Role of Nurse Practitioners in Encouraging Use of Personal Health Records

Abstract. With increased mobility, it is important that individuals keep their own personal health records (PHRs). We encourage nurse practitioners to assume greater responsibility for PHR adoption and recognize the key role they play in recommending PHR use. We also briefly report college students' perceptions on their exposure to online PHRs.

Keywords: personal health records, electronic health records, role of nurse practitioners, Microsoft HealthVault, Google Health

Introducing Personal Health Records in Practice Settings

Personal health records (PHRs) are electronic health records that individuals create and maintain (see Figure 1). PHRs can enhance the flow of health care information by allowing instant access to vital health information when individuals are away from their primary care providers (PCPs), when they relocate and have to find new PCPs, or when they experience health care emergencies. Individuals who suffer from chronic diseases necessitating ongoing monitoring such as diabetes, asthma, attention deficit, cancer, or HIV/AIDS reap particular benefits, as PHRs provide easy online accessibility to health information with patient portals and educational tools tailored to the needs of persons with specific disease states.

PHRs have the potential to play a significant role in health care interoperability by enhancing multidisciplinary communication among providers. Since individuals own their PHRs, they have control over what content is posted and can grant permission to others for access to their health information. Typically, PHRs include core health information such as personal and demographic information, current health issues, insurance information, medical history, family history, medications, allergies, and laboratory and radiographic test results. Some also include advance directive forms, spiritual affiliation, and lifestyle habits. Figure 1 shows a sample PHR as viewed in the free online system HealthVault[TM] (www.healthvault.com) by Microsoft. The potential for PHRs to contribute to public health initiatives, such as monitoring disease outbreaks has not been explored, but one can imagine use in monitoring the health status of various populations, assisting in management of disease outbreaks, empowering individuals to take control of their own health, and contributing to research.[1] For example, the influenza epidemics early in the 20th century took thousands of lives. If individuals had kept personal health records at that time, public health professionals could map not only the patterns of disease

spread, but also document cohorts who escaped being infected. [2] These data are perhaps all the more important in an age of global community, new diseases, and more virulent strains of old bacteria and viruses.

In spite of the aforementioned notable potential benefits, consumers in general have been slow to adopt PHRs.[3] In a July 2004 Harris Interactive online poll of 2,242 U.S. adults, 42% of the respondents reported keeping personal medical records,[4] but the vast majority did so on paper. Little has changed in terms of PHR adoption in the past several years. According to the IDC Health Insights' survey of 1200 consumers in February, 2011, only 7% of respondents reported ever having used a PHR, and fewer than half of these (47.6%) were still using one to manage their family's health.[5] Of interest are 50.6% of the respondents in a study on consumer adoption of PHRs who reported that the reason they had not used the online technology was lack of familiarity with the concept of a PHR.[3]

The Role of Nurse Practitioners in Introducing PHRs

In 2012, the American Nurses Association (ANA) endorsed the use of online personal health records.[6,7] This action was a follow up to ANA's 2008 document *Nursing Informatics: Scope and Standards of Practice*. In an effort to involve and empower consumers to partner with caregivers, ANA is challenging all nurses to obtain their health care records and create PHRs.[6]

With the increased mobility of the US population, people often are away from their primary care providers, have fragmented health records, and may rely on others to manage their health information. Using a PHR could provide individuals a context within which to better understand their health and make more informed health care decisions. Since the US population is increasingly computer savvy, the information age creates an opportunity for healthcare providers to discuss the importance of personal health records and to shift toward taking

responsibility for stewardship of personal health information. Further, such discussions might motivate individuals across the lifespan to take charge of their health and make better lifestyle choices and other preventative decisions.[5]

As caregivers to individuals across the lifespan in a wide variety of clinical settings, nurse practitioners are key to introducing patients to the idea of electronic PHRs. To address the projected shortages of primary care providers reported by the Health Resources and Services Administration (HRSA) in 5700 geographic areas with 55 million residents, the Robert Wood Johnson Foundation and Health Affairs published a health policy brief proposing expansion of the role of nurse practitioners in many more areas of US, and allowing NPs to provide a wider range of preventive and acute health care services. When this role expansion occurs, NPs will be key to introducing new cohorts of patients to PHRs.[8]

How does one create a PHR?

