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This study surveyed professionals in health information technology (HIT), health informatics, and healthcare to identify the ideal components of an integrated personal health record (PHR) and to determine their concerns about the design and implementation of PHRs. In addition, the study investigated participants' opinions on the possibility of sharing health information electronically between providers and patients as well as the idea of patients sharing their personal health information electronically with individuals of their choice. The study found strong support in favor of both concepts. Participants voiced concern over maintaining patient privacy and providing security to protect health information; however, with appropriate protections, respondents supported a number of PHR functionalities that would begin to shift this tool from being a standalone product to an integrated part of an individual's health record.

Headings:

Medical Records – Health Records, Personal

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BRIDGING THE GAP BETWEEN HEALTH RECORDS  
AND PERSONAL HEALTH INFORMATION

by  
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## Introduction

The implementation of electronic health records is a top priority in the field of Health Information Technology (HIT). Health (or medical) records are defined as “a record of a patient's medical information (as medical history, care or treatments received, test results, diagnoses, and medications taken)” (Merriam-Webster’s online Medical Dictionary, n.d.). There are two separate types of electronic health records, electronic health (or medical) records (also known as EHRs or EMRs) and personal health records (also known as PHRs). According to the National Committee on Vital and Health Statistics (1998), an EHR is implemented at the doctor’s office and can support tasks such as billing, sharing patient information with other healthcare providers, sharing health information with patients, etc. This tool is used to record information related to that one particular healthcare facility and will not typically provide a full health history for a given patient. In contrast, a PHR is defined by Medline Plus (2009) and the Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services (2009) as a tool that is managed by the patient and provides a means of tracking an individual’s entire health history as well as family members' health histories.

The past decade has seen a lot of attention paid to the topic of electronic health information and yet electronic medical records systems have yet to be implemented on a global scale. In addition, the basic standardized structures of electronic health records, for both personal use and institutional use, have yet to be determined (Halamka, Mandl, & Tang, 2008).

The exact degree of utility of PHRs remains unclear; in part, this is due to the limited use of EHRs and PHRs by healthcare providers and patients. The existing empirical research indicates that electronic health information tracking tools will increase efficiency and quality of care over time. What remains to be decided is exactly how PHRs might be useful to patients beyond their obvious use as a location to track and store health information.

There is great potential in the use of PHRs to improve healthcare and the scope of their usefulness has yet to be fully realized. PHRs could become a tool not only for tracking health information that is received and produced by a healthcare provider, but also for consumer health information that is retrieved by the patient him/herself. Health related research information and data are becoming increasingly available to the public. This information helps to inform people's decisions when they have to consider a course of treatment for an illness or when attempting to better understand a particular disease or ailment. As time passes and research improves our understanding of a disease or statistics about a health issue change, the information they used in their original decision making process may have become moot. However, the original resources that were used to inform the patient at their time of need, an "information snapshot" so-to-speak, can help to remind individuals why they selected a course of treatment, or how the health profession and public understood the disease at a particular moment in time. That perspective and reference point can assist patients in making future decisions and providers to better understand the choices their patients have made in the past. In the case where a child or spouse may become a caregiver, this research information, in

connection to the health record, can also increase that caregiver's understanding of past health related choices.

An additional goal is to create PHR products that will relay information back and forth between the healthcare provider and the patient. In this idealized scenario, the provider and patient remain more fully informed throughout the process of giving and receiving healthcare. To take this one step further, there have been multiple discussions in the published literature about developing PHRs in a way that facilitates additional personal information management, and supports patient-related tasks such as scheduling appointments and sharing health information with a variety of individuals, based on their relationships to the patient. The iMed group based at the University of Washington, focuses on improving information interactions for patients, clinicians, and biomedical researchers. This group currently performs research with breast cancer patients and has attempted to identify the exact information collection, dissemination and interaction needs of individuals who are dealing with very intensive health issues. For example, breast cancer patients have multiple healthcare professionals involved in their treatment. The patient is ultimately responsible for ensuring that their doctor visits and test results are shared with all providers involved in their care. This task can be overwhelming when the tools used for sharing information are paper based and not set up in a manner that ensures dissemination in a timely manner to all the individuals in need of the information. The development of PHR tools that can help to facilitate these types of information sharing and access needs would greatly improve the patient experience (Pratt, Unruh, Civan, & Skeels, 2006); however, it is not yet known which tools are considered the most

desirable/valuable in the opinion of the medical community , nor which are within our reach from the perspective of developers.

There are many potential benefits from the design and implementation of PHRs. PHRs could become a repository not only for tracking health information that is received and produced by a healthcare provider, but also information that is retrieved by the patient him/herself from research resources including the worldwide web, newspapers, magazines, books, research articles, etc. More specifically, the primary investigator hypothesizes that a PHR that links medical records information to digitized health information/research obtained by the patient will increase the individual's recall concerning health decisions made in the past as well as the understanding of a disease or health-related issue that existed when the decision was made. In addition, information related to the management of current health issues can be more directly linked to the patient's health record. In turn, the patient can supply their healthcare providers as well as their caregivers or family members with a more thorough medical history and background on decisions made in the past. Functionality such as appointment scheduling, sending and receiving test results, and sharing information with caregivers, family and friends will improve the patient's experience of receiving healthcare while providing them with an opportunity to be more proactively involved in the process. It is believed that creating enhanced PHR systems that provide a personal information management component will increase the quality of healthcare from the patient's perspective, but those that are included must have the buy-in of professionals involved in both development and use.

This research project aims to identify the tools that are both desirable and possible, from the perspective of health information technology and medical professionals. The purpose of this study is to engage the health information technology, health informatics, and medical communities in identifying the most useful components of an idealized and integrated personal health record (PHR). These groups will be asked to contribute their professional opinions on what type of functionalities PHRs should include in the future to more actively address the needs of patients who wish to manage the full spectrum of their personal health information.

## Literature Review

Health information technology has enormous potential to impact healthcare systems around the globe. The potential to improve healthcare through the use of EHRs and PHRs is enormous. Modern versions of these tools are being developed simultaneously and the scope of their usefulness has yet to be fully realized. At this time, the majority of existing research is concerned with the development and implementation of electronic medical records in the healthcare setting, and offers a limited number of empirical research studies on the topic. Those articles that are empirically based tend to analyze the use of EHRs from the perspective of the provider, with analysis of both implementation and benefits of use. There is little research attention paid to the role of the PHR as a health information tool, making this research project's focus an area ripe for investigation. Because there is limited research on the topic of PHRs, studies of EHRs also helped to inform this research project, by filling in the knowledge gaps and establishing the utility of these tools as part of the healthcare delivery system.

This literature review will be organized into three sections. The first will cover the topic of EHRs/EMRs and the second will discuss research in the area of PHRs. Both of these sections will be broken into two sub-sections, research related to the United States and then those articles that provide an international perspective. While only a limited number of studies with an international perspective are included, it was necessary to provide this viewpoint since the survey was directed to an international audience. The third section will focus on the topic of this research project, PHRs as a health information management tool.

The premier journal in the field of HIT is the Journal for the American Medical Informatics Association (JAMIA). JAMIA provides the most comprehensive single resource of research in the field of EHRs and PHRs. Another leader in this area of literature is the BMC Medical Informatics and Decision Making journal. The goals of this publication are to address the following: “the design, development, implementation, use, and evaluation of health information technologies and decision-making within the healthcare setting” (BMC Medical Informatics and Decision Making, n.d.). Other notable journals in this field include the International Journal of Medical Informatics and the Journal of the American Medical Association (JAMA), however JAMA offers very little empirical research in the area of PHRs. A number of non-profit and government supported organizations offer information resources on the topic of EHRs and PHRs, such as Medline Plus, the American Health Information Management Association (AHIMA), the Department of Health and Human Services (DHHS), and the Robert Wood Johnson Foundation, to name a few. The Association for Computing Machinery (ACM) Digital Library was another resource for articles on the topic, but also provides a limited



number of empirical research resources. Because EHRs and PHRs have risen from the emerging field of HIT and the stakeholders in this field range from non-profits to for-profit businesses, current and future research will also come from a variety of organizations. An article published by the Center for Information Technology Leadership by Johnston, Pan & Middleton (2002) recommends that academic, corporate, and provider-related organizations be involved in investigation of the role and value of HIT across sectors.

