of perceived usefulness for PHRs.

Computer Anxiety. This construct expresses an individual's apprehension or fear when faced with the possibility of using a computer.[25] Previous research has found a negative relationship between computer anxiety and perceived usefulness of new technology, as well as to intention to use a new technology.[26, 27] This results in the following propositions:

H3: Level of computer anxiety will be negatively related to the perceived usefulness of PHRs.

H4: Level of computer anxiety will be negatively related to the intention to use PHRs.

Privacy, Security, and Trust. These concepts have been consistently found in large scale studies to have an impact on consumer interest in online PHR adoption.[28] While some surveys showed two-thirds of adult consumers were concerned about security and privacy of their health data,[17] other market studies found that consumers actually using a PHR did not worry too much about its privacy implications.[29] The chronically and acutely ill and others who often require healthcare appear to have fewer concerns about privacy than do health professionals.[30, 31] Consequently, we propose the following hypotheses:

H5: Consumer perceptions of appropriate security and privacy of PHRs, and trust in PHR providers will positively affect their perceptions of PHR usefulness.

H6: Consumer perceptions of appropriate security and privacy of PHRs, and trust in PHR providers will positively affect their intention to adopt PHRs.

Perceived Usefulness. This construct is a widely known and strong extrinsic motivator of technology use. It expresses “the degree to which a person believes that using a particular system would enhance his or her job performance”.[32] In the case of PHR use, job performance (expectancy) would refer to being able to self-monitor accurately certain health parameters. Thus, it is logical to formulate the hypothesis below:

H7: Higher perceived usefulness for PHRs leads to a higher level of intention to adopt this technology.

The proposed constructs and their related hypotheses are shown in Figure 1 in the form of a theoretical model of PHR adoption. The final endogenous construct of this model is Behavioral Intention to adopt PHRs that measures potential user intentions regarding this eHealth support tool.

*** Insert Figure 1 here. ***

Figure 1 Theoretical model of PHR adoption

MATERIALS AND METHODS

Participant recruitment and data collection

The theoretical model proposed by this study was tested with empirical data collected through an online survey of Canadian consumers. Both French and English versions were prepared and pre-

tested with graduate students and practitioners in a Canadian university. The full scale survey was approved by the Research Ethics Board of the university and subsequently conducted with a Canadian Internet panel of consumers through a market research company. There is no relationship between the researchers and this company, and the company was not allowed to analyze nor retain any copies of the data collected during the survey.

Participants were required to be at least 18 years old and willing to report their health condition. Participants were provided detailed descriptions of a chronic illness condition and of its typical degrees of severity: mild, moderate and severe. 800 of the participants who had pre-registered with the market research company participated in the experiment: the sample was stratified to select exactly 400 who reported a chronic illness or disability at various levels of severity, and exactly 400 who did not report such a condition. These two strata will be indicated in the remainder of this study as ‘Ill’ and ‘Well’.

All participants were presented a detailed description of an electronic Patient Health Record system and then asked to answer an online questionnaire. The questions it contained were meant to measure the multi-item latent variables in the theoretical model described in Figure 1, together with relevant demographic characteristics of the participants surveyed. Most of the survey questions were adapted from those validated by previous research in healthcare (e.g., *Information Seeking*)[33] and information systems (e.g., *Personal Information Technology Innovativeness*, *Computer Anxiety*, *Perceived Usefulness* and *Behavioral Intention*).[24, 27, 32] Measures for the only formative construct in the model, *Security, Privacy and Trust*, although initially sourced from separate constructs in relevant information systems literature, were designed and validated as describing a single variable for this research. Measurement scales are

included in Appendix A. All responses were collected on 7-point Likert scales ranging from Strongly Disagree (1) to Strongly Agree (7), with an additional Not Applicable option. Cases with more than 10% missing answers were deemed invalid and removed from the data analysis.

Theoretical model evaluation

As this research was intended mainly for exploratory purposes, data analysis was done with Partial Least Squares (PLS) due to the suitability of this Structural Equation Modeling methodology for complex exploratory models,[34] using formative indicators[35] such as the Security, Privacy and Trust construct used in this research. PLS analysis was carried out with the SmartPLS software tool[36] and included two successive model assessments: measurement tests (assessing the reliability and validity of the construct measures), followed by structural tests (evaluating the relationships between model constructs).[37] Each analysis for the two sub-samples (Ill and Well) was done separately using the same model.

Use of the PLS tool for analysis determined the minimum study sample size. As the study involves a complex formative construct (i.e., Security, Privacy and Trust), the sample size should be at least ten times the number of its indicators.[38] Furthermore, sample size should account for possible high non-response rates or invalid cases in health-related studies. These considerations led to the target of 400 respondents in each of the two sub-samples.

Assessment of differences between ill and well individuals

Results of theoretical model tests for the two sub-samples were compared through differences in terms of the values of the path coefficients determined by PLS analysis.[38] The degree of difference was assessed with the t-statistic with $N1+N2-2$ degrees of freedom,[39-41] where:

$$t = (Path1 - Path2)/[Spooled*\mathrm{sqrt}(1/N1+1/N2)]$$

Here, $Path1$, $Path2$ are the corresponding path coefficients in the model results and $N1$, $N2$ are the respective sub-sample sizes.

$Spooled$ represents the pooled estimator for the variance and is calculated from:

$$Spooled = \mathrm{sqrt}\{[\text{square of } (N1-1)/(N1+ N2-2)]*\text{square of } SE1 + [\text{square of } (N2-1)/(N1+ N2-2)]*\text{square of } SE2\}$$

Here $SE1$, $SE2$ are the standard errors of the corresponding path coefficients in the two sub-sample model results.

RESULTS

Characteristics of study participants

After removing the invalid cases, a total of 389 Ill cases and 383 Well cases remained and were used in further statistical analyses. Raw data analyzed in this study were part of a larger project conducted in this setting. Table 1 shows comparative demographic characteristics, summarized for the two strata.