So, how does one get a PHR for oneself and one's family? One can:

- Check with one's health care organization to see if her PHR can be populated from one's Electronic Health Record (EHR)

- Check with you insurer to see if one's PHR can be populated with one's claims data

- Check with one's employer who may have a PHR with health risk assessment(s), healthy lifestyle resources, and online support for chronic conditions

- Create one's own free PHR online (for example, Microsoft HealthVault™ www.healthvault.com). This PHR is available free online and is based on a business model of attracting more users to advertising-based web sites. It provides a person the options to:

1. add or update health information. A sample PHR is shown in Figure 1. Figure 2 shows the types of items that one can add to one's Personal Health Record.

2. get medical records into HealthVault (using various apps and devices),

3. prepare for an emergency (by printing a wallet card, sharing emergency profile or finding emergency apps),

4. maintain or reach weight goals,

5. share health information with family, and

6. exchange encrypted email with participating doctors.

Under their 'How it works' section[9], five sample stories are provided of people who use the online tool to manage family health information, manage a chronic condition, and be prepared for an emergency, work towards weight or fitness goals and to share the care of an elderly family member.

The Lister Hill National Center for Biomedical Communications[10] provides a good resource on PHRs with a number of snapshots on personal health records.

How Do Patients Respond to PHRs

According to data from research conducted by the California Health Care Foundation, over 60% of health care consumer respondents wished that their providers had more time to talk to with them about their health status and that of their families[11]. More than half of the consumers also reported difficulties in keeping track of their health information. Using PHRs helps individuals organize categories of health information.[11]

PHRs are just beginning to emerge as topic in health care settings including student health services and in the electronic health (e-health) movement. Empowering patients to take

charge of their health, and to be collaborative partners with their health care providers, requires that they have access to their health information.   Today, many health care institutions allow patient panels to access their electronic health records (EHRs).   Consumers are signing up for electronic access, not only to their EHRs, but also for communicating with their health care providers via email, online appointment scheduling, and prescription refills.

PHRs create a venue for individuals to securely store all their health information and consolidate these data into an easily accessible account. Creating a PHR helps people to become more informed and active in managing their own health care. However, there is no exact definition for PHRs, since they are continuously evolving. The American Health Information Management Association (AHIMA) defines a PHR as "*an electronic, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR does not replace the legal record of any provider.*"[12] Healthcare Information and Management Systems Society (HIMMS) defines an electronic PHR (ePHR) as "*a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations.*"[13]

Current PHRs comprise one of a few basic models: 1) provider hosted patient portal; 2) payer hosted patient portal; 3) employer sponsored; 4) vendor hosted; and 5) consumer created. All aforementioned PHR models serve as secure repositories for patients to store, retrieve, and manipulate their own health records. Each is password protected and the individual patient controls access to the information and can choose what can be shared with others including health care providers. All models include uploading and storage of health records, as well as search engine capabilities.[5] It should be noted that the PHR platform offered by Google was shut down last year due to lack of consumer interest[14].

PHRs can include insurers' claims data, clinician electronic health records (EHRs), pharmacy records, laboratory results, and patient entered data. Some PHRs also include clinical decision support systems and a variety of convenient applications such as appointment scheduling, referral requests, medication refills, and online billing payment. Patients can store health information obtained from a number of sources; upload information from health and fitness devices; provide information to multidisciplinary providers, schools, and trainers, and access a myriad of emerging social media.[15]

PHRs can afford patients the opportunity to become more active participants in their care since they can create, access, manage and maintain their own health care records. As heath care reforms evolve and more consumers become strategic partners in their health care, it is likely that health care delivery models will change. One of the major catalysts catapulting the consumer movement is the World Wide Web. Health care information and knowledge are no longer just in the hands of health care providers. The Internet has democratized access to knowledge and created a new generation of net savvy consumers who are also patients across all health care agencies and systems.[15, 16, 17, 18]

