

PREDICTING PERSONAL HEALTHCARE MANAGEMENT: IMPACT OF
INDIVIDUAL CHARACTERISTICS ON PATIENT USE OF HEALTH
INFORMATION TECHNOLOGY

A DISSERTATION
SUBMITTED TO THE FACULTY OF
UNIVERSITY OF MINNESOTA
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

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FEBRUARY 2017

Acknowledgements

Many people have been influential in the successful completion of this project.

Dr. Stuart Speedie, my faculty advisor, for his countless hours of constructive feedback, guidance, and support. Without his helpful insights and mentoring, this project could not have been realized. I would also like to thank the members of the preliminary oral and final examination committees, including Dr. David Pieczkiewicz, Dr. Saif Khairat, Dr. Bonnie Westra, Dr. Rui Zang and Dr. Paul Kleeberg for their feedback, support and advice through this journey.

Dedication

To my wife, Sarah Elizabeth Sandefer, for her unwavering support, encouragement, and love. Having my back assured my success.

To our children, Isla, Brogan, and Torin—that their passion and zeal for life continue to inspire themselves and others to learn, grow, and transform the world.

To my family, thank you so much for the ongoing love, support and dedication that keeps me grounded.

To my friends, thank you for your patience and support.

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CHAPTER 1

INTRODUCTION

1.1 Background

Individuals and families are increasingly turning to the Internet and online tools for tracking their personal health information, searching for accurate health information, and participating in condition specific patient communities. Moreover, the U.S. Government and healthcare organizations are promoting the use of technology and information sharing to improve consumer understanding of health conditions and healthcare costs. In this project we are interested in how demographic, socioeconomic and health-related variables affect personal healthcare management (PHM). PHM, as defined here, refers to the individual use of internet-based technology to access personal health information or communicate with healthcare professionals regarding patient health information. PHM is considered active participation with a healthcare entity through the use of technology and PHM refers to use of technology-mediated applications by an individual to assist in meeting her or his healthcare-related needs.

According to one estimate, one out of every twenty Google searches is health related [1]. The web browser Google reports that one percent of all its searches are symptom-related [2]. Over 80 percent of all Internet users have searched for health-related information online, which is an increase from approximately 62 percent in 2001, and an over one-third of U.S. adults have used the internet to diagnose themselves or someone else. In fact, only the activities of email and researching products prior to purchase were reported more frequently by Internet users [3]. The issue of using the Internet for

conducting health-related searches is important because studies have shown that individuals who seek health information report better health and are more active participants in healthcare than individuals who do not seek health information [4]. Studies have shown that access to health information improved quality of life, timeliness of care, and use of healthcare services [5-8].

Consumers are also desiring access to their medical records in online formats. According to one study, 86 percent of U.S. adults rate electronic access to personal health records and online health information as important [3]. Research shows there is also a relationship between accessing information in personal health records or patient portals and improvements in health management, patient satisfaction, communication, and health outcomes [9-13].

While there is a relationship between health-related internet searches and electronic access to health information, there are disparities in individual use of both. Self-reported Internet searching has been positively associated with younger age, higher income, better health, and higher education [14, 15]. It has also been associated with higher use among women, Caucasians, and non-Hispanic whites [15, 16]. There are similar disparities in use of patient portals and personal health records. Individuals who are younger, Caucasian, wealthier, and healthier report higher use of patient portals and personal health records [17-22].

1.2 Patient-Focused Technologies and Patient Engagement

There is increased national attention on the use of patient-centered technologies in an effort to engage patients and families in their healthcare, particularly in an effort to

address the rise of chronic conditions and managing the complexity of health conditions. The Centers for Medicare and Medicaid Service's (CMS) Electronic Health Record (EHR) Incentive Program and its "meaningful use" objectives have drawn attention to the value of using patient portals and personal health records to better connect patients with their health information. The EHR Incentive Program has four goals that guide the entire program: 1) "Improve quality, safety, efficiency, and reduce health disparities"; 2) **"Engage patients and families"** [emphasis added]; 3) "Improve care coordination, and population and public health"; and 4) "Maintain privacy and security of patient health information" [23].

The use of patient portals, personal health records and other patient-focused technologies is intended to improve the level of patient engagement. The Agency for Healthcare Research and Quality (AHRQ) completed an environmental scan on the topic of patient and family engagement. AHRQ defined patient engagement as "a set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients family members as active member of the health care team and collaborative partnerships with providers and provider organizations" [24]. Patient engagement has been defined as the "interventions designed to increase [patient activation]; and patient's resulting behavior, such as obtaining preventive care or engaging in regular physical exercise" [25]. The Institute for Health Technology Transformation (2013) defined patient engagement as "an activity that involves a series of proactive and calculated actions between providers and patients. Actions should be taken based on patient data, population health data and evidence-based best practices" [26]. Current efforts to encourage patient engagement rely

heavily on the use of technology to improve the relationships between patients and providers and to assist decision-making processes.

1.3 Disparities in the Use of Patient Portals and Personal Health Records

Despite all of the focus on these patient centered technologies, there has been little growth in the uptake of these technologies among the general population or among those most likely to benefit from its immediate and prolonged use. Users of these technologies are most likely to be educated, female and Caucasian [27]. Health literacy is cited as a primary barrier to the effective use of personal health records and patient portals for the self-management of chronic disease [28]. According to a study that examined the utilization of patient portals, 88% of Caucasians had a college degree, compared to 49% of African American users [18]. There are also clear ethnic/racial and educational disparities in use of patient portals offered by large integrated delivery systems [18]. While Caucasians are more likely to utilize patient portals, African American patient portal users are significantly more likely to have the presence of a chronic disease and thus be in greater need of the services such portals provide [29]. According to one study, “those with limited health literacy were less likely to activate their patient portal account, sign in using their personal login and password, and to use any of the functions” [18]. Despite these studies, little is known about the national trends in using patient portal features across geographic regions and by specific socio-demographic groups. Overall, the generalizability of findings from previous studies is limited due to small sample sizes, focus on urban areas, and use of data from large, integrated delivery networks.

1.4 Chronic Disease, Health Literacy and Use of Patient Portals and Personal Health Records

The Institute of Medicine reports that nearly 50% of the population of the United States has limited health literacy and those individuals with lower health literacy are more likely to experience disproportionately worse health outcomes [18]. The rise of chronic disease is a major public health problem facing the United States. “Chronic diseases--such as heart disease, stroke, cancer, and diabetes--are among the most prevalent, costly, and preventable of all health problems” [30]. In fact, chronic diseases cause 70% of deaths in the United States annually and over 75% of healthcare costs. Furthermore, the CDC reports that chronic diseases cut across all demographic strata. Between the 1960s and 2005, the number of children and adolescents in the United States living with a chronic condition increased by over five percent.

Healthcare stakeholders are increasingly aware that technology is a critical factor for monitoring chronic conditions, improving decision-making, and creating a healthcare system that is more proactive and less reactive in caring for these patients. The use of patient portals, for example, has been associated with the self-reported quality of care received by patients. Recent research indicated that patients who access and utilize their health information in online information systems are more satisfied with their healthcare [9].

As the United States healthcare system continues to move additional services online and expect patients to interact with their care providers via the Internet, those individuals already suffering from health disparities risk falling further behind.

The use of patient-centered technologies to improve chronic disease management is increasingly important [31, 32]. Generally, these technologies have had limited functionality, with their capabilities revolving around entering or reviewing health data. The technologies, however, are increasingly intelligent and interactive, thereby providing both patients and clinicians, for example, with triggers regarding interactions of drugs or allergies that could lead to an abnormal medical event [33].

In addition to the barriers to patients using portals, the willingness of clinicians to use patient portals or PHRs to connect with patients is far from universal. A national survey of physicians found that 64% of physicians had never used a personal health record, 42% were willing to try, and, interestingly, rural physicians were more likely than urban physicians to be willing to use personal health records [34].

1.5 The Impact of Secure Messaging

There is considerable evidence related to the benefits of using the secure messaging functionality of patient portal systems [35, 36]. In a study involving 35,423 patients with diabetes, hypertension, or both diabetes and hypertension, Zhou, Kanter, Want and Garrido (2010) assessed the impact of secure patient-physician email on the quality outcomes as measured by diabetes and hypertension-related quality measures included in the Healthcare Effectiveness Data and Information Set (HEDIS). “The five leading reasons for patients to email their physicians were to report a change in a condition (16 percent), discuss lab results (14 percent), discuss a new condition (12 percent), discuss changes in prescription dose (11 percent), and discuss the need for a new prescription (10 percent)” [36]. Physicians receive, on average, between two and

twelve messages per day, each requiring an average of 3.5 minutes per response. The study used administrative data on secure email use between patients and providers, as well as nine HEDIS measures. The findings show that users of secure email had significant improvements in outcomes related to HbA1c screening and control, retinopathy screening, nephropathy screening, and blood pressure control. Interestingly, those patients who had multiple email threads with the provider had an increased likelihood of improved performance on four of the diabetes measures [36]. In other words, the frequency of messaging between a patient and provider is associated with clinical outcomes improvement.

In a similar study focused on provider productivity related to the use of secure messaging, Zhou, Garrido [8] conducted two retrospective studies. The study was intended to test the impact that the adoption of a patient portal has on appointments with physicians, nurse practitioners, and physician assistants in adult primary and urgent care. It also tested the impact that patient portal adoption has on telephone contact rates with internal medicine and family practice physicians, nurse practitioners, and physician assistants. To evaluate the impact of secure messaging on primary care physicians, the study compared the difference in primary care office visit rates and documented telephone call rates. In the cohort study, primary care office visits among the sample decreased significantly by 9.7% (from 2.47 per patient per year to 2.24). Similarly, in the matched control study, the annual office visit rate for those patients using secure messaging decreased significantly by 10.3%, as compared to a decrease of 3.7% in the control group. The difference between groups regarding documented telephone contacts was also significant—controls made 13.7% more telephone contacts than those patients

using secure messaging [8]. The impact of secure messaging on provider productivity shows varying results, however. Harris, Haneuse [37] found a positive relationship between secure messaging use and number of outpatient visits, including primary care, specialty, and emergency-related visits.

Wade-Vuturo, Satterwhite Mayberry [35] conducted a mixed methods study to evaluate the use of a patient portal by patients with type 2 diabetes, secure messaging within the patient portal, and the relationship between secure messaging and glycemic control. The findings from the study indicated that there is a significant association between patients who self-reported frequently using secure messaging within the patient portal—either messaging a provider or requesting an appointment—and lower Hemoglobin A1c values (i.e., glycemic control) [35].

Harris, Haneuse [37] conducted a cross-sectional study to test if secure messaging through a patient portal was associated with higher quality of care and lower care utilization. The study used administrative data from all patients older than or equal to eighteen years within the electronic health record who had been diagnosed with diabetes as documented by greater than or equal to three ICD-9 outpatient diabetes diagnoses within the previous two years. The patients within the secure messaging group were slightly younger than those in the non-secure messaging group (average age of 58 vs 63) and were significantly more likely to have a female primary care provider. Regarding the quality measure of HbA1c <7%, patients sending secure messages had higher rates of control than those who had patient portal accounts and did not send messages or those subjects in a comparison cohort. In fact, among patients with greater than or equal to 12

threads of secure messages, the number of patients with HbA1c <7% was 36% greater than in the control group [37].

Ralston, Carrell [38] conducted a retrospective study of patient portal users at Group Health in Seattle. The study included two components. First, all patients who received care at Group Health or within the Group Health network between September 2002 and January 2005 were included in the analysis of patient portal adoption as measured by portal registration and ID verification. Those who registered for an account were provided access to basic portal services; those patients who completed that additional step of ID verification were provided access to additional portal features, such as secure messaging. The study compared utilization of portal features based upon care setting, registration versus ID verification, age, gender, and insurance type [38].

Approximately 25% of all Group Health patients were registered for patient portal accounts by the end of the study period in 2005. The users of the patient portal were more likely to be women (59%), approximately 50 years of age, covered by commercial insurance, and expecting moderate clinical needs. The patient portal features most frequently used by patients (as measured by unique users per 1,000 members) were 1) Review of medical test results (54 per 1,000); 2) Medication refills (44 per 1,000); 3) After-visit summaries (31 per 1,000); and 4) Patient-provider clinical messaging (31 per 1,000) [38].

1.6 Patient Activation Measure

Many healthcare policies are promoting patient engagement as a mechanism for improving quality and lowering cost. In an effort to address the question of the specific

“skills, knowledge, beliefs, and motivations” necessary to engage (or “activate”) patients to be more effective, Hibbard et al. (2004) have developed a “Patient Activation Measure (PAM).” Patient activation is defined as “a patient’s willingness and ability to take independent actions to manage their health and care...patient activation [is] understanding one’s role in the care process and having the knowledge, skill, and confidence to manage one’s health and health care” [25]. The PAM is a “valid, highly reliable, unidimensional, probabilistic Guttman-like scale that reflects a developmental model of activation” [39]. The PAM consists of 13 Likert-items (the initial score was based off of 22 items) that fall within four categories (1 refers to least activated and 4 the most activated): 1) *Believes Active Role Important*; 2) *Confidence and Knowledge to Take Action*; 3) *Taking Action*; and 4) *Staying the Course Under Stress* [39].

In a pilot study focused on the PAM, Hibbard et al. (2004) tested 22 measures for their predictive ability on health outcomes. The results show that individuals with higher patient activation scores demonstrate improved health outcomes and healthier behavior. Respondents with higher PAM scores had significantly fewer clinical office visits, ER visits, and hospital stays; were significantly more likely to exercise regularly, eat fruits and vegetables, and not smoke; were significantly more likely to engage in consumer health related behaviors; were significantly more likely to self-manage chronic conditions; and were significantly less likely to be fatalistic about personal health [39]. The research using PAM demonstrated that engaged patients have improved health outcomes, lower care costs, and increased patient satisfaction scores. If patients who use PHM are more engaged with their healthcare then they should also have improved clinical outcomes, lowered care costs, and improved patient satisfaction.

1.7 EHR Incentive Program and Patient and Family Engagement

According to the Department of Health and Human Services, the patient and family engagement goals of the meaningful use program aim “to improve patients’ understanding of their health and related conditions so they take a more active role in their health care. It also encourages the involvement of patients’ families, as many patients depend on their support” [40].

The EHR Incentive Program’s Stage 2 Final Rule included measures of patient engagement as a mechanism to address two “critical priorities” outlined in the National Strategy for Quality Improvement in Health Care that was submitted to Congress by the Secretary of the Department of Health and Human Services—1) Ensuring that each person and family are engaged as partners in their care and 2) Promoting effective communication and coordination of care [23]. In terms of how to achieve these goals, the Meaningful Use program included three measures that are centrally focused on patient engagement and can be summarized as: providing patients copies of their health information; providing patients electronic access to their health information; and encouraging patients to communicate electronically with their healthcare providers.

The electronic access to health information is provided through the use of either a personal health record or a patient portal. According to the Markle Foundation, a PHR is “an electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorized, in a private, secure and confidential environment” [41]. The Health Information Management Systems Society (HIMSS) has similarly defined an “electronic” PHR as:

A universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations [42].

Regarding patient portals, the Office of the National Coordinator for Health Information Technology has defined a patient portal as “a secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection. Using a secure username and password, patients can view health information” [43]. Viewing laboratory results, scheduling appointments, sending secure messages, and refilling prescriptions are the most commonly used functions of patient portals [36]. However, the information available in patient portals varies by vendor and/or organization, but the information could allow patients to access the following information or complete the following actions:

- Recent doctor visits
- Discharge summaries
- Medications
- Immunizations
- Allergies
- Lab results
- Exchange secure e-mail with their health care teams
- Request prescription refills
- Schedule non-urgent appointments
- Check benefits and coverage
- Update contact information
- Make payments
- Download and complete forms
- View educational material [43]

The EHR Incentive Program’s Stage 2 objectives inclusion of additional requirements related to patient engagement were hotly debated and highly contested due to the potential complications for compliance. The updated objective required healthcare providers to 1) provide greater than 50% of their patients access to patient portals (or Personal Health Records) that will allow patients to view, download and transmit their health information electronically and 2) facilitate more than 5% of unique patients viewing, transmitting, or downloading their electronic health information and transmit the information to a third party. Moreover, there is a requirement that at least 5% of all unique patients send a secure message using the patient portal technology. In short, the updated program requirements are emphasizing the utilization of the electronic health information, and not simply access to the information, in an effort to increase patient engagement, improve quality and decrease costs [23].

The Final Rule described the patient and family engagement clinical quality measures as those “that reflect the potential to improve patient-centered care and the

quality of care delivered to patients. They emphasize the importance of collecting patient-reported data and the ability to impact care at the individual patient level as well as the population level through greater involvement of patients and families in decision making, self-care, activation, and understanding of their health condition and its effective management” [23].

The third stage of the EHR Incentive program accelerated and expanded the focus on patient and family engagement. In terms of the goal of engaging patients and families in their care, Stage 3 expanded the Stage 2 requirement that greater than fifty percent of all unique patients are provided timely electronic access to view, download or transmit their health information—under the Stage 3 requirements, 80 percent of unique patients are provided electronic access to their information within 24 hours. Additionally, the patient or patient-authorized representative must be provided to a certified API (Application Program Interface) that can be used by a third party to provide access to health information within 24 hours. The Stage 3 final rule also expanded the requirement to provide patient-specific educational materials to patients based upon clinically relevant information within the EHR to more than 35 percent of unique patients [44].

The Stage 3 final rule also included a new objective titled “Coordination of Care Through Patient Engagement,” which included three distinct measures. First, more than 10 percent of unique patients or authorized representative will be required to access their health information through the use of an API. Second, more than 25 percent of unique patients or authorized representatives will be required to send a secure message through the certified EHR system. Finally, Stage 3 requires that for more than five percent of

unique patient generated data or data from a non-clinical setting is incorporated into the EHR [44]. The national trend is aimed at significantly increasing the use health information technology for engaging patients, including developing a relationship between measures of patient and family engagement and healthcare reimbursement.

1.8 Adoption and Use of Patient-Focused Health Information Technologies

The EHR Incentive Program has had a profound impact on the adoption of patient-focused health information technologies. The results of a survey illustrated the impact of meaningful use on the adoption of patient portals and personal health records. According to the study, between 2011 and 2012, “physician adoption of EHR technology to meet nine Meaningful Use Core objectives increased by at least 21%....[Moreover,] from 2011 to 2012, growth in physician adoption of EHR technology to engage patients and families in their health care was especially strong; the share of physicians with computerized capability to provide patients with clinical summaries after each visit increased by 46%” [45]. This study indicated that over half of all ambulatory care providers in the United States had the ability to provide patients with electronic copies of health information, and the percentage of providers with the ability of exchanging secure messages with patients increased by 40% between 2011 and 2012. Another study of U.S. hospitals showed similar results—adoption of “basic” EHRs had increased by 82% between 2010 and 2011. More importantly, the rates of “comprehensive” EHR use by U.S. hospitals had tripled from 1.6% in 2008 to 8.8% in 2011 [46]. A more recent KLAS study found similar results regarding patient portals specifically [47].

Even though the EHR Incentive Program has spurred the adoption of electronic health records in this country and therefore the implementation of associated patient portal applications, the overall numbers of individuals who are offered access to these technologies remains low. Thirty-eight percent of U.S. adults were offered electronic access to their medical records in 2014, which was up from 28% in 2013 [48]. While these technologies are being looked at as a method to connect with patients effectively with providers for self-management and shared decision-making, there continues to be a lack of overall usage by patients as well. According to one study, 21 percent of U.S. adults who were offered electronic access to their health information accessed their health information in 2014, up from 13 percent in 2013 [48]. Another study estimated that approximately 13 percent of U.S. adults communicated with a doctor or doctor's office using email, and 10 percent used the Internet to track health information personal health information [49].

As a result of meaningful use, there is definitely a growth in the capabilities of providers and hospitals related to patient portals and personal health records. Despite having the functional capability, as stated above, the overall numbers of patients adopting these technologies is low. Thus, these new requirements are a significant step in the world of health information technology and patient engagement, and healthcare organizations will need to conduct significant analysis to understand which factors are influencing patient portal adoption and use, particularly among those populations who are more likely to struggle with the adoption of these technologies.

1.9 Objectives

Many of the major healthcare policy initiatives in the last decade have heavily involved health informatics-driven patient engagement efforts through the use of technology as a primary objective for improving health outcomes and thereby reducing costs. Over the past decade significant progress has been made regarding the adoption of technology for providing consumer access to view and use their own health information. Hospitals and outpatients have adopted electronic health record systems at an unprecedented rate in the past five years, and new regulation have promoted engaging patients to view health information and communicate through messaging with healthcare professionals. Despite the effort to promote patient engagement through these programs, there are disparities in patient use and adoption of these tools for connecting to their health information.

