Patient Sociotechnical Assemblages: The Distributed Cognition of Health Information Management

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Overview

This dissertation investigates complexity and computerization in patient health information work. Personal health information management research has focused on the individuals' practice of a limited set of tasks that do not always support the patients' interaction with healthcare providers. What is needed is a reconceptualization of the unit of analysis and a keen analytical eye on the role of information communication technologies, specifically the personal health record, in patient focused health information management. The proposed research utilizes a conceptual framework of distributed cognition combined with a sociotechnical assemblage perspective of health information management to inform further use and design of these systems. A longstanding personal health record developed by The Department of Veterans Affairs is the central IT artifact of this descriptive multiple-case, cross-case analysis embedded case study research design. This research contributes to implications for the design and development of patient-focused personal health records; it also makes conceptual contributions to the practice of health information management and patient-centered care. Findings from this research are also expected to inform healthcare providers' clinical practices when collaborating with patients using technology, either collocated in a clinical appointment or mediated through a personal health record.

Justification

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, 2011), 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. It is a system that has invested vast amounts of time, money, and political power to enable patients and providers alike to interact with health information digitally. The anticipated outcome 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 technical systems (Grove, 2005).

Research in personal health information management has created a body of literature which provides analysis and contributions concerning patient focused work. Patients can be overwhelmed by both information overload and information management fatigue (Pratt, Unruh, Civan, & Skeels, 2006) as well as other barriers such as time, storage, and emotional response to interacting with health information (Unruh & Pratt, 2008a). Personal health information management work is complex, yet patients develop situated idiosyncratic strategies for dealing with important healthcare work, especially using artifacts around the home (Moen & Brennan, 2005). In fact, the distributed nature of information, regardless of materiality, appears to be important to the practice of personal health information management (Piras & Zanutto, 2010). This is a burgeoning area of research with gaps in knowledge concerning taxonomies of users, practices of subpopulations and different patient types, and comparative effectiveness of information management practices (Agarwal, 2009).

Reviewing personal health information management (PHIM) research reveals 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 are positive and even 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, Shih, & Hayes, 2011), interoperability issues (Beale, 2005), patient entered data concerns (Simborg, 2009), and problems in designing for different users (Kutz & Ekbia, 2011). The relationship of PHIM and PHR research is a strong grounding in academic literature to understand the change occurring in health consumer practices and technologies (Swan, 2009). The combination of these 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. 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).

In an effort to move toward a modern health IT infrastructure, personal health records (PHR) are but one of many popular strategies 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 represent potential for patients to be responsible for and generate a large quantity of personal health information. The work and mental energy expended in managing, organizing, maintaining, and using this personal information infrastructure repeatedly makes up the

work practices that any given patient will develop and implement over time. This work that patients engage in when practicing personal health information management matters; it has effects on the delivery of healthcare and patient satisfaction (Saranto, Brennan, & Casey, 2009). Because PHRs are created to support these patient health information management practices, it follows that the use of health IT has an effect on the patient-provider relationship (Ventres et al., 2006).

Conceptual Framework

The conceptual work guiding this research is framed by weaving together concepts of Hutchins' distributed cognition (Hutchins, 1995) and sociotechnical assemblages as conceptualized by DeLanda's perspective from Deleuze's original work (DeLanda, 2006). One attractive component of assemblage, for the purposes of this work, is the modular nature of the perspective. In which parts of an assemblage can be extracted from one set of users and adapted to other users in a similar context. The relations of these parts are contingent, but not necessary. Assemblages are encapsulated contexts, tools, and possible actions. Sociotechnical assemblages are defined by the use of social actors and technologies. As discussed previously, a sociotechnical perspective is concerned with the mutual constitution of social actors and technological entities. Thus, a sociotechnical assemblage seeks to understand the social and technical and the relations between them through other qualities such as practices, policies and objects. Assemblages can also be thought of as personal, whereas information systems are institutional and communal. Assemblages are also not characterized by a set of functions or features that constitute an assemblage, but by practice and enacted practices (Sawyer, Crowston, & Wigand, 2014).