Table 1 Participant characteristics

		Ill Participants	**Well Participants**
Sample size		389	383
Age (years, average)		52.5	46.5
Gender			
	Female	248 (63.7%)	221 (57.7%)
	Male	141 (36.3%)	162 (42.3%)
Subject maintains up-to-date PHRs on paper			
	Yes	132 (34.0%)	74 (19.2%)
	No	257 (66.0%)	309 (80.8%)
Subject maintains up-to-date electronic PHRs			
	Yes	46 (11.7%)	22 (5.8%)
	No	343 (88.3%)	361 (94.2%)
Number of visits with a doctor during past 6 months (average)		5.0	2.3
Number of doctors seen during past 6 months (average)		2.3	1.4
Number of children 12 years old or younger for whom they have main care responsibility at home (average)		0.2	0.3
Subject (or someone for whom they are responsible) has a chronic disease that requires continuing medical attention			
	Yes	308 (79.2%)	81 (21.2%)
	No	81 (20.8%)	302 (78.8%)
Subject (or someone for whom they are responsible) has a disability that requires continuing care			
	Yes	205 (52.7%)	42 (11.0%)
	No	184 (47.3%)	341 (89.0%)
Subject is caring for elderly person(s)			
	Yes	49 (12.6%)	21 (5.5%)
	No	340 (87.4%)	362 (94.5%)
Subject is interested in regularly maintaining records about health			
	Yes	323 (83.0%)	247 (64.4%)
	No	66 (17.0%)	136 (35.6%)
Average amount of time spent using the Internet at home daily (largest two categories out of five)			
	31 - 60 minutes	263 (67.7%)	222 (58.0%)
	11 - 30 minutes	99 (25.5%)	111 (29.0%)

Theoretical model evaluation

An initial evaluation of the *measurement model* that comprised 22 items indicated the necessity of dropping 2 items when running it with the Ill data sample and 3 items when running it with the Well data sample, because of unsatisfactory significance and loading values of these items. After re-running SmartPLS for the remaining items, all reflective constructs for both samples displayed Cronbach's alpha and composite reliability values above 0.7, Average Variance Extracted (AVE) values above 0.5, and item loadings above 0.7, while the remaining items of the formative construct Security, Privacy and Trust in PHR were significant and had loadings above 0.5. Thus, the measurement model was considered to have acceptable reliability and convergent validity for both sub-samples.[38 ,42, 43]

A visual inspection of a matrix having the square root of AVEs on the diagonal and the correlations between all reflective constructs in the off diagonal cells showed diagonal numbers to be larger than all numbers on the corresponding rows and columns for both sub-samples (Table 2). This led to the conclusion that the model's reflective constructs had sufficient discriminant validity for both sub-samples.[37] Consequently, the measurement tests of the model for both sub-samples indicated adequate reliability and construct validity for all measurement instruments, either adapted from previous research or developed by this study. This allowed the second step of the PLS process, which was to perform the structural analysis of the model.

Table 2 Reflective construct correlations and square root of AVEs (Ill sample numbers off parentheses and Well sample numbers in parentheses)

	Computer Anxiety	Behavioral Intention	Information Seeking	Perceived Usefulness	Personal IT Innovativeness
Computer Anxiety	**0.89 (0.91)**				
Behavioral Intention	-0.51 (-0.38)	**0.87 (0.93)**			
Information Seeking	-0.13 (-0.13)	0.27 (0.24)	**0.86 (0.88)**		
Perceived Usefulness	-0.47 (-0.31)	0.76 (0.75)	0.33 (0.34)	**0.92 (0.92)**	
Personal IT Innovativeness	-0.33 (-0.17)	0.46 (0.38)	0.07 (0.03)	0.39 (0.42)	**0.92 (0.94)**

Evaluation of the *structural model* involved running SmartPLS with a bootstrap of 200 re-samples. Results for path coefficients, their significance levels, and the values of R^2 are compared in Figure 2 for both sub-samples.

*** Insert Figure 2 here. ***

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

SmartPLS results also provided the total effects of the factors in the theoretical model on behavioral intention to use PHRs, for the two categories of participants (Table 3).

Table 3 Total effects and their significance levels on behavioral intention to adopt PHRs

	Ill Sample		Well Sample	
Antecedent Construct	**Coefficient**	***P*-value**	**Coefficient**	***P*-value**

Computer Anxiety	-.327	<.001	-.212	.01
Information Seeking	.118	.01	.141	.01
Perceived Usefulness	.601	<.001	.565	<.001
Personal IT Innovativeness	.100	.08	.162	.01
Security, Privacy, and Trust	.377	<.001	.479	<.001

All characteristics in Table 1 were tested as potential control variables. In the case of the PHR Ill sub-sample the only influence came from the factor '*subject is interested in regularly maintaining records about health*'. This factor influenced positively the Perceived Usefulness construct (path coefficient of .234 at a P =.02 significance level) and increased the variance explained by this construct from R^2 = 0.473 to R^2 = 0.521). In the case of the PHR Well sub-sample the same interest in regularly maintaining records about health influenced positively the Perceived Usefulness construct (path coefficient of .171 at a P = .04 significance level and increased the variance explained from R^2 = 0.474 to R^2 = 0.499). In addition for this sub-sample, the factor increased Behavioral Intention (path coefficient of .154 at a P = .03 significance level and increase of variance explained from R^2 = 0.620 to R^2 = 0.640). So, the results for the control variable '*subject is interested in regularly maintaining records about health*' played a significant role in both sub-samples.

The self-reported degree of severity of the chronic illness or condition (i.e., mild, moderate or severe) was tested as a possible control variable for the Ill sub-sample. No statistically significant effects on the theoretical model were noticed.

Assessment of differences between ill and well individuals

The results of the differences between the path coefficients of the model for the two sub-samples are presented jointly in Table 4. No *P*-values were calculated since the lack of statistical significance, at a level of probability $P < .05$, of the difference between the results from the two sub-samples (indicated by the low absolute *t*-value of the difference) is very clear.

Table 4 Statistical analysis of differences between Ill and Well consumer sub-samples

Path	Ill Sub-sample Path Coefficient	Well Sub-sample Path Coefficient	Absolute *t*-value of Difference
Computer Anxiety → Behavioral Intention	-.177	-.142	0.348
Computer Anxiety → Perceived Usefulness	-.249	-.123	1.021
Information Seeking → Perceived Usefulness	.196	.249	0.479
Perceived Usefulness → Behavioral Intention	.601	.565	0.255
Personal IT Innovativeness → Perceived Usefulness	.167	.287	0.982
Security, Privacy, and Trust → Behavioral Intention	.140	.244	0.717
Security, Privacy, and Trust → Perceived Usefulness	.393	.416	0.161

DISCUSSION

Principal findings and comparison with prior work

The objective of this study was to determine the key motivators for individuals to adopt electronic Personal Health Records, through a theoretical behavioral model developed here. Furthermore, as previous research and theoretical reasoning indicated that people with chronic illnesses may be more likely to be favorable to the adoption of PHRs than people who are well,[9] in our study we use the model we developed to compare two sub-samples drawn in

Canada from these two populations in order to assess empirically the possible behavioral differences and their determinants.

