A Conceptual Model of Online Information Behavior in the Chronic Disease Trajectory

A Thesis

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Online resources have become an important source of health information for many people managing a chronic disease over a long period of time. The rapid growth of the Web makes readily available information from health organizations and peer-produced content from other patients. The primary objective of this study is to investigate and model changing online information behaviors, as the patient searches and learns over time, in the chronic disease trajectory.

Thirty participants with Type I or Type II diabetes were recruited for the study. Data was collected in semi-structured interview sessions where participants reported events or incidents in the past that led them to look online for diabetes related information. A model of online information behavior in the chronic disease trajectory, as the patient gains ability over time, was developed inductively from the data.

Emerging information behaviors have a considerable influence on our participants’ self-management practices. Our model characterizes online health information behaviors in three stages. First, a Diagnosis with the Disease, stage where participants use online health resources to help understand the disease and adjust to its impact. Second, a Forming of Ability stage, where participants start to feel empowered and begin developing information behaviors that support their unique
experiences. In the final stage, Established Ability, participants primarily seek to access personally relevant information and stay up to date with news related to their condition.

The theme of emerging abilities arose from our analysis and led to the development of our model. Long-term online information behaviors are described in three successive stages, where the searcher attempts to achieve a measure of ability and expertise in an unfamiliar yet critically important domain. The emergence of advanced online information behaviors, from a state of low ability near the time of diagnosis, towards one of high ability after substantial experience using online resources, are explored.
CHAPTER 1: INTRODUCTION

The Web is an important source of health information for a majority of adults in the United States. Eighty percent of all US adults who use the Internet, equaling 60% of the entire US adult population access online health information resources (Ybarra & Suman, 2006; Atkinson, Saperstein, & Pleis, 2009; Fox & Jones, 2009; Fox, 2011a). After email and search engine use, accessing health-related information is reported to be the third most popular online behavior among Internet users (Fox, 2011a). Online health information is used for researching a variety of medical conditions and situations, including management of a chronic condition. A study from the Pew Internet and American Life found that people who have a chronic disease with Internet access are more likely to use the Internet to find health-related information than Web users without a chronic disease (Fox & Purcell, 2010). One such chronic disease is diabetes, which affects millions of people in the United States and around the world.

Diabetes is a widespread chronic illness affecting millions of people in the United States and around the world. This work focuses specifically on the use of online health resources (hereafter referred to as OHRs) by chronic disease patients. The group under investigation in this study is people who use OHRs in their self-management of the chronic disease diabetes. Self-management practices are the ongoing “tasks an individual must undertake to control or reduce the impact of disease on physical health status” (Clark et al., 1991, p. 5). Diabetics manage their
condition for a lifetime, spending much of the time making health decisions on their own. Examples of health decisions include determining insulin dosages or deciding on safe and appropriate foods to eat. Most of these decisions and time spent on chronic disease management happens within a patient’s daily life, away from hospitals and doctors offices (Clark et al., 1991).

People managing a disease over time may achieve increased expertise in the topic, as they gain experience (Matson & Brooks, 1977; McCaughan & McKenna, 2007; Shaul, 1995), particularly among diabetes self-managers (Ellison & Rayman, 1998; Paterson & Thorne, 2000; Price, 1993). Information search behaviors may be influenced by changing experiences, ability, and expertise (Marchionini, 2006; Bates, 1989; White, Dumais, & Teevan, 2009). This expertise and ability informs critical care decisions in chronic disease self-management that are made without the help of doctors or other health professionals. These decisions cover medical, emotional, and lifestyle needs – and many are aided by the use of OHRs, which include websites from medical authorities and social media websites that feature the advice and experiences of other patients.

This work investigates online information behaviors related to self-management of the chronic disease diabetes over time, which can be many months and years, as people move through the trajectory (Corbin, 1998; Corbin & Strauss, 1991) of a chronic disease. Trajectory describes the patient’s experiences with an illness as a series of stages that encompasses their entire lives. This trajectory includes not only
the progression of the condition, but also “the actions taken by various participants to shape or control that course” (Corbin, 1998, p. 35).

Thirty people who use the Web as part of their diabetes self-management were recruited for this study. In one-time interview sessions participants were asked to describe events or incidents in the past that led them to look online for diabetes related information. Examples of such incidents include diagnosis with the disease, introduction of new medicines or technologies into the management routine, changes in their state of health, and the desire for affective or emotional support.

Patients have an increasingly responsibility to manage their own care. The medical community now views the patient as a primary decision maker in their own care (Goldman & Schafer, 2011), while a shift towards Web-based health information is a response to several factors related to patient information needs: patients are more involved in decision-making than in the past, the vast amount of information available today is beyond the ability of clinicians to keep up, limited time for doctors to spend with patients, promotion of self-care and prevention by health plans, and interest in alternative approaches (Eng et al., 1998). Taken together these trends suggest fast and convenient access to health information by patients can be an important part of chronic disease care in the modern health system.

Health practitioners consider it essential “that individuals with diabetes assume an active role in their care,” and that an important part of diabetes care is “education and development of problem-solving skills” (American Diabetes Association, 2012, p.
Many diabetics want more information and support regarding the disease, particularly when they are diagnosed, (Peel, Parry, Douglas, & Lawton, 2004). As will be discussed in the present work much of this additional information near the time of diagnosis and throughout the chronic disease trajectory is likely to come from self-directed Web searching and browsing, and is used in evolving ways as the patient moves through the chronic disease trajectory.

The Internet is an important tool in disease self-management. People like to use online health information because it is convenient to access, more information is available than from other sources, and it can be accessed anonymously (Rainie & Fox, 2000). While our focus is on online information behaviors, prior to the popular adoption of the Web patients used information sources that include health professionals, friends and family, and mass media (Napoli, 2001). These offline resources are still used today, however advantages of online information over offline resources include widespread access, interactivity, messages tailored to the individual, interaction and support from others, and anonymity (Cline & Haynes, 2001).

The remainder of this chapter first discusses the broad reach of diabetes in our society. Next we introduce the context of online information in chronic disease self-management and define information behaviors for the purposes of our work. We offer a short history of online health information in order to provide context for the vast array of websites and social media sites available today. We then introduce the
concepts of health literacy and e-health literacy to review the skills patients must have to understand and use the information they find online. Last, we conclude with the problem statement and significance of the study.

1.1 Diabetes and Society

The large population diagnosed with diabetes, estimated at 22.3 million individuals in the United States (American Diabetes Association, 2013), and 382 million around the globe (International Diabetes Federation, 2013) provides the opportunity to perform research that has a broad impact. The prevalence of the disease and its complicated management imposes a substantial burden on the healthcare system, and other difficulties such as the need for friends or family to act as caregivers. Diabetes can have serious long-term health consequences; including eye, kidney, and nerve damage among other complications. Additionally, diabetics can suffer from periodic health challenges like hyperglycemia (high blood sugar) and hypoglycemia (low blood sugar) due in part to lifestyle factors such as diet and exercise.

In addition to medical concerns diabetes, has a substantial economic impact in the United States. According to the American Diabetes Association (2013) the economic cost of the disease is an estimated $245 billion dollars. $176 billion of this total is for direct medical costs, and $69 billion in indirect costs due to decreased productivity, such as missing work or disability. The average medical expenditure of a person with
diabetes is $13,700 per year, with $7,900 attributed to diabetes care. This is more than double the cost of care than in the absence of diabetes.

Given the profound social and economic burdens imposed by the disease, and the prevalent use of the Internet by patients, we believe studying the online information behaviors of diabetics is a worthy goal. Fortunately, many diabetics can effect positive changes in their health outcomes by managing their lifestyle, following care guidelines from their doctors, and forming personalized management practices that work in the unique context of their experience with the disease. Controlling diabetes can lessen the use of healthcare resources and lead to an improved quality of life.

Effective self-management of this disease is critical as “the effects of daily decision-making can have immediate impact and result in potentially life-threatening complications” (Thorne, Paterson, & Russell, 2003, p. 1343). Diabetics in particular can have a substantial impact on their health by learning about and actively self-managing their condition. OHRs can serve as an important source of information, supporting and informing self-management decisions that lead to positive health outcomes. While many people with a chronic disease use online resources, as of yet there is little study of online information behaviors over the chronic disease trajectory.

1.2 Chronic Disease Self-Management and Online Information

People using online information to help make decisions about their health care and disease management are referred to hereafter as \textit{e-patients}, following terminology
found in the influential series of Pew Internet and American Life reports (Fox, 2007).

Chronic disease self-management entails the patient making “day to day” decisions about an illness (Bodenheimer, Lorig, Holman, & Grumbach, 2002) and the actions needed to maintain health. For example, diabetics may check their blood sugar, plan exercises, and monitor the condition of their feet each day. In today’s information rich landscape many people inform their self-management practices by accessing OHRs. These e-patients are exposed to online diabetes information by *actively seeking* information in response to a persistent need or a new event, through *monitoring* (Ellis, 1989) resources known to have periodically updated material, and by *encountering* diabetes related topics in their daily lives or non-health web browsing.