## Section 1 – Electronic Health Records

### United States Of America

The majority of research relating to EHRs finds evidence to support the hypothesis that as these tools are implemented effectively they are already improving, and will most likely continue to improve, our healthcare system. This has been shown to be the case from a number of different perspectives within healthcare. For example, Bardach, Huang, Brand, and Hsu (2009) conducted a historical observation study that linked health information technology (HIT) to a faster turnaround of documented diagnoses, but not necessarily an increased number in those diagnoses. This study suggests that increases in efficiency could lead to improvements in delivering healthcare and managing patient needs. Venkatraman, Bala, Venkatesh, and Bates (2008) use the Veteran Health Administration (VHA) as an example of an organization that was transformed from an inefficient, sometimes dangerous, healthcare facility to one that is now touted as one of the “industry leader(s) in safety and quality because of its high quality IT systems” (p. 141). This article emphasizes the dramatic improvements that are possible through investments in high quality health information technology systems, such

as the EHR system now being used at the VHA.

The most thorough investigation of the EHR systems that was found in the literature came from an analysis of three primary health care facilities located in Eastern Massachusetts over the course of a one-year period. El-Kareh, Gandhi, Poon, Newmark, Ungar, Lipsitz, and Sequist (2009) found that implementation of an EHR system initially reduced efficiency, lengthened the time required to effectively conduct a patient visit, and increased the amount of time providers had to invest in documenting clinical visit information; however, as the year progressed participants reported a positive shift, indicating a reverse of the negative consequences they experienced after initial implementation. In addition, the survey findings report that clinicians experienced the following positive outcomes of using an EHR system over the course of that year: first, an overall increase in quality of care; second, a reduction in medication related errors; third, better follow-up of test results; and fourth, improvements in communication among clinicians. The outcomes of this study are critical to our understanding of the ability for EHR systems to positively affect healthcare. Because this study was conducted over the course of one year, the results are able to explain how and EHR system could be viewed negatively at initial implementation, but once clinicians become adept at effectively using the tool, an EHR system can have a strong positive impact on the healthcare organization.

Zhou, Soran, Jenter, Volk, Orav, Bates, & Simon (2009) offer a dissenting opinion on the impact of EHRs. This group conducted a study analyzing data on Massachusetts physicians' adoption of EHRs and their quality of care measures as providers, and found some evidence suggesting that the "EHR use was not associated with improved quality of care" ( p. 463). However, the limitations of the study include:

duration of EHR use was not recorded, and only a small number of known long-time users were available when the study was conducted, preventing the authors from analyzing the impact of EHRs on quality of care over time; this was an observational study and confounding factors may have played a role in the findings; quality performance was measured using HEDIS (a set of performance measures used in healthcare), which may not be a sensitive enough tool for identifying those instances where EHRs had a positive impact on quality of care; and it is possible that because information was self-reported there may have been a bias for physicians to overestimate their EHR usage. As a result of these limitations, the authors eventually suggest that the EHR may be one of a number of tools key to improving the quality of healthcare. It is also important to note that while this article was published in 2009, the study itself was conducted in 2005. At this point in time, EHR systems were not as commonplace as they are today. It would be valuable to perform this survey again, now that EHR systems have been integrated into many more healthcare settings.

The majority of the studies presented here indicate that EHRs will play a role in improving healthcare: from the provider side, improving access to patient information, streamlining how information is recorded and shared (with the patient, for the purposes of billing, etc.); from the patient's perspective, a more streamlined healthcare experience as well as increased access to their health information. Because development and implementation of EHRs is an ongoing effort by healthcare facilities and companies offering EHR systems, it is critical that gaps in the knowledge be reduced while these products are under development and being put to use in order to ensure the outputs are as effective at improving the healthcare process as possible.

## International

The literature that was collected to give an international perspective of EHRs provided some useful insights into how successful these tools have been so far as well as a sense of the public's level of acceptance for them. Ludwick and Doucette (2009) provide a systematic review of recent literature on EHR systems from the following countries: Canada, the United States, Denmark, Sweden, Australia, New Zealand and the United Kingdom. The authors conclude that in order for these systems to realize their full potential, it is critical that the necessary technical support for both implementation and ongoing use be provided in order to avoid handicapping healthcare institutions from performing their primary task of providing care to patients. The authors also report that there is little research that directly addresses the patient/provider relationship and the role that EHRs could play in changing that dynamic; they strongly suggest that this be an area that is explored by research in the future.

Another study by Hoerbst, Kohl, Knaup & Ammenwerth (2009) addresses the topic from the perspective of the public, in two similar cities, one located in Austria and the other in Germany. The results of this study show that, in general, citizens felt positively about the use of EHRs by their healthcare providers. There was also interest shown in using EHRs as an interactive tool between the provider and patient to help manage their health. In some cases, respondents voiced concerns over privacy and the potential for health information to be used to harm individuals, should it fall into the wrong hands. However, it does not seem as if these concerns would keep individuals from wanting to use EHRs, but that they would prefer strict precautions be taken in order to ensure their privacy.

A survey of Canadian CEOs from a number of hospitals conducted by Urowitz, Wiljer, Apatu, Eysenbach, DeLenardo, Harth, Pai, and Leonard (2008) measured the general readiness of these healthcare facilities to provide patient access to their EHRs. The authors conclude that the question of who owns a patient's health information must first be answered before any such system can be implemented, in order to obtain the support of all stakeholders. They also suggest that PHR products will not be effective health information management tools until high quality EHR systems are developed and implemented on the provider side of healthcare. It was also noted that a shift in organizational culture may be necessary before providers see the added value of collaborating with their patients by providing access to their health records, rather than viewing themselves as the sole experts and gatekeepers in the healthcare setting.

## Section 2 – Personal Health Records

### United States Of America

There are significantly fewer studies of personal health records (PHRs) than EHRs. In part, this is probably due to the fact that identifying and recruiting PHR users is very difficult. So in many cases, research relating to PHRs analyzes their utility from the perspective of the patient/provider interaction or studies simply review the tools themselves, leaving the patient out of the research altogether.

The American Academy of Pediatrics released a policy statement in 2009 that strongly encourages the use of PHRs in pediatric care. This recommendation is meant to apply to the patient (the child), the healthcare provider, and family members who are responsible for the wellbeing of the child (Council on Clinical Information Technology, American Academy of Pediatrics, 2009, p. 406). Mathematica released an article, based

on a study funded by the Robert Wood Johnson Foundation, that discusses whether or not PHR tools meet the needs of underserved populations in the United States. The article concludes that in order to reach these groups, who desperately need HIT tools to help them achieve the highest possible healthcare outcomes, “developers may need to step up their efforts to assess the usability of their products by low-income minority populations with limited access to computers and low health literacy” (Mathematica Policy Research, Inc., 2007, p. 4).

