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Patient Sociotechnical Assemblages: The Distributed Cognition of Health Information Management

Matthew Andrew Willis
Syracuse University

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Abstract

Personal health records (PHR) are shifting the capabilities and responsibilities of both patients and providers. Influenced by health IT, concepts like patient-centered care, meaningful use, and patient empowerment are commonplace in the healthcare system. As the popularity of personal health records increases, medical providers, healthcare organizations, and health information system stakeholders require a thorough understanding of how patients use these patient facing information portals in conjunction with other artifacts, objects, and practices to manage and maintain their health.

Exploring health information management as a distributed sociotechnical assemblage is the conceptual approach of this research. A distributed cognition perspective lends insight to drawing boundaries and establishing connections of personal health information management practices in conjunction with PHR use. The Department of Veterans Affairs provides a unique setting to further understand PHR use and personal health information management practice through the observation of U.S. military veterans enrolled in the My HealtheVet PHR. This context and conceptual framework lead to the research questions for the proposed study:

RQ1a: What are the personal health information management practices of veterans who use a personal health record?

RQ1b: What health information management practices become distributed beyond the veteran patient?

RQ2a: What health information management assemblages emerge from the distributed work of Veterans that use a personal health record?

RQ2b: What are key functions of the health information management assemblages of veterans?

Through the use of semi-structured in depth interviews, observations, and surveys, data were collected on 22 patients along with their primary care providers and caretakers. Results from a two cycle qualitative coding analysis and analytical cognitive mapping technique reveal bundles of practices for creating reminders, organizing information, and creating information for asking questions and working with primary care providers. Distributed practices emerged that detail the managing of medication, information that is socially distributed, and patient-provider communication through secure messaging. Three health information management assemblage components emerged from the analysis: Health events and experiential information, information techniques, and technology and material practices. Each of these components is understood by the ways they become stabilized or destabilized. This research contributes to implications for the design of patient-focused personal health records and informs clinical practice of patient-centered care. The research also makes conceptual and empirical contributions to the practice of health information management and a patient-centered care model of healthcare delivery.

Patient Sociotechnical Assemblages:
The Distributed Cognition of Health Information Management

By

Matthew A. Willis

B.A., University of New Mexico, 2006

M.A., University of New Mexico, 2009

M.Phil, Syracuse University, 2014

Dissertation

Submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in *Information Science & Technology*

Syracuse University

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Chapter One

1. Introduction

Healthcare is an information based activity for both patients and providers; while providers must gather, synthesize, and act upon information, so too must patients (Hersh, 2002). The proliferation of Internet connectivity, mobile computing (Smith, 2012), online health information seeking (Buente & Robbin, 2008; Fox, 2008), and overall ease of information access across all age groups in recent years (Fox, 2011a), makes it critical for patients, providers, health technology developers and researchers to continue to support and improve the use of technology in the United States healthcare system. This is a system that invests vast amounts of time, money, and political power to enable patients and providers alike to interact with health information digitally. The hope is that through the application of technology to the healthcare sector costs will be cut, fees lowered, patient satisfaction increased, and similar efficiencies associated with the use of technology improved (Grove, 2005).

In an effort to move toward a modern health IT infrastructure, personal health records (PHR) are a popular strategy for supporting patients, increasing patient satisfaction, and motivating and empowering patients to be involved in their health care. PHRs are seen as a priority to provide for patient use because information overload is common in the complex, cognitively intense work in which patients engage when they manage their own health information. Patients receive pamphlets, pages of literature, instructions, directions, and summaries; they take notes, write down questions, log routines, keep appointments, and generate information based on research using the Internet. These actions mean there is

opportunity for patients to be responsible for and generate a large quantity of personal health information. The repeated practices that patients engage with such as organizing and storing documents, printing information, researching using the internet, and remembering questions to ask are all forms of work for patients. These kinds of personal health information management work matter. This manner of patient work can affect the delivery of healthcare and patient satisfaction (Saranto, Brennan, & Casey, 2009). The PHR is perceived as a tool to support these patient health information management practices and as a tool to disseminate information to patients. Electronic health records and health information systems have become used by both patients and providers and the use of this technology has created new dynamics between those groups (Ventres et al., 2006).

The availability of PHRs and other health information communication technology for patients has created a proliferation of social media networks, mobile applications, information sources, and online communities that provide patients more opportunities to connect with additional information, other patients, caretakers, and providers. While the support and convenience that information communication technologies give patients and health consumers is undeniably a positive experience, these technologies are in early development. It is a matter of convenience to design an information communication technology to let a patient pay hospital bills online. It is a complex sociotechnical problem to create information communication technologies designed to show patients their own medical information, foster patient-provider communication, and aid patients in decision making. This sociotechnical problem becomes more challenging when considering the fact that health information

communication technologies need to promote and enable certain qualities including concepts like patient satisfaction, meaningful use, and patient-centered care.

The concept of meaningful use, patient satisfaction, and patient-centered care all exist to serve as guidelines for institutions and healthcare professionals and stakeholders concerned with the practice and delivery of healthcare. These concepts are starting to become applied to the function of technology in healthcare. Beyond simply implementing and using technology because it is exciting or perceived as useful, these concepts elicit more specific ideas that the technology in use must have a pragmatic goal. For example, does the technology improve health outcomes? Does it increase patient satisfaction? Are patients able to accomplish necessary health related tasks using the technology? These are just some of the questions that become part of a discussion when implementing or developing patient facing information communication technology. These concepts exist for good reason, to sensitize developers, implementers, practitioners, and researchers to unintended consequences and problems that may result from the use of information communication technology (Ahern, Woods, Lightowler, Finley, & Houston, 2011; Ash, Berg, & Coiera, 2004; Krist & Woolf, 2011; Krupat, Bell, Kravitz, Thom, & Azari, 2001). However, patient satisfaction and health outcomes are moving targets that do not always have positive connotations. The patient may have good health outcomes but be completely unsatisfied, or vice versa. Research shows that using PHRs to improve health outcomes is poorly understood, there are no correlations between the two concepts, and further research is needed (Saparova, 2012; Shaw & Ferranti, 2011; Wiljer, 2010; Winkelman, Leonard, & Rossos, 2005).

1.1 Background and phenomenon

The following section explores two factors at work in the United States healthcare sector. Broadly, these two concepts of patient facing health information systems (i.e. PHRs) and personal health information management (PHIM) illustrate the state of the art of the healthcare field: increasing computerization of patient work, changing dynamics in the patient-provider relationship, and the important role of understanding situated patient health information management practices. Understanding patient work and interaction with consumer facing health information systems must extend beyond usability and interface design of personal health records. To understand the computerization of patient work and the function of health information systems on patient work we must inquire beyond the basic desire to provide patients with health information systems in order to understand how personal health records actually facilitate, or not, the activity they were designed for: supporting personal health information management.

1.1.1 Consumer focused information communication technology and patient-centered care

There is a notion of a shift from patients as passive consumers of healthcare to active agents in the education, treatment, decision making, and maintenance of their healthcare (Funnell and Anderson, 2003; Salmon and Hall, 2004). Patients have more opportunity to become involved in shared decision making with their healthcare providers. Shared decision making is a counterpoint to a diagnostic model of healthcare, where patients meet with their healthcare provider to receive a diagnosis, adhere to the provider's treatment plans, and minimize communication and shared decision making (Stewart et al., 1995). Proponents of shared decision making, facilitating positive patient provider communication and participatory

practices in healthcare, turn to technological solutions to facilitate these qualities (Gerber & Eiser, 2001; Lovell, Lee, & Brotheridge, 2010; Wilson, 2003). Fostering an environment of empowered patients in a productive relationship with medical providers is a complex task to achieve and maintain--made more challenging when technology is added to the equation.

To situate the literature review in chapter two, I look at the coalescence of two factors that shape the modern healthcare system. The first is an emphasis on health technologies like personal health records and mobile devices. Healthcare is a field that is known for embracing new technology and applying technology in novel ways (Robson & Baek, 2009). However, the use of a new technology like a CAT, PET, MRI, or other tools for diagnosing and treating a patient is a fundamentally different use of technology than a personal health record system. Technology like MRI, CAT, and similar medical diagnostic technologies are used by specialists to examine the patient body and ultimately administer or guide medical treatment. Personal health records do not function in this capacity. They do not produce new data from an array of sensors or scientific testing. Personal health records are, nevertheless, an important technology for healthcare. PHRs present a significant amount more complexity than an MRI and similar medical technologies because PHRs are a social communication technology. As a social technology, an information communication technology, the PHR functions as a way to connect multiple providers or social actors and serve as a complete history of a person's health (Simborg, 2009). This connects to the second shaping factor of healthcare, the patient-provider relationship.

The second factor emerging in healthcare is the relationship between the patient and healthcare provider, specifically the emphasis improving their relationship through

communication and shared decision making. A prime example of one such model that concerns patient-provider communication is the aforementioned patient-centered care (PCC) model. While PCC is not a new concept, it sees mutual respect and sharing management of illness as a cornerstone in the patient-provider relationship. It is also an approach which has a growing evidence base emerging for improving health outcomes (Bauman, Fardy, & Harris, 2003). Indeed, PCC has had more success for impacting health outcomes than the idea of satisfaction or use of technology. Acceptance of technology in healthcare can be a detriment to patient-provider communication if used improperly. Social faux pas exist around using mobile phones in clinical rooms, patients prefer doctors look at them and not their phone or tablet during the appointment when appointment times have already decreased in duration. A strong patient-provider relationship is essential for quality and satisfactory patient care and the establishment of therapeutic relationships built on trust and respect (Teutsch, 2003; Wright, 2008).

Another need for patient-centered care and patient empowerment through technology is the concern in the clinical practice of healthcare that providers focus on treating and managing diseases rather than on people and their health problems (Bauman et al., 2003). A rigid perspective on patient involvement creates challenges for patients' health information management. Patients that feel valued and listened to result in improved outcomes and satisfaction (Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001).

Patients access health information online (Fox & Jones, 2009; Fox, 2011b) and if they so desire can even track their own health using a variety of sensors and mobile devices. The use of PHRs has been repeatedly identified as a powerful method of supporting and enriching patient involvement in care (HealthyPeople 2020, 2012; Ueckert, Goerz, Ataian, Tessmann, & Prokosch,

2003). Empowering a patient to be more engaged in their healthcare experience, whether it be through self-tracking technology, PHRs, or concepts like patient-centered care, is a way to improve clinical decision making, increase efficiency, and strengthen the patient-provider relationship (Ball & Lillis, 2001). This has encouraged providers to re-evaluate how they communicate with patients and what they assume about patients and continue to transition away from the previously mentioned diagnostic model of healthcare delivery (de Bocanegra & Gany, 2004).

The work that patients perform, such as managing a treatment routine, documenting information, seeking medical information, or organizing the scores of information collected, increases in complexity when caretakers and other social actors supporting the patient are added to the equation. Many of the tasks for managing health information can be delegated to caretakers. Husbands, wives, relatives, friends, family members, and other primary caretakers are part of a support system with whom patients want to share access to their health information with (Patel et al., 2011). The ability for health information systems to support delegation, i.e. cooperation between patients and caretakers, is an essential functionality PHRs must support.

The personal health record is a technology without a long history of use in the healthcare sector. So thinking about the personal health record as a digital file which follows the patient for the entirety of their life is infrequently discussed. Lifelong use of a personal health record further complicates their perception and application in healthcare. As PHRs continue to improve in adoption, the notion of a lifelong health record will become an issue that must be addressed. Though not widely discussed, a single PHR that patients have over the

course of their life is not a new concept. Researchers and providers are keen to emphasize the importance of having one health record that a patient may always access and is available throughout a patients' life (Tang & Lansky, 2005). The purpose for a lifelong record is simple: health consumers might utilize one network or health insurance provider and may be triggered to change those services or providers the moment a job changes, a family moves, or other life events occur. Following any such changes, new PHR systems, new ways of conducting business, and problems of interoperability between systems may be introduced.

The greatest barrier to a reality of lifelong PHRs is interoperability. In the same article, Tang and Lansky (2005) acknowledge the policy hurdles that fully interoperable PHR systems would need to overcome, which is unlikely to be possible at any time in the near future given the fragmented nature of the North American healthcare system. This fragmentation is what has institutionalized the practices of patients and providers to be solely responsible for keeping health records consolidated, updated, and checked for accuracy. The current market for PHRs casts a grim outlook on the goal of PHR interoperability. There are over 200 PHR products on the market (Gearon, 2007; Jones, Shipman, Plaut, & Selden, 2010; Nazi, 2010), all of which are independently developed using a myriad of technical architectures. While the ability to export patient data may be a feature of one PHR system, this is not true for many other PHRs in development.

Aside from the technical challenges that exist to grow PHR technology and enable true interoperability, I turn to one understudied area which are the situated practice of personal health information management. Applying an understanding of personal health information management practices will shape patient-centered care and the meaningful use of these

technologies. Understanding the patient's strategies for information management also has clinical significance since it informs providers how to engage and anticipate patient needs; it is well known that patient work is commonly underestimated by medical staff and providers (Strauss, Fagerhaugh, Suczek, & Wiener, 1982). These observations demonstrate why it is important and relevant to investigate how patients use a PHR but also to understand what health information management practices occur in tandem with use of a PHR. This is to say that the PHR cannot support everything a patient must do to manage health information, and that the work a patient does outside of a PHR is relevant to the continued use and development of it.

1.1.2 Personal health information management

Healthcare has always been an information intensive activity for health consumers, whether patients are managing pathology, seeking information, engaging in health prevention activities, or organizing personal health information. All of these activities are cognitively intense and, most importantly, the methods and strategies a patient can perform are highly personalized and individualized (Agarwal, 2009). A report on personal health information management and the design of consumer health information technology authored by Agarwal (2009) for the Agency for Healthcare Research and Quality (AHRQ) found multiple gaps in the knowledge of this area. Among them are the need to understand situated personal health information management (PHIM) practices, functional requirements of technology and design philosophies, motivations to engage in PHIM, and conceptualizing PHIM as a wholly different activity or special case of personal information management (PIM). Lastly, the challenge found in all information management activities, but magnified in health information management is

the challenge of the mismatch between the complexity of people's lives and their cognitive ability. Agarwal (2009) points out three specific mechanisms in this challenge: (1) to remember what is known, (2) find what is needed, and (3) to manage every piece of information on the personal self, for the personal self, at the level of the personal self, and by the personal self.

In light of the growth of health IT, eHealth initiatives, and mobile computing, consumers have options for how they can engage with health information management as well as a growing list of health information access points and inputs of data. The growing number of mobile devices (Smith, 2012) and the expanding notion of everyday health and quantified self-metrics (Swan, 2009) means that there is more information to track, manage, read, visualize and with which to interact. This increase in information availability and tools for managing health information also points to multiple configurations in which physical and digital health information can be collected, stored, and accessed. This leads to a variety of ways that health consumers engage with information in a process of sense making (Jones, 2008). Patients may prefer not to use technology for anything health information related, or to only use technology for certain tasks (Hill, Burge, Haring, & Young, 2012).

Adding to the complexity of information management, different groups of users need technology designed in a specific way (Kutz & Ekbia, 2011). For example, technologically mediating personal health information management tasks can provide value over performing those same tasks entirely with paper. Disease management activities, self-reported health measures, journals, log books, and information/education management work, health and information seeking are practices that may be beneficial for the patient-provider relationship (Weinert, Cudney, & Kinion, 2011). Weinert et al (2011) look at self-management using a paper

based personal health record targeted at a rural population. While there has been much promise about the interoperability and value added from electronic based PHRs, the authors note that given the right context paper based PHRs have value that exceeds that of a computerized health record. This example highlights the need to consider context both in technology development and in how patients are actually managing health information. With a good understanding of how patients manage health information, better technologies can be developed to seamlessly support the patient in this endeavor. A patient-centered approach is the means understanding how patients manage health information and implementing those ideas into future technologies and tools for patients.

1.2 The Department of Veterans Affairs

In this section, I provide some context and framing of the research site, a VA Medical Center that is a part of the VA healthcare system. Because all participants in this study are veterans receiving care at the VA Medical Center, it is clear that the VA as an organization is a relevant factor to help situate this research. In this section, I also provide context of the population of interest, U.S. military veterans, and the central information communication technology artifact of interest, My HealtheVet.

The United States Department of Veterans Affairs (VA) was established as an independent agency under the President on July 30, 1930 by executive order 5398. The mission statement of the VA is to fulfill President Lincoln's promise: "To care for him who shall have borne the battle, and for his widow and his orphan" (Lincoln, 1865). This makes the VA the principal advocate for veterans to ensure medical care, benefits, social support, and lasting memorials. The VA vision to support veterans is carried out through three strategic goals. These

goals are to empower veterans to improve their well-being, enhance and develop trusted partnerships across agencies and external institutions, and to manage and improve VA operations to deliver seamless integrated support (Department of Veterans Affairs FY 2014-2020 Strategic Plan, 2014).

The VA is a customer service oriented institution and a model organization for the practice of patient-centered care (Kuehn, 2012). It manages the largest medical system in the United States by caring for over 8 million Veterans with over 180,000 medical professionals across 160 hospitals, 800 clinics, and 135 nursing homes (Deegan, 2003). All use a single enterprise wide electronic health record system called Veterans Health Information Systems and Technology Architecture (VISTA). Since over 60% of all U.S trained physicians rotate through the VA on clinical electives, VISTA is the most widely used clinical electronic record system (Jha et al., 2009). Because VISTA is public domain software, some form of VISTA has been used in non-government hospitals as well as various modules deployed internationally. Most importantly, for the purposes of this research, VISTA connects to MyHealtheVet (MHV) and bridges all clinical information from the electronic health record over to the personal health record.

The VA provides a rich setting to observe emergent phenomena of patient information management in conjunction with personal health record use. The department is the world's leader in using telehealth and has one of the largest telehealth programs in the world (Lindeman, 2010). The VA also offers a personal health record system that has one of the largest adoption rates for a PHR, making it feasible to understand the role of the PHR in information management activities. This is an important factor to seek out in research,

especially when PHR adoption rates are typically low (Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011), making users of PHR difficult to include in research. The goal of this research is to understand the role of the PHR on PHIM and patient work and this setting is an ideal type of living laboratory to study this phenomenon (Sawyer, Crowston, & Wigand, 2014).

I am involved with various VA projects as an intern since early 2011, working with both the Center for Integrated Healthcare and the My HealtheVet Program Office intermittently. This has given me the opportunity to understand the organizational culture of the VA and other important social factors relevant to this research. Additionally, it has given me a keen understanding of conducting social science research in VA facilities with the Veteran population. This understanding of how research is to be conducted with Veterans is important to get the most out of this study. My experience as an intern and research assistant has exposed me to the details and functionality of My HealtheVet that are only learned over time. In qualitative work this level of understanding is important to aid in the articulation and later analysis of the research.

1.2.1 U.S. military veterans

The veteran population is an appropriate population for this study because veterans represent the complexity in health information management, self-management, and idiosyncratic work practices that this study investigates. On average, male veterans have 5.5 concurrent chronic conditions (multi-morbidity), with the three most common being hypertension, hyperlipidemia, and coronary heart disease (Steinman et al., 2012). One of the hallmarks of information management is having a health concern or chronic condition to

manage. These issues of health management are ones that not only affect veterans but also millions of other American patients.

Veterans may go outside of the VA to receive treatment and care. This means personal health information must be shared between providers at the VA and private providers or providers outside the VA. This unique opportunity means further complexity is introduced into the management of health information by coordinating providers at multiple institutions. Even though 91.1% of non-VA providers indicate they regularly share medical records with the VA, these providers report they rely on the patients (veterans) to provide information about their history and care at VA medical centers (Nayar et al., 2013).

Understanding the use of technology is also important to this study, and to the future of consumer focused health information technology. Veterans have expressed willingness to use the Internet to obtain VA related information about their benefits and care (68.8%) and also to apply for those benefits (65.6%). The majority of veterans have access to the Internet (72.3%) and access it daily (68.4%) at the home or workplace to perform tasks such as to check email. Consistent with national statistics, Internet use is higher in younger veterans age 18-30 (98.7%) than World War II Veterans (33.5%) (Westat, 2010). Internet use is a factor which much be selected for in this study because use of a personal health record is prefaced on access and use of the Internet. Also, the Internet is inseparable from an attempt to understand health information management and personal health record use.

Previously discussed patient-provider communication and patient-centered care is essential to the VA's model of healthcare delivery. Findings show that the veterans connection to and close bond with their clinician or therapist is a key factor in determining how well a

veteran will perform in a medical or treatment program (Gade & Wilkins, 2013). This finding showcases the importance of the patient-provider relationship and makes clear why healthcare institutions and policymakers are interested in using technology to foster and support patient-provider communication. This survey of veteran health, information use, and veterans' participation in the proposed research provides the opportunity to understand and support these complex scenarios.

1.2.2 My HealtheVet

The Department of Veterans Affairs launched My HealtheVet (MHV) to all VA facilities nationwide in 2003. The record system was developed to address the need for providing health information to the veteran patient (Schneider, 2008). The system allows data to be entered by veterans and also integrates data from the VA's unified clinical electronic health record (EHR) system, which is referred to as a Computerized Patient Record System (CPRS). MHV as a personal health record system also has a collection of tools for health education information, health management, links to resources, pharmaceutical prescription ordering and refills, exporting data, and secure messaging between patients and providers (Nazi, 2010). The health information the veteran can access also includes behavioral health notes from therapists. This functionality is significant because only a handful of hospitals allow patients to view mental health notes through what is known as the open notes project (Kahn, Bell, Walker, & Delbanco, 2014).

My HealtheVet allows for all of the data to be exported from the system as a PDF or text file through functionality known as the Blue Button. This means that patients can print their entire health record, share it with others, or work with documents in printed form rather than

electronically (Vogel, 2010). Veterans that use the Blue Button functionality found it beneficial to help understand their health history to a better extent and to provide information to non-VA providers (Turvey et al., 2014).

As the system continues to grow, it is evaluated through the use of the American Consumer Satisfaction Index (ACSI) survey to gauge satisfaction and steer future development of the system. Satisfaction has consistently been rated as high, with users likely to return to the site for regular use of pharmacy-related features including medication reconciliation (Nazi, 2010). This makes the MHV system an appropriate and useful personal health record that can help add further context to the study of personal health information management practices.

To get an idea of the size, scope, and usage of the MHV system, MHV serves more than 2.4 million registered users, which make up 35% of the VA patient population, as of September 2013. More than 1.3 million VA patients have gone through an additional in-person authentication process to obtain a premium account, which makes available additional information in MHV; about 24% of the VA patient population has gone through this process. Veterans have requested more than 45 million prescriptions through MHV and more than 789,000 VA patients have opted-in to use Secure Messaging features. Secure messaging can be thought of like a secure email. It allows patients to securely message and correspond with their healthcare provider through MHV asynchronously. When providers send a secure message to a patient, that patient is notified through their personal email that they have a new secure message to read. The content of the secure message is not displayed in the personal email message. The email only serves as a notification. Patients must then log into the MHV portal to read the content of the secure message.

The VA Blue Button was deployed in August 2010 and since then has been used by more than 881,000 unique users who have downloaded more than 4.7 million files from their personal health record (Nazi et al., 2010). Over 61,000 unique users have downloaded more than 235,000 continuity of care documents. The VA CCD is designed for Veterans to share health information electronically with non-VA providers. Use of My HealtheVet continues to expand, with new account registrations increasing 22% in fiscal year 2013 compared to the same time period for the previous year. Similarly, use of Secure Messaging increased 162% in fiscal year 2013. Table 1 below summarizes the features available to MHV users based on the account type they possess.

Table 1: My HealtheVet Personal Health Record features by account type. Reproduced from (Nazi et al., 2010)

Feature key: A = All site visitors, R = Registered users, A = Authenticated users	V	R	A
<i>General information and resources:</i> Access information about Federal and VA benefits and resources, VA-related news and events. Link to additional resources	X	X	X
<i>Research health:</i> Browse and search collections of evidence-based health information including Healthy Living Centers, Condition Centers, and medical databases. Access health screening tools, mental health resources, and articles	X	X	X
<i>My HealtheVet Learning Center:</i> Take online courses to promote mental health	X	X	X
<i>Personal information:</i> Store and maintain contact information including emergency contacts. Manage account profile, preferences, and options		X	X
<i>Get care:</i> Store and maintain information pertaining to caregivers and providers, treatment facilities and locations, and health insurance coverage		X	X
<i>Health information card:</i> Print selected personal and medical information on a pre-formatted wallet card for a convenient reference		X	X
<i>Personal health history:</i> Record important health history information and events		X	X
<i>Family health history:</i> Record family member's health history and events that may affect health		X	X

<i>Military health history:</i> Record important events from military service including assignments related to health history, potential exposures, and treatments	X	X
<i>Personal health summary:</i> Select information to print out as a personal health summary report to share with providers	X	X
<i>Health eLogs:</i> Track and graph common health measures (blood pressure, blood sugar, cholesterol, body temperature, weight, heart rate, pain, pulse oximetry, INR)	X	X
<i>Allergies:</i> Record allergies by date, severity, reaction, diagnosis, and add comments	X	X
<i>Immunizations:</i> Record the immunization, date, method used, and any reactions	X	X
<i>Tests:</i> Record tests by test name, date of test, location where the test was performed, provider's name, results, and add comments	X	X
<i>Medical events:</i> Keep track of illnesses, accidents, or other events by logging the date, treatment prescribed, and any comments regarding the event	X	X
<i>Food and activity journals:</i> Record food intake to monitor diet or control weight, and keep track of exercise routines. Print journal worksheets for easy tracking	X	X
<i>Health calendar:</i> Add events, set reminders, utilize a to-do list	X	X
<i>Medications, over-the-counter drugs, herbals, and supplements:</i> Record the name, starting and ending date, prescription number, and dosage	X	X
<i>Prescription refills:</i> Request refills for VA prescriptions online (authenticated users can view medication names when ordering refills)	X	X
<i>VA prescription history:</i> View a record of all VA prescriptions		X
<i>My complete medications:</i> View and print a complete summary of both VA and self-entered medications to support medication reconciliation		X
<i>Wellness reminders:</i> View customized reminders for preventative care and screens		X
<i>Secure messaging:</i> Exchange secure electronic messages with your healthcare team for non-urgent needs (currently available at 8 sites with further expansion planned)		X

While MHV is an established PHR that has existed for over a decade, specific user practices and distributed health information management are not well understood; additional observation and mixed method study designs will play an important role in growing this area of research because of the complex situated nature of consumer healthcare management

(Chumbler, Haggstrom, & Saleem, 2010). One study using a self-report survey method showed a majority of users feel that MHV helps them better prepare for office visits, improve the quality of care, understand instructions from providers, obtain more control over managing their information, and feel that they are part of a team with their provider (Lee, 2006). While the measures used in the survey are self-reported perceptions of constructs like satisfaction and health literacy, it does indicate that users have perceived benefits through use of a PHR. These positive perceptions coincide with other studies in the literature that find benefit from the use of a PHR (Ball, Smith, & Bakalar, 2007; Endsley, Kibbe, Linares, & Colorafi, 2006; Ross & Lin, 2003; Tang & Lansky, 2005).

Personal health record systems are not the only health information systems in use that have potential benefits for users. A similar study looked at emerging practices of electronic medical records, specifically the VA's clinical electronic record system, used in the patient-provider clinical visit (Veinot, Zheng, Lowery, Souden, & Keith, 2010). The researchers performed 64 observations of clinical consultations at two VA facilities. The fieldwork revealed four specific stages that providers go through when using the clinical electronic record. They conclude that the affordances of CPRS allows practices that were not possible prior to using an EHR in the clinical consultation. While the Veinot study looked at a clinical record system and not a patient facing record system like MHV, it is the assumption of this dissertation work that personal health records and health information management practices include work that is distributed, and that distributed practices have different properties and require different technological functionality to support them than personal individualistic practices.

1.3 Overview

The following sections provide a brief overview of the rest of the dissertation. The literature review is summarized, a pilot study is presented, the methods section is previewed, and expected contributions are discussed. These sections are reviewed to briefly survey the ideas contained within this dissertation research. The concepts I evoke in these sections are discussed in greater detail in the appropriate chapters.

1.3.1 Literature review

The context of this research is explored using the academic literature of personal health information management and personal health record research. This dissertation argues that the phenomenon of the computerization of patient work is best conceptualized through the perspectives of sociotechnical assemblage and distributed cognition, both of which are practice based perspectives. This creates a productive framework to reconfigure the phenomena from an individual activity to a distributed cognitive network that invokes different configurations of social and technical actors. The strategy to carry this research forward is to construct a qualitative study of veterans that use the My HealtheVet personal health record and are receiving treatment at a Department of Veterans Affairs medical facility in the Syracuse region or at surrounding community based outpatient centers.

1.3.2 Pilot study

A pilot study was conducted using semi-structured interviews with VA employees at multiple VA facilities across the country. The goals of this exploratory study was to explore the practicality of the proposed methods, understand preliminary patient information management techniques that are visible to healthcare professionals, and to test the feasibility of conducting

the study within the VA organization. Phone interviews were conducted (n=15) with a diverse set of participants across the VA, including: directors, managers, education coordinators, librarians, MHV coordinators, project managers, volunteers, and health providers. The questions focused on the information needs of Veterans, strategies for management they have observed Veterans using, and personal health information work that is carried out within the VA medical center. The findings from this pilot study are promising for further investigation of this phenomenon and to the development of patient-centered care. Notable findings include the use and continued importance of paper documents despite the availability of health information technology, and the differing assumptions made by patients and medical providers when using My HealtheVet. These and additional findings are discussed as part of the third chapter which details the methodology and research design of this dissertation.

1.3.3 Methods

This study does not seek to unobtrusively manipulate participant behavior or administer usability tests of personal health record technology. Nor does this research seek opinions or satisfaction with health record technologies. The study considers context a crucial part of the phenomenon of inquiry. The approach for this research is a practice-based perspective, which acknowledges that the researcher can study interactions with technologies through observation of those interactions and through interviews with those participants about how they use technology. Patients navigate their information needs and management strategies, their repeated practices make up the phenomenon of health information management. Given this, the research design used for this study is an explanatory single case study design (Baxter & Jack, 2008; Yin, 2014b). It is the goal of this research to clearly understand the phenomenon of

patient work in a contemporary context of health information technology, distributed health information management tasks, and the role of artifacts. Unit of analysis is an important factor to consider when utilizing case study research designs. The unit of analysis is further discussed in the conceptual and theoretical framework section of the literature review in chapter two. In brief, the presented framework conceptualizes the patient not as a single participant but as a network or web of relations and associations among technical and social actors that rely on one another to perform a task or goal (Hollan, Hutchins, & Kirsh, 2000). Theoretical sampling was utilized to select veteran patients currently managing their own health information and enrolled in the VA personal health record, My HealtheVet. The properties and traits used for theoretical sampling are driven by concepts derived from the literature and the pilot study discussed in chapter three methods (Corbin & Strauss, 2008a). An important trait selected for in each case are various types of use of the My HealtheVet personal health record. Another factor I select for when recruiting veterans is diversity in age cohort, gender, and variety of consumer technology use. By selecting different participants from a shared context or similar setting, mutual agreements and understandings between and among participants can be uncovered from the research. This is known as intersubjectivity and helps to triangulate data sources and generalize concepts (Walsham, 2006).

Participants were recruited through use of a recruitment data spreadsheet. This was obtained through an IRB review and data request at the local VA medical center. The recruitment spreadsheet identified veterans with MHV accounts in the surrounding area. It also contained contact information for recruitment through phone calls. In tandem with veteran patient recruitment is the recruitment of primary care providers (PCPs). A presentation of this

research proposal was provided to PCPs at the all clinical staff weekly meeting at the VA medical center. Following the presentation, providers were contacted through an email that solicited participation. Once participants were recruited into the study, data was collected through observations, field notes, surveys, and semi-structured interviews.

Data analysis is intended to remain flexible and iterative as data is collected. Data were analyzed and managed using the computer assisted qualitative data analysis software Atlas ti. The plan for analysis of all textual data was a two cycle qualitative coding technique. After attribute coding and initial data exploration, the first cycle is process coding. This first coding cycle entails looking for actions and understanding the process of health information practices and personal health record use. The second cycle of coding was a meta-analysis of the first cycle codes. These codes are reanalyzed and categorized, through grouping the processes together patterns emerge that point to the conceptual assemblage framework of interest to this study (Saldana, 2013). These cycles are iterative and continue until data saturation was reached. That is, the occurrence that no new categories can be created from the data collected, and that adding further data would not substantively change the analysis codebook (Corbin & Strauss, 2008a).

In conjunction with this two-cycle computer assisted qualitative data analysis method is the continued development and refinement of analytical memo writing and development of analytical cognitive maps. I kept the practice of analytical memo writing throughout the research process, starting with initial fieldwork and immediately after every interview, through each coding cycle, and as I wrote up the findings. Similarly, the analytical cognitive maps are a data visualization technique I used to understand the social and technical actors, practices, and

artifacts enrolled in each case. These maps, similar to a concept map or network map, are developed directly after each interview and refined over the course of data analysis and memo writing to ensure their accuracy and fidelity in communicating the details of each case.

1.3.4 Contributions

This research makes contributions to several communities that are interested in empirical, conceptual, pragmatic, and technical outputs from this research. Each contribution is discussed below. A table that summarizes each contribution, intended audience, and the type of contribution can be found at the end of this section.

The current healthcare system emphasizes the patient's involvement in care, meaningful use of technology, and positive patient-provider relationships. This has created a need for further study of the work patients practice outside of the clinical office visit, particularly as this health management work becomes embedded and entangled in technological systems like PHRs and mobile platforms. Much of the work patients do to support their health and educate themselves is invisible to health providers (Piras & Zanutto, 2010; Strauss et al., 1982; Unruh & Pratt, 2008b). This research enterprise seeks to expose contemporary configurations of patient work and to communicate awareness of patient work practices to medical professionals. One of the contributions this research makes is pragmatic to the community of practicing medical clinicians. Providing clinicians with strategies to connect with patients using personal health records and also informing clinicians about typical patient routine post appointment is a valuable way to align clinical appointment information distribution outputs with current patient health information management practices.

The community of information system implementers and software developers will benefit from a clear depiction of distributed health information management practices detailed by this research. Providing these communities with insight into social and technical functions such as how health information flows between paper documents and digital platforms such as email and Google Docs. These depictions have implications for the adoption, implementation, and use of patient-facing systems. As well as understanding the broader scope of important tools and practices may inform the development of tools and other features important to patient-facing health information systems. This research will also give software stakeholders an understanding of how the tools and technologies they develop impact the practices of patients and other social actors.

Another audience that will benefit from this research are the organizations and stakeholders that focus on health services research, quality of care and patient satisfaction. The overarching research questions provide practical findings that are important when promoting, understanding, and communicating findings concerning best practices or problems with the complexity of patient-facing technology and meaningful use practices.

A practical contribution will be made for patients and health consumers who must manage, use, and understand health information. One of the aims of this study is to create an empirically informed set of guidelines and procedures for patients. Content analysis of in depth interviews will identify useful ideas and strategies. Relevant findings that inform strategies of patient information management and how to effectively communicate with healthcare provider teams using technology will be made available publically for patients to access as a document in the form of either a brochure or set of PowerPoint slides. Additionally, research participants

may benefit from discussion during interviews about their health information management work practices. The interviews allow participants to reflect on and improve the strategies they employ to make decisions in their healthcare.

One of the main conceptual and empirical contributions of this dissertation is the practice of and current understanding of patient-centered care, especially when mediated with personal health records. I apply an understanding of the complex situated practices found throughout distributed health information management practices to PCC. The importance of and need for future research on using technology to foster PCC is clear in the literature (Ahern et al., 2011; Finkelstein et al., 2012; Jayadevappa & Chhatre, 2011; Mardon, 2013), and this research can address the need by understanding what patient-centered values emerge out of distributed health information management that align with the idea of patient-centered care. Through a study of patient engagement practices while working on health information management tasks, associated practices can be understood as a set of guidelines for developing patient-facing health information systems that support patient practices. An understanding of how practices manifest, and other important values that relate to the tenants of patient-centered care, will benefit the organizational practice of patient-centered care and connect to the clinical implications previously discussed.

Because this study is set in the VA healthcare system, findings are relevant to VA stakeholders that inform policy focused on patient-facing technology use and distributed patient health information management. Also, because the VA is a customer service based healthcare organization, this research may be applicable to similar organizations that operate

on a customer service based model of care as well as organizations that have personal health records available for patient use.

Findings from this dissertation are applicable to implementers and developers of patient-facing health information systems. Specifically, to inform the development of health information exchange architectures. There is a need to further understand the data patients generate, use, and need through different formats across multiple systems (Ancker, Miller, Patel, & Kaushal, 2013). This study contributes to informing health information exchange decisions through providing detailed qualitative data informed by observations of the practice of health information management across multiple systems and social actors, and the provenance of the information they manage. This benefits health information exchange design decisions through a clear understanding of patient workflows and provides empirical evidence to inform value added features. Data informed by empirical research can aid designers in developing realistic patient personal health record and information management use cases (Kernisan, 2013).

Table 2: Summary of contributions

Contribution Type	Audience for Contribution	Contribution Description
Conceptual, empirical	Academics, health service researchers, health information system stakeholders	Advance concept of patient-centered care supported by technology.
Pragmatic, empirical	Healthcare providers, administrators, policymakers	Informing use and practice of patient focused health information communication technologies at the VA and other organizations that have a customer service based patient-centered model of care.
Pragmatic	Practicing medical clinicians	Inform clinical practice by educating healthcare providers on patient-centered

		care strategies using a personal health record.
Empirical	Information system implementers and developers	Clear depiction of a patients distributed health information management practices to understand use cases.
Technical	Implementers, health information system stakeholders	Informing health information exchange architectures.
Pragmatic, document	Patients, health consumers	Documentation on useful strategies and factors to consider when health consumers must manage health information of a family member or themselves.
Empirical	Health service researchers, software developers	Public data set to help model patient use cases and complex routines.

Chapter Two

2. Literature Review

Medicine and healthcare services are becoming more individualized and patient centered (Robson & Baek, 2009). The industry of healthcare is and always has been an information intensive activity for all parties involved (Hersh, 2002). Yet, there is a deficiency in both the perspective and understanding of how patients work with technology, other social actors, objects, and innate patient expertise (Civan, McDonald, Unruh, & Pratt, 2009; Fitzpatrick & Ellingsen, 2012) with regard to the recovery and maintenance of their health.

My objective in this literature review is to start with the theoretical and conceptual base that frames the study. Then, I review the contextual literature to situate the phenomena. Specifically, my review foregrounds a conceptual perspective of complex sociotechnical interactions and the distributed processes and systems of systems that permeate the experience of healthcare consumers and patients. I posit that sociotechnical assemblage and distributed cognition frameworks are appropriate intellectual tools for this work (Reddy, Bardram, & Gorman, 2010). This theoretical lens is useful for understanding patient health information management because it emphasizes that social interactions consist of repeated practices and are made up of people, processes, practices, tools, objects, and technologies and that these elements facilitate other practices, cognition, and ways of knowing (Feldman & Orlikowski, 2011). This is in contrast to a perspective on health and patient work that that only happens in a hospital, during a clinical appointment, or during specific parts of the day.

After the conceptual framework is provided, I explore the context of the phenomenon through the relevant literature of personal health information management (PHIM) and personal health record (PHR) research. These two literatures are important for the study of consumer health information management because both PHR and PHIM research findings must rely on each other in order to progress the area of research, and to address the challenges and requirements of a healthcare system that increasingly demands consumer engagement, involvement, participation, and technological proficiency.

Just like the everyday practice of personal information management, the practice of personal health information management is, at its core, a process of sense making (Jones, 2008). PHIM is one of many significant tasks patients face outside of the clinical encounter. I frame personal health records as technological artifacts to address the patient's need for information. At the conclusion of this literature review, I pose four research questions. These questions are motivated by the identified gaps in the surveyed literature and an intention to contribute toward the design of patient-facing health information systems. Also, the research questions are posed to advance a framework of distributed health information management.

2.1 Theoretical perspective: Health information management as a distributed cognition assemblage

This literature review casts a wide net into several intellectual communities that are investigating the use of technology for health. These communities are found in medical informatics, consumer informatics, human computer interaction, computer supported cooperative work (CSCW) and sociotechnical scholarship. The community of CSCW scholars has long been interested in the use of computer technologies used in social interactions to support work. It is a multi-disciplinary community connecting to areas of research in sociology,

anthropology, informatics, artificial intelligence, cognitive science, and social psychology (Schmidt & Bannon, 1992; Stahl, 2011). There are many perspectives that fit within the sociotechnical community including the Tavistock tradition, Nordic and Scandic approaches, science and technology studies, social shaping and social construction of technology (Sawyer & Jarrahi, 2013). What unites all these perspectives is their interest in the mutual constitution of the social and the technical. Rather than pick a single perspective from one of these communities as a focal point for the literature review I instead look at how the social and technical have been approached in the healthcare and health services literature to better understand how technology and social interaction are understood in the phenomenon of inquiry.

The application of CSCW ideas and sociotechnical thinking into the domain of information communication technologies used in healthcare contexts is not new. In fact, theories of cognition and sociotechnical perspectives are important to the continued development of the healthcare sector and yield useful insight unique from other approaches (Berg, 1999; Chisholm & Ziegunfuss, 1986; Munson, Cavusoglu, Frisch, & Fels, 2013; Stahl, 2011). Findings from sociotechnical approaches produce new interpretations of problems, advance policy, inform design of information technologies, and generate new areas of inquiry. An example of a sociotechnical issue in healthcare, closely related to the research at hand, is the clinical electronic medical record. The clinical record is a collaborative tool linking together different medical professionals and staff, and it introduces complexities such as awareness states, workflow differences, domains of individual activity and behavior resulting from individual activity with a system (Pratt, Reddy, McDonald, Tarczy-Hornoch, & Gennari, 2004).

One article from Fitzpatrick and Ellingsen (2012) systematically analyzed 25 years' worth of CSCW research and outlines a rich set of accounts of the collaborative activities and work routines of clinical workers, primarily focusing on doctors and nurses (Fitzpatrick & Ellingsen, 2012).

Lacking in this 25 year summary is the patient perspective, a voice that is being investigated only recently (Reddy et al., 2010). Much of the CSCW literature includes workplace studies, which amount to detailing a single environment or setting. This is to say that much has been learned about information communication technologies in clinical contexts and how medical work gets done. These studies have made contributions to the design and development of supporting clinical work flows and processes and how organizational information systems are implemented (Bardram & Doryab, 2011; Johansen, Scholl, Hasvold, Ellingsen, & Bellika, 2008; Reddy, Dourish, & Pratt, 2001, 2006). Yet, more work is needed to understand patient practices as the patient perspective on the use of technical systems has been far more under researched compared to the clinical context of health information systems.

While CSCW has investigated many clinical and medical information systems, it is important to understand some differences between the inherent qualities of discretionary and mandated information communication technologies, as the concept of discretionary and mandated software is essential to understand one of the major differences between clinical systems and patient facing health information systems. The use of information communication technologies in healthcare organizations and clinics are mandated for healthcare professionals to use. This means that doctors, nurses, and other healthcare staff do not get a decision in choosing to use one information system over another, unlike patients who may choose among

many different options of consumer facing information systems. These clinical systems are supported by IT departments, installed by third parties, and undergo consideration by stakeholders before the software and technology is adopted. Patients' and other health consumers' use of software and information communication technology is discretionary (Grudin & Palen, 1995). The key difference between mandatory and discretionary is that the choice of which software and information systems to use are not left to the users of those systems. Patients' use of technology is discretionary. Because patients can choose the configuration of information communication technologies, they face a greater cognitive burden in making a decision, learning a system, and adapting that technology, not just to a work context but to their personal lives (Agarwal, Grandison, Johnson, & Kiernan, 2007; Agarwal & Angst, 2004). Although in a system like the VA, the personal health record is mandated in that patients do not have a choice among several PHRs to adopt. However, the platforms and consumer technologies patients choose to adopt are discretionary. This includes discretionary technologies like which internet browser to choose, or which operating system, brand of desktop or laptop computer, and others decisions about software configurations and alternatives. Many of these decisions have an impact on the use of the PHR like the type of browser or form factor of the device used to access the internet, such as a phone or laptop.