There has been little comparative research done on the use of PHM across chronic conditions and, moreover, the vast majority of the research conducted on the use of PHM has been within healthcare organizations that are early adopters of health information technology. There has been limited research characterizing PHM use on a national level that also includes those with self-reported chronic conditions. While the literature is growing on this topic, there is still not adequate knowledge regarding the factors that drive PHM usage. A clearer understanding of the determinants of PHM use can be used in efforts to provide patient-specific education and engage patients through technology. Moreover, insights regarding the disparities in PHM use can provide information

regarding the challenges associated with engaging patients through accessing health information online.

For the purpose of this project, PHM was operationally defined as the individual use of health-related information to email healthcare providers, using a computer to schedule a healthcare appointment, or using a computer for requesting a prescription refill. PHM use is differentiated from health-related information seeking. PHM involves the use of technology associated with healthcare professionals or organizations, while health related information seeking is driven by individual-level Internet searching.

This project is comprised of a collection of three studies that investigate predictors of personal healthcare management. The following chapters provide the detail related to achieving the objectives of this project, including:

- Identifying the associations between one consumer eHealth behavior (health information seeking) and demographics, health measures, and personal healthcare management;
- Determining the relative levels of personal healthcare management use and variations in the determinants of PHM use among healthy, single and multiple chronic disease patient populations;
- Exploring predictors of personal healthcare management use among patients with cancer and compare them with those of a healthy population.

CHAPTER 2

DETERMINANTS OF CONSUMER EHEALTH INFORMATION SEEKING BEHAVIOR

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Publication: 2015 American Medical Informatics Association (AMIA) Symposium Proceedings (accepted)

Patients are increasingly using the Internet and other technologies to engage in their own healthcare, but little research has focused on the determinants of consumer eHealth behaviors related to Internet use. This study uses data from 115,089 respondents to four years of the National Health Interview Series to identify the associations between one consumer eHealth behavior (information seeking) and demographics, health measures, and Personal Health Information Management (PHIM) (messaging, scheduling, refills, and chat). Individuals who use PHIM are 7.5 times more likely to search the internet for health related information. Just as health has social determinants, the results of this study indicate there are potential social determinants of consumer eHealth behaviors including personal demographics, health status, and healthcare access.

2.1 Introduction

Engaging consumers in managing their health as a key to solving the core problems of healthcare access, quality, safety, efficiency, and effectiveness is an assertion boldly outlined by a plethora of landmark publications, including Institute of Medicine (IOM) reports [50-55]. The import of these problems is exacerbated by out-of-control spending in health care that is expected to reach \$4.6 trillion or 19.8% of the nation's gross domestic product by 2020 [56]. Moreover, the already strained health care system will face an influx of patients as 30 million additional Americans obtain health insurance [57]. Chronic health conditions are the leading cause of death and consume 75% of health care dollars in the U.S. [58]. Individuals with chronic conditions are more likely to be older, experience medical emergencies, and have higher healthcare expenses than other adults [59]. The socioeconomic differences in health outcomes have been defined as the “social determinants of health” [60].

Multiple federal health policies and financial programs require or substantiate the need for consumers to engage electronically with their health care providers through the use of health information technologies (IT). The Centers for Medicare and Medicaid Services' (CMS) Incentive Program for Meaningful Use of Electronic Health Record (EHR) requires health care providers to give consumers access to their health information and in future stages must allow submission of patient-generated information into EHRs [23, 40]. Emerging programs focused on care coordination and cost reduction also emphasize the use of patient portals and/or personal health records (PHRs), including the

Accountable Care Organization (ACO) and the Patient Centered Medical Home (PCMH) programs [61].

Recent research indicates that consumers and their families who use personal health information management (PHIM) applications such as PHRs have increased control over their personal health information and their use is associated with better health management, improved patient satisfaction, improved health care quality and safety, and more effective communication and collaboration between patients, doctors, caregivers and other stakeholders [4, 7, 9-11]. Approximately 86% of U.S. adults rate electronic access to PHRs and online health information as important [3]. The use of PHRs is beneficial for patients and their providers in managing chronic diseases such as diabetes, hypertension, congestive heart failure, and depression [27, 62-65] PHRs are also known to be beneficial for medication management, [14, 66, 67] prevention screening [68, 69], clinical trial recruitment [70], patient education [71], and information exchange [72]. There is a significant association between use of secure messaging with providers and lower Hemoglobin A1c values (i.e., glycemic control) [35, 37]. A greater frequency of secure email communication was associated with significant improvements in outcomes related to HbA1c screening and control, retinopathy screening, nephropathy screening, and blood pressure control; providers had an increased likelihood of improved performance on four diabetes measures [36].

Patients are increasingly using the Internet as a source for obtaining health-related information. According to a study conducted by the Pew Research Center, 62.6% of Americans looked for health information online within the past year [3]. An estimated

4.5% of all Internet searches are health related [73]. Research has shown that there is variation in the quality of the information obtained from the Internet [74] and the impact of the information obtained from Internet searches on daily life is low [75]. While a large number of Americans are using the Internet to search for health-related information, significantly fewer are adopting technologies such as PHRs to collect and store their personal health information and engage with healthcare providers [76].

There is, however, a mismatch between the perceived importance of access to PHIM tools versus their actual use. According to one estimate, only 7% to 9% of American adults used the Internet for tracking information in their personal health records [77]. Use varies based on a variety of factors [77, 78]. PHR use is predominantly associated with people between the ages of 45 to 70 [18, 29, 38, 77]. Racial disparity has been associated with patient portal use [18] with higher use among Caucasians [18, 22, 27, 79]. Inconsistencies in Hispanic use of PHIM exist with the implication that further studies of culturally-diverse populations are needed [18, 77]. Females are reported to use PHRs more frequently than males [18, 27, 77]. In a systematic review of PHR studies, Archer identified higher PHR use rates among individuals with chronic health conditions, those with frequent visits to health care providers, and families caring for older adults [80]. Low income and low education levels are two additional factors that influence lower use of patient portals or other health IT for PHIM [18, 22, 27]. Because PHIM is known to play an important role for those with chronic conditions [22, 29, 38, 77, 80], it is fundamentally important to identify the actual need and perceived value of PHIM among diverse users.

The use of the Internet for conducting health-related searches has been examined in terms of the socioeconomic factors, and research has shown that using the Internet for health-related searches is a more common among Americans than other PHIM activities [59, 76]. This is likely due to relatively few barriers, such as interdependencies with organizations, username and password issues, privacy and security concerns, and technology usability limitations. There has been limited research regarding the use of PHIM tools such as a PHR and its relationship to eHealth behaviors such as searching the Internet for health related information. The purpose of this study is to examine the association between those health-related Internet searches and use of at least one PHIM tool, including emailing healthcare providers, scheduling appointments online, refilling prescriptions using the Internet, and participating in health-related chat groups as well as other sociodemographic and health-related concerns.

2.2 Methods

This study used U.S. National Health Interview Series (NHIS) data that was collected by the Integrated Health Interview Series (IHIS) [81]. The Centers for Disease Control and Prevention conducts the NHIS annually “to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability in the United States and the services rendered for or because of such conditions.” The NHIS randomly samples approximately 35,000 households and 87,500 persons annually, and the average response rate for the survey is near 90% of eligible households in the sample. Samples are drawn from each U.S. State and the District of Columbia and it is representative of

the U.S. population. The NHIS has been conducted annually since 1957 [82] and details about the NHIS have been published elsewhere [83, 84]. Data were extracted from the NHIS as a SAS text file, and the SAS text file was read into R and converted to a data set for all analyses.

The NHIS includes questions on a variety of health outcomes, demographic variables, and individual characteristics. The measure of information seeking as an eHealth behavior was the questionnaire item “During the past 12 months, have you ever used computers [to] Look up health information on the Internet.” Responses were categorized into “Yes,” “No,” “Refused,” “Not Ascertained” or “Don’t Know.” For the purpose of the analysis, “No” was coded as 0 and “Yes” was coded as 1. The following variables were also included in the analyses: sex, gender, race, ethnicity, age, education level, health status, income, geographic region, care access, and hypertension prevalence. Hypertension was included in the analysis as a measure of a chronic condition for two reasons: there has been limited research examining PHIM among patients diagnosed with hypertension and hypertension is the most frequently reported chronic condition on the NHIS (47% of respondents reported hypertension). Education level was recoded into five categories (less than high school, high school or GED, some college or two year degree, bachelors degree, and graduate degree). Income was recoded into five categories (<35k\$, \$35-49.9k, \$50-74.9k, \$75-99.9k, and \$100k +). The variable PHIM was created by combining together responses to questionnaire items related to the use of online health-related chat groups, email with healthcare providers, scheduling healthcare appointments online, and refilling prescriptions online. Responses were categorized into “Yes,” “No,”

“Refused,” “Not Ascertained” or “Don’t Know,” and a response of “Yes” to any of these four questions resulted in a positive PHIM response. For the purpose of the analysis, “No” was coded as 0 and “Yes” was coded as 1. Any response of “Refused,” “Don’t Know,” or “Not Ascertained” were treated as missing values in the analysis.

For the purposes of this study, survey data regarding adults 18 years old or greater from 2009, 2011, 2012, and 2013 were combined. The 2010 survey was excluded since it did not address use of the Internet for seeking health information. Between 2009-2013, 492,948 individuals were interviewed across 191,395 households. The data used in this study was limited to adults responding “Yes” or “No” to the question regarding eHealth behavior, and was further limited to only individuals with complete data for the variables included in the logistic regression, resulting in a study sample size of 115,089 individuals. The University of Minnesota IRB deemed analysis of the NHIS data exempt from review.

In order to understand the characteristics of adults who engage in the eHealth behavior of information seeking, proportions and a Multivariable logistic regression were computed using the R version 3.1.0. Proportions were used to calculate the use of the Internet to search for health information across multiple variables. Multivariable logistic regression models were estimated to determine which variables were related to this eHealth behavior. Demographics, health and PHIM measures were included as independent variables in the logistic model. While PHIM activities are reported less frequently than using the Internet for health information seeking, the PHIM factor is included in this analysis to test the association between eHealth behavior and PHIM. The

answer to the question about the use of the Internet to search for health information was the dependent variable. The results of the logistic regression are presented as odds ratios (OR) with the corresponding standard errors, 95% confidence intervals, coefficients, and Wald Statistic.

2.3 Results

Descriptive statistics are presented in Table 1. Overall, 45% of respondents reported using the Internet to search for health-related information but this ranged from 49.8% in 2009 to a low of 41.5% in 2012. Females were much more likely to search for health information than males (49.7% versus 39.8%, respectively). Adults were also more likely to search for health information if they were younger, white, highly educated, employed, and had higher incomes. Over 72.3% of adults reporting a graduate level education used the Internet to search for health-related information; 13.3% of adults with less than a high school degree reported conducting health-related searches. There were slight differences in geographic variation in health-related searching—the West and the Midwest had the highest rates (47.5% and 47.3%, respectively), while the Northeast and the South had the lowest (45.2% and 42.2%, respectively). Those individuals who have been diagnosed with hypertension reported searching for health information at a lower rate than those without hypertension (37.4% and 48.8%, respectively), as are those individuals who reported being in poor health compared to excellent health (24.9% and 51.7%, respectively). Adults who reported not having a usual place for medical care also

reported searching for health information at lower levels (37.9%, and 46.6%, respectively).

Individuals who reported using the Internet for health-related searches also reported higher rates of PHIM activity. The overall rate of PHIM use is low—14.2% of respondents reported using at least one mode of PHIM such as use of online chats (3.6%), email with provider (5.9%), scheduling healthcare appointments online (4.7%), and refilling prescriptions online (6.7%). Individuals who reported using PHIM reported higher levels of using the Internet to search for health-related information than those who did not use PHIM (87.1% versus 37.9%).

Table 2 summarizes the output from the logistic regression on the eHealth behavior of using the Internet for health related searches. All the following results for each independent variable take into account adjustments for all of the other independent variables. Adults using PHIM were significantly more likely to use the Internet to search for health information (OR 7.50). Having a usual place for medical care was positively associated with using the Internet for health-related searches (OR 1.20). Adults reporting a diagnosis of hypertension are significantly more likely to conduct health-related searches (OR 1.08), and individuals who report being in Fair or Good Health were significantly more likely to conduct health-related searches (OR 1.22) than those reported being in poor health.

Adults who were younger, non-Hispanic, white, female, and had higher incomes were significantly more likely to conduct health-related searches. Adults who reported being in poverty were less likely to conduct health-related searches, but employment

status was not significantly associated with conducting searches. These results are similar to previous research [85]. Education level was positively associated with health-related searches. Adults with a graduate level education were over 9 times more likely to report a health-related searching than those with less than a high school degree.

Table 1. Use of Internet for Looking Up Health Information by Respondent Characteristics*

		% Respondents n = 115,089	% Using Internet to Search for HI
Demographics			
Sex	Female	55.1	49.7
	Male	44.9	39.8
Age (years)	18-30	21.3	53.4
	31-40	18.2	54.1
	41-50	17.5	49.1
	51-60	17.5	46.4
	61-70	13.6	38.4
	71+	12.1	17.9
Education	Less than High School	16.0	13.3
	High School	25.6	31.1
	Some College	30.7	52.5
	Bachelors	17.8	66.5
	Graduate	9.9	72.3
Year	2009	21.3	49.8
	2011	25.5	44.6
	2012	26.5	41.5
	2013	26.6	45.9
Income	<35k\$	41.5	31.7
	\$35-49.9k	14.7	43.4
	\$50-74.9k	17.0	51.7
	\$75-99.9k	10.4	58.0
	\$100k +	16.5	66.0
Poverty	In Poverty	18.4	28.9
	Not in Poverty	81.6	48.9
Employed	No	40.7	34.2
	Yes	59.3	52.8

Geography	Midwest	21.4	47.3
	Northeast	16.2	45.8
	South	36.7	42.2
	West	25.7	47.5
Race	White	75.3	47.4
	Black/AA	15.6	34.6
	AI/AN	1.0	32.8
	Asian	6.2	45.7
	Multi-Race	1.8	50.9
Ethnicity	Non-Hispanic	82.3	48.4
	Hispanic	17.7	30.4
Health Measures			
Have a Usual Place of Care	Yes	83.9	46.6
	No	16.1	37.9
Hypertension	No	68.3	48.8
	Yes	31.7	37.4
Health Status	Poor	3.6	24.9
	Fair	11.4	31.0
	Good	58.7	46.3
	Excellent	26.4	51.7
eHealth Measures			
Consumer PHIM	No	85.2	37.9
	Yes	14.2	87.1

*Except Geography (West & Midwest) and Age (18-30 & 31-40) all proportions are significantly different at $p < 0.01$.

Table 2. Logistic regression results (ORs) for Use of Internet for Looking Up Health Information

		β	SE β	Wald Stat.	OR (95% CI)
Demographics					
Sex	Female	Ref	Ref	Ref	
	Male	-0.560	0.015	-38.402	0.57*** (0.56-0.59)
Age (years)	18-30	Ref.	Ref	Ref	
	31-40	-0.201	0.022	-9.015	0.82*** (0.78-0.85)
	41-50	-0.493	0.023	-21.311	0.61*** (0.58-0.64)
	51-60	-0.679	0.024	-28.259	0.51*** (0.48-0.53)
	61-70	-1.089	0.027	-39.841	0.34*** (0.32-0.36)
	71+	-1.983	0.033	-59.575	0.14*** (0.13-0.15)
Education	Less than High School	Ref.	Ref	Ref	
	High School	0.750	0.027	27.365	
	High School	1.422	0.027	53.862	

	Some College	1.883	0.030	62.449	2.12*** (2.01-2.23)
	Bachelors	2.197	0.035	62.466	4.23*** (4.01-4.46)
	Graduate				6.57*** (6.20-6.97)
					8.99*** (8.40-9.64)
Year	2009	Ref	Ref	Ref	
	2011	-0.289	0.021	-13.974	0.75*** (0.72-0.78)
	2012	-0.455	0.021	-22.145	0.63*** (0.61-0.66)
	2013	-0.247	0.021	-12.037	0.78*** (0.75-0.81)
Income	<35k\$	Ref	Ref	Ref	
	\$35-49.9k	0.165	0.024	7.014	1.18*** (1.13-1.24)
	\$50-74.9k	0.277	0.023	12.619	1.32*** (1.26-1.38)
	\$75-99.9k	0.327	0.027	12.192	1.39*** (1.32-1.46)
	\$100k +	0.431	0.025	17.260	1.54*** (1.47-1.62)
Poverty	No Poverty	Ref	Ref	Ref	
	In Poverty	-0.247	0.024	-10.419	0.78*** (0.75-0.82)
Employed	Yes	Ref	Ref	Ref	
	No	0.021	0.017	1.224	1.02 (0.99-1.06)
Geography	Midwest	Ref	Ref	Ref	
	Northeast	-0.001	0.023	-0.054	1.00 (0.96-1.05)
	South	-0.049	0.019	-2.578	0.95** (0.92-0.99)
	West	0.100	0.021	4.728	1.11*** (1.06-1.15)
Race	White	Ref	Ref	Ref	
	Black/AA	-0.573	0.021	-27.317	0.56*** (0.54-0.58)
	AI/AN	-0.326	0.074	-4.407	0.72*** (0.62-0.83)
	Asian	-0.696	0.030	-22.874	0.49*** (0.47-0.52)
	Multi-Race	0.046	0.052	0.888	1.04 (0.94-1.15)
Ethnicity	Hispanic	Ref	Ref	Ref	
	Not Hispanic	0.606	0.021	28.804	1.83*** (1.76-1.91)
Health Measures					
Have a Usual Place of Care	No Usual Place	Ref	Ref	Ref	
	Usual Place	0.182	0.020	9.001	1.20*** (1.15-1.25)
Hypertension	No	Ref.	Ref	Ref	
	Yes	0.079	0.017	4.46	1.08*** (1.05-1.12)
Health Status	Poor	Ref	Ref	Ref	
	Fair	0.151	0.048	3.139	1.16** (1.06-1.28)
	Good	0.201	0.045	4.488	1.22*** (1.12-1.34)
	Excellent	0.054	0.047	1.158	1.07 (0.96-1.16)
eHealth Measures					
Consumer PHIM	No	Ref	Ref	Ref	
	Yes	2.014	0.025	79.195	7.50*** (7.13-7.81)

** p<0.01, ***p<0.001

2.4 Discussion

After examining the impact of social determinants of health, our findings show that individuals who report engaging in consumer eHealth applications by using online chat groups to learn about health topics, communicating with health care providers using email, scheduling an appointment with a healthcare provider using the Internet, and refilling prescriptions on the Internet are nearly 7.5 times more likely to search for health-related information online. This finding suggests that there is an association between PHIM and general engagement in healthcare information seeking. Given that consumer eHealth is negatively impacted by a variety of social determinants of health, the promotion and use of a single consumer eHealth modality (searching the Internet for health information) may promote wider adoption of consumer eHealth (PHIM). Considering the strong relationship between consumer eHealth engagement and the use of the internet for conducting health related searches, healthcare providers should be encouraging their patients to use the Internet as this may be an entry point for patients into using PHIM [86]. Individuals who email healthcare providers, schedule appointments online, and request prescription refills online are significantly more likely to search for health-related information online, and individuals who are more engaged with consumer eHealth report better health outcomes, patient satisfaction, and other measures of healthcare quality [3, 7, 14, 27, 59, 62-69]. This finding validates previous research demonstrating patient health status, experience, and knowledge of the Internet has a significant impact on seeking information online [87].

Overall, our findings indicate that engaging in the eHealth behavior of using the Internet for health-related searches is much lower than has been previously reported (45% versus 63%) [88], and that rate has been lower than 50% from 2009 to 2013. Previous estimates by the Pew Internet Research Project [4] were based on a telephone survey with a much lower response rate than the NHIS survey [74] (18.1% and 75.5%, respectively), which potentially resulted in non-response bias. Our findings indicate that up through 2013 the level of adoption of these consumer eHealth practices has been generally low (14.2%).

Our research demonstrates a relationship between what have been labeled by the World Health Organization as the “social determinants of health” and using the Internet to conduct health-related searches [60]. Individuals with a lower socio-economic status, lower levels of education, and non-White race or Hispanic ethnicity are less likely to engage in the eHealth behavior of using the Internet to search for health information, which confirms previous research [18, 22, 27, 76, 79].