PHRs will create new opportunities to increase collaboration of care and foster partnerships between providers and patients. Providers will be able to link tailored health information based on a patient's medical condition(s), thus providing more patient-centric, individualized care. It is anticipated that this may lead to patients achieving a better understanding of their health problems, health care responsibilities and disease management strategies. According to the Markle Foundation, the majority of consumers would like to use a PHR to help them understand their providers' instructions more clearly.[19] Forker-Dunn[17]discussed the next generation of health care delivery systems and the growth of a generation of net savvy patients.   She posited that the eHealth train has not only left the station, but is rapidly moving down the track carrying tens of millions of e-patients and many possibilities for transforming patient self-empowerment, improving health outcomes and enhancing the patient–clinician relationship.[17]

Ferguson and Frydman described the first generation of e-patients and noted that e-patients have "better health information and services and have different, not necessarily better, relationships with their providers." [20, p.1148] PHRs hold the promise of empowering all persons by making them the stewards of their own health care data. Funding of the Healthcare Innovation and Marketplace Technologies Act (HITECH) for 2013 is pending, as Congress struggles with details of the fiscal 2013 federal budget.[21] Financial incentives to providers and primary care teams for prevention and for meeting expected guidelines might encourage behavior change toward more active support of self-management and PHRs. Notably absent from the federal budget, however, was any mention of PHRs.

The potential for PHRs to contribute to public health initiatives such as monitoring disease outbreaks, for example, the norovirus, has not been looked at but holds potential value.[22]

A first step, however, is encouraging individuals to keep their own PHRs. In order to make this possible, health care providers need to understand and address key barriers to full adoption.

The notion of patient ownership, control, and storage of data continues to be hampered by major unresolved issues in PHR adoption. Traditionally, providers have been legally responsible for recording and safely storing accurate and timely patient care health records.   Some of the unanswered questions that continue to inhibit more widespread use of PHRs include the following: 1) How much provider-generated information do patients have a right to view? 2) What if patients' care providers do not agree to share information? and 3) How will an individual's data be incorporated into providers' electronic records? For example, will blood pressure, peak flows or glucose readings from home, health information from a variety of caregivers, and care settings be populated in the same portion of the database?[23]

Currently, there are no stipulations to guide how access to and interoperability of PHRs will be provided. These are critical issues to solve, as most individuals' medical records are scattered in many different locations with a variety of providers. PHRs vary in their content, scope, source of information, owner, location of the record, technical approach and access to the record.   Unfortunately, to date most PHRs are not standards-based and few support an easy way to transport records between PHR products.   Security concerns are also a potential barrier to widespread PHR adoption.   The Markel Foundation reported that the majority of participants in their research studies believe that technology provides adequate security protection and they would not be reluctant to use PHR features.[19]   In a Harris poll, almost two thirds of respondents were most concerned about privacy and security.[4]   Other concerns were potential error, access to their information in an emergency, and inability to keep their information up to date. Further, respondents did not want their PHRs managed by their insurance companies or the government.

However, they reported trust in their providers to host, manage and access their PHR.[22] Lack of computer literacy also represents a significant barrier to widespread PHR adoption, but less so in a college population as most college students are computer literate, and even net savvy, as they are required to be by their educational institutions.[23]

Thus, there will need to be a significant socio-cultural paradigmatic shift to address the challenge of instituting the ubiquitous use of PHRs on college campuses. However, issues of software incompatibilities with PHRs and thus lack of interoperability with an institution's Electronic Medical Records must be addressed.   Nurses, as the largest number of knowledge workers in US health, will need to receive sufficient continuing education in order to become part of the PHR movement and become involved in educating the public. Finally, ethical issues, especially those of security and privacy protections must continue to be addressed by proponents of PHR for both consumers and providers.