Diabetes specific websites, and the diabetes related sections of general health websites sponsored by recognized medical authorities (e.g. WebMD.com, MayoClinic.com) offer medically approved health information, but are not the only information resources used by e-patients. Social media sites like online diabetes forums (e.g. tudiabetes.com), diabetes sub-sections of social media sites (e.g. reddit.com), and general social media sites (e.g. Facebook) are also information sources for self-management activities. These social media resources complement the information provided to e-patients by healthcare professionals and authorities, help with persistent needs like diet and exercise, and provide social connections for emotional support and sharing experiences with other diabetics.
We will investigate changing information behaviors and corresponding information needs that evolve in the chronic disease trajectory. E-patients must locate appropriate resources, evaluate, and interpret the material they find in order to make informed decisions (Savolainen, 2006a) in the context of their own care. Many factors contribute to the selection of OHRs by an e-patient, including judgments of its relevance and utility to the need at hand (Johnson & Meischke, 1993; Zhang, 2012), therefore each individual will make decisions unique to their own needs. These needs change over time. Health resources provided by medical authorities may be used to research biomedical information, while social media resources may provide more personalized, and situationally relevant material (P. Wilson, 1973), that can include biomedical information, advice, and affective support from others who share similar characteristics and experiences.

1.3 Information Behaviors

This study uses qualitative methods to investigate the online information behaviors of people in their self-management of the chronic condition diabetes over time. For the purposes of this study we adopt T.D. Wilson’s (2000) definition of information behaviors:

the totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use. Thus, it includes face-to-face communication with others, as well as the passive reception of information (p.49).
As part of information behaviors, T.D. Wilson (2000) includes *information seeking behavior*, which is actively seeking information to satisfy a goal, as a sub-component information searching. Also included is *information use behavior*, which is incorporating information into the person’s current knowledge. Information behaviors of e-patients with a chronic condition include actively searching for and using information found online to support activities in disease self-management (Figure 1). We expand T.D. Wilson’s (2000) “face-to-face” communication from his definition of information behaviors to contain interpersonal communications about diabetes mediated in an online environment. Communications between e-patients may include real-time communication in chat rooms, and asynchronous communication like that found in social media such as Web forums, message boards, and question and answer websites.

![Diagram of Information Behaviors](image)

*Figure 1. Information behaviors: information seeking and information use are primary components of chronic disease self-management with online resources*

Health-related information has long appeared on many social media resources, in addition to that which was found on websites created by established medical
authorities. Around the mid 2000’s health and disease-specific social media websites were launched, such as the site patientslikeme.com. As these new Web2.0 or “Medicine 2.0” (Eysenbach, 2008) resources came to be widely adopted, the information options for e-patients grew to include online access to the advice and experiences of fellow e-patients (Figure 2), which historically had been available only in real-life interpersonal encounters. While it remains a concern that social media use in healthcare may result in harmful information being accessed, e-patients may develop methods to distinguish between information to be accepted, and that to be disregarded.

Figure 2. An example of e-patient social media use for chronic disease management (emphasis added).

1.4 Brief History of Online Health Resources

1.4.1 The National Library of Medicine

Patients have not always had the easy access to the Web-based health information resources that they value today (Rainie & Fox, 2000). Consumer-friendly health Web services grew out of previous efforts to develop networked professional health materials (Miller, Lacroix, & Backus, 2000). The availability of digital health information largely follows the history of services offered by the National Institute of
Health’s National Library of Medicine’s (NLM) (Lindberg, 2000). Over time, information availability has moved from a closed network with limited access to an open network with public access (Figure 3). Following this trend, early systems held only content from established publishers, while today the World Wide Web provides access to information from a vast assortment of content providers.

![Figure 3. Evolution of electronically available health information](image)

In 1964 the NLM pioneered large-scale electronic storage and search for health information resources with the launch of The Medical Literature Analysis and Retrieval System (MEDLARS). This in turn led to the 1971 launch of MEDLINE (MEDLARS Online), a system available via a nationwide telecommunications network. An early study of the system reported MEDLINE users preferred it to searching printed indexes and the results assisted clinical and research work (Moll, 1974). Additional studies reported that most access was primarily research oriented.
and searches targeted broad topics (Greenberg, Breedlove, & Berger, 1977; McCarthy, Maccabee, & Feng, 1974; Tagliacozzo, 1975). End-users often submitted MEDLINE requests through an intermediary, generally a medical librarian. Direct end-user access was facilitated by a software interface, Grateful Med, in 1986 and was followed a decade later by the Internet Grateful Med which debuted in 1996 (Figure 4). MEDLINE was made freely accessible to the public in 1997 via PubMed on the World Wide Web (WWW), and today provides access to full-text articles through PubMed Central (launched 2000). The primary audience for MEDLARS, MEDLINE, and PubMed was, and remains, trained medical professionals. However, with the relatively easy public access afforded by the Web, patients became consumers of this health information leading the NLM to begin offering patient oriented resources.

The response to the 1997 launch of PubMed marked a significant change for the NLM. Although the NLM "traditionally focused its services on health professionals" (Miller et al., 2000, p. 11) approximately one third of early PubMed searches were by the general public (NLM, 1998), leading to the launch of the patient-oriented website MedlinePlus. The Director of the NLM at the time emphasized their expanded mission now included providing "high quality electronic health information services for the public" (Donald Lindberg, 2003, p. n.p.), in addition to serving health professionals. MedlinePlus today contains information from over 1,000 organizations and over 35,000 links to health information. The system serves millions of users each year. Most recently, the growth of Web2.0, social media websites, and the mobile web led to the launch of a twitter feed in 2009, Facebook pages, and Mobile MedlinePlus in 2010.

1.4.2 The Shift to Social Media

Beginning in the 1990’s health organizations and social media resources joined the NLM in serving health consumers, including popular sites like WebMD.com, MayoClinic.com (both launched in the mid-1990’s), and later the online patient forum patientlikeme.com (founded in 2004). Hesse et al. described this as a "tectonic shift in the ways in which patients consume health and medical information" (2005, p. 2618). No longer were gatekeepers, like publishing houses or medical organizations that serve to signify safety and trustworthiness, required in the provision of medical information. E-patients were now left largely to their own devices, locating and evaluating information with limited support or guidance.
Health information seeking is now a self-directed exercise comprising many decisions:

Today, most people search for themselves and search from non-library or evaluated information environments... In consequence, they are forced to make the evaluations once made by librarians, and with so much choice and new products coming on stream, they have to make many, many evaluations. They largely do this with the help of a search engine, on the basis of long-experience with searching the Web, practice in making constant comparisons and a process of trial and error (Nicholas, Huntington, Williams, & Dobrowolski, 2004, p. 39)

E-patients have access to online information from not only authorities, but also social media sites containing other e-patient’s experiences such as blogs and web forums (Figure 5). E-patient advice and experiences, a substantial component of Medicine 2.0 (Eysenbach, 2008), can be beneficial for the chronic disease patient. The knowledge found on these social media sites complements the knowledge provided by medical experts (Hartzler & Pratt, 2011). E-patients may find information from fellow patients that more readily matches their experiences than that found in the medical literature (Mankoff, Kuksenok, Kiesler, Rode, & Waldman, 2011). This information can be more lifestyle related, but still have an impact on quality of life (i.e. how to select an insulin pump suitable for outdoor activities like hiking and camping). However, on the social web where almost any person can publish information, e-patients must exercise judgment and evaluate resources based on the providers external characteristics and the e-patient’s appraisal of the
content, which requires the ability to logically analyze informative materials (Chaiken, 1980; Petty & Cacioppo, 1986).

![Figure 5. Screencapture of the reddit.com diabetes discussion, circa 2014](image)

### 1.5 Health and e-Health Literacy

The abundance of health information available today, and the many decisions an e-patient must make, requires that e-patients develop skills in order to successfully use the information they find online. E-patients need to develop a high degree of health literacy in order to make informed decisions about their healthcare. Ratzan and Parker (2000, p. vi) define health literacy as:

> the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
A 2003 survey found 12% of Americans had proficient health literacy, 53% intermediate, 22% basic, and 14% below basic (Kutner, Greenberg, Jin, & Paulsen, 2006). Low health literacy has been associated with adverse health outcomes (Berkman et al., 2004).

Information technology may play a large role in enhancing health literacy (Leroy, 2008). Expanding on this concept, e-patients must possess a measure of *e-health literacy* in order to safely and successfully use OHRs in their self-management. We use Norman and Skinner’s (2006b, np) definition of eHealth literacy:

> the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.

