

USE OF PERSONAL HEALTH RECORDS BY HEALTHCARE OR HEALTH
INFORMATION TECHNOLOGY PROFESSIONALS

BY

KRYSTAL LLOYD

A CAPSTONE

Presented to the Oregon Health & Science University's
Department of Medical Informatics & Clinical Epidemiology
in partial fulfillment of
the requirements for the degree of
Masters of Biomedical Informatics

Capstone Advisor
Holly Jimison, Ph.D.

School of Medicine
Oregon Health & Science University

CERTIFICATE OF APPROVAL

This is to certify that the Master's Capstone Project of

Krystal M. Lloyd

*"USE OF PERSONAL HEALTH RECORDS BY HEALTHCARE OR HEALTH
INFORMATION TECHNOLOGY PROFESSIONALS"*

Has been approved

Capstone Advisor

TABLE OF CONTENTS

ABSTRACT.....	4
INTRODUCTION.....	6
Background.....	6
Use of PHRs.....	7
Types of PHRs.....	7
Components of PHRs.....	8
Potential Benefits of PHR.....	8
Research Question.....	17
METHODS.....	18
RESULTS AND DISCUSSION.....	18
SUMMARY AND CONCLUSIONS.....	29
APPENDIX A: Consent Form Survey.....	32
APPENDIX B: Personal Health Record Survey.....	33
REFERENCES.....	37

ABSTRACT

BACKGROUND: A Personal Health Record (PHR) is an electronic record where individual can create and maintain information related to their health. There are many components and benefits to a PHR. A few of those components are making use information is correct, knowing more about your care, and sharing information with your family. There are also many activities available on the Internet that individuals are able to do and some of those are communicating with a health care provider and searching for information online about a health condition.

OBJECTIVE: The goal of this paper is to explore whether or not professionals in healthcare or health information technology professions use personal health records and consumer health information technology more than the general public.

METHODS: A survey was targeted for the healthcare or health information technology professionals via LinkedIn. The results of this survey were compared with the National Consumer HIT survey. We measured 45 questions from the original survey that were done for the National Consumer HIT survey and compared those to the professional group. We looked at whether individuals had a Personal Health Record, as well as their attitudes about the use and usefulness of the features of PHR. We also searched for an indication of whether they had used consumer health information technology functions online.

RESULTS: The survey showed statistically significant differences for a professional group using PHRs, having online PHRs, making sure information is correct, and made it easier to talk to your family about your health. For those individual that did not have a PHR there was statistically significant between the group for all the questions related to

the way people can use their information online. For the rest of the questions they were related to online activities and a few of those included looking at test results, searching for information about a disease, communication with a provider, and renewing prescriptions online.

Conclusion: The findings of this study demonstrate that professionals do find value in PHRs like the consumer population. Findings were also statistically significant for that the professional group found were interested in the tools available online related to health.

ACKNOWLEDGEMENTS

My thanks go to my advisor Dr. Holly Jimison, for her support and guidance, and for giving me the opportunity to work on this project. I am extremely happy for her encouragement and guidance throughout this project.

Most importantly, I thank my family, my husband Mike, my children Brent and Elizabeth, and my mother. Thank you to my father, who I know is looking down with a big smile on his face because I am working on my education, and who always said, "Your education is something no one can ever take away."

INTRODUCTION

Background

Personal health records (PHRs) have a long history in this country and in fact have been in existence for many years. PHRs started with minimal technology that individuals and families used for many decades. Information was stored in paper, including copies of laboratory reports, reports from various providers, and information in baby books for child development and immunization. Some information, such as medical and emergency contacts, allergies, and blood type, was carried in wallets. MedicAlert™ necklaces and bracelets were examples of the ways that individuals used to communicate basic personal health information with the medical community in emergency situations.¹

As technology in various fields has evolved, so has the technology for PHRs. Many of the first PHRs were created and updated on word processors or spreadsheet applications to assist individuals in managing chronic diseases. The compilation of lifelong personal health information has also evolved into CD-ROMs, USB, online services, provider-based services, and insurance-based services.

Some lessons about the value of PHRs and computer-based records have been learned from the tragedies that occurred during the SARS epidemic and Hurricane Katrina, as well as from the delayed response and recovery times, and costs incurred because of the absence of these systems.¹

As technology has evolved, so have the various definitions of PHR. Many current definitions state that PHRs include some sort of computer- or electronic-based system and also talk about individuals managing and accessing the information within the system and sharing relevant parts with those who need it.²⁻³

For the purposes of this project, we have decided to a single definition, from the National Alliance for Health Information Technology:

An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.

According to an article by Tang, et al., “the U.S. Secretary of Health and Human Services, the National Coordinator for Health Information Technology, and the Administrator of the Centers for Medicare and Medicaid Services (CMS) have all identified PHRs as a top priority.”³

Use of PHRs

The Markle Foundation, Connecting for Health researchers found in a 2008 survey that most Americans (57.3%) did not keep health records at home, although of the approximately 40% who did keep paper records at home, 2.7% used some type of electronic record.⁴ The California Healthcare Foundation determined in a 2010 survey that the number of Americans using an electronic PHR had increased to 7%, roughly double the amount highlighted by the prior survey. The 2010 survey also showed that approximately 40% of Americans were interested in electronic PHRs.⁵

Types of PHRs

There are several types of PHRs to choose from: paper, provider-based, insurer-based, web-based, and standalone PHRs on USB drives or CDs.^{3, 6} The California HealthCare Foundation survey reported that of the individuals who had PHRs, 51% used

one by the health insurance plan, 26% by their doctor/health care provider, 4% by their employer, 6% by other, and 13% were not sure.⁵

Components of PHRs

The Healthcare Information Management Systems and Society (HIMSS) along with several other organizations and authors have stated that there are some components that are important to have in a PHR. Some of those components include personal identification with emergency contact information; primary care and other current providers; active medications; history of medications and why they were discontinued; over-the-counter medications; allergies; diagnoses; immunizations; test results; past medical, surgical, family, and social histories; and healthcare power of attorneys and proxies.⁷ According to a policy statement from the American Academy of Pediatrics, birth history and information on weight, stature, BMI, head circumference, and developmental milestones should also be included.⁸

Potential Benefits of PHR

PHRs have the potential to assist consumers' abilities to improve their health and manage chronic medical conditions. This tracking of chronic medical conditions will help lower communication barriers between patients and care providers through ongoing connections and shorten the time it takes to address any problems. Data collected in PHRs may help clinicians make better decisions.³

Making Sure Information Is Correct

In a survey by the California Healthcare Foundation, 64% of respondents found it very useful or somewhat useful to make sure information was correct in their PHRs, and 12% found missing information or something wrong with the online information when using a PHR in the same survey.⁵ A study by the Markle Foundation reported that 87% believe a PHR would improve their ability to check for errors or mistakes in health records.⁴ As part of the Health Information Portability and Accountability Act, patients have been given more information about the ability to make corrections and/or amendments to health information.

Section 164.526 states that individuals have the right to ask a covered entity (i.e., a hospital, physician, or other health care provider) to make an amendment to correct information in the record when maintained as part of the designated record set if the information in such a set is inaccurate or incomplete.⁹ Additionally, the ability to check and correct information is a type of information self-management according to Kaelber et al., meaning it would potentially have the ability to improve patient-provider relationships.²

Know More About Your Care

Fifty-two percent of those surveyed by the California Healthcare Foundation indicated that one of the effects of using a PHR was that they knew more about the care provided by their doctors.⁵ One of the rules in Recommendation 4 of the book *Crossing the Quality Chasm* is that “Care is based on continuous healing relationships. Patients should receive care whenever they need it and in many forms, not just face-to-face visits.” This rule implies that the healthcare system should be responsive at all times (24 hours a

day, every day) and that access to care should be provided over the Internet, by telephone, and by other means in addition to face-to-face visits.¹⁰

Asking Questions About Your Health

According to the California Healthcare Foundation survey, 40% of individuals agreed that one of the effects of using a PHR was that it helped patients ask their doctors questions they might not have previously asked.⁵ The ability to ask your physicians questions also goes along with the recommendations found in *Crossing the Quality Chasm*. Another aspect of Recommendation 4 dealt with shared knowledge and the free flow of information, stating that “Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.”¹⁰