Exploring Perceptions of PHRs

To examine the reactions of individuals to PHRs, we sought information on college students' exposure to online PHRs and compared their perceptions of the two major online PHR systems Google Health™ and Microsoft HealthVault™. Both were free and served as a secure repository for study participants to store, retrieve, and manipulate their own health records. Both included uploading and storage of health records, as well as search engine capabilities. It is important to note, however, that Google Health ™ was discontinued as of January 1, 2012.[14] Users were given until January 1, 2013 to download data stored in Google Health™. Microsoft HealthVault™, on the other hand, continues to be freely accessible.

The study sought to explore the extent to which college students been exposed to PHRs, and their comparative perceptions of the two online PHR systems. For this randomized cross-

sectional study, we utilized a repeated measures crossover design. We created six subscales to measure perceptions: computer self-efficacy, subjective satisfaction, perceived value of service, ease-of-use, confidentiality, and intention of long-term use.[22-23, 24-28]

The survey questionnaire was designed for this pilot study by the authors and included 38 items to assess perceptions (see Table 1), two questions to determine exposure to PHRs, and five demographic items – leading to a total of 45 questions that respondents had to answer. The survey was titled, "Comparing college student's exposure and perception of online personal health records: Google Health versus Microsoft HealthVault". A 7-point Likert scale (1= strongly disagree, 7= strongly agree) was used for all perception questions, so participants could indicate the degree to which they agreed or disagreed with each statement. Internal consistency reliability testing was completed on each of the 6 subscales using Cronbach's alpha with values ranging between .893 and .995 for Google Health and between .882 and .979 for Microsoft HealthVault (see Table 2). The target study population included undergraduate and graduate students, all health majors, and library and information science students enrolled at a small university in New England. The college's Institutional Review Board (IRB) granted approval for the study.

With the permission of instructors, the study was presented to potential participants in a classroom setting. The study was briefly described to students using handouts and PowerPoint presentations. Using the same set of handouts and presentations across different classes enhanced the consistency of communication between the researchers and study participants. Presentations included information such as study objectives, eligibility criteria, the risks and benefits of participation, confidentiality, and student's right to withdrawal from the study at any time without the risk of penalty or repercussion. Participants were also informed that their classroom

grade would not be affected irrespective of their decision to participate or not in the study.

Following each presentation, students were encouraged to ask any questions regarding

participation. Paper-based surveys and study information were then distributed in a randomized

fashion to potential participants. The random allocation included handing out one of two types of

survey questionnaires (which were stacked alternatively). The first required creating a health

record using Google Health, and then followed by Microsoft HealthVault. The second required

creating a health record using Microsoft HealthVault, followed by Google Health. This was done

to eliminate any effects of the order of use of one system versus the other. The surveys were

completed in the privacy of the participant's home, were completely anonymous, and researchers

did not have access to the participants' personal health information. Out of 200 students

recruited, only 34 chose to participate in the study and to return completed questionnaires after

they had tried out both the systems in their homes. The majority of study participants 97% were

female; 84% were graduate students and 16% undergraduates. Study majors included nursing

and physical therapy. Three percent of the study sample identified themselves as

Hispanic/Latino and the remaining 97% as Caucasian. In a separate item, 18% of respondents

reported being multi-racial. The mean age of participants was 27.97 years. None of the

participants had ever used the Google, Microsoft, or any other PHR tool prior to the study.

Table 3 shows the means and standard deviations of each subscale for Google Health and

Microsoft HealthVault. Higher means are indicative of more agreement.   The Wilcoxon

matched pairs signed ranks test was used to compare the two PHR tools on each of the subscale

scores as well as a survey item on withholding survey data. None of the tests was statistically

significant. There were no statistically significant differences in participants' perceptions of the

two PHRs. Perceived Value of Service was the only subscale that showed a marginally

significant difference between Google Health and Microsoft HealthVault (p=.088). Overall, the 34 participants had a moderately positive perception of both PHRs with means ranging from 5.00 to 6.39 on a 7-point scale. However, participants were ambivalent about long-term use of the systems (with means of 3.78 and 3.28, respectively, for the Google and Microsoft tools). The subscale with the highest overall ratings for both PHRs was Computer Self-Efficacy.