Our study (Table 3 and Figure 2) confirms largely the findings of research in information systems according to which Perceived Usefulness is the key explanation of the behavioral intention to use an information technology application.[44] Therefore individuals, either chronically ill or well, would use PHRs only if they see the usefulness of these artifacts. This is concordant with findings on other empirical studies on PHRs that showed relative advantage[22] or perception of empowerment[45] as key motivators of adoption.

As expected from previous research,[17] the perception of Security, Privacy, and Trust in PHRs is a significant motivator for use in both categories of individuals surveyed. Table 3 shows this factor is second in terms of total effect to Perceived Usefulness only, being significant at $P <$ .001 for both sub-samples. Interestingly, Security, Privacy, and Trust in PHRs has a non-significant direct influence on Behavioral Intention to use PHRs for the Ill sub-sample (coefficient = .140, $P = .15$). This means security, privacy and trust mean less for ill people – the association of these features with usefulness is more important in the adoption equation. This is confirmed by previous research showing that benefits of access to medical records online may outweigh privacy risk perceptions.[46]

Study results confirm that Information Seeking and Personal IT Innovativeness are motivators of PHR use for both categories of potential users while exerting their influence through Perceived Usefulness (Table 3 and Figure 2). However, the total effect of Personal IT Innovativeness over adoption intention is not significant for the Ill sub-sample, but it is for the Well sub-sample (Table 3).

As hypothesized, Computer Anxiety is the only deterrent on PHR adoption in the theoretical model proposed by this study. It has a negative total influence significant at $P < .001$ for the Ill sub-sample and at $P = .01$ for the Well sub-sample (Table 3).

All demographic characteristics measured and reported in Table 1 were tested as control variables but had no effect for either sample with the exception of participant interest in regularly maintaining records about health. This factor was positive for both sub-samples but more so for the Well one. Therefore, individual interest in self-monitoring health makes them better able to perceive PHR usefulness and to want to use these systems.

Overall, the original model proposed by this study to explain the adoption of PHRs had moderately high variance explained values for all the endogenous constructs, for both sub-samples (R^2 of 0.473/0.474 for Perceived Usefulness and 0.620/0.626 for Behavioral Intention) and 6 out of 7 significant paths in both cases (Figure 2). Therefore, from the statistical point of view, this model could be considered to be reasonably good.[47]

Assessment of differences between ill and well individuals

The key outcomes from the study of perceptions on PHRs of Ill and Well individuals in Table 4 show that there were no statistically significant differences (at a level $P<.05$) between the two sub-samples for any of the paths in Figure 2. On the surface, these outcomes appear to contradict what we had expected – that people with chronic illnesses or disabilities are more interested in PHR adoption than are well people. We suspect that the differences are masked by the fact that many of the people in the Ill sample were, in fact, not seriously ill. The low rate of current PHR use in the both sub-samples could be another explanation for the non-significant differences in perceptions between them. Findings from consumers, especially those with serious chronic illnesses, who had a considerable amount of experience with well-designed PHRs, might be more conclusive than the results from this comparative survey.

Limitations

As in virtually any empirical research, this study has some limitations. First, it is likely that the functionalities that accompany PHR systems would have a strong influence on their adoption. This aspect was not measured in this study. Second, the participants were all Internet users, so it excluded many, particularly older, consumers who were not. In fact more than 60% of the survey participants overall claimed to use the Internet for from 30 to 60 minutes per day. On the other hand, the proportion of Internet and portable device users falls off rapidly with age beyond 65 years,[48] especially for lower income seniors. Therefore, "those who can benefit the most from a PHR system may be the least able to use it".[49] In addition to all these limitations, the most important for a comparative study such as this, participant health conditions were self-reported and not diagnosed by practitioners. Therefore, it is possible that the difference we found in overall perceptions between the two sub-samples was not significant because the difference in participant self-reported health condition between the two sub-samples was weak.

CONCLUSIONS

Despite the inherent limitations of an exploratory study, this research has the merit of investigating individual perceptions about electronic PHRs, using a rigorous theoretical approach that considers the perspectives of ill and well people separately. While remaining parsimonious, the theoretical model developed by this research has the merit of explaining a reasonably high percent of the consumer intention to use electronic PHRs and thus could be a starting point for researchers examining more complex models of eHealth adoption.

According to the findings of this research, to maximize the chances of adoption for PHR support in self-management initiatives, it appears necessary to enhance the motivators, especially the perceptions of usefulness as well as that of security, privacy and trust in PHRs, while mitigating anxieties associated with computer use. Developers and implementers of electronic PHRs should try to enhance the perceptions of positive factors among consumers, and focus on the benefits of using these systems in particular, since favourable factors are far more important than deterrents in the overall adoption equation.

A first exposure to PHRs did not reveal significantly different perceptions of this tool between individuals who reported having a chronic illness and those who reported being well. Therefore it appears that both categories of potential users should be addressed by promoters of PHRs in much the same way in terms of motivating and demotivating factors. However, caution is advised regarding assumptions of equivalence between individuals who report being chronically ill and those who have been diagnosed accordingly. Thus, future studies should attempt to survey chronically ill patients recruited through the healthcare system, after having a specified experience with self-managing their conditions with the aid of PHRs. A comparison of their perceptions of PHRs with those of well individuals would help to improve our understanding of how the adoption of PHRs could be increased overall.

Contributorship Statement

Both authors

1) made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

2) contributed to drafting the article or revising it critically for important intellectual content; and

3) gave final approval of the version to be published.

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Figure legends

Figure 1 Theoretical model of PHR adoption

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

Research Article

Title:

Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

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Perceptions of Chronically Ill and Healthy Consumers about Electronic Personal Health Records: A Comparative Empirical Investigation

ABSTRACT

Objective To develop a model of consumer perceptions of electronic personal health records (PHRs) and validate it in a comparative study between consumers who report having a chronic illness and those who report being well.

Materials and methods A model of PHR use motivators and barriers was built and tested through a national survey across Canada. Data were collected from 800 individuals 18 years or older. Half reported having a chronic illness or disability and half reported being well. Analyses were done with Structural Equation Modeling techniques.

Results A total of 389 answers from chronically ill and 383 from well participants were collected. Perceived Usefulness was the key explanation of the intention to use PHRs for both ill and well people (total effect of .601 and .565, respectively) followed by Security, Privacy, and Trust in PHRs (total effect of .377 and .479, respectively). Conversely, Computer Anxiety was perceived as a significant barrier (total effect of -.327 for ill individuals and -.212 for well individuals).

Discussion The model proposed was appropriate in explaining key consumer positive and negative perceptions on electronic PHR use. We found little difference in perceptions of

electronic PHRs between chronically ill and well individuals, although self-reporting their health status might have influenced the results.