However, health and eHealth literacy are not fixed. As both e-patients and the healthcare “community” (Bodenheimer, Wagner, & Grumbach, 2002) in which they function change over time (due in part to emerging and evolving technology), so will health literacy and eHealth literacy for each individual:

- “health literacy is a *dynamic* state of an individual during a health care encounter. An individual’s health literacy may vary depending upon the medical problem being treated, the health care provider, and the system providing the care” (Baker, 2006, p. 878).
- “eHealth literacy is influenced by a person’s presenting health issue, educational background, health status at the time of the eHealth encounter, motivation for seeking the information, and the technologies used. Like other literacies, eHealth literacy is not static; rather, it is a process-oriented skill that evolves over time as new technologies are introduced and the personal, social, and environmental contexts change” (Norman & Skinner, 2006b, np).
1.6 Problem Statement

Health information retrieved from online resources may directly affect health outcomes (Fox, 2006). The impact of online health information includes influencing how an illness is treated, changes in patient-doctor communication, lifestyle changes, self-diagnosis or alternate treatments, and changes in the way searchers think about their health status (Fox & Jones, 2009; Google, 2009). The quality of health information found on the Web may have an influence on the effectiveness and quality of care (Dutta-Bergman, 2006). Previous research suggests many benefits for diabetics who utilize Web-based health resources as part of their self-management (Greene, Choudhry, Kilabuk, & Shrank, 2010; Mamykina, Mynatt, & Kaufman, 2006; Or & Tao, 2014; Shaw & Johnson, 2011).

E-patients today have access to many OHRs and the results of online activities can impact health outcomes, however the evolving online information behaviors that occur in the course of chronic disease management are not well studied. A goal of the present study is to investigate how e-patients use the vast collection of OHRs available to them, as they learn and develop new abilities, in their self-management practices.

The primary outcome of the present investigation is a model of e-patients’ online health information behaviors in the chronic disease trajectory. We adopt T.D. Wilson’s description of a model as a “framework for thinking about a problem” that may take the form of an “attempt to describe an information-seeking activity, the
causes and consequences of that activity, or the relationships among stages in information-seeking behavior” (1999, p. 250). We undertake a qualitative research study with the goal of describing stages of online information behaviors for people managing diabetes.

Previous studies of online information behaviors for healthcare typically have often focused their research on a limited time frame, evaluating an intervention, or are not focused on chronic disease that entails many years of health information interaction. E-patients likely learn over time in exploratory search (Marchionini, 2006), leading to increased knowledge about their condition (J. Wilson, 1999) and changing information behaviors for future information needs due to the change in ability. A first step towards the types of contextually relevant, adaptive tools seen in the area of web search is to understand the progression of information needs and abilities of e-patients with a chronic condition as they change from diagnosis onward. The model resulting from the present study is intended to help provide understanding of different stages in information seeking: as e-patients search and learn about their condition, their abilities, interests, and needs change over time.
Health consumers have a growing responsibility for guiding their own healthcare in the modern medical system. The *principle of patient autonomy*, proposed by the American Board of Internal Medicine and the European Federation of Internal Medicine, states that “physicians make recommendations but patients make the final decisions” (Goldman & Schafer, 2011, p. 2). This patient responsibility can be particularly relevant in the management of a chronic disease, where e-patients make most care decisions and are ultimately responsible for the consequences of their choices (Clark et al., 1991). Examples of decisions made by diabetes e-patients can include changing insulin doses, determining the correct amount of carbohydrates to eat, or whether or not to contact a health professional in a time of instability or crisis. Most often these decisions are made without the input of a medical professional.

This investigation of the online health behaviors of e-patients, and our review of previous research, draws primarily from two areas. First, we draw from works in the health and medical domain that examine the place of an active patient in the medical system. Included in this domain are frameworks that describe the development of expertise as an e-patient moves from a naïve state at diagnosis to one of considerable experience, or “mastery” in their self-care (Shaul, 1995). Second, we draw from the information sciences that investigate how people find, access, and use information, particularly in the online environment. In this domain
the impact of time, learning, and experience on information behaviors are of particular relevance. The intersection of these two areas (Figure 6) is our area of interest.

![Figure 6. Area of interest for the present work.]

This chapter will situate our study within previous research in the health sciences and information sciences and is structured as follows. We first review models that examine Chronic Disease treatment from a health professional perspective. Next, patient-centered studies that characterize the experiences and growing abilities are reviewed. We then discuss the role of exploratory search and time in the information sciences, and the growing responsibilities of e-patients as they utilize OHRs without assistance from information professionals. Finally, we summarize e-patients evaluation of OHRs and informative content.

2.1 Models of Chronic Disease Management
Models of chronic disease self-management developed by medical professionals place the patient as a central figure in their own care, recognizing the need for an
informed patient. These models, along with the principle of patient autonomy, put a substantial responsibility on the e-patient to have suitable health literacy and to be an active participant in the course of their treatment. Common themes include patient empowerment and self-management efficacy which provides patients the tools to manage their disease, with the expectation that this will help improve health outcomes (Krumholz et al., 2006). Two influential frameworks, the Chronic Illness Trajectory Framework and the Chronic Care Model are used in this study to provide a structure for the e-patient’s online information behaviors in their chronic disease care.

2.2 Chronic Illness Trajectory Framework

Chronic diseases follow a path, called a trajectory, with the patient progressing through many phases in a lifetime. Corbin & Strauss (1991) developed their Chronic Illness Trajectory Framework\(^1\) for clinician use in nursing care and chronic illness management. This trajectory framework, developed over several years by Corbin and colleagues in clinical healthcare settings, is “a conceptual model built around the idea that chronic conditions have a course that varies and changes over time” (Corbin & Strauss, 1991, p. 156). This varying course over time is important for the present study, as it indicates e-patients will have information needs that likewise vary overtime. Therefore, we may expect to see ebbs and flows of information behaviors over the trajectory, as the e-patient responds to changing conditions.

\(^1\) Anselm Strauss, together with Barney Glaser, also developed the qualitative research method grounded theory (Glaser & Strauss, 1965), which originated in research on dying hospital patients.
The model was refined in the late 1990’s to reflect technological advances like health information access via the Internet, changes in health insurance systems such as Health Maintenance Organizations (HMOs), and a shift towards illness management in the home (Corbin, 1998). In the updated model it was noted that patients can become more knowledgeable than was possible earlier, and “take more responsibility for, their illnesses” (Corbin, 1998, p. 35). The updated trajectory framework defines chronic disease management in the following stages (Corbin, 1998):

- **Pre-trajectory**: prior to the disease onset
- **Trajectory onset**: Appearance of symptoms and diagnosis
- **Stable**: Condition and symptoms are under control. Everyday life goes on as normal, illness management is centered in the home.
- **Unstable**: Condition and symptoms are not under control. Everyday life is disrupted, however care remains centered in the home.
- **Acute**: Symptoms or complications require hospitalization or other measures. Everyday life activities are cut back or severely curtailed.
- **Crisis**: A life-threatening situation that requires emergency care. Everyday life is placed on hold.
- **Comeback**: A return to everyday life activities, possibly with changed ability for everyday life activities.
- **Downward**: Decline associated with increased disability and trouble controlling symptoms, requires adaptation in everyday life activities.
- **Dying**: Death of the patient.

For the present study, the trajectory onset, stable, the unstable stages are most relevant because this is when the e-patient maintains substantial control over their care. For example, many diabetics can control or treat their symptoms by adapting their lifestyle in ways such as developing an exercise regimen or modifying insulin doses if they encounter difficulty in an otherwise stable period. The pre-trajectory
phase is also of interest due to the potential that e-patients develop some health information behaviors prior to diagnosis with diabetes, due to researching diabetic symptoms, investigating a prior illness, or by acting as caretakers for others. Chronic conditions, however, do not remain static in these stages, there will be periods that require substantial attention: “within any particular phase there might be periods of several weeks or even months that can be characterized as a reversal, plateau, upward movement or a drop.” (Corbin & Strauss, 1991, p. 162). E-patients continuously monitors and makes adjustments when needed, working to maintain good control (Corbin & Strauss, 1985).

During the trajectory onset phase a “person begins to discover and cope with implications of diagnosis” (Corbin, 1998, p. 36). This phase relates to the initial diagnosis with diabetes and the time immediately following as the e-patient comes to terms with their disease. E-patients in this stage want to learn about the disease and its impact on their lives, often with little prior knowledge. In the stable phase, the illness and symptoms are under control and the e-patient works to maintain this stability. Efforts to remain in a stable condition include monitoring and control of their diet and exercise, and use of technology like insulin pumps to maintain appropriate blood sugar levels. In the unstable phase, the e-patient has disruptions to their everyday life and undertakes adjustments in their regimen of care with the goal of returning to good control. Instability in diabetes care may be due to causes such as comorbidity, progression of the disease, or the effects of diet and exercise.
The acute phase is more serious than the unstable phase, and is not a primary focus of the present study. The e-patient in this phase may experience substantial disruptions to their everyday life, including hospitalization, until the illness is under control. Comeback for an e-patient means returning to everyday life activities and self-management, however they may have to adjust to limitations or changes in the daily life due to the disease. For example, a diabetic may suffer reduced ability due to complications with their feet or eyes, including amputation or blindness, as the disease progresses. The remaining phases in the trajectory model occur during life-threatening situations that require the direct supervision of health professionals where the e-patient may have little direct control over the outcome (crisis, downward, and dying).