The use of the Technology Acceptance Model (TAM) theory as postulated by Davis[24] and Davis, Bagozzi, and Warshaw[28] provides a useful theoretical perspective to advance the understanding of this work. Moreover, since use of electronic PHRs is in its infancy, there are opportunities to introduce in primary care settings where many NPs practice.

This was a pilot study to ascertain how college students perceive PHRs. It gives us some insight into perception and possible adoption. The study showed that most respondents hadn't heard of such systems. This calls for the role of Nurse practitioners in helping change the scenario and facilitate greater awareness and adoption of PHRs.

The Future of PHRs

Personal Health Records have the potential to place patients at the center of health care information exchange and empower individuals to become the stewards of their own health care information. PHRs can have a significant effect on the health of individuals and continuity of care by facilitating health data information exchange among the patients and their multiple providers, settings, and disciplines. As clinicians learn to manage health care in an ever-evolving environment of advanced web-based communication, it is essential that they understand the value of e-communication tools such as PHRs to provide coordinated, comprehensive, quality care. Having essential health information accessible to providers at each health care encounter will result in patients receiving more efficient care and achieving more effective health

care outcomes. There is a need for clinicians to be educated on the usefulness and power of

PHRs, and to participate in the PHR movement and education of all their patients in all care

settings.

Noblin and colleagues[29] noted the limitation of the utility of PHRs with individuals with

low health literacy and the need to provide tools to aid these individuals in understanding and

interpreting the content of PHRs. These investigators reported that 74% of the patients in a

practice serving low health literacy patients intend to adopt a PHR.

The ready availability of data in PHRs raises issues about protecting private data and who

may access those data. Only those personal health records offered by health care providers and

health plans are covered under the HIPAA Privacy Rule. Those offered by vendors that are not

HIPAA covered entities are governed by the privacy policies of those PHR vendors as well as

any other applicable laws.

Moving forward, a significant paradigm shift will be necessary to address the challenges

of assuring the ubiquitous adoption of PHRs.   For PHRs to be most useful, consumers will need

to be able to add information themselves and have the ability to import information from health

care organizations, health insurance plans, and individual clinicians.[15-16, 19, 30] With the

continuing rise of smartphone and tablet adoption and use, the ability of consumers to be able to

add their personal health information on the fly becomes increasingly important. A number of

PHR apps are already available. Examples, in no particular order, include Capzule PHR by

Webahn, Inc., ZenVault Medical PHR by ZenVault Medical Corporation, Minerva PHR Viewer

by Minerva Health Technologies, Inc., Stabilix PHR Lite by Stabilix Corporation, MTBC PHR

by MTBC, ORBIT PHR by IGI Health, ADVantis PHR by Advantage Health Solutions, Inc.,

OnPatient Personal Health Record by DrChrono.com Inc., MyChart by Epic, GoPatient by

Medfusion, Inc., MedXCom for Patients by Giffen Solutions, Inc. and YourHealthRecord Mobile by WWW Machealth Pty Ltd, among others. The U.S. Federal Government's 'Blue Button' initiative[31] encourages patient websites and portals to display a blue button. By clicking on the button, the patient can download his/her PHR into a computer or a mobile app of one's choice.

Introducing the use of PHRs to all patients will facilitate use in several arenas including collection and pooling of data on injuries, acute illnesses, onset of chronic diseases, monitoring of health status across the lifespan, and documenting health promoting behaviors.[1] The American Health Information Management Association website cites a report from the Center for Information Technology Leadership at Partners Healthcare System in Boston that estimated that widespread use of PHRs could save the US healthcare industry between $13 and $21 billion a year.[32] Tang and Lee reported that the adoption of PHRs is reaching a tipping point in some regions of the country.[33] In an example, these authors noted that of the 250,000 patients in the San Fransico Bay Area who received primary care at a region of the Palo Alto Medical Foundation, 50% of adults use the group's PHR.[33] As key providers of care across a wide variety of health care settings, nurse practitioners have the opportunity to introduce PHRs to their patients. The rapid adoption of technology and electronic modes of communication around the world provides a strong argument for the use of PHRs in all health care settings. Nurse practitioners are caring for e-patients across the lifespan. The health informatics train has already left the station. It is important that nurse practitioners be leaders through introducing patients to PHRs as an adjunct to the electronic health care records kept by their health care providers.