Family Health History

On November 24, 2010, the U.S. Surgeon General, Regina Benjamin M.D., issued a statement that the Thanksgiving holiday was an opportunity for families to share their family’s health history. The Surgeon General stated that knowing your family’s health history is the key to prevention. Your family’s health history may assist you and your physician by allowing a more careful screening for diseases and will give you the ability to alter your lifestyle for disease prevention.¹¹ This was not the first time that this statement had been issued from the U.S. Surgeon General's office. A statement in 2008 from Acting Surgeon General, Steven K. Galson M.D. M.P.H., declared that Thanksgiving was the fifth annual "National Family History Day."¹² A possible effect of this was that 31% of respondents in the National Consumer HIT survey agreed that having a PHR made

it easier to talk to their family about health, while 38% said that it was "very" or "somewhat useful" for information sharing with their family.⁵

Connected to your doctor

According to the Institute of Medicine, patient-centered care is defined as, "providing care that is respectful of and responsive to an individual patient's preferences, needs, and values, and ensures that patient values guide all clinical decisions."¹⁰ One idea that has been proposed is to achieve this by giving patients access to their personal healthcare information through PHRs. Part of this is allowing patients to have a better sense of their illness and greater control that correlates to the doctor's, along with the patient's, experience with the self-management of diseases.¹³ The California HealthCare Foundation found that 38% answered that the effect of a PHR caused them to feel more connected to their doctors, while 25% were less likely to switch doctors.

The National Consumer HIT survey also found that 41% of respondents found hearing their physician's instructions "very" or "somewhat useful."⁵ This finding is supported by a study conducted in the UK in 2005. One of the quotes dealing with the subject of the relationship between patients and medical professionals stated: "There is no secrecy at all; what the doctor writes about the patient is available for the patient to see, so it's more open."¹⁴

Computer Competency and Health Literacy

The California HealthCare Foundation also included questions regarding an individual's familiarity with the different aspects of health information technologies. In his 2009 article, "Characteristics of the Ideal Personal Health Record," Kahn argues consumer adoption will require attention to at least three areas: computer competency, Internet

access, and health literacy. Computer competency goes beyond turning the computer on and off; it also includes Web navigation, searching for and saving information, and sending and receiving email. Health literacy and health information technologies seem to go together¹⁵. Improving health literacy is a key component of improving health. A low level of health literacy is associated with fewer activities that influence good health, according to Healthy People 2010¹⁶. Many online activities can affect an individual's health literacy. Some of these undertakings include looking for information about diseases or medical problems, viewing test results online, exchanging emails with a doctor, and renewing a prescription online. People can also connect home monitoring devices, such as glucose meters and blood pressure monitors, to computers. In addition, various websites help individuals monitor their eating and exercise habits. The Internet also gives patients the opportunity to search for many physicians online¹⁷.

Search for Information About a Disease or Medical Problem

In the survey conducted for the National Health Care Foundation, the majority of respondents said that they had searched online for information about a disease or medical problem in the past.¹⁴ There are many Web sites where such information can be found, for example, WebMD.com and MayoClinic.com. A simple Web search should produce these and other results. Results from a recent survey by the Pew Internet & American Life Project reported that 59 percent of Internet users have looked online for information about any of 15 health topics, including specific diseases and treatments.¹⁵

Send and Receive E-mail

The results for the national consumer survey on HIT showed that the majority of individuals have never sent an e-mail to or received an e-mail from a provider. EPIC is a

software developer that has made this procedure accessible through MyChart, the PHR or portal for records. One of the features available in MyChart is the ability to “send and receive messages with providers.”¹⁶ EPIC is one of many companies that have this ability. The American Medical Association has created guidelines for physicians on physician - patient electronic communication that is available on their website¹⁷.

Renew Prescriptions Online

Another item on the survey was concerned with whether individuals were renewing prescriptions online. The consumer survey on HIT found that the majority of individuals have not reviewed or renewed a prescription online.¹⁴ There are several companies that allow individuals to renew their prescriptions online. If you Google companies that allow you to renew your prescriptions online, several of the major pharmacies come up, including Walgreens, Wal-Mart, and CVS. Similarly, tethered PHRs like Epic’s MyChart allow prescription renewal online.

Information about Exercise and Weight

Individuals were also surveyed on their use of Web sites to record information about what they eat, how much they exercise, and what they weigh. The HIT survey discovered that approximately one-quarter of the participants had used such a Website.¹⁴ One example of this is Live Health Iowa, where individuals track exercise and weight loss during a 100-day competition.¹⁸ Also, the online version of Weight Watchers® lets one track weight loss and record food intake. This also can be done with a Smartphone.¹⁹

Information About a Chronic Illness

The HIT survey also asked whether individuals had ever typed information into a Website about a personal chronic illness. About 20% of respondents said they had.¹⁴ A

Pew Internet report on *The Social Life of Health Information* noted that caregivers were more likely to use these sites than the sufferer was.²⁰ In Tenforde's 2011 article on "The Value of Personal Health Records for Chronic Disease Management: What Do We Know?" the authors state that in chronic disease management, PHRs hold a great potential. Clinicians have a limited amount of time to spend with patients during outpatient appointments, and this time is inadequate to teach patients and families about the complexities of chronic disease management. Also, according to the article, with the aging population of the United States comes an increasing demand for healthcare organizations, along with the increasing demand to shift from a paternalistic model to a patient-centered one. For the paradigm shift in health care, it was stated that PHRs are in the ideal situation to assist with this²¹.

Devices That Measure Health Information Connected to Your Computer

In the HIT survey, people were also asked whether they had used a device that connects to a computer and measures blood sugar or blood pressure. Most respondents said they had not used a device connected to a computer, in fact only 6% of respondent said they had used a device connected to a computer.¹⁴ One example is a blood sugar meter called the OneTouch Diabetes Management Software Kit by Johnson & Johnson. The Website states that individuals are able to identify trends in their blood glucose levels, print and share reports with their doctors, and find high, low, and average levels.²² This is just one of many devices that can connect to a computer. An article by Kaelber et al. indicated that this would be an example of patient-oriented disease information and decision support, helping patients to manage their own health.² In a publication by the IBM Institute for Business Value, there is a report about *The Future of Connected Health*

Devices Liberating the Information Seeker, which states that as our home lives become more interconnected and intelligent, home monitoring solutions will become more affordable and win over healthcare payers and seekers. A few of the examples given in the article may be able to help encourage individuals with the challenges faced by trying to break bad habits (e.g., smoking and overeating), assist the frail or elderly to live more independently, help those who have difficulty complying with treatment regimens, and help develop individualized treatment plans for those who struggle with conditions requiring significant trial and error.²³

Smartphone Use

Another item discovered by the national consumer survey is that the majority of individuals have not used an application on an iPhone or other cell phone for related activities.¹⁴ According to Kahn et al., this is another ideal characteristic for a PHR. It was stated that Internet access is not as high as mobile phone usage in underserved communities and that mobile phone usage may serve as an important opportunity for these underserved individuals to access PHRs as well as help change the behavior of text messages to have them serve as customized reminders.²⁴ On the Apple Web site, there is a listing of the most popular applications related to healthcare and fitness, including Diet & Food Tracker by SparkPeople, Micromedex Drug Information, BMI Tool, Weight Watchers Mobile, CVS Pharmacy, Daily Cardio Workout Free, and MyFood - Nutrition Facts.²⁵

Online Group for Health Issues

Another survey by the National Consumer Survey on HIT asked whether respondents had joined an online group for a health issue that they or their family

members have. The majority of respondents answered that they have not joined an online group.¹⁴ Back in 2001, it was reported that online support groups are expanding. It was also reported that there are several advantages to online support groups, including the ability to access them 24 hours a day, seven days a week, and the anonymity that allows for the discussion of embarrassing and sensitive subjects. For those with uncommon illnesses, online connections may be the only way to communicate with others dealing with the same issues.²⁶ One example of these online groups can be found at CancerCare.org. These groups are directed at individuals and families, as well as for those who are grieving.²⁷

Searched for Information on a Doctor

Another task that individuals are able to do online is research healthcare providers. The National Consumer Survey on HIT found that half of the respondents had conducted an online search for information about a doctor.¹⁴ A couple of ways to find information about a doctor are health grades at www.healthgrades.com or the Web sites of the State Board of Medical Examiners.