Sociotechnical assemblage necessitates that the unit of analysis cannot be placed on any one person. The challenge of this unit of analysis is where to draw boundaries when in the field, when to include a node in the network, what edges connect actors, and how to determine when something is not relevant in the unit of analysis. This study determines the network through the actions and practices of patients' personal health information management. This is to say that it is necessary to go where the

traffic is (Hollan, Hutchins, & Kirsh, 2000), by casting an analytical eye on events where patients rely on distributed resources. This is why distributed cognition is important for identifying these boundaries because of its emphasis on the functional system rather than on every possible relationship, no matter how weak the link. The perspective of distributed cognition (DCog) is not only interested in what people know but how they go about using what they know to do what they do (Hollan et al., 2000). The premise of the theory is that cognition is a distributed process that uses both internal and external processes. Cognition is traditionally conceptualized as entirely occurring in the inner workings of the mind. 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 et al., 2006), distributed cognition theory highlights additional actors and settings where health information processing is happening. Figure 1 provides an example of a potential patient health information assemblage. The health information assemblage concerns broader concepts like policies, organizational structures, and technical systems that affect the patient. Whereas distributed cognition concerns immediate practices of technology in use, medication regimen, and health information management practices. This dissertation weaves both of these conceptual frameworks together to advance a concept of a distributed patient health information sociotechnical assemblage to be used in healthcare organizations that practice patient centered models of care.

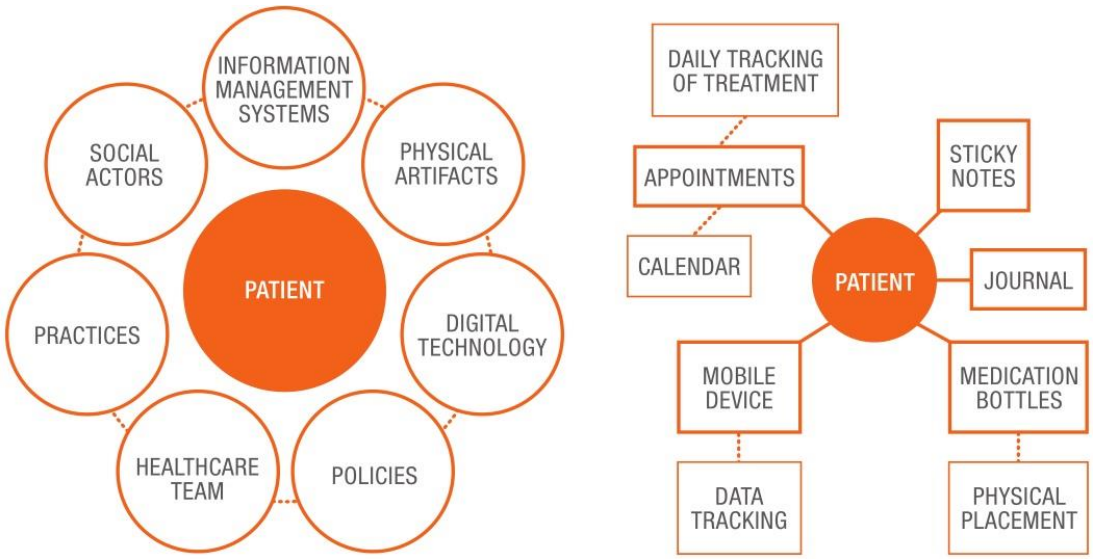

Figure 1 Examples of patient health information assemblage (left) and patient cognition map (right).

Research Questions

Informed by a literature review and pilot study (detailed in method section), the following four research questions are put forth:

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?

The first is a baseline to articulate the primary activity under investigation: health information management practices. 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 many types of patients in various use cases with different personal health record technologies. Research questions 1a and 1b 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 posed 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.

Research question 2a and 2b are grouped together in order to address the assemblages, and therefore the broader context, that these situated practices of distributed health information management occur. These two research questions emerge out of the lack of relevant literature on the bundle of practices, technologies, objects, and actors which view patient work as a system of systems. As such, it is critical 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.

Significance

This research makes multiple contributions to numerous communities in the form of concepts that are empirical, conceptual, pragmatic and technical. These contributions are summarized in the table below.

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 or report	Patients, health consumers	Documentation on useful strategies and factors to consider when health consumers must manage health information of a family member or themselves.