Acknowledgement

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Figure 1. A Sample Personal Health Record in Microsoft HealthVault^{TM}
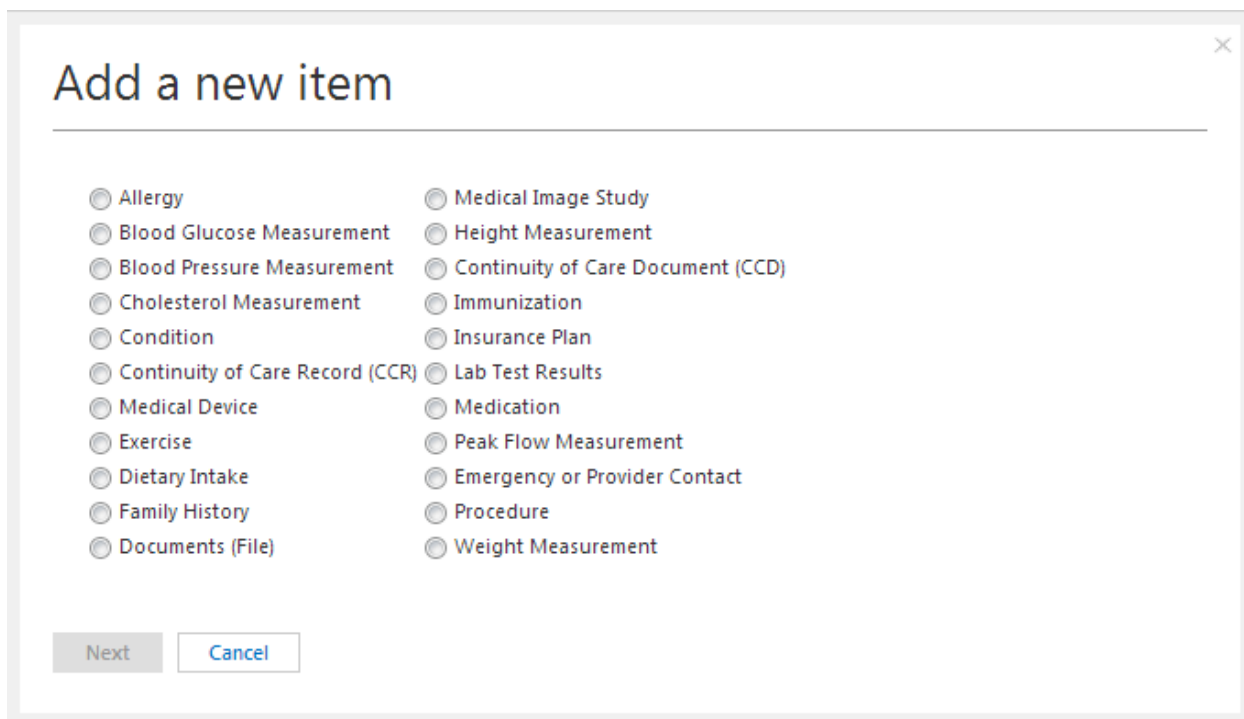
Figure 2. Adding a new item to one's PHR using Microsoft HealthVault^{TM}