Discretionary and mandated uses of technology are important to consider because the different ways information systems are used necessitate distinct theoretical perspectives. We must be mindful of the discretionary nature of patients' interactions with technologies for their healthcare. Health consumers have the possibility of multiple technologies that may be used

conjointly, whereas healthcare providers are mandated to use what their hospital or organization has implemented--and only those information communication technologies.

Up to this point I have discussed the sociotechnical position in research. How sociotechnical studies require a keen analytical eye on both the system, in this case the PHR, and the people that use the technical system, in this case veterans, friends, and family members with PHR access. However, this sociotechnical approach is just that, an approach. Not a theory or specific set of analytical tools. However, I discuss this sociotechnical approach briefly in the literature before I review the theory literature because this approach greatly influences how I perform fieldwork, conduct interviews, and analyze the data.

Given this history of how technology in health contexts has been studied, the lack of inquiry into the patient, and markedly different concepts underpinning the use of technology by different users, there is opportunity for using new perspectives to look at patient work. Concepts of distributed cognition as developed by Hutchins (1995a) and sociotechnical assemblages as conceptualized by DeLanda's perspective derived from Deleuze's original work (DeLanda, 2006) can be used as lenses for studying information management that is practice based, distributed among objects and social actors, idiosyncratic, and mediated through technology. I now move on to reviewing the literature of a theory of assemblages followed by distributed cognition theory.

2.1.1 Assemblages

I posit the argument that the use of the biopsychosocial model in healthcare functions as a way to refocus the analytical eye of medical professionals on novel areas of pathology and treatment. This is a useful analogue to the application of sociotechnical assemblages to patient work and interaction with technology. The biopsychosocial model evolved out of the need to understand other important contextual factors of complex medical conditions. Similarly, guided by assemblage, perspectives can provoke similar reactions to understanding the work of patients and the development of resources to support patients. The findings of research informed by the perspective I construct here will address calls for research and deficiencies in perspective currently in personal health information management and personal health record research.

To understand the function of *context* in healthcare, it is important to understand the different qualities of two specific medical models within which the ideology of healthcare operates. These models are important to understand because they are indicative of change occurring in the healthcare sector as discussed in the first chapter. Furthermore, the biopsychosocial model is one of the underpinnings of the patient-centered care movement. To discuss PCC is to concurrently evoke a corresponding and underlying medical care delivery model such as biopsychosocial. The biomedical model of medicine posits that every disease and illness can be explained by a deviation from a normal, stable state of health or vitality. These deviations are caused by purely biological phenomena, such as a virus, developmental abnormality, or injury (Engel, 1977). The biopsychosocial model is embraced as a holistic approach to the complexity of illness. A biopsychosocial perspective of medicine has cued many

clinicians onto the social factors which influence the recovery and maintenance of mental health (Cohen, 2004; De Silva, McKenzie, Harpham, & Huttly, 2005; Kawachi & Berkman, 2001). Proponents of the model stress the need to consider not only biological factors, but social factors (economic, cultural, environmental) and psychological factors (thoughts, emotions, behaviors), hence the name biopsychosocial (Santrock, 2007). The point of mentioning these two specific and popular models, of the many ideologies of medicine, is not to detail and debate their merits or validity (Ghaemi, 2009). It is to establish a parallel between the use of one perspective (biomedical), which is very specific and focused, with that of one of the challenging perspectives (biopsychosocial) that helps to identify additional relevant contextual factors, has contributed to the legitimacy of interdisciplinary healthcare fields, and advanced medical theory (Havelka, Lucanin, & Lucanin, 2009).

To assist in understanding the problem of shifting perspective in ways that may not otherwise be conceived I unpack the work of a scholar that tries to bridge communities of social science research and public health. Duff writes about the empirical procedures (i.e. physical processes and tools) required for drug use and the role of space (i.e. where the person lives or uses drugs) in drug abuse, the role of bodies (a drug user's body and other bodies involved during use), and effects which become part of the drug assemblage. The use of a gun, a stolen car, outrunning the cops, and a robbery would all be enrolled in an assemblage that describes a person stealing property in order to finance a drug addiction. Or tracing the history of understanding mental health with the goal to develop a model that requires the consideration and interrogation of social, political, and psychological factors in addition to the classic medical understanding of mental illness. Known as the biopsychosocial model (Gilbar, 1996), that has

typically been used to educate social workers and other healthcare professionals. The importance of Duff's work in this area is that it introduces new ways of thinking about a problem, in this case drug addiction, and as a result new ways of treating that problem can be possible. Also, that this perspective can identify components to an empirical case that were previously through unrelated, in essence this is a perspective of generating connections and relationships. The crux of Duff's work is to look at a grand view of health through the assemblage perspective that attends to the relationships between transitions of the body and emotions in the role of recovery and well-being. Similar to Paoli and Kerr's understanding that assemblages use multiple perspectives and use them to see the greater whole, Duff uses social science ethnography and public health approaches to attain grander views of social problems like drug addiction.

The concept of an assemblage is primarily associated with Deleuze's work (Smith & Protevi, 2012) as a collection of heterogeneous elements, objects, or concepts that become related with one another. These multiple components mean assemblages are never composed of entirely one thing, but contain multiple relevant parts, which can be technologies, communication, emotions, people, physical objects, social structures, and so on. For example, a university can be broadly interpreted as an assemblage. There are material components to a university: the buildings, parking spaces, bus routes, and the physical campus. There are technological components: computer labs, university wide wireless Internet access, a finance system or administrative personnel system, course management software, an information technology and help desk department, the laptops and other technological devices that students use on campus. Then there are the human components of a university including

undergraduate students, graduate students, university and departmental staff, faculty of various ranks and tenure, janitors, physical plant staff, and different levels of administrators. Each of these components: the human, the material, and the technological have their own connections and rules and structure for how they interact and create actions and practices. Factors that territorialize or bring this assemblage and the interactions between people together are the policies of the university, its mission, contracts and compensation that make a university a place where faculty, staff, and administrators want to work. Other factors that bring the assemblage components together are expressions of identity and connections to the community, such as sports and collegial events. Deterritorializing factors which disrupt and threaten to dismantle the stability of an assemblage are factors such as financial bankruptcy, scandals, or events that call for change or closing of a department, faculty and staff that have no confidence in university policies or administration, or any major event or change that threatens the identity and durability of a university. This example paints the assemblage perspective in broad strokes, but is meant to convey the general idea of the concept. This perspective facilitates a network or system like unit of analysis and suggests studying one group of the university insufficient if we want to know more about the entire system and its interactions. This perspective conveys the idea that there are components that have their own characteristics and features which all come into being in a coordinated manner to allow actions and practices to happen. That can be rephrased to say in order for an event to occur, for example management of a health condition, what assortment of things (tools, objects, people, practices, technologies) become active to allow the event or task to occur.

Paoli and Kerr (2009) use assemblages to frame their study of a massively multiplayer online roleplaying game (MMORPG) toward the goal of a sociotechnical description of cheating in the game (Paoli & Kerr, 2009). They describe the software programs, software licenses, policies, social engineering, gameplay techniques, automations, code, and other player characters. While all of the components of the cheating assemblage function individually as components to different functions and systems, when these factors enter into a relationship (are territorialized) together, they assemble into a meaningful whole in which in-game cheating is enacted. The contribution of the authors work is creating a new approach to address cheating in MMORPGs. It also offers an alternative explanation to existing literature on cheating when compared to research through computer science and technical literature that only describes technical solutions to cheating. It also presents an alternative to media studies literature that describes cheating as the result of player actions and proof of player power.

We see from this example, and the way in which assemblages encourage the investigator to think, that there is the tendency for assemblages to bridge multiple approaches of inquiry. The authors note that both computer science and media studies have different approaches on the study of cheating. Yet, with assemblages as a framework the code and licensing become just as important as the player's actions, and relations between those important factors become apparent. This is an important idea to the research proposed here, the joining of different perspectives that tend to focus on specific components of the assemblage and bringing those different components together.

Assemblages are encapsulated contexts, tools, and possible actions, they are defined by the use of social and technological actors. *Assemblages* can be thought of as being personal,

whereas *information systems* are institutional and communal. This connects with the previous discussion that PHRs are discretionary software, meaning the choices to use those discretionary software and systems are personal choices requiring volition. Assemblages are also not characterized by a set of functions or features that constitute an assemblage, but by practice and enacted practices (Sawyer et al., 2014).

For all of the detail Duff (2014) brings to the study of health and wellness using assemblage theory, he does not thoroughly consider the role of technology or implicate it in any aspects of the exploration of health assemblages. Especially given many of the directives and mandates from the Institute of Medicine, the White House, and NIH, among others, on the importance of technology for patients and healthcare consumers (Bush, 2004; HealthyPeople2020, 2012; Medicine, 2001). This reveals opportunity in expanding on the development of an assemblage framework in the context of certain patient practices, especially given the need to understand context and situated practices in the enactment of personal health information management (Agarwal, 2009) and the lack of efficacy in PHRs to change behavior (Saparova, 2012). Assemblage thinking also provides alternative ways to address the main problem in PHR research: that adoption and usability issues stem from PHRs being developed without understanding of the broader patient experience (Liu, Shih, & Hayes, 2011). Understanding usability and design of PHRs will only address part of the problem; the future of patient interaction with technology for the benefit of health and wellness relies on understanding patient information management in tandem with patient sociotechnical interactions.

Assemblages appear a strong fit for the theoretical base of this work: a perspective on patient interaction with technology. However, it is important to be critical of assemblages and know the weak points of the concept. Neither the conceptualizations of assemblages by Deleuze (Smith & Protevi, 2012) or DeLanda (DeLanda, 2006) are entirely clear or analytically specific. While an assemblage is a collection of heterogeneous elements that come into being and connect themselves with one another, there is little in the way of consistency and coherence in how these assemblages arise. Deleuze has specified that these properties of consistency and coherence, too, emerge in an assemblage (Deleuze & Guattari, 1987). However, there is the sense that assemblages can become unwieldy and contain complexities that prevent in-depth analysis by encouraging an endless chain of associations. In an attempt to add more analytical clarity to assemblage thinking and address the problem of clarity, DeLanda argues for a concepts of *territorialization* and *detrterritorialization* (DeLanda, 2006), where territorialization is a process that stabilizes an assemblage, and vice versa, detrterritorialization destabilizes the assemblage.

The strategy I present to provide theoretical support for unwieldy associations and connections is to weave the assemblage concept with distributed cognition (discussed later in this chapter) to scope a network appropriately while providing additional analytical and descriptive precision. These two concepts are mutually beneficial because they do not attempt to privilege one unit of analysis over another. There are assemblages at the organizational level and at the individual level, from macro to micro; they are multi-scaled concept that does not function only at a particular unit of analysis. It can function at the personal level, societal level, and all scales in between (Little, 1990).

The reason that assemblages are provocative to generating new perspectives and ways of knowing is that Deleuze conceptualized the perspective as a reconceptualization of ontology (Srnicek, 2007), and Deleuze conceptualized assemblage as an alternative or replacement to understanding the concept of behavior. Given this, it is beyond the scope of this work to fully unpack and wholly commit to the entirety of an assemblage ontology. The function of assemblage thinking in this work is to assist in the investigation and interpretation of people who interact with information communication technologies, other people, and physical objects and artifacts toward the goal of understanding how veterans use a personal health record and how information management practices support healthcare work. The concept will shed new light on patients' personal practices of health information management and use of personal health records for the benefit of their health.

An attractive component of considering patient work as an assemblage is the modular nature of the perspective in which parts of it can be extracted from one set of users and adapted to other users in a similar context. While assemblages by their very nature are personal and individualized, there are still portions of an assemblage that can be identified and described that are relevant to people in similar contexts. The relations of these parts are contingent, but not necessary. A kitchen can be viewed as an assemblage. There are places for knives, pots, pans, spices, and all the other accoutrements that are commonly found in a kitchen. However, the locations of items within the kitchen's assemblage may be different from one to the next. The qualities and quantities of items within the kitchen assemblage may differ as well. The point is that a person can be taken outside of their familiarly constructed kitchen assemblage, be placed in another's kitchen and, generally, make their way around and use it.

2.1.2 Distributed cognition

The unit of analysis cannot be placed on any one person. The challenge is how to draw boundaries when in the field, decide when to include a node in the network, and how to determine when something is not relevant in the unit of analysis. The logic of how this study goes about determining this network is through the actions and practices of work relating to the context of patients in a technologically-enabled healthcare system. This issue, in part, is where distributed cognition plays an important role for scoping the boundaries of an assemblage. Distributed cognition helps identify an assemblage by going where the “traffic” of actions and practices are (Hollan et al., 2000), and by casting an analytical eye on events where patients rely on distributed resources when working with health information. Hollan et al. (2000) explain the strategy of “going where the traffic is,” which is a way to scope the connections of distributed actors and practices. It simply means to follow what people do and trace connections through their practices. A patient who writes medical information on a dry erase board in their office is a possibility if the patient has the available tools (whiteboard and dry erase marker) Yet, if they never use the tools for that particular practice of writing health information on the whiteboard, it would not be included in the account. Excluding artifacts and potential practices if they aren’t actualized is to put boundaries around the objects of analysis to help the researcher scope the distributed artifacts, actors, and practices into a manageable whole as they assemble themselves. Distributed cognition is important for identifying these connections between people, objects, tools, technologies, and practices. Through distributed cognition, the emphasis is on the functional system in use rather than on every possible relationship.

Now, I turn to the concept of distributed cognition (dcog) and its use for adding analytical precision to assemblage thinking to develop the theoretical base of this research, which I have eluded to part of the function of dcog in this research slightly already. The single driving force of this perspective is articulated through asking the question “how do people go about using what they know to do what they do” (Hollan et al., 2000). The premise is that cognition is a distributed process that uses both internal and external processes. An internal process means that cognition happens in the mind, people think about concepts and ideas, speak to themselves in their own mind, have memories and experiences all internal to a person’s thoughts. This internal process is in line with the classic view of cognitive science (Newell & Simon, 1972). However, the radical shift that distributed cognition provides in this area of study is that cognition is also external, and the distributed cognitive approach focuses on how cognition happens external to the mind, looking outward toward the environment.

External cognition is about context and interaction between situated practices that emerge out of the improvisational nature of human activity (Suchman, 1985). The ways in which external cognition is mediated is through what Norman (1991) calls cognitive artifacts. These artifacts are objects and artifacts that aid the human mind. Humans have the ability to imprint information on mundane objects and artifacts like books, pictures, medication bottles, staplers, lamps, tables, remote controls, literally any artifact that exist outside of the mind. Most notably the field of human computer interaction has pioneered the study of humans’ interaction with the ultimate cognitive artifact: the computer.

The issue of perspective that I discuss at length during the assemblage section of this literature review is applicable to the distributed cognition perspective as well. Distributed

cognition can narrowly focus on artifacts like interfaces and human task interaction (Norman, 1991). The research presented here is not interested in issues like interface or time-to-task interactions, but in understanding the use of items as artifacts for health information management in their given context. The exciting part of distributed cognition is its connection to assemblages that I am pioneering with this research. Also, that thinking about objects as supporting cognition can reveal useful properties of design and help to understand what artifacts are important for patients managing health information. The management of medication and use of medication bottles is a perfect example of studying cognitive artifacts in healthcare. Medication related practices involve many cognitive artifacts that facilitate clinician-patient communication outside of clinical appointments, help engage patients in medication management, and were easy for the patient to use (Mickelson, Willis, & Holden, 2015).

Like assemblage perspectives, dcog is not committed to a fixed unit of analysis but allows for a variable unit of analysis. It falls in line with other perspectives and approaches to sociotechnical systems that construct the unit of analysis as a system rather than as a network of simple associations (Kling, McKim, & King, 2003; Meyer, 2006). As classical PHIM research has focused on the patient's organizational schema (Pratt, Unruh, Civan, & Skeels, 2006), distributed cognition theory highlights additional actors and settings where health information processing is happening.

Scholarship closely related to the current proposed research has not explicitly used distributed cognition theory but can be interpreted as having a distributed cognition perspective. Previous research found that patients construct networks of objects to aid in tasks,

such as taking medication, remembering a treatment regimen, or managing medical information (Aarhus & Ballegaard, 2010; Palen & Aaløkke, 2006; Piras & Zanutto, 2010). These networked objects, i.e. medicine bottles, pill boxes, prescription renewal reminders, and other related physical health information are placed in physical spaces and places around the home that trigger the cognition of the patient, for example placing a pill box bedside is a reminder to always take a medication before bed. To clarify, I call these *networked objects*, meaning they are related or connected by a set of practices, not to mean any sort of technological networking connects these objects together. What the findings in those articles demonstrate is how cognitive properties are embedded and exist in the environment around the patient. Patients use objects, spaces, places, and practices in order to trigger cognition, ideally at the right time in the right place. These studies are framed by concepts like boundary objects, work practices, and a general perspective of human factors or computer supported cooperative work. The studies cited above are concerned with understanding specific environments (e.g the home) and are entirely centered on the patient and the physical objects with which patients interact. The aim of this type of research is to inform the design of technologies like a personal health record, or the functionality of a medically assisted home. These types of studies are important, both to grow the literature of understanding patients' needs and to inform the design of better healthcare technologies.

However, few studies examine health practices in this way, or they only portray part of the picture. They are also limited in sample population diversity--specifically age and health condition. The previously noted studies along with others (Andersen, 2010; Moll, 2010) look at health information technology design focused on patients and adopt a participatory design

perspective. The use of participatory design requires close work with the patient (or subject of study) using methods such as focus groups and in depth interviews or task analysis with the goal of the researcher understanding the needs of the patient and how to design for those needs (Andersen, 2010). The intended use of participatory design is to empower end users in the workplace by making worker knowledge and skills part of the design process (Ehn, 2008). With the prevalence of patients who use the Internet to seek health information (Fox, 2008), the use of social media for patient recovery and health maintenance (Frost & Messagil, 2008), and mobile health technologies becoming expected norms in healthcare (Klasnja & Pratt, 2012), it is an important time to better understand these distributed information processing assemblages, and that new technologies might not only benefit from participatory design, but from cognitive design.

Understanding the cognitive components of patient information management, such as the relevant cognitive artifacts to health information management, promises to have important findings with respect to digital technologies and interactions with information communication technologies. Especially detailing the cognitive components of people relevant to the patient and the role of personal health record use.

Hutchins' (1995b) investigation of how airline pilots interact with cockpit controls and systems informed the design of aircraft cockpits so that instrument design supported the cognitive heuristics that more experienced airline pilots develop (Hutchins, 1995b). This comes from Hutchins' finding that analogue airspeed gauges were modified and used in a specific way that was meaningful to experienced aircraft pilots. The idea is that more experienced pilots, or indeed any skill that a person becomes proficient at, have developed techniques and practices

which use the environment around them to support and augment cognition in order to increase performance. However, Hutchins (1995b) noted that when these airspeed gauges became digital they lost much of the cognitive support they were used for (Hollan et al., 2000). This finding shows that translating the properties of a digital artifact to a physical artifact or vice versa can have a detrimental impact to the user and become inefficient. In other words, the materiality of objects and technologies with which people interact matter, especially when cognition is concerned.

Hutchins' initial development of dcog took place in a context that did not involve digital technologies or information communication systems. He ethnographically studied the crew of a naval ship as they set course to dock with the harbor. The findings detail the complex coordinating of different crew members, media, and artifacts as a highly orchestrated activity with the purpose of ensuring the ship is on course (Hutchins, 1995a). It is important to note that while dcog is not a perspective that originated from the study of digital technologies and software, it has found useful application in human computer interaction research and most certainly has the ability to uncover findings of not only physical objects and artifacts but digital tools and technologies as well (Hollan et al., 2000). In fact, dcog has many applications in sociotechnical problems and it may be best suited to sort out interactions involving software and digital technologies.

Distributed cognition, like many theoretical frameworks, is not a perspective that is intended to be easily picked up off a shelf and applied to a technical design problem (Rogers, 2004). Given the commitments of a distributed cognition perspective, it is reasonable to conclude that the assemblages of patient sense making work, coordinating with other people,

and use of a personal health record is an appropriate domain in which to use dcog. As shown with previous literature, and will be further supported in the next section on context, cognition is one of the core operating factors of health information management practices. It is logical to follow that building a framework to study distributed health information management practices would involve, or can be interpreted by, looking at how cognition is supported.

The goal of this dissertation is to use assemblage theory and distributed cognition in concert to form a perspective that encapsulates the patient's sense making assemblage. This will include the technologies, people, objects, work practices and information that assemble around the patient and serve as cognitive tools. An example of both a potential patient assemblage and a patient distributed cognitive network are illustrated in the figure below.

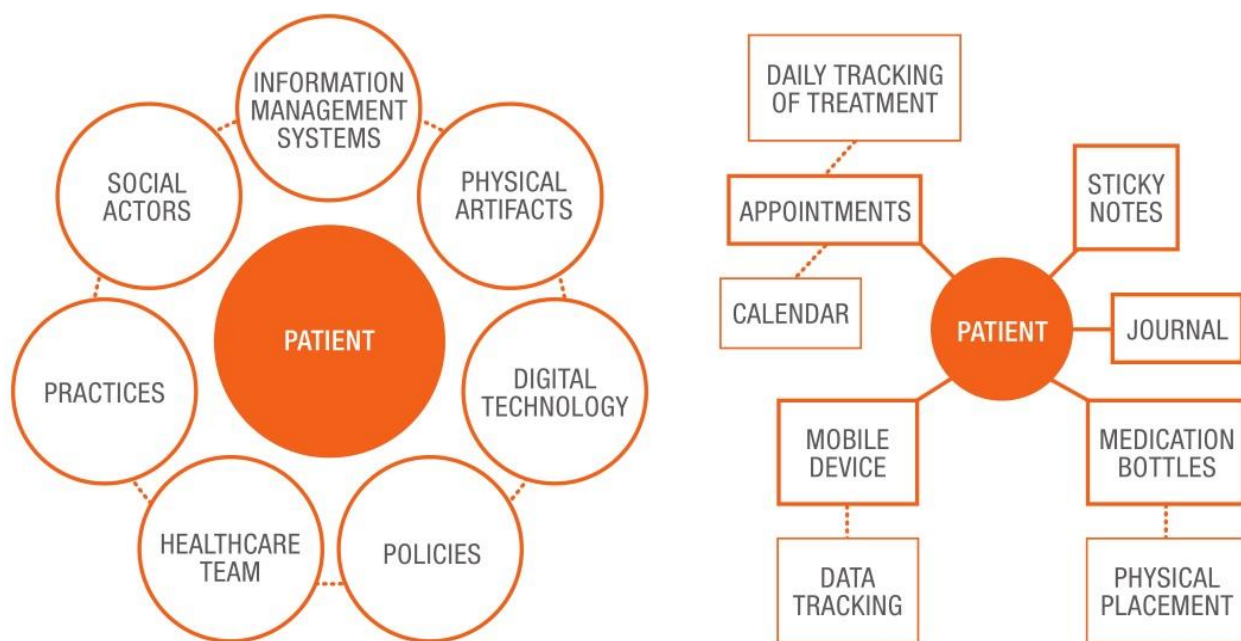


Figure 1 Examples of patient health information assemblage (left) and patient cognition map (right).

The above figure is greatly simplified to help portray the conceptual framework I construct. It is informed by some of the findings known from the literature concerning practices in which patients engage when managing health information. The diagram on the left shows entities that become assembled around patients when they interact with the healthcare system. As illustrated, this can include a series of policies, practices, technologies, healthcare workers, family members, and objects. Interwoven into the experience of the patient managing health information are objects and social actors that support and augment a patient's cognition, depicted in the diagram on the right. The distributed cognition diagram is concerned with items or elements that support the cognition of a patient. For example, if the patient uses a series of sticky notes to remember treatment plans or to engage in health related information management, this would be included in an analysis of a cognitive map. Patients may also manage temporal information using a calendar, mobile device, and data sensor, or a combination of these options. The artifacts in a cognitive map are also used to coordinate work among different social and technical actors. These artifacts become mutually understood representations of a particular practice or shared goal. Thus, extending the perspective of traditional personal health information management work into a perspective that relies on distributed actions, shared points of collaboration, and artifacts with multifaceted uses.

The defining characteristics I see as most important between each perspective are the entities and elements in which each theory attends. Assemblage attends more to the context of patients and their surrounding social and technological structures. Assemblages, as I conceptualize the perspective, give credence to the idea of patient-centered care and further understanding of where there may be problems and challenges to patient information

management combined with a distributed cognition approach. Dcog attends to the practices, objects, tools, and other material that patients assemble through their information management needs. While distributed cognition, too, is about context, I view it as a more localized, immediate, and situated context. Assemblages capture a larger context of how those local cognitive practices fit within a larger whole. Assemblage adds to the systems of systems perspective premised in this work.

Having reviewed relevant theoretical literature with the goal of articulating the perspective I take in this study, the next section provides a review of contextual literature. The theoretical concepts presented in the first section of this chapter are used to contemplate the literature and frame the phenomenon as explored through the literatures of personal health information management and personal health record research.

2.2 Context: Patient health information management and the use of personal health records

Bridging the two literatures of personal health records and personal health information management is important because studying a technology in isolation of users and context can be dangerous. Previous research details unintended consequences of using technology in healthcare, which include more work for the clinician, counterproductive workflow changes, perpetual system resource demands, conflicts between what is paper and what is digital, negative user emotions, changes in institutional norms, generation of new errors, and overdependence on technology (Jones et al., 2011). Although PHIM literature focuses on the patient and the context of patient use, there is a missed opportunity in the PHIM practices and activities that go beyond the singular patient but instead become distributed to include caretakers, family members, and consumer information communication technologies. On the

other hand, PHR literature lacks an understanding of the greater context of use, and just exactly how the PHR fits into existing PHIM practices.

Prior to detailing the literature on personal health information management, personal health records, patient-centered care, and how these concepts fit together in this research, it is essential to take a step back and situate the specific personal health record of study (My HealthVet) within the larger context of personal health records. While there are now over 200 personal health records in the marketplace (Gearon, 2007; D. A. Jones et al., 2010; Nazi, 2010), that has not always been the case. Adoption of PHRs by both institutions and patients has historically been low and slow due to a variety of issues from usability to technical and educational (Liu et al., 2011). Also, the PHR is a technology in which its success is linked to the growth of the electronic medical record (Archer et al., 2011). That is, clinical provider facing electronic medical records (EMR) are the foundation of data for personal health records. Furthermore, the term 'personal health record' can be misleading as it refers to at least three technologies with entirely different foundations.

Early personal health records were paper based. The idea of patients managing their own health information and the idea of a patient record has been around since the dawn of medicine (Robson & Baek, 2009). There are three classifications written about in the literature by Tang and Lansky (2005) that classify electronic personal health records. One classification of PHRs were software programs the user would install, unconnected to a provider's electronic medical record, that would allow the user to enter their own information and manage it electronically through the software. Other classifications of PHRs include those that are web-based, the model that continues to be popular today, where data is pulled directly from the

hospital's clinical data. The third is a patient portal, still web based, that would capture information from every source and also allow patients to input their own information and share it with providers (Tang & Lansky, 2005).

There are other ways to classify a PHR by looking at what the technology is tethered to for the acquisition of patient data. Davidson et al (2015) note four arrangements of data flow for a PHR. There are PHRs that are tethered to (1) the electronic medical record, (2) the insurer, (3) a standalone health record app, or (4) a platform or ecosystem. Even these methods by which the PHR populates patient data has implications for the patient, the software vendors, healthcare providers, and administrators. It is no wonder that the ambiguity of the technology and multiple visions for its development and use has created multiple competing conversations in the literature (Davidson, Østerlund, & Flaherty, 2015).

Some healthcare organizations have created their own personal health record for use inside their own healthcare system, such as Kaiser Permanente or the VA. Other personal health records are in use across an entire country and funded by the government. This is the case in Denmark where the government introduced a personal health record for its citizens called *sunhed.dk* (*health.dk*) (Østerlund, Kensing, & Gherardi, 2014). Then there are other companies that are in the business of developing and supporting their own personal health record, such as Epic Systems (Ball, Costin, & Lehmann, 2008). Additionally, there are personal health records designed for a specific health condition. The designers of PHRs can be government, for profit, nonprofit, universities, hospitals, and insurance companies (Brennan, Downs, Casper, & Kenron, 2007).

The Department of Veterans Affairs personal health record, My HealtheVet (MHV), is an amalgam across each of the areas I list. Adoption has not been an issue for MHV as it has over a million users, is widely promoted across the VA system, and has been in development for over a decade. While this is beneficial for the purposes of recruitment, not every PHR has been in development for this long or has as large a user base. The classification of MHV is a *patient portal*. It is web based and pulls data from the clinical electronic medical record known as CPRS (Computerized Patient Record System). This is another factor that makes MHV unique as a PHR in that it is linked with CPRS. As previously cited, the success of a PHR partly depends on the clinical electronic record system it is connected with. CPRS is embedded into the entire VA system, and it is used at every VA facility across the United States. These factors coupled with additional functionality, such as medication refill at VA pharmacies, and open notes, the ability to see all doctors notes, makes MHV uniquely stand out from other PHRs (Delbanco et al., 2010). While some of the functionality available in MHV may not be the norm for other PHRs, I have shown that the field of PHRs is so varied and diverse it would be impossible for a single PHR to represent every type.

I contend that MHV merits an interesting and important PHR to study health information management practices, primarily because it is a popular and widely used portal based PHR. MHV has also been in development for over a decade and has millions of users with well established health record practices. A newly developed PHR would likely have fewer users that are still learning the system. The work of understanding PHR use practices is best pursued when the patient has had time to develop practices and integrate them into their health information management assemblage. Users just beginning to use a PHR will still be navigating

the PHR and learning its functionality. Assessments of functions and usability are not in the scope of this research.

2.2.1 Patient work and personal health information management

Patients work in many different contexts and settings (Aarhus & Ballegaard, 2010; Unruh, Skeels, Civan-Hartzler, & Pratt, 2010). When patients use a personal health record (PHR), it is to assist in the complex, situated practice of health information management. Personal health records are designed to be a tool that address the patient's need for information (Archer et al., 2011; Ball et al., 2007). The entire enterprise of a patient working with a provider on a health concern has become a sociotechnical issue. This is true because of the variety of information systems and health technologies available to patients. This is especially relevant to veterans who receive care from a VA medical provider where they have access to a personal health record that is integrated across the entire VA enterprise; veterans can also export data and see all of their medical data through this system (Schneider, 2008; Turvey et al., 2014; Vogel, 2010). Indeed, the number of technologies available to patients now constitutes a system of systems and represents one of the most challenging subjects compared to those in other industries to which sociotechnical thinking has been applied (Chisholm & Ziegunfuss, 1986).

Patients approach receiving treatment and tending to health concerns with different idiosyncratic organizational schema using a variety of consumer technologies, friends, and family members. To date, the literature emerging around both personal health records and personal health information management does not highlight these the areas of literature together. PHR literature's focus on assuming that technology will get better with time (Agarwal

& Angst, 2004), and that the existence and use of PHR systems will have multiple positive effects on the health care industry, patients, and health providers (Diamond & Shirky, 2008). This type of magical thinking, as Diamond and Shirky (2008) call it, is caused by the health sector looking at the computerization of other industries and assuming technology will fix problems with patient engagement. As PHR use has diffused through the health care industry, the research has begun to recognize that for all its potential benefits, health information technology has more challenges than anticipated (Beale, 2005; Terry, 2008).

Several robust literature summaries and annotated bibliographies are available in the context of personal health information management, the design of health information technology, and personal health records (Agarwal, 2009; Archer et al., 2011; Bensberg, 2007; Lahtiranta, 2009; Turner, 2009; Westra et al., 2012). Of the six literature summaries, two focus on personal health information management literature, three on personal health records and one on patient centered care and patient engagement in healthcare. A number of insights can be learned from these resources.

Agarwal (2009) offers a thorough synthesis and identification of research gaps on personal health information management and the design of consumer health information technology. Among them are the need to understand situated personal health information management (PHIM) practices, functional requirements of technology and design philosophies, motivations to engage in PHIM, and the conceptualization of PHIM as a wholly different activity or special case of personal information management (PIM). Lastly, the challenge found in all information management activities, but magnified in health information management is the challenge of the mismatch between the complexity of people's lives and their cognitive ability.

Agarwal points out three specific mechanisms in this challenge: (1) to remember what is known, (2) find what is needed, and (3) to manage every piece of information on the personal self, for the personal self, at the level of the personal self, and by the personal self.

In a review of 27 articles analyzed for challenges in personal health information management, Lahtiranta (2009) identified three categories of challenges present in the literature. First is patients that try to integrate different types of information (i.e. personal, professional, and health related). Second, use of information to make health related decisions. Third is sharing information with different people, including personal, professional, and medical. This analysis has identified the need to investigate and understand the broad use of information for healthcare, and how that information is shared and distributed beyond the patient. Most importantly, Lahtiranta echoes the call to problematize information management and expand the concept into an activity that happens throughout a lifetime. The author then compares the problems which exist in PHIM research to different PHR products to conclude that no current PHR system addresses and alleviates every previously identified challenge (Lahtiranta, 2009).

Lahtiranta (2009) proposes the term *citizen pathways* as an idea they developed to guide patients on different journeys in the healthcare system. Citizen pathways amount to flowcharts or scripts that can influence policy and organizational structure. There is little insight in the way of using citizen pathways for the design and development of technology or how the concept is used in collaboration with personal health records. The concept also places a large burden on organizations and other entities that would be required to rearrange organizational processes on a large scale.

Personal health information management literature is undergoing a fluctuation in both technology supporting information management, and in the focus of the field. Personal health records represent an infusion of new practices and information systems into how information is managed. Additionally, there are a variety of approaches to studying personal health information management and what the contributions should be (Burrington-Brown et al., 2008). Is the goal of studying PHIM to support decision making? Or to develop models for strategies and use? Or to support adoption and interoperability? As the literature in this area advances, it gives voice to the idea that PHIM is a set of practices patients can engage with to take part in their own care and make sense of their health (Civan, Skeels, Stolyar, & Pratt, 2006; Pratt et al., 2006). It is a natural fit, then, that PHIM should be thought of as the practices patients can apply to use a PHR. Yet, a PHR is a complex technological tool that can shape practices, making the study of PHIM and PHR to be reciprocal.

2.2.2 Personal health records and patient-centered care

Personal health records have become inextricably connected to personal health information management because the PHR system is designed to support patient-centered healthcare by making medical information available to the patients, and to assist patients in the work of information management. One of the first systematic analyses of PHR literature reviewed 130 studies and categorized the types of research being done (Archer et al., 2011). The table below reconstructs the work of Archer et al (2011) as it displays the category and number of studies which occur in each one.

PHR Research Category	Number of Studies Published in this Category
What content belongs in a PHR	13
PHR System architecture	14
Privacy and security	14
Functionality	27
Cost and financing	6
Patient-provider communication	22
Education and interventions	10
Health and self-management	6
Adoption and use	39
Satisfaction	6
Usability	9
Barriers to adoption and use	6
Clinical outcomes	10

Table 3: Number of PHR studies by category

The table shows that most PHR research has reported on the adoption, use, and functionality of PHR systems along with its effects on patient-provider communication. A similar collection of PHR literature, presented as an annotated bibliography, was produced in 2009 and came up with many of the same categories (Turner, 2009). Though the Turner annotated bibliography provided none of the analysis that Archer et al. (2009) have, it is an exercise in reproduction of categorizing the literature. It also provides evidence that the literature has a sense of coherency and direction to it, which is interpreted consistently by different researchers. Concerning the Archer et al. (2009) review, it is no surprise that the line of research concerning adoption and implementation is the most frequent area of research. The early literature praising the usefulness and transformative capability of PHRs quickly evolved into studies of the increase of PHR systems' adoption since it has been a traditionally slow process.

Another annotated bibliography of PHR literature was conducted for the Robert Wood Johnson Foundation in 2012. Though it is not focused solely on PHRs, it also looks at the concept of how health consumer engagement is facilitated or activated by use of technology (Westra et al., 2012). While broader in scope, the Westra et al (2012) bibliography categorizes much of the same literature and raises an important point: that health consumer satisfaction, engagement, and participation has become directly linked with health information technologies. The concepts of patient engagement and participation are more formally known in the health services research field as patient-centered care (PCC). In its most basic terms, PCC exists when opportunities for choice, access, and open communication are provided for the patient by healthcare organizers and providers. One of the most thorough reviews of PCC literature identified several barriers to PCC, including: patients lacking confidence, clinicians struggling to work beyond a biomedical model of care, and time constraints (Bensberg, 2007).

The concept of patient-centered care emerged in the early 1950s and exploded in healthcare policy and research in the late 1990s (Jayadevappa & Chhatre, 2011). The Jayadevappa and Chhatre analysis of PCC studies found that when PCC is practiced there is an increase in quality of care, efficiency of care, fewer referrals, and greater patient satisfaction. This is why organizations like the Agency for Healthcare Research and Quality (AHRQ) have invested grant monies and several streams of research devoted to facilitating the concepts of PCC through information communication technologies (Mardon, 2013). What is important about the PCC concept is that much of the health information technology movement has focused on clinicians' and providers' use of technology, but PCC has placed an emphasis on

developing information communication technologies based on patients' values and practices (Krist & Woolf, 2011).

One study created a framework for how PHRs can support elements of PCC. The authors developed a framework and questionnaire to compare seven different organizations' uses of PHRs; the framework consist of: 1) respect for patient values, 2) information and education resources provided, 3) support to access care, 4) emotional support to relieve fear and anxiety, 5) involvement of family and friends, 6) continuity and secure transition between providers, 7) physical comfort, and 8) coordination of care (Reti, Feldman, Ross, & Safran, 2010). What they found was that different PHRs supported some of the PCC framework but not all of it. While the authors gathered data at different organizational settings, such as ambulatory care clinics, university hospitals, insurer and health plan providers, they did not interview a single active patient. All interviews were conducted with managers or senior staff in the organizations and, while these individuals were knowledgeable of the PHR system being evaluated, it is essential that patients be included in studies on patient-centered care. While organizations, insurers, and providers can certainly influence and support PCC efforts, the patients are key to shaping PCC. For example, the Reti et al (2010) study analyzes PHRs by asking questions of the technology such as: Does it support delegation? Can patients control who sees their record? Can clinicians respond to patient emails? These are yes or no questions and, while they may contribute to the overall broad development of a PHR system, many questions remain and the answers lie with patients and their experiences using PHRs. A PHR system may have functionality deemed central to PCC practices, yet patients may not use the functionality for a variety of reasons. Or, patients may develop alternative ways to use and reinvent properties of a health information

communication technology and these expert practices may be overlooked by traditional PCC framing. This need is similar to the previous example of distributed cognition in which pilots imposed new cognitive tools and heuristics onto the flight cockpit controls, which redesigned the controls and resulted in the loss of those expert tools. Given the importance of PCC to a modern healthcare system and to healthcare organizations, all future research concerning patient interaction with technology and patient health information assemblages must consider how the research connects to and influences notions of patient-centered care (Finkelstein et al., 2012). Furthermore, patient-centered care presents opportunities for new classes of information systems contexts and opportunities to theorize information systems research (Baird, 2014). It would seem, then, that what is needed is a theoretical framework informed by patient practices using a sociotechnical perspective.

The literature on personal health information management and personal health records have few concepts resembling a health information assemblage as I discuss in the theoretical framework section of this literature review chapter. However, there are similar burgeoning concepts in development. One such idea is that of information workspaces. The logic of information workspaces is that patients face numerous challenges in a clinical environment including information management problems, communication issues, stress, lack of advanced information, and separation from information artifacts. Because of these challenges, there is a need to develop spaces and strategies in clinics and hospitals to support patients' information work (Unruh et al., 2010). The study from Unruh et al raises an issue of lack of infrastructure in hospitals and clinics and focuses on physical descriptions, such as the way patients sit, location of objects, configuration of waiting rooms and examination rooms. The results of this research

provide some important and useful strategies for organization to implement in order to improve the patient experience. These include redesign of certain key physical locations, encouragement of collaborative uses of technology such as multiple monitors and systems for patients and providers to collaboratively review information and automatically capture information for patients. This research is important, both for addressing PCC and for the design and development of information communication technologies which support patient work and information management. Yet, it is only one study focused solely on breast cancer patients and only in the clinical context. While all of these factors give an appropriately narrow scope to the study, certainly more about patient information work can be learned from additional perspectives with an expanded patient population.

Health information management is a complex activity and practice. People do things in different ways. PHRs, or any other health information technology directed at patients, can only exist in the larger context of the health information environment. Purin and Piras (2011) set a call for researchers to think of PHRs and similar information communication technologies as sociotechnical arrangements, and that these larger environments must be considered when attempting to investigate patients and personal health records. The authors also stress the importance of personal health information management, self-management of treatment regimes, and self-care as windows into patient experience which can be extrapolated into useful design techniques and strategies. The most significant insight from their analysis of the prototyping and testing of a regional PHR is that most of the characteristics of PHRs are implicitly positivistic and techno-centric and the use of these systems, both for patients and the more clinically focused systems, are often overly optimistic. The authors note that most

electronic medical records (the clinical counterpart of a personal health record) have yet to create a seamless web of communication and collaboration among medical providers and staff. They posit three levels of analysis for future research in this area: local healthcare system context, regional e-health infrastructures already in place, and patients' wisdom or personal health information management (Purin & Piras, 2011). However, further research is needed to identify other possible levels to arrive at a detailed picture of PHRs and patient-focused design. This research is, in part, intended to address the production of additional research that Purin and Piras identify as being deficient.

I conclude the contextual literature review of PHRs and PHIM with some highlights from the literature that summarize important gaps before presenting research questions. The work from Agarwal's (2009) synthesis of personal health information management and the design of information technology is highly influential for scope and direction of this dissertation. It points to the emphasis on personal health information management as a core patient activity, and demonstrates that PHIM is an activity that is practiced repeatedly and as such can and does inform patients' use of technology, also, concepts like patient-centered care and patient engagement stem from PHIM practices. Additionally, several previously discussed reviews of literature (Archer et al., 2011; Turner, 2009) illustrate a remarkably low number of studies on patient information management. Absent from these reviews of PHR literature are studies that assert that the larger social and technical environment must be understood where PHRs are used. Observing the successful use of a PHR and what factors occur in that assemblage could have informative findings for adoption, use, and development of other PHR systems. As

evidenced by the Lahtiranta (2011) review, the future research in this domain is gravitating towards understanding the distributed contexts and broader units of analysis.