Our findings do indicate that individuals with hypertension (a chronic condition) are slightly more likely to conduct health-related Internet searches than individuals without hypertension, thus validating previous research [76, 79]. Individuals reporting a “Good” health status were also slightly more likely to conduct health-related searches. These findings suggest that those populations in poor health are somewhat less likely to engage in conducting health-related Internet searches. Indeed, this study provided additional evidence for a digital divide in consumer eHealth, implying that programs

aimed at engaging patients through technology will struggle to reach underserved populations.

Our results also show that individuals who do not have a usual place for medical care are somewhat less likely to conduct a health-related Internet search. This demonstrates that access to medical care—a social determinant of health—is also a possible determinant of consumer eHealth behavior. The use of consumer eHealth applications, including patient-provider email, has been promoted as a tool for improving understanding and therefore decision making between patients and providers and increasing the level of patient and family engagement generally in healthcare.

Our results also suggest that patients who have a healthcare “home,” a place where they routinely obtain healthcare, are somewhat more likely to engage in searching the Internet for health information. This result supports recent initiatives aimed at promoting consumer eHealth, including the meaningful use requirement that 5% of unique patients have communicated with a healthcare provider through an online portal.¹³

There are several limitations with this study. First, the data was limited to self-reported responses regarding using the Internet to search for health information and use consumer eHealth applications. There are no additional details regarding the types of information searched or the frequency of searching by individual respondents, nor do we have details about frequency of emailing providers, scheduling appointments, refilling prescriptions, or participating in online chat groups.

Additional research is needed to evaluate the factors that drive adoption of consumer eHealth by individuals least likely to use the Internet for conducting health-

related searches, and research is also needed to assess trends in consumer eHealth adoption by specific groups, including more detailed analysis of PHIM use by individuals who report chronic conditions. Research is also needed regarding the means by which individuals are conducting these searches and accessing eHealth technologies, including the use of mobile devices and mobile applications. This research could be useful for identifying best practices for engaging patients in personal health information management, and developing tools to assist healthcare organizations and individual healthcare professionals meet patient needs.

2.5 Conclusion

This study has demonstrated that there is significant relationship between the use of the Internet for conducting health-related searches and the use PHIM. This engagement is, however, impacted by a variety of demographic and health-related factors—“determinants of consumer eHealth.” Overall, the adoption of PHIM remains low, and to be successful, consumer health information technology must be designed to address the needs of people of varying ages, socio-economic status and geographic location. While many consumers are ready and willing to access their health information online, much less is known about consumer motivations related to personal health information management. The perspectives of a variety of consumers from diverse population groups are requisite to gaining an improved understanding of their personal health information management needs so that technologies that effectively capture and sustain their interest in managing their own health can be effectively designed and deployed.

CHAPTER 3

PERSONAL HEALTHCARE MANAGEMENT: ASSESSING THE RELATIONSHIP WITH CHRONIC DISEASE PREVALENCE

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Background: The use of personal healthcare management (PHM) is increasing rapidly within the U.S. due to implementation of health technology across the healthcare continuum and increased regulatory requirements for healthcare professionals and organizations to promote the use of PHM, particularly the use of messaging, online scheduling, and online requests for prescription renewals. Limited research has been conducted comparing PHM use across groups based upon chronic condition.

Objectives: The purpose of this research is to describe the overall utilization of PHM and compare individual characteristics associated with PHM in groups with no reported chronic conditions, with one chronic condition and with two or more such conditions.

Methods: Datasets drawn from the National Health Interview Series were analyzed using multiple logistic regression to determine the level of PHM use in relation to demographic, socioeconomic, or health-related factors. Data from 47,814 individuals were analyzed using logistic regression.

Results: Approximately 12 percent of respondents reported using PHM, but higher rates of use were reported by individuals reporting higher levels of education and income. The overall rate of PHM remained stable between 2009 and 2014, despite increased focus on

promoting patient engagement initiatives. Demographic factors were predictive of PHM use. Respondents who were younger, non-Hispanic, and lived in the western region of the United States were the most likely to use PHM. There were also differences in PHM use based upon socioeconomic factors. Respondents with college level education were over 2.5 times more likely to use PHM than respondents without college level education. Health related factors were also predictive of PHM use. Individuals with health insurance and a usual place for healthcare were more likely to use PHM than individuals with no health insurance and no usual place for healthcare. Individuals reporting a single chronic condition or multiple chronic conditions reported slightly higher levels of PHM use than individuals reporting no chronic condition. Individuals with no chronic conditions who did not experience barriers to accessing healthcare were more likely to use PHM than individuals with one or more chronic conditions.

Conclusions: The findings of this study illustrated the disparities in PHM use based upon number of chronic conditions. Multiple factors influence use of PHM, including economics and education. These findings support the challenge associated with engaging patients through the use of electronic health information as the healthcare industry continues to evolve.

Keywords

Personal Health Information, Consumer Participation, Social Determinants of Health, Personal Health Records

Target Publication: *Journal of Medical Internet Research* (Not Submitted)

3.1 Background and Significance

Patient access to their electronic health information has been identified as a key priority for improving care quality and efficiency [44, 51]. Individual access to and personal use of health information is a cornerstone of recent national healthcare efforts. “With access to their electronic health information, individuals can serve as intermediaries of information exchange among providers and use innovative applications to better manage their health” [20]. The Centers for Medicare and Medicaid Services (CMS) have incorporated electronic access to health information within the Electronic Health Record (EHR) Incentive Program, which requires eligible professionals and hospitals to demonstrate meaningful use of EHR systems. Patient and Family Engagement is one of four primary goals of the EHR Incentive Program, and the program includes multiple measures of engaging patients and family through the use of health information technology, including sending and receiving secure messages between patients and providers, providing online access to view, downloading and transmitting health information, and identifying and providing patient specific educational resources based upon clinically relevant information housed within the certified EHR system [44]. The CMS Accountable Care Organization also promotes patient engagement and care coordination in an effort to restrain costs, improve patient experience of care, improve self-management, and facilitate communication between patients and providers [89].

These federal programs require measures of patient and family engagement because of the impact of the individual use of health information on care quality. Multiple studies identified an association between personal use of health information and

improvements in chronic disease management [27, 62-65]. Studies also have shown an association between personal use of health information and improvements in clinical quality outcomes, patient satisfaction, and overall perceptions regarding the efficacy of communication between patients and healthcare stakeholders [4, 7, 9-11].

In an effort to meet these program goals of the EHR Incentive Program and Accountable Care Organizations, U.S. healthcare organizations have started implementing EHRs, patient portals, and personal health records at an unprecedented rate. The number of U.S. non-federal acute care hospitals with the capability of offering patients the ability to electronically view, download, and transmit their health information has increased from 10% in 2012 to 69% in 2015. Over 95% of U.S. hospitals provide patients the ability to view their health information in electronically [90]. Similarly, between 2013 and 2014, the number of individuals offered access to their online medical records increased from 28% to 38%. Over half of the individuals who were offered access to their online medical record in 2014 accessed it [48].

Despite the rapid increase in the capability of viewing, downloading, and transmitting personal health information, there are disparities regarding individual access and use of their health information. According to one estimate, approximately 4 of 10 U.S. adults used some type of health information technology in 2013, but individuals with less education, lower incomes, and who lived in rural areas were less likely to email healthcare providers, view laboratory results online, and access health-related information with smart phones [20]. Similar research has demonstrated disparities in access and use of electronic health information [77, 78]. Use of technology for managing

personal health information is associated with age [18, 29, 38, 77], race [18, 22, 27, 79], ethnicity [18, 77], and gender [18, 27, 77]. The socioeconomic factors of income and education level are also related to an individual's use of technology for accessing and using health information [18, 20, 22, 27].

Individuals who report having chronic conditions are more likely to electronically access and use personal health information and are also more likely to access personal health information repeatedly [22]. Nearly half of the U.S. population suffers from at least one chronic condition, and nearly 12 percent of the U.S. population reports having three or more chronic conditions [91]. The advantage of using technologies to electronically access health information is the more effective management and coordination care. Individuals managing one or more chronic conditions, likely across numerous healthcare providers and institutions, have the potential to benefit from accessing their information electronically, downloading the information, and sharing with the others members of the care team.

3.2 Objectives

While individuals with chronic health conditions appear to access electronic health information more frequently than others, there has been little research conducted regarding the relationship between the number of chronic conditions and participation in electronic personal healthcare management (PHM). The purpose of this research is to describe the overall utilization of PHM and compare individual characteristics associated with PHM among groups with no reported chronic conditions, with one chronic condition and with two or more such conditions.

3.3 Methods

3.3.1 Sample

Data from the U.S. National Health Interview Series (NHIS) that was aggregated by the Integrated Health Interview Series (IHIS) was used for this analysis [81]. The Centers for Disease Control and Prevention annually conducts the NHIS “to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability in the United States and the services rendered for or because of such conditions.” The NHIS sample is representative of the U.S. population drawn from each U.S. State and the District of Columbia and includes approximately 35,000 households and 87,500 persons annually. It has an average response rate of nearly 90% and has been conducted annually since 1957 [82]. Multiple publications have detailed the use of the NHIS [83, 84]. For the purpose of this project, a SAS text file was downloaded from the IHIS portal and imported into the R statistical software package for analysis.

NHIS survey data regarding adults 18 years old or greater from 2009, 2011, 2012, 2013, and 2014 were combined for this study. The 2010 survey was excluded because it did not collect information regarding PHM that was required for this analysis. Between 2009-2014, 605,001 individuals were interviewed. The data used in this study were limited to adults who were asked and responded “Yes” or “No” to specific questions regarding PHM, and were further limited to only individuals with complete data for the variables included in the analysis, resulting in a study sample size of 50,062 individuals.

3.3.2 Variable Selection

The NHIS includes items related to a variety of healthcare-related characteristics, demographics, health conditions and behaviors. A dichotomous variable labeled Personal Healthcare Management (PHM) was calculated based on the questionnaire items related to emailing healthcare providers, refilling prescriptions online, and scheduling healthcare appointments online. PHM indicates use of electronic health information management. The levels of responses for each question were “Yes,” “No,” “Refused,” “Not Ascertained” or “Don’t Know.” A response of “Yes” to any of the three questions resulted in a “Yes” PHM response otherwise a “No” was assigned. For the purpose of the analysis, “No” was coded as 0 and “Yes” was coded as 1. Any response of “Refused,” “Don’t Know,” or “Not Ascertained” to any of the three questions resulted in the removal of that respondent from the analysis. Individuals use of PHM was assessed as the dependent variable. Demographic variables included age, sex, race, ethnicity, U.S. born, and geographic region. Socioeconomic variables included education, family income, poverty status, employment status, number of employer’s employees, health insurance status, housing status, food security, existence of financial and other barriers to accessing healthcare. Finally, health-related variables included the number of chronic conditions (zero, single, and multiple chronic conditions), overall health status, smoking status, alcohol use status, whether or not they had a usual source of healthcare, anxiety status, depression status, and level of moderate physical activity. Table 1 lists these variables along with their assignable value sets.

3.3.3 Statistical Analysis

The R statistical software package, version 3.2.3, was used for all statistical analyses. Multiple logistic regression was used to identify predictors of PHM among multiple independent samples based on chronic condition status.

Three different models of PHM were created to characterize and compare the three subgroups of respondents. The first model included only respondents who did not report any of the five chronic conditions (diabetes, hypertension, asthma, heart condition, or arthritis) and represented the ability to predict PHM for individuals without chronic conditions. The second model included only individuals reporting having one of the five chronic conditions. The third model included all observations where respondents reported having two or more of the five chronic conditions included in this study.

Descriptive statistics were for each group and each predictor variable were also calculated. A two-sample test for equality of proportions was used to compare PHM use.

3.4 Results

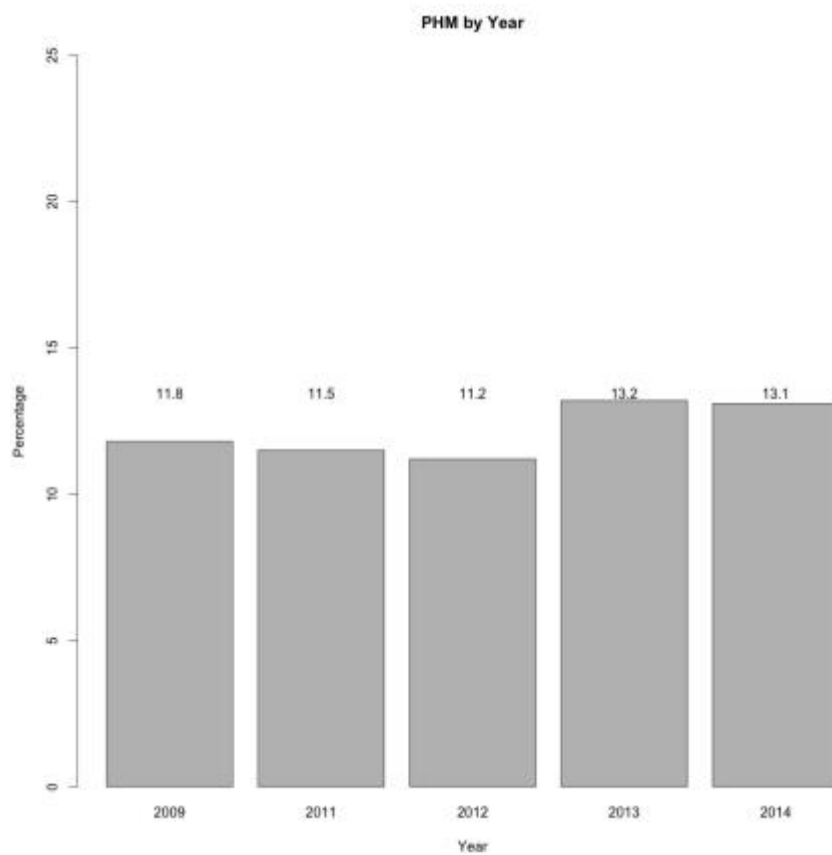
3.4.1 Respondent characteristics

The total NHIS sample for this study after exclusions was 47,814 individuals. The NHIS sample was separated into three mutually exclusive subgroups based upon number of reported chronic conditions. The sizes of the samples were as follows: 22,929 (no chronic condition), 12,415 (one chronic condition), and 12,470 (multiple chronic conditions).

3.4.2 Overall Personal Healthcare Management (PHM) Use

The overall proportion of U.S. adults who reported PHM use between 2009 and 2014 was 12.2%, and the use of PHM has increased slightly over that time period (see Figure 1). There was an increase in reported PHM use from 11.2% to 13.2% between 2012 and 2013.

Figure 1: Proportion of U.S. Adults Using PHM by Year



PHM use for each subgroup characterized by demographic, socioeconomic, and health-related characteristics is listed in Table 3.

Table 3. Characteristics of Respondents Who Reported PHM Use by Number of Chronic Conditions

		No CC		One CC		Multi CC	
		n=22,929		n=12,415		n=12,470	
Demographics		%n	%PHM	%n	%PHM	%n	%PHM
Age	18-40 years	59.6	12.0	34.8	17.7	9.7	19.4
	41-60 year	31.5	11.3	38.8	14.9	33.9	18.1
	60+ years	8.9	8.4	26.4	10.6	56.4	11.9
Sex	Male	47.2	8.5	46.0	12.4	41.6	15.7
	Female	52.8	14.1	54.0	16.8	58.4	14.0
Race	White	75.9	11.8	76.1	15.3	76.5	16.0
	Non-white	24.1	10.5	23.9	13.1	23.5	10.6
Ethnicity	Not Hispanic	77.8	12.7	85.5	15.8	88.8	15.2
	Hispanic	22.2	7.1	14.5	10.6	11.2	8.1
US Born	Yes	75.2	12.4	84.6	15.5	88.3	15.7
	No	24.8	8.5	15.4	11.2	11.7	7.5
Geography	Midwest	21.2	11.1	21.5	13.8	21.5	13.7
	Northeast	15.5	10.4	16.2	13.0	16.3	14.0
	South	35.0	10.3	36.3	14.1	38.6	12.7
	West	28.4	13.8	26.0	17.8	23.6	19.1
Socioeconomic Status							
Education	No College	36.7	3.8	38.9	5.2	47.2	5.9
	College	63.3	15.9	61.1	21.0	52.8	22.5
Family Income	<50k\$	52.3	7.0	53.7	9.0	62.8	8.5
	\$50k +	47.7	16.3	46.3	21.6	37.2	25.2
Poverty	Yes	18.3	5.3	17.1	6.6	18.2	5.2
	No	81.7	12.8	82.9	16.5	81.8	16.8
# Employees	<50	66.6	9.3	63.7	12.7	61.3	12.8
	51 +	33.4	15.8	36.3	18.7	38.7	17.8
Employed	Employed	72.5	12.9	60.9	17.7	36.1	22.0
	Unemployed	27.5	7.8	39.1	10.2	63.9	10.6
Insurance	Yes	77.9	13.8	84.4	16.4	92.3	15.3
	No	22.1	3.4	15.6	6.0	7.7	7.5
Housing	Own Home	52.3	12.8	60.8	16.1	65.8	16.5
	Do Not Own	47.7	10.0	39.2	12.7	34.2	11.3
Food Security	Insecure	5.6	6.5	7.6	7.0	10.7	9.4
	Secure	94.4	11.8	92.4	15.4	89.3	15.3
Cost Barriers	Yes	16.6	9.3	20.4	12.5	19.5	13.5
	No	83.4	11.9	79.6	15.4	80.5	15.0
Other Barriers	Yes	7.9	9.3	11.5	18.9	84.3	14.3
	No	92.1	10.8	88.5	14.3	15.7	16.8
Health-Related							
Health Status	Fair/Poor	4.6	5.7	12.9	9.2	32.5	10.2
	Good/Excellent	95.4	11.7	87.1	15.6	67.5	16.9
Usual Place of Care	Yes	76.8	13.4	87.8	15.7	95.7	15.0
	No	23.2	5.0	12.2	8.0	4.3	8.2

Alcohol	Non/Former	31.1	7.4	33.0	8.8	45.0	9.3
	Current Light	63.1	13.3	61.0	17.9	50.0	19.2
	Current Heavy	5.8	13.4	6.1	15.3	5.0	17.9
Smoking	Never	66.7	12.3	56.3	16.5	48.7	15.3
	Former	15.2	13.4	22.5	16.5	34.0	16.2
	Current	18.2	7.0	21.2	8.4	17.3	10.0
Limits from Chronic Conditions	Yes	5.1	9.9	16.2	10.6	40.3	11.4
	No	94.9	11.6	83.8	15.6	59.7	16.9
Depression	Never	65.8	10.0	57.8	13.9	51.3	14.0
	Few times/yr	23.1	14.6	26.4	17.0	25.3	17.0
	Monthly	5.2	15.4	6.3	17.8	6.7	16.4
	Weekly	3.6	12.7	5.3	12.9	8.1	13.6
	Daily	2.2	10.5	4.3	11.3	8.6	11.9
Anxiety	Never	44.9	7.9	39.7	11.7	36.3	12.1
	Few times/yr	30.1	13.0	30.0	16.3	29.3	16.5
	Monthly	9.5	17.8	9.8	19.3	8.5	16.1
	Weekly	9.2	17.0	11.1	19.0	11.8	17.4
	Daily	6.4	12.6	9.5	13.7	14.1	14.5
Moderate Physical Activity Level	Daily	15.0	12.3	14.8	15.7	14.5	16.2
	Weekly	44.7	15.2	42.9	19.5	35.4	20.6
	Monthly	2.6	12.9	2.7	16.6	2.7	17.5
	Annually	0.6	15.3	0.6	16.7	0.6	12.0
	Never	37.2	6.5	39.0	9.1	46.9	9.7

The overall level of use of PHM varied slightly by group. The highest overall rates of PHM use were among individuals reporting a one chronic conditions (14.8%), followed by multiple chronic conditions (14.7%) and no chronic condition (11.5%). The proportion of PHM use was significantly higher for individuals reporting either a single chronic condition or multiple chronic conditions than those with no chronic conditions ($p < 0.001$). There was no difference between in the proportion of PHM use between those who reported a single chronic condition or multiple chronic conditions ($p = 0.842$).

3.4.3 PHM use Among Different Groups and Factors that Predict It.

Figures 2-4 show the results of the logistic regression analyses where PHM use was the dependent variable and demographic, socioeconomic, and health-related indicators were the predictors.