Posted Online About Health or Healthcare

The survey from the National Consumer Survey on HIT showed that a majority of individuals do not post information online about their health or healthcare.¹⁴ Individuals are also able to post information about them or a loved one's going through difficult times on personal blogs or sites they have created. An example of this is the CaringBridge.org. According to Rice in 2006, this is a source for support and interaction to promote a sense of understanding to patients, families, and friends²⁸. Also, in the issue it was stated that

the use of Internet for information sharing and online self-help programs will empower the patient.²⁹

Each of the topic areas mention above applies to PHR use or use of the Internet for online activities and how this might impact PHRs. The National Consumer HIT survey published focused on adult consumers nationwide. The research also shows how PHR use could be important to patient-centered care. For the project described in this paper, we conducted a similar survey, but targeted potential PHR users who were professionals in health care fields, the findings of which will be summarized in the *Results* section.

Research Question

This work explores the use of personal health records and consumer health information technology by professionals in the healthcare or health information technology fields. The primary research question was:

Do healthcare or health information technology professionals use PHRs more frequently or in a different way than the general public?

To investigate this research question, we had two specific aims:

Specific Aim 1: Evaluate the percentage of healthcare or health information technology professionals using personal health records as compared to the general public.

Specific Aim 2: Determine how these individuals are using personal health records as compared to the general public.

METHODS

Study Sample

This study sample looked at two different target areas: clinical professionals and health technology professionals. The target populations for the survey were identified through LinkedIn professional network groups. Contacts were made with target state associations for the target groups or through social media to send e-mail links to the study focus areas.

Our target groups were the following LinkedIn groups: HIMSS, Nurse, RN, or Medical Professionals. The Medical Professionals group includes RNs, pharmacists, residents, PAs, physicians, and other health professionals.

Collection of Data

Data was collected using the survey tool “Survey Monkey.” Appendix A: Shows the script that was used for the recruitment of participants. Appendix B: Shows the questions that were asked of the participants. The data was downloaded and imported into SPSS for analysis.

RESULTS AND DISCUSSION

Initially, postings were also made in the HIMSS group, Health Information Technology group, and Registered Nurses group to target health technology and clinical professionals for the survey. An attempt was also made to join a closed group called Medical Professionals, but we were unable to obtain access for the purpose of conducting a survey. With the posting of the survey to these groups very few responded to the survey therefore, we decided to use the LinkedIn messaging process. A total of 443 messages

were sent out through the LinkedIn messaging process in the Health Information Technology group with a total of 72 responses for a response rate of 16.25%.

Given that we were looking at professionals in the health care field, we were interested in what type of professional they were. The graph in Figure 1 shows the distribution of respondents. It illustrates that a majority of respondents were clinical professionals. A few of the individual responses in the other categories stated that they were project managers, patient advocates, and students.

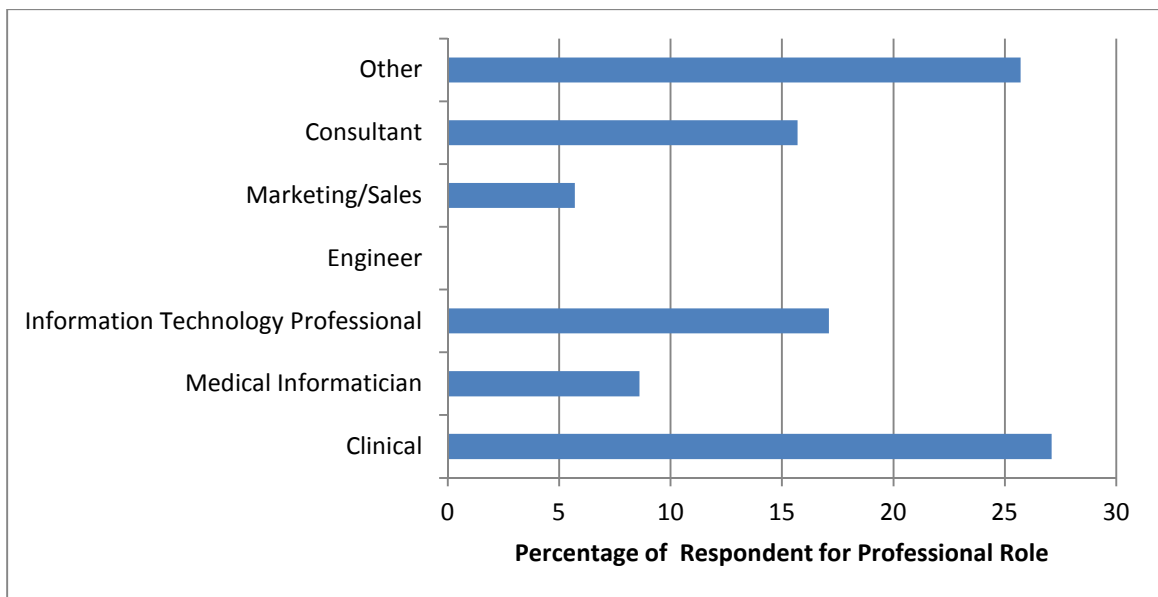


Figure 1: This graph shows the percentage of respondents in each field.

Regarding the number of years in the profession, the graph in Figure 2 shows a bell curve with a spike at 26-30. It goes toward a six to 10-year range with a drop of those in the field when the chart extends greater than 31.

The spike in the category *6-10 years in the profession* may correlate to back in 2004 when former President Bush, in his State of Union address, called for every American to have electronic health records³⁰.

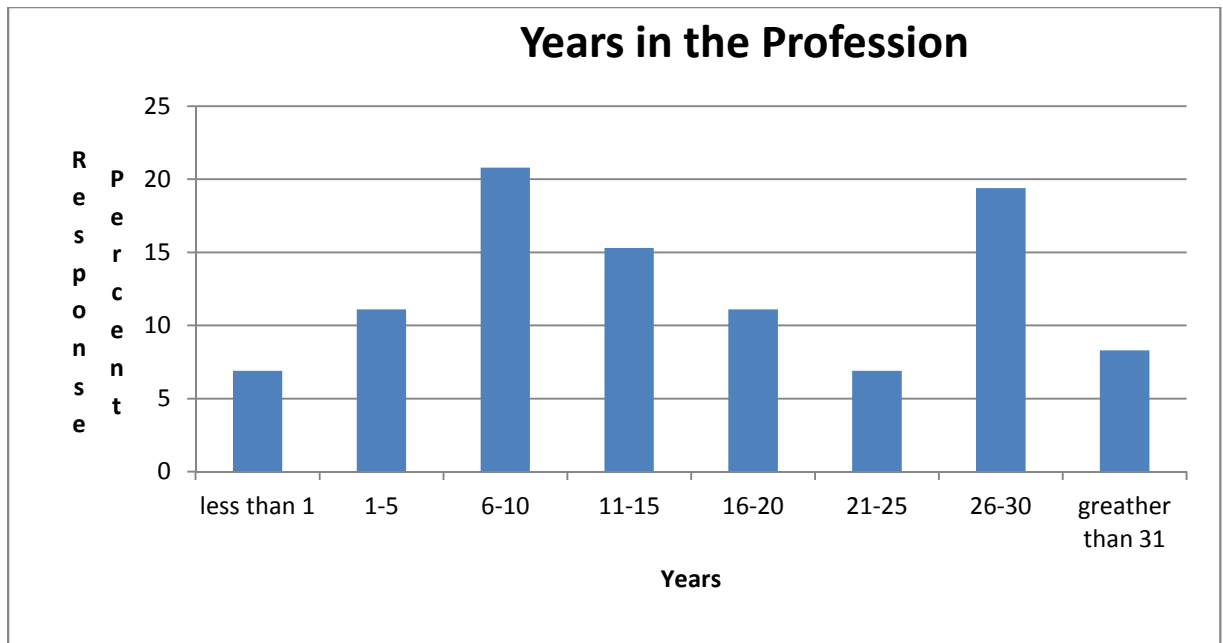


Figure 2: This graph shows the percentage of respondents' years of experience.