Conclusions To increase the adoption rate of electronic PHRs among both chronically ill and well consumers it is necessary to reinforce consumer perceptions of the usefulness of and trust in these eHealth technologies while mitigating their anxieties about computer use in general.

Strengths and limitations of this study

- This study developed an unbiased theoretical model of consumer perceptions of electronic personal health records (PHRs).
- The model was validated through empirical research comparing the perceptions of chronically ill and well consumers about electronic PHRs.
- The health condition of study participants was self-reported and not diagnosed by practitioners.

OBJECTIVE

Given the current shortage of medical resources available for managing the growing numbers of patients with chronic illnesses, it is becoming apparent that patient self-management is key to managing such illnesses and improving health and quality of life.[1, 2] To manage this process effectively it is important for patients to maintain up-to-date and readily accessible health records.[1, 3] An online health self-management system that is grounded in the chronic care model[4] and that utilizes the patient's health record as a repository can support a system with self-management functionalities for assisting in improved patient-centerd care.[5-8]

Health records maintained and accessible by individual consumers are referred to as Personal Health Records (PHRs). Although they can be recorded and maintained in paper form, a fast emerging trend with the advent of digital data and the Internet is to keep them in an electronic format. Therefore, we will assume throughout this paper that PHRs refer to electronic records on digital media. A PHR can be defined as "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment".[9] This is in contrast with EHR/EMRs (Electronic Health Records/Electronic Medical Records) which contain patient data gathered during the course of patient visits to healthcare providers, and are managed solely by healthcare providers or healthcare institutions. Also, most EHR/EMR data are based on acute care episodes[10] since people are more likely to see their doctors when they have an acute problem.

An ideal form of a PHR is one that exchanges data freely, as authorized by the patient and physician, between the physician's EHR/EMR and the patient's records, as needed.[11]

In theory, PHRs can be of great use to patients in the self-management of chronic diseases and disabilities, but there are significant obstacles to their sustainability, which refers to their adoption and continued use. Trials of eHealth implementations tend to be prone to participant dropouts (attrition).[12] Reported attrition rates from the use of PHRs for health self-management vary widely, from as low as 3% for an interactive web-based intervention that included telephone counseling, to 65% in a smoking cessation program, and to an enormous rate of 99% in a panic disorder self-help program.[13, 14] Although factors affecting attrition tend to be complex,[15] they must be addressed effectively if the benefits of self-management interventions are to be maximized.

The goal of better health may not be sufficient to motivate people to use PHRs, although there are techniques to predict in advance whether patients will adopt and continue with beneficial healthcare behaviors.[16] If patient motivation to adopt PHR innovations were better understood, resulting reductions in attrition rates would lead to improved outcomes from health self-management interventions.

Accordingly, the objective of this study is to determine the key motivators and barriers for individuals to adopt PHRs. As there are indications that people with serious chronic ailments and disabilities are more likely to be favorable to the adoption of PHRs than people who are well,[9] we compared these two groups of people empirically to determine possible differences between adoption factors. Finally, we discuss the results and their significance to further sustainable development and implementation of PHRs, and consumer motivation to adopt and use them.

BACKGROUND AND SIGNIFICANCE

Personal Health Records background

Studies done in various parts of the world have indicated a great deal of public interest in PHRs. For instance, a major motivation for over 70% of U.S. consumers is that they believe having access to PHRs would improve the quality of their healthcare,[17] although as yet there is no convincing evidence that this is the case. Field studies report the greatest interest in PHRs is manifested by the chronically ill, frequent users of healthcare, and caregivers for elderly parents.[9,18] The same studies show that among American consumers saying they were not interested in using PHRs more than 55% indicated that worries about privacy and confidentiality affected their reluctance. Moreover, about 90% of consumers surveyed felt that the provision of privacy, record access, and user remedies would be significant factors affecting their agreement to use an online PHR service.[17] Conversely, some barriers to maintaining and accessing PHRs include cost and loss of interest over time.[19]

Through online and decision support for patient-centerd care, changes in healthcare practice can often help to meet practice and patient goals. For example, research has demonstrated improvements in diabetes outcomes and chronic illness self-management when behavioral support is forthcoming from relevant technologies, improving dietary practices, physical activity, and adherence to medication regimens.[20] Other studies indicate that social activities are particularly important for older people, with health benefits that may include less chance of mortality, disability, and depression, and better cognitive and health-related behaviors.[21] Empirical studies have shown that relative advantage, ease of use, trialability, perceptions of privacy and security, age, and computer experience were positive predictors of the value of

PHRs for supporting communications with the doctor's office.[22] Therefore it is important to understand the key motivators and deterrents for PHR adoption, with the target of improving the adoption rate and sustainability of these systems.

Theoretical model and hypotheses

In the following, we develop a theoretical model that takes into account the above considerations and test it for chronically ill and disabled consumers on the one hand and with consumers who feel that they are relatively healthy on the other hand, in order to compare their perceptions of PHRs. For this purpose we use a number of key constructs validated by previous research in information systems and healthcare, and propose hypotheses regarding their relationships, based on empirical findings and theoretical reasoning.

Information Seeking. Although patients may prefer not to make all their own decisions about their healthcare, they do want to be kept informed. Reportedly, over 40 percent of patients with chronic conditions prefer to receive more information from their healthcare providers than they actually receive.[23] It seems, therefore, that patients with higher information seeking preferences are more likely to feel that PHRs are useful in accessing information on their health status than those who do not. Therefore, we propose the following hypothesis:

H1: Consumers with higher information-seeking preferences will tend to believe that PHRs would be more useful.

Personal Information Technology Innovativeness. This construct captures the willingness of an individual to try out an information technology, as it relates to the concept of technology

acceptance.[24] This indicates that people exhibiting high levels of information technology innovativeness will be more interested in accepting PHRs than those who do not. This leads to the hypothesis:

H2: Individuals with higher levels of IT innovativeness will exhibit higher levels of perceived usefulness for PHRs.

Computer Anxiety. This construct expresses an individual's apprehension or fear when faced with the possibility of using a computer.[25] Previous research has found a negative relationship between computer anxiety and perceived usefulness of new technology, as well as to intention to use a new technology.[26, 27] This results in the following propositions:

H3: Level of computer anxiety will be negatively related to the perceived usefulness of PHRs.

H4: Level of computer anxiety will be negatively related to the intention to use PHRs.