Construct	Items	Item Wording	Ref.
Computer Self-Efficacy		I could learn how to use an online system if:	25,18
	CSE1	▪ there was no one around to tell me what to do as I go	
	CSE2	▪ I had never used a product like that before.	
	CSE3	▪ someone showed me how to use it first.	
	CSE4	▪ I had seen someone else using it before trying it myself.	
	CSE5	▪ I could call someone for help if I get stuck.	
	CSE6	▪ someone else had helped me get started.	
Perceived Value of Service		Considering the _____: * using [] is a good deal. + using [] is worthwhile.	22,18
	VAL1	▪ time I would invest and the health data management services I would get, *	
	VAL2	▪ time involved in using [] and the increased effectiveness in my health care management I would get, +	
	VAL3	▪ effort I would put in and the health data management services I would get, +	
	VAL4	▪ privacy risk involved in putting my health data on [] and the one-stop place I get for all my health records, +	
	VAL5	▪ privacy risk involved in putting my health data on [] and the rapid access to my health information I get, +	18
	VAL6	Overall, using [] would deliver me good value.	22, 18
Ease of Use	EOU1	Learning to operate [] was easy.	24, 18
	EOU2	The [] online tool was clear.	
	EOU3	The [] online tool was understandable.	
	EOU4	The [] online tool was easy to become skillful in.	
	EOU5	The [] online tool was easy to use.	
	EOU6	The [] online tool was flexible.	
Confidentiality		I am confident that the:	18, self-developed
	CONF1	▪ personal health information stored on [] is confidential.	
	CONF2	▪ personal health information stored on [] is secure.	
	CONF3	▪ healthcare providers whom I allow access to my [] PHR will use my health information in an ethical way.	
	CONF4	▪ healthcare providers whom I allow access to my [] PHR will use my health information in a responsible way.	

		I trust that [] will comply with national health information:	27, 18, self-developed
	CONF5	▪ privacy standards.	
	CONF6	▪ privacy laws.	
	CONF7	I would withhold entering sensitive data (e.g. HIV/AIDS status, mental health conditions, etc.) on [] to avoid the risk of this information being used inappropriately.	
User Satisfaction		I am satisfied that []:	27, 18, self-developed
	SATF1	▪ is a reliable system to enter my personal health information.	
	SATF2	▪ is a dependable system to enter my personal health information.	
	SATF3	▪ is convenient to use.	
	SATF4	▪ is comprehensive enough to manage my personal health information.	
	SATF5	▪ will meet my expectations for an online PHR management system.	
	SATF6	Overall, I am satisfied with [].	
Intention of long term Use	USE1	I would likely continue to use [] to manage my PHR after my study participation.	18, self-developed
	USE2	It is likely that I would consider using [] to manage my PHR in the short term.	
	USE3	It is likely that I would consider using [] to manage my PHR in the long term.	
	USE4	I believe that long-term use of the [] PHR will benefit my healthcare delivery in the future.	
	USE5	If I need to use an online health information management system, [] would be my first choice.	
	USE6	I am skeptical of long term benefits of the [] PHR.	
	USE7	I would continue using [] PHR even if I had to pay a small fee.	

Table 1. Items for Constructs in Survey Instrument

Survey Subscale	Google Health	Microsoft HealthVault
Computer Self-Efficacy	.893	.904
Perceived Value of Service	.951	.952
Ease-of-use	.995	.979
Confidentiality	.915	.908
Subjective Satisfaction	.931	.932
Intention of Long-Term Use	.922	.882

Table 2. Cronbach's Alpha Coefficients for Google and Microsoft PHR Tools

Survey Subscale	Google Health	Microsoft HealthVault	Wilcoxon Matched Pairs Tests
	Mean (SD)	Mean (SD)	P-values
Computer Self-Efficacy	6.30 (1.02)	6.39 (1.08)	.345
Perceived Value of Service	5.15 (1.57)	5.00 (1.27)	.088
Ease-of-use	5.93 (1.35)	5.76 (1.26)	.180
Confidentiality	5.34 (1.28)	5.20 (1.14)	.303
Subjective Satisfaction	5.38 (1.33)	5.32 (1.14)	.399
Intention of Long-Term Use	3.78 (1.58)	3.28 (1.32)	.199
Survey Item on Withholding Sensitive Data	5.24 (1.32)	5.09 (1.57)	.911

Table 3. Subscale Means, Standard Deviations and Wilcoxon Matched Pairs Tests