For the rest of the questions, statistical significance was calculated using the CHI-square significance test for comparing two proportions. When performing more than one statistical significance test, significant findings are more likely to occur by chance unless one corrects for the number of test performed (i.e., number of survey items tested). We used the Bonferroni technique “new α -level (p) = (desired α for the entire study)/ j(number of significance tests)”³¹. We desired a resulting significance level of p = 0.05, so with the Bonferroni technique, our new p = 0.001. We tested to see if health care or health information technology professionals use PHR and consumer health information technology more than the general population, as surveyed by the National Consumer HIT survey.

The analysis yielded a total of 35 respondents (48.6%) who indicated they have a PHR. We compared this to those surveyed for the National Consumer HealthCare where 7% had a PHR. Thus, the finding was statistically significant at both p < 0.05 and p < 0.001. I believe that along with the fact that a PHR is being kept, it is of interest to know

how an individual PHR is being kept. I also found that the majority of professionals keep copies of these records online or in combination with some type of online component (Figure 3). In comparison, it was reported by the National Consumer HIT survey that 82% keep these records on paper and only 7% use an online site to keep health information. I also found that for those who stored their PHR online the majority used the service provided by the health information plan (51%), the rest was divided between a health care provider (27.8%), health insurance plan (22.2%), and online service (27.8%) (Figure 4).

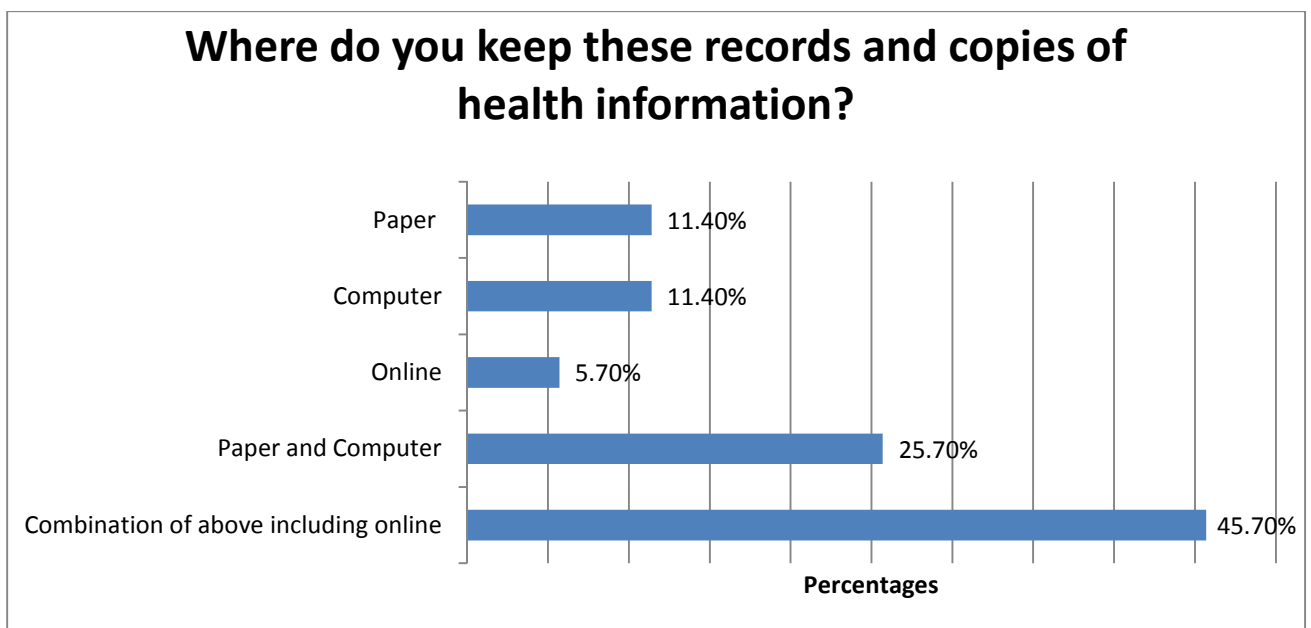


Figure 3: This graph shows the percentage of where individuals who have PHR store the information.

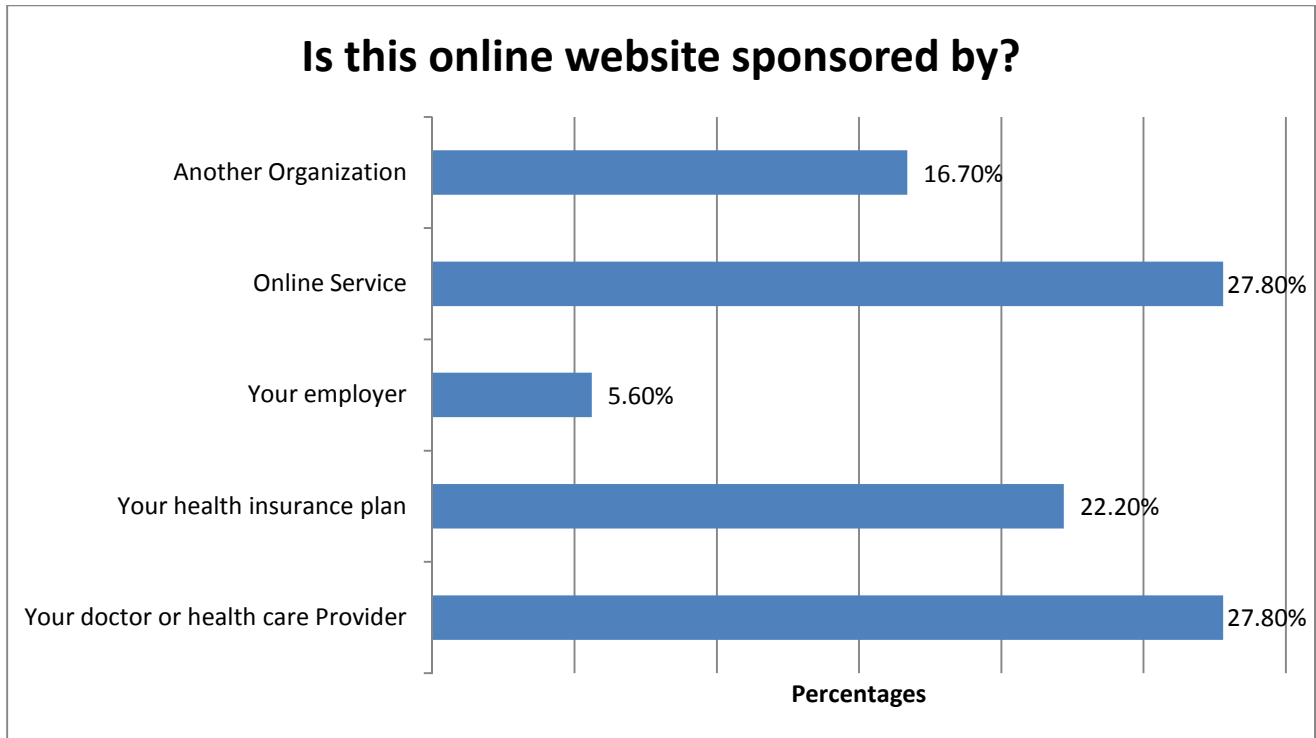


Figure 4: This graph shows where individual who have online PHR store the information.

The next set of questions will try to look at your health information online.

I compared the responses I received with the National Consumer HIT survey using the Chi Square. With the Bonferroni correction, the results were significant (i.e., at $p < 0.001$ level) for the questions: "Has this led you to do something to improve your health?" and "Has it made it easier to talk to your family about your health?"