2.2.1 Chronic Care Model

In addition to a view of chronic disease in a trajectory of stages, health practitioners have considered the organization of the health system in its entirety as it provides care for those with chronic conditions, as opposed to patients with an acute condition. One such view, the Chronic Care Model (CCM) was originally developed as a guide to develop effective clinical care for chronic conditions and improve illness management (Bodenheimer, Wagner, et al., 2002; Bodenheimer T, 2002; Wagner, 1998; Wagner et al., 2001). Applications of the CCM in health systems have shown improvements in the care for diabetics (Bodenheimer, Wagner, et al., 2002; Bodenheimer T, 2002).
Chronic care in the CCM takes place in a system with 3 “overlapping galaxies” - the entire community, health care systems, and the health provider (Bodenheimer, Wagner, et al., 2002). Identified in the most recent update of the model are six elements:

- the community
- the health system
- self-management support
- delivery system design
- decision support
- clinical information systems.

Figure 7. The Chronic Care Model. Reproduced with permission of the MacColl Center, for Healthcare Innovation (http://www.improvingchroniccare.org/index.php?p=Versions_of_the_CCM&s=1380)
The present study is primarily related to the initial three elements of the model, the community, the health system, and self-management support. The remaining elements largely concern activities and organization of professional health providers. As shown in Figure 7, community consists of resources and policies that recognize the place of patient interaction and information sharing in chronic disease care. Self-management support recognizes the central place of the patient in their care, and the many significant decisions they make that greatly affect health outcomes. This support should help patients and families acquire skills and confidence needed to manage their disease (Bodenheimer, Wagner, et al., 2002). The health systems element consists of professional care providers along with insurance companies and other agencies that provide care. For the purposes of this work, we are concerned principally with e-patients’ physicians, health organizations who publish information online, and the insurance companies that pay for the ongoing care. Taken together, all of these elements influence an e-patient’s care. As technology advances, for example with the growing presence of social media on the Web, models like the CCM may require additional updating to include new health information activities.

The Chronic Illness Trajectory framework and CCM place the patient as a central actor in their own care. The two models serve complementary roles in framing the present study (Table 1). The Chronic Illness Trajectory framework is a model “built around the idea that chronic conditions have a course that varies and changes over time [that] can be shaped and managed” (Corbin & Strauss, 1991, p. 156), while the CCM describes a structure for the healthcare system, including an emphasis on
linking to resources in the community and self-management support with a goal of improving care for chronic disease (Bodenheimer, Wagner, et al., 2002). Our study seeks to find the place of OHRs and their use over time by patients who self-manage within the overlapping galaxies of the CCM.

Table 1. Present study focus compared to chronic disease management models

<table>
<thead>
<tr>
<th>Present Study</th>
<th>Chronic Illness Trajectory Framework</th>
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<tr>
<td>Online health information behaviors as the e-patient progresses with the disease</td>
<td>Distinct stages in the progression of a chronic disease</td>
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<tr>
<td><strong>Chronic Care Model</strong></td>
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<tr>
<td>E-patient use of online health resources to gather information from other patients, health professionals, and health organizations in order to become informed and empowered.</td>
<td>Overlapping “galaxies” in the healthcare system that support chronic disease management.</td>
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2.3 Progression and Development of Expertise in Chronic Disease Self-Management

The CCM and Chronic Illness Trajectory Framework look at chronic disease self-management through the lens of patients and their relationship to the health system and health professionals. The main audiences of those two models are medical professionals designing healthcare and chronic disease treatment organizations. Complementing this health-organization centric research is work that has looked at self-management in diabetes and other chronic diseases from a patient-centered perspective. Several studies discussed below report that patients
with chronic diseases progress through several stages as they gain experience and take charge of their care, although not always in a linear fashion. Similar to the dynamic nature of health literacy and e-health literacy, the e-patient experience in the chronic disease trajectory is dynamic and ever changing. These studies, however, do not focus on OHRs that are today utilized by many to help self-manage a disease.

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<td>Becoming aware</td>
<td>Traumatised</td>
<td>Denial</td>
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<tr>
<td>Trial and error</td>
<td>Taking it on</td>
<td>Resistance</td>
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<tr>
<td>Mastery</td>
<td>Taking control</td>
<td>Affirmation</td>
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<td>Integration</td>
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Studies of multiple sclerosis patients (Matson & Brooks, 1977), cancer patients (McCaughan & McKenna, 2007), and rheumatoid arthritis patients (Shaul, 1995) found stages of self-management efficacy for people with these diseases, beginning with diagnosis and ending with the patient experiencing a sense of control and empowerment in self-management (Table 2). Findings of these studies generally align with research studies investigating the development of expertise in diabetic self-management (Ellison & Rayman, 1998; Paterson & Thorne, 2000; Price, 1993). Common findings patients include having little knowledge when they are first diagnosed. Next they begin a phase of trial and error, to learn what self-management practices work best for their own unique lifestyle and circumstances. Finally, patients enter a phase where they are successful self-managers exert control
over their situation and live their lives within the known, and managed, context of the disease.

2.3.1 Developing Expertise in Chronic Diseases

Shaul (1995) investigated the experience of women learning to live with rheumatoid arthritis. Results from 30 interviews indicate a three-stage process of learning. First, “becoming aware” participants started to notice the first signs of symptoms and their impact on lifestyle. In the second stage, patients went through a period of “trial and error” while learning how to manage the condition. Finally in the third stage, “mastery,” patients “acquired new knowledge about the disease and how to live with it” (Shaul, 1995, p. 295). The women in this stage sought information about medical management and also sought emotional support. Mastery is marked by a greater control over everyday life and taking charge of management:

To achieve mastery, the individual must gain a sense of empowerment over the situation and develop a repertoire of strategies on which to draw in order to cope with the changes in the process and context of the illness. (1995, p. 296)

McCaughan and McKenna (2007) in a study of people battling cancer developed a theory labeled “Never-ending making sense.” In their framework, patients diagnosed with cancer moved from a “traumatised” stage of low experience and ability, to a “taking it on” stage where patients begin to actively seek and process information. The taking it on stage is similar to Shaul’s trial and error stage where the patient gains ability to self-manage by taking action then interpreting and
responding to the results. Finally, patients start “taking control” of their situation, utilizing a more selective process of finding and using information, similar to the “mastery” stage in Shaul’s model. Throughout these stages there is an ongoing process of discovering and using health information and varies by individual:

This journey from ‘being traumatized’ to ‘taking control’ is by no means linear. Some patients never take control and others experience periods of relapse. The pace and timing of these transitions also vary according to individuals (McCaughan & McKenna, 2007, p. 2102).

Matson and Brooks’ (1977) study of 174 multiple sclerosis patients found patients advanced through one or more of four stages: denial, resistance, affirmation, and integration. In the denial stage patients have an “unwillingness to accept the diagnosis” (1977, p. 249) and refuse accept help. During the next the resistance stage, “the patient attempts to gain some control over the disease” (1977, p. 249), and show some interest in meeting other patients, seeking help, and recognizing life is changing. This stage is similar to McCaughan and McKenna’s taking it on stage, and Shaul’s trial and error – as patients begin working to exert some control of their circumstances and experience with their condition. However, the patient has not yet gained the ability needed to be highly effective in their self-management. Next in the affirmation stage the patient learns to accept help and constructs new meanings of their condition. Finally, in the integration stage the patient deals with new problems as they appear. This last stage “not only takes a relatively long time to achieve but must also be reestablished with each exacerbation” (1977, p. 250),
meaning as new complications arise the patient must learn about and address the new circumstance. The final two stages affirmation and integration appear similar to McCaughan and McKenna’s taking control stage, and Shaul’s mastery – where the patient is increasingly able to manage their condition.

The three models described above share many characteristics throughout the stages, however Shaul’s model of rheumatoid arthritis appears to diverge from the others at the beginning stage, becoming aware. These differences may be because cancer and multiple sclerosis can be far more debilitating and disruptive than rheumatoid arthritis, leading the patients to hold on to their life for a period of time as if the disease were not present. Despite the differences in the diseases studies, similarities in the models include a stage of beginning to take on the disease by learning and using information resources, and a stage of being in control through the use of information and learning with a return to getting on with life, although with changed circumstances. These studies, and those investigating diabetes that follow, found that people managing a chronic disease progress over time and can become effective and able self-managers.

2.3.2 Developing Expertise in Diabetes Self-Management

As in other chronic diseases, people suffering from diabetes have also been found to move through a series of stages in developing expertise and self-management practices and processes (Table 3). Beginning with diagnosis, studies of the diabetes self-management experience appear to show common attributes of that mark each
stage in the patient’s progression from a low level of ability at diagnosis towards becoming high ability “successful self-managers” (Ellison & Rayman, 1998, p. 327). Below we discuss research of a patient’s progression in diabetes self-management, which has been described as a:

Developmental process similar to the more general processes of moving from childhood through adolescence and finally toward a more adult level of responsibility in their disease management, regardless of their age and stage at diagnosis (Thorne & Paterson, 2001, p. 84).