Cimino, Patel, & Kushniruk (2002) studied the use of a system called PatCIS, which combined a number of functions, including elements of the PHR along with health information resources, in one tool. The authors conclude that patients and practitioners alike found the tools to be useful. Beyond that simple observation though, the following feedback expresses the sentiments of the participants while demonstrating the ripple effect of improvements capable when using such systems: “patients and physicians felt that the limited time available during the subsequent patient-physician interaction was used more efficiently, allowing for an enhanced level of discussion about the patient’s problems and issues such as compliance” (p. 125). These findings weigh heavily in favor of developing PHR and EHR systems that can facilitate the patient/doctor relationship. With more efficient use of their time at doctor’s visits, perhaps patients will experience a reduced need to visit the doctor and show better adherence to health plans as a result.

Kim & Johnson (2002) provide an analysis of the existing PHR products of the time. When this study was performed in 2002, there were PHR products available but they had very limited utility. This article gives a good historical perspective and baseline measure of the development of PHRs; however, it provides very few recommendations

except for the very last sentence, which suggests that “future development of PHRs should be guided by patient-oriented research targeted to evaluate the performance and usability of evolving applications” (p. 179). This gap in the knowledge – how a PHR can be used to achieve patient-oriented goals through a product that individuals manage themselves – is part of what makes this paper’s research topic timely and appropriate.

An article from the *Annals of Behavioral Medicine* provides an additional perspective on the issue of providing improved information tools for the patient in order to assist them in making informed health-related decisions. This article, written by Auerbach in 2000 concludes that while additional research is needed, the evidence as it exists suggests that patients who wish to be informed participants in their health-related decisions respond well to the opportunities that PHR systems and decision aids afford them. Auerbach goes on to propose that future research should focus on studying patients who are facing critical health decisions and how they go about using these tools to exercise their choices. While the above recommendation is not an explicit goal of this research project, the suggestion certainly relates to the topic and is supportive evidence of the need for additional studies that look at the role of information tools in supporting health-related decision-making.

Kaelber, Jha, Johnston, Middleton, & Bates (2008) explicitly recommend that future research focus on addressing the topics that this research project investigates. In their analysis of the existing research areas, the authors identify ‘PHR Function Evaluation’ as one of the most critical areas for PHR research. In the description of this topic, the authors discuss the need for an examination of “functions that allow patients to record, track, and edit information about their own health/healthcare, as well as obtain

relevant patient oriented disease information and decision support” (p. 730).

### International

While there is very little literature on PHRs and their influence on healthcare in the United States, there is even less to provide an international perspective. International research covers many of the same topics as those already discussed in the PHR section above. In many cases, it seems that the continued concerns with privacy, accessibility, and the degree of influence that PHRs can have on improving healthcare are all critical topics that must be directly addressed by future research (Comini, Mazzu, and Scalvini, 2008).

### Section 3 – Personal Health Information Management

Studies relating to PHRs and EHRs provide substantial evidence in support of increasing patient access to their health records and supporting additional functionality in those tools. There is very little research that directly addresses the potential of PHRs to facilitate the personal health information management needs of the public. However, the research that does exist on this topic is very good at defining the concept of the “integrated” PHR, discussing how such a tool could improve healthcare from the patient and provider perspectives, and the necessary infrastructure and product definitions that must be established in order for health records to reach their full potential.

According to Halamka, Mandl, & Tang (2008), EHR developers are creating products that will link the EHR on the provider side to the PHR from the patient side to increase sharing of information across boundaries. Their study focused on identifying whether the implementation of these systems was feasible, if patients actively used them to complete health related transactions, and whether providers and patients found the



tools to increase the value of healthcare. Summarizing implementations at three institutions, the authors found that successful implementation and use hinged upon careful policies concerning “privacy, security, data stewardship, and personal control” (p. 7). Once the systems were up and running, patients and providers alike found that they had a positive influence and provided an opportunity for patients to become more involved in their healthcare experiences. These findings are encouraging in that they identify multiple examples of real-world implementation of PHR/EHR systems with positive outcomes and offer evidence that supports further development of these tools.

Going beyond the above analysis of the relationship between EHRs and PHRs, there are a number of articles that more directly relate to the primary topic of this research project, the first of which comes from a research group called iMed from the University of Washington’s Information School. This article summarizes the findings of an initial investigation that attempts to identify whether or not a PHR product that also functions as a personal health information management system would increase the quality of care/experience for a patient needing to manage a major health issue (Pratt, Unruh, Civan, & Skeels, 2006). The paper looks at the problem through the lens of breast cancer patients who are faced with enormous information management issues on multiple levels as well as the problem of sharing information with numerous groups of people and institutions. The findings of the research indicate that an enhanced PHR/EHR system that assists the patient in scheduling doctor’s appointments, sharing test results and health updates with family and friends, and disseminating test results and treatment decisions across multiple healthcare venues would significantly improve the patient’s experience.

The research study was in the form of multiple interviews over the course of 12 weeks that aimed to identify the information management activities of breast cancer patients. The interviews uncovered the need for enhanced systems that would facilitate sharing information as well as helping the patient to manage the large volume of information coming from multiple venues. The study identifies three key areas where patients could benefit: 1) integrating personal, professional, and health-related information; 2) using integrated information to make health-related decisions; and 3) sharing information with individuals from social, professional, and health-care networks while maintaining personal privacy (Pratt, Unruh, Civan, & Skeels, 2006).

The second of the articles that most closely relates to this research study was not an empirical study, but rather an essay on the topic of PHRs and the added value to healthcare that could be realized by combining the health record with digitized health information resources. Humphreys (2000) asserts that linking the electronic health record to the digital library is a Web-era reformulation of the long-standing informatics goal of seamless integration of automated clinical data and relevant knowledge-based information to support informed [health] decisions” (p. 444). This article provides additional evidence of the important role a multi-tasking PHR can play in supporting patients’ efforts to make informed health decisions as well as providing a reference point for patients who return to this digital archive of health information in later years.

A roundtable was held in the fall of 2006 that brought together professionals from both the public and private sectors to discuss the integration of EHRs and PHRs. This group was convened with three primary goals: identifying the transformative potential of integrated PHRs, identifying barriers to realizing this potential, and identifying a

framework for action to move integrated PHRs closer to the healthcare mainstream (Kaiser Permanente Institute for Health Policy, 2006). This roundtable discussion did not result in immediate changes to the relationship between PHRs and EHRs, but it did begin the discussion of how these products can work together to provide patients with a more comprehensive tool to manage their health information. This paper also identifies a number of areas where additional research is needed, including identifying and understanding the applications and devices that hold the greatest transformative potential. This particular recommendation is especially important for the research questions that this study intended to address, in particular the part of the survey that asks health information technology, health informatics, and healthcare professionals to identify the functionality that should be included in future PHRs that will more effectively support health information management goals of the public.

Detmer, Bloomrosen, Raymond, and Tang (2008) report on the roundtable discussion mentioned above. Their article expands on the report initially released from Kaiser Permanente by identifying four areas where an integrated PHR can positively impact healthcare: first, increased availability of patient information at the point of care; second, enabling electronic connectivity between clinical care managers and patients or their caregivers that can be leveraged to realize innovation in care management; third, shifting the control of health information from the provider to a more “shared control” model where patients can more actively engage in managing their health information; and fourth, reducing costs and improving healthcare delivery by a number of different means, all relating to the use of an integrated personal health record. While the authors also identify a number of barriers to both the integration of and potential impact of an

integrated PHR, the overall message of the article is that once this type of tool becomes a reality and is utilized by both the provider and patient, there is major potential for a positive impact on our healthcare system.

A rather short publication from HIMSS regularly reports the findings from surveys of healthcare IT professionals on current industry trends. This particular survey found that “three-quarters of respondents believe that PHRs need to be integrated with an electronic medical record in order to have value in patient treatment” (HIMSS, 2008, p.1). While very few details are given on the methodology and information on respondents is quite limited, it is encouraging to see that professionals in the field believe in the value of connecting PHRs and EHRs for the benefit of the patient.