Privacy, Security, and Trust. These concepts have been consistently found in large scale studies to have an impact on consumer interest in online PHR adoption.[28] While some surveys showed two-thirds of adult consumers were concerned about security and privacy of their health data,[17] other market studies found that consumers actually using a PHR did not worry too much about its privacy implications.[29] The chronically and acutely ill and others who often require healthcare appear to have fewer concerns about privacy than do health professionals.[30, 31] Consequently, we propose the following hypotheses:

H5: Consumer perceptions of appropriate security and privacy of PHRs, and trust in PHR providers will positively affect their perceptions of PHR usefulness.

H6: Consumer perceptions of appropriate security and privacy of PHRs, and trust in PHR providers will positively affect their intention to adopt PHRs.

Perceived Usefulness. This construct is a widely known and strong extrinsic motivator of technology use. It expresses "the degree to which a person believes that using a particular system would enhance his or her job performance".[32] In the case of PHR use, job performance (expectancy) would refer to being able to self-monitor accurately certain health parameters. Thus, it is logical to formulate the hypothesis below:

H7: Higher perceived usefulness for PHRs leads to a higher level of intention to adopt this technology.

The proposed constructs and their related hypotheses are shown in Figure 1 in the form of a theoretical model of PHR adoption. The final endogenous construct of this model is Behavioral Intention to adopt PHRs that measures potential user intentions regarding this eHealth support tool.

*** Insert Figure 1 here. ***

Figure 1 Theoretical model of PHR adoption

MATERIALS AND METHODS

Participant recruitment and data collection

The theoretical model proposed by this study was tested with empirical data collected through an online survey of Canadian consumers. Both French and English versions were prepared and pre-

tested with graduate students and practitioners in a Canadian university. The full scale survey was approved by the Research Ethics Board of the university and subsequently conducted with a Canadian Internet panel of consumers through a market research company. There is no relationship between the researchers and this company, and the company was not allowed to analyze nor retain any copies of the data collected during the survey.

Participants were required to be at least 18 years old and willing to report their health condition. Participants were provided detailed descriptions of a chronic illness condition and of its typical degrees of severity: mild, moderate and severe. 800 of the participants who had pre-registered with the market research company participated in the experiment: the sample was stratified to select exactly 400 who reported a chronic illness or disability at various levels of severity, and exactly 400 who did not report such a condition. These two strata will be indicated in the remainder of this study as 'Ill' and 'Well'.

All participants were presented a detailed description of an electronic Patient Health Record system and then asked to answer an online questionnaire. The questions it contained were meant to measure the multi-item latent variables in the theoretical model described in Figure 1, together with relevant demographic characteristics of the participants surveyed. Most of the survey questions were adapted from those validated by previous research in healthcare (e.g., *Information Seeking*)[33] and information systems (e.g., *Personal Information Technology Innovativeness*, *Computer Anxiety*, *Perceived Usefulness* and *Behavioral Intention*).[24, 27, 32] Measures for the only formative construct in the model, *Security, Privacy and Trust*, although initially sourced from separate constructs in relevant information systems literature, were designed and validated as describing a single variable for this research. Measurement scales are

included in Appendix A. All responses were collected on 7-point Likert scales ranging from Strongly Disagree (1) to Strongly Agree (7), with an additional Not Applicable option. Cases with more than 10% missing answers were deemed invalid and removed from the data analysis.

Theoretical model evaluation

As this research was intended mainly for exploratory purposes, data analysis was done with Partial Least Squares (PLS) due to the suitability of this Structural Equation Modeling methodology for complex exploratory models,[34] using formative indicators[35] such as the Security, Privacy and Trust construct used in this research. PLS analysis was carried out with the SmartPLS software tool[36] and included two successive model assessments: measurement tests (assessing the reliability and validity of the construct measures), followed by structural tests (evaluating the relationships between model constructs).[37] Each analysis for the two sub-samples (Ill and Well) was done separately using the same model.

Use of the PLS tool for analysis determined the minimum study sample size. As the study involves a complex formative construct (i.e., Security, Privacy and Trust), the sample size should be at least ten times the number of its indicators.[38] Furthermore, sample size should account for possible high non-response rates or invalid cases in health-related studies. These considerations led to the target of 400 respondents in each of the two sub-samples.

Assessment of differences between ill and well individuals

Results of theoretical model tests for the two sub-samples were compared through differences in terms of the values of the path coefficients determined by PLS analysis.[38] The degree of difference was assessed with the t-statistic with $N1+N2-2$ degrees of freedom,[39-41] where:

$$t = (Path1 - Path2)/[Spooled*sqrt(1/N1+1/N2)]$$

Here, $Path1$, $Path2$ are the corresponding path coefficients in the model results and $N1$, $N2$ are the respective sub-sample sizes.

$Spooled$ represents the pooled estimator for the variance and is calculated from:

$$Spooled = sqrt\{[square\ of\ (N1-1)/(N1+ N2-2)]*square\ of\ SE1 + [square\ of\ (N2-1)/(N1+ N2-2)]*square\ of\ SE2\}$$

Here $SE1$, $SE2$ are the standard errors of the corresponding path coefficients in the two sub-sample model results.

RESULTS

Characteristics of study participants

After removing the invalid cases, a total of 389 Ill cases and 383 Well cases remained and were used in further statistical analyses. Raw data analyzed in this study were part of a larger project conducted in this setting. Table 1 shows comparative demographic characteristics, summarized for the two strata.

Table 1 Participant characteristics

		Ill Participants	**Well Participants**
Sample size		389	383
Age (years, average)		52.5	46.5
Gender			
	Female	248 (63.7%)	221 (57.7%)
	Male	141 (36.3%)	162 (42.3%)
Subject maintains up-to-date PHRs on paper			
	Yes	132 (34.0%)	74 (19.2%)
	No	257 (66.0%)	309 (80.8%)
Subject maintains up-to-date electronic PHRs			
	Yes	46 (11.7%)	22 (5.8%)
	No	343 (88.3%)	361 (94.2%)
Number of visits with a doctor during past 6 months (average)		5.0	2.3
Number of doctors seen during past 6 months (average)		2.3	1.4
Number of children 12 years old or younger for whom they have main care responsibility at home (average)		0.2	0.3
Subject (or someone for whom they are responsible) has a chronic disease that requires continuing medical attention			
	Yes	308 (79.2%)	81 (21.2%)
	No	81 (20.8%)	302 (78.8%)
Subject (or someone for whom they are responsible) has a disability that requires continuing care			
	Yes	205 (52.7%)	42 (11.0%)
	No	184 (47.3%)	341 (89.0%)
Subject is caring for elderly person(s)			
	Yes	49 (12.6%)	21 (5.5%)
	No	340 (87.4%)	362 (94.5%)
Subject is interested in regularly maintaining records about health			
	Yes	323 (83.0%)	247 (64.4%)
	No	66 (17.0%)	136 (35.6%)
Average amount of time spent using the Internet at home daily (largest two categories out of five)			
	31 - 60 minutes	263 (67.7%)	222 (58.0%)
	11 - 30 minutes	99 (25.5%)	111 (29.0%)