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<td>(1) trying it out</td>
<td>(1) management-as-rules</td>
<td>(1) passive compliance</td>
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<tr>
<td>(2) figuring it out and (3) trial and error</td>
<td>(2) management-as-work</td>
<td>(2) naïve experimentation</td>
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<tr>
<td>(4) basic routine</td>
<td>(3) management-as-living</td>
<td>(3) rebellion</td>
</tr>
<tr>
<td>(5) applies basic routine to new diabetic situations</td>
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<td>(4) active control</td>
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Price (1993) investigated how type 1 diabetics learned self-management, developing “An Experiential Model of Learning Diabetes Self-Management” that consists of two high level phases, which five distinct stages that evolve over time. The first phase, “getting regulated” consists of the first three stages, while the second phase “being regulated” consists of the final two stages.
The first stage, “trying it out”, begins at diagnosis and is characterized by a strict adherence to prescribed regimens. Here the patient dutifully follows the guidelines and advice of health professionals. Due to disruptions in life-style or negative physical effects, patients next moved to the “figuring it out” stage, where modifications start to be made to the management routine. Stage three, “trial and error” marks an “intensification of self-management efforts toward finding ‘what works for me’” (1993, p. 40). Patients may change routines or activities and interpret responses in their health and lifestyle. However, patient in this third stage are not confident in their ability to predict outcomes or plan for the future.

Stage four in Price’s model, “basic routine” is a bridge between phase one (getting regulated) and phase two (being regulated). In this fourth stage, patients are confident in their abilities, and establish practices that work for them based on their previous experiences. This confidence and experience signal the move to the second phase, being regulated. In stage five, which is wholly a part of phase two, patients may revert to trial and error when encountering new situations. However, the overall management of diabetes usually adheres to a routine developed by the patient, which has been judged to be effective in maintaining a suitable lifestyle and health status.

Ellison and Rayman (1998) investigated the experiences of women with type 2 diabetes that were considered experts in self-management. Their research found that participants moved through three phases of learning they labeled,
“management-as-rules”, "management-as-work", and “management-as-living.” The process of becoming a good self-manager was described as an "uneven and nonlinear" (1998, p. 327). Each person had a unique experience with their disease, not all participants reached all stages, and progress through the stages was variable.

In the first phase of Ellison and Rayman’s model “management-as-rules”, patients felt alone and afraid after being introduced to their management routine. Learning to manage emotional responses that had a negative impact was a crucial step in becoming better decision makers. Conquering this fear, and a feeling of the need to “get on with life” marked a “turning point in management” (1998, p. 327). This turning point resulted in a transition to phase 2, "management-as-work", where patients “became engaged in the work of self management” (1998, p. 327). Management included three types of simultaneous work, understanding physical needs, responding to events, and developing new skills. Patients used their “knowledge of the disease and its management" and “began interpreting information” (1998, p. 328), while adapting what they learned to their personal circumstances. Feelings of responsibility and success in management were common. This second stage appears similar to the stages figuring it out and trial and error in Price’s work.

A “competency” was reported that marked phase two and which could take months or years to develop. Recognizing their success as self-managers was a transitional event leading to stage three, “management-as-living.” Patients in this third stage
“viewed themselves as experts” (1998, p. 328). Expert patients had developed management strategies and felt confident in their decisions, and had a “feeling of being in control” (1998, p. 328). In this stage, “participants clearly owned their management” (1998, p. 328), consulted with health professionals after their own self-management strategies failed, and evaluated the situation and questions they had. Participants also reported a social aspect, such as sharing information and a sense of cooperation with other diabetics. Patients in this final, advanced, stage “relied on their own expertise in self-managing their day to day needs” (1998, p. 328). Price’s basic routine and applies basic routine to new diabetic situations appear consistent with this stage.

Paterson and Thorne (2000) investigated the process of gaining expertise by diabetics. Becoming an expert was described as a “shift from being controlled by the disease to controlling the impact of diabetes” (2000, p. 415). Like Price (1993), and Ellison and Rayman (1998), Paterson and Thorne found a progression of stages as the patient moves from novice to expert: “passive compliance”, “naïve experimentation”, “rebellion”, and “active control.” As in previous studies, each participant’s experience was unique and not all moved forward in a linear fashion. Participants might experience fluctuations along the way, but show a consistent progression and learning about their condition, summarized as “you never go back to where you were before” (2000, p. 409).
The first phase in Paterson and Thorne’s study, “passive compliance” is characterized by a shock at diagnosis and strict compliance with regimens of care provided by health professionals. Patients are not yet willing or able to investigate different care options. A move to “naïve experimentation” comes about due to a desire for greater control, however in this phase knowledge and ability are not sufficient to support successful self-management. Patients engaged in trial and error to test their self-management practices. The next phase, “rebellion,” “was characterized by denial of the diabetes” (2000, p. 411). Participants in Paterson and Thorne’s study report reaching this phase from passive compliance or trial and error. A desire to be the same as peers, or a feeling of constraint brought about by treatment regimens influence participants to rebel. Finally, participants “made a conscious decision to assume control of their diabetes self-management” (2000, p. 412), and moved to the “active control” stage, where they had a feeling of controlling diabetes rather than being controlled by it. Participants in this phase described developing expertise as “an ongoing learning process” (2000, p. 413).

2.3.3 Summary of Progression and Expertise Development in Chronic Disease Patients

Thorne and Paterson (2001) summarize the trajectory of becoming an expert in diabetes self-management as a process involving many years of learning. Beginning with a stage of adherence to prescribed regimens, diabetics and other chronic disease self-managers move on to experimenting with different approaches to tailor self-management practices to their own unique needs. Over time, this process of
trial and error leads to a sense of control, characterized as mastery or empowerment, in patient self-management practices. Expertise requires a “complex set of intellectual processes inherent in expert self-care decision making” (Thorne et al., 2003, p. 1349). Each patient in the chronic disease trajectory is unique, and each follows his or her own path through stages from diagnosis to expertise. The models discussed above allow for periodic trial and error due to events or circumstances that arise in the course of disease management.

These studies of chronic disease patients show patients moving from low ability to high ability over time, as they come to terms with their disease. The more debilitating conditions, cancer and multiple sclerosis, include a stage of denial where the patient pushes back or ignores their diagnosis. Common to the models are a period of trial and error, as the patient attempts self-management practices and adjusts their behaviors based on health results. Learning is also inherent, as the patient learns over time they are not able to go back to a more inexperienced state, and can use what they learned for future events or situations in their disease management (Paterson & Thorne, 2000).

The relatively recent rise of Web-based health information available on websites and social media are not the focus of these previous investigations of patients in the chronic disease trajectory. However, their findings still provide a good basis for planning investigations of online health behaviors. These works establish the
trajectory of a patient moving from a state of low ability to high ability and state of continuous learning.

Patients and health professionals have long recognized the need for education and active participation by the patient in their own care. In the following section, Online Health Information Behaviors, we focus on research from the information sciences that investigate how people search and learn using information systems over time.

2.4 Online Health Information Behaviors

2.4.1 Exploratory Search Behaviors

Health information seeking is often an exploratory search task (Marchionini, 2006) where the information sought is often ambiguous and unknown to the searcher. In contrast to single-item, or known-item, lookup tasks, exploratory search features “information-seeking processes that are opportunistic, iterative, and multi-tactical” (White & Roth, 2009, p. 6). Exploratory searchers learn as they go, using acquired knowledge to guide future search strategies and information use.

Health consumers visit many resources across the unstructured Web (White & Horvitz, 2009; Google, 2009; Fox, 2006; Fox & Jones, 2009), following a berrypicking path (Bates, 1989) through sites hosted by medical institutions, commercial organizations, government, personal blogs, social media, and others. Nicholas et al. (2006) found 71% of e-patients regularly visit more than one website for reasons that include distrust of a single source, comparing site information between sites, and the belief that no one website provides comprehensive information. Similarly,
Fox (2006) reports 72% of e-patients visited two or more sites during their last health information session. A study sponsored by a major search engine (Google, 2009) found the Internet was used more than a primary care physician (53%), or friend, relative or colleague (37%) to find health information; and 75% of respondents research symptoms online before talking to a doctor. Hesse et al. (2005) found the Internet is the first source of information consulted by a majority of e-patients. These findings suggest that the Web is an important information source, users visit multiple sources of information to find comprehensive health information, and acquire information from many sources as they iterate through searches.