Another essay, this one published in the Family Medicine Journal, provides a very interesting perspective of the impact of PHRs in empowering patients. The article, while primarily an opinion piece, suggests that the role of the primary care physician will shift significantly as the patient becomes more empowered through the use of tools such as the PHR and other Internet resources. An empowered patient could mean a reduced role for physicians in managing the full spectrum of patient care. “The Internet makes it possible to give patients more control over their care and challenges the concept of physician-directed care” (Scherger, 2009, p. 286). This article highlights the transformative impact that electronic health information management tools can have on the patient-doctor relationship. The introduction of such high-impact tools can significantly increase the role of the patient in managing their healthcare. As this takes place, the role of the doctor or healthcare provider can become more focused on providing high quality health evaluation and care, rather than having to actively manage patient needs that do not

actually require a healthcare provider's intervention or expertise.

Scherger (2009) takes this argument one step further, by suggesting that an entirely new model of care could be the result of the implementation of sophisticated health information management tools. This new model will have the patient and provider working as more of a team instead of the current gatekeeper system we now have, where patients must go to their primary care provider for nearly all medically related needs. This new model of care will require a different approach to teaching medical school students, one where students are encouraged to consider the value of partnering with their patients to achieve the best outcome. While a number of the ideas presented in this article are somewhat extreme, and surely many years from becoming reality, it encourages the reader to consider a very different approach to giving and receiving medical care from what we have in our healthcare system today. The fact that this new model of care is even a possibility goes to show just how strong the impact health information management tools could have on our society and healthcare systems.

This literature review provides an analysis of the research available concerning the history of and impact of EHRs, PHRs, and integrated PHRs (or PHRs as personal health information management tools) on healthcare. Overall, the research shows that these tools are expected to have a continued positive influence on healthcare systems around the world. Some of these benefits are already being realized and as these changes occur, the focus of research has shifted simply looking at the benefits of these tools in "silos" to identifying ways in which they can be integrated in order to maximize their potential.

While research efforts have begun to focus on the integrated PHR as a health

information technology tool, there are still many topics relating to this area that have yet to be addressed by empirical research. This study aims to fill in some of the gaps of knowledge by identifying the types of functionality that would best serve patients and providers in an integrated PHR and also to get an overall sense of what professionals in fields directly relating to HIT think of developing and implementing such a tool.

Specifically, the research questions this study aims to answer are:

1. Do HIT and healthcare professionals support the possibility of sharing health information electronically between providers and patients?
2. Do HIT and healthcare professionals support the idea of patients sharing their personal health information electronically with individuals of their choice?
3. What functionalities should be available in an integrated PHR?
4. What opinions and concerns do HIT and healthcare professionals have regarding PHRs?

## Research Methodology

This research project was conducted in the form of an online survey. The survey questions were both quantitative and qualitative, with an overall goal of identifying the components of an integrated personal health record (PHR). A survey was selected as the methodology for this research project in order to most easily reach the intended participants. The survey was shared with health information technology, health informatics, and healthcare professionals around the globe, which necessitated that the survey be conducted online. The survey was administered through the use of Qualtrics Survey Software.

The survey was shared with prospective participants through completely electronic communications. First, the survey was posted as a discussion item on the following LinkedIn Groups: American Medical Informatics Association (AMIA), the International Medical Informatics Association (IMIA), the American Health Information Management Association (AHIMA), the Healthcare Information and Management Systems Society (HIMSS), the American Society for Information Science & Technology (ASIS&T), and the American Medical Association (AMA), and the Medical Group Management Association (AGMA). An initial invitation was posted to the above LinkedIn Groups in the middle of February, was followed by two reminder postings, and a final reminder was posted to each group in the middle of March. Second, a news item was posted to the IMIA website and the IMIA Twitter feed announcing the online survey and suggesting that members participate. And finally, a link to the survey was posted to the primary investigator's Twitter and Facebook accounts. Altogether, the survey collected responses from February 15, 2010 through March 29, 2010.

The survey itself included both quantitative and qualitative questions. The majority of qualitative question were used to follow up on the quantitative questions in order to give respondents an opportunity to explain their answers and/or provide comments. The survey was comprised of 19 questions, including the consent to participate. The overall themes the questions aimed to address were the following: sharing information electronically between patient and provider; sharing information electronically between the patient and other individuals (such as family members, friends, colleagues, etc.); additional functionality that might be included in future PHRs; and an opportunity for participants to comment or share their thoughts on any/all of the above

themes. The final section of the survey included a number of demographics questions to help the primary investigator better understand sample of participants who chose to respond to the survey. A copy of the survey is available in Appendix A.

The results of the survey were then exported from Qualtrics to SPSS 18.0, a statistical analysis program. Analysis of the quantitative question results was fairly straightforward in that the goal of this survey was to identify those tools that should be considered for future versions of PHRs. The overall positive or negative opinions of the tools that were suggested in the survey are included in the results section. Analyzing the qualitative questions required a more hands on approach to discovering themes and overall consensus.

Rubin & Rubin (2004) offer very helpful guidelines for analyzing qualitative data. The analysis was conducted as follows. First, a review of all the qualitative responses was performed in order to identify key phrases and ideas. Second, these key concepts were then extracted and stored in an excel spreadsheet. Third, coding was performed to organize the key phrases/idea into groups, once they were all identified.

The fourth step was to analyze the coded data. In this step, themes and key statements were identified that related to both the overall development of future PHRs and the opinion of respondents on the concept of the PHR as a personal health information management tool. In the fifth step, these themes were compared to one another; this step gave the researcher an opportunity to use the small amount of personal data on the participants to look for differences in responses based on demographics such as age, sex, educational background, profession, work environment, and professional association memberships. Themes were reviewed to ensure that all relevant ones were



accounted for.

## Results

The survey for this study was open for six weeks. In that time, 138 responses were received. Of the 138 responses, there were nine individuals who opened the survey but either chose not to participate after reading the informed consent question or they closed the survey before seeing any of the survey questions. Additionally, 21 of the remaining 129 participants did not complete the survey in its entirety, but did answer at least one of the survey questions. The percentage results reported in this paper are based on the number of responses for each of the individual questions, excluding those who viewed the question but did not necessarily provide a response and excluding those who never viewed the question. The effective completion rate for this survey was 84% - 116 completed the survey of the 138 who opened it.

Table 1	
Question	Response
1) Would you like to see future PHRs allow healthcare providers to share information directly to the patient electronically?	Yes - 96.8%
	No - 3.2%
2) Would you like to see future PHRs allow the patient to share their health information with their healthcare providers electronically?	Yes - 95.2%
	No - 4.8%
3) Would you like to see future PHRs allow the patient to share their health information with other individuals they select electronically?	Yes - 80.3%
	No - 19.7%

Statistical analysis was performed to see whether or not a participant's response to the first set of questions (see Table 1) was influenced by demographics. The analysis

showed that there were no statistically significant differences in responses between males and females, between age groups, between educational levels, or between professions.

The first question asked respondents about information sharing functionality in PHRs. Ninety-seven percent of respondents (n=125) indicated that they would like to see future PHRs allow healthcare providers to share information directly to the patient electronically. Respondents were offered the opportunity to provide comments or feedback on the idea presented. Some respondents provided feedback on the concept of an integrated PHR in addition to providing feedback to the question asked. The commentary provided by individuals was overall in favor of implementing this type of functionality in a PHR. Respondents felt very positively about using the PHR as an electronic means of sharing information between providers and patients. Many comments emphasized that health records are the property of the patient and should be made easily available to them. Responses also indicated that this tool could be an ideal means of sharing educational/informational materials with patients concerning a health issue, sharing basic lab results with patients so that they can track their progress/health over time, etc. On the flip side, the number of respondents voiced concerns over sharing sensitive results such as cancer screenings or HIV tests without the proper counseling from a physician. Also, five individuals mentioned that privacy and security would be critical factors to deciding how a PHR should be used so that it does not compromise a patient's private health information.