2.3 Research Questions: Toward constructing an assemblage of health information management

My review of personal health information management (PHIM) literature reveals that the electronic personal health record (PHR) is inextricably bound to the idea of patient information management (Smolij & Dun, 2006) and that PHRs may help address the patient's burden of information overload (Burrington-Brown et al., 2008). While part of the conversation about PHRs as an information management solution is positive and even overly optimistic, there are a number of issues in the use of PHRs. These include low adoption rates ("Consumers and Health Information Technology: A National Survey," 2010, "Labs, PHRs, Platforms & Consumer Engagement: A Presentation," 2009), usability problems (Liu et al., 2011), interoperability issues (Beale, 2005), patient-entered data challenges (Simborg, 2009), and problems in designing for different users (Kutz & Ekbia, 2011). I operate from the premise that current perspectives on PHR use and PHIM practice are limited. New perspectives to include a wider distributed context and understanding of the role of technology in the patient information management practice, or as I prefer, assemblage, can address some of these issues with personal health records.

The relationship of PHIM and PHR research is a strong foundation grounded in academic literature to understand the change occurring in health consumer practices and technologies (Swan, 2009). The combination of actors, agents, and artifacts make up an intricate and powerful information processing web (Meyer, 2006), within which the patient works for the purpose of maintaining and advancing their health care. Future research on the

computerization of patient work must factor in the use of a personal health record, but not solely focus on the PHR, and consider larger environments and contexts. Because this is state-of-the-art in this domain of research, limited prior research exists in looking at the distributed cognitive assemblages of patient health information. The majority of personal health information management research has focused on the individual patient. To address problems of adoption, design, and use, it is important to theorize a model of health information management in which practice is framed as distributed and involves an increasing number of objects, social actors, information systems, and other technologies (Greenhalgh, Potts, Wong, Bark, & Swinglehurst, 2009). Given the problems and gaps identified in this literature, the four following research questions are proposed to advance understanding in this domain and inform future research.

RQ1a: What are the personal health information management practices of veterans who use a personal health record?

RQ1b: What health information management practices become distributed beyond the veteran patient?

I pose this first research question as a baseline to articulate the primary activity under scrutiny in the phenomenon. The few studies on how patients manage health information focus on cancer patients, elderly with chronic disease, patients with diabetes, Spina Bifida, or tracheotomies (Aarhus & Ballegaard, 2010; Berry et al., 2011; Moen & Brennan, 2005; Østerlund, Dosa, & Smith, 2005; Palen & Aaløkke, 2006; Piras & Zanutto, 2010; Unruh & Pratt, 2008a, 2008b). The literature in this area does not yet represent a robust and diverse sample of different types of patients in different use cases with different personal health record

technologies. This is one motivation for studying the Veteran population. Veterans are also underrepresented in the literature and present complexities and use cases which may be generalized to other non-veteran populations. Both research question 1 a/b are grouped together because they are motivated by distributed cognition to describe health information practice as a distributed cognitive set of activities and practices. Part b of the first research question is passed to address the same previously cited literature that has limited analysis concerning how other people and technologies also contribute, support, or help realize patient health information management.

For instance, a veteran can use My HealtheVet to obtain their lab tests. They may print them out, transfer them to another piece of software or mobile device and give a copy to a family member. The information management task may be straight-forward: sharing my lab work with another physician outside of the VA network. But the ways in which that information can travel, and how it may be manipulated, stored, and remixed are many. I want to know what practices and tasks are more likely to be distributed, or rely on technical objects and social actors, rather than solely the patient in addition to how those health information management practices become distributed.

RQ2a: What health information management assemblages emerge from the distributed work of Veterans that use a personal health record?

RQ2b: What are key functions of the health information management assemblages of veterans?

Research question 2 a/b are grouped together in order to address the assemblages, and therefore the larger context, in which these situated practices of distributed health information

management occur. This research question emerges out of the lack of relevant literature which does not consider the bundle of practices, technologies, objects, and actors which view patient work as a system of systems. As such, it is critical then for this study to not only identify the scope of these distributed health information management assemblages but to also understand how assemblages facilitate or hinder different information management practices. This second group of research questions relies on the first set of research questions in part. This is because the framework of distributed cognition is employed in this perspective to identify and articulate points of the assemblage which become stable or change, and how.

2.4 Summary

A health consumer engaged in the modern healthcare system must emphasize involvement in care. This has created a need for further study of the ubiquitous work patients practice outside of the clinical office visit, particularly as this health management work becomes embedded and entangled in sociotechnical systems and specifically PHRs. The proposed research investigates the computerization of consumer focused health information management and the role of information management technologies and practices. This phenomenon was explored using the academic literature of personal health information management and personal health records. An argument is put forth that the context of inquiry should be conceptualized by weaving concepts of sociotechnical assemblage and distributed cognition, both practice-based perspectives, to reconfigure the phenomena from an individual activity to an assemblage of distributed cognitive activities and practices. The methodological strategy to conduct this research is the use of a multi-phase, primarily qualitative study of Veterans receiving treatment at the Department of Veterans Affairs medical facilities in the

Syracuse region and surrounding community-based outpatient centers. This study anticipates contributions to advancing conceptual models of patient-centered care and patient-facing information management system design. Also, it hopes to inform health service professionals who evaluate patient-centered care services. Developers and designers will also benefit from the identified design implications for patient-facing health information systems.

Chapter Three

3. Methods

This chapter concerns the series of methodological choices to investigate health information management assemblages. The chapter begins with the design and presentation of results from a pilot study used to inform follow-up fieldwork and research design. The next section is a discussion of the case study research design. I explain the unit of analysis and the setting of the research. I justify and explain the selection criteria for the multi case study, along with the recruitment methodology, informed consent strategy, and the data management, security, and protection measures. The data collection procedures are described as well as the plans for analysis. Finally, the credibility, transferability, dependability, and confirmability of the study are discussed.

3.1 Pilot study

A pilot study was conducted in the summer of 2012 with the goal of exploring medical provider and healthcare staff observations and interactions with veterans' health information management practices and use of My HealtheVet. When veterans and caretakers of veterans interact with the healthcare system at the VA, they access doctors, physicians, nurses, medical technicians, and other staff. These interactions often end in procuring information in the forms of paper printouts and written notes. These interactions also require that information be organized and processed beforehand, i.e. information about where to go for an appointment, questions to ask the doctor, social history, and relevant life events related to the veteran's treatment, or questions about an upcoming course of treatment. The questions and reasons for

treatment are many and diverse depending on the veteran's illness trajectory. Given this context in which an abundance of information is made available, the pilot study sought to understand some of the basic interactions, mediated by My HealtheVet, between medical providers and veteran patients.

The design of this pilot study used qualitative semi-structured interviews and thematic content analysis to analyze the data. These methods and techniques have a clear precedent in similar projects. In conducting a content analysis, a list of emergent themes and relevant topics was created. A total of 15 interviews were conducted; the average interview lasted for an hour. Interview participants were from diverse professional positions across the Veterans Health Administration, including: department directors, managers, education coordinators, librarians, MHV coordinators, project managers, volunteers, research coordinators, and practicing and non-practicing (research focused) medical providers. All interviewees were involved with veterans to some capacity with different aspects of the healthcare system. Participants self-enrolled through an email that was sent out to a listserv. Membership to the listserv is for VHA employees to receive news and stay involved in the development and use of the My HealtheVet personal health record. Additionally, snowball sampling was used by asking participants for suggestions of other potential participants who interact with veterans and are familiar with the My HealtheVet system.

The pilot study interview questions (appendix A) are used as a starting point for the discussion, and follow up questions and probes were used in each interview to elicit specific information about the personal health information management of veterans. These interview questions are framed with the purpose of exploring patient work from a high level, and to

inform future research on ways to further investigate personal health information management and use of personal health records. The exploratory interview questions are informed by a review of the literature and personal experience working at the VA as a research assistant for over a year. Questions are categorized to interrogate concepts related to: the observable information management practices of veterans at VA facilities'; the use and role of space and place in the concept of patient health information management; patient use of tools and technology; experience of the staff answering questions from veterans that are related to information management and health literacy issues; observable issues related to veterans managing health information; and, staff experience assisting veterans with information management work. Additionally, the interview protocol contains several provider specific questions about experience working with veterans in the clinical encounter and the role of health information management from a provider perspective.

After performing a constant comparison method of inductive content analysis (Leech & Onwuegbuzie, 2007), 10 unique themes emerged. The process of code saturation was reached, meaning that no additional coding categories could be developed that did not already fit in a preexisting category. The numbers in parentheses after each code are the frequency count of that code's occurrence across the entire collection of interviews. The list of codes follow:

Practices (38): Observations and demonstrations of patients' use of and practices of working with their own personal health information.

Space & Place (11): Concerning the location of technology or other object as well as the use of physical space.

Needs (8): Explicit needs and support concepts that would presumably benefit the patient, provider, organization, or any combination of these stakeholders.

Limitations (9): Characteristics that place MHV and relevant actors at a disadvantage. These characteristics can create a problem for the use of technology, a user, a physician, or other individual.

Threats (23): Characteristics that may pose a threat to a current or existing practice.

Opportunities (23): Concepts and ideas that are emerging and can be advantageous to future development projects or to help adjust current behaviors and practices in a beneficial way.

Design Considerations (18): Beneficial principles and practices of design and development that are important to consider or implement.

Education & Outreach (12): Opportunities, need for, or examples of education efforts that would benefit patients, providers, and practices.

Policy (3): Issues and concepts of policy related to PHR use, patient-provider communication, or interaction with the patients' health information.

Observation (11): A catchall of general observations and insights that come from the participant's experiences about patients' interactions and experiences with health information.

Analyzing interview data revealed four leading issues that concern veteran health information management best practices and important concepts to further investigate. The first is the purposeful uses of MHV that were clear for interviewees to identify. Indeed, tasks such as *prescription orders, calendar, and secure messaging* are observed repeatedly. Many of the participants reported these uses as exclusive to many patients' sole use of MHV. Other functions of MHV, while available, are underused or ignored. This would suggest that further

research with the intent to describe and measure the actual use of specific functions by users, along with a description of the type of user, would be fruitful knowledge for future design.

The second characteristic of veterans' information management practice that permeated almost every interview is the patient's use of delegation. Delegation was noted as a practice especially in older patients who wanted significant others, family members, or health professionals to access and manage health information with the patient's permission.

The third characteristic is that veterans who use MHV adopt certain behaviors and assumptions when using the system. While this discovery may be more precise and robust in future follow up research, there is an observable trend that veterans assume that their providers coordinate and communicate digitally because of MHV. The assumption is that, because the patient now has a MHV account, it must relay information to multiple doctors as well as doctors outside of the VA. Whether this belief results from inexperience with the system or from wishful thinking is not clear at this point. However, this finding does indicate that veterans may have certain constructs or expectations about using MHV that may not be made overt or explicit upon using MHV.

The fourth dominant issue that emerged from these data is that paper still plays an important role in the information management routines of veterans. This finding lends further evidence to the need for investigating and understanding information management contexts and practices that occur outside of the personal health record. It is common for veterans who use MHV to continue to rely on and use paper for specific tasks. Continuing to support practices of paper use through tools like the Blue Button is important. The Blue Button allows veterans to download the entirety of their health information hosted on My HealtheVet and save that

information to a standard PDF format or a variety of other options for printing and document portability.

Unfortunately, this pilot study was unable to directly observe and question patients and users of the MHV system. This is due to practical matters of limited time and IRB approval for this stage of the research. However, this study frames the follow up dissertation data collection and analysis. This pilot study also provides further evidence of the need to continue this research with veterans who are enrolled in the My HealtheVet PHR. It is clear that patients in this population use more than MHV. Therefore, the follow up research, as framed by the established conceptual perspective, will follow other practices that patients enact to help manage their health information.

Another outcome of this exploratory work is the evidence that family members and caregivers become implicated in the patient's health information management network. Once again, this provides further justification for the proposed research to cast an analytical gaze on social actors and their roles in health management. The systematic and structured framework of distributed cognition and sociotechnical assemblages are used to understand and interpret the complex act of personal health information management. This proposed study will detail specific functions of patient work and how patients work with technology to accomplish (or not) their health care goals.

3.2 Case study research design

Being a patient within the current healthcare milieu is a complex sociotechnical phenomenon (Lahtiranta, 2009; Swan, 2009). The ways in which patients interact with health information technology are shaped through repeated practices, and in turn technology must be

developed for patients; this is a recent concept with little investigation (Piras, 2013).

Furthermore, as patient agency is emphasized in the healthcare system, detailed patient work practices are not clearly and completely understood (Agarwal, 2009). The increase in technology, inclusion of social actors beyond the patient's involvement, and provider care teams are common events in contemporary healthcare. To understand distributed health information management practices and the role of the PHR in that work suggests a detailed case study design in which the objective is to detail the phenomenon and explore the sociotechnical configurations that exist in the practice of health information management.

Using a case study research design, I selected for different amounts of time spent using MHV and types of MHV use by patients; this allowed me to gain a better understanding of the emergent phenomena of distributed health information assemblages. Different practices emerged detailing patients' reliance on a PHR and how a PHR becomes integrated into distributed health practices. This strategy also served as a point of comparison of how a frequent user of a PHR might lean more on making the PHR perform most of the PHIM work. An infrequent user of the PHR might develop other practices in lieu of a limited role of PHR use.

I contend that the best environment to study the context of health information management practices of PHR is with veteran patients who are enrolled in the My HealtheVet personal health record. This is because MHV is a PHR that has existed since 2001 and has diffused through the veteran population. Veterans have used the PHR for years, allowing use practices to develop and stabilize. Also, MHV has a large user base from which I recruited. This is contrary to a PHR which may have low adoption and therefore present challenges in recruitment of users who interact with the PHR. Lastly, MHV is a PHR portal that allows

unfettered access to the entirety of a veteran's medical information, including progress notes. This equates to more information availability to the veteran, more for them to manage, and additional practices to observe. If personal health records are to be one of the major tools that continue to see development and adoption in healthcare, then it is imperative to study a population that has been using a personal health record for over a decade in order to have a clear understanding of how the technology can influence patient-centered care and information management.

Prior work in this area clarified the importance of qualitative methods for data collection and analysis (Civan et al., 2009; Trisha Greenhalgh & Swinglehurst, 2011; Klasnja, Hartzler, Unruh, & Pratt, 2010; Palen & Aaløkke, 2006; Piras & Zanutto, 2010; Pratt, Reddy, McDonald, Tarczy-Hornoch, & Gennari, 2004; Pratt et al., 2006; Unruh & Pratt, 2008; Unruh, Skeels, Civan-Hartzler, & Pratt, 2010; Ventres et al., 2006). These methods yield beneficial results that contribute to the concept of patients' individualized and personalized information management practices. The sociotechnical perspective of this study also emphasizes the use of technologies and applications in work practice for empirical qualitative insight (Berg, 1999). Specifically, detailed participant observation and interviews are used because of the method's ability to detail complex idiosyncratic social practices that cannot necessarily be quantified (Greenhalgh & Swinglehurst, 2011). Qualitative research designs are appropriate for this kind of investigation because one of the goals of qualitative research is to establish shared meaning in contexts where concepts are not well understood or there is an emerging phenomenon. Shared meaning emerges from the intersubjectivity of research participants (Walsham, 2006); this can be captured from different participants and theoretical samples for maximum variation and

multiple data sources that are triangulated. The research design is thus a descriptive, multiple-case, cross-case analysis embedded study. In order to thoroughly explore and describe the processes functioning within health information assemblages, cases were purposefully selected for variation in use of personal health record (Corbin & Strauss, 2008; Patton, 2002).

Case study designs enable the investigation of in-depth, complex, and detailed research questions (Yin, 2014a). A case study research design was appropriate for this study because context was critical to the goals of this study. It would be insufficient to design this research around an experiment or to only measure the usability of patients in order to understand the role of the PHR in information management. Many factors are involved in health information management including: the role of caretakers, the various ways patients organize and review information, the different physical tools and digital technologies in use and the unique practices of each individual involved in patient support. These factors must be understood as a coherent whole. From the analysis of the entire system assertions were made about the important factors of distributed health information assemblages. Thus, a case study design allowed me to select multiple cases and compare each case in the sample to understand what factors were important and bring to light specific mechanisms of distributed health information assemblages and in what ways those structures were configured.

The research questions are directed toward the practice, process, and events of individual experiences while connecting those individual practices to a broader context. This specific type of research design is an embedded multiple case design with nested data collection. The context is patient health information management, and I selected multiple instances of this context. Within this context there were multiple units of analysis, from

individual patients and providers to the processes of information management, emergent practices, and distributed use of objects. Data was collected from each unit using the same data collection techniques for each case: questionnaires, in depth semi-structured interviews, field notes, and observations. These data collection techniques were nested within each case study. The above mentioned data collection techniques were embedded *within* each case after I selected each case and recruited each participant. This is opposed to a design where data collection techniques are used *outside* of the case and would serve to inform the selection of participants within the case (Yin, 2014a). Hence, these techniques were not used to select a case study, but to interrogate the already recruited participants of each case. The case selection strategy is reviewed in section 3.2.2.

A single case for this study began with the patient, and branched out to include their caretakers and family members, as appropriate. I also included the primary care provider with whom the patient exchanges or discusses information that they must later manage. Also encapsulated in this case are: the My HealtheVet technology; any mobile or digital technologies the patient engages with for managing information; and the physical objects that are used by the patient to manage his or her health information, such as file cabinets, placement of medications, use of clinical devices in the home, placement of files in the home, paper journals, appointment calendars, mobile devices, wearable health sensors, and many other objects and digital technologies that are a part of the greater health information management context. The collection of actors, digital technologies, and physical objects all assembled around the patient's information management comprised a single case in this study. The case study design,

use of data collection instruments embedded in each case, and recruitment process is visualized in figure 2 below.

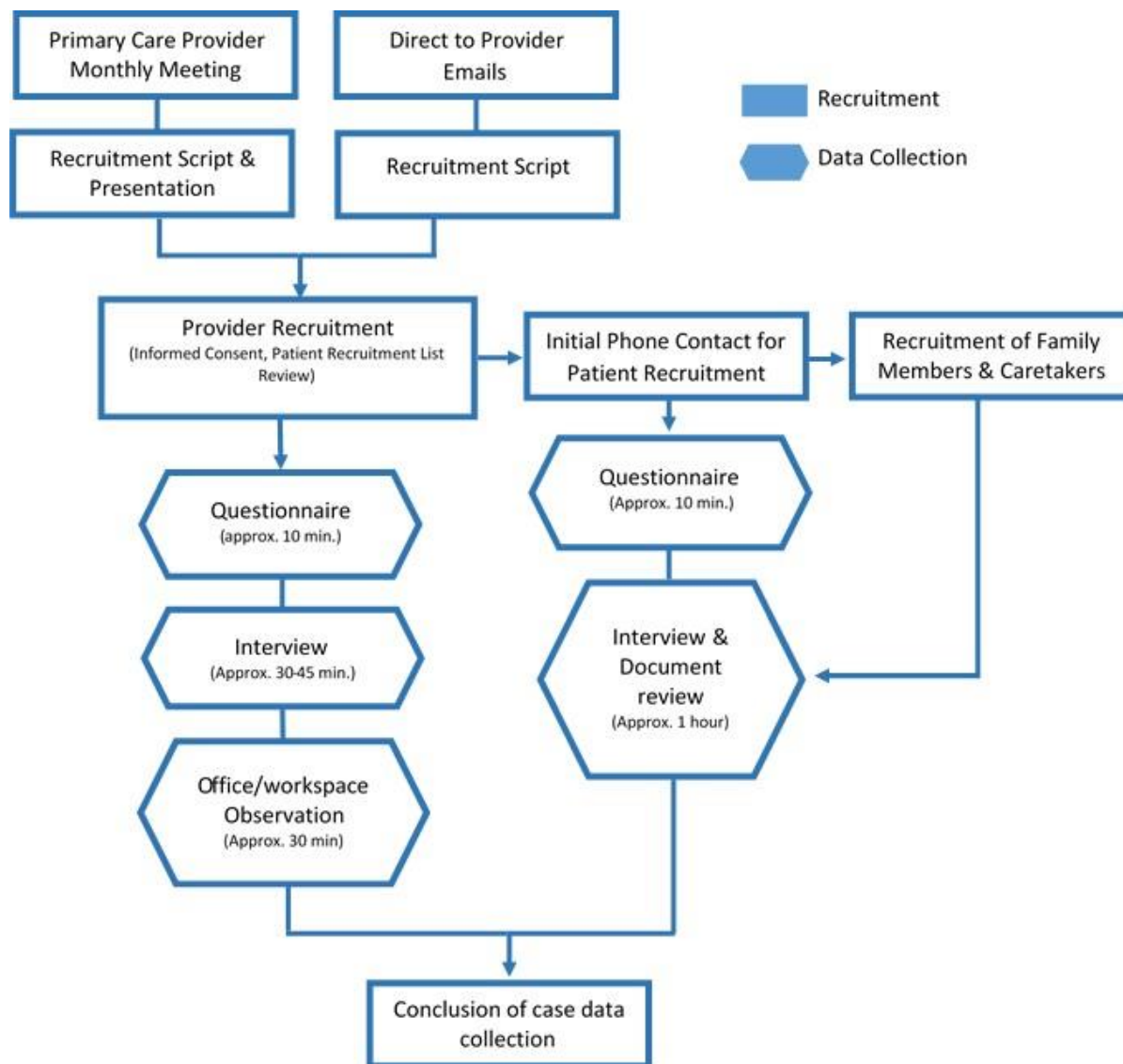


Figure 2 Visualization of the recruitment process and embedded measures for a single case

3.2.1 Setting and unit of analysis

This study clarifies that a singular focus on the patient is a narrow perspective not reflective of a modern healthcare system. Other social and technical actors, objects, and documents are involved beyond the patient. The mix of these actors, agents, and artifacts make

up an intricate and complex assemblage of relations, objects, and practices within which the patient works for the purpose of maintaining and advancing their health care. To draw boundaries and scope the patient's assemblage, I focused on objects and social actors that support the patient's cognitive work related to information management. These perspectives necessitate that the unit of analysis cannot be placed on any one person. Following this perspective, the research proposed here recruited patients, providers, family members and caretakers. Each case contained at least one patient, one provider and the use of MHV with an assortment of tools, technologies, and documents. However, not every case contained the same number of relevant family members or caretakers as some patients lived alone, had no caretakers, or family members did not play a role in their health information management.

One of the ways I determined who was involved in each case was to use distributed cognition as a perspective for identifying these boundaries. Dcog requires me to look at the functional system, not just the actors within the system (Hollan et al., 2000). This means that social actors aside from the patient and initial provider become relevant and were eligible for recruitment into this study when there was a task or action of information management distributed to the prospective participant. Objects, actors, and practices were identified by tracing their connections to an information management task or outcome. As such, I established a provenance in the data of each practice and how this practice is supported. This can be imagined as telling a story about a patient's task in order to trace the need to perform that work and learn how the variety of people, objects, software, and contexts become involved and to what extent to accomplish said task. This strategy helped construct the

relationships of activity through distributed cognitive support. These distributed cognitive actions are part of the local situated assemblage context.

3.2.2 Sample and case selection

Veteran participants are ideal for this study as they all have access to the My HealtheVet personal health record. While there are many personal health records available, My HealtheVet offers a large user base. This is important as adoption issues and an exceedingly small user base would pose a challenge to recruiting a variety of patients and use cases. Additionally, MHV has been developed for over a decade, ensuring it has a variety of functions and possibilities of use. If, for example, MHV only allowed a veteran to renew their prescription, then the use and role of the PHR in the patients' health information management assemblage would be trivial and without the level of complexity that needs to be investigated. However, because MHV offers several functions on par with many other PHRs, the complexity of the PHR in the larger health assemblage is increased. By complexity of use, I mean the possibilities and potential that patients can interact with the health record. While MHV has some functions and features that are veteran specific it still has much in common with other PHRs in terms of capability and features. Namely, the ability to input information, export personal health information, renew medications, communicate with health providers, see medical tests, and many other functions detailed at length in table 1.

This setting and context of veterans receiving care in the VA healthcare system is ideal for this study because the community involves a complex social and technical infrastructure. Like any patient, veterans have a system of filed documents, archives in flux, permanent archives for safe keeping, and frequent information in use located in places like desks, offices,

and coffee tables. Understanding these distributed practices revealed the important management trends and flow of information in patients who use a personal health record and the role of personal health records in a health information assemblage.

For the purposes of recruitment, I submitted a data request to obtain a data spreadsheet to support the recruitment of patients and providers for this study. The result of this data request was a recruitment spreadsheet that provided names, contact information, demographic information, confirmation of My HealtheVet account activation, and the names of each veteran's primary care provider. This list contained 4,416 veterans that met the study criteria described below. In order to understand the population from which I recruited, I conducted basic demographic analysis of the age distribution (figure 3) and period of military service (figure 4). These statistics are reflective of the sample that participated in this study. The specific demographics for participants that were recruited and completed the study are discussed in the findings chapter.

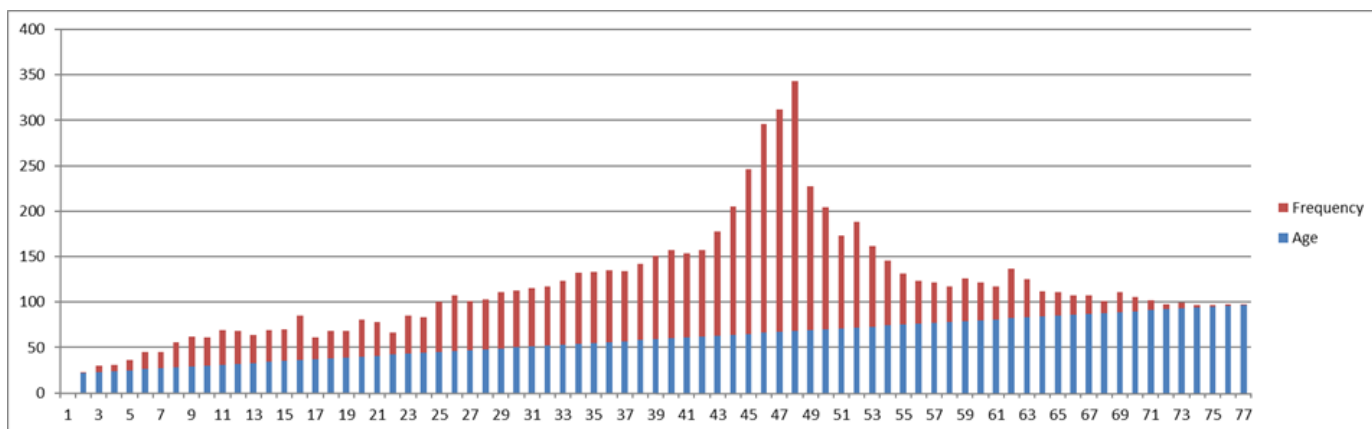


Figure 3 Age distribution of all local veterans that meet recruitment criteria

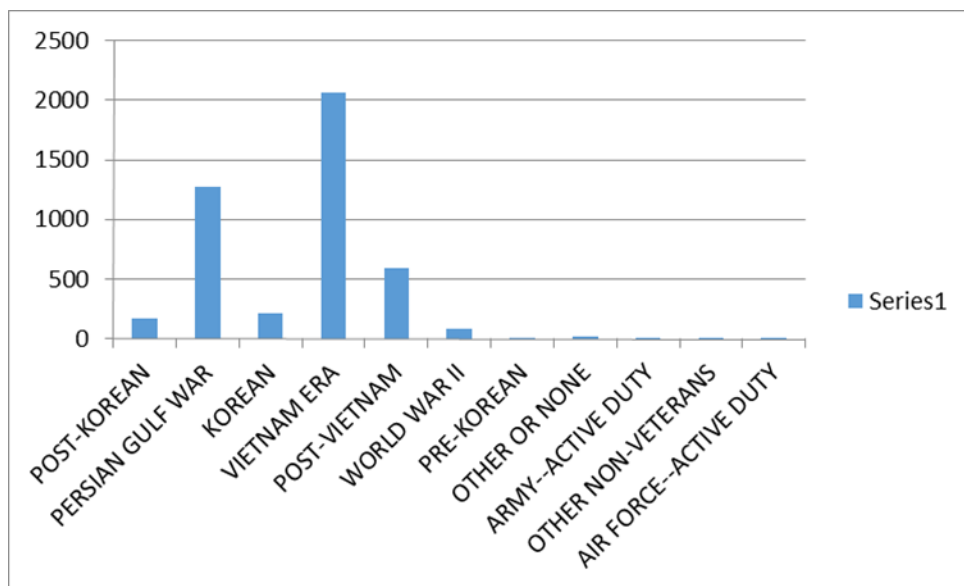


Figure 4 Period of service of all local veterans that meet recruitment criteria

For the matter of practicality and protocol, recruitment began with contacting healthcare providers that use My HealtheVet. Providers were recruited first into the study because VA policy requires that the patient's primary care provider be aware of and allow for any research involving a patient of that provider. Additionally, healthcare providers are pressed for time and comprise a challenging population to involve in research. Thus, recruiting providers first assured that healthcare providers were appropriately represented in this research and can be connected to the patients' distributed information assemblages. Prospective healthcare provider participants who met the following criteria were considered ideal candidates to participant in this study:

- Are treating a patient that is enrolled in My HealtheVet.
- Has used My HealtheVet in the clinical encounter with a patient as an informational aid.

- Are willing to talk about strategies, organizational schema, software, tools and systems they have seen patients use to aid them in managing health information.
- Are willing to talk about information (such as print outs, brochures, or websites) they provide.
- Are willing to talk about the clinical perspective of using and providing information to patients.

As figure 2 shows, two recruitment techniques are used to make first contact with prospective primary care provider participants. First, all primary care providers at the Syracuse VA medical center attend a monthly meeting. I attended a meeting to get a feel for how information from this meeting becomes relevant and disseminated to the patient and also to deliver a short presentation of this study to attending primary care providers. After the presentation, providers were encouraged to participate if they had a patient who was enrolled in MHV. The second recruitment strategy was a series of follow up emails to primary care providers that both attended the meeting or were not in attendance of the meeting. When contacting providers through email I used a recruitment script (appendix B). Using these two recruitment methods I recruited ten providers who also had patients enrolled in MHV and varied in their use of MHV. The details of MHV use by patients was identified in the initial conversation with providers upon recruitment. After providers agreed to participate in the study, an initial meeting was scheduled between myself and the primary care provider. These meetings took place in the primary care provider's VA office. During this initial meeting, primary care providers were able to ask me any questions they had about the research and sign informed consent documents. Most importantly during this meeting, providers reviewed a list

of their patient panel consisting of only the patients found in the recruitment data set I obtained from the data request. The objective of this review was to identify patients that should not be contacted based on two factors: 1) remove patients from the recruitment list that are not capable of participating in an interview either cognitively or based on any other health consideration and, 2) remove patients from the recruitment list that have moved, are out of the country, are recently deceased, or no longer receive care at the VA. After going through this review process with each recruited provider, the process produced a list of 340 veteran patients that met all study criteria and were pre-approved by their primary care providers as safe to contact.

The 22 patients recruited for this study were contacted by phone call and read an IRB approved recruitment script (appendix C). Patient participants who met the following criteria were considered ideal candidates to participate in this study:

- Use My HealtheVet.
- Have internet access at home or can access the internet.
- Have access to a computer or mobile device.
- Own, have used, or have access to mobile devices such as a tablet, smartphone, or laptop.
- Are willing to talk about the health management tasks they perform.
- Have managed their own, or have a caretaker who manages, health information (both physical and digital information).

Additional desired patient recruitment criteria included selecting patients who varied in their use of the PHR (time spent using, reasons for use, type of patient treatment) (Agarwal, 2009),

and who used other objects and artifacts beyond the PHR for information management (Piras & Zanutto, 2010). During the first contact phone call participants were able to ask questions about the study and told the process for participating in the study. It was also during the first contact phone call that the interview was scheduled around patients upcoming clinical appointments.

Patients were encouraged to invite caretakers or family members to take part in the interview as well. Prospective friend, family member, and caretaker participants who met the following criteria were considered appropriate candidates to participate in this study:

- Has helped to manage the associated patient's health information.
- Has used or is familiar with My HealtheVet.
- Is willing to talk about their relationship to the patient and experience with working with the patients' health information.

The duration of each patient's participation in a study of this design and scope was, of course, variable. Participants received an initial questionnaire that took 10-15 minutes of their time. The initial interview was expected to last approximately an hour, with most being around an hour and others reaching close to two hours or over if caretakers were present during the interview.

3.3 Data Collection

Data collection for this case study was embedded into each selected case. This study recruited and developed 22 separate cases through 32 interviews, 22 interviews with patients and caretakers when appropriate, and 10 interviews with the patient's respective provider. Within each case, three distinct data collection techniques were used. They included

questionnaires, interviews, and observations. Figure 2 above illustrates the process of recruitment and the stages of informed consent. It also shows when each method was employed in the research design and the duration of each method of data collection. The following sections elicit the protocol details for each method.

3.3.1 Questionnaire

After a participant enrolled in the study and signed an informed consent, the first way they engaged with this research was through a short questionnaire. The questionnaire was developed to be taken either printed on paper or online through a hosted survey service. The content of the questionnaire for providers involved taking an inventory of devices and digital technologies they own, such as laptops, mobile phones, and tablets. I posited that providers with easy access to and frequent use of digital technologies have practices more likely to share information through digital channels, and that the provider's practices would influence the patient's own information management practices. Thus, it is important to know tools and technologies available to the provider as well, since the literature points out that providers have influence over patient decisions (Goldzweig et al., 2013; Tang, Ash, Bates, Overhage, & Sands, 2006). The questionnaire also asked questions about the level of engagement with My HealthVet, how they used the system with patients, the kind of materials the provider shared with patients during a clinical encounter, the provider's experience with having family members and caretakers who attended clinical meetings with the patient, and other questions that related to identifying information the provider shared with the patient and vice versa.

The patient-focused questionnaire differed from that of providers by asking patients their experience using MHV as an information management tool, the type of account they had,

use of secure messaging, time spent using MHV, and other data and information they used in conjunction with or when using MHV. Questions on the patient questionnaire focused on eliciting events and processes of patients' health information management experiences whether those experiences were with MHV, without MHV, using physical objects or any other means they managed health information. It is easier for patients to remember events that are associated with particular practices, for example why they write down their blood pressure might be linked with a particular event. Distributed cognition is an event-focused framework that is most fruitful when looking at the collaboration and work done around specific events. Given this, I asked multiple questions framed by events so that those events might be unpacked further and more clearly by the patient as they focused on events they remembered rather than try to answer general questions about specific behaviors. This strategy also allowed me to understand more about what and how particular events became distributed to other actors and objects.

The questions posed in the questionnaires were open ended and designed to generate in depth conversation about the process, problems, technologies, and distributed aspects of information management. The function of the questionnaire was to give the participant time to compose their thoughts and provide information to be discussed during the interview, allowing me to get to more detailed information during the interview. This strategy also familiarized each participant with the general theme and direction of the study and better primed them to think about experiences and practices of interest to this study. The questionnaire is located in appendix four.

3.3.2 Interviews

All 22 patients participating in this study were U.S military veterans enrolled in My HealtheVet with an in-person authenticated account. The in-person authentication means that the veteran has access to the entirety of their medical record at the VA. In order for a veteran to have access to every aspect of their personal health record, they must show up to a VA My HealtheVet coordinators office at a VA medical center with a form of government ID. After going through this process the veteran is authenticated, and thus receives additional access to their medical record. They can then view the medical education library, renew prescriptions, send secure messages to their various health providers—both specialist and primary, view lab work and test results, see clinical notes including mental and behavioral health clinical notes, view an appointment calendar, and finally export all documents into a variety of document formats.

Every patient was interviewed at the Syracuse VA Medical Center in a private office routinely used for in depth interviews. The room contains a desk with a computer, a round table and three chairs next to a window. Critical to the interview is that the room is in a quiet location and has a door that can be shut for increased privacy. The privacy of participants is key because talking about the use of technology, My HealtheVet, and the role of family members and caretakers for managing and organizing health information is inextricably bound up in the health events of every participant. Additionally, interviews were scheduled when participants had just finished a clinical appointment, right before they were to attend a clinical appointment, or within days of attending a clinical appointment. This was also integral to the interview process because patients often brought information relevant to the clinical

appointment with them. This allowed me to take notes about objects and ask the participants to walk me through how they use technologies such as phones and tablets. The interval of time between a clinical appointment and this interview is also critical because participants had often just performed many of the practices relevant to the inquiry of this study, facilitating vivid recall and often reminding participants of additional experiences relevant to this study.

All interviews with patients were conducted using a semi structured interview protocol to allow for consistent data gathering. Probing questions and follow up questions were used as the interview unfolded to investigate different concepts essential to the research questions this study asks. The nature of all patient interviews are to understand the use of information, strategies developed, and organizational techniques of the patient. This includes which technologies are used, what the patient does, what other social actors do in this ensemble, decision criteria and logic behind choices for why to use paper or a digital technology, and how they use My HealthVet for health information management. Because the act of organizing, using, and creating health information or interacting with a health record is inextricably bound to the health of that individual, the interviews are deeply connected with stories about surgeries, long term illnesses, cancer diagnoses, PTSD, weight loss programs, mental and behavioral health therapy, Parkinson's disease, and many other health events that cause people to organize, use, and act upon information to learn about their health conditions, work together with providers, understand treatments, maintain healthy routines, and overcome a myriad of health issues.

Because interviews took place before or after a clinical appointment, I was able to view documents and ask that participants walk me through how they use their smart phone or

tablet, which was carried on their person, when attending an appointment or for managing health information. We discussed the phone apps (applications) they use and how various home screens are organized. Though not every participant used a smartphone or tablet to access and organize information, this often provided yet another way to develop a picture of the general workflow of patients' information management strategies and how these PHIM practices are assembled over time.

The protection and security of recorded interview data is of the utmost importance to this study. Other than informed consent documents or the list of participant names and pseudonyms, recorded interviews are the only information collected for this research that contains identifying information. Participants may be identified by the sounds of their voice if someone were to listen to the interview recording and recognize the sound of a participant's voice. To this end, digital sound recordings were transported securely in a briefcase using a combination lock while in transit from the research site to my office where interview data was uploaded to a secure network drive. Any documents collected, while none contained identifying information, were also secured in the briefcase while in transit.

3.3.3 Observation

As evidenced by the pilot study and contextual literature review of related studies, physical objects are important to patients who work with health information. This study observed the use of documents and mobile phones that encapsulate the ways in which people manage health information. Because interviews were secluded before or after a patient's clinical appointment, many patients had important documents on their person or their caretaker was able to provide documents during the interview. Additionally, patients that use a

mobile phone allowed me to observe the ways in which they used the phone for health information management. The physical documents patients possessed in conjunction with mobile phones provided a great window into the type of distributed health information that patients carry on their person.

Additionally, over 15 hours were spent on unobtrusive observation of patients in waiting rooms, pharmacy pickup areas, common areas, and throughout the medical center. This unobtrusive observation supported the overall understanding of the role of documents and information to the patient in the medical center. Observations were also performed in the provider's office where each provider was asked about their workflow and interaction with MHV. During these observations providers spoke aloud how they would use the computer as they reproduced common practices. Throughout this process of observation field notes were written and later elaborated through analytical memos.

3.3.4 Data Management, Security, and Protection

Physical informed consent documents along with any physical documents and notes were secured in the investigators locked fireproof filing cabinet. I developed a data codex to manage the variety of digital documents. This data codex included participant pseudonyms (no linking or identifying information) along with materials collected and generated by each participant including analytical memos, digital field notes, photos, and transcript documents. The data codex also listed the meta data of each digital document including location of the file and a short descriptive note about the document. The data codex was maintained throughout the course of the study and is a summative and descriptive spreadsheet which provides a high level snapshot as to the status of collected data and data generated from analysis.

While the data was organized and managed through a clear file folder structure, the qualitative data analysis software Atlas.TI also possesses data management tools. Data was imported into Atlas.TI from the location on the network drive. Once in Atlas.TI the data could be commented on and connected to provide further organizational schema. Transcripts were anonymized by removing any specific names, dates, or individually identifiable health information.

Digital audio files of interviews were uploaded to my personal data space inside the Syracuse University network. The computer used to access the Syracuse University (SU) data space is password protected and two factor authenticated. Additionally, I connected to the Syracuse University data space using an encrypted VPN tunnel. All accounts are secured using a complex password and two factor authentication. The method of two factor authentication is a hardware token requiring authentication through a USB interface, the token generates a one-time password that is validated through an Advanced Encryption Standard (AES) check. This data resided on the SU server while interviews were transcribed and data was analyzed.

The Syracuse University dataspace is backed up on a nightly basis to an on campus datacenter. Once each week, the datacenter is backed up to encrypted tapes and stored at a secured offsite location. My personal dataspace is private and linked only to my own account. The physical servers are used to routinely store sensitive and private data. As such all management access to these servers (remote desktop, remote PowerShell, RCP) is restricted to the CSS management servers which are protected with a two-factor authentication method and only available from specific secured machines on the campus network.

The participant dataset that connects a participant to a pseudonym, and any identifying details such as an address for a home visit, were not stored with the research data. The database of pseudonyms and any identifying information that was collected to conduct this research resided on the VA internal network, specifically the X drive developed and used by the Center for Integrated Healthcare (CIH). This network drive is routinely used for sensitive research data. The X drive is backed up, redundant, encrypted, and secured both physical access and technical access. I connected to this network drive using an authenticated VA account through a secure VPN tunnel and complex personal password. In case of a data breach or leak of information suspected, or if research instruments such as physical questionnaires or audio recorded were lost, an information privacy officer and information security officer at the Department of Veterans Affairs would have been promptly contacted and made aware of the situation. This did not occur during my study. Upon the conclusion of this research, all collected data was archived on the CIH X drive for the length of time as recommended by VA best practices.

3.4 Data Analysis

With careful consideration of the needs of the study and construction of this research design, I weighed appropriate analysis techniques to determine that computer assisted qualitative data analysis (CAQDA) offered the best fit for this study. My logic for arriving at this decision was four fold. First, CAQDA offered data management and analysis tools that helped standardize each step in the analysis. Second, qualitatively coding the data is a focused, analytical process with many methods of coding available that are capable of analyzing many diverse data forms. Third, coding the different forms of data is an iterative process that

required that the researcher work closely with data. Because I will perform observations, conduct interviews, write field notes, and administer questionnaires, coding these data afforded me additional close connection to the data, allowing for greater insight. Fourth, and most important, the methods of qualitative coding I selected connect to and compliment the conceptual framing of this dissertation research.

The research questions posited in this study are rooted in an epistemological understanding of the phenomenon of interest; they ask ‘what’ questions and are concerned with influential factors and the exploration of patient actions and processes in the data (Trede & Higgs, 2009). The research design is a descriptive multiple-case cross-case analysis between frequent and infrequent users of My HealthVet. It follows that the methodological needs were descriptive and the analysis was appropriate for case study design research. Because semi-structured interviews and observation were two of the main data collection methods, analysis had to support open-ended investigation. Additionally, this study is framed by theories of assemblage and distributed cognition, so a reasonable analysis needed to be framed by these perspectives.

The coding framework that provided substantive analysis is a two cycle method. The first cycle used process coding and the second cycle pattern coding (Saldana, 2013). The logic for this configuration along with further guidelines are discussed in 3.4.1. Throughout the process of data coding, I wrote analytic memos during all coding cycles as both a reflective practice for data analysis and to serve as an additional analytical tool. Also, throughout memo writing and data coding I developed cognitive maps as an additional analytical tool.

