

# Towards a Method of Documentary Practices for Personal Health Information Management

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## Abstract

Many intellectual fields study patients' use of health information systems, yet there is little innovation in the variety and richness of methodologies employed to investigate the complex socio-technical relationship between health consumers who use technical systems to engage in the practice of personal health information management. This is, in part, due to the methodological challenges of studying patients' documentation practices. In this note, we present the early development of a document practice approach to address these gaps. The documentary practice approach is rooted in the socio-technical perspective that social systems and technology are intricately connected and recursive. Documentary practice methodologies are mindful of this entanglement in studying the work practices of actors by connecting practice to the use of documents, both physical and digital, and mapping the patient's field of documents and technical infrastructure within which health management occurs.

*Keywords:* practice theory, personal health information management, socio-technical, documentary practice, personal health record

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## Introduction

Healthcare is an information intensive activity for health consumers, whether they are managing pathology, seeking information, engaging in health prevention activities, or organizing personal health information in a journal or diary. All of these activities are cognitively intense and, most importantly, the methods and strategies a patient can perform are highly individualized and change over time (Agarwal, 2009). In light of the growth of health IT, eHealth initiatives, mobile computing, and personal health records, consumers have a growing list of options when they decide how to engage in health information management. Additionally, the growing number of smartphone and mobile device usage (Smith, 2012), broadband access (Internet Use and Home Broadband Connections, 2012), and the expanding notion of everyday health and quantified self-metrics (Swan, 2009) means that there is more information to track, manage, read, access, visualize, interact and otherwise demarcate. The increase in health information support systems and tools for managing information means that the technical infrastructure (both physical and digital documents) can be configured in a variety of ways. For example, paper plays an important role in personal health information management (PHIM) even when digital tools are available (Piras & Zanutto, 2010). A deeper understanding of how patients and consumers engage in PHIM is a necessary stream of research that will inform the development of health IT artifacts, software systems, facilitate consumer empowerment, and support the core characteristics of patient centered care (Reti, Feldman, Ross, & Safran, 2010). Temporality has been clearly described in previous medical work (Reddy, Dourish, & Pratt, 2006), yet an investigation of patient temporality in relation to PHIM document practices is under-investigated.

Our motivation is grounded in the perspective that the work patients carry out when they interact with personal health information matters and has effects on the delivery of healthcare (Saranto, Brennan, Casey, 2009), as well as the construction of patient driven models of care such as patient centered care

(Berwick, 2009; Swan, 2009). We focus on making two distinct contributions with this paper. First, we propose a documentary practice approach as a method for addressing current methodological gaps in the literature. Second, we purport that a document practice approach helps expand the common conceptualization of health information management work. Specifically, that PHIM work is not an occasional task individuals decide to practice, but permeates an individual's entire life, akin to illness trajectories (Glaser & Strauss, 1968) or illness careers (May, 2010), and may aid in our understanding of how to best support lifelong personal health records and other PHIM tools.

To better understand the emerging literature of personal health records and how patients harness these opportunities to document health information, we ask the question: How has PHIM been studied methodologically in the literature to date? To answer this question, we gathered a small pool of studies that empirically observe PHIM work practiced with either physical documents, personal health record systems or both.

### **Patient Work with Personal Health Information Documents**

The small set of studies we synthesize for methods and findings in PHIM work run from 2005-2010. The literature featured here is selected because of its specific focus on the information management work practices of patients. To begin, Moen and Brennan (2005) utilize interviews, semi-structured questionnaires, artifact collection, and photographs of volunteers. In their analysis, four strategies are developed that explicate the material storage strategies used for health information in homes. Also looking at the role and importance of material objects in organizing a patient's health information, Palen and Aaløkke (2006) utilize ethnography to observe elderly individuals' routines for following medicine regimens. They conclude that the participants use their home infrastructure of spatial, temporal relationships to form a home distributed cognition; elders also had computers installed in their homes to document medication intake and other health measures. The next study transitions from studying PHIM in the home to the clinical environment. Acknowledging the ubiquity of health information and the complex ad hoc networks that patients construct, Unruh & Pratt (2008) use an extensive method of in-depth interviews, critical incident interviews, demographic surveys, personal health information collection reviews, photo diaries, log books, and fieldwork to study breast cancer patients' in situ PHIM work. They develop four patterns of invisible work that individuals encounter in a clinical visit which have implications for both patients' information work practices and design considerations. These findings underline the difficulty of studying patient information management work, and that to support patient work practices will have beneficial outcomes for patients, providers, and patient driven models of health.