3.4.3.1 No Reported Chronic Conditions Subgroup

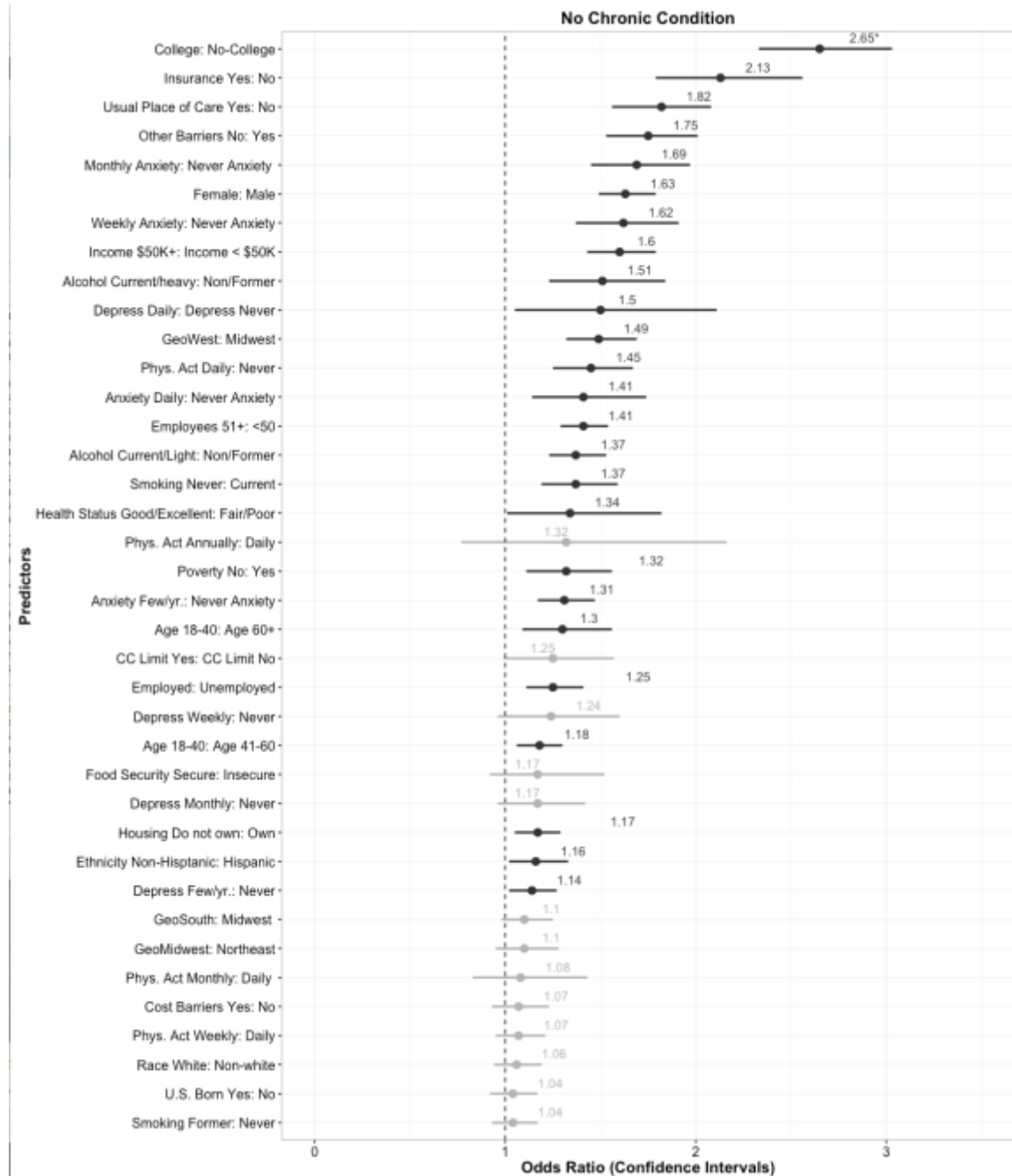
The lowest level of PHM use was from individuals reporting no chronic conditions (11.5%). Among all factors reported in Table 3, the highest proportional use of PHM was among individuals who reported monthly (17.8%) or weekly (17.0%) anxiety. Those without health insurance had the lowest proportional use of PHM (3.4%), followed by those without college level education (3.8%), and those in poverty (5.3%). Educational attainment was the factor with the greatest difference in PHM use between levels. Nearly 16% of individuals reporting college level education used PHM, whereas less than 4% of individuals without college level education reported PHM use.

Figure 2 displays the odds ratios and confidence intervals for the variables used in predicting PHM use for respondents reporting no chronic conditions with significant odds ratios highlighted. Interpretations of the odds ratios using the term “likelihood” or “likely” explicitly refers to a comparison of odds used to calculate the odds ratio for each variable. For this group, individuals with college-level education were over 2.6 times more likely to use PHM than those without a college-level education (OR 2.65; CI 2.33-3.03). Respondents with health insurance were over two times as likely to use PHM than those without insurance (OR 2.13; CI 1.79-2.56). Those reporting a usual place of care were nearly twice as likely to use PHM than those without a usual place of care (OR

1.82; CI 1.57-2.08), and individuals reporting no other barriers to accessing healthcare were more likely to use PHM than those reporting such barriers (OR 1.75; CI 1.53-2.01). Women (OR 1.63; CI 1.49-1.79) and individuals reporting higher family incomes (OR 1.60; CI 1.43-1.79) were also more likely to use PHM. PHM use was higher for those individuals who reported depression on a daily basis than those who reported no depression (OR 1.50; CI 1.05-2.11), and individuals who reported having anxiety a few times per year (OR 1.31; CI 1.17-1.47), having anxiety monthly (OR 1.69; CI 1.45-1.97), having anxiety weekly (OR 1.62; CI 1.37-1.91), and having anxiety daily (OR 1.41; CI 1.14-1.74) were more likely to use PHM than those who reported no anxiety. Individuals living in the West were more likely to use PHM than individuals in the Midwest (OR 1.49; CI 1.32-1.69). Individuals who reported engaging in moderate physical activity daily were nearly one and a half times as likely to use PHM as individuals who reported never engaging in moderate physical activity (OR 1.45; CI 1.26-1.67). Individuals who reported working at organizations with more than fifty employees were more likely to use PHM than those working in organizations with fewer employees (OR 1.41; CI 1.29-1.54); and those who reported being employed were more likely to use PHM than those who reporting being unemployed (OR 1.25; CI 1.11-1.41). Individuals who reported a good or excellent health status were more likely to use PHM than those reporting fair or poor health (OR 1.34; CI 1.01-1.82). Respondents who indicated current heavy (OR 1.51; CI 1.23-1.84) or current light (OR 1.37; CI 1.23-1.53) alcohol consumption were more likely to use PHM than individuals who reported not currently consuming alcohol, and

individuals who reported not ever smoking were more likely to use PHM than those who reported current smoking (OR 1.37; CI 1.20-1.59).

Figure 2. No Chronic Condition Forest Plot – Multivariate Logistic Regression Odds Ratios and 95% Confidence Intervals for All Predictor Variables Ordered by Magnitude.



* Significant odds ratios are bolded.

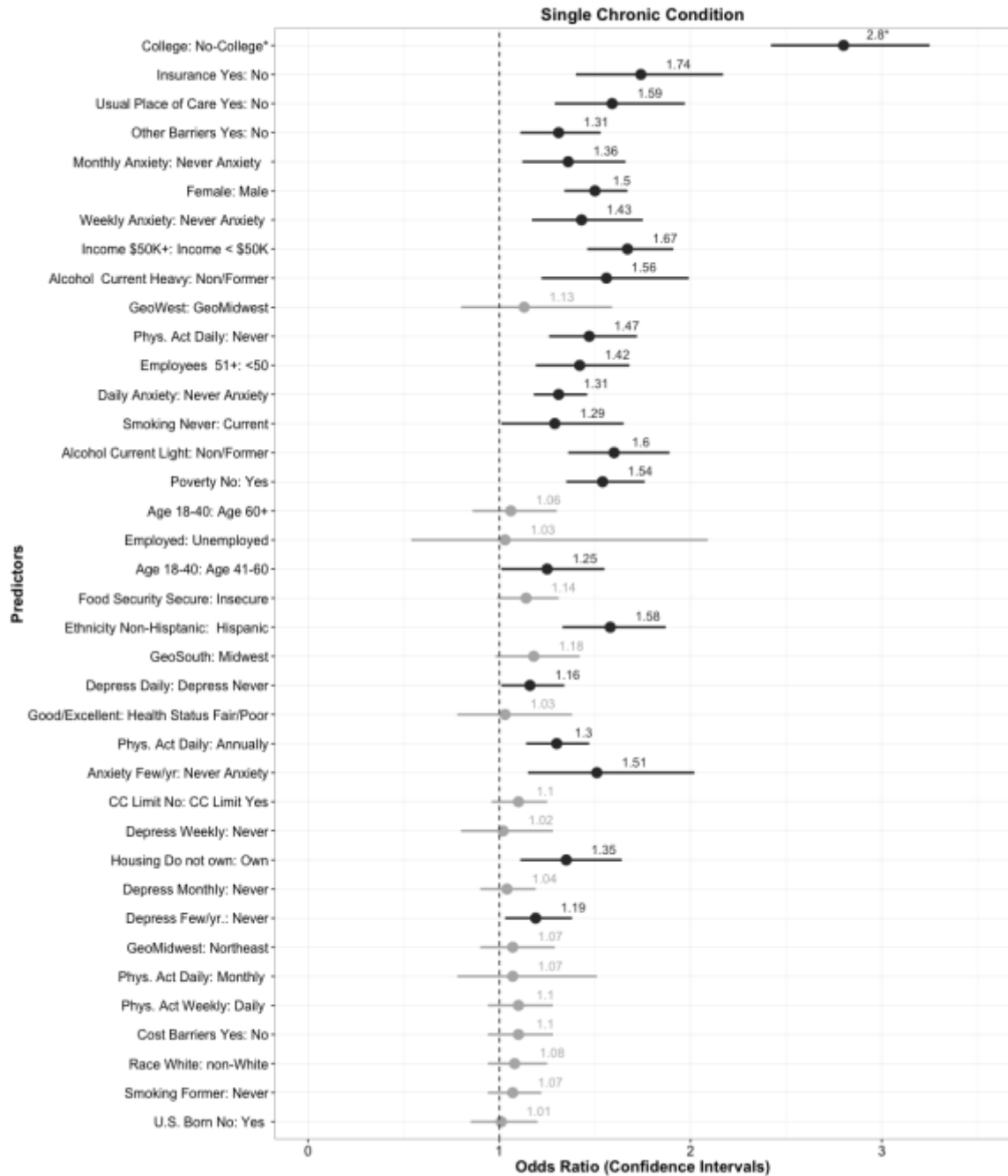
3.4.3.2 Single Chronic Condition Subgroup

PHM use for individuals reporting a single chronic condition was 14.8%. Among all factors included in the analysis (see Table 1), the highest proportional use of PHM in this group was among individuals who reported incomes greater than \$50,000 per year (21.6%), college level education (21.0%), and moderate physical activity weekly (19.5%). Those without college level education (5.2%), without health insurance (6.0%), and reporting being food insecure (7.0%) had the lowest proportional use of PHM. Education level was the factor with the greatest difference in PHM use between levels. Twenty-one percent of individuals reporting college level education used PHM, whereas less only 5.2 percent of individuals without college level education reported PHM use.

Figure 3 illustrates the predictors of PHM use among individuals reporting a single chronic condition. Respondents with a single chronic condition who reported having a college-level education had an increased likelihood of using PHM compared to those without college level education (OR 2.80; CI 2.42-3.25). Individuals who reported having insurance (OR 1.74; CI 1.40-2.17), a median family income of greater than fifty thousand dollars per year (OR 1.67; CI 1.46-1.91), never smoking (OR 1.60; CI 1.36-1.89), and having a usual place of care (OR 1.59; CI 1.29-1.97) were more likely to use PHM than those who reported no health insurance, median family income of less than fifty thousand per year, currently smoking, and not having a usual place of healthcare. Adults aged 18-40 were more likely to use PHM compared to adults sixty years and older (OR 1.58; CI 1.33-1.87) and those aged forty-one to sixty years (OR 1.30; CI 1.14-1.47). Respondents who reported an alcohol status of current heavy (OR 1.56; CI 1.22-1.99) or

current light (OR 1.54; CI 1.35-1.76) were more likely to use PHM than those who reported no alcohol consumption. Individuals who reported being food secure were more likely to use PHM than those who reported being food insecure (OR 1.51; CI 1.15-2.02), and those respondents not in poverty were more likely to use PHM than those in poverty (OR 1.25; CI 1.01-1.55). Women were more likely to use PHM compared to men (OR 1.50; CI 1.34-1.67), and respondents who reported a non-Hispanic ethnicity were more likely to use PHM than those reporting a Hispanic ethnicity (OR 1.35; CI 1.11-1.64). Respondents living in the Western (OR 1.47; CI 1.26-1.72) and Southern (OR 1.19; CI 1.03-1.38) regions of the U.S. had an increased likelihood of PHM use compare to those living in the Midwest region. Frequency of anxiety was also a predictor of PHM use. Individuals reporting anxiety on a weekly (OR 1.43; CI 1.17-1.75), monthly (OR 1.36; CI 1.12-1.66), or daily (OR 1.29; CI 1.01-1.65) basis were more likely to use PHM than those reporting never having anxiety. Respondents reporting daily levels of moderate physical activity were more likely to use PHM than those who never engage in moderate physical activity (OR 1.42; CI 1.19-1.68), and individuals who report experiencing barriers to accessing healthcare were more likely to use PHM than those who reported no barriers to accessing healthcare (OR 1.31; CI 1.11-1.53). Finally, individuals who reported being employed (OR 1.16; CI 1.01-1.34) or who worked at organizations with greater than fifty employees (OR 1.31; CI 1.18-1.46) were somewhat more likely to use PHM than those who reporting being unemployed or working at organizations with fifty employees or less.

Figure 3. Single Chronic Condition Forest Plot – Multivariate Logistic Regression Odds Ratios and 95% Confidence Intervals for All Predictor Variables Ordered by Magnitude of No Chronic Condition Group.



*Significant odds ratios are bolded.

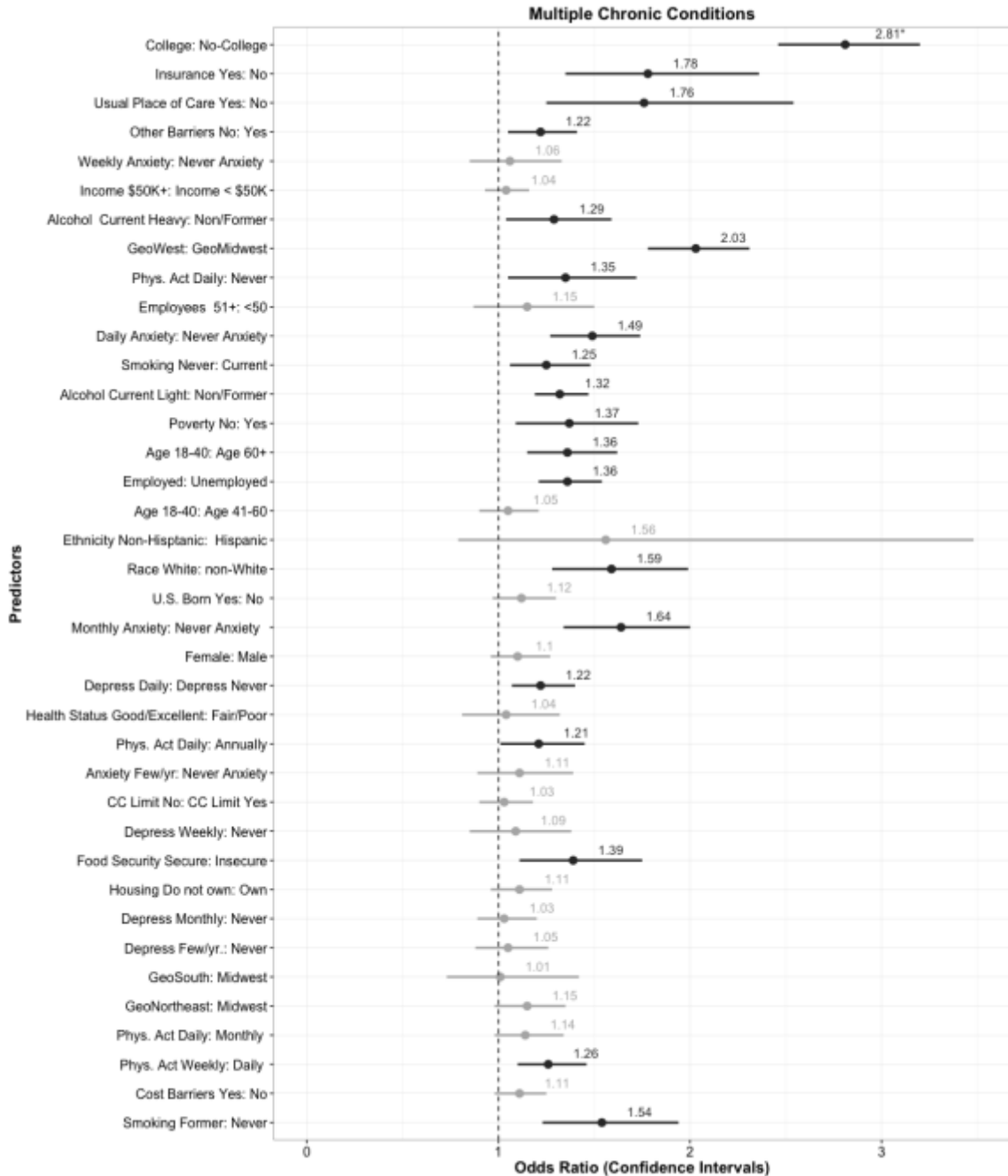
3.4.3.3 Multiple Chronic Conditions Subgroup

PHM use for individuals reporting multiple chronic conditions was 14.7%. Among all factors listed in Table 1, the highest proportional use of PHM in this group was among individuals who reported income greater than \$50,000 per year (25.2%), had a college level education (22.5%), and had current employment (22.0%). Those reporting being in poverty (5.2%), without college level education (5.9%), without health insurance (7.5%), and those who were born outside the United States (7.5%) had the lowest proportional use of PHM. Education level and income were the two factors with the greatest difference in PHM use between levels. There was nearly a seventeen-point difference in PHM use between those who earned less than fifty thousand dollars per year and those who earned more than fifty thousand dollars per year and those with college level education and those without college level education.

Figure 4 indicates that college level education was the strongest predictor of PHM use among individuals with multiple chronic conditions (OR 2.81; CI 2.46-3.20) and individuals who reported family incomes greater than fifty thousand were more likely to use PHM than those earning less (OR 2.03 1.78-2.31). Similarly, individuals who reported not being in poverty were more likely to use PHM than those in poverty (OR 1.59; CI 1.28-1.99). Respondents with health insurance were nearly twice as likely to use PHM than those without health insurance (OR 1.78; CI 1.35-2.36), and individuals with a usual place of care had an increased likelihood of PHM use compared to those without a usual place of care (OR 1.76; CI 1.25-2.54). Respondents who were born in the U.S. were more likely to use PHM than those who were born outside the U.S. (OR 1.54; CI 1.23-

1.81). Individuals who reported living in the West were more likely to use PHM than those in the Midwest (OR 1.49; CI 1.27-1.74). Non-Hispanic respondents were more likely to use PHM than respondents who were Hispanic (OR 1.39; CI 1.11-1.75), and Caucasians were more likely to use PHM than non-Caucasians (OR 1.26; CI 1.10-1.46). Individuals aged 18-40 were more likely to use PHM than those aged 41-60 (OR 1.21; CI 1.01-1.45) and those older than sixty years old (OR 1.64; CI 1.34-2.00). Anxiety was also a predictor of PHM use. Individuals reporting daily (OR 1.37; CI 1.09-1.73) or weekly (OR 1.29; CI 1.04-1.59) were more likely to use PHM than individuals reporting never having anxiety. Respondents who reported never smoking were more likely to use PHM than those reporting currently smoking (OR 1.36; CI 1.15-1.62). Individuals reporting current light alcohol use (OR 1.36; CI 1.21-1.54) or current heavy alcohol use (OR 1.35; CI 1.21-1.54) were more likely to use PHM than non-alcohol consumers. Respondents who reported working at organizations with more than fifty employees were more likely to use PHM (OR 1.32; CI 1.19-1.47), and individuals who reported being employed were more likely to use PHM than individuals who reported an unemployed status (OR 1.22; CI 1.07-1.40). Individuals who reported engaging in physical activity daily were more likely to use PHM than those reporting never engaging in physical activity (OR 1.25; CI 1.06-1.48).

Figure 4. Multiple Chronic Conditions Forest Plot – Multivariate Logistic Regression Odds Ratios and 95% Confidence Intervals for All Predictor Variables Ordered by Magnitude of the No Chronic Condition Group.