Theoretical model evaluation

An initial evaluation of the *measurement model* that comprised 22 items indicated the necessity of dropping 2 items when running it with the Ill data sample and 3 items when running it with the Well data sample, because of unsatisfactory significance and loading values of these items. After re-running SmartPLS for the remaining items, all reflective constructs for both samples displayed Cronbach's alpha and composite reliability values above 0.7, Average Variance Extracted (AVE) values above 0.5, and item loadings above 0.7, while the remaining items of the formative construct Security, Privacy and Trust in PHR were significant and had loadings above 0.5. Thus, the measurement model was considered to have acceptable reliability and convergent validity for both sub-samples.[38 ,42, 43]

A visual inspection of a matrix having the square root of AVEs on the diagonal and the correlations between all reflective constructs in the off diagonal cells showed diagonal numbers to be larger than all numbers on the corresponding rows and columns for both sub-samples (Table 2). This led to the conclusion that the model's reflective constructs had sufficient discriminant validity for both sub-samples.[37] Consequently, the measurement tests of the model for both sub-samples indicated adequate reliability and construct validity for all measurement instruments, either adapted from previous research or developed by this study. This allowed the second step of the PLS process, which was to perform the structural analysis of the model.

Table 2 Reflective construct correlations and square root of AVEs (Ill sample numbers off parentheses and Well sample numbers in parentheses)

	Computer Anxiety	Behavioral Intention	Information Seeking	Perceived Usefulness	Personal IT Innovativeness
Computer Anxiety	**0.89 (0.91)**				
Behavioral Intention	-0.51 (-0.38)	**0.87 (0.93)**			
Information Seeking	-0.13 (-0.13)	0.27 (0.24)	**0.86 (0.88)**		
Perceived Usefulness	-0.47 (-0.31)	0.76 (0.75)	0.33 (0.34)	**0.92 (0.92)**	
Personal IT Innovativeness	-0.33 (-0.17)	0.46 (0.38)	0.07 (0.03)	0.39 (0.42)	**0.92 (0.94)**

Evaluation of the *structural model* involved running SmartPLS with a bootstrap of 200 re-samples. Results for path coefficients, their significance levels, and the values of R^2 are compared in Figure 2 for both sub-samples.

*** Insert Figure 2 here. ***

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

SmartPLS results also provided the total effects of the factors in the theoretical model on behavioral intention to use PHRs, for the two categories of participants (Table 3).

Table 3 Total effects and their significance levels on behavioral intention to adopt PHRs

	Ill Sample		**Well Sample**	
Antecedent Construct	**Coefficient**	***P*-value**	**Coefficient**	***P*-value**

Computer Anxiety	-.327	<.001	-.212	.01
Information Seeking	.118	.01	.141	.01
Perceived Usefulness	.601	<.001	.565	<.001
Personal IT Innovativeness	.100	.08	.162	.01
Security, Privacy, and Trust	.377	<.001	.479	<.001

All characteristics in Table 1 were tested as potential control variables. In the case of the PHR Ill sub-sample the only influence came from the factor '*subject is interested in regularly maintaining records about health*'. This factor influenced positively the Perceived Usefulness construct (path coefficient of .234 at a P =.02 significance level) and increased the variance explained by this construct from R^2 = 0.473 to R^2 = 0.521). In the case of the PHR Well sub-sample the same interest in regularly maintaining records about health influenced positively the Perceived Usefulness construct (path coefficient of .171 at a P = .04 significance level and increased the variance explained from R^2 = 0.474 to R^2 = 0.499). In addition for this sub-sample, the factor increased Behavioral Intention (path coefficient of .154 at a P = .03 significance level and increase of variance explained from R^2 = 0.620 to R^2 = 0.640). So, the results for the control variable '*subject is interested in regularly maintaining records about health*' played a significant role in both sub-samples.

The self-reported degree of severity of the chronic illness or condition (i.e., mild, moderate or severe) was tested as a possible control variable for the Ill sub-sample. No statistically significant effects on the theoretical model were noticed.

Assessment of differences between ill and well individuals

The results of the differences between the path coefficients of the model for the two sub-samples are presented jointly in Table 4. No *P*-values were calculated since the lack of statistical significance, at a level of probability $P < .05$, of the difference between the results from the two sub-samples (indicated by the low absolute *t*-value of the difference) is very clear.

Table 4 Statistical analysis of differences between Ill and Well consumer sub-samples

Path	Ill Sub-sample Path Coefficient	Well Sub-sample Path Coefficient	Absolute *t*-value of Difference
Computer Anxiety → Behavioral Intention	-.177	-.142	0.348
Computer Anxiety → Perceived Usefulness	-.249	-.123	1.021
Information Seeking → Perceived Usefulness	.196	.249	0.479
Perceived Usefulness → Behavioral Intention	.601	.565	0.255
Personal IT Innovativeness → Perceived Usefulness	.167	.287	0.982
Security, Privacy, and Trust → Behavioral Intention	.140	.244	0.717
Security, Privacy, and Trust → Perceived Usefulness	.393	.416	0.161

DISCUSSION

Principal findings and comparison with prior work

The objective of this study was to determine the key motivators for individuals to adopt electronic Personal Health Records, through a theoretical behavioral model developed here. Furthermore, as previous research and theoretical reasoning indicated that people with chronic illnesses may be more likely to be favorable to the adoption of PHRs than people who are well,[9] in our study we use the model we developed to compare two sub-samples drawn in

Canada from these two populations in order to assess empirically the possible behavioral differences and their determinants.

Our study (Table 3 and Figure 2) confirms largely the findings of research in information systems according to which Perceived Usefulness is the key explanation of the behavioral intention to use an information technology application.[44] Therefore individuals, either chronically ill or well, would use PHRs only if they see the usefulness of these artifacts. This is concordant with findings on other empirical studies on PHRs that showed relative advantage[22] or perception of empowerment[45] as key motivators of adoption.