The next three studies take place in 2010, the first of which is Piras and Zanutto's (2010) semi structured interviews of families' work with printed health information documents in the household. They observe three record keeping strategies similar to the findings that Moen and Brennan report, as well as four outcomes of work practices that occur in the household. The findings emphasize the flow of documents that patients use and how documents have emotional value to patients, which has an impact on patients' information management work. Next, Klasnja, Hartzler, Unruh, and Pratt (2010) conduct a qualitative field study of breast cancer patients' PHIM work in clinical environments. Their findings detail unanchored work, or work that is performed without sufficient support, and identify five patient work strategies and six design principles. In this study the authors showcase the fluidity of information documents and how cognitively taxing and stressful maintaining a patients information ecosystem can be. Lastly, Unruh, Skeels, Civan-Hartzler, & Pratt (2010) utilize ethnography of breast cancer patients in the clinical environment. The findings of this study describe various physical challenges and post visit challenges to patient information work. This work highlights the need to support patient work practices and the importance of information documentation, as work in the clinical environment is stressful and patients' ability to capture information is fleeting. From this literature synthesis, we move to a discussion of the three themes that emerged from the literature.

### **Investigating Patient Documentary Practices**

All of the studies we describe employ qualitative data gathering techniques of either field work or ethnography. While these methods can collect mountains of data, it is often done haphazardly and is rarely linked with good understanding of the larger body of documents and technical infrastructure with which they are connected (Østerlund, Sawyer, & Kaziunas, 2011). A document practice approach builds

on three methodological guidelines that support the collection of any form of information in the field. The first is that all documents are socio-technical artifacts and inseparable from either social or technical structures. When collecting data, this should be acknowledged and lengths should be taken that allow the investigator to connect the document to these originating structures. Second, the purposeful blending of qualitative and quantitative techniques is used in order to analyze documents and document infrastructure with the understanding that they are connected to a larger supportive network. The third guideline is that there is an implicit understanding that documents are a bicolage of other documents; every document has a sociotechnical infrastructure supporting it. In examining these documents, we can uncover both the embedded knowledge of actors that collaborate around the document, and the technical infrastructure that supports the document (Østerlund, 2007).

Data gathering for the documentation practice approach consists of scoping the relevant network of documents and systems and then gathering as much data as possible, including both physical and digital documentation. For example, if the research site is a hospital environment, the investigators would look at offices, desks, patient computer labs, the medical library, physical and digital filing systems and photo or video documentation as interesting spaces and appropriate tools to capture where, how, and when patients perform PHIM work (Østerlund, Dosa, & Smith, 2005). When collecting documents and details about documents, it is important to pay attention to the organization schemes employed by patients in both physical and digital spaces. This is a method that investigates an actor's work, in this case a patient, by looking at the documents they create and annotate, and then analyzing those documents for insight into the work practices of personal health information management. Both content analysis and network analysis are encouraged during this phase to elicit the basic structure of a patient's documentation work.

Once the first step of gathering and mapping documents has concluded, the second step in the document practice approach focuses on tracking the process of documentation work through four data gathering techniques to add depth and understanding to the socio-technical infrastructure. First, it is important to understand how patients organize health information. Do they solely use a personal health record? How do they store this health information? What documents are physical, what documents are digital, and how are they each organized? Do other family members help with PHIM? How much delegation occurs? Who contributes to what document? What documents do healthcare providers see and use? What documents are for patient use? What are highly relevant documents that are opportunistic for patient-provider collaboration? What are the topic and media networks? How does pathology management connect to the use of each document? These are example questions that drive the first data gathering phase. Software can be used to identify which individuals are in the network and track knowledge (Østerlund et al., 2011) across both virtual and physical domains.