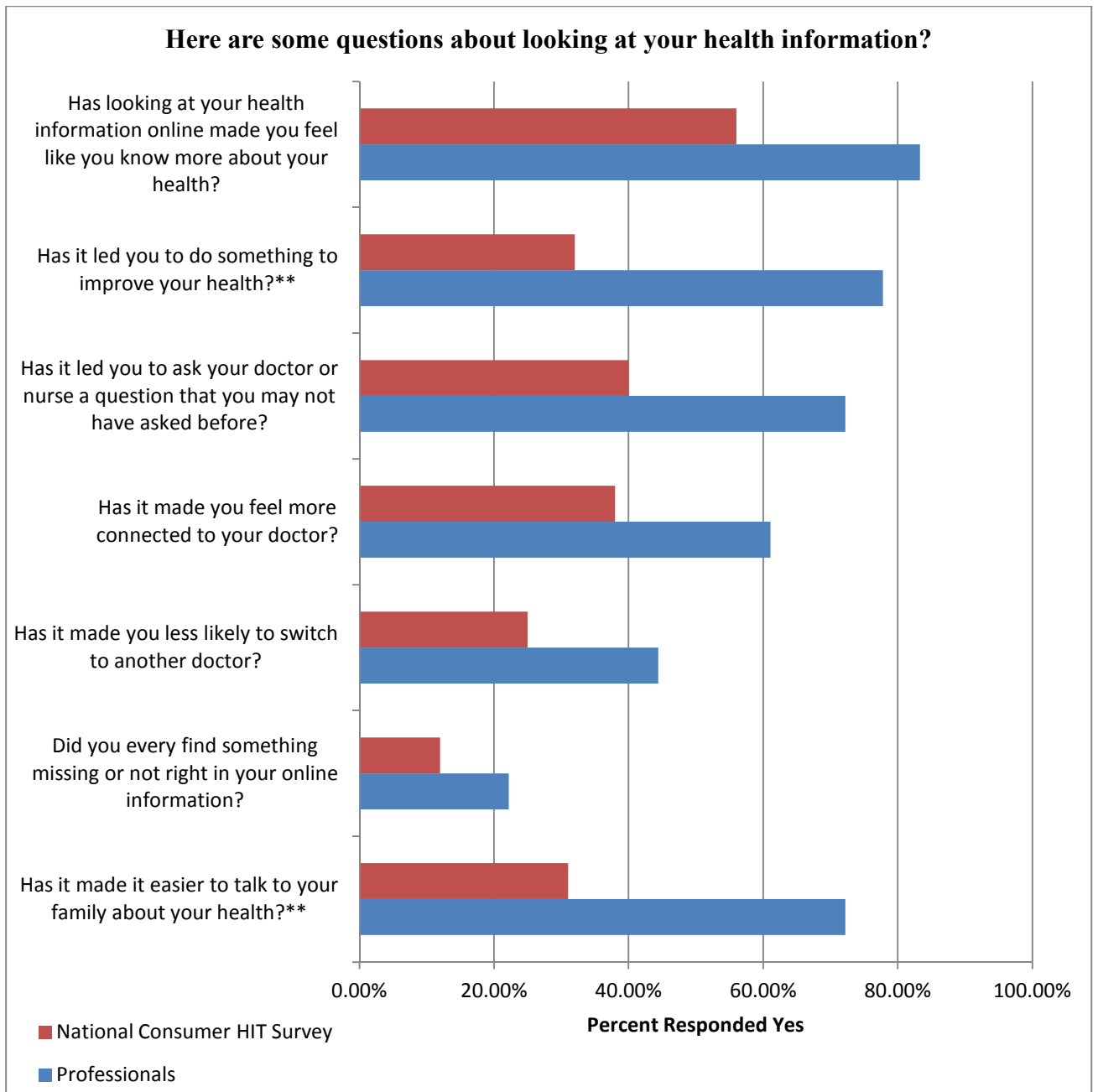


Figure 5: This graph shows the percent who responded yes to the question.
**** Statistically Significant Responses at $p < 0.001$**

By analyzing the results, I discovered that the following features were very useful or somewhat useful in each of the categories, with the National Consumer HIT survey being statistically significant for one question at the $p < 0.001$ level. This was calculated

using the Chi Square and for significance at $p < 0.001$, taking into account the Bonferroni correction method. Individuals were asked the question “How useful was each of these to you?” During the times they have looked at their online medical and health information. Graph 6 displays the percent responses for each of the items that the individuals were asked to think about. I found for this series of questions only one response was statistically significant and that was related to "making Sure Information is Correct".

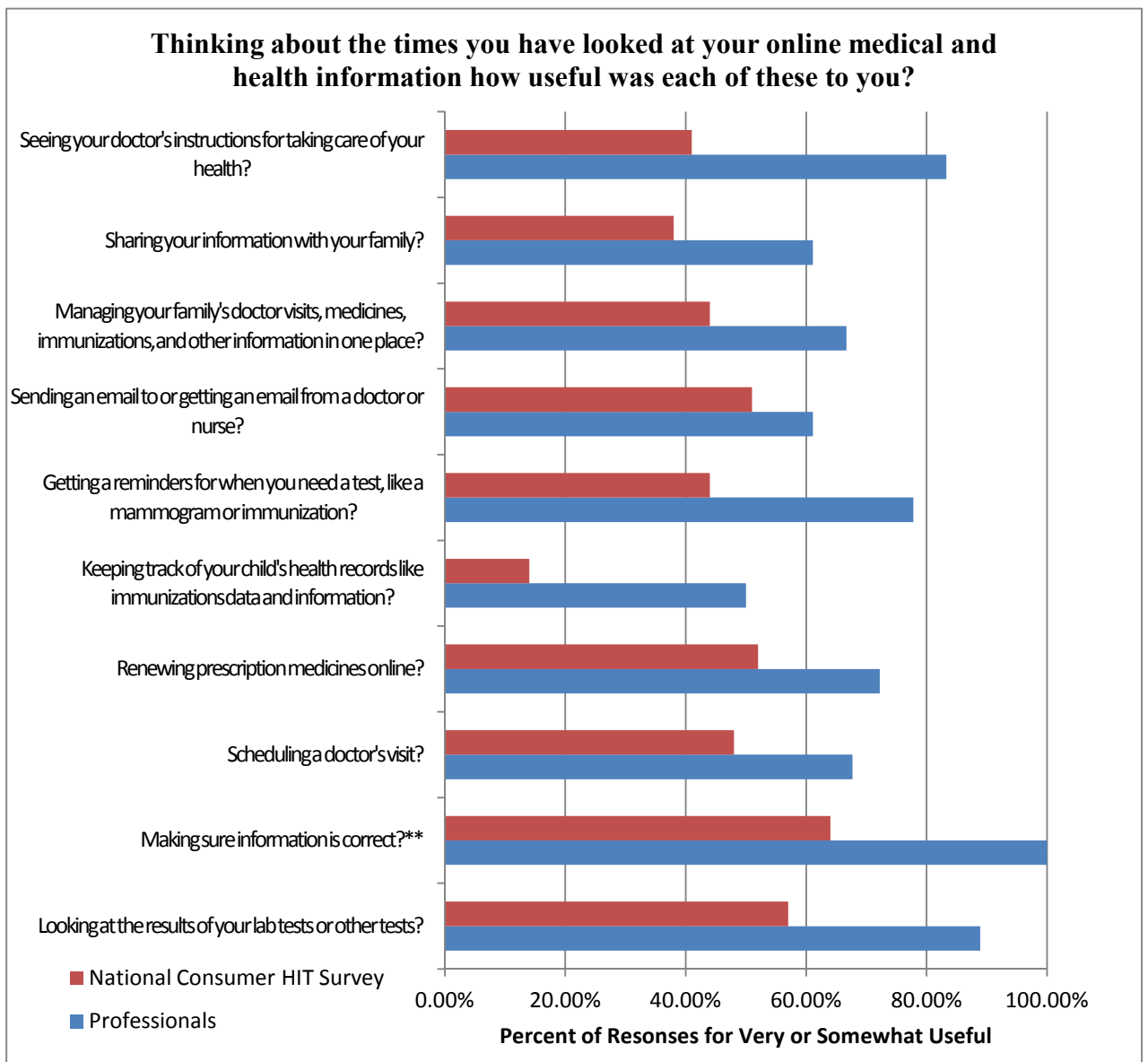
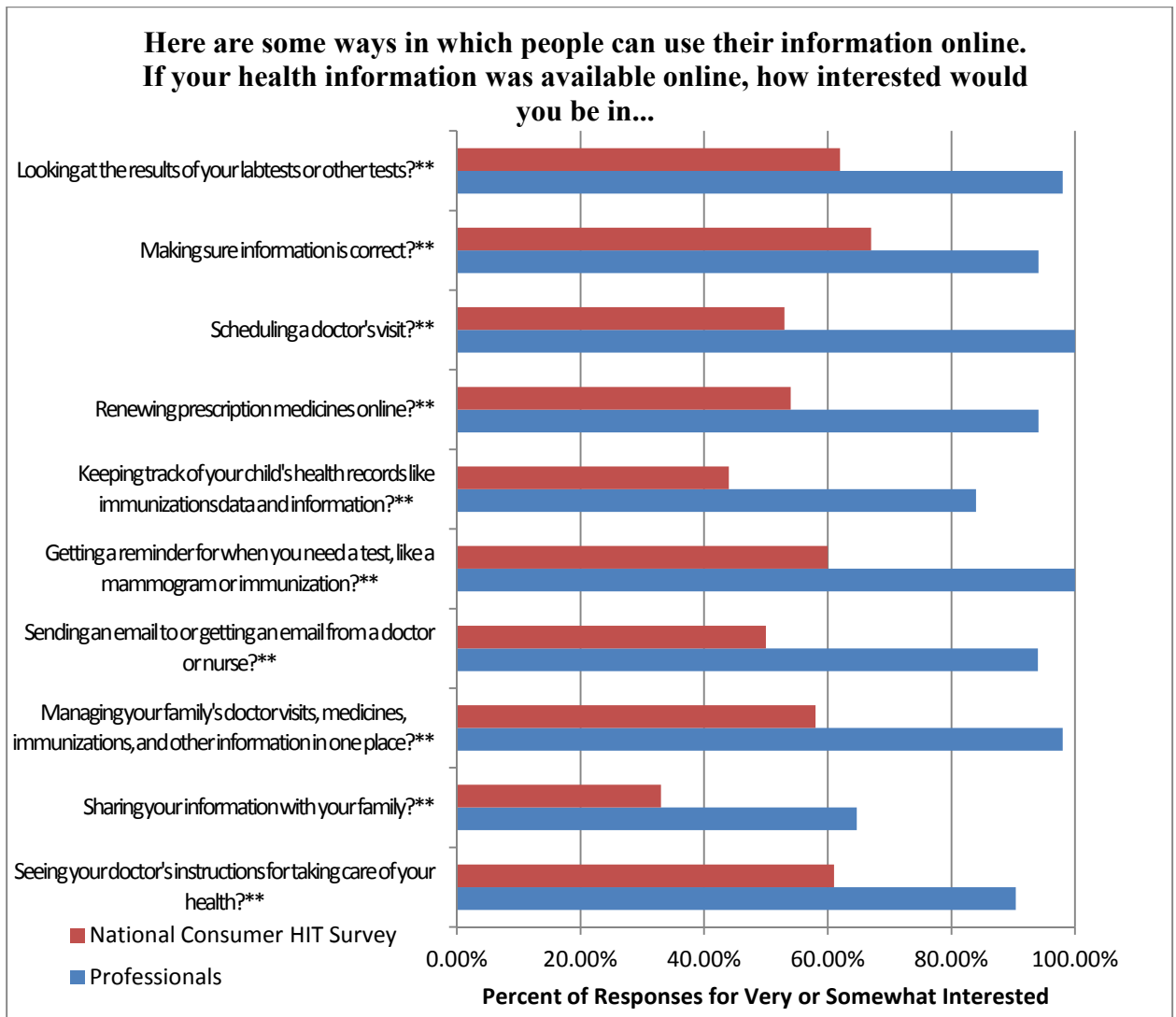