*Significant odds ratios are bolded.

3.4.4 Comparisons Across Groups

For the logistic regressions, college education consistently had the largest odds ratios, with analyses from all subgroups reporting respondents with a college education being nearly three times as likely to report PHM use. Interestingly, women reporting no chronic conditions or one chronic condition were more likely to use PHM than men, and only among respondents reporting multiple chronic conditions was race found to be a significant predictor. Table 4 reports the odds ratios and confidence intervals for all significant factors across the no chronic condition, single chronic condition, and multiple chronic conditions groups. There were few differences in significant predictors between the three models. Based on non-overlapping confidence intervals, the odds of using PHM were higher for those with no chronic conditions who reported no other barriers to accessing care than those reporting the same with one or more chronic conditions. Similarly, based upon a slight overlap in confidence intervals (0.05), the odds of using PHM among those with higher family incomes was higher for those with multiple chronic conditions compared to those with no chronic conditions.

Table 4. Comparison of PHM Use by Significant Characteristics between Respondents Reporting No Chronic Conditions, One Chronic Condition, and Multiple Chronic Conditions.

		No CC	One CC	Multi CC
		<i>n=22,929</i>	<i>n=12,415</i>	<i>n=12,470</i>
Demographics		OR (CI)	OR (CI)	OR (CI)
Age	18-40 years	1.30 (1.09-1.57)*	1.58 (1.33-1.87)*	1.64 (1.34-2.00)*
Sex	Female	1.63 (1.49-1.79)	1.50 (1.34-1.67)	<i>1.04 (0.93-1.16)**</i>
Race	White	<i>1.06 (0.94-1.19)</i>	<i>1.08 (0.94-1.25)</i>	1.26 (1.11-1.46)
Ethnicity	Not Hispanic	1.16 (1.02-1.34)	1.35 (1.11-1.64)	1.39 (1.11-1.75)
US Born	Yes	<i>1.04 (0.92-1.17)</i>	<i>1.01 (0.85-1.20)</i>	1.54 (1.23-1.94)
Geography	South	<i>1.11 (0.98-1.25)</i>	1.19 (1.03-1.38)	<i>1.03 (0.89-1.20)</i>
	West	1.49 (1.32-1.69)	1.47 (1.26-1.72)	1.49 (1.27-1.74)

Socioeconomic Status				
Education	College	2.65 (2.33-3.03)	2.80 (2.42-3.25)	2.81 (2.46-3.20)
Family Income	\$50k +	1.60 (1.43-1.79)	1.67 (1.46-1.91)	2.03 (1.78-2.31)
Poverty	No	1.31 (1.11-1.55)	1.25 (1.01-1.55)	1.59 (1.28-1.99)
# Employees	51 +	1.41 (1.29-1.54)	1.31 (1.18-1.46)	1.32 (1.19-1.47)
Employed	Employed	1.25 (1.11-1.41)	1.16 (1.01-1.34)	1.22 (1.07-1.40)
Insurance	Yes	2.13 (1.79-2.56)	1.74 (1.40-2.17)	1.78 (1.35-2.36)
Housing	Do Not Own	1.17 (1.05-1.29)	<i>1.10 (0.96-1.25)</i>	<i>1.03 (0.90-1.18)</i>
Food Security	Secure	1.51 (1.15-2.02)	1.51 (1.15-2.02)	<i>1.11 (0.89-1.39)</i>
Other Barriers	Yes	1.75 (1.53-2.01)	1.31 (1.11-1.53)	1.22 (1.05-1.41)
Health-Related				
Health Status	Fair/Poor	1.34 (1.01-1.82)	<i>1.06 (0.86-1.30)</i>	<i>1.05 (0.90-1.21)</i>
Usual Place of Care	Yes	1.82 (1.56-2.08)	1.59 (1.29-1.97)	1.76 (1.25-2.54)
Alcohol	Current Light	1.37 (1.23-1.53)	1.54 (1.35-1.76)	1.36 (1.21-1.54)
	Current Heavy	1.51 (1.23-1.84)	1.56 (1.22-1.99)	1.35 (1.05-1.72)
Smoking	Never	1.38 (1.20-1.59)	1.60 (1.36-1.89)	1.36 (1.15-1.62)
Depression	Few times/yr	1.14 (1.02-1.27)	<i>1.04 (0.90-1.19)</i>	<i>1.11 (0.96-1.28)</i>
	Daily	1.50 (1.05-2.11)	<i>1.13 (0.80-1.59)</i>	<i>1.15 (0.87-1.50)</i>
Anxiety	Few times/yr	1.31 (1.17-1.47)	<i>1.14 (0.99-1.31)</i>	<i>1.12 (0.97-1.30)</i>
	Monthly	1.69 (1.45-1.97)	1.36 (1.12-1.66)	<i>1.06 (0.85-1.33)</i>
	Weekly	1.62 (1.37-1.91)	1.43 (1.17-1.75)	1.29 (1.04-1.59)
	Daily	1.41 (1.14-1.74)	1.29 (1.01-1.65)	1.37 (1.09-1.73)
Moderate Physical Activity Level	Daily	1.45 (1.26-1.67)	1.42 (1.19-1.68)	1.25 (1.06-1.48)

* Ages 18-40 had significantly higher odds than both other age categories.

**Italics indicate non-significant findings.

3.5 Discussion

Online interactions between patients and health organizations related to accessing health information is becoming a focused area of attention. Between 2009-2014, there has been an increase in the use of secure email to communicate with healthcare providers [92]. The impact of patient access and use of health information has been thoroughly documented in the literature [93]. However, more detailed studies have shown that individuals who engaged with PHM were more likely to report an improved experience of care, improved outcomes, and improved health literacy. Despite increased attention to

engaging patients and families in health decision-making by providing access to electronic health information, there has been an overall low level of use of these tools by patients for personal healthcare management (PHM). Findings from this study support that assertion in that we found that only 12.2% of American adults reported PHM use between 2009-2014, and the percentage of PHM use among this group has remained relatively stable over this time period—only increasing slightly less than 2 percentage points from 2009 to 2014. This slight increase may be partly explained by the adoption of EHR systems that have the ability to engage patients. For example, the rate of adoption of systems with patient engagement functionality increased from 28% to 40% between 2009 and 2012 [94].

This study has demonstrated that there are differences in PHM use across demographic, socioeconomic, and health-related individual specific factors, and the proportions of persons reporting PHM use are different across groups with no chronic conditions versus group with one or multiple such conditions. A greater proportion of individuals with chronic health conditions reported PHM use compared to those without chronic health conditions, and this finding is consistent with prior research [95]. The use of PHM by a greater proportion of individuals suffering from chronic conditions may be partly explained by clinical need. Individuals with chronic conditions may have complex treatment plans, more frequently seek health care, and the management of chronic conditions typically requires medication management [96]. Thus, individuals accessing and managing care more frequently may result in greater use of scheduling appointments

online, requesting prescription refills online, or communicating with healthcare providers online.

3.5.1 Demographic Factors

Demographic factors clearly influenced PHM use across all three groups. Individuals who were younger, non-Hispanic, and who lived in the West reported the greatest levels of PHM use. Individuals reporting being born in the U.S. with multiple chronic conditions were more likely to use PHM compared to the other two models. Previous research has shown that Caucasian [18, 22, 27, 79] and non-Hispanic individuals are more likely to use PHM than other racial or ethnic groups [18, 77]. Our findings suggest a relationship between complexity of condition and PHM use. Previous research has also demonstrated that patients who are younger and non-Hispanic are more likely to be engaged in their healthcare. Our results confirm this previous research as related to individuals who reported a single chronic condition. Among the no chronic condition and single chronic condition groups, women were more likely to use PHM than men, and this finding is also consistent with previous research [18, 27, 77].

3.5.2 Socioeconomic Factors

Socioeconomic factors were the most predictive of PHM use across all three groups. Across all the groups, those with a college level education were more than 2.5 times as likely to use PHM. Research has shown that there is a relationship between education level and health literacy, and that health literacy increases a patient's

engagement in healthcare decision-making [22]. An individual's level of education is also associated with socioeconomic status. Because socioeconomic status impacts an individual's health literacy, access to routine healthcare services, and also access to internet and computer technology, education level is a critical determinant in whether an individual emails a healthcare provider, schedules an appointment online, or requests a prescription refill online [4, 18]. Similarly, insurance coverage and family income were among the strongest predictors of PHM use across the three groups, and these factors have been previously shown to be associated with patient engagement [27, 35, 97]. These findings are consistent with prior research regarding disparities in the use of patient-centered technology to connect patients to electronic health information [20, 22]. Having a lower socioeconomic status may indicate the lack of internet access that would enable an individual to connect to their electronic health information [21]. Lower socioeconomic status may also indicate lack of employment and health insurance, thus an increased likelihood of encountering barriers to accessing healthcare and therefore electronic health information provided by healthcare organizations [4, 18].

3.5.3 Health-Related Factors

Another predictor of PHM is having a usual place for receiving healthcare. Research has shown there is variation in EHR adoption nationally [98, 99]. Different rates of EHR system adoption among both inpatient and ambulatory healthcare organizations may be impacting the PHM use. Because PHM is associated with communicating with healthcare providers and using technology associated with

healthcare organizations, having a usual source for receiving healthcare and therefore potentially having stronger relationships with healthcare providers on the surface would facilitate increased use of PHM [76]. Having a usual place of care also may indicate that these individuals routinely attend the same place for their clinical encounters and potentially obtain care from the same clinicians. This routine care from the same clinic and care team indicates that having an organization that one may consider a health care “home” produces an environment that promotes communication between clinicians and patients through technology.

Engaging in moderate physical activity was also associated with increased PHM use. Research has shown that there is a relationship between health status and patient engagement, and these findings suggest that individuals who are more active and therefore potentially healthier are more likely to engage in managing their health information through technology.

Interestingly, individuals with one chronic condition who reported current light alcohol use and daily moderate physical activity were more likely to use PHM than those reporting never consuming alcohol and never engaging in moderate physical activity. These findings can partly be explained by the association between health status and PHM use. Individuals who reported healthier lifestyle behavior, such as physical activity, moderate alcohol consumption, and not smoking were also more likely to use PHM. Research has shown that patients who are less physically active are more likely to be disengaged in their healthcare [100]. Individuals who report never participating in moderate physical activity are less likely to use PHM than individuals who participate in

moderate physical activity daily, which indicates a relationship between a general health-related lifestyle or physical ability and use of technology for accessing personal health information. Research has shown that there is a relationship between social determinants of health, such as access to resources, and an individual's level of physical activity [101].

Individuals who reported daily and weekly anxiety were more likely to use PHM than those who reported never having anxiety across all three subgroups. Previous research has found a relationship between anxiety and use of technology [102-104]. Research related to the Unified Theory of Acceptance and Use of Technology (UTAUT) found that increased anxiety levels related to use of computers is negatively associated with behavioral intention to use technology [104]. Our findings suggest that there is an association between individual anxiety level and use of technology to email healthcare providers, schedule appointments online, or request prescription refills online. This may be partly explained by the relationship between chronic disease, stress, and anxiety [105]. Research has shown that "health anxiety" influences patient care and information seeking behavior [106].

3.5.4 Model Differences

This study also demonstrated a small number of differences between the models for respondent subgroups. The odds of using PHM were higher among those without a chronic condition who do not experience barriers to accessing healthcare. This finding suggests that those individuals who do not experience challenges to accessing care and who have chronic conditions may be using PHM to complement their typical access to

healthcare professionals or assist in managing their disease. Certain demographic factors also differed across models. Women without chronic conditions were more likely to use PHM than woman with either one or multiple chronic conditions, and this finding is consistent with previous research [18, 19, 27, 77].

3.5.5 Limitations

There are several limitations with this study. The findings are limited by the use of existing data collected through the NHIS survey for a purpose different from this study. The study depended upon the use of the standardized items included through self-reporting in the data collection process. Self-reported survey data has the potential of being biased by social desirability that leads to providing answers which the respondent perceives as more desirable. This could have led to an overestimate of the PHM use as compared to measurement of actual use. Another potential limitation to this study is the combined measure of PHM. The measure was constructed to reflect personal use of technology related to healthcare organizations, but the construction of the measure was limited to the three pre-defined items related to technology use. Furthermore, the questions asked only if the respondent had ever engaged in the activity so that responses did not reflect the intensity of use. This may lead to underestimates of actual use since respondents who reported engaging in the behavior based on only one incident are lumped with those who undertook the same behavior frequently. We conclude that the questions related to emailing healthcare providers, requesting prescription refills online, and scheduling appointments are aggregable into a single PHM measure because of their

high rates of co-occurrence in the dataset. There may also be additional measures that also reflect PHM that were not included in the dataset such as patient review of laboratory tests or visit summaries that were not included in the survey and have been reported previously. Leaving out these frequently reported behaviors could lead to an underestimate of use. These limitations of the dataset may separately lead to either over or underestimates of PHM use. We argue that this implies that our reported results are reasonable estimates but may have wider confidence intervals than calculated. The NHIS did not collect information related to PHM in 2010, which may impact the overall proportional use of PHM across all years but this was addressed by excluding this year from the analytic data set.

3.6 Conclusions

The purpose of this research was to describe the overall utilization of PHM and compare individual characteristics associated with PHM in groups with no reported chronic conditions, with one chronic condition and with two or more such conditions. The results indicate that the overall usage of PHM is not increasing in step with the increase use of EHRs in the United States, even when clinical providers and hospitals are offering PHM features to patients. The overall use of PHM has increased slightly since 2009, but individuals reporting one or more chronic conditions used PHM at higher rates than individuals reporting no chronic conditions. The findings of this study also illustrated the disparities in PHM use across multiple factors, including economics and education in a nationally representative sample of individuals. These findings support the

challenge associated with engaging patients through the use of electronic health information as the healthcare industry continues to evolve. While healthcare organizations continue to adopt electronic modes of communication to facilitate interactions between patients and healthcare organizations, there are significant gaps related to the use of these tools for connecting consumers to health information. For each chronic condition category analyzed, demographic and socioeconomic factors appear to be driving PHM use. Research has demonstrated that patient-centered technologies are associated with improved clinical outcomes, patient experience, and health literacy. If action is not taken to address disparities in PHM use, individuals with lower socioeconomic status are at risk of seeing gaps in health disparities widen. In the short-term, it is imperative that healthcare organizations develop initiatives aimed at promoting adoption of these tools by all individuals, regardless of socioeconomic status. Initiatives must be sensitive to health literacy, race, ethnicity, and other social determinants of health in their design if substantial progress in PHM use is to be achieved. In the long-term, technologies that support PHM use must be designed to better meet the needs of patient populations. The current rate of use reflects the general lack of adoption of these tools, which can be partly explained by the lack of interest or need to access electronic health information online. If PHM use is to increase over time, there needs to be better access to healthcare information across the continuum of care, and more integration of tools and information related to personal fitness, diet, and lifestyle into the systems that support PHM use. Attention needs to be placed on developing technology solutions that meet the needs of all individuals regardless of educational achievement.

Future studies should investigate the relationship between PHM use and clinical outcomes across different chronic conditions, as well as the relationship between PHM use and usability of systems that support PHM-related functions. An additional level of analysis is warranted in which multiple significant predictors are clustered rather than having 22-25 variables analyzed separately.

Clinical Relevance Statement

Previous research has indicated a relationship between the PHM and improved patient satisfaction, care outcomes, and knowledge. This work demonstrated that even though there was an overall low level of PHM use, there were clear disparities across demographic, socioeconomic, and health-related variables. The research showed that having a chronic condition is not the characteristic that best explains PHM use.

Conflict of Interest

The authors declare that they have no conflicts of interest in the research.

Protection of Human and Animal Subjects

Analysis of the NHIS data was deemed exempt from review by the University of Minnesota IRB.

Acknowledgements

The authors wish to acknowledge the Integrated Health Interview Series and the Minnesota Population Center at the University of Minnesota.

CHAPTER 4

IDENTIFYING PREDICTORS OF PERSONAL HEALTHCARE MANAGEMENT AMONG INDIVIDUALS WITH CANCER

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Background: Personal healthcare management (PHM) involves the consumer use of technology to connect with healthcare professionals or organizations related to healthcare services. There is a growing focus on the personal use of health information and technology in an effort to promote optimal care; research has shown an association between the use of personal healthcare management-related activities, clinical outcomes, and administrative efficiency. More specifically, there is an association between use of personal health information-related technology and improvements in outcomes for cancer patients.

Objectives: To describe the user characteristics and predictors of patient healthcare management (PHM) use among American adults who report having cancer as a chronic disease compared to those reporting no chronic diseases.

Materials and Methods: The study used data from the National Health Interview Series (NHIS), a national, representative sample of the U.S. population that collects information on healthcare trends and services. Data from 4,386 respondents between 2009-2014 was analyzed using multivariable logistic regression analyses.

Results: Overall, PHM use is significantly higher for those reporting cancer compared to

previously reported healthy respondents (16.3 versus 11.5 percent). Education (ORs 2.77 and 2.65) and income level (ORs 2.11 and 1.60) are significant predictors of PHM use for both groups. Mental and behavioral factors were also significant predictors of PHM use. Individuals with cancer who reported weekly (OR 1.78) or monthly (OR 1.62) anxiety were more likely to use PHM than respondents who reported never having anxiety.

Discussion: The likelihood of using PHM is heavily influenced by education-level, income, and having a usual place for healthcare services, but other factors also influence PHM use among those battling a specific disease. Individuals with cancer have an increased likelihood of PHM use if they also report higher levels of anxiety. However overall the factors influencing PHM use among cancer patients are not materially different from those affecting such use among healthy respondents.

Conclusions: In a nationally representative sample, cancer patients demonstrated higher PHM usage than healthier individuals but predictors in both groups were similar. Thus there are significant socioeconomic disparities in PHM use, including education level, income, race, ethnicity, and age regardless of whether or not cancer is present. Efforts need to focus on ensuring PHM meets user needs to address the disparities in in all populations including cancer patient populations.

Keywords

Personal Health Information, Consumer Participation, Health Literacy, Social Determinants of Health, Personal Health Records, Cancer

Target Publication: *Applied Clinical Informatics (Not Submitted)*

4.1 Background and Significance

Patient and family engagement has become a central element in the delivery of quality healthcare services [51, 107, 108]. Patient engagement has been called a “blockbuster drug” [109]. Multiple initiatives focused on patient engagement through technology have been implemented in the past several years, including the electronic health record (EHR) Incentive Program’s patient access objectives, the Blue Button initiative’s expansion to connect patients to health information, and the Clinical Laboratory Improvement Amendment’s changes to allow patients direct access to laboratory data [20].

In an effort to engage patients more effectively with information regarding diagnoses, conditions, medications and other information, healthcare organizations have begun using information technology (IT) to provide patients access to their personal health information [110, 111]. Research has shown that approximately 30% of physicians engage in secure messaging with patients and 24% provide patients online access to medical records [112]. It is estimated that in 2013, 12.58% of U.S. adults communicated with a physician using the internet (up from 8.44% and 9.11% in 2008, respectively) and 10.98% of U.S. adults tracked health information using the internet [49].

Consumer use of technology for engaging with their health is viewed as a mechanism for improving quality of health outcomes [44, 113]. Research has shown a relationship between the use of patient-focused IT and improvements in health outcomes and disease management, patient satisfaction, and administrative efficiency [4, 7, 9-11]. Other research has shown that improved patient engagement is related to reduced costs

[114]. Despite the association between patient use of IT and improved outcomes, evidence suggests there are disparities in the use of consumer IT applications across demographic, socioeconomic, and health-related factors [18, 22, 29, 115]. Research suggests a relationship between social determinants of health and the use of technology for patient engagement [116]. In 2014, nearly 40% of U.S. adults were offered access to their online medical records. Individuals with higher levels of education and income were more likely to be offered access to online medical records and more likely to access them [48]. The Institute of Medicine has recommended that measures related to the social determinants of health be collected in EHR systems [117].

In this study we are interested in the relationships between demographic, socioeconomic and health-related variables and personal healthcare management (PHM). PHM refers to the individual use of internet-based technology to access personal health information or communicate with healthcare professionals regarding patient health information. PHM is considered active participation with a healthcare entity through the use of technology (or technology-mediated applications) to assist in meeting her or his healthcare-related needs. PHM involves the use of technology associated with healthcare professionals or organizations, while health related information seeking is driven by individual-level web searching.