As expected from previous research,[17] the perception of Security, Privacy, and Trust in PHRs is a significant motivator for use in both categories of individuals surveyed. Table 3 shows this factor is second in terms of total effect to Perceived Usefulness only, being significant at $P <$ .001 for both sub-samples. Interestingly, Security, Privacy, and Trust in PHRs has a non-significant direct influence on Behavioral Intention to use PHRs for the Ill sub-sample (coefficient = .140, P = .15). This means security, privacy and trust mean less for ill people – the association of these features with usefulness is more important in the adoption equation. This is confirmed by previous research showing that benefits of access to medical records online may outweigh privacy risk perceptions.[46]

Study results confirm that Information Seeking and Personal IT Innovativeness are motivators of PHR use for both categories of potential users while exerting their influence through Perceived Usefulness (Table 3 and Figure 2). However, the total effect of Personal IT Innovativeness over adoption intention is not significant for the Ill sub-sample, but it is for the Well sub-sample (Table 3). ~~This suggests that technical innovativeness means less for ill people than it does for~~

~~well people, indicating that ill people are less interested in adopting a PHR just because it is innovative, but for other reasons, including the value it can provide in managing their disease(s).~~

As hypothesized, Computer Anxiety is the only deterrent on PHR adoption in the theoretical model proposed by this study. It has a negative total influence significant at $P < .001$ for the Ill sub-sample and at $P = .01$ for the Well sub-sample (Table 3). ~~Results in Figure 2 confirm that the influence of Anxiety is less apparent for the Well sub-sample compared to the Ill sub-sample. Therefore ill individuals, who presumably might be attracted to using PHRs, would be more concerned about the skills necessary to access computer-based PHRs. Their concerns would clearly have to be addressed in order to increase PHR adoption.~~

All demographic characteristics measured and reported in Table 1 were tested as control variables but had no effect for either sample with the exception of participant interest in regularly maintaining records about health. This factor was positive for both sub-samples but more so for the Well one. Therefore, individual interest in self-monitoring health makes them better able to perceive PHR usefulness and to want to use these systems.

Overall, the original model proposed by this study to explain the adoption of PHRs had moderately high variance explained values for all the endogenous constructs, for both sub-samples (R^2 of 0.473/0.474 for Perceived Usefulness and 0.620/0.626 for Behavioral Intention) and 6 out of 7 significant paths in both cases (Figure 2). Therefore, from the statistical point of view, this model could be considered to be reasonably good.[47]

Assessment of differences between ill and well individuals

The key outcomes from the study of perceptions on PHRs of Ill and Well individuals in Table 4 show that there were no statistically significant differences (at a level $P<.05$) between the two sub-samples for any of the paths in Figure 2. On the surface, these outcomes appear to contradict what we had expected – that people with chronic illnesses or disabilities are more interested in PHR adoption than are well people. We suspect that the differences are masked by the fact that many of the people in the Ill sample were, in fact, not seriously ill. The low rate of current PHR use in the both sub-samples could be another explanation for the non-significant differences in perceptions between them. Findings from consumers, especially those with serious chronic illnesses, who had a considerable amount of experience with well-designed PHRs, might be more conclusive than the results from this comparative survey.

Limitations

As in virtually any empirical research, this study has some limitations. First, it is likely that the functionalities that accompany PHR systems would have a strong influence on their adoption. This aspect was not measured in this study. Second, the participants were all Internet users, so it excluded many, particularly older, consumers who were not. In fact more than 60% of the survey participants overall claimed to use the Internet for from 30 to 60 minutes per day. On the other hand, the proportion of Internet and portable device users falls off rapidly with age beyond 65 years,[48] especially for lower income seniors. Therefore, "those who can benefit the most from a PHR system may be the least able to use it".[49] In addition to all these limitations, the most important for a comparative study such as this, participant health conditions were self-reported and not diagnosed by practitioners. Therefore, it is possible that the difference we found in overall perceptions between the two sub-samples was not significant because the difference in participant self-reported health condition between the two sub-samples was weak.

CONCLUSIONS

Despite the inherent limitations of an exploratory study, this research has the merit of investigating individual perceptions about electronic PHRs, using a rigorous theoretical approach that considers the perspectives of ill and well people separately. While remaining parsimonious, the theoretical model developed by this research has the merit of explaining a reasonably high percent of the consumer intention to use electronic PHRs and thus could be a starting point for researchers examining more complex models of eHealth adoption.

According to the findings of this research, to maximize the chances of adoption for PHR support in self-management initiatives, it appears necessary to enhance the motivators, especially the perceptions of usefulness as well as that of security, privacy and trust in PHRs, while mitigating anxieties associated with computer use. Developers and implementers of electronic PHRs should try to enhance the perceptions of positive factors among consumers, and focus on the benefits of using these systems in particular, since favourable factors are far more important than deterrents in the overall adoption equation.

A first exposure to PHRs did not reveal significantly different perceptions of this tool between individuals who reported having a chronic illness and those who reported being well. Therefore it appears that both categories of potential users should be addressed by promoters of PHRs in much the same way in terms of motivating and demotivating factors. However, caution is advised regarding assumptions of equivalence between individuals who report being chronically ill and those who have been diagnosed accordingly. Thus, future studies should attempt to survey chronically ill patients recruited through the healthcare system, after having a specified experience with self-managing their conditions with the aid of PHRs. A comparison of their perceptions of PHRs with those of well individuals would help to improve our understanding of how the adoption of PHRs could be increased overall.

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Competing interests None.

Ethics approval Research Ethics Board of a Canadian university.

Data sharing statement No additional data available.

Figure legends

Figure 1 Theoretical model of PHR adoption

Figure 2 Path coefficients, significance levels and R^2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)

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APPENDIX A

Measurement scales

Information Seeking

I believe that doctors should explain the purpose of laboratory and other tests.

I believe that the results of laboratory and other tests should be made available to patients.

I believe that people should know all the important side effects of their medications.

Personal Information Technology Innovativeness

If I hear about a new information technology I look for ways to experiment with it.

Among my friends I am usually the first to try out new information technologies.

In general, I am eager to try out new information technologies.

Computer Anxiety

I would feel apprehensive about using an Electronic Personal Health Record system.

It scares me to think that I could lose a lot of information using an Electronic Personal Health Record system by hitting the wrong key.

Using an Electronic Personal Health Record system would make me nervous.

Security, Privacy and Trust

From a security and privacy perspective I would prefer to maintain up-to-date electronic personal health records on a system that:

Ran strictly on my own personal computer.

Ran strictly on my own personal computer, with provision to take the records with me on a secure memory device, such as a smart card, as needed.

Is accessible through a secure Internet web site that is maintained by the provincial government's health authority.

Is accessible through a secure Internet web site that is maintained by my own family doctor.

Is accessible through a secure Internet web site that is maintained by a private company.

Perceived Usefulness

Using my own Electronic Personal Health Records would help to support critical aspects of my health care such as scheduling appointments, recording my health status, etc.

Using my own Electronic Personal Health Records would enhance my effectiveness in managing my own health care, such as managing medications, reviewing my progress, etc.