Figure 6: This graph shows the percent of respondents who answered very or somewhat useful to the series of questions related to how useful different functions were. ** Statistically Significant at $p < 0.001$

I found that when comparing the responses for non-PHR users between the National Consumer HIT survey and the professionals survey in all of the questions related to “Here are some ways people can use their health information online. If your health information was available online, how interested would you be in...” it was statistically significant for each responses. The percentages shown in the figure below are for those respondents who answered that they were either very interested or somewhat interested. I found the results to all be significant at the $p < 0.001$, with the Chi Square with the Bonferroni correction.



**Figure 7: This graph shows the percent of responses for those who answered very or somewhat interested related to the question how people can use their information online.
** Statistically significant at $p < 0.001$**

I determined that for the following figures, all of the results were statistically significant for yes responses for the professionals group when compared to the consumer group surveyed for the National Consumer HIT survey using the Chi Square with the Bonferroni correction at a $p < 0.001$.

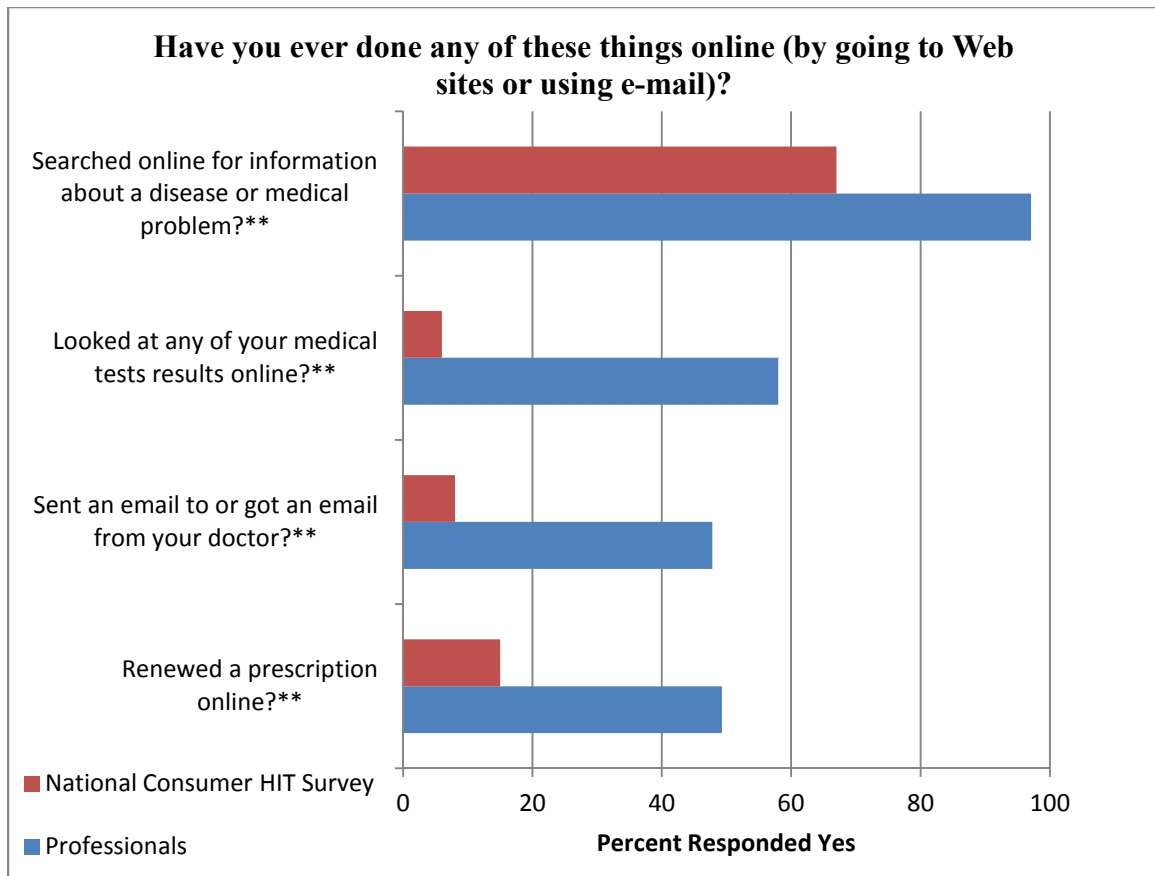


Figure 8: This graph shows the percent who responded yes to online activities related to health.
**** Statistically significant at $p < 0.001$**

Respondents were then asked a series of seven questions about "Have you ever done any of these things?" When comparing the yes responses, I found that for the professional group, all of the questions were statistically significant using the Chi Square with the Bonferroni correction.