Our previous research has shown an association between a variety socioeconomic, demographic, and health-related factors and PHM use [92, 93, 118]. Through multivariable logistic regression, we have found the strongest predictors of PHM use to include education, income, age, sex, race, ethnicity, health status, and geographic region

[93]. Results related to predictive factors of PHM use among those who reported no chronic conditions (healthy individuals) have also been reported previously [118]. Overall, healthy individuals were less likely to use PHM than those with one or more reported chronic conditions. The lack of a reported chronic health condition may partly explain the lack of use of PHM—these individuals are healthier and less likely to use healthcare services and therefore less likely to need access to health information regarding those clinical encounters. We found that individuals who reported college education were over two and a half times more likely to use PHM than those who reported no college level education, those who reported insurance coverage and a usual place for accessing healthcare were about twice as likely to use PHM than those who did not. Those who reported no barriers to obtaining healthcare to accessing healthcare and those who reported higher frequency of anxiety were more likely to use PHM. PHM use is clearly associated with adequate access to healthcare (including insurance coverage and primary care services) [118]. The strongest predictors of PHM among individuals with no chronic conditions are all associated with having a higher socioeconomic status. The AUC was 0.76 for this model.

Cancer-related care has been identified as a clinical area that could benefit greatly from coordination through PHM-related technology, such as personal health records and patient portals. Cancer care is increasingly complex and challenging to coordinate, partly due to the need to organize care between multiple providers and organizations. Cancer patients and families have summarized the concern regarding the challenge of organizing care as “information deficits, uncoordinated care, and insufficient psychosocial support”

[119]. The use of secure email, for example, provides cancer patients the ability to ask questions related to complex information that is provided, as well as follow-up with providers regarding questions related to information potentially shared during clinical encounters. Because cancer patients have the potential to receive care from multiple individuals, departments, and organizations throughout their treatment, these technologies provide an opportunity to improve continuity and avoid gaps in care [120]. Research has demonstrated that the use of patient-focused technology resulted in improved social support, negative emotions, participation in health care, and information competence for women diagnosed with breast cancer [5, 6, 121]. While studies have been conducted on the implementation of patient portals within cancer centers [122, 123], there has been limited research on the utilization of patient portal features by the broader population diagnosed by cancer.

4.2 Objectives

The goal of this study was to describe the user characteristics and predictors of patient healthcare management use among American adults who report having cancer as chronic disease and to compared to those findings with our previous findings for healthy individuals.

4.3 Methods

4.3.1 Sample

After the University of Minnesota IRB deemed analysis of the NHIS data exempt from review, data from the National Health Interview Series (NHIS) were downloaded and used for this study [81]. The Centers for Disease Control and Prevention annually conducts the NHIS survey. The NHIS survey represents a nationally representative sample of the U.S. population (approximately 35,000 households and 87,500 individuals), and it aims “to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability in the United States and the services rendered for or because of such conditions” [82]. The NHIS has a nearly 90% response rate [82]. The questions related to PHM were collected from a nationally representative sample of U.S. adults. The use of the NHIS has been published previously [83, 84].

The NHIS data for this study was limited to information from adults eighteen years old or older from the years 2009, 2011, 2012, 2013, and 2014, which represents a total of 605,001 respondents during these years. The NHIS did not include the items used in this study in 2010. The data for this study was limited to adult respondents who reported “Yes” or “No” to regarding PHM questions, and was again limited to only include responses that include complete data for all variables included in the analysis. The group of interest was identified by limiting the dataset to individuals who reported being diagnosed by a doctor or other health professional as having cancer. The resulting sample for the analysis consisted of 4,386 observations.

4.3.2 Variable Selection

The NHIS includes items regarding healthcare, demographics, health conditions and behaviors. A variable labeled Personal Healthcare Management (PHM) was created based on the NHIS items regarding emailing healthcare providers, refilling prescriptions online, and scheduling healthcare appointments online. PHM refers to individual use of electronic health information management. We assessed individual use of PHM as the dependent variable. Each question included multiple levels of response, including “Yes,” “No,” “Refused,” “Not Ascertained” or “Don’t Know.” A “Yes” PHM response was recorded if a response of “Yes” was provided for any of the three questions—a “No” PHM response was assigned otherwise. If an individual responded with “Refused,” “Don’t Know,” or “Not Ascertained” to any question, the response was removed from the analysis. Age, sex, race, ethnicity, U.S. born, and geographic region were included as demographic variables. Education, family income, poverty status, employment status, number of employer’s employees, health insurance status, housing status, food security, existence of financial and other barriers to accessing healthcare were included as socioeconomic variables. Finally, overall health status, smoking status, alcohol use status, whether or not they had a usual source of healthcare, anxiety status, depression status, and level of moderate physical activity were included as health-related variables. Table 1 lists these variables along with their assignable value sets.

4.3.3 Statistical Analysis

For the purpose of this project, a SAS text file was downloaded from the IHIS portal and imported into the R (version 3.2.3) statistical software package for all data analysis. Descriptive statistics related to each predictor variable were also calculated. PHM use was compared using a two-sample test for equality of proportions. The next step in the analysis was to fit a multiple logistic regression model for PHM for individuals who reported having cancer. The logistic regression model included estimates of the confidence intervals and odds ratios for each predictor variable, as well as the AUC measure for estimating model performance on the entire dataset. Logistic regression was used to identify the significant predictors of PHM. The cancer model's AUC was compared to the no chronic conditions model AUC using Delong's test for unpaired ROC curves [124].

4.4 Results

4.4.1 Respondent Characteristics

Descriptive statistics are presented in Table 5. Among all factors included in the analysis, the highest proportional use of PHM was among individuals with cancer who reported incomes of greater than fifty thousand dollars per year (25.6%), reported being currently employed (24.9%), and reported college level education (23.3%). Individuals reporting weekly or monthly anxiety also reported high rates of PHM use (22.4% and 22.4%, respectively). The lowest proportional PHM use for those with cancer was reported by those annually participating in moderate physical activity (4.4%), followed

by those reporting being in poverty (5.5%) and those having no college education (6.1%).

Interestingly, of the 43% of those with cancer who report never engaging in moderate physical activity, only 9.9% report PHM use.

Table 5. PHM Use by Respondent Characteristics for Respondents Reporting Cancer.

		Cancer	
		<i>n=4,386</i>	
Demographics		%n	%PHM
Age	18-40 years	7.5	20.3
	41-60 year	28.3	21.9
	60+ years	64.2	13.4
Sex	Male	40.7	16.9
	Female	59.3	15.9
Race	White	87.0	17.1
	Non-white	13.0	10.8
Ethnicity	Not Hispanic	93.5	16.8
	Hispanic	6.5	9.2
US Born	Yes	91.3	16.9
	No	8.7	9.7
Geography	Midwest	22.5	14.8
	Northeast	17.1	14.2
	South	36.4	15.7
	West	24.0	20.2
Socioeconomic Status			
Education	No College	40.5	6.1
	College	59.5	23.3
Family Income	<50k\$	55.9	8.9
	\$50k +	44.1	25.6
Poverty	Yes	12.3	5.5
	No	87.7	17.8
# Employees	<50	60.7	14.8
	51 +	39.3	18.6
Employed	Employed	34.9	24.9
	Unemployed	65.1	11.7
Insurance	Yes	94.6	16.5
	No	5.4	13.0
Housing	Own Home	73.1	17.2
	Do Not Own	26.9	13.8
Food Security	Insecure	6.9	11.5
	Secure	93.1	16.7
Cost Barriers	Yes	15.2	16.2
	No	84.8	16.3
Other Barriers	Yes	13.0	19.5
	No	87.0	15.8

Health-Related			
Health Status	Fair/Poor	26.5	11.2
	Good/Excellent	73.5	18.2
Usual Place of Care	Yes	96.3	16.6
	No	3.7	9.8
Alcohol	Non/Former	40.0	9.7
	Current Light	54.4	20.7
	Current Heavy	5.6	20.1
Smoking	Never	49.0	17.5
	Former	36.0	16.8
	Current	14.9	11.1
Limitations from Chronic Conditions	Yes	35.0	12.3
	No	65.0	18.5
Depression	Never	55.7	15.6
	Few times/yr	24.8	18.4
	Monthly	5.8	19.4
	Weekly	6.7	15.1
	Daily	7.1	13.5
Anxiety	Never	39.3	12.9
	Few times/yr	30.4	17.5
	Monthly	8.3	22.4
	Weekly	10.1	22.4
	Daily	11.9	15.2
Moderate Physical Activity Level	Daily	15.4	18.7
	Weekly	38.5	22.5
	Monthly	2.6	18.8
	Annually	0.5	4.2
	Never	43.0	9.9

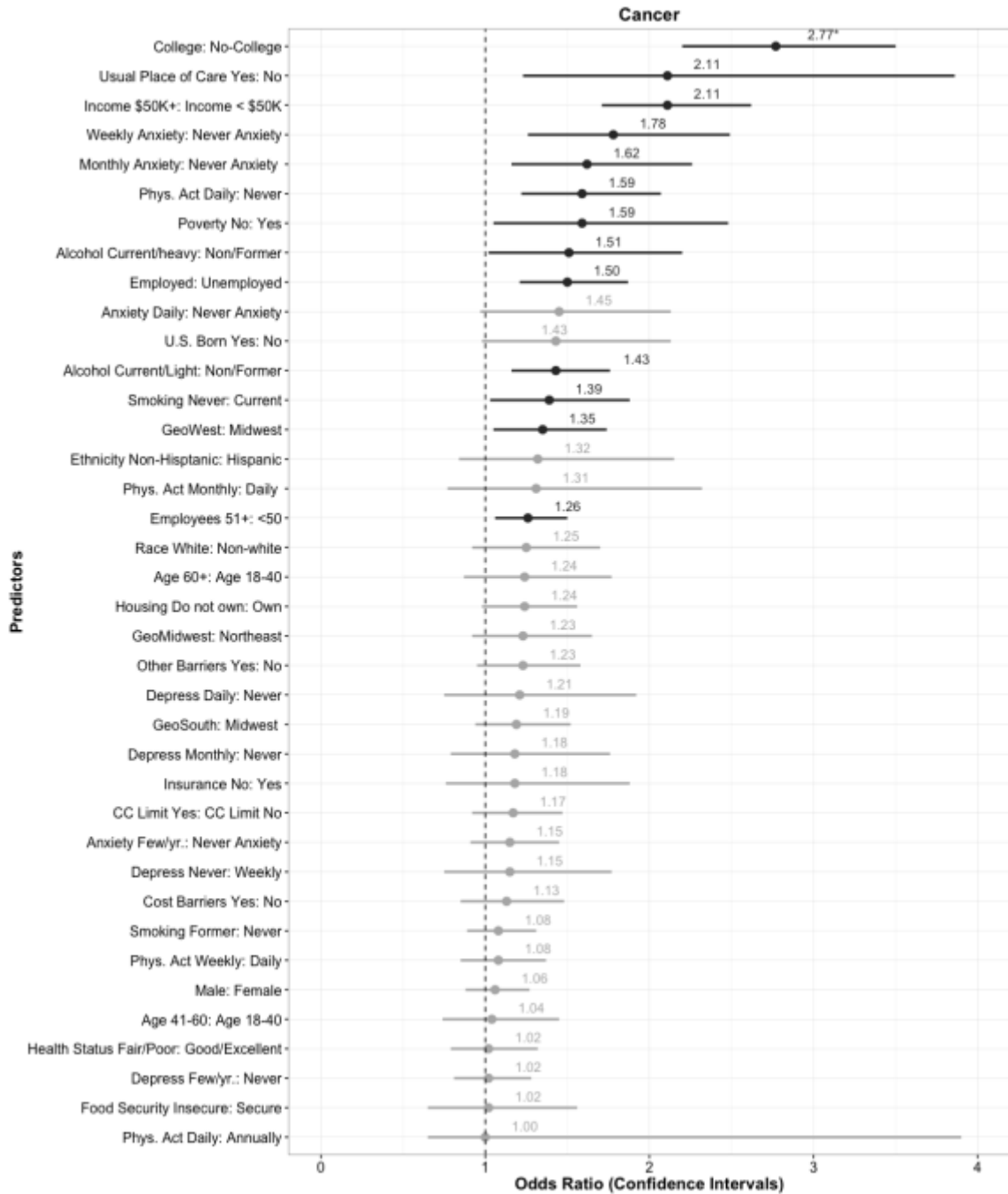
Respondents who reported a diagnosis of cancer had a higher overall PHM use than individuals who reported no chronic conditions, 16.3 percent compared to 11.5 percent ($p < 0.001$) [118].

4.4.2 Factors Influencing PHM use Among Individuals with Cancer

The odds ratios and confidence intervals for each factor regarding individuals who reported cancer are presented in Figure 5. Based upon results of a multivariable logistic regression, college level education was the strongest overall predictor of PHM use among individuals with cancer. Individuals that reported college-level education were

over two and a half times as likely to use PHM than those without a college education (OR 2.77; CI 2.20-3.50). Individuals reporting a usual place of care (OR 2.11; CI 1.23-3.86) were more likely to use PHM than individuals reporting no usual place of care. Those earning more than \$50,000 per year were more likely to use PHM than those earning less (OR 1.68; CI 1.03-2.81). Individuals who reported weekly anxiety (OR 1.78; CI 1.26-2.49) or monthly anxiety (OR 1.62; CI 1.26-2.49) were more likely to use PHM than those that reported never having anxiety. Respondents who reported daily physical activity were more likely to use PHM than those reporting never participating in physical activity (OR 1.59; CI 1.22-2.07). Respondents who were not in poverty were more likely to use PHM than those in poverty (OR 1.59; CI 2.48), and individuals that reported heavy alcohol use (OR 1.51; CI 1.02-2.20) were more likely to use PHM than nondrinkers. Respondents who were employed had an increased likelihood of PHM use compared to unemployed respondents (OR 1.50; CI 1.21-1.87, and individuals that reported light alcohol use (OR 1.43; CI 1.16-1.76) were more likely to use PHM than nondrinkers. Individuals who reported never being smokers (OR 1.39; CI 1.03-1.88) were more likely than current smokers to use PHM. Respondents who reported living in the Western United States were more likely to use PHM than those living in the Midwest (OR 1.36; CI 1.05-1.74), and individuals who worked at organizations with more than fifty employees were more likely to use PHM than those employed by organizations with fewer than fifty employees (OR 1.26; CI 1.06-1.50).

Figure 5. Cancer Subgroup Forest Plot – Multivariate Logistic Regression Odds Ratios and 95% Confidence Intervals for All Predictor Variables Ordered by Magnitude.



* Significant odds ratios are bolded.

The AUC for the cancer group model was 0.76. There was no difference in the AUC values between the cancer and the previously reported healthy individuals group ($p=0.76$).

Table 6 shows the significant predictors for both the cancer and no chronic condition (healthy) groups—all odds ratios for the other variables were not significant for both cancer respondents and healthy respondents. Based upon non-overlapping confidence intervals, there are no differences in the magnitudes of predictors between the two groups—all confidence intervals overlapped. However, four odds ratios for the significant predictors within the cancer group (family income, poverty status, employment, and usual place of care) fell outside the estimated confidence intervals of the corresponding healthy group.

Table 6. Comparison of PHM Use by Significant Characteristics between Respondents Reporting Cancer and Those Reporting No Chronic Conditions.

		Cancer	Healthy [118]
		<i>n=4,386</i>	<i>n=22,929</i>
Demographics		OR (CI)	OR (CI)
Age	18-40 years	1.04 (0.74-1.45)	1.30 (1.09-1.57)**
Sex	Female	1.06 (0.88-1.27)	1.63 (1.49-1.79)
Ethnicity	Not Hispanic	1.32 (0.84-2.15)	1.16 (1.02-1.34)
Geography	West	1.35 (1.05-1.74)	1.49 (1.32-1.69)
Socioeconomic Status			
Education	College	2.77 (2.20-3.50)	2.65 (2.33-3.03)
Family Income	\$50k +	2.11 (1.71-2.62)	1.60 (1.43-1.79)
Poverty	No	1.59 (1.05-2.48)	1.31 (1.11-1.55)
#Employees	51 +	1.26 (1.06-1.50)	1.41 (1.29-1.54)
Employed	Employed	1.50 (1.21-1.87)	1.25 (1.11-1.41)
Insurance	Yes	1.18 (0.76-1.88)	2.13 (1.79-2.56)
Housing	Do Not Own	1.24 (0.98-1.56)	1.17 (1.05-1.29)
Other Barriers	Yes	1.23 (0.95-1.58)	1.75 (1.53-2.01)
Health-Related			
Health Status	Fair/Poor	1.02 (0.79-1.32)	1.34 (1.01-1.82)
Usual Place of Care	Yes	2.11 (1.23-3.86)	1.82 (1.56-2.08)

Alcohol	Current Light	1.43 (1.16-1.76)	1.37 (1.23-1.53)
	Current Heavy	1.51 (1.02-2.20)	1.51 (1.23-1.84)
Smoking	Never	1.39 (1.03-1.88)	1.38 (1.20-1.59)
Depression	Few times/yr	<i>1.02 (0.81-1.28)</i>	1.14 (1.02-1.27)
	Daily	<i>1.21 (0.75-1.92)</i>	1.50 (1.05-2.11)
Anxiety	Few times/yr	<i>1.15 (0.91-1.45)</i>	1.31 (1.17-1.47)
	Monthly	1.62 (1.16-2.26)	1.69 (1.45-1.97)
	Weekly	1.78 (1.26-2.49)	1.62 (1.37-1.91)
	Daily	<i>1.45 (0.97-2.13)</i>	1.41 (1.14-1.74)
Moderate Physical Activity Level	Daily	1.59 (1.22-2.07)	1.45 (1.26-1.67)

* Italics indicate non-significant findings.

** Ages 18-40 had significantly higher odds than both other age categories.

4.5 Discussion

This study evaluated the effect of demographic, socioeconomic and health-related factors on PHM usage for individuals who reported a diagnosis of cancer. Research has shown that demographic factors such as race, ethnicity, and sex are strong predictors of PHM use [92, 93, 118]. For individuals reporting cancer, however, the only significant demographic factor for predicting PHM use was geography. For individuals reporting no chronic conditions, those who were younger, female, and not Hispanic had an increased likelihood of using PHM. These results are partly explained by clinical need. Individuals with a diagnosis of cancer are more likely to use PHM to communicate with healthcare providers than individuals who do not report a chronic condition, regardless of demographics.

Socioeconomic factors, however, are highly predictive of PHM use. Individuals reporting cancer and no chronic condition were more likely to engage in PHM use if they were more highly educated. Education has been a consistent strong predictor of PHM use across multiple analyses [92, 93, 118]. College-educated individuals use PHM at a significantly higher rate than non-college educated individuals in both groups. Over 20

percent of individuals in both the cancer and no chronic condition groups who reported having college-level education also reported PHM use. Among those individuals without college-level education, only 3.4 percent of those without chronic conditions and 6.1 percent of those with cancer reported PHM use. Previous research has shown a strong relationship between education and the use of patient-focused health information technology [21, 92, 93, 116]. According to one estimate, fifty-two percent of individuals with a four-year college degree were offered access to their online health information, while only 19% of individuals without a high school degree were offered access. One systematic review of the literature found that in twenty-eight studies the acceptance of consumer health information technology increased with additional education [125]. Individuals with college level education were more likely to request access to a patient portal and also access the technology [18, 19]. Use of personal health records was higher in geographic areas with higher education rates [27]. Individuals with college-level education are more likely to use any form of health information technology than individuals with lower levels of education, including text messages, use of mobile applications, emailing with healthcare providers, or accessing health information online [20]. Individuals who live in geographic areas with a higher proportion of individuals who did not graduate from high school are less likely to use patient portals [126]. PHM provides individuals with cancer the opportunity to engage with their health information and healthcare providers through technology. While a higher proportion of individuals who reported cancer and no college education used PHM compared to individuals without chronic conditions and no college education, this study demonstrates that there

are wide disparities in PHM use among individuals with cancer based upon education level.

The pattern of PHM use is also observed across other socioeconomic variables included in the analysis, including family income. This finding is consistent with previous research related to PHM use. Research has shown an association between economic status and use of patient-focused technologies [20, 92, 93]. One study found that fifty-six percent of individuals who made over \$100,000 per year were offered online access to their health information, while only twenty-seven percent of individuals making less than \$25,000 per year were offered access [20]. Individuals with lower incomes were also less likely to register for and use a patient portal [18, 127]. Individuals with higher income levels were found to send secure email messages more frequently than individuals with lower income levels [128]. Among registered users of patient portal systems, individuals with lower household income were more likely to have unread messages than those with higher incomes [129]. Individuals who live in geographic areas with a proportion of individuals living in poverty are less likely to use patient portals [126].