It is helpful to highlight a few contributions from the above comprehensive table. 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 seek to apply an understanding of the complex situated practices found throughout distributed health information management practices to patient-centered care (PCC). The importance of and need for future research on using technology to foster PCC is clear in the literature (Ahern, Woods, Lightowler, Finley, & Houston, 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. Values of patient-centered care, such as coordination, communication, autonomy and patient guided decision making, are evident in clinical settings and understood in broad terms in the patient's private life. A clear understanding of how some of these values manifest, and other important values that relate to the tenants of patient-centered care, will benefit organizational patient-centered care initiatives.

Much of the work patients engage in to support their health and educate themselves is invisible to health providers (Piras & Zanutto, 2010; Strauss, Fagerhaugh, Suczek, & Wiener, 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. Another contribution 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 practice with patient-centered care ideals.

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 a 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.

The data rendered from this dissertation will be de-identified and provided publically. The reasoning for this is that realistic data that illustrates complex health information management practices and patient use of personal health records is difficult to create from scratch. Data informed by empirical research can aid designers in developing realistic patient personal health record and information management use cases (Kernisan, 2013).

Method

The research design and method was constructed to make use of multiple data collection techniques and be able to capture rich data on study participants as well as technologies of interest. After a brief description of the pilot study used to inform post proposal data collection, the research

design is detailed, followed by the sample population and setting of the study, and concludes with the data collection and analysis protocol.

Pilot Study

A pilot study was conducted with Department of Veterans Affairs employees located at VA facilities across the country. The goals of the exploratory study are to test the proposed methods, understand preliminary patient information management techniques that are visible to healthcare professionals, and to gain experience in conducting fieldwork and interviews at various VA facilities. Structured phone interviews were conducted (n=15) with a diverse set of participants, including: directors, managers, education coordinators, librarians, My HealtheVet coordinators, project managers, volunteers, and clinical health providers (medical doctors). Interview questions focus on the information needs of Veterans, strategies of information use and management Veterans have been observed practicing, and personal health information work that is carried out within the VA clinical setting. Notable findings include the use, continued importance and specific role of paper documents despite the availability of health information technology. Also noted is the need for patients to delegate information to people closest to the patient, and how that process is supported or unsupported. Last, and of most interest, is the different assumptions made by patients and medical providers when using the VA personal health record, My HealtheVet. Multiple informants experienced situations during which patients assume their health providers are communicating and coordinating because the patient has a MHV account. Whether this belief results from inexperience with the system or from wishful thinking is not clear at this point. However, these findings merit follow up research and suggest that findings in the area of patient health information management can also have implications for patient-provider communication and provider-provider communication.

Research Design

Prior work in this area has made clear the importance of using 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 individualized and personalized information management practices by the patient. 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 a new 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 are purposefully selected for variation in use of personal health record (Corbin & Strauss, 2008; Patton, 2002).

This case study research design will select for different amounts and types of MHV use by patients, this will allow me to gain a better understanding of the emergent phenomenon of distributed health information assemblages. Different practices emerge in how patients rely on a PHR and how a PHR becomes integrated, or not, into distributed health practices. This strategy also serves as a point of comparison for how a heavy user of a PHR might lean more on making the PHR perform most of the

PHIM work. Whereas a light user of the PHR might develop other practices in lieu of a limited role of PHR use.

A single case for this study starts with the patient, and branches out to include their caretakers and family members, as appropriate. I also include their primary care provider and any other health care worker 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. That collection of actors, digital technologies, and physical objects all assembled around the patient's information management comprise 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.