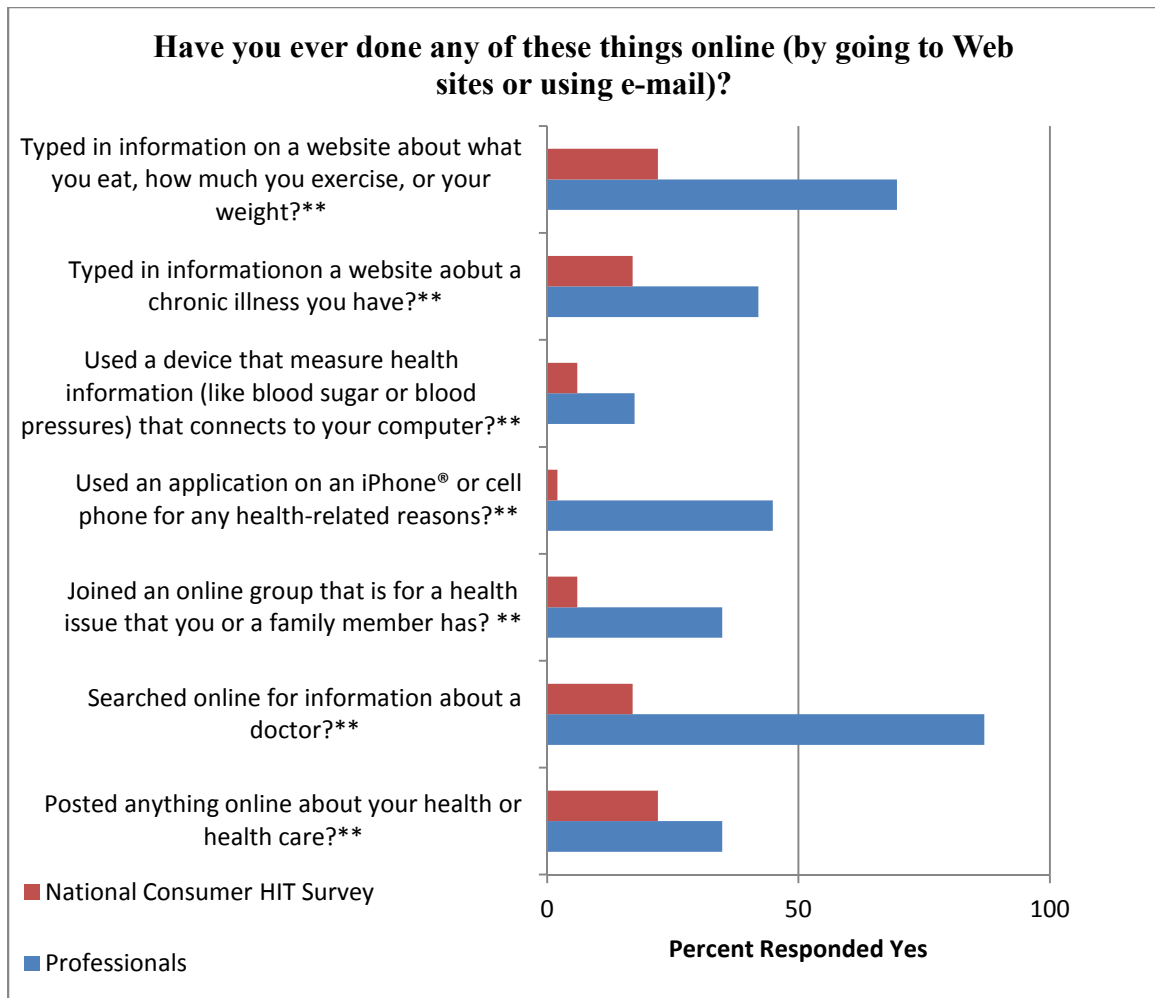


Figure 9: This graph shows the percent who responded yes to the questions asking about if they had ever done any of the things online.

**Statistically significant at $p < 0.001$

I found that the professionals who were PHR users stated that the features of PHRs were very or somewhat useful, more so than the National Consumer HIT (reference) survey individuals indicated. Compared to the responses from the National Consumer HIT (reference) survey, I found that non-PHR users who were also professionals thought they would be very or somewhat interested in the features that people could use online when looking at their health information.

A limitation of the study is the difference in the time frame of the National Consumer HIT survey and the professional survey. We are not able to determine if there would be less statistical differences in the study if more current consumer information was available to be used. Another limitation is that the general healthcare professionals who use networking services like LinkedIn may be more technologically inclined than a larger population of general healthcare workers.

Areas for further research include completing a consumer survey at the same time as a professional survey to determine true differences. Another area for further research would be a qualitative study to find out why more professionals are using PHRs and how they are using them. Along with that would also be the questions how and why professionals are using the additional functionality that is available online, as asked in the question "Have you ever done any of these things?" Another area for further research would be to identify ways to educate the consumer population of the value and usefulness of PHRs. I did find through the study that more professionals are using PHR and they find the features useful.

SUMMARY AND CONCLUSIONS

The survey revealed that the healthcare or health information technology professions use PHRs more frequently than indicated by the National Consumer HIT survey. The results of the study suggest that the professional group for several of the question are aware of the benefits of PHRs and use online therefore more professionals use PHRs when compared to the National HIT survey respondents. Along with that more

professionals kept the information online over the National HIT survey group that we compared with.

In the series of questions that dealt with online PHRs "Here are some questions about looking at your health information" as displayed in Figure 5: there were two questions that was statistically significant for a difference and that is where it was asked "Has it made it easier to talk to your family about your health? and "Has it led you to ask your doctor or nurse a question that you may not have asked before?" In Figure 6: another statistically significant finding was "Making Sure Information is correct?" when asking individuals to "Think about the times you have looked at your online medical and health information how useful was each of these to you?" I see these questions related to each other when you find your information is correct it makes it easier to show your family members exactly what has been put in PHR from an insurance or health care provider online site and it is also easier to see about family to see and not rely on interpretation. It would also make it easier for the individual to identify what they were told by their health care provider matched what was documented. There were not that many questions for those that had PHRs that were statistically significant. For the questions displayed in Figure 7 showed the differences between the professional group and the National Consumer HIT survey group for non-PHR users. There were a number of questions where there was a statistically significant difference between the groups. This may be well be due to the professional group knowing more about the features and benefits of online PHRs.

The last part of the survey dealt with online activities. The results of the survey found that for these questions a majority of the difference in responses were statistically

significant for the professional group over the National Consumer HIT survey, this may be due in part to the professional group having more health and technology literacy.

With the findings in the study there are several areas for further research. One of these is a larger population groups to represent the proportion of health care clinical and technology professionals. Another area for further research also may be a qualitative study to ask questions as to why the statistical significant differences occurred and way to better education the public on the benefits of online PHRs. Professionals recognize the benefits and value of PHRs.

APPENDIX A: Consent Form Survey

Greetings,

I am conducting a survey to better understand professionals' use of personal health records and would very much appreciate your input. If you are willing to participate, please click on the link at the bottom of the screen to begin the survey. The survey will take approximately 15 minutes to complete. Your responses will be anonymous and I will be happy to provide you with the results from this study. If you have questions, please feel free to e-mail me at lloydk@ohsu.edu.

Thank you in advance for your time and support in completing this project.

Krystal Lloyd

Master's Candidate, Biomedical Informatics
Oregon Health & Science University

http://www.surveymonkey.com/s/Personal_Health_Records

APPENDIX B: Personal Health Record Survey

I am studying information about professionals in the health care industry regarding whether they use personal health records (PHRs) and the benefits of a PHR.

A PHR is where you or someone in your family keeps any records or copies of your medical history, treatments, medicines, or other health information. This allows you or someone else in your family to access, manage, store, and share your health information.