Employment and size of employer are also predictors of PHM use. Individuals who are employed and work for organizations with more than fifty employees were more likely to engage in PHM use. This may be explained by the fact that employers, and larger organizations, are more likely to offer workplace wellness programs that promote engagement in healthcare, and these initiatives focused on chronic disease management, weight loss, and healthy behaviors may also impact PHM use [130]. There was also an

association between size of employer and PHM use. Interestingly, individuals with cancer who work for organizations with more than fifty employees were more likely to engage in PHM use. This may be explained by the fact that larger organizations are more likely to offer workplace wellness programs that promote engagement in healthcare, and these initiatives focused on chronic disease management, weight loss, and healthy behaviors may also impact PHM use [130].

PHM use was also influenced by health related factors. Individuals reporting cancer were more likely to engage in PHM use if they were more physically active, reported higher levels of anxiety, and reported a current light level of drinking. This suggests that those individuals who have a chronic condition, but report generally healthier behaviors such as moderate drinking and physical exercise are more likely to engage with their personal health information.

Anxiety level was a factor with one of the highest proportional use rates for any factor. This is consistent with previous research that showed anxiety level influenced technology use [131]. This finding suggests an association between feelings of anxiety and use of PHM to connect with healthcare organizations and providers. The results indicate that individuals with cancer who report higher levels of anxiety are more likely to use technology associated with emailing a healthcare provider, scheduling appointments, or requesting prescription refills.

The cancer model identified daily participation in moderate physical activity as a predictor variable. Respondents who reported never participating in moderate physical activity were less likely to use PHM compared to those who participated in moderate

physical activity daily. This finding suggests that individuals who are physically capable and active are also more likely to engage in non-physical health-related activities, namely emailing healthcare providers, scheduling healthcare appointments online, or requesting prescription refills online. This finding is consistent with previous research that showed that individuals who were generally healthier were more likely to be engaged patients. This finding is consistent with previous research that demonstrated an association between physical activity and personal health record use. In addition to the limitations to physical activity, research has shown that barriers such as computer literacy, health literacy, cognitive impairments, and computer anxiety were also associated with personal health record use [132].

Alcohol consumption and anxiety level variables were also predictive in the cancer model. Compared to individuals who reported never having feelings of anxiety, those who reported feelings of anxiety were more likely to use PHM. Research has demonstrated that cancer diagnosis and treatment is related to increased levels of psychological stress and reduced quality of life, both of which have been shown to be associated negative health behaviors among patients with cancer [133-135]. On the other hand, stress associated with cancer diagnosis and treatment has also been shown to “influence the initiation or frequency of positive health behaviors” [134]. Previous research has found that there is also a relationship between anxiety and intention to use and actual use of technology [102-104]. Research related to the Unified Theory of Acceptance and Use of Technology (UTAUT) found that increased anxiety levels related to use of computers is negatively associated with behavioral intention to use technology

[104]. Research has found a positive association between moderate worry regarding cancer among women and the ability to predict mammography adherence [102]. Other research has shown that individuals who utilize web-based technology for accessing personal health information see improvements in cognitive functioning over time, including improvements in negative emotions [5]. In the present study, individuals who reported feeling more frequent anxiety reported greater PHM use than individuals who never feel anxiety. Our findings suggest that feelings of anxiety generally are predictive of PHM use. This may be partly explained by the specific application of the web-based technology related to PHM use. Individuals with greater levels of anxiety, such as the mammography example above, may be more inclined to access their health information online or contact a provider via email.

To our knowledge, this is the first study that has investigated the predictors of PHM for adults reporting cancer and comparing them to a “healthy” population reporting no chronic conditions. The overall proportion of individuals who report PHM use is higher among those with cancer than with no chronic conditions (16.3 compared to 11.2 percent, respectively). There was an overlap in confidence intervals for all significant factors across both models, likely related to the small sample size of the cancer group and the associated confidence intervals. Presumably, a larger sample size could reveal potential differences in predictive factors between the two groups based upon this trend. The number of significant predictors for PHM use among the cancer group was lower than those reporting no chronic condition (13 versus 25, respectively) again which could be attributed to the difference in sample sizes (4,386 versus 22,929). There was also no

difference in the predictive abilities of the two models. Both the no chronic condition and cancer models classify PHM use equally well but leave room for improvement.

The results presented here have several limitations. The results of our analysis are dependent upon existing data collected through the National Health Interview Series, including the standard items that were included in the data collection process. The NHIS is a survey that relies on self-reporting. Self-reported survey data has the potential of being biased by social desirability, which has the potential to lead respondents to provide answers they may perceive to be more desirable. This may have led to higher reported levels of PHM compared to actual PHM use. Another potential limitation to this study is the combined measure of PHM. The PHM was constructed based upon three pre-defined items of technology use. The items used to construct the measure, moreover, only related to utilization generally and did not address frequency or intensity of use. This may have led to underestimates of actual PHM use because respondents who reported PHM use based on one action are combined with those who undertook the same activity more frequently. Because of their high rates of co-occurrence in the dataset, the authors contend that the questions related to construct the PHM are aggregable into a single PHM measure. Another limitation of this study was the small sample size of the cancer group. The small number of observations may have led to underestimates. There could be measures that also reflect PHM, such as viewing health information online or online payment that were not collected as part of the NHIS. Leaving these measures that are associated with PHM out of the analysis could have led to an underestimate of use of PHM features. The NHIS also did not collect information related to PHM during the

2010 reporting year and this could have impacted the overall reported use of PHM. Consequently, all data from this year was excluded from the analysis. These limitations associated with the secondary use of the NHIS dataset may have impacted the estimates of PHM use. Because of these noted limitations, we contend that that the results included in this study are reasonable estimates but may have wider confidence intervals than presented. Future studies should focus on obtaining a larger sample size for identifying predictors of PHM use among individuals with cancer and comparing them against healthy populations. Future research should investigate a core set of measures related to PHM use.

4.6 Conclusions

Individuals with cancer who responded to this national survey have a higher proportional use of PHM which is associated with several socioeconomic and health-related factors. Despite the increased focus on using PHM-related technologies for obtaining the potential benefits, clear disparities exist in the adoption and use of PHM. Our findings reveal that education and socioeconomic status are critical factors for predicting PHM use by those reporting cancer as a chronic condition. However, these factors are quite similar to the factors predictive of PHM use for healthy respondents to the NHIS survey. Since the survey uses a nationally representative sample our findings provide further, more generalizable evidence regarding the challenge of engaging patients and families in the healthcare decision making through health information technology. They demonstrate the importance of using social determinants of health for explaining consumer use of health

information technology.

Conflict of Interest

The authors declare that they have no conflicts of interest in the research.

Protection of Human and Animal Subjects

Analysis of the NHIS data was deemed exempt from review by the University of Minnesota IRB.

Acknowledgements

The authors wish to acknowledge the Integrated Health Interview Series and the Minnesota Population Center at the University of Minnesota.

CHAPTER 5

CONCLUSION

The use of health information and health information technology by consumers is a major factor in the current healthcare systems' effort to address issues related to quality, cost, and access. Patient engagement in the healthcare process through access to information related to diagnoses, procedures, and treatment has the potential to improve health outcomes [136]. The use of patient-focused technologies that connect healthcare professionals to healthcare consumers has the potential to improve outcomes, efficiency, patient and clinician satisfaction, and communication [4, 9-11, 136]. Efforts to better engage patients through technology and information has also been identified by the American Medical Informatics Association as a key strategic priority for informaticians [137].

Despite the efforts to increase the use of patient-focused technologies, there is an overall low level of adoption and these initial studies indicate that there are significant disparities in the use of health information and technology by American adults. The underlying hypothesis for these studies was that certain individual characteristics predict individual engagement with health information and health information-related technology. American adults with certain demographic, socioeconomic, and health-related characteristics are more likely to conduct health-related internet searches, participate in online health-related chat groups, email healthcare providers, request prescription refills online, or schedule an appointment with a healthcare provider online. To test this hypothesis, four specific aims were identified. First, to investigate predictors

of personal healthcare management (PHM) use among American adults. Second, to examine the relationship between health-related internet seeking and PHM use among American adults. Third, to evaluate the impact of chronic health conditions on PHM use. Fourth, to identify predictors of PHM use among individuals with cancer.

In determining characteristics associated with online health information seeking behavior in the first paper, the study identified multiple predictors associated with individual health-related internet searching. Education-level was the strongest predictor of individual-level health-related internet searches. It was identified that individuals with higher levels of education had an increased likelihood of conducting health-related internet searches. In fact, individuals with graduate level college education were nearly nine times more likely than individuals without a college degree to conduct health related internet searches. Factors considered social determinants of health, including family income, race, access to healthcare services, and ethnicity, were also found to be associated with conducting health related internet searching. Of particular importance, it was demonstrated that relatively few individuals are engaged in PHM, but those that used PHM are significantly more likely to conduct health-related internet searches. These results provide preliminary evidence suggesting that there are disparities in health-related internet searching based upon a number of demographic, socioeconomic, and health-related factors. Our results also suggest that there may be an association between patient-level engagement with consumer eHealth applications, such as emailing healthcare providers, scheduling appointments online, and other forms of patient engagement, such as health-related internet searching.

In determining the predictors of chronic condition prevalence on PHM use, it was found that individuals who reported a single chronic condition or multiple chronic conditions used PHM at a slightly higher level compared to individuals without chronic conditions, but these differences were not significant. It was found that the predictors of PHM use varied considerably based upon chronic condition status. Across all groups, individuals who reported college level of education had an increased likelihood of PHM use compared to those who did not have college-level education. Individuals without chronic conditions were more likely to use PHM if they reported having a usual place for obtaining healthcare and engaging in moderate physical activity daily. Women were also more likely than men to use PHM. These findings are all consistent with previous research.

The predictors for individuals reporting a single chronic condition varied from those without a chronic condition. While socioeconomic predictors were associated with PHM use among individuals reporting a single chronic condition, including higher median family income and a college-education, the strongest predictor of use was whether an individual reported feeling depressed on a monthly basis. Race and ethnicity were also significantly associated with PHM use among individuals reporting one chronic condition. Previous research has demonstrated that Caucasian and non-Hispanic adults are more likely to use PHM than non-White and Hispanic populations. Our study confirmed previous research. It was found individuals who reported a single chronic condition and who reported a Hispanic ethnicity had a lower likelihood of using PHM. PHM use among individuals reporting multiple chronic conditions was predicted

similarly by education level, family income, and age. However, among this group, the best predictor of PHM use was ethnicity. Individuals reporting a Hispanic ethnicity were significantly less likely to use PHM compared to those reporting non-Hispanic. This paper contributed to our understanding of PHM use by confirming an association between socioeconomic, demographic, and health related factors and chronic condition prevalence, and the work demonstrates the impact of education on the potential patient engagement related to PHM use. These findings also added to the literature by demonstrating a relationship between PHM use and the frequency of feelings of depression and physical activity.

The third paper described the characteristics of PHM use among individuals who reported a diagnosis of cancer, and compared predictors of PHM use among individuals reporting no chronic conditions and individuals with cancer. PHM use is higher among individuals with cancer than with no chronic conditions, and PHM use among individuals with cancer is predicted by college level education and age, consistent with previous research. Frequency of anxiety was also a strong predictor of PHM use among individuals reporting cancer. Twice as many respondents who reported having anxiety on a monthly basis used PHM compared to those individuals who responded never having anxiety. The findings from this study contribute evidence regarding the association between anxiety level among individuals with a cancer-related diagnoses and the individual use of PHM.

The findings presented in this research represent the first figures that characterize PHM use among a nationally representative sample of U.S. adults, including comparisons

based upon number of chronic conditions, and across groups who are considered healthy, have chronic conditions, and have cancer. Overall, the level of PHM use is low in the United States is low (approximately 12%). Moreover, the adoption of PHM use has not increased in step with the heightened focus on patient engagement related to adoption of EHRs in the United States. The results from the three studies also indicate important socioeconomic disparities in health-related internet searches and PHM use. As clinical providers and hospitals adopt EHRs in greater numbers, there has been a rise in the number of patients who are offered PHM features as part of their clinical encounters. Despite this trend, our studies demonstrate there are disparities in PHM use across demographic, socioeconomic and health-related factors.

5.1 Overall Study Limitations

These three studies share a common limitation to understanding the predictors of PHM use among American adults due to their reliance on data collected as part of the National Health Interview Series (NHIS). The PHM measure was constructed by combining three individual items from the NHIS. It is possible that the inclusion of additional measures related to PHM could provide alternative explanations regarding predictors of PHM use. For example, there is currently not a NHIS item associated with accessing personal medical records using the Internet, though that activity is currently the focus of federal initiatives aimed at engaging patients and families in their healthcare. NHIS respondents who are using technology to access medical records or connect with healthcare professionals or healthcare organizations in different ways that are currently

associated with accessing personal health records or patient portals may not be represented as PHM-users in this study. This may have led to underestimating PHM use because it limited the types of activities included in the measure and does not. The NHIS measures also do not provide any indication regarding the intensity of use, including how regularly a respondent engaged in the associated activity. This may have led to underestimates of PHM use because it combined all PHM use into two categories (users and non-users) regardless of whether a respondent had used PHM once or more frequently. Despite these potential limitations, we conclude that the items related to emailing healthcare providers, requesting prescription refills online, and scheduling appointments online are aggregable into a single PHM measure because they co-occur so frequently.

The NHIS data is self-reported survey data and there are limitations inherent in this type of information. Respondents may not be accurate with reporting specific information, which could lead to either overestimating or underestimating specific behavior such as PHM. The PHM measure is self-reported and is limited to whether an individual has engaged in PHM within the past year. There are no additional details regarding the frequency of engaging in these activities, the quality of the experiences, the types of information shared, or the overall impact on individual healthcare engagement. Additionally, the results related to PHM use among individuals reporting a diagnosis of cancer are based off a dataset that included fewer responses than each other group.

Generally, these limitations of the dataset may have led to either over or underestimates of PHM use. Consequently, our reported results are reasonable estimates of PHM use, but may have wider confidence intervals than presented.

Although the results of these studies demonstrate associations between demographic, socioeconomic, and health-related factors, the findings are not necessarily causal in nature due to the use of the NHIS data and its method of collecting data simultaneously. A larger, longitudinal dataset may improve the ability to make causal inferences regarding PHM use.

5.2 Contributions and Future Directions

These studies make significant contributions to the field of health informatics in important ways. One research study has been published as part of the Proceedings of the American Medical Informatics Association Annual Symposium, and manuscripts associated with this research will be submitted to relevant journals in the field.

Secondary analysis of a nationally representative sample of American adults regarding consumer engagement in healthcare focused on technology is relevant in an age when multiple federal programs are focused on expanding consumer interaction with health information technology. These studies represent an effort to demonstrate predictors of PHM, and the studies have demonstrated that many predictors of PHM are social determinants. Our research has shown that vast disparities exist in reported patient

engagement with emailing healthcare providers, requesting prescription refills online, and scheduling appointments online.

Finally, these studies have important implications for patient engagement efforts, both at the local and national levels. Multiple programs have focused efforts on increasing communication between patients and providers through health information technology. The goal of these efforts is to increase engagement in healthcare, improve patient understanding of healthcare, improve patient adherence, and reduce the overall cost of healthcare through improved decision-making. However, our results indicate that socioeconomic factors largely predict PHM use, including individuals without chronic conditions, single chronic conditions, multiple chronic conditions, and those with cancer. Considering the goals of recent programs are to improve health through improved communication between patients and healthcare organizations, the results of these studies indicate that the potential benefits associated with the use of PHM are not distributed evenly across our society. The potential benefits are skewed based upon education, income, race, ethnicity, age, and other factors. The results of these studies can be used to illustrate the need for new initiatives and educational programs aimed at promoting adoption of consumer-focused health information technologies among diverse populations. It is clear from our results that innovation is needed in the design, promotion, and use of PHM-related technologies to spur adoption PHM by a wider range of patient populations.

Based upon the data collected for this study, there are many opportunities for additional research related to this topic. Future studies should investigate the relationship

between PHM and clinical outcomes and operational outcomes across multiple chronic conditions, including measures of quality, cost, and patient experience of care. Future studies should also examine the association between the frequency of PHM use and health literacy. There is also needed research related to the relationship between sustained PHM use and the usability of the PHM-related health information technology, including the cognitive processes of patients when interacting with PHM-related technologies.

BIBLIOGRAPHY

1. Google. *A remedy for your health-related questions: health info in the Knowledge Graph*. 2015 [cited 2016 August 8]; Available from: <https://googleblog.blogspot.co.uk/2015/02/health-info-knowledge-graph.html>.
2. Google. *I'm Feeling Yucky : (Searching for symptoms on Google*. 2016 [cited 2016 August 8]; Available from: <https://googleblog.blogspot.com/2016/06/im-feeling-yucky-searching-for-symptoms.html>.
3. Fox, S., *Pew Internet: Health*. highlights of the Pew Internet Project's research related to health and health care, 2013.
4. Feinberg, I., D. Greenberg, and J. Frijters, *Understanding Health Information Seeking Behaviors of Adults with Low Literacy, Numeracy, and Problem Solving Skills: Results from the 2012 US PIAAC Study*. 2015.
5. Gustafson, D.H., et al., *Impact of a patient-centered, computer-based health information/support system*. American journal of preventive medicine, 1999. **16**(1): p. 1-9.
6. Gustafson, D.H., et al., *Effect of computer support on younger women with breast cancer*. Journal of general internal medicine, 2001. **16**(7): p. 435-445.
7. Jamal, A. *The Impact of Online Health Information Seeking Behavior on Self-Care Activities among Adult Diabetic Type-2 Patients*. in *Medicine 2.0 Conference*. 2014. JMIR Publications Inc., Toronto, Canada.
8. Zhou, Y.Y., et al., *Patient access to an electronic health record with secure messaging: impact on primary care utilization*. American Journal of Managed Care, 2007. **13**(7): p. 418-424.
9. Turley, M., et al., *Association Between Personal Health Record Enrollment and Patient Loyalty*. American Journal of Managed Care, 2012. **18**(7): p. e248-e253.
10. Finkelstein, J., et al., *Enabling patient-centered care through health information technology*. 2012.
11. Gibbons, M.C., et al., *Impact of consumer health informatics applications*. 2009.
12. Hogan, T.P., et al., *Technology-assisted patient access to clinical information: an evaluation framework for blue button*. JMIR research protocols, 2014. **3**(1): p. e18.
13. Nazi, K.M., et al., *Evaluating patient access to Electronic Health Records: results from a survey of veterans*. Medical Care, 2013. **51**: p. S52-S56.

14. McInnes, D.K., et al., *Use of electronic personal health record systems to encourage HIV screening: an exploratory study of patient and provider perspectives*. BMC research notes, 2011. **4**(1): p. 295.
15. Tennant, B., et al., *eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults*. Journal of medical Internet research, 2015. **17**(3): p. e70.
16. Kelley, M.S., D. Su, and D.H. Britigan, *Disparities in Health Information Access: Results of a County-Wide Survey and Implications for Health Communication*. Health communication, 2016. **31**(5): p. 575-582.
17. Jhamb, M., et al., *Disparities in electronic health record patient portal use in nephrology clinics*. Clinical Journal of the American Society of Nephrology, 2015. **10**(11): p. 2013-2022.
18. Sarkar, U., et al., *The Literacy Divide: Health Literacy and the Use of an Internet-Based Patient Portal in an Integrated Health System—Results from the Diabetes Study of Northern California (DISTANCE)*. Journal of Health Communication, 2010. **15**: p. 183-196.
19. Sarkar, U., et al., *Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access*. Journal of the American Medical Informatics Association, 2011. **18**(3): p. 318-321.
20. Patel, V., W. Barker, and E. Siminerio, *Disparities in Individuals' Access and Use of Health IT in 2013: ONC Data Brief, no.26*. 2015.
21. Roblin, D.W., et al., *Disparities in use of a personal health record in a managed care organization*. Journal of the American Medical Informatics Association, 2009. **16**(5): p. 683-689.
22. Ancker, J.S., et al., *Use of an electronic patient portal among disadvantaged populations*. Journal Of General Internal Medicine, 2011. **26**(10): p. 1117-1123.
23. CMS, *Medicare and Medicaid programs; electronic health record incentive program--stage 2. Final rule*. Federal Register, 2012. **77**(171): p. 53967-54162.
24. AHRQ. *Patient and Family Engagement: Environmental Scan Report*. 2012; Available from: <http://www.ahrq.gov/research/findings/final-reports/ptfamilyscan/ptfamily1.html>.
25. Hibbard, J.H., J. Greene, and V. Overton, *Patients With Lower Activation Associated With Higher Costs; Delivery Systems Should Know Their Patients' 'Scores'*. Health Affairs, 2013. **32**(2): p. 216-222.