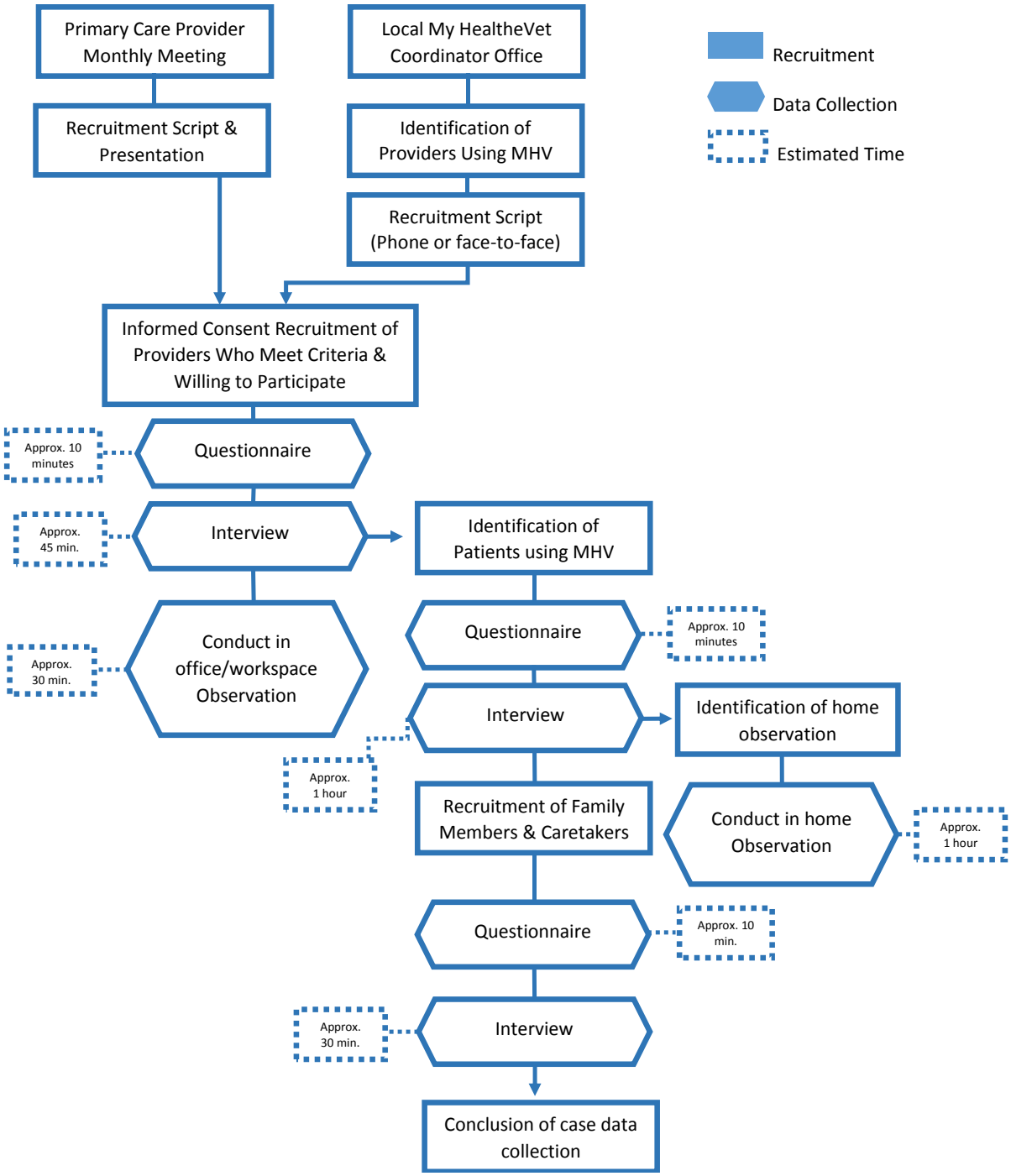

Figure 2 Case study research design showing recruitment process and data analysis

Setting & Sample

This study will use the Department of Veterans Affairs (VA) patient population as well as the VA's enterprise-wide personal health record system, My HealtheVet (MHV). Veteran participants are

ideal for this study as they all have the option to access a computerized medical record. This setting and context is ideal for studying because this community involves a complex social and technical infrastructure that is interwoven with the veterans who seek and receive medical care. 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. This provides opportunity to gather data via photographs to further study documents and objects that are a part of the patient assemblage. Understanding these distributed practices will reveal 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 matter of practicality and protocol, recruitment begins with contacting healthcare providers that use My HealtheVet. Providers are recruited first into the study because VA policy requires that the patient's primary care provider be aware of, and allow, any research involving a patient of that provider. Additionally, healthcare providers are pressed for time and a challenging population to involve in research. Thus, recruiting providers first assures that healthcare providers are appropriately represented in this research and can be connected to the patients distributed information assemblage.

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 will attend these meetings both 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 will be encouraged to participate if they have a patient who is enrolled in MHV. The second recruitment strategy is through the local My HealtheVet coordinator office. The local MHV coordinator can identify providers who have a MHV account. During an initial interview, recruited providers will help to identify a patient who meets the recruitment criteria. The patient will be given a recruitment script with my contact information.