3.4.1 Coding

Upon gathering the data, initial coding took shape in the form of a preliminary analysis using attribute coding (DeWalt & DeWalt, 2010; Gibbs, 2008; Lofland, Snow, Anderson, & Lofland, 2005). I used this coding method early in the analysis as a way to enhance the fidelity of the data by practicing good data management and to add further attributes to the participants of this study. Attribute coding is applicable to all qualitative studies and is the process of documenting general attributes to participants, for example: gender, age, sex, ethnicity, social class, religion, format of the data, date, location of the site, timeframe, list of activities observed, environmental factors, weather, mood, etc. These are examples of attributes and not a list of the attributes this study anticipated collecting. However, attribute coding served as a first pass phase of data analysis, allowing me to get a general feel for the data and to highlight important quotes in the data that stood out and required scrutiny through the more focused first and second cycle coding.

My conceptual bases for additional cycles of coding were assemblages and distributed cognition. These frameworks are practice based perspectives grounded in the idea that social actors create and recreate social structures through practices of health information management. Distributed cognition looks at the artifacts, objects, technologies, software, people, and practices that are imbued with cognitive properties in some way. Similarly, assemblages are a way of thinking about the whole in relation to various smaller parts and contexts which can change over time. Central to assemblages are the collections of elements that the patient knowingly or otherwise calls into action around themselves. These elements come into coordination and stabilize to allow health information management work to be done.

Coding methods should facilitate this theoretical framework and allow the analyst to look for emergent patterns, connections, and relationships from data collection of patient work that is complex, idiosyncratic, situated, distributed among many heterogeneous social and technical actors, yet highly individualized from patient to patient.

For these reasons, I view process coding as a data analysis method that overlaps with the practice based perspectives necessitated by distributed assemblages (Bogdan & Biklen, 2007; Charmaz, K., & Belgrave, 2012; Corbin & Strauss, 2008b). Process coding focuses on “-ing” words, or action words, suggested by the gerund, or non-finite verbs (Saldana, 2013). This method of coding is complimentary to investigations that look at observable behavior as well as conceptual actions. For example, this code method is optimal for analyzing how patients practice health information management through: organizing, searching, taking pills, working with My HealtheVet, and other observable information management work. Equally important are conceptual tasks that patients and associated providers or family members undertake, such as: struggling to understand information, negotiating, thinking of questions, or recalling information mentally. The different processes that each actor in the assemblage undertakes is equally important to its function as a whole. Likewise, digital technologies and objects were also analyzed with this first cycle process coding method. This helped me to understand what tools or social actors were doing what work and to hone in on ongoing actions, practices, and interactions mingling between social actors and objects.

After preliminary attribute coding and first cycle process coding, I concluded coding with a second cycle using pattern coding. Pattern coding is a method to develop meta codes from further categorizing and grouping of the codes developed from the first cycle (Miles &

Huberman, 1994). It is through this pattern analysis that the data are further organized and deeper meaning is attributed. Codes are grouped into focused constructs and major themes in the data such as rules, causes, explanations, examination of networks, patterns of relationships, and the forming of theoretical constructs. Pattern coding proved an important analytical technique because it was where I began to see the larger context and assemblages begin to form through the analysis. This two cycle analysis is framed to first look for connections, distributed interactions and relationships, and then use the second cycle coding to abstract those codes into assemblage-like structures that are the premise to this study. I then applied these assertions to the research questions.

Essential to any form of qualitative coding analysis is the rigor of clarity, documentation, and detail put into the codebook. To develop a rigorous codebook, each code used contained the following seven properties (Bernard & Ryan, 2010):

1. Short description: The name of the code itself or any shortened abbreviation for the code.
2. Detailed description: A two to three sentence description of the coded datums qualities or properties. A longer description of the meaning of the code.
3. Inclusion criteria: Conditions of the datum or phenomenon that merit use of the code.
4. Exclusion criteria: Exceptions or particular instances of the datum or phenomenon that do not merit the code.
5. Typical exemplars: A few examples of data that best represent use of the code.

6. Atypical exemplars: Extreme or special examples of data that still represent the code.
7. “Close, but no.”: Data examples that could mistakenly be assigned this particular code but are not applicable and why. This is to avoid ambiguity and confusion of using certain codes.

To be clear, these seven elements of the codebook were developed as the codebook was finalized and stabilized. The process of developing the codes and associated codebook was inductive and iterative as more data was collected, analyzed, interpreted, and codes were made concrete. While the process of coding was underway I wrote analytic memos in support of my analysis. Once the data was analyzed through CAQDA and the analytic memos were concluded, I used the results to further develop a cognitive map as an analytic method to understand the distributed assemblage and make assertions to the proposed research questions. The following figure visualizes the data analysis workflow. The use of analytic memos is detailed in section 3.4.2, and cognitive mapping detailed in 3.4.3.

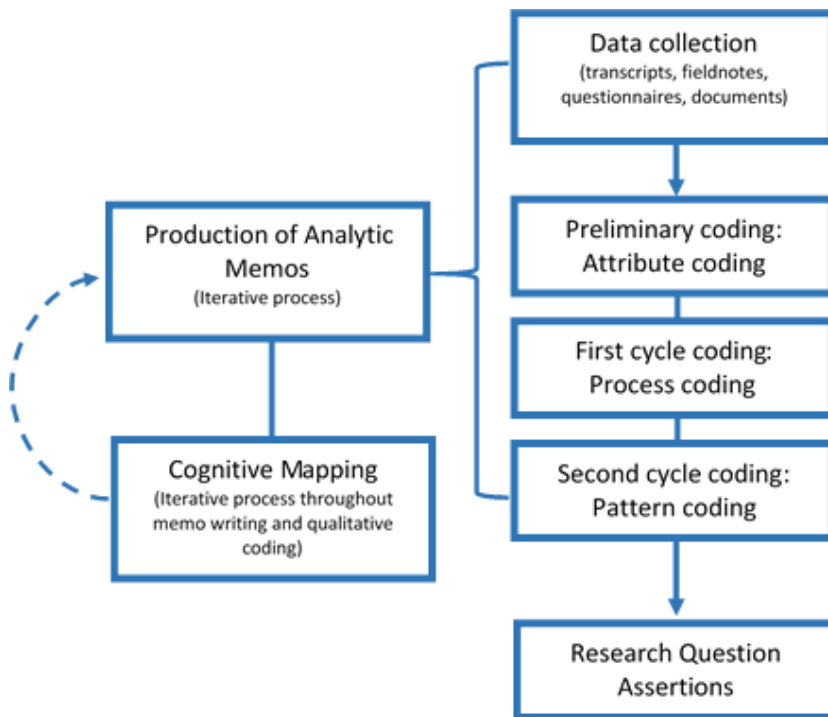


Figure 5 Data analysis workflow

3.4.2 Analytic memos

The use of analytic memos during coding help me reflect on the data. In essence, analytic memos are sites of conversation to the researcher about their data (Clarke, 2005). These memos go hand in hand with qualitative coding as they are a tool to reflect on the coding process, to refine codes, and to interrogate the data further. Memos were produced after every interview and during coding sessions to capture important insights and information during the analytic coding process. Memos were reviewed during data analysis and also integrated into the development of a cognitive map. I adhered to the useful heuristic for memo writing found in the M.E.M.O acronym, meaning: (M) Mapping research activities and documenting the decision-making process of research design and serving as an audit trail, (E) Extracting meaning from the data in the form of analysis, interpretation, concepts, assertions, and theories, (M) Maintaining momentum of perspective, reflexivity in thought, and the evolutionally journey of

the study, and finally (O) Opening communication from researcher to other researchers, team members, or advisors, promoting transparency in data analysis (Birks, 2008).

3.4.3 Cognitive mapping

From chapter two in the review of the theoretical perspective, figure 1 shows an example a cognitive map. However, when informed by empirical data using a case study research design and analyzing the data through process and pattern coding, highly detailed cognitive maps were developed to accurately reflect the social and technical actors in the assemblage. This includes who manages what objects or technologies, how they are used, and what other practices and processes they support, duplicate, or hinder. This cognitive mapping also serves as a partial view into the assemblage, or objects, people, and practices, which come into stabilized coordination around the patient. I used the creation of a cognitive map as an additional analytical frame to understand the data; the production of one cognitive map per case in this study also served as a useful point of compare and contrast for a cross-case analysis design (Miles & Huberman, 1994; Northcutt & McCoy, 2004).

The precise workflow of developing the analytical cognitive maps occurred adjacent to memo writing. Directly after an interview, I developed an initial map alongside the memo. I would plot the patient on the map and draw nodes and edges connecting the different actors while the interview was fresh in memory. I revised this map with each coding cycle, viewing it alongside the textual data. This practice served as an additional check on the data. This allowed me to add any missed connections or actors. Also, the map allowed me to visualize the interview data as I progressed through coding. This practice resulted in a highly organized interview transcript, set of memos, and detailed cognitive map. Surveying the final products of

this analytical process left me with the notion that they clearly and accurately represented each case in great detail. As a result, I found this data analysis workflow to be ideal for crystalizing the interviews, surveys, and field note data to describe each case.

3.5 Credibility, transferability, dependability, and confirmability

Multiple analytical techniques and procedures were deployed throughout this research process with the goal of maintaining dependability and credibility consistently across the study. It is through the rigorous attending to these concepts that research is judged as rigorous and confirmable. In this section, each of these concepts are clarified and a strategy for maintaining credibility, dependability, and transferability is presented.

Traditional criteria for evaluating research include internal validity, external validity, reliability, and objectivity. Alternative ways to think about these concepts in a more qualitative frame are credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Hence, I will be using this qualitatively focused framework to discuss the validity of my research. Dependability is based in the assumption of being able to recreate or reproduce qualitative research, and that the researcher is responsible for adequately describing the research setting and how any changes in the setting may affect the study approach. In essence, is the researcher diligent in capturing the social phenomena and setting. The traditional analogue for this criteria is reliability, which refers to the accuracy of data collection instruments and protocols. In order to estimate reliability, accurately measuring the same concept twice, quantitative researchers utilize notions like true score theory. (Krefting, 1991).

External validity, or transferability, amounts to the generalizability of the research. In qualitative or mixed method research this means analytical generalization rather than statistical

generalization (Yin, 2014b). The transferability of research can be enhanced when the researcher gives thorough descriptions of the context and assumptions of the research. While the context of this study are veteran patients who receive care at VA clinics and facilities, great effort has been put toward theoretical, analytical, and conceptual generalizability in which the findings of this research can be applied to similar contexts and may be useful in similar areas of health services research. Additionally, the conceptual framework of assemblages is a perspective that also supports the idea of generalizability. That assemblages can be transferrable or modular in nature. The components of an assemblage aim to be general enough that those components are likely to be sensitizing concepts in related phenomena or contexts.

Internal validity, or credibility, speaks to the degree to which the study investigates what it has set out to investigate, and if the analysis is also trustworthy, along with the strength of the findings. In qualitative research, this also implies that the participant is accurately portrayed through the research. This is why I emphasize the use of multiple triangulation techniques to accurately portray the participants. Multiple cycles of coding along with extensive memo writing, dissemination focus groups, and the use of the analytical cognitive maps help achieve the accurate and credible representation of participants through the research process.

In research that is qualitatively focused and relies on interviews for data collection, the notion of validation should be a practice that saturates all stages of the research process (Kvale & Brinkmann, 2008). Some of the strategies to incorporate validation techniques include the use of a pilot study, dissertation committee review, and a proposal defense for the research design validity. During data collection, interviews were conducted iteratively and fine-tuned as

additional interviews commenced. Field notes and transcript reviews were also conducted during data collection as a validity check. For data analysis, memos were written and double coding was used in the form of initial coding and focus coding (Miles & Huberman, 1994). Validity in reporting is checked through both peer review and the dissertation committee review of this research. Internal and external validity is checked through the process of multiple reviews, an audit trail of memos, a research reflection journal, and multiple forms of triangulation. The table below provides an overview of the multiple validity checks I implement throughout this study and links each validation check with each phase of the research process.

Phase in Research Process	Validation checks
Conceptual/theoretical framework	Literature review
Research design	Pilot study, dissertation proposal, dissertation committee review
Data Collection	Iterative fine tuning of interviews, field notes, triangulation of sources
Data Analysis	Memo writing, double coding (two cycle coding)
Reporting	Peer review, dissertation committee review
Establishing Credibility	Multiple reviews, audit trail (reflective writing project journal), dissertation committee review
Transferability	Replication of selected cases, description of research context

Table 4: Assuring validity throughout the research process

A widely used form of creating a validity check in qualitative research is the use of member checking or participant review. This strategy means the researcher goes back to the participants of the study to review a provisional report resulting from the analysis. The process can be thought of as “asking the data” and including the participant who provided the data to

review the information and help determine if the researcher has accurately captured and reported the participant's experience (Koelsch, 2013).

Due to the logistics and timeframe of this study, the use of a member check validation strategy was not possible. Many of the participants in this study live far away from the VA medical center where this research took place and participants were only in the area for a clinical appointment they had recently scheduled. Requesting many of the research participants to review a preliminary report of their involvement would place an additional burden of travel. Instead, as an alternative to member checking I relied on a dissemination review group to serve as an additional validity check. The dissemination review group consisted of my dissertation committee, of which two of the members are VA employees.

Chapter Four

4. Findings

The motivation for this study is to understand and articulate the health related information management work of patients, and to frame that work in a context of distributed cognition networks and assemblages of tools, technologies, and people that actuate components of health information management. In this chapter, I display the analysis by research question in order to provide answers to each research question directly as a result of the analysis. Research question 1a addresses the specific bundles of practices of veterans. Additionally, two specific interactions that veterans have with MHV emerged from the analysis. It is in RQ1a that I discuss the two major groups of MHV user types that I use to categorize and organize the data. Then, for research question 1b I begin to trace the distributed practices and components of this health information management work that rely on people other than the immediate patient. It is in research question 1b that I also provide an overview of provider participants in this study and the ways in which providers connect to patients through this sociotechnical infrastructure. Research question 2a displays the three specific assemblage components that were discovered by this research. Lastly, research question 2b evaluates these assemblage components in terms of their functionality to health information management and key factors that stabilize or destabilize a patient's distributed health information assemblage.

Before directly jumping into the research questions I survey the data and situate my analytical process. Evident throughout the qualitative coding process, analytical memos, observations, and during interviews, is a rich set of practices that these veteran patients have developed over years, even decades, for dealing with a variety of diagnoses and health events. The heart of this research is about the distributed practices and the creation of assemblages through health information management. However, the first research question focuses solely on the work of veterans that have access to a personal health record. Analyzing these data, two types of work clearly emerged: work that is distributed to involve other people, such as friends and family members, and work performed entirely by the patient. Both of these types of work include the use of other technologies, tools, and documents. It is a challenge to analytically separate purely individual tasks and purely distributed tasks, so to address this, as shown in Figure 5, I establish a chain of inference through the coding process with the goal of providing a visualization that illustrates the connections between patterns and practices.

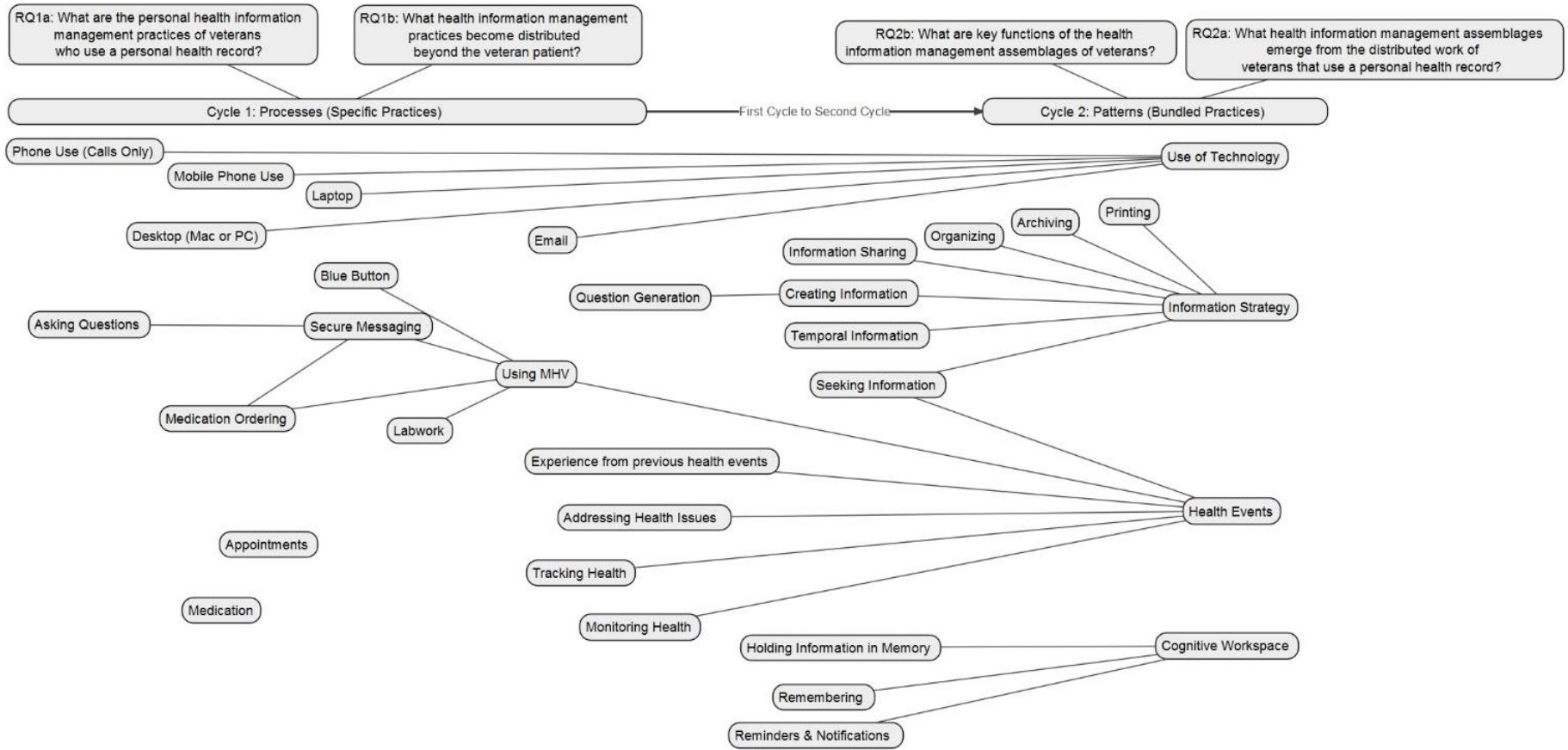


Figure 6 Concept coding map

There are four over-arching patterns that were identified during the analysis. I use these patterns to articulate the implications for the second set of research questions. The practices associated with each set of patterns are used to articulate the first set of research question. Each of these four patterns contain a bundle of practices, people, and technologies associated with each pattern that address the assemblage perspective of this research. Research question 2a looks at patterns that emerged from patients' distributed cognitive information work and asks the question: *what health information management assemblages emerge from the distributed work of Veterans that use a personal health record?* Research question 2b presses on the findings from the aforementioned research questions and demands further analysis of the function and utility of health information assemblages by asking the question: *What are key functions of the health information management assemblages of veterans?*

Patterns of *technology use* are practices and processes where in different technologies, such as laptops, mobile phones, desktop computers, and specific software like email and MHV, are used for health information management. Patterns of *information strategies* are bundles of practices and actions by patients and caretakers for creating information, organizing schema, seeking information, generating questions, storing information and data--all ways of working with printed information and digital information. Patterns of *Health events and wellbeing* emerged from the specific events where participants discussed a variety of health events that were connected to information management tasks. Health events include surgeries, being hospitalized, receiving diagnoses, participating in a health program such as weight loss, and any other even that signified a change in health status or required an action of the patient to address health. It became clear that health events set other information work into motion and

this pattern emerged from the many practices associated with health events, such as tracking and monitoring health that the patient engaged in to address health concerns. The fourth pattern was influenced by the distributed cognition perspective used in this research. The fourth pattern is also reliant on the observational data pointing to the overwhelming amount of information work that patients do using their own memory. In referring to this pattern I use the phrase *cognitive workspace* to highlight this type of work for patients. Cognitive workspace tasks comprise practices like remembering medical information during an appointment, when to take a medication, when and how to engage in a self-treatment routine. These tasks require holding information constant in the mind as veterans research information about a disease they have, or to articulate complex health questions to internet search engines. All of the health information management practices up to this point entail some component of writing information down, storing it in documents or digital files, printing or browsing webpages, and the like. Practices connected to the cognitive workspace pattern of management involve information that was carried from a clinical appointment only in the veterans' memory. This type of cognitive workspace practice includes information that may live only in the patients' mind, specifically experiential information about the side effects of a variety of different medications, the data from using a scale or blood pressure machine daily, or other experiential information and data about the veterans' health. These patterns must be unpacked to understand the practices of veterans; I now proceed with displaying the analysis for each of the four research questions. It is through these four research questions that the previous concepts and practices I have now defined become discussed in greater detail.

4.1 RQ1a: Veterans' personal health information management practices

The first research question I ask functions as a baseline to trace the practices, tools, people, and objects that become enrolled in the veterans' health information work. With this goal in mind, I ask the question: *what are the personal health information management practices of veterans who use a personal health record?*

The three sub sections for the first research question describe themes that emerged from analyzing the data. The three practice themes are: *intentional and coincidental reminder systems*, the *information organization schema* practices that patients develop themselves, and finally practices that involve the *creation of information* such as questions that are derived from gathered health information by the patient. The three themes, which I detail at length below, are broad practices that veterans actuate themselves; they are situated practices performed by veterans inside and outside of the home. Each theme is made up of several singular practices that support one of the three broader themes.

4.1.1 Intentional and coincidental reminders

A logical place to start tracing veteran information management is to look at the work that occurs when a veteran has an appointment. Every veteran in this sample is made aware of an appointment, whether an annual checkup or specific clinical appointment, through a letter. Sending a letter to announce an appointment is standard protocol by the VA. When veterans receive this letter it serves as a reminder and is kept in paper form but also replicated in other areas. Everyone participating in the study also puts this information in a calendar – often two calendars. Those who own a smartphone or any phone that has a basic calendar put in in their phone with a reminder. Everyone also has some form of physical calendar, whether a

whiteboard or traditional wall calendar. This practice serves as a common place for other people in the household to see the veteran's schedule and know when they have an appointment. The location of the physical calendar within the home is also important in that there are specific places a calendar can be located. If a calendar is not placed in a home office, it is placed in a location that was part of the veterans' routine, such as where they make coffee every morning, in the bedroom, or in a hallway they walk through frequently. The following exemplar shows the importance of placement for a physical calendar and an awareness of daily routine. Knowing these two factors, spatial layout and daily routine, enables the veteran to create passive reminders by locating information within the physical context of that routine. The exemplar of this situation is as follows: "I make coffee, look up and there's a calendar there with my appointments on it and I know what's going on that day. I make coffee daily, so it's more like I have to look at the calendar, like today I have an appointment, I wouldn't have known that unless I had written it on the calendar" (Patient #8530). The information for all appointments lives in several places: on the letter, which is kept and placed on a desk or common area, for example by the door, in the house as well as in digital devices when the veteran owns a device, and in a physical calendar. My HealtheVet also stores appointments in a calendar and, when in an office or out of the house or on travel without adequate information, MHV was accessed to view the appointment calendar if the veteran thought they had an appointment soon.

The majority of practices around creating external reminders and the act of remembering is connected to either appointments or medications. Medication management, however, were overwhelmingly handled or shared by caretakers when a caretaker was present.

Practices for remembering appointments include the location of a calendar, digital timed reminders (e.g. in a phone), other people in the house remembering, and the physical location of appointment letters. For other aspects of health management, such as lab work, information seeking, or asking questions, there were no clear reminder systems. These activities are all triggered by health events like feeling ill and subsequently looking up symptoms on Web MD or the MHV educational library. The differentiator between using reminders and not is in the intentionality of the practice. One is entirely intentional: the patient has an appointment they need to remember so they set a calendar appointment reminder in their phone or put the letter in an intentional place they see every day. Things like information research and interacting with the health record are coincidental, the patient may intend to look at a lab but it is actually triggered by another event like being sick or preparing for an appointment. These coincidental reminders were never intentionally set, but motivated by other information or events that trigger an event. Another example is when a veteran has a secure message waiting for them in the MHV account, they receive an email alert that there is a new message waiting for them and to log into their MHV account to see the secure message content. This email alert is coincidental and triggers practices like ordering medication, looking up medical information over the internet, or responding to another message. This coincidental reminder may also generate intentional reminders, often a secure message may be to confirm an appointment, in which case the patient intentionally sets a reminder for the appointment instigated by the coincidental email reminder.

4.1.2 Information organization schema

A clear set of practices emerge around the act of organizing, which in itself is a way of understanding information and expressing thoughts about the information being organized. In a few cases participants had little to no technical skill other than being able to log into MHV and use its features. These participants were still capable of using MHV and interacting with it, but their use of technology was limited to superficial interactions with technology. Participants with limited technical skill still owned consumer electronic technologies, such as mobile phones and tablets and laptops, but the use of these objects was limited. There was no organizing of digital information by the participants. In these cases, if a PDF was downloaded it would be saved to the default download directory, opened automatically in their browser and viewed once. The document would not be deleted or moved or archived but used and then forgotten. If the document needed to be used again, then the veteran would search for the document again, retracing their steps for finding and downloading the document. If something did need to be kept that was digital, it would be printed. The term “hard copy” was repeatedly used among participants who had an ephemeral feeling toward digital documents and that paper copies had a lasting and permanent feeling about them. That digitally-encoded information was not real, nor could it be worked with and manipulated unless it was printed as a hard copy. It was when information was printed or in hard copy form that it would be worked with and used. One veteran explained the usage of hard copy papers as follows: “I do a lot of compare and contrast but only by hard copy. Yeah, I’ll pull up one source and they’ll tell me they’re doing something or what they’re doing, one source, and then I’ll maybe by accident or by choice I’ll have another

source and it gives me a different definition and I'll just look at the two of them. I'll print it out but I like to print, I like hard copies" (Patient #7543).

In keeping with the characteristics of physical or digital documents, from the interviews I conducted those that preferred printed materials had consistent practices for how that information was organized and accessed. In all instances it was either a series of manila folders or similar document storage where printed documents lived into the long term. These health documents often accompanied things like paper military records and other service related documents. The decisions veterans made for keeping printed materials were based on retrievability and the perceived need for the document in the future. Printed clinical materials, such as general information about a particular illness or medication information, were thrown out if they knew they could just as easily find the information online through using a search engine and retracing the steps of keywords they used and links that were clicked. Specific information like lab reports were not kept if patients both knew about and had the skill to find the same lab results in their MHV account. This was a technique found in the information integration group as they had the highest proficiency and familiarity with MHV functionality. The need for the document determined if the paper copy was to be held long term or archived. Things like post-surgery guidance or physical therapy paper documents were far more likely to be kept and used. The refrigerator was a popular location to affix paper documents with magnets. This strategy denoted the document had relevance to other members of the household, or that the document would serve as a reminder. A typical situation follows: "Right now I'm doing therapy so they gave me this [produces paper to show]. When I get home I'll put it on the refrigerator and when I'm done my wife has shoulder problems too and this would be

good for her also” (Patient #4516). In this exemplar it is a physical therapy routine that gets placed in a common location because of the information’s relevance to the veteran’s wife. Other typical uses include appointment letters on the refrigerator when another family member is responsible for the veteran’s transportation.

Paper documents also are important because they are a form of proof. Whenever there were administrative tasks that the participant engaged with, these were exclusively handled through the printing and transfer of paper documents. These documents could have been transferred digitally through email or other systems in some cases, but in all instances the discourse around paper is as an official document, and it was in paper form that documents were used to conduct work with other professionals such as lawyers, doctors, and insurance staff. One veteran kept a letter that explained a diagnoses they had received in order to communicate to others that the diagnosis was authentic and what it meant:

I still have the letter that she sent me telling me that they found nodules in my lungs.

Because how many people do you know have nodules in their lungs, and I would go to my friends and say I’ve heard of cancer, have you ever heard of something called nodules. No, no, nobody, so it was new to me. So for three months I sat petrified thinking I had something super bad and to find out no, it’s an inflammatory illness. (Patient #2251).

Other participants chose to print or keep paper documents to facilitate various exceptional medical or legal work. Several veterans had the experience of developing appeals, claims, or other official cases, and while some of this work was handled digitally only paper documents had an affective association of *proof*, as one veteran bluntly put it: “I’m looking at [printing a document] if I need a piece of paper to prove something to somebody because somebody

called me a liar. It's usually my lawyer and when I got beat up or you needed something to prove to the DA or somebody like that, that needs concrete proof because that's what they need" (Patient #1640).

Participants that used printed documents had remarkably similar practices with how they were used and stored; however, digital documents and digital objects (such as phone apps/applications) had variance in the ways in which they were organized. I refer to the ways that individuals organize things as organizational schema. Meaning a patient's particular approach for how they might organize documents alphabetically, or by the names of surgeries, or by the name of the clinic they attend. There were far more possibilities for organization strategies when interacting with digital documents and objects. The de facto method of organizing PDFs and other documents and objects on local hard drives was to create a "health" or "medical" or "VA" folder and store everything in there. If there were too many files in that folder then similar files would be grouped, typically by health condition or year, and put into their own folder. This method was used by every participant that had digital information in a digital file system and that knew how to browse and organize files on the hard drive. If the participant did not know how to browse a file system and organize files, then every digital file they download was kept in the default downloads folder. If they needed the file again they would download it again.

Other than the default practices of organizing digital files on a local hard drive, I detail three exemplar cases that each feature unique organizational approaches to digital health information management. The first unique digital document organizing strategy arose in more than three cases: the practice of attaching health records and health information documents as

a PDF to emails. These veterans would email themselves digital files they plan to keep; they use email as a storage container and organizing tool for the PDFs. They provided three explanations for this practice. One is the ability to sync files (via an email IMAP server) to other computers or devices. This occurred between different computers or devices in the same household and also occurred between household computers and an office outside the home or work computer. Second, having access to documents at restricted computers in a work location where software is not allowed to be installed. The practice of keeping documents in email allowed them to be viewed directly in the email without the need to save them on a work hard drive. Not only did this circumvent any restrictions on non-personal computers, but it was seen as a security tactic because no documents were saved to the hard drive. The third benefit to participants is they use storage in email as a sharing practice. Caretakers knew how to access the patient's email and reference any document contained therein.

The second strategy I encountered is the use of digital objects and cloud storage services other than email. Specifically, Google docs was used to organize information either in a series of documents or one long running document meant to represent a specific health condition or theme. These cloud based word processor documents are an analog for the health folder. Instead of individual files with patient information all grouped by a common theme represented by the folder, the continuously running text document became the folder. Without the use of a folder to provide a label or category of the contents contained within, the single document became the label or category for the information contained in the document, and the document content grew with information rather than the number of documents multiplying inside a folder. These cloud based documents also had the function of synchronizing to multiple

devices and allowing other caretakers or household members to access the information--a similar practice to how email was used. Smart phones were used to access the internet and search for health related information by every veteran that had access to a phone with a data connection. In most cases various health related tracking or information apps were used to varying degrees of adherence and success. These apps were placed in a "health" related contextual folder or found grouped in their own screen. Smart phones were also used to store quick notes, voice notes, and other scraps of information if paper was not used to capture information.

The third practice unique to digital interaction also occurs with physical documents, but the frequency of information seeking and constant availability afforded by smart phones, laptops, and tablets in any location makes this a primarily digital practice; that is, keeping information in memory. This has been discussed in the findings here as a concept I described earlier called *cognitive workspace*. This theme arises throughout several points in the findings because it was ubiquitous.

Every participant that had the capability to run a search query on their phone did so. A handful used their phone's internet browser to log into MHV to reference information while they were not at home. Accessing and working with information on the go like this creates the need to remember information that had not been written down or stored. This scenario and its ramifications for health management is the crux of the cognitive workspace. Up to this point the practices I have described have been performed by the individual patient, such as the ways veteran patients organize information, interact with the My HealtheVet personal health record technology, and distribute reminders to other objects and social actors. These are all ways the

patients' cognition is imbued on external objects, organizational schema, practices, and social actors. The identification of cognitive workspace practices presents a challenge to distributed health information assemblages because there is no external information outside of the patients own cognition. Some of this information may eventually become written down in a secure message, a note on a phone, or find its way to a scrap of paper. However, the majority of cognitive workspace practices are *experiential* as in they add to and concern the participants' experience and knowledge about themselves, their body, their health condition, and how they live life. These kind of cognitive workspace practices include keeping gym routines, workouts, and repetitions in memory, remembering body weight numbers, blood pressure trends, blood glucose and other bloodwork and lab result data, remembering conversations with providers about treatment regimens and special instructions, remembering medication effects, and remembering questions. I situate these cognitive workspace practices in the organizational schema section of personal health information management practices because even with the absence of external information, this is still an organizational schema. Rather than write things down and work with documents and objects, information is organized and interacted with in the patients' cognitive workspace.

Cognitive workspace practices are strictly immaterial in how the information is managed. Each patient has variability in what practices they allocate to a cognitive workspace and which ones they engage with in a way that is external to their cognition with some kind of material information or digital object. A popular practice was for patients to keep questions written down in a familiar location. Questions that were not bound to a physical or digital document meant that all other patients' held this information in their cognitive workspace. The third

section of health information practices presents the findings associated with *creating information*. If a patient does not engage with information in their cognitive workspace, then they actuate a set of practices I categorize as creating information in which veterans actively synthesize information from multiple sources into meaningful organized representations for later use.

4.1.3 Creating information

Another important practice that emerged out of looking at the ways in which patients organize, manage, research, and consume their health information is the ways they create information. The most common process of this practice is generating questions to be discussed during a clinical visit between the patient and provider. Generating questions means having a way to record the question or information and then retrieving those questions during a clinical appointment, an appointment which could be months away. Unless the question was urgent and asked directly in a secure message, patients had a common place for capturing provider questions. If the patient preferred to write questions on paper, observed practices included writing on sticky notes, scraps of paper, the appointment letter itself, or using an index card. As one veteran prefers: “write it on paper normally. You know stuff like an index card in my pocket. I haven’t quite gotten to a point where I use my stylus on my notepad, even though I have a notepad app and all that other stuff. I haven’t quite gotten to that point.... I remember it because it’s sitting in my pocket, you know. That sort of thing... tactile, that kind of thing” (Patient #8574). As this quote eludes to, questions may also be written in a commonplace note taking app on the phone which was used less frequently than scraps of paper. Veterans also generated information in a similar technique that was to be shared with caretakers. Because

patients and caretakers in this sample all lived in the same household, all observations of patient creating written information for caretakers was entirely physical specifically on whiteboards and post it notes.

Creating information to support health information research over the internet is another important practice to emerge in this theme. Of the times that patients take notes in clinical appointments it is to capture the name and spelling of a medication, disease, diagnosis, treatment or surgery. This information is then carried to the home where it is used to support a search query. While a veteran researches health information on the internet, they can also continue to create questions and write notes on paper while they navigate multiple websites. These scraps of paper act as temporary containers for holding information that is time relevant, only while they are in the appointment and briefly after, or only while internet research is being performed.

The most sophisticated information creation practices are by those veterans with medical training or advanced graduate degrees. They end up creating what amounts to an annotated bibliography of relevant health information to share with the provider. In some cases, they write letters to providers and other clinical staff about their health condition. One patient articulated these advanced practices for synthesizing content from the internet and then creating another document out of that work as “looking for patterns,” which was a reoccurring theme and expressed as:

I look for a variety of places some of the big names the mayo clinic the Cleveland clinic those are, or web MD, what you can get. what I do is I'm looking for patterns I look for consistency. So if I search through ten different websites for information on so and so and

I'm getting the same basic thing in all of them I realize okay that's pretty much the standard. And if I find information that's all over the place I realize okay there's not a lot of consensus on it. So I'm looking for consistency (Patient #2221).

This practice of pattern recognition occurred with a varying sophistication among participants. Research at this level was typically used to produce something, whether it was content that was cut and pasted into a word processing document and then into a secure message or a formal letter, it was to support the creation of information. For reference all patient practices are summarized in the table located in appendix E, organized by four themes: practices involving the use of technology, information strategies, health and wellbeing specific practices, and practices of the cognitive workspace.

4.1.4 The role of My HealtheVet in health information management

Discussion about the use of My HealtheVet is a means to talk about the role of the personal health record in a personal health information management assemblage. Health information management assemblages are a larger constellation of tools, technologies, people, and practices that all interact and become configured to accomplish health information management tasks. However, in this section I focus on the one technology that all participants have in common: My HealtheVet personal health record. It is the directive of this research to situate the PHR technology within the larger health information management context. MHV was a widely used (in different ways) tool for supporting veteran's individual health information management practices. My analysis revealed two ways patients use MHV and that those uses influence other possibilities and decisions about their health information management. These

qualities emerged from the analysis of the data using a first cycle coding schema sensitized by process coding.

I call these two categories *Self-Service oriented* and *Information Integration oriented* to classify patient interaction styles with My HealthVet. To preview these two terms briefly: in short, self-service oriented users are those veterans that interact with MHV as if it were a self-service portal. Similar to employees at large corporations can often use a web based human resources portal to access paycheck stubs, tax information, benefits information, and other administrative tasks that would otherwise be handled by a clerical staff. Those tasks are now offloaded to employees for them to conduct themselves. My observation of MHV as a self-service portal gets the name from these interactions with technology. Using the PHR as though it were a self-service portal for health related documents and administrative paperwork. Whereas users that use MHV to *integrate information* into their health assemblage use MHV as a tool that produces information or that they put information into. Specifically, not just using MHV to renew medication or request appointments, but printing documents for family members to reference or otherwise use in non-administrative ways. The key difference between the two concepts is that those veterans using MHV to integrate information have bundles of practices where information provided by MHV gets organized, managed, understood, reused, and otherwise handled differently by users than those using MHV as a self-service portal.

4.1.4.1 My HealthVet as Healthcare Self-Service

The 11 cases in this group all use My HealthVet as a self-service portal. Reordering prescriptions, printing out a piece of information required for another administrative task, and looking at an appointment are the exclusive uses of My HealthVet for this group. The health records only use is as a method to navigate the administrative components of the healthcare system, much as an employee would navigate their company human resources through the self-service portal tending to basic administrative tasks.

The specific characteristics of note in this group are the relative inflexibility in practices, aspirational themes of use, patterns of time interacting with My Healthvet, and finally the complexity of health information management assemblage. There is no connection between how comfortable with technology the patient is and membership in this group. In fact, some of the informants in this group are highly technical people. Age is also not a factor, as the age range of participants in this group range from 34 to 65. These are also patients who are engaged with the healthcare system, some who have over 300 clinical visits in the span of a year. Members of this group typically access MHV infrequently, once a month to renew prescriptions or even fewer than once a month. While there were some frequent users, it was mostly during health events during which time they needed to print reference information from their medical record to provide a clinic or office.

As summarized in the table below, almost every participant in this group uses prescription ordering and renewal. For many, this is their singular interaction with My HealthVet. There was always an awareness of other features and functionality, but the key explanation behind this was that patients had a routine or method with which they were

familiar to accomplish a task. In other words, participants in this group preferred to order medication a certain way, and it was always through My HealthVet.

Participant ID	Age Range	Period of Service	Visit Range	MHV Uses
2564	61-65	Vietnam era	1-50	RX Ordering
2221	56-60	Persian Gulf	150-200	RX Ordering, Secure Messaging
9243	34-45	Persian Gulf	1-50	RX Ordering, Appointment Reference, Document Reference
9739	56-60	post-Vietnam	250-300	RX Ordering
7146	61-65	post-Vietnam	1-50	RX Ordering
3101	66-70	Persian Gulf	1-50	RX Ordering, Secure Messaging
4516	61-65	Vietnam era	1-50	RX Ordering, Secure Messaging
1630	46-50	post-Vietnam	100-150	Printing reference documents
1010	51-55	Persian Gulf	150-200	Browse Educational Information
1640	61-65	Vietnam era	100-150	Print Information for Reference
9507	46-50	Persian Gulf	100-150	RX Ordering, Browse Educational Information

Table 5: Interaction with MHV as self-service portal user classifications

For example, in explaining why they did not use secure messaging, one veteran put it, “I honestly don't think people bother with that [secure messaging] cause they just want to take care of business. People don't wanna sit down and type and do all that other kind of stuff. I just want my medication (#2564)”. This participant owned a computer and used it for hobbies, but placed an emphasis on practices like scheduling appointments, asking questions, and other health related business as an endeavor that is only done in person or on the phone. This participant was well aware of the other functionality possibly but had a preference for using a computer for certain tasks and the phone or face-to-face conversation for other information management tasks.

Those in the self-service category focused on aspirational practices. This concept was evident when participants talked about wanting to be better at taking notes before, during, or after a clinical appointment. One veteran noted that he typically relies on other sources for

information he could record in note form himself: “I probably should take more notes, like what the heck did they say? You know, but yeah sometimes I will. It depends. So I appreciate it when somebody hands me something. Alright here you go! You don’t have to worry about taking notes” (patient #1079). Another concept that emerged from the aspirational theme is knowing about a particular feature in MHV but not using it, often describing to themselves ways in which it could be used. Aspirational concepts were discussed as curiosity or a verbal commitment that, once time was allotted or the next time an information task needed to be addressed, they would explore that feature or functionality. It was, in all sense of the word, something people aspired to and intended to explore and play with when the context was right. Whereas if it was a feature or function that the patient did not want to use, they simply did not use it, which is not an aspirational practice. Just like the quote from patient #2564 where people “don’t want to be typing that stuff”. They knew they could write a secure message to their provider, they just didn’t want to engage in that particular functionality of the health record, they have other avenues to engage in that task.

Time spent interacting with MHV was another important factor in differentiating these two use groups. Every participant in the self-service group spent large swaths of time without using My HealtheVet. By way of contrast, the group that uses My HealtheVet to integrate information had some form of regularity or routine around use. Self-service use is “bursty”, ad hoc, and driven by mostly clerical needs, such as medication refills or needing paper documents from a medical record for administrative purposes. Although use of a personal health record in both groups was driven in part by health events, veterans in the information integration group had integrated the personal health record into already existing personal health information

management practices found in the way they manage information in other parts of their lives. This finding is discussed in detail in the following section.

In the methods section I detail the use of an analytical cognitive mapping technique. It is a concept mapping strategy where I create a visual map or network that sketches the practices, tools, technologies, and people that become enrolled in the veteran's health information management tasks. This was an iterative practice that started with analytical memo writing after interviews, continued during all coding cycles, and further refined during writing the analysis. The analytical cognitive mapping I performed details practices like when blue button use occurs, what spaces and places are important to health information management, and what practices the caretaker performs and how those practices connect with the patient's own work. I turn to one of these maps now to discuss an additional observation about the self-service group.