Searching and browsing multiple sources are exploratory search behaviors. Exploratory search “blends querying and browsing strategies” that help a person “learn,” and “investigate” (Marchionini, 2006, p. 42). As the searcher gains expertise about a topic, their increased knowledge helps them process information that was previously inaccessible to them due to lack of ability. People starting exploratory searches are generally: “(1) unfamiliar with the domain of their goal (i.e., need to learn about the topic in order to understand how to achieve their goal); (2) unsure about the ways to achieve their goals (either the technology or the process); and/or even (3) unsure about their goals” (White & Roth, 2009, p. 10). Health information searchers starting a search are often unfamiliar with the medical topics they are researching, unaware of the resources and terminology needed to fully investigate their need, and are not sure what information will satisfy their goal.
Over time, as e-patients access information resources for self-management, they may gain expertise in both the medical content they consume and the use of information systems to find material. Advanced information seeking skills can be developed (Marchionini, 1995). Wilson (1999, p. 771) observed that “people living with a long term illness develop expertise and wisdom about their condition.” People operating within a domain can develop expertise about the area of interest while searching and browsing resources, which can influence future search tactics (White et al., 2009; Wildemuth, 2004).

Expertise in a domain consists of knowing both informative content and the knowledge of the resources that provide that content. Bhavnani (2001) describes the advanced domain-specific search abilities learned by health professionals as having *declarative* components and *procedural* components. Declarative components concern the content and content providers, including classifying health websites by type, knowledge of specific URLs, and knowledge of the content found on these websites. Procedural components concern the order in which resources are accessed, including sequencing knowledge (knowing in which order to visit specific websites), and termination knowledge (knowing when to stop searching). An example of an expert-like search may follow the procedure; (1) access a reliable healthcare portal like MedlinePlus (2) access a high-quality source of information within that portal, like the diabetes page, and finally (3) verify the information on another site, such as MayoClinic. Later work by Bhavnani and colleagues (2006) developed a search system built to support procedural search knowledge with a goal
goal of helping novices in the health domain access comprehensive information. In a controlled experiment, their system called “Strategy Hubs” outperformed general health information resources, suggesting expert knowledge and search abilities within a domain lead to more successful searches, and can be built into a search system.

**Time in Information Behaviors**

Searches that support investigation involve multiple iterations that take place over perhaps very long periods of time and may return results that are critically assessed before being integrated into personal and professional knowledge bases. (Marchionini, 2006, p. 43)

The view of searching for information as a dynamic, iterative process “that may cover a rather lengthy temporal span is central to models of information seeking” (Jansen & Rieh, 2010, p. 1525). Savolainen (2006b) suggests that time is an implicit factor in many information seeking models. Information seeking is a process, which can take place over a single session, or many weeks or months, as the user moves from an anomalous or confused state of knowledge to a more coherent understanding of their information need. Fundamental to many models of information seeking is the concept of a “gap” in knowledge as a motivation for using an information system. Influential models in this area include Taylor’s four levels of question formulation (1968), Belkin, Oddy, and Brooks’ Anomalous States of Knowledge (1982), and Kuhlthau’s Information Search Process (1991). These models highlight the notion that information seeking arises from a perceived gap between
the user’s state of knowledge and their desired knowledge level. For an overview of
many such models, Fisher et al.’s (2005) monograph reviewed over 70 information
behaviors frameworks, models, and theories.

Use of an information system is a way to help close the gap through learning and
exploring. Success or failure of the information seeking process occurs not through
measures like relevance or precision in a one-time search and retrieval process, but
rather within the mind of the user over the course of potentially many sessions. As
the information seeker moves through the search process, their state of knowledge
and search needs evolve.

Saracevic’s *Stratified IR* model (1996) abstracted the elements of an information
retrieval (IR) system to (1) users, (2) computer (information system), and (3)
situation. The stratified model includes the assumption that users interact with IR
systems so they can use the information they find, and that using information is
connected with cognition that occurs in a situation (Saracevic, 1997). As the user
interacts with the system, over time both the system and user can adapt to the
other, as each is independent. For example, search engines utilize geographical
information to return localized results for queries. So a search for “pediatrician
offices” on the Drexel University campus in Philadelphia, PA would return results for
offices near that school, while a user in on the campus of the University of
Washington in Seattle, WA would be shown results near that location. The user
adapts to the system by expecting such results and forming judgments based on the
expectations that have arisen over time. Interaction is a “dialogue” between user and system that takes place in the user-interface. Improving this dialogue in the health domain so system and user may more readily adapt to one another is needed, as “information needs of people grappling with chronic illness... are well-served at only the most superficial levels by existing Web search engines” (Marchionini & White, 2009, p. 30).

Characterizations of learning and expertise development in information systems echo the stages of growing abilities described in studies of chronic disease management. As a patient or searcher expends time and effort within a system or domain, he or she gains abilities and expertise. When an information system is viewed through the lens of exploratory search (Marchionini, 2006) and Saracevic’s (1996) stratified model, the potential for systems that serve users using online resources as part of their self-management practices in the chronic disease trajectory can be called out.

2.5 E-patient Responsibilities

Increasingly, the responsibility for health-related matters is passing to the individual. The social norms which cast doctors and public health officials as the brokers of medical information are yielding to an era in which individuals actively seek information. Individuals have to choose between a variety of information sources, including the relatively new sources represented by organizations, and then use the information they acquire to select options for health, for prevention, and for treatment. (Johnson & Meischke, 1991, p. 745)
Eysenbach’s *apomediation* model (2007) provides a bridge between chronic care models that put the patient in charge of their own care and online health information behaviors by describing ways e-patients may find information resources through search, social media, and other channels. The e-patient in Eysenbach’s model is no longer limited to passively receiving information directly from health providers. Rather, as they move through the Web in a *berrypicking* fashion (Bates, 1989), visiting search engines, social media websites, online news media, and other resources e-patients learn and revise search activities. While visiting many websites, e-patients are likely to gain experience and knowledge that affects future information behaviors. During this period in place of traditional intermediaries, like doctors and nurses, that were previously required for health information access are agents called *apomediaries*, that:

> guide a consumer to high quality information and services without being a prerequisite to obtain that information or service in the first place, and with limited individual power to alter or select the information that is being brokered (Eysenbach, 2008, np).

These apomediary guides may include medical authority websites, search tools, friends and family, or strangers on social media. The apomediation model places final responsibility for finding and evaluating resources on the e-patient, similar to the responsibility that the principle of patient autonomy places on the patient for medical care decisions. Lost in the move to self-directed information behaviors are the systematic and heuristic processing skills of human intermediaries, like doctors,
nurses, or librarians, with expertise in the health domain. On the Web today, e-patients are tasked with selecting and evaluating information from a growing number of information sources (Figure 8), and must make an increasing number of choices with concern to health information (Nicholas et al., 2006).

Finding information online without assistance can prove challenging. E-patients may face difficulty when searching for health information online (Toms & Latter, 2007). Comprehensive information about a medical condition may be distributed across several websites (Bhavnani, 2005; Bhavnani & Peck, 2010), making it difficult to get a full view of a topic. In a 2008 study, 21% of participants said health information was often difficult to understand, and a further 42% said it was sometimes difficult...
(Abrahamson, Fisher, Turner, Durrance, & Turner, 2008). In the same study 28% of participants reported they were unsure of what health questions to ask, and 30% reported it was often difficult to determine the quality of health information. Yet despite these challenges, while e-patients report a preference that a healthcare provider be the first source of information for a medical condition, in real-life they more often use the Internet as their first means of finding information (Hesse et al., 2005).

The quantity of material available to health consumers has exploded with the rise of Web2.0 technologies like blogs and wikis, increasing the difficulty for consumers to find and use high quality, trustworthy, and authoritative resources. As Metzger explains:

> in the past, substantial costs of information production and dissemination on a mass scale limited the number of sources to only those with enough authority and capital to justify and sell an information product. In the digital environment, however, nearly anyone can be an author, as authority is no longer a prerequisite for content provision on the Internet. (2007, p. 2078)

The concept of authority, while traditionally vested in the medical establishment, can also sometimes be applied to e-patients who now have the ability to create and deliver helpful content for others across the Web. Peer sources on social media may have cognitive authority, because it is thought the information they provide “is useful, good, current, and accurate” and that e-patients believe “they can trust the information” (Rieh, 2002, p. 146). Examples of patient expertise shared on the web
includes help understanding biomedical concepts, such as medication side effects, or self-care strategies like suggesting new recipes for a restricted diet. Multiple patient viewpoints function like virtual second opinions and help consumers form their own beliefs and strategies. Even if these alternatives are not always endorsed by the medical establishment, they can provide “different possibilities for treatment and new ways to understand their illness” (Mankoff, Kuksenok, Kiesler, Rode, & Waldman, 2011, p. 590).

2.5.1 Social Media for Experiences of Other E-patients

Use of social media in the United States has exploded in healthcare and other areas. Social networking sites are reported to be used by 73% of the adult online population in the United States (Duggan & Smith, 2014), and this use extends to health information. People with a chronic disease, like diabetes, are more likely to look online for content created by others than people without a chronic condition. 23% of Internet users with a chronic condition have gone online to find other people with similar health issues, while just 15% of Internet users without a chronic condition have done so (Fox, 2011b).