26. Hoover, W., *To be effective, patient engagement must be defined.* . Institute for Health Technology Transformation, 2012.
27. Tenforde, M., et al., *The association between personal health record use and diabetes quality measures.* Journal Of General Internal Medicine, 2012. **27**(4): p. 420-424.
28. Mitchell, B. and D.L. Begoray, *Electronic personal health records that promote self-management in chronic illness.* Online Journal of Issues in Nursing, 2010. **15**(3): p. 1-1.
29. Goel, M.S., et al., *Patient reported barriers to enrolling in a patient portal.* J Am Med Inform Assoc, 2011. **18 Suppl 1**: p. i8-12.
30. CDC. *Chronic diseases: The power to prevent, the call to Control—At a glance 2009.* 2009 [cited 2014 February 2]; Available from: <http://www.cdc.gov/chronicdisease/resources/publications/aag/chronic.htm>.
31. Bates, D.W. and A. Bitton, *The future of health information technology in the patient-centered medical home.* Health Affairs, 2010. **29**(4): p. 614-621.
32. Hannan, A., *Providing patients online access to their primary care computerised medical records: a case study of sharing and caring.* Informatics in Primary Care, 2010. **18**(1): p. 41-49.
33. Luo, G., *Triggers and monitoring in intelligent personal health record.* Journal Of Medical Systems, 2012. **36**(5): p. 2993-3009.
34. Wynia, M.K., G.W. Torres, and J. Lemieux, *Many Physicians Are Willing To Use Patients' Electronic Personal Health Records, But Doctors Differ By Location, Gender, And Practice.* Health Affairs, 2011. **30**(2): p. 266-273.
35. Wade-Vuturo, A.E., L. Satterwhite Mayberry, and C.Y. Osborn, *Secure messaging and diabetes management: experiences and perspectives of patient portal users.* Journal of the American Medical Informatics Association, 2013. **20**(3): p. 519.
36. Zhou, Y.Y., et al., *Improved quality at Kaiser Permanente through e-mail between physicians and patients.* Health Affairs, 2010. **29**(7): p. 1370-1375.
37. Harris, L.T., et al., *Diabetes quality of care and outpatient utilization associated with electronic patient-provider messaging: a cross-sectional analysis.* Diabetes Care, 2009. **32**(7): p. 1182-1187.
38. Ralston, J.D., et al., *Patient Web services integrated with a shared medical record: patient use and satisfaction [corrected] [published erratum appears in J*

- AM MED INFORM ASSOC 2008 Mar-Apr;15(2):265*]. Journal of the American Medical Informatics Association, 2007. **14**(6): p. 798-806.
39. Hibbard, J.H., et al., *Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers*. Health Services Research, 2004. **39**(4 Pt 1): p. 1005-1026.
 40. HRSA. *Health IT adoption toolbox*. 2012 [cited 2014 February, 1]; Available from: <http://www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/MeaningfulUse/intro2meaningfuluseandpatientandfamily.html>.
 41. *The personal health working group final report*. 2003, Connecting for Health: A Public-Private Collaborative: Washington, D.C.
 42. HIMSS. *PHRs and patient portals*. n.d. [cited 2014 February 1]; Available from: <http://www.himss.org/resourcelibrary/TopicList.aspx?MetaDataID=1498&navItemNumber=13562>.
 43. ONC. *Meaningful use definition and objectives*. n.d. [cited 2014 February 1]; Available from: <http://www.healthit.gov/providers-professionals/meaningful-use-definition-objectives>.
 44. Medicare, C.f. and H. Medicaid Services *Medicare and Medicaid Programs; Electronic Health Record Incentive Program--Stage 3 and Modifications to Meaningful Use in 2015 Through 2017. Final rules with comment period*. Federal register, 2015. **80**(200): p. 62761.
 45. King, J., V. Patel, and M.F. Furukawa, *Physician Adoption of Electronic Health Record Technology to Meet Meaningful Use Objectives: 2009-2012 in ONC Data Brief*. 2012, Office of the National Coordinator for Health Information Technology: Washington, D.C.
 46. Charles, D., M. Furukawa, and M. Hufstader, *Electronic Health Record Systems and Intent to Attest to Meaningful Use among Non-federal Acute Care Hospitals in the United States: 2008-2011 in ONC Data Brief*. 2012, Office of the National Coordinator for Health Information Technology: Washington, D.C.
 47. Terry, K. *Patient Portal Explosion Has Major Health Care Implications*. 2013 [cited 2014 February 1]; Available from: <http://www.ihealthbeat.org/insight/2013/patient-portal-explosion-has-major-health-care-implications>.
 48. Patel, V., W. Barker, and E. Siminerio. *Trends in Consumer Access and Use of Electronic Health Information: Data Brief Number 30*. 2015 [cited 2016 January 13]; Available from:

[https://www.healthit.gov/sites/default/files/briefs/oncdatabrief30_accesstrends .pdf](https://www.healthit.gov/sites/default/files/briefs/oncdatabrief30_accesstrends.pdf).

49. Ford, E.W., B.W. Hesse, and T.R. Huerta, *Personal Health Record Use in the United States: Forecasting Future Adoption Levels*. Journal of medical Internet research, 2016. **18**(3).
50. Kohn, L.T., J.M. Corrigan, and M.S. Donaldson, *To Err Is Human:: Building a Safer Health System*. 2000: National Academies Press.
51. Kohn, L.T., J.M. Corrigan, and M.S. Donaldson, *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: Committee on Quality of Health Care in America, Institute of Medicine, 2001.
52. Wunderlich, G. and P. Kohler, *Improving the Quality of Long-Term Care (Institute of Medicine Committee on Improving the Quality of Long Term Care)*. Division of Health Care Services, Washington, DC, 2001.
53. Page, A., *Keeping Patients Safe:: Transforming the Work Environment of Nurses*. 2004: National Academies Press.
54. Mills, T.L., *Insuring America's Health: Principles and Recommendations*. Journal of the National Medical Association, 2005. **97**(8): p. 1185.
55. Knebel, E. and A.C. Greiner, *Health Professions Education:: A Bridge to Quality*. 2003: National Academies Press.
56. Medicare, C.f. and M. Services, *National health expenditure projections 2010-2020*. and us bureau of Labor statistics (2012).“consumer Price Index, 2012.
57. Elmendorf, D., *Estimates for the insurance coverage provisions of the Affordable Care Act updated for the recent Supreme Court decision*. Washington DC: Congressional Budget Office, 2012.
58. Hoyert, D.L. and J. Xu, *Deaths: preliminary data for 2011*. National vital statistics reports, 2012. **61**(6): p. 1-51.
59. Fox, S. and M. Duggan, *The diagnosis difference*. 2013: Pew Research Center's Internet & American Life Project.
60. Marmot, M. and R. Wilkinson, *Social determinants of health*. 2005: Oxford University Press.
61. Taylor, E.F., et al., *Coordinating care in the medical neighborhood: critical components and available mechanisms*. 2011, Mathematica Policy Research.

62. Turvey, C.L., et al., *Transfer of Information from Personal Health Records: A Survey of Veterans Using My Health e Vet*. *Telemedicine and e-Health*, 2012. **18**(2): p. 109-114.
63. Sequist, T.D., et al., *Electronic patient messages to promote colorectal cancer screening: a randomized controlled trial*. *Archives of internal medicine*, 2011. **171**(7): p. 636-641.
64. Simon, G.E., et al., *Randomized trial of depression follow-up care by online messaging*. *Journal of general internal medicine*, 2011. **26**(7): p. 698-704.
65. Dorr, D., et al., *Informatics systems to promote improved care for chronic illness: a literature review*. *Journal of the American Medical Informatics Association*, 2007. **14**(2): p. 156-163.
66. Stock, R., et al., *Developing a community-wide electronic shared medication list*. 2008.
67. Luque, A.E., et al., *Barriers and facilitators of online patient portals to personal health records among persons living with HIV: Formative research*. *JMIR research protocols*, 2013. **2**(1).
68. Wagner, P.J., et al., *Personal health records and hypertension control: a randomized trial*. *Journal of the American Medical Informatics Association*, 2012. **19**(4): p. 626-634.
69. Berry, J.G., et al., *Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study*. *BMC health services research*, 2011. **11**(1): p. 117.
70. Wilcox, A., K. Natarajan, and C. Weng, *Using personal health records for automated clinical trials recruitment: the ePaIRing model*. *Summit on translational bioinformatics*, 2009. **2009**: p. 136.
71. Kupchunas, W.R., *Personal health record: new opportunity for patient education*. *Orthopaedic Nursing*, 2007. **26**(3): p. 185-191.
72. Ball, M.J. and J. Gold, *Banking on health: personal records and information exchange*. *Journal of Healthcare Information Management*, 2006. **20**(2): p. 71.
73. Morahan-Martin, J.M., *How Internet Users Find, Evaluate, and Use Online Health Information: A Cross-Cultural Review*. *CyberPsychology & Behavior*, 2004. **7**(5): p. 497-510.

74. Eysenbach, G., et al., *Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review*. JAMA, 2002. **287**(20): p. 2691-2700.
75. Ohlow, M.A., M. Brunelli, and B. Lauer, *Internet use in patients with cardiovascular diseases: Bad Berka Cross- Sectional Study (BABSYS)*. International Journal of Clinical Practice, 2013. **67**(10): p. 990.
76. Bhandari, N., Y. Shi, and K. Jung, *Seeking health information online: does limited healthcare access matter?* Journal of the American Medical Informatics Association, 2014. **21**(6): p. 1113-1117.
77. Wen, K.-Y., et al., *Consumers' perceptions about and use of the internet for personal health records and health information exchange: analysis of the 2007 Health Information National Trends Survey*. Journal of medical Internet research, 2010. **12**(4).
78. Westin, A., J. Lemieux, and S. Subias, *Americans overwhelmingly believe electronic personal health records could improve their health*. Connecting for health. Markle Foundation, 2008: p. 1-7.
79. Ancker, J.S., et al., *The Triangle Model for evaluating the effect of health information technology on healthcare quality and safety*. Journal of the American Medical Informatics Association, 2011: p. amiajnl-2011-000385.
80. Archer, N., et al., *Personal health records: a scoping review*. Journal of the American Medical Informatics Association, 2011. **18**(4): p. 515-522.
81. *Minnesota Population Center and State Health Access Data Assistance Center*. 2012; Version 5.0:[Integrated Health Interview Series].
82. NHIS. *National Health Interview Survey*. 2012 [cited 2014 February 2]; Available from: http://www.cdc.gov/nchs/nhis/about_nhis.htm.
83. Johnson, P.J., et al., *Four decades of population health data: the integrated health interview series as an epidemiologic resource*. Epidemiology, 2008. **19**(6): p. 872-5.
84. Iezzoni, L.I., et al., *Conditions causing disability and current pregnancy among US women with chronic physical disabilities*. Med Care, 2014. **52**(1): p. 20-5.
85. Millard, R.W. and P.A. Fintak, *Use of the Internet by Patients with Chronic Illness*. Disease Management & Health Outcomes, 2002. **10**(3): p. 187-194.

86. Viswanath, K., et al., *Internet use, browsing, and the urban poor: implications for cancer control*. Journal Of The National Cancer Institute. Monographs, 2013. **2013**(47): p. 199-205.
87. Chen, C.-C., T. Yamada, and J. Smith, *An evaluation of healthcare information on the Internet: the case of colorectal cancer prevention*. International Journal Of Environmental Research And Public Health, 2014. **11**(1): p. 1058-1075.
88. Pew. *Pew Research Internet Project: Health Fact Sheet*. n.d. [cited 2015 January 25]; Available from: <http://www.pewinternet.org/fact-sheets/health-fact-sheet/>.
89. Hibbard, J.H., R. Baron, and M. Trisolini. *Patient Activation and Engagement for ACOs*. The Centers for Medicare and Medicaid Innovation Webinar 2012; Available from: https://acoregister.rti.org/index.cfm?fuseaction=dsp_web.
90. Charles, D., M. Gabriel, and J. Henry, *Electronic Capabilities for Patient Engagement among U.S. Non-Federal Acute Care Hospitals: 2012-2014*. . 2015, Washington DC: ONC Data Brief, no.29. Office of the National Coordinator for Health Information Technology.
91. Ward, B.W., J.S. Schiller, and R.A. Goodman, *Multiple Chronic Conditions Among US Adults: A 2012 Update*. Preventing Chronic Disease, 2014. **11**: p. E62.
92. Sandefer, R.H., et al. *Using Publicly Available Data to Characterize Consumers Use of Email to Communicate with Healthcare Providers*. in *MEDINFO 2015: EHealth-enabled Health: Proceedings of the 15th World Congress on Health and Biomedical Informatics*. 2015. IOS Press.
93. Sandefer, R.H., et al. *Determinants of Consumer eHealth Information Seeking Behavior*. in *AMIA Annual Symposium Proceedings*. 2015. American Medical Informatics Association.
94. Technology, O.o.t.N.C.f.H.I. *ONC Budget Performance Measures, Health IT Dashboard*. 2016; Available from: <http://dashboard.healthit.gov/dashboards/onc-budget-performance-measures.php>.
95. Agarwal, R., et al., *If we offer it, will they accept? Factors affecting patient use intentions of personal health records and secure messaging*. Journal of medical Internet research, 2013. **15**(2): p. e43.
96. Holman, H. and K. Lorig, *Patient self-management: a key to effectiveness and efficiency in care of chronic disease*. Public health reports, 2004. **119**(3): p. 239.
97. Bos-Touwen, I., et al., *Patient and disease characteristics associated with activation for self-management in patients with diabetes, chronic obstructive*

- pulmonary disease, chronic heart failure and chronic renal disease: a cross-sectional survey study.* PloS one, 2015. **10**(5): p. e0126400.
98. King, J., M.F. Furukawa, and M.B. Buntin, *Geographic variation in ambulatory electronic health record adoption: implications for underserved communities.* Health services research, 2013. **48**(6pt1): p. 2037-2059.
 99. DesRoches, C.M., et al., *Electronic health records in ambulatory care—a national survey of physicians.* New England Journal of Medicine, 2008. **359**(1): p. 50-60.
 100. Carroll, J.K., E. Antognoli, and S.A. Flocke, *Evaluation of physical activity counseling in primary care using direct observation of the 5As.* The Annals of Family Medicine, 2011. **9**(5): p. 416-422.
 101. Adler, N.E. and K. Newman, *Socioeconomic disparities in health: pathways and policies.* Health affairs, 2002. **21**(2): p. 60-76.
 102. Diefenbach, M.A., S.M. Miller, and M.B. Daly, *Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer.* Health psychology, 1999. **18**(5): p. 532.
 103. Beaudry, A. and A. Pinsonneault, *The other side of acceptance: studying the direct and indirect effects of emotions on information technology use.* MIS quarterly, 2010: p. 689-710.
 104. Attuquayefio, S. and H. Addo, *Review of studies with UTAUT as conceptual framework.* European Scientific Journal, 2014. **10**(8).
 105. Garrido, M.M., et al., *Stress and chronic disease management.* The handbook of stress science: Biology, psychology, and health, 2011: p. 488-500.
 106. Eastin, M.S. and N.M. Guinsler, *Worried and wired: effects of health anxiety on information-seeking and health care utilization behaviors.* CyberPsychology & Behavior, 2006. **9**(4): p. 494-498.
 107. Triberti, S., et al. *Evaluating patient engagement and user experience of a positive technology intervention.* in Walter de Gruyter GmbH. 2016.
 108. Carman, K.L., et al., *Patient and family engagement: a framework for understanding the elements and developing interventions and policies.* Health Affairs, 2013. **32**(2): p. 223-231.
 109. Dentzer, S., *Rx for the 'blockbuster drug' of patient engagement.* Health Affairs, 2013. **32**(2): p. 202-202.

110. Blumenthal, D. and M. Tavenner, *The “meaningful use” regulation for electronic health records*. New England Journal of Medicine, 2010. **363**(6): p. 501-504.
111. Ahern, D.K., et al., *Promise of and potential for patient-facing technologies to enable meaningful use*. American journal of preventive medicine, 2011. **40**(5): p. S162-S172.
112. Furukawa, M.F., et al., *Despite substantial progress in EHR adoption, health information exchange and patient engagement remain low in office settings*. Health Affairs, 2014. **33**(9): p. 1672-1679.
113. Medicare, C.f. and H. Medicaid Services *Medicare and Medicaid programs; electronic health record incentive program--stage 2. Final rule*. Federal register, 2012. **77**(171): p. 53967.
114. Greene, J., et al., *When patient activation levels change, health outcomes and costs change, too*. Health Affairs, 2015. **34**(3): p. 431-437.
115. Goldzweig, C.L., et al., *Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review*. Annals of internal medicine, 2013. **159**(10): p. 677-687.
116. Irizarry, T., A.D. Dabbs, and C.R. Curran, *Patient portals and patient engagement: a state of the science review*. Journal of medical Internet research, 2015. **17**(6).
117. Adler, N.E. and W.W. Stead, *Patients in context—EHR capture of social and behavioral determinants of health*. New England Journal of Medicine, 2015. **372**(8): p. 698-701.
118. Sandefer, R., et al., *Personal Healthcare Management: Assessing the Relationship with Chronic Disease Prevalence*. Manuscript, 2016.
119. Clauser, S.B., et al., *Improving modern cancer care through information technology*. American journal of preventive medicine, 2011. **40**(5): p. S198-S207.
120. Gysels, M., A. Richardson, and I.J. Higginson, *Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review*. Health Expectations, 2007. **10**(1): p. 75-91.
121. Gustafson, D.H., et al., *Use and impact of eHealth system by low-income women with breast cancer*. Journal of Health Communication, 2005. **10**(S1): p. 195-218.
122. Groll, R.J., et al., *Electronic surveillance of testicular cancer: understanding patient perspectives on access to electronic medical records*. Journal of Oncology Practice, 2009. **5**(4): p. 177-181.

123. Snyder, C.F., et al., *The role of informatics in promoting patient-centered care*. Cancer journal (Sudbury, Mass.), 2011. **17**(4): p. 211.
124. DeLong, E.R., D.M. DeLong, and D.L. Clarke-Pearson, *Comparing the areas under two or more correlated receiver operating characteristic curves: a nonparametric approach*. Biometrics, 1988: p. 837-845.
125. Or, C.K. and B.-T. Karsh, *A systematic review of patient acceptance of consumer health information technology*. Journal of the American Medical Informatics Association, 2009. **16**(4): p. 550-560.
126. Mikles, S.P. and T.J. Mielenz, *Characteristics of electronic patient-provider messaging system utilisation in an urban health care organisation*. Journal of innovation in health informatics, 2014. **22**(1): p. 214-221.
127. Ketterer, T., et al., *Correlates of patient portal enrollment and activation in primary care pediatrics*. Academic pediatrics, 2013. **13**(3): p. 264-271.
128. Haun, J.N., et al., *Large-Scale Survey Findings Inform Patients' Experiences in Using Secure Messaging to Engage in Patient-Provider Communication and Self-Care Management: A Quantitative Assessment*. Journal of medical Internet research, 2015. **17**(12).
129. Crotty, B., et al., *Prevalence and Risk Profile Of Unread Messages To Patients In A Patient Web Portal*. Applied clinical informatics, 2015. **6**(2): p. 375-382.
130. Mattke, S., et al., *Workplace wellness programs study*. Rand Corporation, 2013.
131. Pierce, T., *Social anxiety and technology: Face-to-face communication versus technological communication among teens*. Computers in Human Behavior, 2009. **25**(6): p. 1367-1372.
132. Lober, W.B., et al. *Barriers to the use of a personal health record by an elderly population*. in AMIA. 2006.
133. Härtl, K., et al., *Personality traits and psychosocial stress: quality of life over 2 years following breast cancer diagnosis and psychological impact factors*. Psycho-oncology, 2010. **19**(2): p. 160.
134. Andersen, B.L., J.K. Kiecolt-Glaser, and R. Glaser, *A biobehavioral model of cancer stress and disease course*. American psychologist, 1994. **49**(5): p. 389.
135. Stagl, J.M., et al., *Long-term psychological benefits of cognitive-behavioral stress management for women with breast cancer: 11-year follow-up of a randomized controlled trial*. Cancer, 2015. **121**(11): p. 1873-1881.

136. Kruse, C.S., K. Bolton, and G. Freriks, *The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review*. Journal of medical Internet research, 2015. **17**(2): p. e44.
137. AMIA. *AMIA Unveils 2017 Policy Priorities, Defines Pillars of New Policy Domain*. 2016 [cited 2016 November 22]; Available from: <https://www.amia.org/news-and-publications/press-release/amia-unveils-2017-policy-priorities-defines-pillars-new-policy>.