The final feature of the self-service use group worth noting is that in general, participants in this group tend to have analytical cognitive maps that are less dense or complex, comparatively, than participants that have a health record deeply integrated into their health information management practices. Personal health record technology introduces a level of complexity into information management assemblages, but also provides opportunities for ease of access and configuration into an assemblage. For example, the analytic cognitive map below (figure 6) shows the practices, technologies, people, and uses of MHV for a veteran that is representative of using MHV as a self-service platform. Practices like searching for information on the internet occur by the caretaker taking responsibility for that task. It also shows the uses of MHV by the veteran. However, what is also powerful about these analytic

cognitive maps are both the birds eye view of the entire ensemble taking place and the story they tell. The practices and tools here can be separated and counted, or the map can be read to show that this particular participant struggled with memory and cognitive issues, relying on the caretaker to help with more complex information seeking tasks to help support this person's memory. The veteran uses their phone to create reminders for appointments but also to schedule these reminders, and that there is a connection between upcoming appointments and preparing questions for the provider by thinking about the appointment. About the most complex information management this veteran performs is having a filing cabinet with military records and a few other paper documents. In section 4.1.4.2 the analysis of MHV being used to integrate information into health information management tasks features an exemplar analytic cognitive map far more complex as a contrast to the self-service map. However, the MHV as

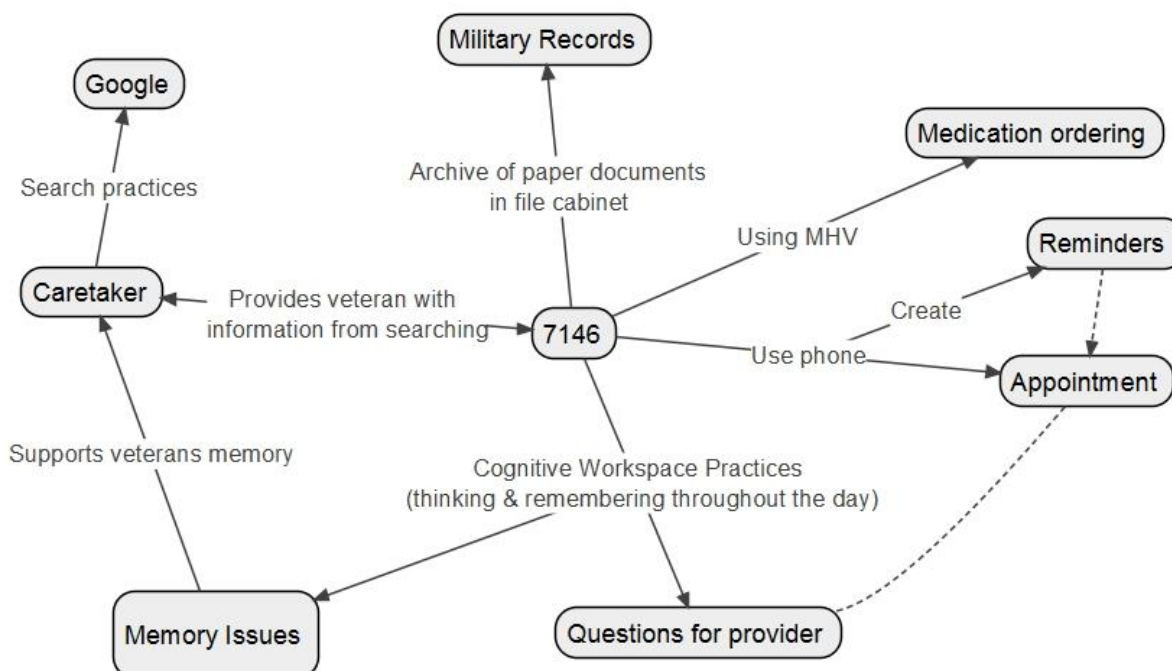


Figure 7 Analytic Cognitive Map of MHV use as a self-service portal

health information integration management participant map also functions the same, showing practices but also telling a story through the sum of its components.

4.1.4.2 My HealtheVet as Information Integration

This second categorization of data represent 11 cases that use My HealtheVet in a different function to a self-service portal. This group is a set of users that use MHV to integrate information into how they manage personal health information. Information from the personal health record is used throughout the veteran's life in addition to the portals administrative capabilities. For example, a veteran uses the medication history list to print out a set of his current medications and turns it into a small piece of paper that can be kept in his wallet or his spouse's purse. He articulated how this practice first started with the following event: "I had a real bad cold last year so she was going to go get me medication at the pharmacy, but she said 'well,' cause she called me and she said 'well, the doctor wants to know, this is like Kinney's or Rite-Aid,' and she goes 'the doctor wants to know what medications you're on,' and I said 'oh, my God,' I said 'I got to go look at my labels on the bottles and all that.' I said, 'forget it.' I said, 'well, hold off, I'm not dying,' and so the point being is that she came home, I went on My HealtheVet, and I called up all the medications, and I printed off a hard copy. She carries it in her purse (Patient #7543)". This quote is an exemplar of the information integration MHV use group because it shows how the veteran and his wife used the medication list contained within the health record as information to support other activities. Printing a medication list and keeping it at hand is a unique use of information and goes beyond using MHV to reorder medications or schedule appointments. Those actions are straightforward clerical uses of the technology. What is interesting about the information integration group is the variety of

practices and strategies employed, some of which are advanced uses of deliberate uses supported by the health record, and others are innovative information strategies like the aforementioned exemplar.

When looking at the demographic information of those that use MHV as a way to integrate information into their health management assemblage there are no stark differences between groups. One notable difference between both MHV use categories is in the visit range. The range of visits means the amount of completed clinical appointments a veteran has had in the last three years anywhere in New York State. I have opted to group these visits into a 50 visit range to establish an additional layer of anonymity. There are slightly more occurrences of visits with the information integration group than with the self-service group. The table below shows the demographic data of veterans that fit the information integration category profile. The outstanding data point is that these users interact with every possible feature available in the personal health record. Additionally, they have developed other practices based on some of the functionality of the PHR. *All functionality* for this group also means use of the blue button to look at provider notes and to export all of the data contained in the health record to a PDF file or text document.

Participant ID	Age Range	Period of Service	Visit Range	MHV Uses
5875	56-60	post-Vietnam	1-50	All Functionality, Regular use
8574	51-55	post-Vietnam	50-100	All Functionality, Printed MHV Information into "Emergency File", Organize Digital Documents in Email, Shared information with spouse
6763	34-45	Persian Gulf	250-300	All Functionality, Data input, transfer information to institutions outside of VA
4285	61-65	Vietnam era	50-100	All Functionality, create spreadsheets from MHV Data
3102	66-70	Persian Gulf	1-50	All Functionality, mobile use
1079	51-55	Persian Gulf	1-50	All Functionality, uses lab work to look for trends
8244	51-55	Vietnam era	100-150	All Functionality, Prints appointments, Printed MHV Information into "Emergency File"
7543	66-70	Vietnam era	200-250	All Functionality, Uses MHV information to formulate question for provider, Print medication list to keep on person at all times
3807	56-60	Persian Gulf	100-150	All Functionality, Prints appointments
8530	56-60	Vietnam era	400-450	All Functionality, Regular use, Uses MHV information to formulate question for provider
2251	56-60	post-Vietnam	50-100	All Functionality, Uses MHV information to formulate question for provider, Uses lab work and provider notes to guide information seeking and research

Table 6: Interaction with MHV as integrating information into health information management practices classifications

Additionally, members of this group use the lab work functionality to view lab reports and tests with the intent of gaining knowledge and understanding their health. Lab work is also used to generate questions for the next visit with their provider and also as a prompt to seek further information. A typical example of lab work use beyond simply viewing the information is

using the lab report to trigger other information management tasks. As one veteran put it:

“When they run lab tests I can get in there and look to see if the lab tests comes back normal or abnormal. If they come back abnormal I write down like in my case abbreviations for what it, I don’t know what the, like A.C.E. test, they ran my A.C.E. levels, that’s abbreviated A.C.E. but it’s angiotensin-converting enzymes and I learned that by looking up A.C.E. levels online. So it tells me what to look for if something comes back abnormal” (patient #2251). Members of the MHV as information integration group had fewer aspirational themes of notetaking because they contained strategies, such as that quoted above. Using lab reports and other data and functionality contained in the health record could be used to trigger their memory and other tasks. Secure messaging is another function used by both groups, but uniquely so in this group. At its basic level, secure messaging allows patients to send a message securely within My HealthVet to their primary care provider team or a specialist. The self-service group uses secure messaging purely as a way to schedule an appointment, request specific medications, or ask a question to a provider.

The group of information integrators use secure messaging for these purposes as well, but also develop unique practices. One such practice is attaching documents to a secure message for the provider to see. Members of this group have a unique practice to send questions to the provider in a secure message before the clinical appointment. One of the more industrious members of this group kept all of his health information digital along with his office work and personal information which he had stream lined together organizationally. This participant encapsulated this practice perfectly: “I use it [secure messaging] to communicate with the health care providers since they don’t have an e-mail that you can, a secure e-mail,

that you can use. It helps to communicate, and I send them my spreadsheets and stuff that I use for my blood sugar and blood pressure. So, I can attach them and send them to them for review before I come in and see them, so they can be informed a little” (patient #4285). This quote evokes the essence of personal health record use for this group. The technology is configured into the rest of their information management assemblage. It is not only used as a way to handle those administrative duties such as reordering prescriptions or scheduling an appointment, tasks that used to be done only over the phone or in person, but also a way to extend the potential and cognitive support of their current information strategy. Patient #4285 can send the spreadsheets of blood pressure and blood sugar historical trend data directly to his provider through a secure channel. The key point here is not the convenience but that the provider is looking at exactly the same document as the patient. Also, this document becomes a point for conversation during the appointment. The experiences, data and memories connecting this document to the patient help support patient #4285’s memory; the patient is not required to work solely from memory during appointments.

These three features: secure messaging, lab work, and the blue button allow patients to configure and integrate functionality from the personal health record into the workflows, practices, and information strategies of their life. Those three specific features are what provide a majority of the information for patients to work with, manipulate, print, alter, and otherwise integrate into their lives. Secure messaging provides a way to send any text or digital object to the provider, and in turn the response from a provider can be taken out of the secure messaging and pasted to another document, for example. The lab work information allows the patient to interact with medical information, specifically information about measuring and

tracking health, to generate questions and reuse that data in other ways. Such as keeping lab data in a spreadsheet so it can be visualized through charts and graphing when needed. The blue button is designed to export the entirety of the health record into a variety of file formats such as a PDF file or a text file. It is an export function and is also the only way to see clinical notes and mental health notes.

Information management practices in one domain of life affect inform practices in other domains of a person's life. The prior knowledge veterans have in managing other aspects of their lives is experience that they apply to the management of health. This observation applied to both information integration and self-service groups. If someone managed recipes by printing them out and storing that information in a folder or binder, for example, they would handle their health information in the same manner. Patient #4285 not only put information he tracked in a spreadsheet document, he managed much of his business and personal information in spreadsheets. Another patient is a musician and the practices and strategies he exercises for researching and organizing music notes and developing songs were remarkably close to how he works with personal health information. In part this finding is another way of saying *we do what we know* when it comes to information management practices. The crucial part of how the patient assemblage forms and maintains over time is the degree to which the technology (personal health record) allows for flexibility and adaptation in the patients existing information management practices.

As temporality in use was a factor for veterans that use MHV as a self-service tool, *temporality* has an important role in information integration. While I observed that time is "bursty" with long periods between use in the information self-service group, this information

integration use group interacted with the different functions of MHV on a more frequent basis. Use of time became an apparent factor when analyzing the *health events* associated with MHV and the *times when MHV was used* and under what conditions. Patients that had a long term condition that required consistent attending to the condition were more likely to interact with MHV frequently. Lab work became a powerful tool that kept patients involved with the health record. For example: "I go up and look at the labs after they've been done, I know when I had the lab done and I know it takes four to five days before you see it out there. It doesn't show up right away, it takes some time (patient #4285)." Patient 4285 has a sense of time, and is aware of the temporal rhythm, for when the lab work is ready and will log in to stay engaged with the data coming from the lab results.

Temporality emerged as an important theme for the information integration group because they interact with their health record on a more frequent basis, and use it other than solely as a self-service tool. Members of the self-service use group have developed non-PHR related practices to accomplish a task, whereas that task might otherwise be accomplished through the use of MHV. For example, instead of a self-service group member using MHV to reference data or an appointment, they keep that information in a calendar or reference information from a printout. I want to highlight that there are alternate paths for information work to get done. Users in the information integration group have spent time, gained experience, and maintain other skills that allow them to perform practices in a manner that includes MHV. Whereas the self-service portal users do not have MHV deeply embedded into their information work practices. Instead, they have alternate methods of accomplishing information work as shown in the aforementioned example.

Patients in the information integration group classification know to go to MHV for certain information, and they have made MHV part of their information management assemblage that facilitates the use of information in flexible and creative ways. When talking about ways that MHV supports cognition, one veteran phrased it as follows:

and then I use that [MHV] as a reference, too. I go back and historically you look at the notes that were posted already there. And then the communication I had with my provider. For example, I found out I have a thoracic aortic aneurysm and eventually I'm going to have surgery. So I wanted to see what the doctor I remembered the doctor telling me that I 'needed to be x-rayed or CT scan', whatever, 'every six months'. And I said 'okay, this is about six months', so I went and opened the secure message that my provider responded cause I asked him a question. He says 'once a year, not every six months'. So what I remember him saying and what he actually wrote down are two different things. So obviously what's written down is the accurate thing. although next month is six months I'm not going to worry about it because he said 'it's a year' (Patient #5875).

Information integration practices by this group means not only going to MHV for specific information as a reference, to trigger a memory, or support cognition, but also to put information into MHV. While serious health tracking and data collection by veterans was only performed in a handful of cases, all of those cases make up the information integration group. As one patient that uses a mobile app to enter data and then inputs that information into his health record discussed their workflow for how they integrate MHV into health tracking: "Like my blood, I take a morning blood sugar and I take an afternoon one, and if I start to feel shaky I

take one. So I keep track of it on my phone. I mean I have the note four has all that I can put in there. Yeah I use it, I use the health app, it's great, but I transfer it once a week over to My Healthy Vet" (Patient# 6763). This quote exemplifies the multiple situations where veterans are actually inputting data into MHV, but also repurposing information from MHV in interesting ways. Another example is a veteran that filled out the emergency and next of kin information and then printed out that information to keep in an emergency file for his spouse and the rest of his family.

In the previous section for MHV self-service user profiles I concluded with an analytic cognitive map to show the look of the important tools, people, technologies, and practices. I claim that after viewing these maps the information integration group tend to have dense maps by comparison.

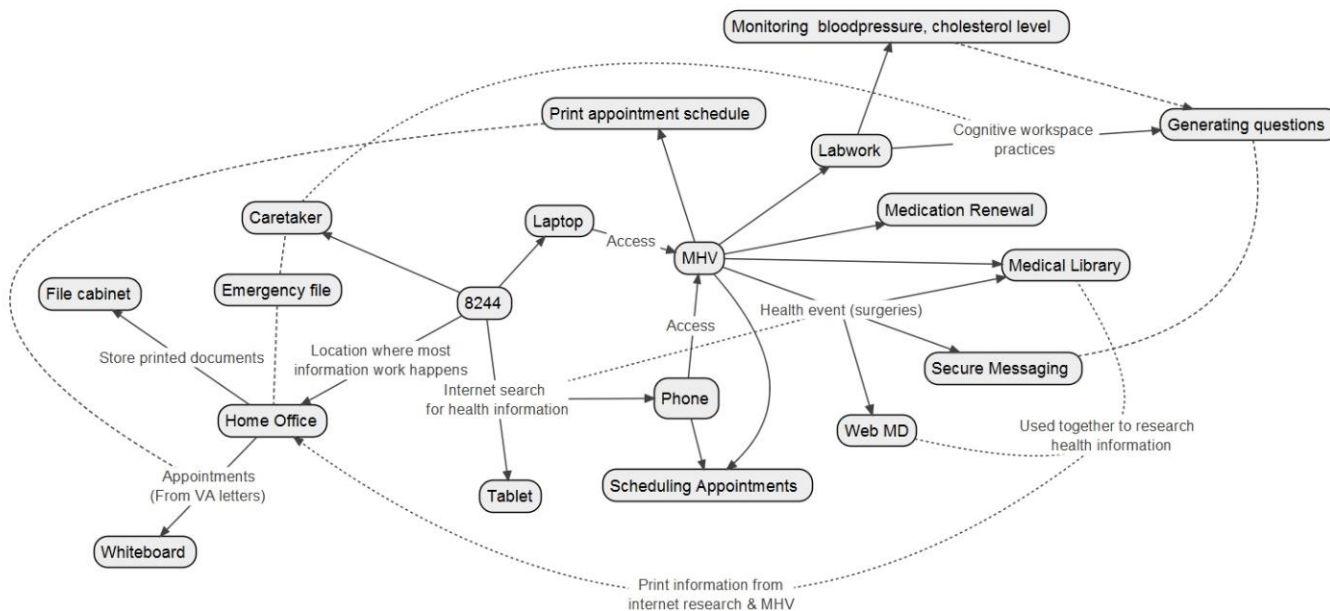


Figure 8 Analytic Cognitive Map of MHV use as integrating information into assemblage

The first noticeable difference in this analytic cognitive map is the amount of “stuff” going on: the type, role, and number of social and technical actors. The map is a crystallization of how the interview unfolded. Patient #8244 is connected to their tablet, caretaker, laptop, and phone. Through these actors they receive support to access MHV and access the internet where they can research health information as needed. As the map dictates, internet access is the sole purpose of their tablet, but the patient prefers to use the phone for appointments as well as MHV access and other health related website visits. The patient almost interacts with every feature of use for MHV. Because this patient has had a number of surgeries, they spent time researching each one when it occurred. The patient always began the search at the MHV medical library and specifically visited Web MD for a “second opinion” in conjunction with general searches on the internet. Patient #8244’s caretaker plays a pivotal role in maintaining their emergency information file, as well as supporting the patient’s cognitive workspace when they generate and ask questions for the provider to answer. The patient and caretaker are in the habit of reviewing lab work results before clinical appointments as a way to generate questions and understand the course of the patient’s journey through the surgery and onto recovery. As they research information online and through MHV, this participant applies a specific practice of printing information from both sources and keeping that printed information in their home office to read, store, archive, or dispose.

4.2 RQ1b: Mapping distributed cognition

The findings concerning research question 1a showed the practices that these veterans have established in dealing with remembering information, organizing their health data, and the kinds of health information they create and use. All of those practices, save the previously

discussed cognitive workspace specific practices, are distributed outside of the patient. This means they are not immaterial thoughts; the ways information is directly organized, printed, and worked with can be directly observed or exist outside of the patient's own cognitive function. Research question 1b is framed to ask: What becomes distributed socially beyond the patient? Of the practices and imbued objects that have been analyzed, what are the connections to caretakers and providers? Of course the environment external to the patient's cognition contains meaning and information that supports cognition, as I have shown. But the goal of this research question is understanding joint use of a cognitive artifact by someone other than the patient. I use the phrase cognitive artifacts to refer to objects, which can be digital or non-digital, that capture, display, provide, or otherwise represent information supporting and shaping cognition. They are externalized objects which offload cognition and are best studied in relation to the people who use these cognitive artifacts.

When looking at what practices and cognitive artifacts become distributed beyond the patient and onto other people it was clear that practices associated with medication is the one area of management that all caregivers support through the organization of medication outside of the containers into a pillbox or pill organizer, administering medications, refilling prescriptions, and locating of prescription medications. Multiple medications increased the complexity of the caretaker's medication practices significantly. Requiring the need for additional information like writing step by step list on paper for the veteran to follow if the caretaker was absent. In addition to medication practices, caregivers provided the following: helped with daily tasks, served as another external reminder for appointments or treatment

regimens, helped with therapeutic practices, and provided transportation to clinical appointments.

Opportunities for embedding cognitive information onto pill bottles included color coding them with a predetermined meaning, or writing on the prescription label to include information that was previously absent from the medication label that is relevant to the patient. One caretaker appended the information “morning” and “night” to each bottle since, due to a recent change in medication and new diagnosis, the patient had to adopt a new routine of taking medications at morning and nighttime rather than once a day.

In addition to demarcating information on the medicine container or label, caretakers used the property of medication bottle placement as a way to affix information. Medication containers were never haphazardly or aimlessly placed in their location. One caretaker had numerous pills she would administer daily. The way she talks about her medication practices are exemplary for the caretakers in this sample. Her explanation follows:

His medication is kept in the bedroom, I give his medication daily so I use pill cups, for morning, noon and night. It's always in the same location, always. So anything, I mean he has, he's borderline diabetic, so all that stuff is kept in the bathroom. He knows where it's at, so everything mainly stays in that area and I don't take it out anywhere, you know, bring it out to the living room or the kitchen or anything like that. I have a little basket and there's three rows so from right to left is where I start and then I go back to the second row and work my way from right and then the third row is usually bedtime medication, so I don't touch that until it's time, you know. [When a bottle is empty] I take the label off the bottle itself, throw it away and then the bottles themselves get recycled (Patient #9739).

Because caretakers all worked with multiple medicine containers the order and placement became an important way to attribute meaning to the containers. For particularly complex configurations of medication management, the caretaker would write up a step by step list of what medications go in what pill container and when. This practice of writing down directions, such as the medication organization list, unveils another theme in distributed work.

Emergency files were another shared practice found in many of the cases that emerged when talking about what information is important to keep. Though these files were not entirely health information focused, such information would inevitably make it into the collection of documents contained in the emergency file. While what I call an emergency file went by different names, I use the term described by a participant that they keep all of their important documents, passwords, and bills in one location in a folder marked “emergency.” Other’s called it the “end of the world” folder or simply “important information.” The goal of this collection of documents was the same: if the veteran became incapacitated, or the caretaker, or other family members in the house, this collection of documents served as a confluence of all the information needed to maintain a sense of control and normalcy. The information contained in this collection of documents would allow access to accounts, end of life protocols, and otherwise inform the reader what the most important bits of information are for work to be done when a spouse is experiencing a crisis. In every instance this file was paper based, a bricolage of papers and documents from a variety of sources. My HealthVet played a role in this emergency file by providing a printout of health information vital to the document collection. Specifically, it provided a list of current and past medications as well as emergency contact information and next of kin information that MHV allows the patient to access. Also in

the emergency file were passwords, including the password to MHV and steps for how to log in, as well as other online systems such as finance and email. These emergency bundles of information served a unique purpose, they were always ready to be used and kept up to date. But they were not necessarily a document archive (placed somewhere and forgot about), nor were they actively used on a frequent basis, they were somewhere in-between. They contain the most vital bits of information and a perfect example of a cognitive artifact to transfer knowledge from what the patient knows to the caretaker at a time when it is needed.

Thus far I have discussed environmental information and objects that are part of health information management that connect patients and caretakers. The primary cognitive artifact between patients and providers is secure messaging. Every participant who engaged with secure messaging has developed a history and set of experiences of digital interactions between the patient and the provider. While patients interact with providers through face-to-face clinical appointments and over the phone, secure messaging is the only communication channel where the entirety of the interaction is documented in text. These secure messages are often referenced at different times by patients. Interviews with the medical providers of each veteran in this sample revealed that providers document specific secure messages to the official clinical medical record. It should be noted that if a secure message is charted, then the secure message is located in two places: the official electronic medical record and in the history of the secure messaging interface. Whereas for patients, unless they print the message, the secure message is only found in the secure message history of My HealtheVet. There were no patients that printed secure messages in this sample. If a secure message needed to be referenced it was always done through the MHV interface by logging in.

Secure messaging is actuated by patients for three specific reasons: A message is sent to 1) reorder specific medications or (re)schedule some appointments; 2) ask questions about medications, treatments, therapies, or a recent appointment; and, 3) to relay information to providers such as information the patient wants the provider to know e.g. recent health events or to provide data from home monitoring and health tracking. Secure messaging allows for the most fluid representation of patient-provider interaction beyond the clinical encounter. Because secure messages are saved on the patients MHV account it also serves as a reference point for patients and caretakers. Whereas unless the patient or caretaker takes notes during the clinical meeting, it is all cognitive workspace practice for the patient. One particular user of secure messaging was prolific in the number of messages they sent and frequency they used it. The analytical cognitive map below is a typical view of patients that had a secure messaging practice. In the case of the cognitive map below, this patient also used email outside of secure messaging to communicate certain information to their VA provider. They also used email to

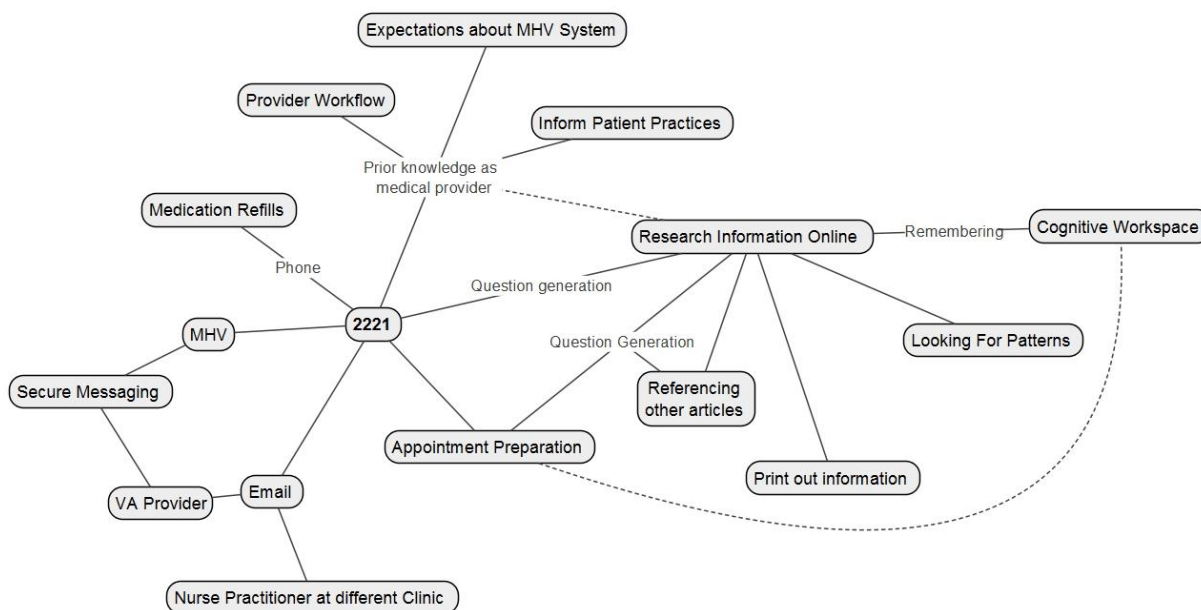


Figure 9 Example of provider and patient interaction through secure messaging and email

contact the nurse practitioner outside of the VA healthcare system. As seen in figure 9, the patient was also a retired medical doctor. Their prior knowledge and experience played a strong role in informing their practices as a patient specifically influencing their health information seeking practices.

4.2.1 Provider information flows

Distributed cognitive artifacts such as the emergency folder, medications, and secure messages are all points of collaboration where practices of patients and other social actors meet for the purposes of health information management. Just like caretakers, primary care providers were an important part of the patient's distributed cognitive network. As I have demonstrated above, the main point of connection between patients and providers, other than clinical appointments, are through secure messaging. In the present section, I want to highlight provider work that impacts patients' health information management practices. In the following section, I describe the decision criteria for provider's interaction with secure messaging and discuss the kinds of information that providers produce that becomes relevant to patient health information work.

The nature of provider interviews was focused on the ways the providers' information work overlaps and intersects with patient information work. The interview started with inquiry into secure messaging, then use of the computer in the clinical office, printed information, channels of communication, and what decisions go into determining when to use a particular medium to share information with the patient.

Provider use of MHV is limited to the ability to respond to secure messages. Because My HealthVet is a *patient* health record it supports little to no functionality for providers other

than communication through secure messages. Providers interact with a different system for medical information, charting, and virtually all other digital tools (of which there are over a hundred). This platform is called VistA (Veterans Information Systems and Technology Architecture), and tools like the electronic medical record, called Computerized Patient Record System (CPRS), are a part of the VistA platform. Providers perform a variety of information work: entering information into the patient chart, creating histograms and any other data visualization, referencing clinical tests, and viewing archived patient records. All of this work happens in a variety of applications connected to the VistA platform, no matter what the task if the work is on the computer it becomes connected to VistA. This means the providers work is highly routinized. I have discovered variability in information work that connects to patients in three key areas: the triage of secure messages, the decisions for entering secure message information into the patient medical record (charting), and the selection of communication channel.

Every provider, except for one, practices a set of triage techniques for dealing with incoming secure messages. In the one outlier case, the provider received all incoming messages and replied to all secure messages personally in the morning. In all other cases, the process of triage involves care teams at the primary care clinics and how they distribute messages to care team members. This distribution typically happens based on level of medical training and knowledge with the goal of shielding the primary care provider from having to respond to every message. There is only one medical doctor (primary care provider) or physician's assistant on a care team. A nurse case manager reviews all incoming secure messages and delegates the messages to other care team members that have appropriate knowledge to answer the message content.

Medication questions get assigned to another nurse on the care team that typically handles medication questions, for instance. The primary care provider only sees secure messages if the message has to do with specific medical knowledge or test result questions that the provider must answer. The protocol for answering secure messages goes up through the ladder of medical knowledge starting with the first point of contact and up to the primary care provider.

There are two ways in which a secure message comes into existence. Either the provider initiates a message to the patient, which is a rare instance, or the patient sends a message to the care team. Whether a secure message is initiated by a provider depends on the relationship between the provider and patient. In every interview it was clear that every provider had a relationship with the patient that included knowing the patients preferred methods of communication and family dynamics. Providers initiated messages more frequently if they knew the patient was very active on MHV. Rather than sending a letter, as would typically be done, the provider would initiate a secure message of test results. Or if the provider knew that the veteran had a family member or caretaker that preferred to talk on the phone then a phone call would be the preferred method of communication.

Even though the primary care provider has a variety of ways to communicate with patients, the time spent interacting with patients was ranked from most frequent interaction to least in the following order: face-to-face, letters and mailed material, phone calls, secure messages. The final point of variability in provider information practices when interacting with MHV is in the form of charting information to the patient's medical record. On occasion providers receive secure messages that the provider deems appropriate to enter into the patient's medical record. This means other providers and specialists can see the secure message and the data is

located in the same container as provider notes and lab test data. The decision to chart a secure message uses the following logic: if the provider wrote a message that has to do with the patients' therapeutic treatment, such as a change in medication, the provider would include that message in the chart essentially archiving the message as "doctor's orders". On occasion the provider will receive attachments from patients, such as patient #4285's spreadsheet of blood pressure and blood glucose levels. These attachments go through a similar set of decisions if they are to be entered into the chart.

Every provider at the VA has a desktop computer and monitor setup in the clinical office. This desktop computer functions as the traditional "paper medical chart" for the primary care provider. During the visit providers enter information and notes into the chart. They also use various graphing capabilities in VistA if the need arises to graph longitudinal data, such as weight fluctuations or blood pressure trends. In every case the provider used the computer as an opportunity to share information with the patient by turning the screen toward the patient and sharing the monitor. The only resource used outside of the VistA platform is Google images to view dermatological images or other visual medical images as examples. Every provider also has the ability to print information for the patient to take home. I found that while the functionality is available and ready to use, it was not used often. In fact, providers reported that they had printed out information during a clinical appointment for a patient only a handful of times. When information was printed, it was printed at the end of the clinical appointment and the patient picks up the print out at the front desk of the clinic. This makes clear that information printed by providers was not used during a clinical appointment in any way for the

patient to take notes on or use as a point of shared content as happens with the desktop computer monitors.

However, one important piece of shared printed material is the health report card. The health report card is a summary of the veterans' health over time, showing trends in weight, blood pressure, and other variables the veterans provider is tracking. This card functions as a snapshot of where the patient has been and where they are currently with various health indicators. Aside from notes and questions written on paper or on the patients' phone, the health report card is a key artifact that was used in appointments as a point of conversation and reminding patients to ask questions. The health report card was also one of the few types of information that became a quick reference. Both the physicality of the report card (a small single page card) and the summative information contained on it made this artifact useful to 'keep at arm's reach', rather than archiving it in a folder or cabinet. The reasons for keeping this artifact at the ready are motivational and reflective; it allows the patient to reflect on the status of their health previously, and when they see improvement they continue to maintain a healthy status. The following exemplar shows the emotional connection to the health report card document: "So my son who is a Marine captain and I would show him, I would say 'look at this [health report card]', I said 'this is after three years, look at that'. 'I'm ranked right where I'm supposed to be'. He looked and he said 'well that's great!'" (Patient #7543). This participant beamed with a sense of pride that was evoked by this physical health summary card. Looking at lab results on a personal health record would not replicate this kind of emotional connection. Nor would it allow for information to be as portable and at hand as a printed small card.

4.3 RQ2a: Assembling health information management

Research questions 1a and 1b present data from a deep dive into the practices of veterans' health information management and then an analysis of how these information management practices and cognitive artifacts involve other actors. The analysis of those first set of research questions (RQ1 a/b) were derived from the first cycle coding data. The second set of research questions discussed in the following two sections are informed by the second cycle of coding. These second cycle patterns were further analyzed to create abstract themes that are representative of the sociotechnical interaction between patients, caretakers, providers, and the bundles of practices with My HealtheVet, information technologies, and health information management practices.

In this section I discuss the assemblage components that are in operation when veteran patients work with health information. Specifically addressing RQ2a *What health information management assemblages emerge from the distributed work of Veterans that use a personal health record?* I identify three unique components that operate in the veteran distributed health information assemblage. The first component is *health experience and health events*. This speaks to the factors of prior experience with different health conditions, and how health drives information seeking and use of information. The second are the *information techniques* that become enrolled (i.e. active) when patients engage with health information across physical or digital types of information. Third, the rich configuration of *technologies and materials* that facilitate the containing, transfer, learning, manipulation, and working with information.

4.3.1 Health events and experiential information

The first major theme that arose from analysis is the way practices become enrolled into an assemblage differently based on health condition or health events that the patient is experiencing. It is clear that the current health condition and previous experiences with health impact how a patient manages health information. One veteran expressed this idea directly and concisely when discussing a chronic condition they have been dealing with for over 5 years. When asked about how they retain questions: “If I feel bad I try to remember, if I know that I’ve got an attention span of a gnat I bring a printout with me there and I ask the doctor” (Patient #2251).

Veterans with mental and behavioral health histories have many different practices and needs, thus a different assemblage configuration, when compared with veterans that have intermittent health histories with events like surgeries or routine checkups. Unique to mental and behavioral health patients is the social distribution of information. Caretakers played a varied role beyond medication assistance when they were part of a mental and behavioral health assemblage. For example, one participant told a story about experiencing difficulty in both a public setting and during a clinical appointment due to anxiety. The caretaker played a pivotal role in helping the patient remember questions, focus the patient’s thoughts, and supported the patient in the waiting room through conversation and relaxation techniques. I refer to these actions as *socially distributed information* and include not only the caretaker but also family members, coworkers, veterans’ organizations, and church members. People know

the veteran through these organizations and roles. Through conversation and interpersonal relationships these social actors help support the patient in different roles in their life and often times providing health related information when needed. Several interviewees shared that when veterans have family members in a medical profession, more information seeking happens through that interpersonal channel than through internet information seeking. The occurrence of socially distributed information was prevalent with mental and behavioral health patients than with patients being treated for any other health condition such as surgeries or pain management.

In addition to socially distributed information being an important aspect of health events and experience, *information access location* is also an important element in health events and experience. Framing information access in this component is done because health events determine the kind of health information to be accessed. Returning to the mental health case, a different participant emphasized it was important to have resources such as the veterans' crisis website available on his phone along with other veteran specific web resources when he needed them. During difficult situations in public, he would access those resources and also practice therapeutic techniques he learned. This example illustrates that the physical location of information access, is motivated by health events. That is, mental and behavioral health patients have more practices related to needing information in public locations or in waiting rooms. Other patients' will access information on the internet or using MHV when they are located in their home office or work office.

Lastly, *temporality* is an important factor in this component of health information management assemblages. I use temporality to refer to the importance and role of time in

many health information management decisions and tasks. Again, in mental health events, time and the ability to quickly access information when it is needed (location) is an essential feature compared to non-mental health patients. Other examples include many participants that had blood work done at the lab before they had a clinical appointment so they could review the lab reports on MHV. There was a very clear and precise temporal rhythm to this practice but it was a different temporal rhythm than a mental and behavioral health temporal rhythm would be.

Figure 10 below is the first in a series of three that visualize the important factors I have talked about in each element of health information management assemblages. I conceptualize these figures as concentric interrelated circles to show the relationships involved with each element. I hesitate to conceptualize these patterns as any kind of map or flowchart that denotes a specific process. Primarily because neither assemblages or distributed cognition are intended to provide causal or directional ordering of the concepts discussed in the findings. Also, I do not assign any specific order because I do not have evidence of that sort of causation in the data. These are concepts that become active over periods of time and intermittently. Sometimes aspects of these components are in use and other times they are not. These components are configurational and not causational. Each figure are the assemblage components that are simultaneously enacted in various configurations.

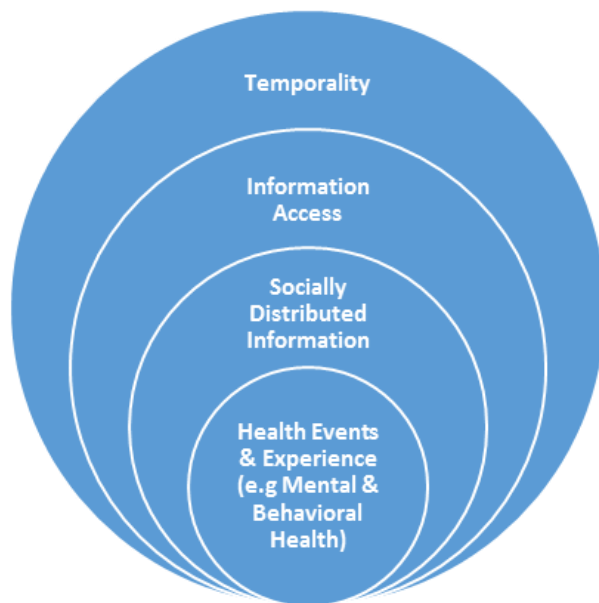


Figure 10 Elements of the health events and experience assemblage component

4.3.2 Information techniques

The second component to health information management assemblages is what I refer to as *information techniques*. These are the applied practices and collections of health information management schema that influence the decisions veterans make about how they manage and use health information. The interviews and observation of technology use clarified how the participants' knowledge with managing personal information, broadly speaking, was used as a template that was then directly applied to their use of health information. The *personal information management schema* became an important characteristic in this regard. Participants have a variety of hobbies that emerged naturally from the discussion. The experiences of cooking and working with recipes, sewing and working with patterns and templates, writing music and looking up music notation, research on ice fishing, and research on golfing are all personal hobbies that involve collecting, managing, retrieving, and using information. Whether it is cooking recipes or sewing patterns, participants learned from these

hobbies how to bookmark online resources or develop organizational systems that support their hobby and allow them to gain increased skill in their pursuit of the hobby. When participants articulate their strategies for health information management they often started by discussing one of the aforementioned hobbies as a heuristic for integrating their health information into their lives.

In section 4.3.1 and 4.3.2 I discuss the emergence of two uses of the My HealtheVet personal health record. One is information integration in which veterans use MHV as a source of generating information and integrating that into their health information management schema. The other use type is a self-service tool, in which the PHR is used as a way to offload administrative tasks such as scheduling appointments and renewing medication. In both cases the use of *digital communication* is the act of participants interacting with the VA health system through digital means. The generation of secure messages, the use of digital objects such as spreadsheets and word processing documents, meticulous organization of bookmarks and phone applications are all practices that express the patients' information techniques. It is the preference they have for communicating and working with information. In this sample all participants had access to a personal health record portal, yet the use of this information tool was configured differently among participants. Digital communication is a factor of the information technique component because it is also the only channel outside of the clinical appointment that allows patients and providers to connect either through phone calls or secure messaging, meaning the use of digital communication contains its own unique challenges and opportunities to health information management assemblages.

As previously discussed a theme emerged around aspirational uses of MHV or ideal organizational schema and ideal practices, such as writing down questions for the provider or tracking health measures better. This aspirational talk of wanting to fully engage with a personal health record or come up with an ideal workflow conflicts with the time a person *invests in different practices*. Participants knew about additional functionalities or perceived better ways to accomplish a task such as requesting new medication. However, it would take time to learn and implement those new ways of doing something into their existing ensemble of accomplishing a task. It would destabilize the assemblage for a duration of time as the patient reconstructs the way a practice is performed. Some participants recalled times when they started performing a task a different way, when they first adopted MHV and began ordering medications, or changing to a new clinic and noticing the way in which information is provided to them to be different. When talking about storage techniques of keeping all of a veteran's military and health records on a USB drive compared to cloud storage and potential benefits it would offer, the veteran expressed the following example of needing to invest their time to develop a new practice: "Really I have thought about it and what it boils down to is I just haven't had the time to invest in really centralizing all that data, and deciding what's really important enough because maybe you get 5 gigs for free and then you can pay for the additional. But what's really important is to fill up that 5 gigs, what should I put on there" (Patient #9243). In all circumstances when a participant signaled the need to change the configuration of the current way they perform a task, the barriers to reconfiguring those elements were either lack of time, lack of technical skill, or not remembering to try a new practice when they did engage with a stabilized practice.

Because remembering and non-physical information is an important part of these information techniques that veteran patients develop, the cognitive workspace practices I previously identified are enfolded into the information techniques component of health information management. There is no physical or digital information to manage from the act of remembering. A participant uses their mental capacity to hold data and information about their health constant in their mind. However, information in a patients' cognitive workspace may be eventually expressed in a secure message, used to make decisions about health, or recorded at a later date in a digital object or scrap of paper. These cognitive workspace tasks operate as tendons that connect the muscle of the assemblage components together. The information techniques that veterans develop play a crucial role in their health information assemblages, and the three factors discussed are integral to how those information techniques develop and carry out over time.

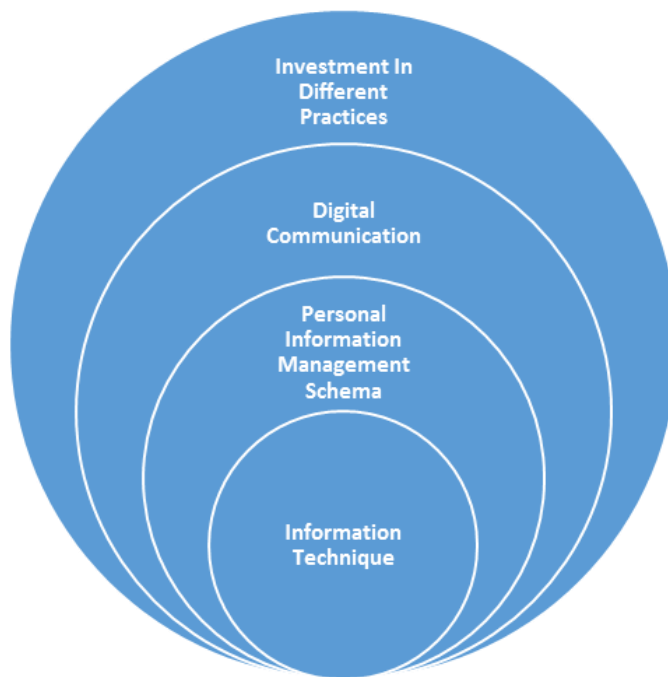


Figure 11 Elements of the Information Technique assemblage component

4.3.3 Technology and material practices

The two previous components concern the practices and experience of veterans. The third component addresses the actual use of technologies and the choice of materials – physical or digital — and factors like the location of information work. I use materials to refer to the actual physical qualities of the objects these patients use, things like laptops, tablets, and phones or paper and non-digital tools like printed calendars and notebooks. Through the interviews and observations of how these veterans use phones and what printed information they carry on hand it was evident that there are reasons behind why a particular technology or type of material is used, and that decisions impact what the patient is able to do.