E-patients are willing to post and share information about themselves if doing so may help others. Among social media users in the United States, 94% support sharing their health data to help other patients, and the same proportion of 94% support sharing their health data to help doctors improve care, assuming anonymity can be preserved (Grajales et al., 2014). While a large proportion of e-patients
appear to support sharing, in practice a much smaller percentage actually contribute
to social media. Just 6% in a Pew study reported posting health comments to an
online discussion or forum, and 5% posting comments to a blog; however 60% of e-
patients, equaling more than one third of all US adults, have accessed information
online created by another patient (Fox & Jones, 2009).

Several sites have launched to foster diabetic communities and sharing of
experiences and advice. These online communities, typified by the website
patientslikeme.com, provide “disease specific tools that allow patients to track and
share relevant information such as symptoms, treatments, and medical data”
(Brubaker, Lustig, & Hayes, 2010, p. 1). Website features allow users to compare
their experiences to other patients and can empower them to take a more active
role in determining treatment options with their care providers. Examples of these
sites include:

- Diabetes specific sites: tudiabetes
- Health sites, with diabetes sub-site: patientslikeme
- General social media, with diabetes sub-site: reddit.com
- Medical authority sites that allow some user contributions: webmd.com

2.5.2 Evaluation of Online Resources

The aim of information seeking is to get relevant information into one’s head
and use it in conjunction with known information to take some action or
integrate it into the knowledge base. This is accomplished by coordinating
information-seeking factors in systematic and heuristic ways. (Marchionini,
1995, p. 195)
Dutta and Bodie (2008) suggested the information evaluation methods found in *dual-process theory* would be valuable in investigations of e-patient behavior on the Web, where e-patients evaluate resources in relation their unique characteristics. Dual-process theory emerged in the mid 1980’s to characterize human evaluation along two parallel tracks, labeled *heuristic processing* and *systematic processing* in Chaiken’s (1980) Heuristic-Systematic Processing Model (HSM), and referred to as the *peripheral route* and *central route* in Petty and Cacioppo’s (1986) Elaboration Likelihood Model of Persuasion (ELM). Although originally developed in the social psychology domain for research on persuasion, dual-process theory has since become viewed as “applicable beyond this one persuasion context” (Chaiken, Liberman, & Eagly, 1989, p. 214). In order to independently self-manage diabetes supported by the Internet, e-patients must have the ability to evaluate information resources by evaluating characteristics of the information resource using heuristics, and by evaluating the content in a systematic way. Research by Sillence et al. (2007; 2006; 2004) and Fogg et al. (2003) suggests e-patients use both *heuristic* and *systematic processing* when evaluating health websites.

Heuristic and systematic processing are parts of dual-process theories of information evaluation. Heuristic processing is a way e-patients can evaluate an information source, which requires comparatively little cognitive effort. The information recipient uses evaluation rules saved in memory, pre-existing ideas, and superficial qualities of the information source to make decisions. A common example of heuristic processing in Web search is using the relevancy rankings created by a
search engine algorithm to inform searchers’ rule-based relevance judgments: “a heuristic strategy to choose the top link of a search engine result page (SERP), because many people believe that the top links are often the best links” (Wirth, Böcking, Karnowski, & Von Pape, 2007, np). Other examples of common heuristics include experts are usually correct and well-designed websites are credible.

Recognizing that the best health information source is not always ranked highly by an algorithm, the search engines Google and Bing tested programs and developed policies to identify and show trusted health information in a prominent location on the results screens thereby making healthcare websites more visible to the user (Fox, 2010; Bing Community Blog, 2010). However, not all health related searches are easily identifiable and it is difficult to include all suitable resources in such systems, thus “natural” search engine ranking remains an important component of a website’s availability to Web users. Johnson and Meishcke (1993) in their Comprehensive Model of Information seeking, which is based on health information seeking, note utility and characteristics of the “information carrier” as a key component leading to information seeking actions. Information carriers, like websites for an e-patient, are evaluated on writing style or tone, understandability, and potential utility.

Systematic processing is a “comprehensive, analytical orientation in which perceivers access and scrutinize all informational input for its relevance and importance to their judgment task, and integrate all useful information in forming
their judgments" (Chaiken et al., 1989, p. 212). In contrast, heuristic processing is "a more limited processing mode that demands much less cognitive effort and capacity than systematic processing" (Chaiken et al., 1989). Systematic processing requires that the message be evaluated logically, which takes more time and effort on the part of the human receiving the message, necessitating a motivated e-patient.

Health information seeking is most often the behavior of a motivated person (Bass et al., 2006). However, motivation alone is not sufficient to produce desired results. A key component of the ELM is the “elaboration continuum,” that describes the impact of a person’s motivation and ability on their elaboration, or cognitive effort. The ELM and HSM both state a user must also have the ability to logically process the information they encounter. As discussed above, health searchers have differing levels of ability to process and absorb health information they find on the Web. Low ability searchers (such as those near diagnosis) may be constrained to heuristic processing, despite having the motivation to perform systematic processing, as this mode is "a more limited processing mode that demands much less cognitive effort and capacity than systematic processing" (Chaiken et al., 1989).

Chaiken & Maheswaran (1994) theorized that the presence of systematic processing can attenuate the impact of heuristic processing and therefore heuristics may not hold as much influence for expert searchers as they do for novices or laypersons, although they still may have an effect. Dual processing theory includes additivity and bias modes. Additivity is the case where heuristics have an independent impact on
judgments when systematic processing and heuristics occur together. For example, a person may accept an argument contained in a message, but accept it at a higher confidence level if the source is a medical research center instead of a wiki. Heuristics may also bias systematic processing. An example of bias is an instance where Web users are more readily persuaded by a message from an expert than one from another patient, thus requiring a lower threshold before accepting the content on a website sponsored by a healthcare organization than that required to accept a message found on a social media website.

E-patients who have extensive experience in self-management are expected to have a greater ability to evaluate information resources using parallel heuristic and systematic processing. Therefore they can operate effectively using the cognitively intensive systematic processing mode. Increased ability may help e-patients access and successfully utilize resources, like social media sites, where heuristic cues may be more nuanced than rules like “experts are usually correct”, and where the content may require analysis and comparison to existing knowledge.

2.6 Summary of Research Background
People with a chronic disease seek information to help them be successful in their self-management practices. They use this information to help satisfy needs, which can include factual biomedical information about the disease, or affective support for dealing with the emotional aspects of disease (Johnson & Meischke, 1991). As OHRs are now a major source of medical content, it is therefore critical to take steps
to investigate the online information behaviors of people managing a chronic disease. Patients with a chronic disease learn and have a growing expertise as they gain experience managing their condition, and people in exploratory search sessions likewise learn over time. However there is a lack of research investigating how online information is used in evolving ways as a patient gains experience in the chronic disease trajectory.

Clark et al. (1991) stated that chronic disease patients “must be sufficiently knowledgeable about their condition and its treatment to make informed decisions about their care” (1991, p. 6). Beginning with the popular adoption of Internet in the 1990’s, information used to gain the knowledge needed for successful self-management has been increasingly accessed online. The availability of health information has moved from closed, expert only systems to the World Wide Web. E-patients have access to a vast range of information, from medical research articles to patient stories on social media. While this openness has many benefits, it also increases the burden on e-patients to find and evaluate information.

Research in the health sciences and information sciences has approached information behaviors for chronic disease sufferers in a complementary fashion. The health sciences have generated models focusing on the patient’s growing responsibility to lead their own care, while information sciences begin to explain human information behaviors in the online environment. However, we do not yet have great insight into the use and influence of OHRs over the many years an e-
patient spends in the chronic disease trajectory. The purpose of the present study is to contribute to our understanding of this area.
Chapter 3: Research Questions and Methods

Broom (2009) suggests the “active” or “informed” patient is safer than the “passive” patient. We hope to expand the understanding of how informed and active e-patients use online resources, such as health webpages and social media sites, as part of chronic disease self-management. This work is intended to investigate how e-patients’ online information behaviors evolve in the context of chronic disease self-management. Chronic disease management models, information behavior models, and observations from a pilot study inform our research questions. Specifically, we aim to characterize e-patient online information behaviors guided by the following questions:

How can we model information behaviors of e-patients in the chronic disease trajectory?

1. How are online information resources used by e-patients as part of chronic disease self-management?

1.1. What is the role of online resources in chronic disease self-management?

2. What changes occur in e-patient’s utilization of online resources over time?
2.1. Which types of online information or online information resources are utilized in different stages of the disease trajectory?

This study follows a “grounded theory” (Glaser & Strauss, 1967) approach, with the analysis and modeling “grounded” in the data collected. Data was collected in one-time interviews guided by the Critical Incident Technique (Flanagan, 1954). Interviews were conducted over the phone or in person where participants were asked to relate events or incidents in their self-management that led them to go online for diabetes health information. Following each interview, transcripts were coded using the constant comparative method (Glaser & Strauss, 1967). The outcome of this work, a description of online health behaviors in the chronic disease trajectory, was inductively developed through substantial interaction with the data.