Using my own Electronic Personal Health Records would make me more effective in providing up-to-date health information about myself when interacting with my physician.

Using my own Electronic Personal Health Records would help to improve my health.

Overall, having my own Electronic Personal Health Record system would be useful in managing my health care.

Behavioural Intention to Adopt an ePHR

If an Electronic Personal Health Record system is made available for me, I intend to use it.

If an Electronic Personal Health Record system is made available for me, I predict that I would use it.

If an Electronic Personal Health Record system is made available for me, I intend to work together with my spouse or other caregiver(s) to use it on my behalf.

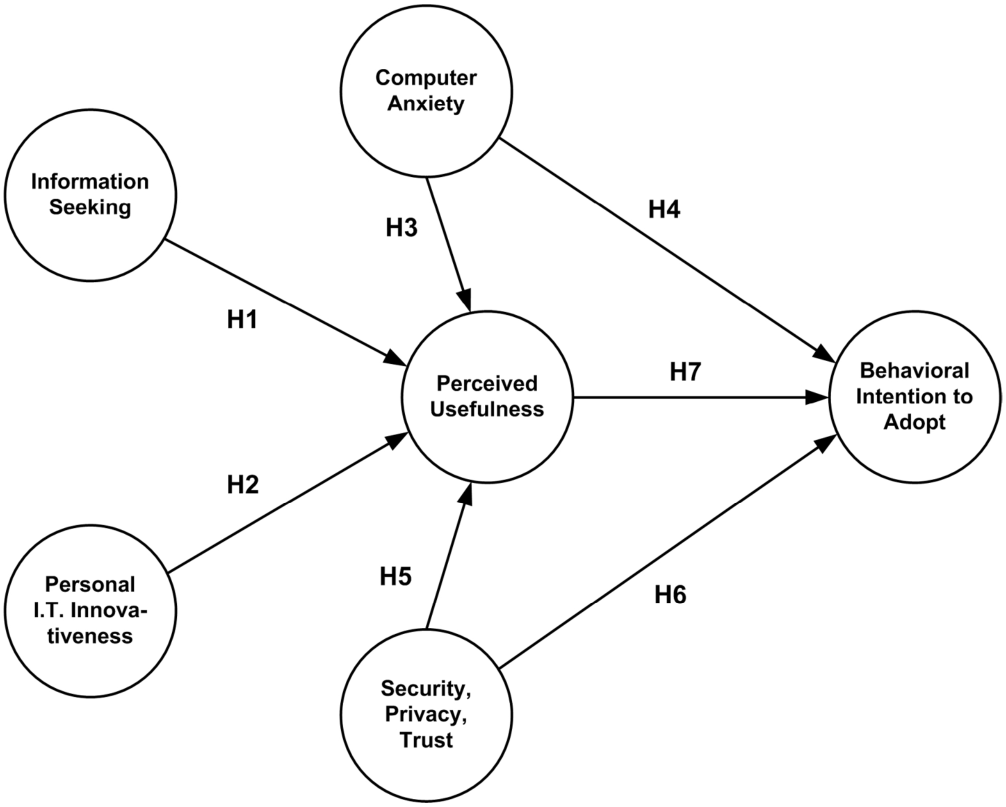

Figure 1 Theoretical model of PHR adoption
163x130mm (300 x 300 DPI)

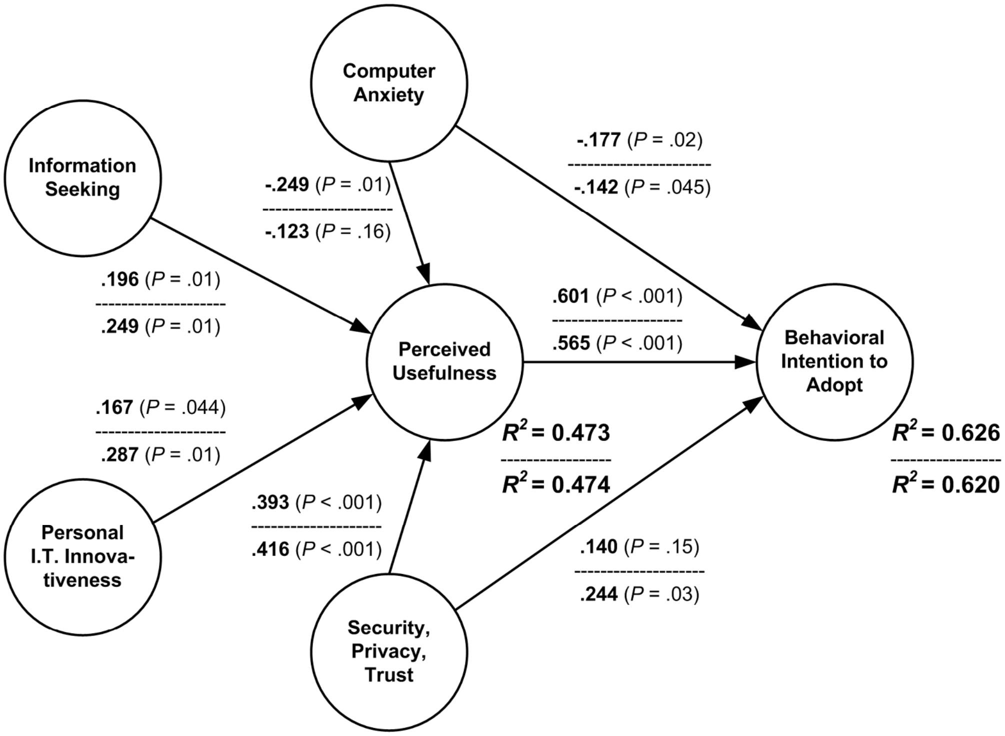

Figure 2 Path coefficients, significance levels and R2 values for the PHR adoption model (Ill sub-sample numbers above the line and Well sub-sample numbers below the line)
179x130mm (300 x 300 DPI)

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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1, 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6-9
Methods			
Study design	4	Present key elements of study design early in the paper	9, 10
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	9, 10
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	9
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	10
Bias	9	Describe any efforts to address potential sources of bias	9
Study size	10	Explain how the study size was arrived at	9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10, 11
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10, 11
		(*b*) Describe any methods used to examine subgroups and interactions	10,11
		(*c*) Explain how missing data were addressed	11
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	12
		(b) Indicate number of participants with missing data for each variable of interest	11
Outcome data	15*	Report numbers of outcome events or summary measures	12
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	14, 15
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	15, 16
Discussion			
Key results	18	Summarise key results with reference to study objectives	16-19
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20
Generalisability	21	Discuss the generalisability (external validity) of the study results	20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.