The next technique of data collection focuses on linking patients' document use with behavior over time. Patients can track use of their own PHIM work with pictures, voice notes, smartphone apps, or other participant documentation tools. Researchers can send follow up questions via email along with short interviews. The point of this technique is to track activity of documents and how patients use these documents in a specific place and time. Technique three of data collection is reserved for identifying key documents important to patients' PHIM work. There should be a consideration of documents that facilitate coordination. Important documents should be tracked in more detail to learn their uses and evolution over time, specifically how they relate to other artifacts and events in the patient's life. The fourth data collection technique uses interviews and or focus groups with patients to elucidate the meaning that patients associate with specific documents. During interviews and focus groups, the investigator can take this opportunity to focus on constructs and meaning that may be specific to a research project; for example, focusing on how patients' documents relate to patient-provider clinical visits and help facilitate coordination of care. It should be noted that the most important practice of this method is the reiteration from document tracking to document collection. The described interviews and focus groups should serve as a touchstone to solicit feedback and clarity on the documents that the researcher is collecting, and how those documents link together. From this feedback the researcher can adjust and refine the documents they are collecting and analyzing. We believe this helps create a "sketch" or a window into patients' documentary practices, reconstructed through the documents they create and interact with. The following diagram was constructed to help elucidate this process. We organize the details of each phase as well as place an emphasis on the reiteration and reexamination of establishing connections between and among documents.

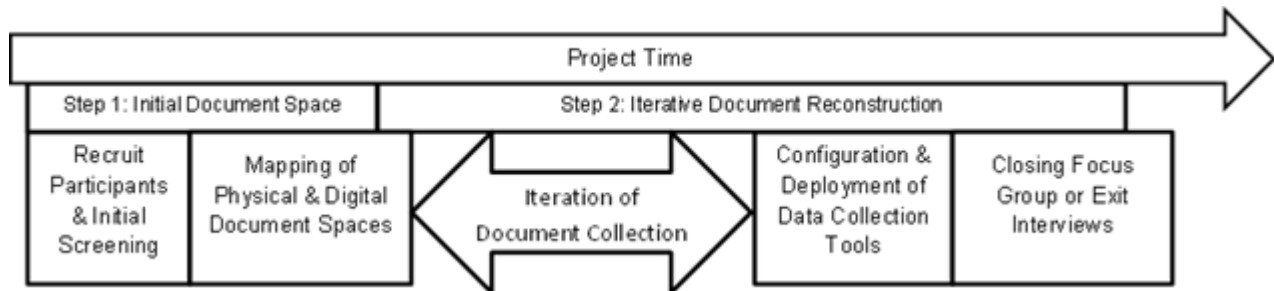


Figure 1. Document Practice Approach Method Diagram

In summation, the following outline details the two steps and four phases of data collection:

- I. Initial mapping and scope of documents to be investigated
  - a. Create a map of the network of relevant documents. Photos and videos can be helpful here.
  - b. Content analysis and network analysis suggested techniques for detailing the structure of document networks.
- II. Tracking of document use and recursive data gathering techniques
  - a. Understand how each participant organizes documents. Collect logs and employ frequent document queries that can clarify specific uses of a document.
  - b. Track participants actions using documents over time, phone calls and follow up emails.
  - c. Identify the key documents that are most important to a participant's work practices. These documents can be tracked in greater detail to focus on specific document networks.
  - d. Employ techniques such as participant observation, interviews, or focus groups to establish meaning and understanding of participants' use of documents. This is a useful opportunity to look at coordination in action.

## Future Work

While documentary practices have prior development elsewhere (Geiger & Ribes, 2011; Prior, 2008; Østerlund, 2003, 2004), it is our goal with this note to adapt documentary practices and develop the method into a strong and robust tool to address a clear gap in the literature previously identified. In follow up work to this note we conduct a study of patient personal health information management practices by studying a unique population that utilizes both paper documents and a nationwide electronic personal health record. The goals of the study are in part contained in this document. For example, many of the opening questions are relevant to our study on locating documents for patient-provider collaboration. We also want to stress the importance of scoping, research design decisions, and strategic use of data gathering techniques to make this method manageable and respectful of time, funding, personnel involved, and other real considerations that affect research projects. It is through the follow-up research to this note that we further develop the documentation practice method, providing exemplars of practicality and utility where the method is understood as a modest and mundane regimen of data collection techniques.

## Contribution

While each of the empirical studies we describe in the brief literature review touch on some of the steps and techniques detailed here, no study, to the best of our knowledge, of patient PHIM has utilized the documentation practice method in the manner which we begin to detail in this note. Studies that address the infrastructure of PHIM work do so without identifying important documents or fully connecting who collaborates on which documents with whom over time.

In this note, we contribute the identification of a gap in the literature along with a call for the importance of studying PHIM work practices across the affordances of paper and digital documents. We present the use of a documentary practice approach for filling in gaps to systematically and holistically

understand this complex and individualized process of patients tracking, updating, and demarcating their personal health information. We believe that this approach is particularly valuable for work practices that use both physical and electronic documents since it helps synthesize and shine a light on space, place, time, and infrastructure of personal health information management.

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