1. Which of the following most describes your professional role?

Clinician (Physician, Nurse, Pharmacist, Physical Therapist, etc.)
Medical Informatician
Information Technology Professional
Engineer
Marketing/Sales
Consultant
Other

2. What is your number of years in the profession?

Less than 1
1 - 5
6 - 10
11 - 15
16 - 20
21 - 25
26 - 30
Greater than 31

3. What is your gender?

Male
Female

4. What age category do you fall into?

18-24
25-29
30-34
35-39
40-44
45-49
50-54
55-59

60-64
65-69
70-74
75 and older

5. Do you or someone in your family keep a Personal Health Record (PHR)? (If the answer is yes, continue to question 6; otherwise, go to question 10.)

Yes
No
Refuse

Concerning how you use your Personal Health Record, please answer the following questions:

6. Where do you keep these records and copies of health information? (If the answer is online or combination of above including online, then go to question 7; otherwise, go to question 10.)

Paper
Computer
Online
Paper and computer
Combination of above including online

7. Is this online website sponsored by?

Your Doctor or Health Care Provider
Your Health Insurance Plan
Your Employer
Online Service
Not Sure
Another Organization

8. Here are some questions about looking at your health information: (Answers: Yes, No, Not Sure)

- a. Has looking at your health information online made you feel like you know more about your health?
- b. Has it led you to do something to improve your health?
- c. Has it led you to ask your doctor or nurse a question you may not have previously asked?
- d. Has it made you feel more connected to your doctor?
- e. Has it made you less likely to switch to another doctor?

- f. Did you ever find something missing or not right in your online information?
- g. Has it made it easier to talk to your family about your health?

9. Usefulness of PHR Features among PHR Users (Answer with *very useful, somewhat useful, not too useful, not at all useful, or have not done.*)

- a. Looking at the results of your lab tests or other tests?
- b. Making sure information is correct?
- c. Scheduling a doctor's visit?
- d. Renewing prescription online?
- e. Keeping track of your child's health records, such as immunizations data and information?
- f. Receiving a reminder for when you need a test, such as a mammogram or immunization?
- g. Sending or receiving an e-mail to or from a doctor or nurse?
- h. Managing your family's doctor visits, medicines, immunizations, and other information in one place?
- i. Sharing your information with your family?
- j. Seeing your doctor's instructions for taking care of your health?

10. Here are some ways people can use their health information online. If your health information were available online, how interested would you be in the following? (Answer with *very interested, somewhat interested, not too interested, not at all interested, or not sure.*)

- a. Looking at the results of your lab tests or other tests?
- b. Making sure information is correct?
- c. Scheduling a doctor's visit?
- d. Renewing a prescription online?
- e. Keeping track of your child's health records, such as immunizations data and information?
- f. Receiving a reminder for when you need a test, such as a mammogram or immunization?
- g. Sending or receiving an e-mail to or from a doctor or nurse?
- h. Managed your family's doctor visits, medicines, immunizations, and other information in one place?
- i. Shared information with your family?
- j. Seen your doctor's instructions for your health?

11. Have you ever done any of these things online (whether by going to a website or using e-mail)? (Yes, No, or Not Sure)

- a. Searched online for information about a disease or medical problem?

- b. Looked at any of your medical test results online?
- c. Sent an e-mail to or received an e-mail from your doctor?
- d. Renewed a prescription online?

12. Have you ever done any of these things? (Yes, No, or Not Sure)

- a. Typed in information on a Website about what you eat, how much you exercise, or your weight?
- b. Typed in information on a Website about a chronic illness you have?
- c. Used a device that measures health information (like blood sugar or blood pressure) that connects to your computer?
- d. Used an application on an iPhone or other cell phone for any health-related reason?
- e. Joined an online group that is for a health issue that you or a family member has?
- f. Searched online for information about a doctor?
- g. Posted anything online about your health or healthcare?

Thank you for your time and assistance in helping with this research. Your efforts are much appreciated.

Thank you.

REFERENCES

1. Detmer DB, Meryl; Raymond, Brian; Tang paul. Integrated Personal Health Records: Transformative Tools for Consumer-Centric Care. *BMC Medical Informatics and Decision Maker*. 2008;8(45).
2. Kaelber DCJ, Ashish K.; Johnston, Douglas; Middleton, Blackford; Bates, David W. A Research Agenda for Personal Health Records (PHRs). *J Am Med Inform Assoc*. November 1, 2008 2008;15(6):729-736.
3. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. *J Am Med Inform Assoc*. March 1, 2006 2006;13(2):121-126.
4. Westin AF. *Americans Overwhelmingly Believe Electronic Personal Health Records Could Improve Their Health* Connecting for HealthSM Markle Foundaiton;2008.
5. Udem T. Consumers and Health Information Technology: A National Survey. 2010; <http://www.chcf.org/~media/Files/PDF/C/PDF%20ConsumersHealthInfoTechnologyNationalSurvey.pdf>. Accessed November 2, 2010.
6. American Health Information Managment Association. myPHR. 2009; <http://www.myphr.com/>. Accessed May 12, 2009, 2009.
7. HIMSS Personal Health Records Definition and Position Statement: Healthcare Information Management and Systems Society; 2007.
8. Policy Statement - Using Personal Health Records to Improve the Quality of Health Care for Children. Vol 124: American Academy of Pediatrics; 2009:403-409.

9. 45 C.F.R. § 164.526.
10. IOM (Institute of Medicine). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
11. Benjamin RM. Thanksgiving: A time for families and family health history. In: Services USDoHH, ed2010.
12. Galson SKMD, M.P.H. Acting Surgeon General Encourages Americans to Know Health History2008.
13. Wagner PJ, Howard SM, Bentley DR, Seol YH, Sodomka P. Incorporating patient perspectives into the personal health record: implications for care and caring. *Perspect Health Inf Manag*. 2010;7:1e.
14. Topline Results From a National Consumer Survey on HIT. 2010; <http://www.chcf.org/~media/Files/PDF/T/PDF%20ToplineResultsNationalConsumerSurveyHIT.pdf>.
15. Fox S. *The Social Life of Health Information, 2011*. Washington, DC: Pew reserach Center's Internet & American Life Project;2001.
16. Personal Health Records (PHRs) and Portals. 2011; <http://www.epic.com/software-phr.php>, 2011.
17. Guidelines for Physician-Patient Electronic Communications. 2011, 2011.
18. Live Healthly Iowa. 2011; <http://www.livehealthyiowa.org/>.

19. Weight Watchers. 2011;
http://www.weightwatchers.com/plan/www/online_01.aspx?navid=onlineaag, 2011.
20. Fox S. *The Social Life of Health Information, 2011*. Washington, DC: Pew reserach Center's Internet & American Life Project;2010.
21. Tenforde M, Jain A, Hickner J. The Value of Personal Health Recors for Chronic Disease Management: What Do We Know? *Family Medicine*. 2011;43(5):351-354.
22. One Touch Diabetes Data Management Software Kit. 2011;
http://www.onetouch.com/software_kit, 2011.
23. Fraser H, Kwon Y, Neuer M. *The future of connected health devices Liberating the Information Seeker*. 2011.
24. Kahn JS, Aulakh V, Bosworth A. What It Takes: Characteristics Of The Ideal Personal Health Record. *Health Aff*. March 1, 2009 2009;28(2):369-376.
25. App Store: Healthcare and Fitness 2011;
<http://itunes.apple.com/us/genre/ios-healthcare-fitness/id6013?mt=8>, 2011.
26. White M, Dorman SM. Receiving social support online: implications for health education. *Health Education Research*. December 1, 2001 2001;16(6):693-707.
27. CancerCare. 2011; http://www.cancercare.org/support_groups, 2011.
28. Rice RE. Influences, usage, and outcomes of Internet health information searching: Multivariate results from the Pew surveys. *International Journal of Medical Informatics*. 2006;75(1):8-28.

- 29.** Boyer C, Geissbuhler A. Health and the Internet for all.
International Journal of Medical Informatics. 2006;75(1):1-3.
- 30.** Bush GW. Address Before a Joint Session of the Congress on the
State of the Union2004.
- 31.** Price I. Research Methods and Statistics Chapter 5: Analysing the
Data Part II: Inferential Statistics. 2000;
[http://www.une.edu.au/WebStat/unit_materials/c5_inferential_st
atistics/bonferroni.html](http://www.une.edu.au/WebStat/unit_materials/c5_inferential_statistics/bonferroni.html).