About 95% of respondents (n=125) indicated that they would like to see future PHRs allow the patient to share their health information with their healthcare providers electronically while 2% skipped this question. Comments following this question

provided some very insightful recommendations. Respondents understood this question in two different ways; the first considered the patient transmitting health data to their providers and the second as a means of contacting their healthcare provider(s). Both approaches are reasonable and applicable to this study, and exemplify how complex and electronic health record system can be. From the perspective of transmitting data, one participant commented that “a standardized format would be very useful (easier to extract meaningful data) for hospital EHRs.” In other words, patient provided information should be imported directly into the EHR in a standardized format so that it can be integrated into the patient’s chart. This viewpoint was echoed by another respondent as well. Other comments emphasized that this functionality could assist patients in tracking and sharing information with their provider such as glucose readings, weight, exercise, and so on. Participants also felt positively about patients using the PHR as a means of contacting and communicating with their healthcare providers, just as long as a response could be expected within a reasonable amount of time. This comment is valuable in that it brings up the point that PHRs systems should not add to the burden of the patient or healthcare provider and that timely responses will be critical to ensuring the PHR is used effectively and with longevity.

There were two participants who were not in favor of PHRs allowing patients to share their health information with their healthcare providers electronically. One of them stated they were concerned this type of communication could be “leveraged against the patient [through] information used by [actuaries] to identify risk, thereby raising costs for people who are in dire need of health services.” The second person voiced concern at the idea of transmitting health information over the Internet. In both cases, the lack of

support for this type of functionality relates to patient privacy and security. These are legitimate and critical points to consider as electronic health tools are developed. These comments emphasize the fact that patient privacy must be a top priority.

The next survey item still received a good deal of support, but only 80% (n = 122) of respondents agreed that they would like to see future PHRs allow the patient to share their health information with other individuals they select electronically. This question received a healthy number of comments, from participants who thought it a good idea as well as those who did not. Positive commentary focused on the idea that this functionality could help family members and caregivers to remain informed of the patient's health, making it easier for them to more effectively engage in caring for the patient. A number of caveats were included in these comments, which cautioned that while this type of information sharing could be very helpful, it is also important for the patient to have the final say as to who sees what information and how those individuals who receive access handle the patient's information. In other words, if a parent decides to share their health records with one of their children, who also functions as their caregiver, the child must abide by the wishes of their parents in terms of how they use that information and share it. Participants also suggested that if individuals should choose to share access to their PHR, the system should be set up so that they can share the full health record or only parts of it, rather than an all or nothing approach. An audit trail was suggested as a means of helping the patient track who is using or accessing their record, and for what purpose. If the patient felt uncomfortable with any of the individuals he or she had granted access to the records, they should have the ability to revoke that individual's privileges. Those who answered "no" to this question felt that it

was unnecessary to provide this type of functionality and that it could lead to more negative than positive outcomes.

The next question asked participants to consider number of different PHR functionalities based on the assumption that “health information/outcomes can be transmitted electronically from the provider to the patient, the patient to other individuals, etc.” Of the functionalities listed, participants were asked to identify those they would “like to see included in future versions of PHR systems to assist users in managing all of their personal health information.” They were given the option to select as many of the suggested functionalities as they wanted. This question received 115 responses, and the results appear in Table 2. The functionalities that received the strongest positive responses included the following, in descending order: a means of sharing lab/test results between the patient and provider (95.6%); a means of sharing current prescriptions between the patient and provider (95.6%); functionality that allows users to have their health records accessed by hospitals, in case of an emergency, where the patient cannot grant access at the time the information is needed (88.7%); appointment scheduling (87.8%); and finally, a means of sharing copies of visit notes between the patient and provider (85.2%). The other types of functionality suggested in this question included a calendar that synchronizes with appointments as they are made (74.8%); a repository that will store research information obtained by the patient on health issues and/or concerns (58.5%); a means of sharing visit outcomes from the patient to their friends, family and colleagues (50.4%); a calendar that the patient may share with friends, family and colleagues (49.6%); and finally, social networking functionality that would allow users to

share their health information/experiences with individuals facing similar health concerns and/or those who share an interest in the health issues addressed by the user (33.9%).

Table 2	
Question	Response
Which of the following would you like to see included in future versions of PHR systems to assist users in managing all of their personal health information? Check all that apply.	
1) Appointment scheduling	Yes - 87.8%
	No - 12.2%
2) Calendar that synchronizes with appointments as they are made	Yes - 74.8%
	No - 25.2%
3) Calendar that the patient may share with friends, family and colleagues	Yes - 49.6%
	No - 50.4%
4) A means of sharing lab/test results between the patient and provider	Yes - 95.6%
	No - 4.3%
5) A means of sharing copies of visit notes between the patient and provider	Yes - 85.2%
	No - 14.8%
6) A means of sharing current prescriptions between the patient and provider	Yes - 95.6%
	No - 4.3%
7) A means of sharing visit outcomes from the patient to their friends, family and colleagues	Yes - 50.4%
	No - 49.6%
8) Functionality that allows users to have their health records accessed by hospitals, in case of an emergency, where the patient cannot grant access at the time the information is needed	Yes - 88.7%
	No - 11.3%
9) Social networking functionality that would allow users to share their health information/experiences with individuals facing similar health concerns and/or those who share an interest in the health issues addressed by the user	Yes - 33.9%
	No - 66.1%

10) A repository that will store research information obtained by the patient on health issues and/or concerns (for example, information on heart disease obtained through research performed on Medline Plus)	Yes - 58.5%
	No - 39%

Immediately following the question above were three open ended ones. The first of these questions gave participants an opportunity to provide recommendations for PHR functionalities that were not identified in the list provided from the survey. For this question, 42 responses were given from the 115 people who viewed it. One individual recommended a “means of patient feeding outcome back to provider” as well as “vital sign/health monitoring, intelligent housing, and clothing monitoring.” The last two suggestions would rely on some very sophisticated tools becoming a part of everyday health care, but it is important that PHRs be developed with future healthcare methods in mind. A number of respondents suggested that the PHR be the method by which patients share ongoing health information with their providers such as blood pressure readings, blood sugar, diet, exercise schedules and routines, weight, and so on. Some suggestions that came out of this question were identified in comments from previous questions, but are worth mentioning again at this point. These include re-filling/requesting prescriptions, scheduling/canceling/reminders for office appointments, ability to share PHR with family/friends who function as caregivers, sharing visit outcomes with healthcare providers in the case where the patient is receiving care from more than one provider, vaccination lists, healthcare proxies and end-of-life/advance directives, and initiating/managing referrals.

There were numerous references to using PHR information as a means of facilitating research. Respondents suggested that de-identified PHR information could be

used as research data and one participant suggested that the PHR could be the means by which patient coordination for medical research is handled.

Some of the more creative suggestions included things such as: having the PHR link to community resources including exercise groups and farmers markets; consumer health information resources; a means of communicating with health insurance companies; online provider consultation; care plans for individuals who have complex health issues; ability to export PHR information to a flash drive or link it to a health card; consumer clinical decision support system; a means of sharing records for legal transactions such as workers compensation; note-taking functionality for multiple caregivers; and a tool that would allow the patient to document symptoms and questions for their provider prior to an office visit.