The first distinctive concept within this component is the idea of having *preferences for specific practices*. As I have shown, patients have a choice in how to complete an information management task. Establishing an appointment in a calendar can be done in a multitude of ways. For various reasons participants have a preference for using either a paper calendar or a digital calendar, some prefer to use both. Another example is the binary between trying to keep health information all digital or all paper based. Each was the preferred mode but for different people in this sample. The veterans' previous military service or career during their service seemed to drive this preference. Veterans who had service careers working around technology preferred to have as much, if not all, of their information management assemblage in digital form. One veteran had experience as a contractor to a defense company and learned many of the practices for managing information without printing from their employer. Essentially they were trained on the job to work with digital health information and applied these learned practices to how they

work with information in their home office. Another preference for the type of practice as relates to the materiality of the information comes from the perception that information is secure and how to securely dispose of it. I previously discuss the ephemerality associated with printed information referred to as a “hard copy” and the ability to store printed documents in a physical location that is preferential to the patient. It is also important to patients who use paper documents to have the ability to reliably destroy those documents. When paper is the main choice of information storage, those patients also had paper shredders and specialized techniques for destroying information when they no longer need it. One of the more elaborate examples for paper document disposal follows:

It's [paper shredder] almost like packing material, mine makes like little oblong things, it's a cross cut and it makes little diamonds. It's impossible [to reconstruct], you go like this [throws hands in the air] and there's dust everywhere so it's really small. But yeah it's good for [burning]. What I've done before I moved, like, I called them paper balls. You get them [paper shredder remains] soaking wet and then I had this little press thing that a buddy of mine made that you compact it and then it dries out with the weight of it and then you have this like fire log ball thing for the bottom [of a fire pit] to light it.

(Patient #1630)

Destroying paper is unlike the deletion of digital objects, there is something physical to be destroyed. With digital documents participants perceived that removing information could be easily retrieved or copied and that digital documents were never truly secure. These participants kept paper records and would shy away from keeping that information digital. The perception of security influenced the type of websites a patient would access or what

kind of information they would look for when using the internet. In multiple instances email was avoided on mobile phones because it was perceived to be insecure. These selected examples are to illustrate that participants had preferences for the location and type of material they chose to engage in health information management.

Closely connected with the material decisions for enacting practices is the *familiarity* with the technology. While a patient may have a preference for working with their health information and keeping it in an all-digital format, the specific situated practices change based on the skill and familiarity with the digital practices. A patient can have a preference for digital information, but not be familiar with it, or be familiar with technological practices, but have a preference for paper. This is to say that the experience patients have with technologies and tools can be different from how they enact health information management practices.

A typical experience with the familiarity of practices and objects were veterans that have an organizational system for managing all of their health records and related information through paper documents and physical storage, such as file cabinets or manila folders. However, because My HealthVet was advertised to the veteran as an essential tool to manage health information, renew medication, and perform other healthcare functions without having to travel to the VA Medical Center, the veteran was persuaded to adopt the new technology and associated practices without any prior familiarity with using the internet or computing. This situation put such veterans at a disadvantage when trying to learn to use both My Healthvet and how to use a desktop or laptop computer to access and navigate the internet.

Patients that research information about their health online talk about the power of, and empowerment in, knowing more about a health condition or disease. In a particularly powerful example of this, a patient says “My Healthy Vet and me having access to my own records any time I want them has improved my life. It’s improved my outlook on my own health, it opened up a lot of things, plus it gave me computer knowledge. See now days they teach all the little brats in school about computers, they didn’t do that with us” (Patient #2251). The participant stated this after they went into detail about symptoms from a rare disease they had been struggling to have diagnosed and treated since 1996 due to the challenge of the pathology. In these instances, it was clear for patients to see the benefits of using the internet to learn about health or to have access to their personal medical information through MHV.

The familiarity veterans had with the technology is an important factor in determining the practices they are likely to use. In the example I provide above, seeing the benefits of using the internet to research personal health was a motivating factor for patients unfamiliar with technology to learn and use. They would compensate for lacking advanced computer use and internet research practices and functionality with other ways such as writing down questions and search results on paper and printing out webpages. Veterans with more familiarity in using the internet to research health did things like use bookmarks, cut and paste text, and save PDF documents in an organized location.

The last element I include in the technology and materials component is the role between the veteran and physical location or place. A quintessential location patients have experience with is the waiting room. The waiting room was used in some instances as a way

to prepare for the clinical appointment: to review questions, talk with a caretaker also attending the appointment to frame the clinical meeting and set expectations, or the patient would engage their cognitive workspace to remember points to make and questions to ask during the appointment. This use of the waiting room — as a way to review, prepare, and frame information used in clinical appointments — was only performed by patients who had a significant appointment scheduled. A significant appointment means something other than an ordinary checkup or follow up to a recent appointment. The significant events that took place for this set of participants were all unforeseen or major health events that required ad hoc organization, research, and planning. Events include cancer diagnoses, results of tests that would determine the need for a major surgery, Parkinson's diagnoses, and appointments where a decision to shift a therapy was made.

The role of the waiting room to patients when there was no significant event was that of simply waiting. Patients did things like bring a book, play games or browse social media on their phone, or find ways to distract themselves while they wait. Significant appointments notwithstanding, preparation for appointments was always done in the patients' home or home office where they had a computer. Typically, the night before or several days before the appointment. Typically, during this time questions would be referenced along with any additional information and additional internet information seeking would be performed. Which brings in the very important role of the home and places within the home, specifically the home office.

Several patients had space in their house for a home office, which was the nexus for working with and storing information of all kinds, especially health information. When a

home office was available to the patient it contained file cabinets, a calendar, and a configuration of a laptop or desktop computer. In homes without an office information work happened on a laptop that would drift to various locations in the house, between kitchen tables, dining room tables, and the living room. Outside of the home, information work happened in work offices. If the participant worked around computers for their current job, or if they had inadequate access to the internet at home, they would access MHV from a work computer or health documents through their email.

Most patients had a specific location where they needed to be in order to engage in health information management practices. These locations were almost always in the home. Or in specific places in the home such as a home office or, in the case of some apartments, the kitchen table. A work office at the participants' place of employment was the other location required for personal health information management because the work office afforded the participant access to a computer. Several participants traveled frequently either for work or as a lifestyle. These participants had the capability to work with health information on-the-go using either a laptop and Wi-Fi access or, primarily, the mobile phone. The majority of mobile work is using a search engine to research information to answer questions the patient has as they enter their cognitive workspace. If a veteran in public and they think of a question or need to know something in order to ask a question for their impending appointment they can type it into their phone on the spot and perform a search. In these mobile situations, they will then have to remember that information and integrate it into their cognitive workspace for the appointment.

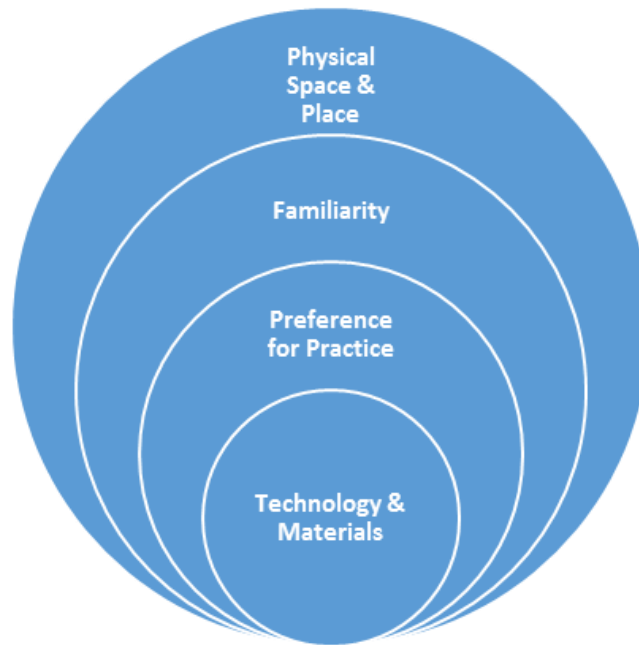


Figure 12 Elements of the technology and materials assemblage component

I set out in this analysis to map and describe the components of personal health information management assemblages. I have described the three operating components in distributed patient health information management assemblages, those components are: health experience and events, information techniques, and the technologies and material practices. Each of these three components have multiple elements encapsulated within. Assemblages always have a set of concepts that refer to the stability of the ensemble, the quality of the collection of components that remain constant over time that allow for work practices to happen, tasks to be completed, goals to be accomplished. These concepts allow the assemblage system to function. These factors that refer to ideas of stability and continued stasis of the components have gone by terms such as *territorialization* and *deterritorialization* and additional terms like *dynamic equilibrium*. These terms are used to express the states of change that occur in assemblages. I now move to unpack the veterans' distributed health

information ecosystem through the classification elements which in aggregate make up those components, and the function with which these components are enacted by the patient and social and technical actors. The fourth and final research question provides analysis for the components presented here, and looks at the key functions and how those components reach stability.

4.4 RQ2b: Key features of health information management assemblages

This analysis has revealed three components that operate in a variety of configurations whenever veterans engage in health information management. These components are always present and go through varying degrees of engagement as veterans perform health information management practices. These components are rooted in the practices, observations, tools, technologies, people, and providers that are inextricably connected to the work of being a patient. I now look at these components to address research question 2b: *What are key functions of the health information management assemblages of veterans?*

The most important variable to every participant in this study was having the right information at the right time. Knowing where to go or how to access that information, and using that information to learn and educate oneself with the goal of making the best informed decisions about health. Although there were different temporal rhythms and levels of urgency associated with having the right information at the right time. As previously discussed mental and behavioral health patients required certain information promptly, whereas others could wait several weeks and often did wait that long. These straightforward manifestations of patient work and health information practices are more complex than they first appear, as this analysis has shown. When patients' need to research their health, recall information, formulate

questions, adhere to a treatment protocol, different information is required. This information has different locations, material forms, functions, and affordances. The information patients need is found throughout the different systems, consumer electronic devices, USB drives, and websites that patients use. Outside of these digital systems this information is also found in paper documents located in a cabinet, in folders, on top of desks, and throughout the house. Information also exists on objects and artifacts around the patient, these objects function as reminders and support the ability to generate questions for healthcare providers, to name a few functions of cognitive artifacts. The affordances of the technologies these participants use allow for a multitude of ways to interact with information, to cut and paste messages and letters, or creating a compendium of multiple documents into one master document.

There are key stabilizing acts performed in each component. The repeated work and experienced gained with these acts influence the assemblage over time, and have an influence over other component's stabilization. I now discuss the role of each component in the process of stabilization. Concerning the health events and experiential information about the patient's own body, this component is much of the contextual information about health that the patient uses. These experiences and prompts by people around the veteran serve as the patient's praxis of health knowledge, which informs all other areas of their health. The ability to recall, access, and use this information and experience is a key stabilizing concept. When the patient is unable to use this health experience these gaps can be filled in by other social actors, as patient health experience and context is often distributed to other social actors in the veteran's life. When there is no social support, this is a destabilizing event.

The second component I have operationalized is about the mental models and organizational schema that patients bring to health information management and the work of being a patient. This component also highlights the unique differences between working with information that is digital versus other forms of information. Essentially the ability to be organized is the key stabilizing concept in action. While there is no correct method or one procedure patients must follow in order to be organized, what emerged from the data is that people have consistent preferences and practices for how information is stored and sorted. The ability for the veteran to follow this schema and integrate information into their schema was a stabilizing factor. Veterans that struggled to track the whereabouts of their health information or simply had problems staying organized is a clear destabilizing factor. The effects of these skills and practices are perfectly illustrated by one outspoken veteran that had strong thoughts on organization and information management in their life. The following participant is also a trained nurse and works with mental and behavioral health patients in a healthcare system outside of the VA.

This is like my constant battle [organizing both personal and health information], my whole life is to figure out some way of staying organized here. I oscillate back and forth between paper and electronics, and everything. I went from full size calendars to little calendars to doing it on the computer, to keeping it on Outlook to this care manager thing that we have at work now to using it on my phone. I find myself trying to stay organized in so many different ways that I'm disorganized, you know what I'm saying. I'm trying to find my way of staying organized, you know. Am I a laptop guy? I'm very envious of people, you know, and I ask people at work, too. I'm like you use that; I see

you keep your calendar. Because I'm very interested in how people stay organized.

Cause I'm very interested in this at work, you know, cause mentally ill are always missing their appointments and I'm like you've got to keep a calendar. How do you stay organized? I'm always interested, how do you stay organized? How do you keep your shit together? (Patient #1079)

This quote really crystallizes the concepts in play: the role of physical and digital materials, the predefined (or not) organizational plans the participant has, keeping these components stable and how stressful it can be to stay unorganized. This participant was an extreme case but summarized all these ideas well. Each of the concepts they discuss in this quote are found in multiple other interviews.

The third concept of distributed health information management assemblages is operationalized as the components of the tools, technologies, materials, physical spaces and places. The key stabilizing concept in this component is the level of proficiency with each of these tools, technologies, platforms, and software. There is no perfect level of skill, the interaction with these objects is a relationship which is constantly evolving and gaining increased understanding of how those objects function for the benefit of the patient's health. However, there is a minimum level of understanding or proficiency in which those aforementioned objects become useful or beneficial. An understanding below that minimum level of proficiency is a destabilizing experience. A destabilizing experience concerning skill proficiency could mean that the patient is struggling to keep these tools in balance to where they are making meaningful progress on a task. For example, using the computer to research

health concerns and consistently needing to reference other resources to use the computer is a secondary task that destabilized the first task: researching health information.

This research question has highlighted the key functions of distributed health information management assemblages. This was shown by highlighting ways that each of the operationalized components become stabilized or destabilized. It should be noted that this is a cyclical, nonlinear process. The ways in which technology use and interaction with information has been analyzed here is using a framework that is focused on holistic relations of large systems, complex webs of interaction that are not always directly causal and mechanical. Instead, looking at a single practice and then a bundle of practices, patterns and routines that span from the cognitive workspace of the veteran and reverberate to other social actors, specifically friends, family members, caretakers, community members, and primary care providers.

4.5 Summary

In this findings chapter I provide an in depth analysis and synthesis of the data. Starting with two distinct use cases that emerged from using My HealtheVet and how personal health record use is connected to the broader environment of health information management ensembles. Next, I move through each research question posed by this study. I describe multiple practices that veterans perform for health information management and group them into three categories: practices for creating reminders and remembering temporal information, practices for organizing and working with information, and practices for creating information and generating questions. Then, I describe practices which are distributed beyond the patient. Put another way, the analysis looks at how the veteran uses the external environment to

contain information relevant to their health. Next, the analysis shifts to understanding how those separate practices become larger patterns that construct a web of interaction consisting of people, practices, places, tools, and technologies. I identify three components or distinct patterns that come into being from the assembling of the aforementioned web of interaction elements. Finally, I highlight key functions of these distributed health information management assemblages and what acts stabilize and destabilize the assemblage.

Chapter Five

5. Discussion

The motivation of this dissertation is to provide a detailed understanding of how patients manage and work with their health information when they have access to a personal health record in a context that involves information work distributed amongst other people. The analysis for this research involved two coding cycles. First, process coding guided the analysis to look for processes and practices that patients discussed during the interviews in conjunction with field notes. Second, pattern coding helped to structure concepts found from the first cycle to identify patterns of interaction and multiple processes which are encapsulated in the pattern. Distributed cognition was pivotal during the first cycle to identify concepts like cognitive artifacts and to focus on practices and the use of objects, tools, technologies, and which caretakers and family members are important to this work. Assemblages were critical to the second cycle when grouping codes and looking for patterns. Assemblages provided a framework for identifying the individual practices and understanding their relationship to higher level abstracted assemblage components.

The results of this analysis yielded two types of use for interaction with My HealtheVet: the identification of specific practices and three assemblage components that operate in a patient's distributed health information management practices. The two types of interaction with the My HealtheVet personal health record are self-service oriented and that integrate health information into the patient's broader information management assemblage. The three

assemblage components include health events and experience, information techniques, technology and material practices.

I now discuss these results in the context of the literature I identified in the review located in chapter two. There, I discussed three broad arguments that emerged from weaving together theoretical and contextual literatures. They are: 1) that a new perspective is needed in the conceptualization of PHR and PHIM literature and assemblages are generative mechanisms for approaching a domain of inquiry; 2) that research looking at patient work to benefit design might look beyond participatory design and usability design to cognitive design; 3) that patient-centered care has been insufficient in understanding the role of technology from a patient's perspective. After I discuss each argument in detail, I provide a conclusion to this research, discuss the contributions, limitations of the study, and end with future research.

5.1 Argument 1: Theoretical approach and shift in perspective

Prior research suggests that personal health records (PHR) have been studied in isolation from patient's other practices relevant to health information management. Alternately, personal health information management (PHIM) has been studied mostly separate from personal health records and only tied to specific objects and limited documents. For the continued progress and advancement of PHR and PHIM research, new perspectives are required in these burgeoning areas of inquiry. The sociotechnical framework I construct is a response to the dominant approaches in the literature. The literature is comprised of hundreds of publications across various areas of medicine, nursing, computer and information sciences, and many social science fields. The vast majority of literature, the result of three literature reviews across the fields of study I previously mention, are focused on adoption, usability,

functionality, satisfaction, and outcomes to name a few (Archer et al., 2011; Turner, 2009; Westra et al., 2012). Many of the publications in medicine are outputs from practicing doctors that have access to either PHR system data or can distribute questionnaires and conduct focus groups with a convenience sample of patients. There is, typically, little to no theoretical application in this research. As a result, it has created a dearth of opinions and descriptions of use that are challenging to develop into a deep body of research literature. The few publications that do provide theoretical insight and design implications are just that: few in number and focused on specific samples of patients, primarily cancer treatment outpatients.

The ability to provide a new perspective and to understand distributed health information assemblages is one of the most exciting of the applications of my conceptual framework to the phenomenon of inquiry. The prior studies I cite in the literature review are foundational and they provided a way to begin thinking about patient health information management, but they are one partial view into the field of inquiry. I liken it to looking at a picture with a sheet of paper in front. The picture is but a faint tracing; the findings from some prior studies have poked a hole in the sheet allowing the viewer to see a portion of the picture. With the use of the theoretical framework I have constructed, I create more holes to provide a better understanding of the whole picture. The motivation of this first argument about the shift in perspective is to recall the prior research that fits into my conceptual assemblage components. Then, to state the additional “views” or functions I have discovered in my research. I now transition in this argument about the conceptual perspective I have shaped and apply to health information management assemblages to address some of the prominent literature with insights from what I have learned through the conceptual perspective.

The conceptual framing of assemblages and distributed cognition has put into perspective much of the conversation about the personal health record technical artifact. Particularly, the information organization and management behaviors associated with PHR use by patients, family members, and caretakers. The current perspective is to test and study concepts like functionality, usability, and adoption and then implement those results to better the PHR. My findings indicate the patient-PHR relationship is far more complex than previous studies suggest. Strategies for focusing on design and usability are essentially endlessly tweaking the system resulting in patients who need to continually adapt, and studies that analyze functionality of PHRs tell us little about how patients will actually use the PHR (Fernández-Alemán, Seva-Llor, Toval, Ouhbi, & Fernández-Luque, 2013). This is not to hamper the development and testing of PHRs, but to highlight that it is more complex than the majority of approaches used. One insight I have from conducting interviews is that although everyone in the study had access to a PHR for years, they would go long swaths of time without logging in or interacting with the PHR. In every instance when a sizeable break occurred between use, the functionality or features of MHV were inevitably updated. Participants drew attention to this and either thought of the idea of continuously updated features as an inconvenience to learn new features, or they were delighted by the additional functionality. This evolving attitude upon adding features is something that can be measured to perpetuity. I argue that once studies intend to look at how technological and social actors mingle in a healthcare context, the aforementioned approaches are limiting.

What the application of distributed assemblages revealed is that far more emphasis needs to be placed on the environment closely adjacent to the PHR. This means that the ways that

patients organize other digital health information in their lives is important to PHR use. Do they have experience in prior jobs working with digital documents and objects? Do patients fluently use the computer to manage information about various hobbies they have? What kinds of strategies and organizational practices does the patient have in other areas of their life? Questions that preview the mental models and concepts patients have for managing information can go a long way into understanding how patients will use a PHR and what they will need.

The essential question is not whether consumers like or would use a PHR as other studies have asked (Kelso & Walker, 2009), but how it fits into the rest of their lives when they use it. The research I conducted begins to address this question of how the PHR connects to the rest of a person's information management assemblage. Rather than profile uses cases, user types, or user personas, what I have done is to categorize the way that My HealthVet is embedded into the assemblage. In other words, I do not ask the question of how the user interacts with the PHR. Instead, I ask the question, how is the PHR processing information in the patient's assemblage? From this inquiry, two categories were discovered that show how the PHR is functioning as an information processing tool. The self-service category of information processing is a view of the PHR that concerns the production of administrative paperwork and supports clerical related tasks. The information integration category deals with information that becomes embedded, used, transferred, and otherwise diffused throughout the patient's assemblage.

Additionally, other research has looked at the idea of engagement with the PHR. It almost goes without saying that patients want privacy, trust, and relevance when using a PHR (Kerns,

Krist, Longo, Kuzel, & Woolf, 2013), as findings that look at PHR engagement and use have concluded. What is more to the point of patient engagement is how patients are using the record and not how the features of the PHR rate; the important part is how the PHR integrates into the patient's assemblage. This means paying closer attention to caretakers and family members since the patient is not always the person using the PHR. Concepts of trust, security, and privacy arose in almost every interview I conducted. Of course, these are concepts that must be present for a PHR to be successful and foster engagement. However, how do patients' perceptions of trust, security, and privacy influence how they use the PHR? Do patients develop practices that exist to build a sense of trust? How do patients establish privacy? Or what practices make patients feel secure? These kinds of questions are what will allow this area of research to advance, not simply by asking whether these components are important. Furthermore, what is also exciting about the sociotechnical practice approach I applied is that it requires the researcher to focus on identification of components in the patient's assemblage that would best support the implementation of an essential privacy practice. For example, this could be the identification of routine uses of computer software used in tandem with the PHR, and the development of integration between that software and the PHR to enhance the security of data between software platforms.

The concept of "aspiration," as revealed through the coding cycles, is an important indicator for how PHRs will be used, how people will interact with them, and how they can be potentially adopted. It may be beneficial to the development of PHRs to set aside asking patients if they would be interested in using a PHR based on the functionality (Patel et al., 2011) but instead frame questions to understand more about the potential for use by looking at the motivating

factors behind the patient's aspiration to use features of a PHR and integrate it into their work as a patient. For example, discussing with patients about the similar activities they may perform that are analogous to the PHR functions, such as online banking or sending email. The possibility of further developing PHRs around curiosity and aspiration is quite interesting and will present new ideas the current research is overlooking.

As Paoli and Kerr (2009) noted from their application of assemblages, multiple components were viewed in tandem rather than different areas of study focusing on a single component. Additionally, assemblages help to understand these components in relation to one another and to the context they are studied. I echo this property of the perspective. In the following literature I cite, I intend to show the relation between individual assemblage components that have been discussed by related literature and the connection to my own research. The role of my research is further detailing these components, discovering new components, and highlighting the links between these components.

The foundational research from Pratt et al (2006) Unruh and Pratt (2008) and Piras and Zanutto (2010) is representative of the data I presented relating to the information techniques assemblage component. The aforementioned research from Unruh, Pratt, Piras and Zanutto is essential to look at patient work, and to understand the information needs of patients and the fundamentals of patient organizational methods. What I accomplish through the application of this perspective is to see where these individual components fit within the larger assemblage and the relationships between components. Piras and Zanutto discuss the detailed work that patients perform with paper documents. They found three record keeping strategies: minimum effort, adaptive, and shared care. Also, three ways in which documents are stored, either in

crossroads locations, in an archive, or an archive in use. Crossroads locations are points of transition located in the home, like on a kitchen table, as the document moves elsewhere. I have found that information lives elsewhere outside of those three locations. Records can be printed out and stored in a person's wallet, affixed to a calendar or refrigerator for long term use, casually referenced from an index card sized note, or stored in a miscellaneous note journal used daily. Crossroads may be too broad a concept for the many ways in which patients use information. One of the three components of a patient's health information assemblage that I identified is all about the physicality of the information with which the patient is working, whether the information is digital or physical and the preferences that exist for how patients approach using information. Health information is also more active than two kinds of archives and temporary locations. Information that supports health is found in multiple locations; patients compile and work with information in order to make sense of their health situation and to make decisions. A purely paper based view does not fully capture the "action" of information, but it does point out some of the preferences that exist for why people use paper documents.

One of the benefits of thinking about PHIM as a distributed cognitive act in which practices and information communication technologies become enrolled as an assemblage is that the perspective encourages thinking about systems. It emphasizes designing for other people in addition to patients and looking at interactions between people and the many different objects that make up a system that is personal in nature. Unruh and Pratt (2008a; 2008b) have an entire stream of research focused on the uses of information and needs of outpatient cancer care patients. They note four findings from their observations and interviews with patients:

documents cause emotional responses and people attach emotion to information, organization is scalable or that small collections are easy to manage and difficulty increases as the collection grows, that time is limited for patients and time is required to learn new information, and finally that patients default to minimal organizational skills. Their findings were derived from the context of patients receiving outpatient cancer treatments. While I had some patients in my sample who fit this description, it was not the focus of the investigation. However, the finding of defaulting to a minimal organizational strategy is an interesting counterpoint to the finding from my research: that people apply their previous mental models and organizational plans from other parts of their lives to new information management opportunities. This suggests that patients need help, particularly at the beginning of a diagnosis or the need to manage health information, learning how to work with health information.

One of the suggestions for PHR design that Unruh and Pratt posit from the above stated research is to prevent unorganized collections. Their point is clear, but to press more deeply on the issue, it is a challenge to understand from a patient's perspective what comprises an organized collection. What may resemble a disorganized hodgepodge of post-it notes, bookmarks, piles of papers, and continuously upended documents are actually perfectly structured for the patient who works with them. However, certainly the organizational patterns noted above can exist and cause the patient great frustration and distress when they attempt to interact with their health information. Thus, I concur with the need to prevent unorganized collections. But my research has learned that if an organizational practice is integrated into the personal health record it must be malleable to support the essential practices of that patient

population. The greater the overlap between the patient's existing organizational strategies and how those strategies are supported in a PHR, the better.

Lastly, Unruh and Pratt suggest to leverage assistance from others and that people have emotional connections to documents and objects. This finding is highly relevant to the practice of health information management, regardless of health situation or context. My own research has shown that information becomes socially distributed to the friends and family around the patient. This social distribution of information can be pivotal with respect to reminders, question generation, and decision making. The social distribution of information appears to be particularly important for mental and behavioral health patients. Likewise, physical and digital objects and documents evoke emotion. The process of working with and configuring those objects, documents, and information is a memory eliciting task. Humans are social, emotional, and cognitive creatures and the inclusion of emotion, memory, prior health experience, and identity is a powerful collection of unique human traits that can be used to support health information work. Hutchins (1995b) describes how the aircraft pilot interacts with cockpit instruments as a way to work through memory, that the design of the aircraft cockpit controls are a process of evoking and harnessing human memory. Similarly, in Hutchins empirical example there is opportunity in using the PHR to exploit these human traits to the ends of patient and family member health information support. This is the essence of my second argument which intends to focus on the elements of cognitive design that emerged from this research and how it informs the extant literature.

5.2 Argument 2: Cognitive workspaces and the role of distributed work

The goal of my second argument is to look at the ways cognition has been discussed in the literature and to posit my own view informed by the research I conducted. I argue that health information management practices and personal health records are best viewed as opportunities for cognitive design and cognitive support rather than used to increase patient motivation or involvement. Patients will become involved and motivated if the cognitive design of the PHR supports the patient. It follows that if the PHR can support cognition that patients will naturally become involved in their care.

Additionally, one of the major themes in the literature I reviewed in chapter two is that distributed cognition operates in the background of many health information management studies. I contend that health information management is best viewed as a cognitive based activity. I discuss the concept of *cognitive workspace* in relation to two other closely related concepts from the literature: information scraps and anchored/unanchored information.

Much rhetoric is constructed around the notion that PHRs “put patients in the driver’s seat” (Smolij & Dun, 2006), offer dozens of benefits (Pagliari, Detmer, & Singleton, 2007), and are useful as motivational tools and persuasive technologies (Saparova, 2012). In general, it is a positive benefit that more information is provided to the patient without the need to go through an unreasonable healthcare system bureaucracy to receive access to personal medical documents. However, the PHR has been evaluated, measured, and written about as though this one technology is the single fix to various healthcare woes. PHRs should not be viewed as a panacea for patient motivation or expected to transform patient attitudes. In an article synthesizing the current state of PHR research and future directions, they suggest four areas for

research opportunities: evaluation of functions, adoption, privacy, and architecture (Kaelber, Jha, Johnston, Middleton, & Bates, 2008). I posit a fifth area for research opportunities, the cognitive design of PHRs.

The cognitive design and future research of PHRs does not, exclusively, depend on the actual PHR. As peculiar as that may sound, the area of PHR research must acknowledge that the practices surrounding the use of the PHR, what I have been calling the health information assemblage, have direct applicability to the PHR. This realization is echoed almost verbatim by Kaelber et al (2008) as well. However, they discuss research applicable to the PHR such as email and computer-mediated medical histories. I take this a step further and, through the majority of this dissertation research, demonstrate that practices which do not involve the computer are applicable to the PHR. One such concept that is both cognitive in nature and related to the PHR is known by other researchers as “information scraps”. Although I do not use this particular term, it is both an example of practices related to the PHR and a finding from the literature that my study can further address.

Information scraps are ad hoc cognitive support tools for temporary storage and reminders using post it notes or actual scraps of paper (Bernstein, Van Kleek, Karger, & Schraefel, 2008). People need to remember something temporarily so they jot it down on a piece of paper until they can make sense of, or take action with, the information on the scrap. This a common practice that fills a basic information need: to remember important information without sole reliance upon memory. However, this comes with challenges: you can lose the scrap of paper and therefore the information associated with it. While Bernstein et al investigate information scraps in the personal information management context with knowledge workers, it is a context

that shares similarity with patient PHIM work. The work of a patient is, in part, knowledge work.

The use of information scraps is a practice I observed on multiple occasions. Patients produced post-it notes, index cards, actual scraps of paper from locations like pants pockets, folders, book pages, cellphone cases, and shirt pockets. Bernstein et al problematize information scraps as an indication of the design needs that are currently unmet by an information capture system. In my research experience, the use of information scraps in the health context cannot be designed around or eliminated as a practice. It is a practice that will always exist and serves a specific purpose. What is interesting is that whether or not information scraps were used by patients, they still relied on cognitive workspace practices.

I see this as one of the functions of the cognitive workspace concept. When patients have the cognitive ability to remember and work with information in their cognitive workspace, it fills in the gaps where there is missing or inadequate information. Cognitive workspaces are used if there is no time or resources to create an information scrap or they can be used in tandem with an information scrap. Through cognitive workspace practices and prior experience, the patient will know that their communication with the provider resides in the secure message history, their mental health history resides in a google doc, and important information resides in the emerging folder in the top right drawer of their office desk. Patients can weave together multiple sources of information and work with them through their cognitive workspace. Thus, cognitive workspace practices represent the *absence* of information scraps or proper information capture tools, but the *presence* of prior experiences, memory, and understanding of their own information management practices, and existing organizational

schema. The cognitive workspace implies some awareness of an assemblage at work for the patient. Patients know they can rely on either a set of intentional or unintentional reminders or other practices that, in combination with their cognitive workspace, allow the patient to accomplish the task.

The concept of a cognitive workspace is not used in PHIM or PHR literature. It is a term I use to refer to the work that patients do using their memory and cognitive faculties that stitch together the physical tools and different forms of information (physical or digital) along with socially distributed information from friends, family, and caretakers. It is a term inspired by distributed cognition research. Distributed cognition is the concept that the external environment, social and physical objects and artifacts, contain information that supports cognitive processes (Hutchins, 1995a). In a remarkably detailed account, Hutchins walks through the information an airline pilot interacts with inside the cockpit to successfully manage the speed of an airplane. The resulting act is the pilot controlling the configuration of information presented before her (Hutchins, 1995b). All of the dials, switches, screens, and instruments are external cognitive artifacts that provoke memory from the pilot, but are not entirely made up of the pilot's memory. The cockpit system is complex because it supports human memory, and so much information must be remembered that the system becomes robust.

This theory of cognition is useful when applied to PHR record use and patient health information work. When thinking about the example of pilot interaction with complex cockpit systems, I began to think about the role of memory and the pilot's cognitive capabilities that connected the pilot's practices to the ability to read and configure the aircraft system.

Obviously, the information work of patients and aircraft pilots are fundamentally different. For instance, the pilot makes quick decisions in a high pressure environment while actively piloting the craft. Unless in a training simulator, the pilot does not interact with the distributed cognitive system while in the shower, having brunch, walking to the store, or performing any other activity aside from being in the pilot's seat. On the contrary, patients can engage in all of these activities and need to rely on what I call a cognitive workspace to work with health information. This is not to say that pilots do not have a cognitive workspace, of course they do. However, the tools and objects they require are entirely situated and bound to the aircraft. Patients can have this information fragmented throughout their lives residing within different tools, technologies, and people, as this research has shown.

A related concept to the cognitive workspace concept I discuss is that of unanchored information (Klasnja, Hartzler, Unruh, & Pratt, 2010). Anchored information is the pilot cockpit and ensemble of instruments, dials and switches. Anchored information is also MHV, the index cards, notebooks, mobile phones, tablets, and other technologies and tools that I observe patients use to make health information work happen. The absence of those tools is unanchored information. A patient might think of a question on the drive to the doctor's office or have a health related thought in the shower; these experiences have no tool, technology, or object that bind them outside of the patient's head. It is information that never becomes assembled into a distributed cognitive system. This concept is seen as a design challenge, a problem of recording information. At its core, the concept of unanchored information is an expression of the importance of distributed cognitive tools, practices, people, and technologies for information work. The sparse research in this area indicates that certain health conditions

require more anchoring than other health conditions. Cancer patients are the only population of study in this area when the design of a system to support unanchored information is considered (Klasnja, Hartzler, Powell, Phan, & Pratt, 2010).

The critical fact of unanchored information is that there will always be unanchored information, just as I also noted with information scraps. Even in the development of the Health Weaver system designed to prevent unanchored information by Klasnja et al (2010), it is a mobile phone application that requires a phone. While mobile technology continues to make strides in battery life, portability, computational power, and affordability, there are still situations where a patient might not have a phone on them or when it might not be convenient to utilize one (for instance, that random health related thought while showering). My research also suggests that among older patients the use of a phone in a clinical appointment is a social faux pas, and the patients opt for transferring information from their mobile phone to a piece of paper as a way to prep the form and function of the information they require. Also, unanchored information may not necessarily be problematic in every instance. Noted causes of unanchored work include diminished attention, lack of familiarity, necessity for mobility, and inadequate work environments (Klasnja, Hartzler, Unruh, et al., 2010). Unanchored work is framed as a situation to be avoided, and rightfully so because memory is not perfect; people can forget. The same research that identified the causes of unanchored information also include strategies to combat unanchored information: use mobile information collections, capture information, then triage at a later point, ask others for help, repurpose resources for health information, and use the environment for anchoring. I have empirical evidence of

patients who naturally perform these various strategies. Yet, the concept of unanchored information still exists within those same patient information assemblages.

The phenomenon of cognitive workspace practices is different from unanchored information in two key ways. First, not all information needs to be written down. Prior experiences, personal health history, understanding of the patient's own body, external environment, and location are all important factors which facilitate cognitive workspace practices. The overwhelming consensus from the interviews I conducted revealed that with certain unanchored information, some of which is previously mentioned, the cognitive workspace is used because to write that information down would be unnecessary. Even in instances where there is new or novel information gained by the patient, that information can be grouped or chunked with existent information. This renders the need for an anchor point or information scrap obsolete. Second, cognitive workspace practices are not entirely a practice to be avoided or seen as problematic. The factors I mention may evoke and support powerful memories and cognitive practices that do not require anchoring; these cognitive practices may influence how patients work with information that is anchored to a specific tool, technology, or document. Both unanchored and cognitive workspace concepts exist in health information management and signal the difficulty in studying the phenomenon and the challenge of patient information work.

The crux of health information management challenges is cognitive capability. The reason that patients distribute information through the use of caretakers, friends, family members, artifacts, and documents and spend time organizing and working with those documents, is to support rigorous cognitive work. Agarwal (2009) talks about the way that

patients are only limited by their cognitive capacity in relation to the complexity of their lives. This simplifies, but accurately identifies, the essence of what challenges patients, whether it is information overload or the struggle to obtain enough information to be confidently informed to make important healthcare decisions. The idea of a cognitive workspace is an intriguing frame in which to view the cognitive challenges patients face. Memory and management tasks are one issue of cognition, but a cognitive workspace is like a desk or workbench that enables patients to work between the gaps in types of information materials (physical or digital) to bring that knowledge together in various places and locations of health information. Cognitive design for memory is about capturing information for later reference and retrieval. In contrast, cognitive design for support of a patient's workspace entails knowledge about the system of information associated with the patient, the assemblage of information, and the relationships between the patient and the assemblage of information. In reviewing participants that had emergent concepts of cognitive workspace practices, I identified commonalities that seem to make it easier to successfully use cognitive workspaces. These are things like *routines*, *predefined places where specific information is located*, and working with information in a way that it *becomes common knowledge or is easily remembered* by the patient. Establishing *routines* like taking blood sugar or blood pressure gave the patient a sense of history and repetition of that information work enabled the patient to remember trends and a long history of the numbers associated with blood pressure or sugar tests. The same was true with lab work; the more patients routinized looking at lab work the better their understanding of the history of lab test data. When other health information was evoked that related to that familiar lab data, patients could connect the new information with the old information. This leads to the

next commonality I noticed: *pre-defined places where certain information lives*. To continue with the example of the patient who remembers lab data from their lab tests, when new information triggers that history of data in their cognitive workspace, the patient knows where to put that new information (such as in a notebook or digital document). Or, they may be more likely to remember the new information that is closely associated with the routine lab data they remember. This process occurs because the patient has worked with the information, writing it down, downloading and reviewing PDFs, typing secure messages, and so on. Whatever way the patient is most often exposed to information it is more likely to be remembered by that patient if they have interacted with the information previously.

While this concept certainly needs further inquiry, it was not the intention of this research to gather data and test the notion of cognitive workspaces. However, the trends I noted above can be informative for considering the cognitive design of patient facing information systems.

5.3 Argument 3: Transitioning from patient-centered care to patient-centered practices

The third and final argument I make deals with the role of patient-centered care (PCC) in patient facing health information systems. I consider this an important argument to address because PCC is one of the common outputs or contributions of health services research. Also, because this research was focused on patients' use of a personal health record and associated tools, people, and practices, it follows that aspects of this research can address patient-centered care. Essentially, assemblages are patient-centered information processing webs. This makes a discussion about patient-centered care relevant to this research. In this section, I discuss the concept of PCC and suggest ways this research may advance or potentially alter the

idea of PCC. Closely associated with PCC, arguably the motivating force for implementing PCC concepts, is improving patient health outcomes. Thus, I also discuss the notion of improving patient health outcomes through technology in this section.

After a thorough review of the literature on PCC and meta-analyses of the state of PCC, I find that the concept is both widely sought-after and amorphous in certain contexts. PCC is a set of ideas that broadly mean patients are valued, respected, heard, and persuaded to participate in their care as a cooperative partner in the patient-provider relationship. Concepts about PCC are implemented and practiced at the institutional level through policy that allows patients access to their information as well as emotional and other types of support they may need. PCC aims to keep patients well informed by their providers' decisions related to patient care, anxiety relief, and physical comfort. The state of the art of PCC as concluded in my literature review is how to enable PCC through technology. Reti et al (2010) consider technology to be more patient-centered if a PHR supports functions like delegation or allows the patient both access to and the ability to download all of their data.

I contend that patient-centered care is a concept which should *not* be applied to the development or use of technology in patient facing health information systems. PCC is a communication concept, improving the patient-provider relationship and including patients in decision making. The term has ballooned in use since its inception in the 50's and has been used as a tool to promote patient focused policy and guidelines for how patients are treated in the healthcare system (Jayadevappa & Chhatre, 2011). Certainly, there are many things that can *contribute* to a model of patient-centered care. I would not say that ability to access and delegate information in a PHR is a patient-centered care concept; it is only a function that is

beneficial to patients. Access and delegation may contribute to informing the patients about decision making, but ultimately PCC is about the relational and communicative aspects of patients and providers working together. I argue that it is more precise to talk about the ways in which technology and cognitive artifacts help patients as *patient-centered practices*.

Designing for PCC should not simply mean giving patients more access and control over different healthcare components. More conceptual precision can direct researchers, healthcare professionals, and stakeholders to think about different ways to benefit patients in healthcare institutions. This idea is informed by a reflection on my research, which looked closely at how patients organize their lives and their health information and what they do when they need to engage with information about their health. The discovery that patients take existing plans and mental models about how they work with information and apply those mental models to the health context leads me to understand that it is essential to focus support on what patients already know and do.

This is why I use the term *patient-centered practices*. It frames a perspective that the design should support the already established practices of the patient. I consider the term *patient-centered practices* to add a degree of conceptual precision over the use of *patient-centered care*. *Patient-centered practices* also provide a view into seeing the technology that patients use as able to embed patients' established practices into the technology. Practices are events which can be observed, understood, and then imprinted into personal health records and other patient facing technologies.

My research directly points to methods of inquiry for informing an approach to improve *patient-centered practices*. For example, referencing appendix five reveals a list of practices

that comes from understanding the patients' use of technologies, the information management practices they perform, and how health events influence and create practices of their own. The mobile phone is a widely available technology that most patients utilize. The use of health apps and services on the phone is a common practice by patients that opt to use those tools. Thus, creating a smartphone app that allows patients to interact with their healthcare through the phone is a patient centered practice. An additional example comes from the prevalence of emergency files and their role in the patient's health information assemblage. Knowing this to be a common practice associated with health information, the personal health record might implement patient-centered practice by creating forms that can be downloaded that already contain much of the data patients need to build their own emergency file. Or, personal health records could contain their own emergency file as a digital bundle of documents and objects, another example of a patient-centered practice design.

I have addressed the issue of patient-centered care by suggesting that patient practices and implementation of assemblage components into the development of patient focused health information systems is an alternative to the use of patient-centered care. I now transition to the notion of health outcomes. The idea that the use of a personal health record can influence and improve health outcomes for a patient is prevalent in the literature; patient-centered care concepts are also associated with improving health outcomes (Ahern et al., 2011; Huba & Zhang, 2012; Jayadevappa & Chhatre, 2011; Valdez, Holden, Novak, & Veinot, 2014)

While the scope of this research did not look at the health outcomes of patients, some of the insight gained by this research is applicable to the discussion on PHRs and health outcomes. Obviously, it is a monumental task to understand how any digital technology

influences behavior, much less the outcome of disease and other complex health situations.

One of the findings of this research is that information is distributed through different physical and digital forms as well as social actors, such as caretakers and family members. In a sense, looking at the PHR as an influence on health outcomes is like saying an athlete who runs while using a smart device to track their running location and steps will be a competitive triathlete due solely to the activities the device tracks. While running with a smart tracking device may be motivating, the individual may also perform a variety of other endurance exercises that the device can't track. Furthermore, they may also have a coach and team members that are motivating and encourage their athletic success.