Once a patient is enrolled to participate in the study, the initial interview with the patient will help identify the patient's family members and caretakers that are essential to assisting and supporting health information management.

The total number of participants across the three roles this study plans to enroll is a maximum of about 70 participants across all cases. This includes patients, relevant family members that help manage health information, and multiple healthcare providers (including doctors, nurses, social workers, and other specialists) that work with the patient. This would allow for 12 to 18 separate cases to be recruited. Each case consists of one veteran patient and a variable number of relevant family members and healthcare providers connected to each patient. Additionally, because cases are selected for amount of interaction with a PHR, I will have six frequent users of MHV to compare with six infrequent users, or up to nine to compare if 18 individual cases are recruited.

Data Collection & Analysis

The research questions asked by 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 HealtheVet. It follows that the methodological needs are descriptive and the analysis should be appropriate for case study design research. Because semi-structured interviews and observation are two of the main data collection methods, analysis must support open-ended investigation. Additionally, this study is framed by theories of assemblage and distributed cognition, so a reasonable analysis will be framed by these perspectives. Computer assisted qualitative coding software is used to both manage and analyze the research data.

The coding framework that will provide substantive analysis is a two cycle method. The first cycle uses process coding and the second cycle pattern coding (Saldana, 2013). Throughout the process

of data coding, I will be writing analytic memos as both a reflective practice for data analysis and to serve as an additional analytical tool. Finally, process and pattern coding are appropriate data analysis techniques to use with cognitive mapping. This data analysis workflow is visualized by figure 3.

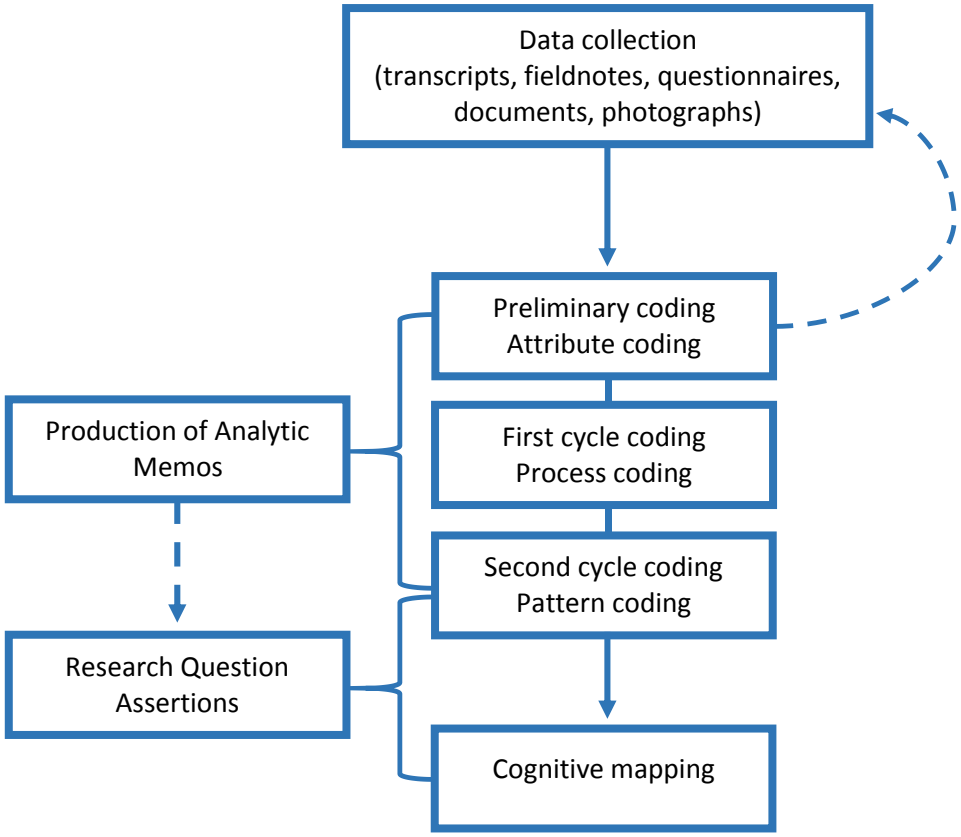

Figure 3 Data analysis workflow

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