The next question asked participants to share any comments/concerns/recommendations about the functionalities chosen in the last question; 115 people saw this question and thirty of them provided responses. Of the 30 people who provided their opinions, eleven (37%) individuals indicated that they had some level of concern about providing a type of social networking functionality that would allow users to share their experiences with other individuals having similar interests or health issues. This very strong response is indicative of some of the serious privacy concerns that were voiced time and again in relation to some of the more modern PHR functionalities discussed in this study. While respondents thought the idea of health related social networking services would be good idea overall, they felt this type of functionality was inappropriate to include in the PHR.



Other responses to this question provided feedback on some of the overall PHR concepts already covered. There was support for the user to set preferences that would allow others to access their PHR, but only as much information as the patient chose to share. In addition, there was continued conversation about concerns relating to privacy and security. One respondent emphasized the importance of viewing the PHR and health-related information sharing as a “narrowcast” rather than “broadcast” activity. By sharing less, rather than more, and only with trusted individuals, the patient can utilize the benefits of having a PHR without sacrificing their security. Another respondent made a strong case for privacy with an international perspective. This individual took the opportunity to discuss the importance of allowing teenage patients the ability to protect their health information, in some cases, even from their parents. The example used was of the “honor killings” in some societies where women, even if they are raped, may be put to death. While much of the conversation regarding privacy and security has been centered on an individual’s rights, this comment was a strong reminder of the consequences a person may bear if their privacy is not protected.

The last of the three open-ended questions asked for participants to provide general comments relating to PHRs; 61 participants chose to respond to this question, over half of the total number of participants who viewed this question ( $n = 115$ ). As was the case in earlier questions, a significant number of responses referenced concern for the patient’s privacy and security. One respondent voiced concern over the fact that in today’s society, many individuals are not proactively protecting their own privacy, but have instead become quite comfortable sharing their personal information with a rather large audience of strangers and friends. To further complicate this issue, these

individuals may not express a desire to have health records companies take the necessary measures to protect their information and their personal interests. It could be the case that laws and regulations will have to be enacted to hold health records companies/organizations accountable for protecting a user's privacy and security. Another respondent stated they were concerned that information in the PHR could be used as a means of targeting marketing campaigns at individuals with particular health conditions or who use certain types of medications. This could be an especially problematic type of privacy violation with companies that do not explicitly state their security and information ownership policies. In some cases, even explicit policies may not deter users from engaging in activities that could compromise their privacy.

Relating to the privacy issue, is the ongoing discussion of who "owns" an individual's health information. While it is recognized that clinics and hospitals are responsible for maintaining patient health records, it is also an individual's legal right to have access to this information. Introducing the PHR to the mix could complicate this idea of ownership since some information would be provided or produced by the patient, but may become an integrated part of the EHR. Another respondent brought up the topic of who owns or is responsible for a patient's record after their demise. As we have seen recently with Facebook, it may be the case that patients have to legally designate ownership of their records to one of their family members or trusted friends. The concept of integrated health records is appealing because it could help to reduce the repetition of unnecessary testing and provide a more complete patient history. On the flip side, it could also complicate already extensive information management issues by introducing numerous vocabularies as well as multiple standards that are not interoperable. From a

system design perspective, these two key concepts could present significant barriers to adoption. And to complicate interoperability even further, mobile applications will also be producing health information that patients may wish to integrate into their PHR and/or to share with their healthcare providers.

In the case where the PHR is shared with healthcare providers, or is a part of an integrated health records system, survey participants voiced a preference for an auditing trail that would allow them to see who accessed their record and for what reasons. This audit trail could help patients quickly identify people or organizations for whom they may want to remove access privileges or to report a concern.

One respondent brought up the idea of cost and where the burden of paying for a high-quality PHR would lie and that if any cost should be borne by the patient, it should be minimal. A number of other respondents discussed the fact that electronic health records of all types are an important step forward for healthcare, and that the PHR could be an especially important tool for individuals who are managing chronic disease or trying to actively maintain their health.

One of the lengthier responses covered a couple of important points relating to PHRs. This individual voiced concern that the public at large may never engage in managing their health information to the extent that it would make the effort of designing and implementing some of these more sophisticated health records systems worthwhile. However, this same respondent seemed to recognize that the PHR could help providers access a more complete patient history but does not suggest that this fact will necessarily improve our healthcare system.

A number of key discussion points from previous responses were repeated in this final open-ended question. These included:

- PHRs should be accessible to healthcare providers in emergency situations.
- A copy of the PHR could be downloaded to a flash drive or accessible through the use of a health card.
- Patient access to their health records could help them to identify when errors or incorrect information have become a part of their official health record.
- PHRs should be developed based on research concerning both functionality and usability.
- A listing/ranking of PHR companies could help individuals make informed selections.
- PHR companies need to be held to HIPAA standards.

Table 3	
<u>Age Category</u>	<u>Response</u>
25 or younger	4.31%
26-30	12.07%
31-35	9.48%
36-40	8.62%
41-45	9.48%
46-50	16.38%
51-55	14.66%
56-60	14.66%
61-65	6.90%
65+	2.59%
No answer	0.86%

Almost 44% of respondents were male and just over 55% were female; two individuals did not provide answers for this question.

The second half of the survey asked participants for some demographic information. At this point in the survey, 116 of the original 129 individuals who started the survey were left. The majority of participants fell into the following age ranges: 26 – 30 (12.07%), 46 – 50 (16.38%), 51 – 55 (14.66%), and 56 – 60 (14.66%).

Table 4	
<u>Gender</u>	<u>Response</u>
Male	43.97%
Female	55.17%
No answer	0.86%

Table 5	
<u>Country of Residence</u>	<u>Response</u>
Australia	0.88%
Austria	1.77%
Brazil	0.88%
Canada	3.54%
Cyprus	0.88%
Finland	1.77%
Germany	0.88%
Greece	0.88%
Ireland	0.88%
Israel	0.88%
Romania	1.77%
South Africa	0.88%
United Kingdom	0.88%
United States of America	83.19%

While 94 of the respondents were from the US, the survey received an international response with participants residing in the following 14 countries (n = 113): Australia, Austria, Brazil, Canada, Cyprus, Finland, Germany, Greece, Ireland, Israel, Romania, South Africa, the United Kingdom, and the United States of America.

Participants were asked to report their educational level (n = 115). They were allowed to select more than one answer to this question in order to record those instances where respondents hold multiple advanced degrees. However, this led to a number of times where the recorded answers showed some overlap. In the cases where this took place, the highest degree selected by a particular individual is reported here. The results show that the respondents have the following levels of education:

- High school (2.61%)
- Some college (7.83%)
- Bachelor's degree (18.26%)
- Some graduate school (16.52%)
- Masters degree (44.35%)
- PhD (14.78%)
- M.D. (9.57%)

- Other graduate degree (8.70%)
- Other education level (6.09%)
- “Prefer not to answer” (.87%)

Participants were given an opportunity to specify their masters degrees, other graduate degrees, and other education levels. The masters degrees reported can be found in Table 6, other graduate degrees in Table 7, and the other educational levels in Table 8 (n = 115).

Table 6
<u>Master's Degrees</u>
Administrative Medicine
Biomedical Informatics
Computer Science
Education/Instructional Design
Family Nurse Practitioner
Health Informatics
Health Services & Healthcare Administration
Informatics
Library & Information Science/Systems
Information Technology
Management
Math
MBA
MPM
MA
Medical Engineering
Medical Informatics
MMIS
MN
MPH
MS
MSN
Preventative Medicine
Public Health
Theater
Theology

Science
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Table 7
<u>Other Graduate Degrees</u>
Technical Communication
Specialty in Dentistry
Medical Informatics
DVM
AAS

Table 8
<u>Other Education Levels</u>
Hospital Diploma
Associate's Degree
Multiple Doctorates
RHIT

Next, respondents were asked to identify their current profession and were allowed to select more than one answer (n = 115). Of the professions listed in the survey, participants fell primarily into the following professional categories: consultant in healthcare or IT (28.70%), IT professional (21.74%), student (18.26%), researcher and or educator (16.52%), healthcare provider (11.30%), library/information professional (11.30%), manager in healthcare setting (10.43%), and manager in IT setting (10.43%). The “other professions” reported by participants can be found in Table 9. A total of three participants (2.61%) preferred not to disclose their profession.