This example demonstrates that outcomes occur beyond the interaction of a single pedometer or smart watch, and that the technology is convenient in that it can influence attitudes and behavior but not always in the intended manner. In both cases, the technology can be novel and motivating. But there is an underlying behavior, specifically a frame of mind, that patients bring to using a personal health record. This suggestion goes hand in hand with the previously mentioned refocus on the PHR and associated patient behavior. As I described the use types of a personal health record, information integrators or self-service users, each type of user will have a different experience in their utilization of a PHR. This may explain why the studies on PHR use and health outcomes find little correlation and conclude with the statement that further research is needed (Saparova, 2012; Shaw & Ferranti, 2011; Wiljer, 2010; Winkelman, Leonard, & Rossos, 2005). If a patient has access to a PHR but does not adapt that PHR into their assemblage in a way that encourages them to create information, communicate with providers, and in a way that fits with existing practices, then the PHR is not

operating as a technology to support health outcomes. This is why I view PHRs and PHIM as entirely connected phenomena; the PHR is a central information communication technology artifact of interest but it is bound up in practices of health information management that cannot be separated from the technology.

Both the development of patient focused health information technology and an understanding of the technologies placed in a patient's information assemblage have progress to make before health outcomes are profoundly impacted. The right path to a bright future of consumer facing health information systems influencing health outcomes is, in part, through inquiry of how patients use existing health information systems and understand the processes behind patient and family member use of the technology. Additionally, this research suggests that certain health conditions may play a greater role in impacting health outcomes. Specifically, the mental health assemblage is an intriguing finding when thinking about health outcomes. Health conditions such as those related to mental and behavioral health patients have a better chance to be successfully supported by patient focused technology because of the information work involved in the maintenance of a state of wellbeing. Alternately, a health condition like minor surgery does not require the level of information support and work as a mental health patient, as this research has shown.

5.4 Contributions

My approach to the contributions of this research is twofold: first, the contributions to the field or intellectual community, methods, and theory; second, the contributions to the community outside of academia that uses, develops, and writes policy for patient facing health information systems and other relevant communities. The second set of contributions I refer to

as implications for design, for which there are multiple target audiences. Thus, I segment the contributions discussion into the research contributions and design implications.

To begin, this research contributes a unique perspective to the research communities of personal health information management and personal health records, respectively. I have clearly articulated in the findings and discussion chapters that the overarching approach used in this dissertation was informed by previous research yet employs a shift in perspective. The findings from this research both compliment and build upon previous studies through a sociotechnical approach that weaves together the PHR technology and patients' social practices.

The cognitive mapping technique developed in this study was informative, useful for analysis, and may provide benefit to similar studies and future research. After interviews in conjunction with memo writing I began to sketch network maps that revealed the connection between patients and every practice, tool, technology, and person that becomes implicated in their assemblage. These maps became powerful guiding tools as they were refined over the course of discussions and memo writing. I returned to the maps during both cycles of coding to both inform the coding process and to use the transcription data to further detail and solidify the cognitive maps. These maps became an analytical tool, allowing me to visualize the patient and enrolled tools, technologies, people, and practices. To involve the map in all aspects of analysis facilitates reflection and elicits detail on each case as I built an inventory of relevant assemblage pieces. I anticipate this technique as both a contribution to this area and an opportunity for future research. Although there is an overwhelming torrent of literature on concept mapping, I think the practice of developing cognitive maps as an analytical tool to

support analysis was important to the findings of this research. This technique can be further explored and developed in relation to sociotechnical perspectives and network or system approaches like sociotechnical interaction networks, actor-network theory, multi modal networks, assemblages, and similar perspectives.

Theoretically, this research contributes a weaving together of two theoretical perspectives with beneficial results. Although the intention of this research was not the development of theory, there is certainly a contribution in further exploring theoretical perspectives and applying them to data collection. I found the integration of a distributed cognition framework to be beneficial in adding analytical clarity to the concept of an assemblage. The logic of external cognition and the need to rely on identification of external objects that support cognition to understand how the external environment becomes a cognitive tool for patients was informative for both data collection and analysis, especially when the assemblage concept has been critiqued for its lack of clarity and analytical specificity.

5.4.1 Implications for practitioners and designers

This research informs the ways that professionals, stakeholders, developers, patients, and providers think about, interact with, design, use, and develop health information systems. In this section, I walk through the major implications that this research provides each of those communities and audiences. I start with implications for the design of patient facing health information systems, then to implications for practicing clinicians and healthcare professionals that interact with patients, and conclude with implications for the model and practice of Patient-Centered Care.

5.4.1.1 Implications for design of PHRs

Designers can learn much to inform design and development by working with patients. Most likely, patients are recruited either in panels, focus groups, or individual surveys and interviews are used to include patient input on health information system development. Regardless of the data collection mechanism being employed, patient inquiry should move beyond questions about feature preference and usability. While those are, of course, relevant questions and areas of inquiry that should include patient input, this research was conducted on an already mature and developed personal health record technology. Some patients have been using My HealthVet for almost a decade or more. Something like a web based personal health record is a technology that continues to develop as new versions of the website and associated software platforms are updated. The design of a system like MHV is continuously evolving and requires no installation or upgrading of software from patients other than the use of a web browser. As a result, usability testing and functionality improvement can continue to perpetuity. What this research has shown, and what designers should take away, is that asking broader questions and seeking conceptual ideas can produce results that may be more timeless than current usability testing. Specifically, conceptual questions derived from personal health information management and personal information management research. For example, thinking about use of a personal health record as a personal health information management task, framing questions to examine how patients prefer to interact with information and what strategies they employ in other aspects of their life, asking how patients receive and seek necessary information, and understanding how people learn and create knowledge as they

work with information. These types of questions are sure to produce data which can direct the design in a fundamentally different way than surveys on ease of use are capable.

Additionally, another implication for design derived from this research is the unique affordances of digital communication and how services similar to secure messaging that allow patients and providers to communicate provide opportunities for integrating that data beyond a simple message archive. For example, using annotation of patient-provider messaging text to provide patients with a summary to be used for preparation of upcoming appointments and to aid in patient question generation. This can limit the use of information scraps and support patient cognitive workspace practices.

In keeping with the theme of digital communication and digital information communication technology use, the evidence of email use to sync and share data along with other platforms that create a flow of patient health information must be considered in future personal health record development and in the wider frame of organizations that provide patients with their health information. Know that patients will work with data and create a bricolage of new documents from multiple documents and digital objects contained in the personal health record. Designs of PHRs should consider integration or compatibility with other platforms. Configurability by patients is an important concept to the future of patient facing health information management systems. As shown by this research: patients use a collection of various digital platforms and services to handle health information in a certain way, just as they would with other personal information from other aspects of their lives. PHR developers can learn from this by understanding how a PHR can connect to other services and platforms. If personal health information is contained only within the PHR, patients will print that

information to paper documents or cut and paste information out of the record. People develop their own practices and methods for working with and organizing data and if that is turned into a design opportunity rather than a design problem it will facilitate patient information work.

Lastly is a design implication for the consumer technology industry at large. One thing that became apparent over the course of this research is that the consumer electronics that are used to support health information management are under designed for older patients. Confusing interfaces, phone screens that are hard to read, lack of accessibility support for veterans with vision problems, and easier functionality to print what is on screen are all problems of technology use that became apparent during many interviews. Although the goal of this research was not to assess the accessibility of technology implicated in health information management, this implication arose from interviews and is worth considering if consumer information communication technology developers plan to target devices to older veteran populations.

5.4.1.2 Implications for Clinical Practice

Interviews with the providers of each patient provided a valuable perspective for ways the PHR can augment the patient-provider relationship. Based on multiple interviews with each provider and observational fieldwork, I have noted implications for the primary care provider clinical practice where MHV is concerned. Providers can use My HealthVet to keep notes for the patient during the meeting, tailored to the patient, and send the patient those notes after the meeting as a debrief. Understandably, providers are already well immersed in writing notes and paperwork; this implication is really about the ability to provide patients with an

information artifact as a product of the meeting. Several patients had trouble remembering information post appointment, or wished they had taken notes. Looking at lab reports and clinical notes only goes so far. Providers that are aware of this have another strategy they can employ to connect with their patient and help to provide them with accurate and useful information. Providing patients with a more informal email-like note can address one of the major issues patients have when ending an appointment: integrating information and remembering what just happened in the clinical encounter.

Another implication informed by my fieldwork is that multiple forms of information become distributed to the patient. Specifically, these are letters containing information also found in the PHR, phone calls, and secure message content. Sometimes, a mix of these types of information were used, other times only one. For example, letters sent explaining lab results. Patients displayed a preference for receiving information; they preferred letters that showed and explained their lab results because they valued physical paper and preferred to keep those letters. Others threw the letters away directly and opted for the information in a secure message in MHV. Providers may save time and wasted effort by considering how patients prefer to receive information. This knowledge would clarify a plan to send specific information through secure messages, show patients where to access specific information in MHV, or send paper documents to the patient's home. Development of an information sharing strategy between patients and providers can increase efficiency and reduce wasted effort.

5.4.1.3 Implications for Patient-Centered Practice

Merely the presence of a personal health record does not make for patient-centered care. It is a useful tool on the path toward a patient-centered model of care. Patient-centeredness covers a vast area of medical and healthcare service related literature. Many concepts are discussed in hundreds of articles on the idea. These concepts considered to be patient-centered are coordination and integration of care; access to information, communication, and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of friends and family; access; learning; patient engagement; and ease of use. However, these are but a few of the literal hundreds of concepts and statements of patient-centered care derived from a meta review of 143 papers and another literature syntheses of well over a thousand articles (Finkelstein et al., 2012; Jayadevappa & Chhatre, 2011). In the discussion section at 5.3, I posit that a more precise term for designing technology for patients is through the concept of patient-centered practices. It is clear that the entirety of the findings from this research are applicable to informing the practices in which patients engage to accomplish the goal of attaining wellbeing, becoming informed about their health, making a health based decision, or conducting a self-treatment routine.

Additionally, developing patient facing health information systems should allow for the flexibility of organizational techniques that patients bring to health information management, that portions of patient work can be delegated to caretakers and family members, and that patients have preferences for the physicality of information with which they work (i.e. physical printed documents or digital documents and objects).

5.5 Limitations

Every research study has limitations and the knowledge of those limitations makes for a stronger study. It is also beneficial for future researchers to be aware of the limitations of previous research. In an attempt at transparency and to reflect on the research conducted in this dissertation I will highlight several limitations with the research.

As was previously mentioned during the literature review, the assemblage concept can lack analytical power and clarity. The role of the perspective in this research is that it functions as a sensitizing concept and a way to interpret data and frame the results. This means that the theoretical lens may not have been as strong as others, lacking in some explanatory and descriptive power. This theory can be made stronger through future studies that focus on developing the analytical strength of the perspective through additional empirical work.

The main data consist of interviews. These interviews are highly reliant on an articulate interviewee. An additional recruitment criteria was used by asking providers to remove any participant not cognitively capable of participating in an interview. However, some participants may have had difficulties expressing their ideas on the subject matter. This was especially the case if the patient's caretaker was heavily involved with the patient's health information management. Talking about some of the more abstract components of PHR use and information management can be a challenge.

This is a qualitative study in which the data are text, observations, and field notes. These data are subject to multiple rounds of qualitative coding analysis and, as rigorous and transparent as I try to be in the analysis, the interpretive nature of this form of inquiry limits the generalizability of the study. Additionally, data were collected at only one VA Medical Center.

Future research in this area would benefit from looking at the concepts and components I describe and understanding the applicability to participants at other VA Medical Centers.

5.6 Future research

The results of this dissertation open up multiple avenues for future research. Perhaps one of the most exciting areas for future research is to begin to look at the assemblage concepts and their role in health conditions in greater detail. Specifically, the unique instance of mental health assemblages was an interesting, unexpected finding. This seems a logical starting point for further inquiry into the influence of health condition on health information management assemblages. This sort of work can be carried out either by looking at the specific mental health assemblage construct, or a focused study on comparing and contrasting different distributed health information assemblage configurations by health condition. Through a study at how assemblages are arranged for mental health patients, different surgeries, diabetes, cancer outpatients, and other chronic diseases, a body of literature will begin to develop around a conceptual perspective. The use of a conceptual perspective is currently lacking in the literature at present.

Another avenue for follow up research is to take a deeper look at the cognitive workspace concept that emerged out of the findings. The concept itself has plenty of opportunity to advance current thinking about health information management. This is the view that the mind is a container which temporarily stores, combines, and alters information in the health information management assemblage. This happens for a variety of reasons, some of them challenges and some of them advantages. Although not an entirely new idea, its understanding in the context of health information management is novel. The investigation of this concept

may bare useful findings for the continued development of patient focused health information systems and for informing patient practice.

The concept of aspirational desires or needs when managing information was an intriguing finding. There is opportunity for future research in this area to look at the practices that patients aspire to adopt and use. The notion of adoption has a large amount of publications in the health information systems space, both adoption of clinical and consumer systems. However, looking at the current practices that a sample of patients have adopted and understanding the factors that influence the desire or aspiration to adopt a new practice is a new way to approach the concept of adoption.

Perhaps the most straightforward area for future research is the continued call to publish in the area of patient health information management practices and the use of patient focused health information systems. This area of research is multidisciplinary, interdisciplinary, complex, and as a result full of different approaches and perspectives. Yet, it is still a nascent area with consumer health technology and personal health records continuing to be developed, adopted, and used in different ways. It's an exciting area of inquiry with many associated sociotechnical challenges. There is also the potential to provide great benefit for patients and the healthcare system through the publication of relevant and credible research that helps this intellectual community understand the role of technology in healthcare, how to use it responsibly, and perhaps most importantly, when not to use it.

Appendices

Appendix A: Pilot study interview questions

1. What experiences have you had in observing or understanding the needs that Veterans have for performing health information management?
2. In what spaces and places have you observed that this work (information management work) occurs? (Some examples might include a dedicated computer lab at your facility, a library, waiting rooms, hallways, and side offices.)
3. What are some strategies, tools, and techniques that you have observed patients employing to manage their health information?
4. What kind of questions, if any, do you get asked that have to do with helping find, manage, or understand health information tasks and information?
5. Are you aware of any of the personal health information management work that Veterans conduct at home?
6. Do you have any ideas based on your experience about how spaces for information management can be improved to better meet the health consumer's needs, if at all?
7. (provider specific question) What are your experiences in dealing with Veterans whom you know are actively involved in personal health information work practices? For example activities like managing blood pressure, nutrition, or exercise on a mobile phone or even on paper in a journal.
8. (provider specific question) What kind of personal health information management work do Veterans engage in that supports and relates to your goals as a provider?

Appendix B: Provider recruitment script

Subject: Attention Please: Research Participation Request – My HealtheVet

Hello [NAME],

I am a researcher with the Center for Integrated Healthcare and the My HealtheVet program office. I am conducting a study on the influence of My HealtheVet (MHV) on veteran personal health information management tasks and patient-provider communication. I presented a brief overview of this research project at the staff primary care provider meeting facilitated by Dr. John Langenberg on August 19th. I am contacting you because you are a primary care provider of several veterans that have in-person authenticated MHV accounts. I would like to ask you a few questions about these MHV users and would greatly appreciate your feedback, which will only take about 10 minutes of your time. If you could let me know when is convenient to contact you so that we may speak further, please either reply to this email or feel free to give me a call anytime at xxx-xxx-xxxx

Thank you for your time and consideration.

Appendix C: Patient recruitment script

My name is Matt Willis and I am a doctoral student at Syracuse University and a researcher at the VA. I am working on a research project that looks at how veterans manage health information and use the my healthvet personal health record. I'd like to tell you a bit about this project and see if you are interested in participating. Is this a good time to talk? I will only need a couple minutes of your time.

The goal of this study is to develop patient centered health information systems and make these systems easier to use by understanding how veterans use MHV and also other resources both online and offline. For example, if you use the internet to look up information or if you write things down using a pen and paper.

I am calling you today because you have an in person authenticated MHV account. I'd like to talk to you about how you use MHV and any other strategies you have for managing health information. Participation in this study is completely voluntary and confidential and you can choose to stop participating at any time. If you choose to participate in this study you will be asked to take a short survey and participate in an interview. The interview will take place in a private conference room at the Syracuse VAMC. The interview is expected to last about an hour. I'd like to schedule this interview with you at your convenience.

Do you have any questions and would you be interested in participating?

Appendix D: Patient and provider questionnaires

Pre-Interview Questionnaires

Health Provider Questionnaire

Responses for the following questions will be used as prompts during the interview. Please, record your responses in bullet points or with a few simple sentences. You will have the opportunity to elaborate and clarify your responses during the interview.

1. What kind of technology do you use for your job? For example, a mobile phone to look up information, a laptop, a desktop, a tablet, or any other information communication technology.
2. Do you use My HealtheVet for secure messaging? If so, how often. If not, skip.
3. Do you use My HealtheVet with patients? If so, how?
4. During an appointment with one of the patients I am also interviewing, what kinds of materials, documents, mobile devices, software or applications have you used to help convey information to them?
5. What kinds of materials, applications, or tools have you seen patients use to help them ask questions, prepare for the appointment, or organize their medical information?
6. Other than CPRS, what techniques or workflows do you have for managing patient health information or preparing for a clinical visit? For example, do you print a problem list, write an outline, or use a sticky note?
7. In your experience, what role do family members or caretakers who accompany the patient to a clinical appointment play?

Patient Questionnaire

Responses for the following questions will be used to explore the ideas in greater depth during the interview. Please, record your responses in bullet points or with a few simple sentences. You can elaborate and clarify your responses during the interview.

1. Please select your current age range. (circle one)
 Under 29 30-34 35-39 40-44 45-49 50-54 55-59 60-64 65-69 70-74 75-79 80-84
 85-89 90+
2. What are some of the activities you use the internet for? For example paying bills online, looking up specific information, or video chat.
3. What type of MHV account do you have? (circle one)
 Basic Advanced Premium

4. How long have you been using MHV?
5. In general, how often would you say you use MHV?
6. What sort of tasks do you use MHV to accomplish?
7. Do you use secure messaging? If so, what kind of events do you use it for?
8. Do family members or other care takers help you manage information about your health? For example, someone may log in to MHV for you to print out information.
9. What is the most important piece of information to you that you must know to help manage your health?
10. Do you do anything special to prepare for an appointment? For example, reviewing information in MHV, writing down questions, or reading health information online?
11. What kinds of strategies do you use to manage health information? For example, do you keep a notebook, a file folder, a food diary, or organize health information on the computer?
12. When you hear the phrase “health information management”, what do you think of?

Appendix E: Table of Patient Practices & MHV Use Classifications

Case ID	MHV Use Classification	Use of Technology	Information Strategies	Health Events & Wellbeing	Cognitive Workspace
2564	Self-Service (SS)	Medication ordering using MHV and phone; laptop; phone	Face-to-face conversation; some paper to archive and reference	Tracking blood pressure; Watching diet	Remembering: blood pressure, weight, diet
5875	Information Integration (II)	All MHV functions, Phone w/ health apps; music; scale; tablet; laptop; desktop	All digital information; reference on phone	Tracking: heartrate, steps, calories, GPS of biking/walking	Cognitive artifacts on phone; reminders and notifications through mobile phone
2221	SS	Secure messaging; email; phone	Look for patterns when researching information; experience as provider; printing out information; document annotation	Researching health condition; some writing of a treatment plan; synthesizing medical literature	Remembering some information and questions that come out of research
8574	II	All MHV functions; laptop; internet access on phone; voice input and speech-to-text; pharmacy app on phone; Personal health record outside VA	Keep notes on index card in front pocket; caretaker medication management; organize health documents in email; emergency folder; organize by diagnosis code	Clinical appointments generate diagnosis codes for participant to manage	Remembers diagnosis codes for insurance
6763	II	Medication ordering on MHV; secure messaging; Google docs; access to three different personal health records; several health focused apps	Caretaker manages medications; caretaker helps organize clinical information and questions during appointment; uses Google docs to keep health information; prints documents to transfer information between organizations	Caretaker important to help with information related to mental/behavioral health condition;	Routinely takes bloodsugar and remembers trends
9243	SS	USB drive of medical records; internet access on phone; laptop; dual monitors; fitbit tracker; backup on external hard drive	Shared calendar; email reminders; research health issues online	Tracking steps; ER visit to reference MHV medication	Remembering questions for provider and health concerns; statistics from health tracker and general feeling of wellbeing
9739	SS	Phone	Caretaker manages medication; caretaker uses MHV	Tracking blood pressure; tracking weight; medicine regimen	Commits questions for provider to memory
7146	SS	Orders medications; phone to create appointments	Archive of military records; Caretaker helps with information	Memory issues	Caretaker helps with memory issues;

			searching online; emergency file		
4285	II	All MHV functions; laptop; scanner; external backups	View lab work to generate questions; track blood pressure and blood sugar in spreadsheet; Manage PDF scans	Tracking blood pressure, blood sugar; surgeries	Remembering health tracking data; researching previous health events
3101	SS	Laptop; phone; order medication	Online searching; wall calendar	Blood pressure cuff	Remembering provider notes to make decisions
3102	II	Laptop; Blue button; phone with calendar; secure messaging; scheduling appointments	Videos of surgeries; online searching;	Blood pressure cuff; surgeries;	Retaining information from surgery videos, using to inform secure messages
4516	SS	Medication ordering; laptop	Online searching; save therapy handouts; put information on refrigerator; wall calendar;	No data available	Remember provider recommendations from appointments
1630	SS	Phone with health apps; run tracking apps;	Store health documents in email account;	Tracking: running distance, water intake, weight	Remembers tracking data results and makes decisions based off it; retain information later for pocket notebook
1079	II	View lab work, phone, laptop; secure messaging;	Struggle to stay organized; multiple calendars digital and physical; questions for provider on notecard	No data available	Trouble staying organized; locations of appointments; remembers questions for provider
8244	II	Tablet; phone with internet; two laptops; All MHV functions; tablet	Organize printed information by health event; emergency file; whiteboard; online information searching	Yearly physical; surgeries	Remembers configuration of office, internet searches, what they do using what type of technology
1010	SS	Phone; laptop	Mobile bookmarks on home screen; prep for appointment in waiting room; bookmarks	Therapy; group therapy; weight tracking	Remembering mental health resources and where to go in times of need
7543	II	Phone; laptop; lab work; secure messaging	Caretaker organize paperwork and document archive; print medication list; emergency file; location of health report card and important documents; post-it notes	Therapy; yearly physical	Remembering what documents are in important paper drawer; remembering milestones on health report card

3807	II	Laptop; secure messaging; appointments; email; tablet; external backup	Writing questions in word; create paper list of questions; hang appointments on wall; put documents on refrigerator	No data available	Remember questions till they can be typed up
8530	II	Medication renewal; secure messaging; MHV library; blue button	Caretaker attends appointments, researches information, helps generate questions, takes notes in appointment; download information on blue button, emergency file	No data available	Caretaker support cognitive workspace; use of location and space in home
1640	SS	Laptop; phone; medication renewal; educational library	Print documents to provide lawyer and other doctors; keep information in briefcase for appointments; Caretaker helps write notes, manage medication, manage finances	No data available	Remember prior health events to ask lawyer, judge, other doctors
9507	SS	Renew medications; laptop; phone	White board; desk with letters in chronological order; archive of manila folders	Two prescribed machines that help with pain	Remembering patterns of body pains and feeling ill
2251	II	Secure messaging; scheduling appointments; research on internet; laptop; phone	Print information organized by condition; bookmarking	Started with unknown disease difficult to diagnose	Years long history of remembering health experience related to chronic condition; remember questions for provider

References

- Aarhus, R., & Ballegaard, S. A. (2010). Negotiating Boundaries: Managing Disease at Home. In *CHI* (pp. 1223–1232). Atlanta, GA.
- Agarwal, R., Grandison, T., Johnson, C., & Kiernan, J. (2007). Enabling the 21st Century Health Care Information Technology Revolution. *Communications of the ACM*, *50*(2), 35–42.
- Agarwal, R. (2009). *Personal Health Information Management and the Design of Consumer Health Information Technology*. College Park, MD.
- Agarwal, R., & Angst, C. M. (2004). Technology-Enabled Transformations in U.S . Health Care: Early Findings on Personal Health Records and Individual Use. *Health (San Francisco)*, 1–40.
- Ahern, D. K., Woods, S. S., Lightowler, M. C., Finley, S. W., & Houston, T. K. (2011). Promise of and potential for patient-facing technologies to enable meaningful use. *American Journal of Preventive Medicine*, *40*(5), 162–172. <http://doi.org/10.1016/j.amepre.2011.01.005>
- Ancker, J. S., Miller, M. C., Patel, V., & Kaushal, R. (2013). Sociotechnical challenges to developing technologies for patient access to health information exchange data. *Journal of the American Medical Informatics Association : JAMIA*, *21*(4), 664–70. <http://doi.org/10.1136/amiajnl-2013-002073>
- Andersen, T. (2010). The Participatory Patient. In *PDC 2010* (pp. 1–4). Sydney.
- Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K. a, & Straus, S. E. (2011). Personal health records: a scoping review. *Journal of the American Medical Informatics Association : JAMIA*, *18*, 515–22. <http://doi.org/10.1136/amiajnl-2011-000105>
- Ash, J. S., Berg, M., & Coiera, E. (2004). Some unintended consequences of information

technology in health care: the nature of patient care information system-related errors.

Journal of the American Medical Informatics Association : JAMIA, 11(2), 104–12.

<http://doi.org/10.1197/jamia.M1471>

Baird, A. (2014). Making the Case for Leveraging the Patient-Centered E-Health (PCEH) Context to Expand Information Systems Theory. *Communications of the Association for Information Systems*, 34(1).

Ball, M. J., Costin, M. Y., & Lehmann, C. (2008). The personal health record: consumers banking on their health. *Studies in Health Technology and Informatics*, 134, 35–46. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/18376032>

Ball, M. J., & Lillis, J. (2001). E-health: transforming the physician/patient relationship. *International Journal of Medical Informatics*, 61(1), 1–10. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11248599>

Ball, M. J., Smith, C., & Bakalar, R. S. (2007). Personal health records: Empowering consumers. *Journal of Healthcare Information Management : JHIM*, 21(1), 76–86. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17299929>

Bardram, J., & Doryab, A. (2011). Activity Analysis – Applying Activity Theory to Analyze Complex Work in Hospitals. In *CSCW* (pp. 455–464).

Bauman, A. E., Fardy, H. J., & Harris, P. G. (2003). Getting it right: why bother with patient-centred care? *Medical Journal of Australia*, 179(September).

Baxter, P., & Jack, S. (2008). Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report*, 13(4), 544–559.

Beale, T. (2005). The Health Record – why is it so hard? *IMIA Yearbook of Medical Informatics*,

301–304.

Bensberg, M. (2007). *Patient Centred Care Literature Review*.

Berg, M. (1999). Patient care information systems and health care work: A sociotechnical approach. *International Journal of Medical Informatics*, 55(2), 87–101. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10530825>

Bernard, H., & Ryan, G. (2010). *Analyzing Qualitative Data: Systematic Approaches*. SAGE Publications, Inc.

Bernstein, M., Van Kleek, M., Karger, D., & Schraefel, M. C. (2008). Information scraps: How and why information eludes our personal information management tools. *ACM Transactions on Information Systems*, 26(4), 1–46. <http://doi.org/10.1145/1402256.1402263>

Berry, J. G., Goldmann, D. a, Mandl, K. D., Putney, H., Helm, D., O'Brien, J., ... Weinick, R. M. (2011). Health information management and perceptions of the quality of care for children with tracheotomy: a qualitative study. *BMC Health Services Research*, 11(1), 117. <http://doi.org/10.1186/1472-6963-11-117>

Birks, M. (2008). Memoing in qualitative research Probing data and processes. *Journal of Research in Nursing*, 13(1), 68–75. Retrieved from <http://jrn.sagepub.com/content/13/1/68.abstract>

Bogdan, R. C., & Biklen, S. K. (2007). *Qualitative research for education: an introduction to theory and methods* (5th ed.). Boston: Pearson Education.

Brennan, P. F., Downs, S., Casper, G., & Kenron, D. (2007). Project HealthDesign: stimulating the next generation of personal health records. *AMIA ... Annual Symposium Proceedings / AMIA Symposium*. *AMIA Symposium*, 70–4. Retrieved from

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2655909&tool=pmcentrez&endertype=abstract>

- Buente, W., & Robbin, A. (2008). Trends in Internet Information Behavior. *Journal of the American Society for Information Science*, (August), 2000–2004.
- Burrington-Brown, J., Claybrook, D., Dolan, M., Goethals, C., Kelly, C. D., LaMoureaux, L., ... Wolter, J. (2008). Defining the Personal Health Information Management Role. *Journal of AHIMA*, 79(6), 59–63.
- Bush, G. W. (2004). *Executive Order 13335 - Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator*. Washington, D.C.
- Charmaz, K., & Belgrave, L. (2012). Qualitative interviewing and grounded theory analysis. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft* (2nd ed., pp. 347–367). SAGE Publications, Inc.
- Chisholm, R. F., & Ziegunfuss, J. (1986). A Review of Applications of the Sociotechnical Systems Approach to Health Care Organizations. *The Journal of Applied Behavioral Science*, 22(3), 315–327. <http://doi.org/10.1177/002188638602200310>
- Chumbler, N. R., Haggstrom, D. a, & Saleem, J. (2010). Implementation of health information technology in Veterans Health Administration to support transformational change: Telehealth and personal health records. *Medical Care*, 48(12), 1–7. <http://doi.org/10.1097/MLR.0b013e3181d558f9>
- Civan, A., McDonald, D. W., Unruh, K. T., & Pratt, W. (2009). Locating Patient Expertise in

Everyday Life. In *GROUP* (Vol. 2009, pp. 291–300). Sanibel Island, FL: ACM. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2955449&tool=pmcentrez&rendertype=abstract>

Civan, A., Skeels, M. M., Stolyar, A., & Pratt, W. (2006). Personal health information management: consumers' perspectives. In *AMIA Annual Symposium proceedings* (pp. 156–60). Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1839450&tool=pmcentrez&rendertype=abstract>

Clarke, A. (2005). *Situational Analysis Grounded Theory After the Postmodern Turn* (1st ed.). SAGE Publications, Inc.

Cohen, S. (2004). Social relationships and health. *The American Psychologist*, *59*(8), 676–84. <http://doi.org/10.1037/0003-066X.59.8.676>

Consumers and Health Information Technology: A National Survey. (2010). Retrieved from <http://www.chcf.org/publications/2010/04/consumers-and-health-information-technology-a-national-survey>

Corbin, J., & Strauss, A. (2008a). *Basics of qualitative research* (3rd ed.). Thousand Oaks, California: Sage.

Corbin, J., & Strauss, A. (2008b). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, California: Sage.

Davidson, E. J., Østerlund, C. S., & Flaherty, M. G. (2015). Drift and shift in the organizing vision career for personal health records: An investigation of innovation discourse dynamics. *Information and Organization*, *25*(4), 191–221.

<http://doi.org/10.1016/j.infoandorg.2015.08.001>

de Bocanegra, H., & Gany, F. (2004). Good provider, good patient: changing behaviors to eliminate disparities in healthcare. *The American Journal of Managed Care*, 10(20), SP20–8. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15481433>

De Silva, M. J., McKenzie, K., Harpham, T., & Huttly, S. R. A. (2005). Social capital and mental illness: a systematic review. *Journal of Epidemiology and Community Health*, 59(8), 619–27. <http://doi.org/10.1136/jech.2004.029678>

Deegan, D. (2003). *Nation's Largest Healthcare System Pledges Involvement in Healthy Hospital Initiative*. Retrieved from <http://yosemite.epa.gov/opa/admpress.nsf/8822edaadaba0243852572a000656841/66a4a31db7c1ae178525703d0067d18b!OpenDocument>

DeLanda, M. (2006). *A New Philosophy of Society: Assemblage Theory and Social Complexity*. Bloomsbury Academic.

Delbanco, T., Walker, J., Darer, J. D., Elmore, J. G., Feldman, H. J., Leveille, S. G., ... Weber, V. D. (2010). Open notes: doctors and patients signing on. *Annals of Internal Medicine*, 153(2), 121–5. <http://doi.org/10.7326/0003-4819-153-2-201007200-00008>

Deleuze, G., & Guattari, F. (1987). *A Thousand Plateaus*. (B. Massumi, Ed.). University of Minnesota Press.

Department of Veterans Affairs FY 2014-2020 Strategic Plan. (2014).

Diamond, C. C., & Shirky, C. (2008). Health information technology: A few years of magical thinking? *Health Affairs (Project Hope)*, 27(5), w383–90. <http://doi.org/10.1377/hlthaff.27.5.w383>

- Ehn, P. (2008). Participation in Design Things. In *PDC 2008*.
- Endsley, S., Kibbe, D. C., Linares, A., & Colorafi, K. (2006). An introduction to personal health records. *Family Practice Management*, 13(5), 57–62. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16736906>
- Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196, 129–136.
- Feldman, M. S., & Orlikowski, W. J. (2011). Theorizing Practice and Practicing Theory. *Organization Science*, 22(5), 1240–1253.
- Fernández-Alemán, J. L., Seva-Llor, C. L., Toval, A., Ouhbi, S., & Fernández-Luque, L. (2013). Free Web-based Personal Health Records: An Analysis of Functionality. *Journal of Medical Systems*, 37(6), 9990. <http://doi.org/10.1007/s10916-013-9990-z>
- Finkelstein, J., Knight, A., Marinopoulos, S., Gibbons, C., Berger, Z., Aboumatar, H., ... Bass, E. B. (2012). *Enabling Patient-Centered Care Through Health Information Technology*. Washington, D.C.
- Fitzpatrick, G., & Ellingsen, G. (2012). *A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas. Computer Supported Cooperative Work (CSCW)* (Vol. 22). <http://doi.org/10.1007/s10606-012-9168-0>
- Fox, S. (2008). *The Engaged E-patient Population People turn to the internet for health information when the stakes are high and the connection fast. Journal of Medical Internet Research*.
- Fox, S. (2011a). *80% of internet users look for health information online*. Washington, D.C. Retrieved from <http://www.pewinternet.org/Reports/2011/HealthTopics/Part->

2.aspx?view=all

Fox, S. (2011b). *Peer-to-peer healthcare*. Washington, D.C.

Fox, S., & Jones, S. (2009). *The Social Life of Health Information*. Washington, D.C.

Frost, J. H., & Messagil, M. P. (2008). Collaborative uses of personal health information: a study of PatientsLikeMe. In *CHI* (pp. 1–4).

Gade, D., & Wilkins, V. (2013). Where Did You Serve? Veteran Identity, Representative Bureaucracy and Vocational Rehabilitation. *Journal of Public Administration Research and Theory, 23*(2), 267–288.

Gearon, C. J. (2007). *Perspectives on the future of personal health records*. Retrieved from <http://www.chcf.org/publications/2007/06/perspectives-on-the-future-of-personal-health-records>

Gerber, B. S., & Eiser, A. R. (2001). The patient-physician relationship in the internet age: future prospects and the research agenda. *Journal of Medical Internet Research, 3*(2), 1–12. <http://doi.org/10.2196/jmir.3.2.e15>.Full

Ghaemi, S. N. (2009). The rise and fall of the biopsychosocial model. *The British Journal of Psychiatry : The Journal of Mental Science, 195*(1), 3–4. <http://doi.org/10.1192/bjp.bp.109.063859>

Gilbar, O. (1996). Introducing a biopsychosocial approach in an oncology institute: a case study. *International Social Work, 39*, 163–176. Retrieved from <http://www.scie-socialcareonline.org.uk/introducing-a-biopsychosocial-approach-in-an-oncology-institute-a-case-study/r/a1CG0000000GgBxMAK>

Goldzweig, C. L., Orshansky, G., Paige, N. M., Towfigh, A. A., Haggstrom, D. A., Miake-Lye, I., ...

- Shekelle, P. G. (2013). Electronic Patient Portals: Evidence on health outcomes, satisfaction, efficiency, and attitudes. *Annals of Internal Medicine*, 159(10), 677–700.
- Greenhalgh, T., Potts, H., Wong, G., Bark, P., & Swinglehurst, D. (2009). Tensions and paradoxes in Electronic Patient Record research: A systematic literature review using the meta-narrative method. *The Milbank Quarterly*, 87(4), 729–788. <http://doi.org/10.1111/j.1468-0009.2008.00538.x>
- Grove, A. S. (2005). Efficiency in the health care industries: a view from the outside. *JAMA : The Journal of the American Medical Association*, 294(4), 490–2. <http://doi.org/10.1001/jama.294.4.490>
- Grudin, J., & Palen, L. (1995). Why Groupware Succeeds: Discretion of Mandate? In *European Conference on Computer Supported Cooperative Work*. Kluwer. Retrieved from <http://research.microsoft.com/en-us/um/people/jgrudin/past/papers/ecscw95/ecscw.html>
- Havelka, M., Lucanin, J. D., & Lucanin, D. (2009). Biopsychosocial model--the integrated approach to health and disease. *Collegium Antropologicum*, 33(1), 303–10. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19408642>
- HealthyPeople2020. (2012). Health Communication and Health Information Technology - Healthy People. Retrieved September 6, 2012, from <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=18>
- Hersh, W. R. (2002). Medical Informatics: Improving Health Care Through Information. *JAMA: The Journal of the American Medical Association*, 288(16), 1955–1958. <http://doi.org/10.1001/jama.288.16.1955>

- Hill, J. H., Burge, S., Haring, A., & Young, R. a. (2012). Communication Technology Access, Use, and Preferences among Primary Care Patients: From the Residency Research Network of Texas (RRNeT). *Journal of the American Board of Family Medicine : JABFM*, 25(5), 625–634. <http://doi.org/10.3122/jabfm.2012.05.120043>
- Hollan, J. D., Hutchins, E., & Kirsh, D. (2000). Distributed cognition: A new foundation for human-computer interaction research. *Transactions on Computer-Human Interaction*, 7(2), 174–196.
- Huba, N., & Zhang, Y. (2012). Designing patient-centered personal health records (PHRs): health care professionals' perspective on patient-generated data. *Journal of Medical Systems*, 36(6), 3893–905. <http://doi.org/10.1007/s10916-012-9861-z>
- Hutchins, E. (1995a). *Cognition in the Wild*. MIT Press. Bradford Books. Retrieved from <http://hci.ucsd.edu/hutchins/citw.html>
- Hutchins, E. (1995b). How a Cockpit Remembers Its Speeds. *Cognitive Science*, 18, 265–288.
- Jayadevappa, R., & Chhatre, S. (2011). Patient Centered Care - A Conceptual Model and Review of the State of the Art Identification of Studies. *The Open Health Services and Policy Journal*, 4, 15–25.
- Jha, A. K., DesRoches, C. M., Campbell, E. G., Donelan, K., Rao, S. R., Ferris, T. G., ... Blumenthal, D. (2009). Use of electronic health records in U.S. hospitals. *The New England Journal of Medicine*, 360(16), 1628–38. <http://doi.org/10.1056/NEJMsa0900592>
- Johansen, M. A., Scholl, J., Hasvold, P., Ellingsen, G., & Bellika, J. G. (2008). “Garbage In, Garbage Out ” - Extracting Disease Surveillance Data from EPR Systems in Primary Care. In *CSCW 2008* (pp. 525–534). San Diego.

- Jones, D. A., Shipman, J. P., Plaut, D. A., & Selden, C. R. (2010). Characteristics of personal health records: findings of the Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force. *Journal of the Medical Library Association : JMLA*, *98*(3), 243–9. <http://doi.org/10.3163/1536-5050.98.3.013>
- Jones, S. S., Koppel, R., Ridgeley, M. S., Wu, S., Palen, T. E., & Harrison, M. I. (2011). *Guide to Reducing Unintended Consequences of Electronic Health Records*. Rockville, MD.
- Jones, W. (2008). *Keeping Found Things Found: The Study and Practice of Personal Information Management* (1st ed.). Burlington, MA: Elsevier Inc.
- Kaelber, D., Jha, A., Johnston, D., Middleton, B., & Bates, D. W. (2008). A Research Agenda for Personal Health Records (PHRs). *Journal of the American Medical Informatics Association*, *15*(6), 729–736. <http://doi.org/10.1197/jamia.M2547.Introduction>
- Kahn, M., Bell, S., Walker, J., & Delbanco, T. (2014). Let's Show Patients Their Mental Health Records. *The Journal of the American Medical Association*, *311*(13), 1–2.
- Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. *Journal of Urban Health : Bulletin of the New York Academy of Medicine*, *78*(3), 458–67. <http://doi.org/10.1093/jurban/78.3.458>
- Kelso, L., & Walker, R. (2009). The consumer view of PHRs. Observational study finds most value PHRs, but issues remain. *Journal of the American Health Information Management Association*, *80*(10), 56–7, 59. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19839440>
- Kernisan, L. (2013). Designing for caregivers. Retrieved from <http://thehealthcareblog.com/blog/2013/05/25/designing-for-caregivers/#more-61936>

- Kerns, J. W., Krist, A. H., Longo, D. R., Kuzel, A. J., & Woolf, S. H. (2013). How patients want to engage with their personal health record: a qualitative study. *BMJ Open*, 3(7), e002931–. <http://doi.org/10.1136/bmjopen-2013-002931>
- Klasnja, P., Hartzler, A. C., Unruh, K. T., & Pratt, W. (2010). Blowing in the Wind: Unanchored Patient Information Work during Cancer Care. In *Computer Human Interaction* (pp. 193–202). Atlanta, GA: ACM. <http://doi.org/10.1145/1753326.1753355>
- Klasnja, P., Hartzler, A., Powell, C., Phan, G., & Pratt, W. (2010). Health Weaver Mobile: Designing a Mobile Tool for Managing Personal Health Information during Cancer Care. *AMIA ... Annual Symposium Proceedings / AMIA Symposium. AMIA Symposium, 2010*, 392–6. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3041373&tool=pmcentrez&rendertype=abstract>
- Klasnja, P., & Pratt, W. (2012). Healthcare in the pocket: mapping the space of mobile-phone health interventions. *Journal of Biomedical Informatics*, 45(1), 184–98. <http://doi.org/10.1016/j.jbi.2011.08.017>
- Kling, R., McKim, G., & King, A. (2003). A bit more to it: Scholarly Communication Forums as Socio-Technical Interaction Networks. *Journal of the American Society for Information Science and Technology*, 54(1), 47–67. <http://doi.org/10.1002/asi.10154>
- Koelsch, L. (2013). Reconceptualizing the Member Check Interview. *International Journal of Qualitative Methods*, 12, 168–179. <http://doi.org/10.1177/1532708611401329>
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45, 214–222.

Krist, A. H., & Woolf, S. H. (2011). A vision for patient-centered health information systems.

JAMA : The Journal of the American Medical Association, 305(3), 300–1.

<http://doi.org/10.1001/jama.2010.2011>

Krupat, E., Bell, R. A., Kravitz, R. L., Thom, D., & Azari, R. (2001). When Physicians and Patients

Think Alike: Patient-Centered Beliefs and Their Impact on Satisfaction and Trust. *The*

Journal of Family Practice, 50(12). Retrieved from [http://www.jfponline.com/the-](http://www.jfponline.com/the-publication/past-issue-single-view/when-physicians-and-patients-think-alike-patient-centered-beliefs-and-their-impact-on-satisfaction-and-trust/03837ec65a4f877648377f2bab378cb2.html)

[publication/past-issue-single-view/when-physicians-and-patients-think-alike-patient-](http://www.jfponline.com/the-publication/past-issue-single-view/when-physicians-and-patients-think-alike-patient-centered-beliefs-and-their-impact-on-satisfaction-and-trust/03837ec65a4f877648377f2bab378cb2.html)

[centered-beliefs-and-their-impact-on-satisfaction-and-](http://www.jfponline.com/the-publication/past-issue-single-view/when-physicians-and-patients-think-alike-patient-centered-beliefs-and-their-impact-on-satisfaction-and-trust/03837ec65a4f877648377f2bab378cb2.html)

[trust/03837ec65a4f877648377f2bab378cb2.html](http://www.jfponline.com/the-publication/past-issue-single-view/when-physicians-and-patients-think-alike-patient-centered-beliefs-and-their-impact-on-satisfaction-and-trust/03837ec65a4f877648377f2bab378cb2.html)

Kuehn, B. M. (2012). Veterans health system cited by experts as model for patient-centered

care. *The Journal of the American Medical Association*, 307(5), 442–443.

Kutz, D. O., & Ekbia, H. R. (2011). Designing for the Invincible: Health Engagement and

Information Management. *2011 44th Hawaii International Conference on System Sciences*,

1–10. <http://doi.org/10.1109/HICSS.2011.150>

Kvale, S., & Brinkmann, S. (2008). Methods of Analysis. In *InterViews: Learning the Craft of*

Qualitative Research Interviewing (2nd ed., pp. 187–209). Sage Publications.

Labs, PHRs, Platforms & Consumer Engagement: A Presentation. (2009). Retrieved from

[http://chilmarkresearch.com/2009/03/18/labs-phrs-platforms-consumer-engagement-a-](http://chilmarkresearch.com/2009/03/18/labs-phrs-platforms-consumer-engagement-a-presentation/)

[presentation/](http://chilmarkresearch.com/2009/03/18/labs-phrs-platforms-consumer-engagement-a-presentation/)

Lahtiranta, J. (2009). Current challenges of personal health information management. *Journal of*

Systems and Information Technology, 11(3), 203–243.

<http://doi.org/10.1108/13287260910983614>

- Lee, M. C. (2006). *Evaluation of MyHealthVet implementation at the Portland Veterans Affairs medical center. Design*. Oregon Health and Science University School of Medicine.
- Leech, N. L., & Onwuegbuzie, A. J. (2007). An array of qualitative data analysis tools: A call for data analysis triangulation. *School Psychology Quarterly*, 22(4), 557–584.
<http://doi.org/10.1037/1045-3830.22.4.557>
- Lewin, S., Skea, Z., Entwistle, V., Zwarenstein, M., & Dick, J. (2001). Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews*, (4), CD003267. <http://doi.org/10.1002/14651858.CD003267>
- Lincoln. (1865). *Second Inaugural Address*. Washington, D.C.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry* (1st ed.). Newbury Park, CA: Sage Publications.
- Lindeman, D. (2010). Lessons from a Leader in Telehealth Diffusion: A Conversation with Adam Darkins of the Veterans Health Administration. *Ageing International*.
<http://doi.org/10.1007/s12126-010-9079-7>
- Little, D. (1990). *Varieties of social explanation* (1st ed.). Westview Press. Retrieved from <http://www.amazon.com/Varieties-Social-Explanation-Introduction-Philosophy/dp/0813305667>
- Liu, L. S., Shih, P. C., & Hayes, G. R. (2011). Barriers to the adoption and use of personal health record systems. In *Proceedings of the 2011 iConference* (pp. 363–370). New York, New York, USA: ACM Press. <http://doi.org/10.1145/1940761.1940811>
- Lovell, B. L., Lee, R. T., & Brotheridge, C. M. (2010). Physician Communication: Barriers to Achieving Shared Understanding and Shared Decision Making with Patients. *Journal of*

- Participatory Medicine*, 2(12). Retrieved from
<http://www.jopm.org/evidence/research/2010/10/13/physician-communication-barriers-to-achieving-shared-understanding-and-shared-decision-making-with-patients/>
- Mardon, R. (2013). *Lessons From the Enabling Patient-Centered Care Through Health IT Grant Initiative*. Rockville, MD.
- Medicine, I. of. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century* (1st ed.). National Academies Press; 1 edition. Retrieved from
<http://www.amazon.com/Crossing-Quality-Chasm-Health-Century/dp/0309072808>
- Meyer, E. T. (2006). Socio-Technical Interaction Networks : A Discussion of the Strengths, Weaknesses and Future of Kling's STIN Model. In J. Berleur, M. . Numinen, & J. Impagliazzo (Eds.), *International Federation for Information Processing* (Vol. 223, pp. 37–48). Boston.
- Mickelson, R., Willis, M., & Holden, R. (2015). Medication-related cognitive artifacts used by older adults with heart failure. *Health Policy and Technology*, 4(4), 387–398.
<http://doi.org/10.1016/j.hlpt.2015.08.009>
- Miles, M., & Huberman, A. (1994). *Qualitative data analysis: an expanded sourcebook* (1st ed.). Thousand Oaks, California: Sage.
- Moen, A., & Brennan, P. F. (2005). Health @ Home: The Work of Health Information Management in the Household (HIMH): Implications for Consumer Health Informatics (CHI) Innovations. *Journal of the American Medical Informatics Association*, 12(6), 648.
- Moll, J. (2010). The Patient as Service Co-Creator. In *PDC* (pp. 163–166). Sydney, Australia: ACM.
- Munson, S. A., Cavusoglu, H., Frisch, L., & Fels, S. (2013). Sociotechnical challenges and progress in using social media for health. *Journal of Medical Internet Research*, 15(10), e226.

<http://doi.org/10.2196/jmir.2792>

- Nayar, P., Nguyen, A. T., Ojha, D., Apenteng, B., Woodbridge, P., & Schmid, K. K. (2013). Transitions in Dual Care for Veterans: Non-Federal Physician Perspectives. *Journal of Community Health, 38*(2), 225–237.
- Nazi, K. M. (2010). Veterans' voices: Use of the American customer satisfaction index (ACSI) survey to identify My HealtheVet personal health record users' characteristics, needs, and preferences. *Journal of the American Medical Informatics Association : JAMIA, 17*(2), 203–211. <http://doi.org/10.1136/jamia.2009.000240>
- Nazi, K. M., Hogan, T. P., Wagner, T. H., McInnes, D. K., Smith, B. M., Haggstrom, D., ... Weaver, F. M. (2010). Embracing a health services research perspective on personal health records: lessons learned from the VA My HealtheVet system. *Journal of General Internal Medicine, 25*, 62–7. <http://doi.org/10.1007/s11606-009-1114-6>
- Newell, A., & Simon, H. (1972). *Human Problem Solving*. Englewood Cliffs, NJ: Prentice-Hall.
- Norman, D. a. (1991). Cognitive artifacts. In *Designing interaction* (1st ed., pp. 17–38). Cambridge: Cambridge University Press. <http://doi.org/10.1145/1254960.1255025>
- Northcutt, N., & McCoy, D. (2004). *Interactive qualitative analysis : a systems method for qualitative research* (1st ed.). Thousand Oaks, California: Sage.
- Østerlund, C., Dosa, N. P., & Smith, C. A. (2005). Mother Knows Best: Medical Record Management for Patients with Spina Bifida During the Transition from Pediatric to Adult Care. In *AMIA Symposium Proceedings* (pp. 580–584).
- Østerlund, C., Kensing, F., & Gherardi, S. (2014). Editorial: Personal Health Records: Empowering patients through information systems? *Information Technology & People,*

27(4), 390–396.

Pagliari, C., Detmer, D., & Singleton, P. (2007). Potential of electronic personal health records.

British Medical Journal, 335(7615), 330–3. <http://doi.org/10.1136/bmj.39279.482963.AD>

Palen, L., & Aaløkke, S. (2006). Of Pill Boxes and Piano Benches: “Home-made” Methods for Managing Medication. In *Computer Supported Cooperative Work (CSCW)* (pp. 79–88).

ACM.

Paoli, S. De, & Kerr, A. (2009). The Cheating Assemblage in MMORPGs: Toward a sociotechnical description of cheating. In *Digital games research association*.

Patel, V. N., Abramson, E., Edwards, A. M., Cheung, M. A., Dhopeswarkar, R. V., & Kaushal, R.

(2011). Consumer attitudes toward personal health records in a beacon community. *The American Journal Of Managed Care*, 17(4), e104–e120.

Piras, E. M. (2013). The shaping of patient 2.0: Exploring agencies, technologies and discourses in new healthcare practices. *Science & Technology Studies*, 26(2), 3–13.

Piras, E. M., & Zanutto, A. (2010). Prescriptions, X-rays and Grocery Lists. Designing a Personal Health Record to Support (The Invisible Work Of) Health Information Management in the Household. *Computer Supported Cooperative Work (CSCW)*, 19(6), 585–613.

<http://doi.org/10.1007/s10606-010-9128-5>

Pratt, W., Reddy, M. C., McDonald, D. W., Tarczy-Hornoch, P., & Gennari, J. H. (2004).

Incorporating ideas from computer-supported cooperative work. *Journal of Biomedical Informatics*, 37(2), 128–37. <http://doi.org/10.1016/j.jbi.2004.04.001>

Pratt, W., Unruh, K., Civan, A., & Skeels, M. (2006). Personal health information management.

Communications of the ACM, 49(1), 51–55. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed/18604979>

- Purin, B., & Piras, E. M. (2011). Personal Health Records among Institutions, Medical Records, and Patient Wisdom: A Socio-technical Approach. In M. Kostkova & P. Szomszor (Eds.), *Electronic Healthcare* (pp. 151–158). Springer-Verlag. <http://doi.org/10.1007/978-3-642-23635-8>
- Reddy, M. C., Bardram, J., & Gorman, P. (2010). CSCW Research in Healthcare : Past , Present , and Future. In *CSCW 2010* (pp. 615–616). Savannah, Georgia.
- Reddy, M. C., Dourish, P., & Pratt, W. (2001). Coordinating Heterogeneous Work: Information and Representation in Medical Care. In *ECSCW* (pp. 239–258).
- Reddy, M. C., Dourish, P., & Pratt, W. (2006). Temporality in Medical Work: Time also Matters. *Computer Supported Cooperative Work (CSCW)*, 15(1), 29–53.
<http://doi.org/10.1007/s10606-005-9010-z>
- Reti, S. R., Feldman, H. J., Ross, S. E., & Safran, C. (2010). Improving personal health records for patient-centered care. *Journal of the American Medical Informatics Association : JAMIA*, 17(2), 192–5. <http://doi.org/10.1136/jamia.2009.000927>
- Robson, B., & Baek, O. (2009). *The Engines of Hippocrates: From the Dawn of Medicine to Medical and Pharmaceutical Informatics* (1st ed.). John Wiley & Sons.
- Rogers, Y. (2004). New theoretical approaches for HCI. *Annual Review of Information Science and Technology*, (38), 1–43.
- Ross, S. E., & Lin, C.-T. (2003). The effects of promoting patient access to medical records : A review. *Journal of the American Medical Informatics Association: JAMIA*, 10(2), 129–138.
<http://doi.org/10.1197/jamia.M1147.The>

Saldana, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). Los Angeles: Sage.

Santrock, J. (2007). *A Topical approach to human life-span development* (3rd ed.). St. Louis: McGraw-Hill.

Saparova, D. (2012). Motivating, Influencing, and Persuading Patients through Personal Health Records: A Scoping Review. *Perspectives in Health Information Management*, 9, 1f.

Retrieved from

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3392953&tool=pmcentrez&rendertype=abstract>

Sawyer, S., Crowston, K., & Wigand, R. T. (2014). Digital assemblages: evidence and theorising from the computerisation of the US residential real estate industry. *New Technology, Work and Employment*, 29(1), 40–56. <http://doi.org/10.1111/ntwe.12020>

Sawyer, S., & Jarrahi, M. H. (2013). Sociotechnical approaches to the study of Information Systems. In A. Tucker & H. Topi (Eds.), *CRC Handbook of Computing* (1st ed., pp. 1–39). Chapman and Hall.

Schmidt, K., & Bannon, L. (1992). Taking CSCW Seriously Supporting Articulation Work. *Computer Supported Cooperative Work (CSCW)*, 1, 7–40.

Schneider, J. M. (2008). My HealthVet: Fighting for health with information. *Journal of Consumer Health on the Internet*, 12(1), 13–21.
<http://doi.org/10.1080/15398280802081410>

Simborg, D. W. (2009). The limits of free speech: The PHR problem. *Journal of the American Medical Informatics Association*, 16(3), 282–283. <http://doi.org/10.1197/jamia.M3069>

Smith, & Protevi. (2012). Gilles Deleuze. Retrieved from

<http://plato.stanford.edu/entries/deleuze/>

Smith, A. (2012). *Nearly half of American adults are smartphone owners*. Washington, D.C.

Retrieved from Pew Research Center's Internet & American Life Project

Smolij, K., & Dun, K. (2006). Patient Health Information Management: Searching for the Right

Model. *Perspectives in Health Information Management*, 3(10). Retrieved from

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2047307/>

Srnicek, N. (2007). *Assemblage Theory, Complexity and Contentious Politics: The Political*

Ontology of Gilles Deleuze. University of Western Ontario. Retrieved from

https://www.academia.edu/178031/Assemblage_Theory_Complexity_and_Contentious_P

[olitics_The_Political_Ontology_of_Gilles_Deleuze](https://www.academia.edu/178031/Assemblage_Theory_Complexity_and_Contentious_P)

Stahl, G. (2011). Theories of cognition in CSCW. In *ECSCW* (pp. 193–212). Aarhus, Denmark.

Steinman, M. A., Lee, S. J., Boscardin, W. J., Miao, Y., Fung, K. Z., Moore, K. L., & Schwartz, J. B.

(2012). Patterns of multimorbidity in elderly veterans. *Journal of the American Geriatrics*

Society, 60(10), 1872–1880.

Stewart, M., Brown, J. B., Weston, W. . W., McWhinney, I. R., McWilliam, C., & Freeman, T. R.

(1995). *Patient-Centered Medicine: Transforming the Clinical Method* (1st ed.). SAGE

Publications, Inc. Retrieved from [http://www.amazon.com/Patient-Centered-Medicine-](http://www.amazon.com/Patient-Centered-Medicine-Transforming-Clinical-Method/dp/0803956894)

[Transforming-Clinical-Method/dp/0803956894](http://www.amazon.com/Patient-Centered-Medicine-Transforming-Clinical-Method/dp/0803956894)

Strauss, A., Fagerhaugh, S., Suczek, B., & Wiener, C. (1982). The work of hospitalized patients.

Social Science & Medicine, 16(9), 977–86. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed/7112176>

Suchman, L. A. (1985). *Plans and situated actions: The problem of human-machine*

communication.

- Swan, M. (2009). Emerging patient-driven health care models: an examination of health social networks, consumer personalized medicine and quantified self-tracking. *International Journal of Environmental Research and Public Health*, 6(2), 492–525.
<http://doi.org/10.3390/ijerph6020492>
- Tang, P. C., Ash, J. S., Bates, D. W., Overhage, M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 13(2), 121–126.
<http://doi.org/10.1197/jamia.M2025.records>
- Tang, P. C., & Lansky, D. (2005). The missing link: bridging the patient-provider health information gap. *Health Affairs (Project Hope)*, 24(5), 1290–5.
<http://doi.org/10.1377/hlthaff.24.5.1290>
- Terry, K. (2008). Will PHRs rule the waves or roll out with the tide? *Hospitals and Health Networks/AHA*, 82(8), 36–39, 1.
- Teutsch, C. (2003). Patient-doctor communication. *Medical Clinics of North America*, 87(5), 1115–1145. [http://doi.org/10.1016/S0025-7125\(03\)00066-X](http://doi.org/10.1016/S0025-7125(03)00066-X)
- Trede, F., & Higgs, J. (2009). Framing research questions and writing philosophically. In J. Higgs, D. Horsfall, & S. Grace (Eds.), *Writing qualitative research in practice* (pp. 13–26). Rotterdam: Sense Publishers.
- Turner, A. (2009). *Electronic health records annotated bibliography*. Group.
- Turvey, C., Klein, D., Fix, G., Hogan, T., Woods, S., Simon, S. R., ... Nazi, K. (2014). Blue Button use by patients to access and share health record information using the Department of

- Veterans Affairs' online patient portal. *Journal of the American Medical Informatics Association*, amiajnl-2014-002723-. <http://doi.org/10.1136/amiajnl-2014-002723>
- Ueckert, F., Goerz, M., Ataian, M., Tessmann, S., & Prokosch, H.-U. (2003). Empowerment of patients and communication with health care professionals through an electronic health record. *International Journal of Medical Informatics*, 70(2-3), 99–108. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12909161>
- Unruh, K. T., & Pratt, W. (2008a). Barriers to Organizing Information during Cancer Care: “I don't know how people do it.” In *AMIA Symposium Proceedings* (pp. 742–746).
- Unruh, K. T., & Pratt, W. (2008b). The Invisible Work of Being a Patient and Implications for Health Care: “[the doctor is] my business partner in the most important business in my life, staying alive.” *EPIC*, 40–50.
- Unruh, K. T., Skeels, M., Civan-Hartzler, A., & Pratt, W. (2010). Transforming Clinic Environments into Information Workspaces for Patients. In *Computer Human Interaction* (pp. 183–192). Atlanta, GA: ACM. <http://doi.org/10.1145/1753326.1753354>
- Valdez, R. S., Holden, R. J., Novak, L. L., & Veinot, T. C. (2014). Transforming consumer health informatics through a patient work framework: connecting patients to context. *Journal of the American Medical Informatics Association : JAMIA*, 1–7. <http://doi.org/10.1136/amiajnl-2014-002826>
- Veinot, T. C., Zheng, K., Lowery, J. C., Souden, M., & Keith, R. (2010). Using Electronic Health Record Systems in Diabetes Care: Emerging Practices. In *International Health Informatics*. Arlington, VA.
- Vogel, L. (2010). “Blue button” access to medical records. *CMAJ : Canadian Medical Association*

- Journal*, 182(16), E746. <http://doi.org/10.1503/cmaj.109-3685>
- Walsham, G. (2006). Doing Interpretive Research. *European Journal of Information Systems*, 15(3), 320–330.
- Weinert, C., Cudney, S., & Kinion, E. (2011). Development of My Health Companion to enhance self-care management of chronic health conditions in rural dwellers. *Public Health Nursing*, 27(3), 263–9. <http://doi.org/10.1111/j.1525-1446.2010.00852.x>
- Westat. (2010). *National Survey of Veterans, Active Duty Service Members, Demobilized National Guard and Reserve Members, Family Members, and Surviving Spouses* (Vol. 20850). Rockville, MD.
- Westra, B. L., Choromanski, L., Cook, J. W., Davies, D. M., Fine, E., & Rajchel, T. (2012). *Annotated Bibliography: Consumer Engagement in the use of a Personal Health Record or e-Portal. Health promotion journal of Australia : official journal of Australian Association of Health Promotion Professionals* (Vol. 25). Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/24739781>
- Wilson, B. E. V. (2003). Asynchronous Health Care Communication. *Communications of the ACM*, 46(6), 79–84.
- Wright, K. B. (2008). Provider-Patient Communication. In K. B. Wright, L. Sparks, & H. D. O'Hair (Eds.), *Health Communication in the 21st Century* (1st ed.). Wiley-Blackwell.
- Yin, R. K. (2014a). *Case Study Research: Design and Methods* (5th ed.). Thousand Oaks, California: Sage Publications.
- Yin, R. K. (2014b). Designing case studies: Identifying Your Case(s) and Establishing the Logic of Your Case Study. In *Case Study Research: Design and methods* (5th ed., pp. 25–66). Sage.

Matthew A. Willis

Syracuse University School of Information Studies 343 Hinds Hall, Syracuse, NY

RESEARCH INTEREST

My intellectual foundation is formed by the disciplines of Computer Supported Cooperative Work (CSCW), Human-Computer Interaction (HCI), Sociotechnical Systems, and Social Shaping of Technology. I connect these disciplines to the research communities of Consumer Health Informatics, Participatory Medicine, Health Informatics and Health Information Systems. My research focuses on the patterns, processes, and practices of patients use of technologies in supporting their health and well being. Outputs of this research include design documents, quality improvement, informing technology and information system development, policy recommendations, development and clarification of sociotechnical processes models and improvement and promotion of patient-centered care at the personal, organizational, and policy levels. As a researcher, I value interdisciplinary collaboration and multi-methodological quantitative and qualitative approaches to both data collection and analysis.

EDUCATION

SYRACUSE UNIVERSITY: SCHOOL OF INFORMATION STUDIES 2016

PhD: Information Science & Technology
 National Physical Science Consortium Fellow
 Dissertation title: *Patient Sociotechnical Assemblages: The distributed cognition of health information management.*

SYRACUSE UNIVERSITY: SCHOOL OF INFORMATION STUDIES 2014

Degree Awarded: M.Phil. Information Science & Technology

UNIVERSITY OF NEW MEXICO: DEPARTMENT OF COMMUNICATION & JOURNALISM 2009

Degree Awarded: M.A. Health Communication
 Thesis: *What do healthcare providers think of patients who use the Internet? An exploratory study.*

UNIVERSITY OF NEW MEXICO: DEPARTMENT OF
COMMUNICATION & JOURNALISM 2006, MAGNA CUM LAUDE

Degree Awarded: B.A. Communication

Awarded University & Departmental Honors

Honors Thesis: *Now thats Funny: The development of humor in small groups.*

RESEARCH EXPERIENCE

CYCLES(6): CYCLES OF YOUR COGNITIVE LEARNING,
ENGAGEMENT, AND SCHEMA SUMMER 2015

Research Assistant

IARPA Solicitation # IARPA-BAA-11-03

This project is a series of Serious Games designed to train intelligence analysts to recognize, discriminate among, and mitigate six cognitive biases. Multiple experiments and gameplay sessions were conducted and I assisted with data analysis of gameplay log data and performed multivariate data transformation, statistical analysis, and correlations of research hypotheses.

NOMADIC WORKERS & MOBILE KNOWLEDGE WORK SUMMER
2015

Research Assistant

NSF Early-concept Grants for Exploratory Research (EAGER) Grant

This study looks at mobile knowledge workers, a specific subset known as digital nomads, and their use of digital infrastructure. For this project I gathered and developed data sets on population workforce mobility. Wrote analysis report of multiple data sources synthesizing findings.

VIRTUAL ORGANIZATIONS AS SOCIOTECHNICAL SYSTEMS:
DOCUMENTS & THE DOING OF SCIENCE FALL 2012 —
PRESENT

Research Assistant

NSF Directorate for Computer & Information Science & Engineering under
Division of Advanced Cyberinfrastructure Grant #1221945

Working on this project since its early inception, this research looks at how social scientists collaborate when the team is distributed. The project focuses on the digital infrastructure, documents, and practices that make science happen. I am responsible for project management, meeting minutes, and coordinating research team. Being involved with this project I have also helped to develop a novel method for studying scientific digital infrastructure. Also performed mixed methods data analysis, including iterative qualitative coding. Developed and deployed surveys.

U.S. DEPARTMENT OF VETERANS AFFAIRS (SYRACUSE, NY)
2011 — PRESENT

Health Science Specialist

I have supported multiple projects at VA. Relevant skills they involve include performing analysis of Computerized Patient Record System (CPRS) data. Including cleaning and preparation of large quantitative data sets for behavioral telehealth program. Other projects include the development of a computational personal health record ontology. Extensive literature review of consumer health record system health outcomes. Developed and maintained shared collaborative research article repository. Independently conducted a quality improvement project.

MEDICAL PICTOGRAM TEXT EVALUATION USING COLLECTIVE
INTELLIGENCE FALL 2011 — SPRING 2012

Research Assistant

This project identified health literacy problems in medical pictograms found on pharmaceutical prescriptions and other patient treatment directions. Developed a research design using Mechanical Turk and organized experiments. Assisted with data analysis & interpretation. Provided additional insight and interpretation of the data through inductive coding.

ANALYTIC SKILLS ASSESSMENT OF TEACHING MATERIALS
FALL 2010 — SPRING 2011

Research Assistant

Performed a gap analysis of teaching criteria to propose a new university course. Conducted interviews to inform the development of a survey. Analyzed syllabi and teaching materials in support of course development.

SYRACUSE STUDENT SANDBOX: VIRTUAL TEAMS AND
TECHNICAL ENTREPRENEURSHIP FALL 2010 – SPRING 2011

Research Assistant

This project studied college entrepreneurs and how these high performing teams worked virtually. I completed content analysis, codebook development, and inductive coding of interview transcripts. Also independently carried out additional quantitative data analysis and model creation from findings.

SANDIA NATIONAL LABORATORIES (ALBUQUERQUE, NM)
SPRING 2008 — SPRING 2010

Research Assistant

Granted Security Clearance by Department of Energy

I primarily worked in the Cognitive Systems organization and gained experience

collaborating with many other scientists and technical staff across the laboratory. Facilitation of experiments in computer lab. Research experience gained includes design of research methods, experiment protocols, and measurements. Quantitative and qualitative data analysis and interpretation. Research report write up, contribution to internal technical documents, and coauthoring of white paper proposals. Assistance with deliverables for several government organizations. Creation of design and development documents. Serious video games design, development, and evaluation.

Associated Grants:

1. Technologies for Accelerated Continuous Learning (TACL): Funded by U.S. Army Research, Development, and Engineering Command (RDECOM).
2. Lab Directed Research and Development (LDRD): Funded by Sandia National Laboratories.
3. Verification & Validation of Human Social Cultural Behavioral Modeling: Funded by Office of the Secretary of Defense (OSD).

CENTER ON ALCOHOLISM, SUBSTANCE ABUSE & ADDICTIONS
(ALBUQUERQUE, NM) SPRING 2008 — SPRING 2010

Research Assistant

My experience at this research and public health campaign center I worked in the area of DWI prevention. As a research assistant I had the opportunity to practice participant observation methods and fieldwork in a wide variety of settings. Conducted structured recorded interviews. Ran HCI usability and user experience data collection and analysis tests. Responsible for database creation and maintenance.

Associated Grants:

1. Web-based Responsible Beverage Service Training: Funded by the National Institute of Health (NIH) Grant # R01 AA014982-01.
2. Web-based Substance Abuse STD/HIV Prevention: Funded by the National Institute of Health (NIH) Grant # R01 DA018575-02
3. University of New Mexico Interdisciplinary HPV Prevention Center: Funded by the National Institute of Health (NIH) Grant # U19AI084081-01
4. Gambling Accountability and Transparency Assessment: Funded by the State of New Mexico Department of Health

HEALTHCARE POLICY INFORMATION SOURCE PREFERENCES OF
NEW MEXICO STATE LEGISLATORS FALL 2009

Research Assistant

Funded by the Robert Wood Johnson Foundation (RWJF) to investigate what sources New Mexico Legislators use to obtain healthcare information. Assisted with design of research protocol to target recruitment methods to specific population. Conducted and wrote comprehensive literature review. Design and programming of online survey, analysis and interpretation of survey data.

PUBLICATIONS

JOURNALS (REFEREED)

- j7. Mickelson, R., Willis, M., & Holden, R. (2015). *Medication-related cognitive artifacts used by older adults with heart failure*. *Journal of Health Policy and Technology*.
- j6. Weiss, D., White, J. M., Stohr, R. A., & Willis, M. (2015). *Influencing healthcare policy: Implications of legislators information source preferences for public relations practitioners and public information officers*. *Online Journal of Communication and Media Technologies*, 5(1).
- j5. Yu, B., Willis, M., Sun, P., & Wang, J. (2013). *Crowdsourcing Participatory Evaluation of Medical Pictograms Using Amazon Mechanical Turk*. *Journal of Medical Internet Research*, 15(6), e108. doi:10.2196/jmir.2513
- j4. White, J.M., Willis, M., & Stohr, R.A. (2013). *Legislators reliance on mass media as information sources: Implications for symmetrical communication between public information officers, public relations practitioners and policymakers*. *PRism*, 9(1): <http://www.prismjournal.org/homepage.html>
- j3. Possemato, K., Bishop, T. M., Willis, M., & Lantinga, L. J. (2013). *Healthcare Utilization and Symptom Variation Among Veterans Using Behavioral Telehealth Center Services*. *The journal of behavioral health services & research*, 40(1). doi:10.1007/s11414-013-9338-y
- j2. Raybourn, E. M., Fabian, N., Glickman, M. R., Tucker, E., & Willis, M. (2011). *Real-time individualized training vectors for experiential learning*. Sandia Report, 0166.
- j1. Raybourn, E., Ames, A., Belasich, D., Bouchard, J., Heaphy, R., Hills, R., Shaneyfelt, W., et al. (2010). *HSCB Generalized Validation & Verification Methodology*. Sandia Report. Albuquerque, NM.http://cognitivescience.sandia.gov/Publications/pub_details.php

BOOK CHAPTERS

- b1. Osterlund, C., Snyder, J., Sawyer, S., Sharma, S., and Willis, M. (2015). *Documenting work: From participant observation to participant tracing*. In Roderick M. Kramer and Kimberly D. Elsbach (Eds). *Handbook of Innovative Qualitative Research Methods: Pathways to Cool Ideas and Interesting Papers*. Routledge, Taylor and Francis Group, New York

CONFERENCE PROCEEDINGS (SELECTIVE)

- c10. Sharma, S., Willis, M., Snyder, J., Osterlund, C., & Sawyer, S. (2015). *Using an Ethnography of Email to Understand Distributed Scientific Collaborations*. Proceedings of the 2015 iConference. Newport Beach, CA.

- c9. Sharma, S., Snyder, J., Osterlund, C., Willis, M., Sawyer, S., Brown, M., & Skolozar, D. (2014). Document Practice as Insight to Digital Infrastructures of Distributed, Collaborative Social Scientists. Proceedings of the 2014 iConference. Berlin, Germany.
- c8. Willis, M., Sharma, S., Snyder, J., Brown, M., Osterlund, C., & Sawyer, S. (2014). *Documents & Distributed Scientific Collaboration*. Proceedings of the 2014 CSCW Conference. Baltimore, MD.
- c7. Willis, M., & Osterlund, C. (2013). *Towards a Method of Documentary Practices for Personal Health Information Management*. Proceedings of the 2013 iConference, Fort Worth, TX.
- c6. Raybourn, E.M., Fabian, N., Glickman, M., Willis, M., & Tucker, E. (2010). *Beyond Game Effectiveness Part II: A Qualitative Study of Multi-role Experiential Learning*. Proceedings of the 2010 Interservice/Industry Training, Simulation, and Education Conference, Orlando, FL.
- c5. Willis, M., & Raybourn, E.M. (2009). *Leveraging Mobile Devices to Develop Intercultural Competency for Digital Students*. Proceedings of the 13th International Human Computer Interaction Conference, San Diego, CA.
- c4. Willis, M. (2009). *eLearning networks in the University: Understanding portable media devices as educational tools*. Presented at Popular Culture and American Cultural Studies Association, New Orleans, LA.
- c3. Willis, M. (2009). *Digital students: Using portable media devices as educational tools*. Presented at Western States Communication Association, Phoenix, AZ.
- c2. Willis, M. (2008). *Technoscape & Digital Divide: Evaluating terminology & technology*. Presented at Popular Culture and American Culture Association Conference, San Francisco, CA.
- c1. Willis, M. (2008). *Being Digital: A transactional theory of cognitive processing and Internet media use*. Presented at Rocky Mountain Communication Association Conference, Fort Collins, CO.

DELIVERED CONFERENCE PRESENTATIONS, INVITED TALKS, & WORKSHOPS

- d19. Willis, M. (2015). *Patient Sociotechnical Assemblages: The Distributed Cognition of Health Information Management*. The 78th annual meeting of the Association for Information Science and Technology. Presented at award-winning paper session. November 10, 2015. St. Louis, MO.
- d18. Willis, M. (2015). *Patient Sociotechnical Assemblages*. The 16th annual meeting of the Association of Internet Researchers Doctoral Colloquium. October 21, 2015. Phoenix, AZ.

- d17. Willis, M. (2015). *Patient Sociotechnical Assemblages: The Distributed Cognition of Health Information Management*. 7th Doctoral Consortium on Sociotechnical Issues in Biomedical Informatics. November 14, 2014. Washington, D.C.
- d16. Mickelson, R., Willis, M., & Holden, R. (2015). *What do patients need? A sociotechnical systems approach to the analysis of current tools used by older adults with heart failure*. In Summer Institute on Nursing Informatics. July 22-24. Baltimore, MD.
- d15. Willis, M. (2012). *Brainstorming Design for Health: Helping Patients Utilize Patient-Generated Information on the Web*. Computer Supported Cooperative Work 2012 Annual Conference (pre-conference workshop). Seattle, WA.
- d14. Willis, M. (2011). *Productivity Tools & Techniques for Graduate Students*. Presentation for School of Information Studies graduate students (workshop). Syracuse University, Syracuse, NY.
- d13. Willis, M. (2011). *Sociotechnical ontology of consumer focused health systems: A pilot study*. Presentation for School of Information Studies graduate students. Syracuse University, Syracuse, NY.
- d12. Willis, M. (2011). *Nvivo Veritas: Using Nvivo for Content Analysis & Grounded Theory*. Guest Lecture for IST800: Seminar on Text as Data by Bei Yu, PhD.
- d11. Willis, M. (2011). *Organizational Ontology: Mapping MyHealthVet as Socio-technical Knowledge*. Presentation for Department of Veterans Affairs MyHealthVet Program Office. Behavioral Health Outpatient Center, Syracuse, NY.
- d10. Willis, M. (2011). *Citation Needed: Integrating Mendeley into the Research Workflow*. Department of Veterans Affairs Upstate New York VISN 2. Behavioral Health Outpatient Center, Syracuse, NY.
- d9. Willis, M. (2011). *Keep your head in the cloud: Cloud computing, software services, and strategies for using cloud computing in a library context*. Presentation for Northern New York Library Network 46th annual meeting and mini-conference. Riveredge Resort, Alexandria Bay, NY.
- d8. Willis, M. (2009). *Analytical Design & Presenting Information Workshop*. Envision New Mexico: The Initiative for Child Healthcare Quality Program. Embassy Suites, Albuquerque, NM.
- d7. Willis, M. (2009). *Freshman Learning Community: Integrating technical competency into coursework*. Faculty Learning Institute, University of New Mexico. Albuquerque, NM.

- d6. Willis, M. (2009). *Technology, Health, and Culture*. Invited as guest lecturer for HMVM 310: Health and Cultural Diversity by Nagesh Rao, PhD. Invited back for Spring 2010.
- d5. Willis, M. (2009). *Games: Evolution of games*. Panel participant at New Mexico Media MIX Conference, Albuquerque, NM.
- d4. Willis, M. (2009). *Palette Builder: A Simulation to Teach Color Theory*. University of New Mexico Organizational Learning & Instructional Technology Program. University of New Mexico, Albuquerque, NM.
- d3. Willis, M. (2008). *Communication Senior Seminar* Invited back for Fall 2008, and Spring 2009. Invited by Judith Hendry, PhD. University of New Mexico, Albuquerque, NM.
- d2. Willis, M. & Carter, J. (2007). *Internet Technology Colloquium*. Workshop at University of New Mexico Department of Communication & Journalism. Albuquerque, NM.
- d1. Willis, M. (2007). *Critical & Cultural Studies Colloquium*. Presented at University of New Mexico Student Union Building, Santa Anna Room. Albuquerque, NM.

TEACHING EXPERIENCE

SYRACUSE UNIVERSITY

SPRING 2012

Statistical Methods in Information Science & Technology Course Title: IST 777: Statistics in IST Catalog description: Classical statistical procedures used in information transfer research. Emphasis on underlying rationale for each procedure and on criteria for selecting procedures in a given research situation. Teaching assistant to Professor Bei Yu

SYRACUSE UNIVERSITY

FALL 2011

Introduction to Information Management: Discussion Section Instructor
Course Title: IST 621: Intro to IM
Catalog description: Overview of general management concepts, IM implementation concerns and strategies, information life cycle management, and preparation for an IM career.

UNIVERSITY OF NEW MEXICO

FALL 2007 — SPRING 2009

Communication & Journalism: Instructor of Record
Course Title: C&J 130: Public Speaking
Fall 2007 (2 sections), Spring 2008 (2 sections), Fall 2008 (1 section), Spring 2009 (2 sections) Catalog description: A performance course that deals with the analysis, preparation, and presentation of speeches.

UNIVERSITY OF NEW MEXICO

FALL 2008, FALL 2009

Freshman Learning Community 603: Teaching Assistant, Instructor of Record
 Course Title: Web Collectivism & Our Brains Fall 2008 (1 section), Fall 2009 (1 section)
 Catalog Description: This special topics course looks at the neurological system of the brain in the context of new media, HCI, and Internet use. The goal of the course is to examine how students use the Internet and its effects on their thinking and daily routine.

AWARDS, HONORS, GRANTS, & FUNDING

AWARDS

**Association for Information Science and Technology (ASIS&T)
 Doctoral Dissertation Proposal Scholarship Award (Fall 2015)**

Awarded scholarship for best dissertation proposal and invited to present my dissertation research at the annual ASIS&T conference and attend the doctoral colloquium.

Association of Internet Researchers (Fall 2015)

Selected participant of 16th Doctoral Colloquium of Internet Researchers

American Medical Informatics Association NSF Doctoral Consortium (Fall 2014)

Selected participant of 7th Doctoral Consortium on Sociotechnical Issues in Biomedical Informatics

National Physical Science Consortium (2009)

Funded NPSC Research Fellow of Sandia National Laboratories

University of New Mexico — Department of Communication & Journalism (Spring 2009)

2009 International Communication Association Outstanding Graduate Teaching Assistant

University of New Mexico — Office of Graduate Studies (Fall 2008)

Teaching Assistantship Tuition Award

University Of New Mexico — Teaching Assistantship Resource Center (Fall 2007)

Certificate in Teaching Excellence

State of New Mexico (2007)

Educational Assistant License
 Substitute Teacher License

FUNDING

University of New Mexico

Research Project & Travel (RPT) Grant

Awarded \$850 (Spring, 2009)

Student Conference Award Program (S-CAP) Grant

Awarded \$600 (Spring, 2008)

MEMBERSHIPS & AFFILIATIONS

PROFESSIONAL ORGANIZATIONS

- Association for Information Science and Technology (ASIS&T) (2015)
- Association of Internet Researchers (2015-2016)
- American Medical Informatics Association (2014-2015)
- New York Academy of Sciences (2012-2014)
- International Communication Association (2009-2010)
- Western States Communication Association (2009-2010)
- Popular Culture and American Culture Association (2009-2011)
- Rocky Mountain Communication Association (2008-2009)

SERVICE

SYRACUSE UNIVERSITY

FACULTY SEARCH COMMITTEE SPRING 2014 — FALL 2014

Member of committee for search, review, and interview of new faculty hires.

FALL RETREAT COMMITTEE CHAIR 2010 — 2012

Founded the annual Fall Retreat Committee. Committee is responsible for planning, coordinating, and advertising a yearly retreat with the goal of strengthening the academic community and exposing graduate students to team building exercises.

DOCTORAL ADMISSIONS COMMITTEE MEMBER FALL 2010

Responsible for Doctoral and Executive Doctoral admissions process: reviewing applications, interviewing applicants. Review of Doctoral and Executive Doctoral program requirements including dissertation and examination requirements.

UNIVERSITY OF NEW MEXICO

GRADUATE AND PROFESSIONAL STUDENT ASSOCIATION (GPSA) 2009

Chair of Research Board. Responsible for promoting and coordinating graduate student research at the University of New Mexico. Reported to executive board on needs of the graduate research community. Coordinated statewide graduate research symposium.

GRADUATE AND PROFESSIONAL STUDENT ASSOCIATION (GPSA) 2008

Member of Computer Allocation Committee. Responsible reviewing applications and for awarding computer systems to student organizations.

MERCER SCHOLARSHIP SPEECH COMPETITION 2008

Judge for the Joann and Steve Mercer Memorial Scholarship, sponsored by the University of New Mexico Department of Communication & Journalism.

COLLABORATIVE PUBLISHING & JOURNAL DATABASE 2008

Programming & design of collaborative wiki about academic publishing and created a database of journals for departmental use by faculty & graduate community.

FACULTY COLLOQUIUM PANEL 2008

Produced, coordinated, promoted, and moderated a colloquium on academic publishing. The colloquium featured a panel of faculty members and a Q&A session for the graduate community.

HISTORIAN OF THE COMMUNICATION GRADUATE ASSOCIATION (COMGRADS) 2007 — 2009

Photographed events, developed multi-media presentations of previous years special events and gatherings.

ASSISTANT ENGINEER, COMMUNICATION & JOURNALISM DEPARTMENT 2007 — 2008

Troubleshooting, repair, and instruction of computer, projection, camera, and touch screen technologies.

VOLUNTEERING

COMPUTER SUPPORTED COOPERATIVE WORK (CSCW)
ANNUAL CONFERENCE 2014 — 2015

Conference Reviewer.

MEDICINE 2.0 INTERNATIONAL ANNUAL CONFERENCE 2014

Conference Reviewer.

JOURNAL OF MEDICAL INTERNET RESEARCH PROTOCOLS 2012

Journal Reviewer.

SOCIAL COMPUTING, BEHAVIORAL MODELING AND
PREDICTION (SBP) 2012 CONFERENCE 2012

Reviewer for Health Applications of SBP Papers.

MEDICINE 2.0 INTERNATIONAL ANNUAL CONFERENCE 2012

Student Volunteer for conference.

INTERNATIONAL COMMUNICATION ASSOCIATION (ICA) 2009

Reviewer for Digital Game Studies Division Papers & Presentations.

NATIONAL COMMUNICATION ASSOCIATION (NCA) ANNUAL
CONFERENCE 2008

Reviewer for Mass Communication Division Papers & Presentations.

HUMAN COMPUTER INTERACTION INTERNATIONAL (HCII)
CONFERENCE 2009

Student Volunteer for conference.

SCRIBENDI 2006-2007

Editor of National Honors Magazine of Student Art & Literature. Contributed to the production, design, and editing of digital and print layout. Responsible for the selection of submissions to the magazine.

COMMUNITY

SYRACUSE ARTS, LEARNING, & TECHNOLOGY (SALT) MAKERSPACE

2014

Volunteered at community maker space to support development, administration, and maintenance of website, domain, and email servers.

MANZANO MESA MULTI-GENERATIONAL COMMUNITY CENTER 2009

Volunteered to instruct a course for Senior citizens on Microsoft office, desktop publishing, and basics of using the Internet.

SKILLS

ATLAS.TI Nvivo SPSS R HTML XML CSS L^AT_EX Python

COURSEWORK

RELEVANT DOCTORAL COURSEWORK

Natural Language Processing	Text as Data
Information Retrieval	Library & Information Science
Statistics for Research in Information Transfer	Information Systems
Human Computer Interaction	Computer Supported Cooperative Work
Information Policy & Economics	

RELEVANT MASTERS COURSEWORK

Communication Theory	Research Methods
Quantitative Data Analysis	Instructional Use of Computer Simulations
Diffusion of Innovations Theory	Health Communication
Health Communication Campaigns	Health Communication & Community Research

REFERENCES

Jennifer Stromer-Galley (Advisor)

Associate Professor — School of Information Studies
 Director — Center for Computational and Data Sciences
 President — Association of Internet Researchers

Contact info.

Syracuse University

220 Hinds Hall
Syracuse, NY 13244-1190
phone: (315) 443-1823
email: jstromer@syr.edu
web: www.stromer-galley.com

Steven Sawyer

Professor — School of Information Studies

Contact info.

Syracuse University
344 Hinds Hall
Syracuse, NY 13244-1190
phone: (315) 443-6147
email: ssawyer@syr.edu
web: <http://sawyer.syr.edu>

Bryan Semaan

Assistant Professor — School of Information Studies

Contact info.

Syracuse University
338 Hinds Hall
Syracuse, NY 13244-1190
phone: (315) 443-5441
email: bsemaan@syr.edu
web: <https://bsemaan.expressions.syr.edu>