Table 9	
<u>Profession</u>	<u>Response</u>
Consultant (in health care or IT)	28.70%
IT professional	21.74%
Student	18.26%
Researcher and/or educator	16.52%
Health care provider (physician, nurse, dentist, pharmacist,	11.30%

clinician, etc)	
Librarian/Information professional	11.30%
Manager in health care setting	10.43%
Manager in IT setting	10.43%
Medical records director	6.09%
Scientist	6.09%
Database designer or manager	5.22%
Programmer	5.22%
Government employee	0.87%
Human Resources	0.00%
Prefer Not to Answer	2.61%
Other	17.39%
- Associate at veterinary medicine private practice	
- CEO	
- Clinical informaticist	
- Consultant in records management	
- Design and clinical information systems (EHRs)	
- Editor at news service	
- Graphic designer	
- Health information management professional at nonprofit	
- Healthcare IT sales	
- HIM intern	
- Information architect	
- Manager in a health insurance setting	
- PhD candidate	
- Professional corporate trainer & student for HIT	
- Seeking employment	
- Retired	
- RHIA	
- Stay-at-home mother	
- Unemployed	

Respondents were then asked to identify the type of organization where they are currently employed, and multiple selections were allowed for this question as well (n = 115). The primary types of settings where participants are employed include: college/university (26.09%), software/database development company (19.13%), and



hospital (14.78%). The “other” employment organizations specified by participants are listed in Table 10. Six individuals (5.22%) preferred not to answer this question.

Table 10	
<u>Professional Setting</u>	<u>Response</u>
College/University	26.09%
Software/database development company	19.13%
Hospital	14.78%
Clinic/doctor's office	6.09%
Health Insurance company	3.48%
Laboratory	0.87%
Library	0.87%
Pharmaceutical company	0.00%
Prefer Not to Answer	5.22%
Other	30.43%
- Big 4 consulting company	
- Consultant/contractor	
- County government in a service bureau for countywide library consortium	
- Department of Biomedical Informatics at a university	
- EMR consulting company	
- Healthcare services	
- HMO type setting	
- Home office	
- Home care nursing	
- IDN	
- Independent policy advisor	
- Information consulting	
- Medical billing	
- Medical management	
- News service	
- NGO	
- No employer	
- Nonprofit (including membership association)	
- Private R&D	
- Referral practice	
- Self-employed	

- Small company
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The very last question of the survey asked participants to identify the professional associations of which they are current members, and multiple selections were allowed for this question (n = 115). The survey included a list of associations as well as an opportunity for participants to add “other” associations not provided on the list. All responses can be found in Table 11.

Table 11	
<u>Professional Associations</u>	<u>Response</u>
American Medical Association (AMA)	1.74%
American Medical Informatics Association (AMIA)	19.13%
International Medical Informatics Association (IMIA)	8.70%
American Health Information Management Association (AHIMA)	17.39%
American Society for Information Science & Technology (ASIS&T)	9.57%
Healthcare Information and Management Systems Society (HIMSS)	28.70%
Other	29.57%
- Administrators and Academic Psychiatry	
- American Association of Equine Practitioners	
- American Association of Pharmaceutical Scientists	
- American Chemical Society	
- American College of Healthcare Executives	
- American Library Association	
- American Medical Women’s Association	
- American Nurses Association	
- American Nursing Informatics Association – Capital Area Roundtable on Informatics in Nursing	
- American Psychological Association	
- American Public Health Association	
- American Veterinary Medical Association	
- Aquatics Exercise Association	
- ARMA (Records Information Management)	
- Association for Information and Image Management	

- Association for Psychological Science
- Association of Medical Directors of Information Systems
- Australian College of Health Informatics
- British Computer Society
- Dental Informatics Online Community
- Deutsche Gesellschaft für Medizinische Informatik (GMDS)
- German Informatics Society
- Healthcare Financial Management Association
- Honor Society of Nursing
- IEEE (association for the advancement of technology)
- Institute of Certified Records Managers
- International Association for Cryptologic Research
- International Association of Dental Research
- Library and Information Technology Association
- Medical Group Management Association
- National League for Nursing
- OCG (full name not supplied)
- Project Management Institute
- Society for Technical Communication
- South African Health Informatics Association
- Special Library Association
- Tennessee Health Information Management Association
- Texas Health Information Management Association
- Twin Cities Healthcare Professionals' Network Group
- World Federation of Dentists

## Discussion

The goal of the survey was to engage the health information technology, health informatics, and medical communities in identifying the most useful components of an idealized and integrated personal health record (PHR). The survey accomplished this by first establishing that there is strong support for sharing health information and outcomes electronically between the patient and provider. There is also significant support in favor of giving the patient the ability to share access to their health record with other individuals, as they see fit. Throughout the survey responses, participants voiced concern

over maintaining patient privacy and providing ample security to protect sensitive health information. However, with appropriate protections in place, respondents supported a number of PHR functionalities that would begin to shift this tool from being a standalone product to an integrated part of an individual's complete health record. Capabilities such as sharing lab/test results between the patient and provider, sharing current prescriptions between the patient and provider, allowing users to have their health records accessed by hospitals in case of an emergency, appointment scheduling, and sharing copies of visit notes between the patient and provider all received significant support from participants. Very few respondents supported social networking functionality within the PHR; those who were against it felt that it unnecessarily exposed patients to the possibility that their personal health information would be used recklessly. However, a number of respondents suggested that this type of functionality could have a very positive impact, just so long as it is not connected to the PHR.

The survey results indicate that professionals in the critical fields relating to electronic health records recognize the value of investing in electronic tools to support the patient/provider relationship. But with such a significant number of respondents voicing concern over privacy and security issues, it is clear that the proper protections must be established before an integrated PHR can be launched and used in a way that will benefit the patient without exposing them to possible abuses of their health information. And to ensure the longevity of PHR usage, respondents pointed out that usability will be a critical component to the success of electronic health records systems, especially those that become integrated.

## Conclusion

### Limitations of Study

There were a number of limitations to this study. The first is that survey participants were recruited through each of the aforementioned professional associations' official Groups on LinkedIn, rather than through an e-mail solicitation to the association listservs. This was a necessary step since the listservs were not intended to serve as a means of recruiting participants for research studies. However, it is highly unlikely that the survey invitation was actually seen by all of the individuals who would have been reached through a listserv e-mail invitation.

The second limitation is that it seems as if a number of participants did not completely understand some of the concepts introduced in the survey. The question that suggested creating a repository of research information gathered by the patient may have been misinterpreted. The commentary following this question made it seem as if participants thought the survey was suggesting a repository of research data be collected through the use of PHR information. This was not the intention of the primary investigator, and so responses relating to this question should be discounted. Participants may have also misunderstood questions relating to the idea of a patient choosing to share parts or all of their PHR with individuals that they hand select. A number of responses led the primary investigator to believe that respondents may have thought the survey was suggesting that the PHR be shared with other individuals, but not necessarily at the discretion of the patient. It also seems that the idea of sharing even minimal amounts of information with colleagues or friends was not properly introduced in the survey. This type of functionality was included in the survey to account for those instances when

patients who are faced with very complex health issues may need to share information with their colleagues and/or supervisors. It was not the intention of the survey to suggest that this functionality be used by all PHR owners, but that it might be helpful to individuals who are managing a major illness or health related problem.

While there are a number of limitations relating to this study, overall they do not impact its validity. In the case of the way in which participants were recruited, it would be ideal to reach out to individuals directly through their professional association memberships rather than through a social networking utility such as LinkedIn in the future. As far as the possible misinterpretation of some of the questions, it is unfortunate that this happened, but to be expected when complex concepts are introduced in a survey where participants may be skimming questions or rushing through the survey itself. Fortunately, the responses provided are still quite relevant, even if they did not answer the question the primary investigator had intended to ask.

### Importance of Study

Electronic tools for managing health information are at the forefront of the current President's political agenda, offering major incentives to practitioners to implement EHRs. At the same time, PHR tools are being developed to facilitate even greater improvements in communication between patients and providers. Beyond the government's investment in these tools, hospital systems such as UNC Health Care have invested nearly 20 years into developing electronic systems that are intended to improve efficiency, reduce errors, and facilitate improved means of providing and receiving healthcare.

The healthcare industry (clinics, hospitals, providers, etc) and patients alike have a vested interest in the development of an integrated PHR that can connect an individual's health record to those that exist at healthcare facilities. Providing an electronic means of managing an individual's full spectrum of health information from appointment scheduling to creating a repository of consumer health information resources could allow the patient to focus on actively managing their health, especially for those dealing with serious illness or medical traumas, rather than managing their health information. An added benefit is that through the use of these tools, providers will have access to greater amounts of accurate information that will assist them in practicing better medicine.

PHR tools already exist and even more are being developed and implemented across non-profit and for-profit sectors. Both groups have a great incentive to identify and utilize cost-effective tools that will promote a more efficient and effective healthcare system. From an academic standpoint, this survey gave social, physical and medical science professionals an opportunity to express their opinions relating to the concept of the PHR as a personal health information management tool and also to identify those functionalities that will have the greatest positive impact on healthcare. At the same time, participants had a chance to provide feedback on electronic health records as a whole, what they see as critical components for success in those areas that are in dire need of improvement to avoid failure.

This study adds to the existing research literature by having engaged individuals from all of the stakeholder professions relating to electronic health records. This unique

perspective provides an essential foundation by confirming that electronic health records are seen as a critical component in transforming and improving our health care system. It also identifies what components should be a part of future PHRs and the critical factors of privacy and security that must be addressed so that electronic health record systems can be safely and effectively used.

### Future Steps

If the recommendations from this study are implemented, then development of PHR tools that function as personal health information management systems will have to be one of the first steps taken. At the same time, security and privacy issues must be addressed before these advanced PHRs can be implemented in a way that could lead to any sort of transformation of our healthcare system. And while the development of personal health information management type-PHRs is obviously necessary, usability will be a critical factor to the long-term success of electronic health record systems. Furthering the research of Marchionini, Rimer, and Wildemuth (2007) in the area of PHR usability will increase the likelihood that advanced PHR tools achieve widespread adoption. These tools must be developed in a way that will meet the needs of all the user groups involved in managing health information, including healthcare providers, patients, and information technology professionals working on both development and implementation.



## Appendices

### Appendix A – Survey Introduction & Questions

The goal of this survey is to solicit your opinion on how Personal Health Records (PHRs) can be expanded to include functionality that will help users to maintain and share their personal health information (examples include doctor's appointments, test results, office visit notes, courses of treatment, etc). A PHR is defined as a tool that is managed by the patient and provides a means of tracking an individual's entire health history.

The questions in this survey will ask you to consider a number of possible components, as well as offer an opportunity for you to suggest other options, that will help to make future PHRs more useful to individuals who would like to manage all of their health information through a single system.

#### Question 1:

Would you like to see future PHRs allow healthcare providers to share information directly to the patient electronically?

Available options: Yes & No

Comments:

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Question 2: Would you like to see future PHRs allow the patient to share their health information with their healthcare providers electronically?

Available options: Yes & No

Comments:

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Question 3: Would you like to see future PHRs allow the patient to share their health information with other individuals they select electronically?

Available options: Yes & No

Comments:

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#### Question 4:

Assuming that health information/outcomes can be transmitted electronically from the provider to the patient, the patient to other individuals, etc., please consider the following

additional PHR functionalities. Which of the following would you like to see included in future versions of PHR systems to assist users in managing all of their personal health information? Check all that apply.

1. Appointment scheduling
2. Calendar that synchronizes with appointments as they are made
3. Calendar that the patient may share with friends, family and colleagues
4. A means of sharing lab/test results between the patient and provider
5. A means of sharing copies of visit notes between the patient and provider
6. A means of sharing current prescriptions between the patient and provider
7. A means of sharing visit outcomes from the patient to their friends, family and colleagues.
8. Functionality that allows users to have their health records accessed by hospitals, in case of an emergency, where the patient cannot grant access at the time the information is needed.
9. Social networking functionality that would allow users to share their health information/experiences with individuals facing similar health concerns and/or those who share an interest in the health issues addressed by the user
10. A repository that will store research information obtained by the patient on health issues and/or concerns (for example, information on heart disease obtained through research performed on Medline Plus).
11. Other functionality – Please list and describe any additional PHR functionality that you think would improve users’ ability to manage the full spectrum of their personal health information.

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Question 5:

Do you have any comments/concerns/recommendations to add about the functionalities you chose in Question 4?

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Question 6:

Please provide any general comments you have about PHRs. In this area, please discuss your expectations and opinions about the future of PHRs. For example, you may want to discuss their perceived usefulness, what functionality would have to be created in order to improve them, and any issues or concerns you might have about the public’s use of PHRs including privacy concerns, whether or not these tools will actually help to improve healthcare, etc.

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In order to help us describe our sample and understand our findings, please tell us a bit about yourself.

D1. What is your age category?

1. 25 years or younger
2. 26-30 years
3. 31-35 years
4. 36-40 years
5. 41-45 years
6. 46-50 years
7. 51-55 years
8. 56-60 years
9. 61-65 years
10. Prefer not to answer

D2. What is your sex?

1. Male
2. Female
3. Prefer not to answer

D3. What is your country of residence? \_\_\_\_\_

D4. What is your educational background?

1. High school
2. Some college
3. Bachelor's degree
4. Some graduate school
5. Master's, please specify \_\_\_\_\_
6. Ph.D.
7. MD
8. Other graduate degree, please specify
9. Other educational level, please specify \_\_\_\_\_
10. Prefer not to answer

D5. How would you describe your current professional position? Select all that apply.

1. Consultant (in healthcare or IT)
2. Database designer or manager
3. Government employee
4. Healthcare provider (physician, nurse, dentist, pharmacist, clinician, etc)
5. Human resources

6. IT professional
7. Librarian/Information professional
8. Manager in healthcare setting
9. Manager in IT setting
10. Medical records director
11. Programmer
12. Researcher and/or educator
13. Scientist
14. Student
15. Other, please specify \_\_\_\_\_
16. Prefer not to answer

D6. How would you describe the organization where you are currently employed?  
Select all that apply.

1. Clinic/doctor's office
2. College/University
3. Health Insurance company
4. Hospital
5. Laboratory
6. Library
7. Pharmaceutical company
8. Software/database development company
9. Other, please specify \_\_\_\_\_
10. Prefer not to answer

D7. What professional associations are you a member of? Select all that apply.

1. American Medical Association (AMA)
2. American Medical Informatics Association (AMIA)
3. International Medical Informatics Association (IMIA)
4. American Health Information Management Association (AHIMA)
5. American Society for Information Science & Technology (ASIS&T)
6. Healthcare Information and Management Systems Society (HIMSS)
7. Other, please specify \_\_\_\_\_

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