![Figure 9. Process for recruiting, collecting, and analyzing data.](image)

In the remainder of this chapter we provide the rational for using an interview study to collect data and explain the researcher’s background and experience. We then
describe the research methods used to collect the data, including recruitment and the interview sessions.

3.1 Rational for an Interview Study

Interviewing is a qualitative research method, and qualitative methods are well-suited to our study because they support “understanding the particular context within which the participants act, and the influence that this context has on their actions” (Maxwell, 2005, p. 22). The present study is meant to investigate e-patient actions in the context of managing a chronic disease, with the goal of understanding the role of online information behaviors in the chronic disease trajectory.

As Zhang states, “in order to design more effective systems to improve users’ overall experience with health information searching, it is necessary to understand health information searching as a process from a holistic perspective and in the context that it actually takes place” (2012, np). Through participants’ recounting of past behaviors and their subjective interpretations of incidents and events, our work gains insight into the process of finding, using, and learning from health information found online, in the context of self-managing the chronic condition diabetes. We hope that by modeling such behaviors, future researchers may utilize our model to guide investigations of e-patient behaviors, and future information system designers may leverage our findings to support adaptive, personalized resources that contribute to positive health outcomes for their users.
The method originally considered for this research project was a diary-based study meant to collect longitudinal data. However, we were dissuaded from such an approach after consulting with diabetes health professionals at Pennsylvania Hospital in Philadelphia, PA. This decision was confirmed in conversations with consumer health researchers. The researchers and health professionals unanimously made clear that the diary approach has limitations that make an interview study preferable for this investigation. Chronic disease e-patients look for online health information periodically (Fox & Purcell, 2010). Collecting data sufficient to investigate these many stages presents many challenges, as it could entail participants completing a diary over many months or possibly even years – with potentially long periods of inactivity. Second, a diary approach could only collect data for a relatively limited period of time in the relation to the trajectory, which can last a lifetime. Our interview-based study has an advantage as it provides the opportunity for a researcher to gather reports of multiple incidents at many stages in the chronic disease trajectory. Interviews allowed us to gather in-depth, contextual accounts of online health information behaviors desired for the present study from participants who can share accounts from recent, and past experiences.

The scarcity of previous research directed at e-patients’ use of OHRs in the chronic disease trajectory means this work is largely exploratory and leads to a new model of information behaviors. Qualitative research methods, like those used in this work, are well-suited to this task and “can support the development of new theories and models” (Zhang & Wildemuth, 2009, p. 11) in the information sciences.
3.1.1 Critical Incident Technique (CIT)

Savolainen (1995) describes health needs as a “critical incident” in his exploration of everyday life information seeking. In order to gather retrospective data from participants we utilize data collection methods from the Critical Incident Technique (Flanagan, 1954), an investigative technique described as well suited for exploring qualitative research questions (FitzGerald, Seale, Kerins, & McElvaney, 2008). The technique elicits data from participants through semi-structured interviews and its objective is to gain understanding from the perspective of the participant (Chell, 2004).

Critical incident technique was chosen to guide data collection because it captures the data from the participant’s perspective. Incidents are characterized as “any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act” (Flanagan, 1954, p. 1). CIT provides a methodology for collecting participant’s activities and behaviors, and has been used in previous research studies in health sciences and information sciences (Betts, Dirkx, & Ruud, 1993; Hughes, Williamson, & Lloyd, 2007; Radford, 2006; Siegel, Rapp, & Lindberg, 1991; Zhang, 2012).

Demonstrating the broad reach of CIT, Fivars and Fitzpatrick (2001) compiled a bibliography of research studies using the technique that reached over 300 pages. Previous researchers in the health and information sciences have used CIT to investigate online health information seeking. For example, an early and influential
study of the NLM’s MEDLINE system sought to evaluate the impact on clinicians. This study resulted in a taxonomy of MEDLINE use with three primary facets: why medical information is sought, the immediate effect of having (or not having) the information sought, and the ultimate outcome of the situation (Siegel et al., 1991). We investigate similar questions, and draw from Siegel et al.’s investigative methods, however in place of professional users and controlled resources we instead focus on e-patients (untrained laypersons) and uncontrolled Web resources.

3.2 Researcher’s Experience and Identity

Qualitative research requires interpretation by the researcher. According to Marshall and Rossman, a researcher’s “identity, experience, and values (also known as biases)... should be articulated as elements” of the study design and implementation (2011, p. 96). A researcher’s life experiences are likely to shape their perspective and should be acknowledged as we do below. In order to mitigate the effect of bias or perspective we used two methods in order to validate the interpretation of the data. First, intercoder reliability was used to validate the researcher’s analysis of interview data. Second, member checks were used to again validate the researcher’s analysis of interview data, and also to validate the modeling of behaviors over the chronic disease trajectory. These methods are further explained in the Data Validity section of this thesis.

The desire to study e-patients and their existing practices comes from the researcher’s library science and Web development background, where he has seen
the power of digital technology in helping people access and learn from electronic resources. One of the researcher’s first professional experiences was helping to develop and build an online learning platform for medical students. Later, research into medical websites developed for consumers (Yang, Winston, Zarro, & Kassam-Adams, 2011) and health search tools (Zarro & Lin, 2011) helped shape the researcher’s area of interest. Seeing first-hand the positive effects of medical information found in electronic formats influenced the researcher to investigate this domain for health consumers.

As the previous literature shows, the nature of health information found on the Web is undergoing a dramatic change. The finding that a majority of health information seeking sessions begin with a general search engine (Fox, 2006) and growth of social media led the researcher towards investigating e-patients in the environment where they are already operating, exploring their existing behaviors rather than developing an intervention, such as the work building and testing diabetes health apps by Mamykina et al. (2008). The same idea led the Library of Congress (Springer et al., 2008) and Smithsonian Institution (Kalfatovic, Kapsalis, Spiess, Van Camp, & Edson, 2009) in the library sciences to adopt the social media site Flickr for their image tagging studies, in place of standalone resources which are often little utilized in the library and museum worlds (Marty, 2011). The researcher felt that investigating participant’s real world experiences would prove beneficial in the health sciences, as our study is meant to help health organizations and e-patients understand current
online health behaviors; and develop processes, systems and techniques to leverage existing practices.

3.3 Participant Recruitment

This study investigates the online behaviors of people managing diabetes over many years. E-patients using online resources in their self-management of the chronic condition diabetes were recruited using messages posted on the Drexel University campus, Internet message boards, and through word of mouth referrals. Three methods of recruitment were used:

1. Posting invitations on Internet message boards related to diabetes, subject to site restrictions, such as the American Diabetes Association Facebook thread Twitter, and the reddit.com diabetes discussion forum.

2. Word of mouth online through retweets, liking, or otherwise drawing attention to the invitation by others (unsolicited by the researcher).

3. Flyers posted on the main campus and medical campus of Drexel University.

Participants self-selected based on inclusion requirements (Table 4), which were described in the recruiting materials, and contacted the researcher via email volunteering to participate in the study. An example of the recruiting flyer inviting participants to take part is included in Appendix C. After the initial contact email was received, the researcher responded with available times for interviews, details of the length and expected activities, and provided any additional information requested.
In order finalize the interview appointment, the participant emailed the researcher with their selected date and time that was then confirmed.

The Drexel Institutional Review Board (IRB) approved the study design, and participant data is kept confidential. Creswell (1998) suggests qualitative researchers interview between 20 and 30 people. A total of 30 participants were interviewed for this study. Participants aged 21 to 65 were invited to participate. The National Institutes of Health (NIH) definition of a child for grant purposes is an individual under the age of 21. We also felt it important to avoid any complications with using a potentially vulnerable population, over the age of 65, and those age 65 and over are reported less likely to go online than younger populations (Zickhur, 2010)

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>21–65 years old</td>
</tr>
<tr>
<td>Gender</td>
<td>No criteria</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>No criteria</td>
</tr>
<tr>
<td>Language</td>
<td>Fluent in English</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Diabetes or Pre-Diabetes</td>
</tr>
<tr>
<td>Web use for health</td>
<td>Within the past 12 months</td>
</tr>
<tr>
<td>Web use, general</td>
<td>At least the past three years</td>
</tr>
</tbody>
</table>
All participants agreed to have the conversation recorded. Interviews were recorded using Quicktime audio recording on a Macbook laptop computer. All but one interview was conducted over the phone or Skype (audio only), with the single in-person interview conducted in a conference room at Drexel University. The researcher took handwritten field notes during the interview, to record interesting concepts or areas that deserved further probing or follow up.

Participants overwhelmingly expressed gratitude that they were included in the study and were eager to share their experiences, with the hope that they may benefit other diabetics. Each was remunerated $20 for their time. However, several participants refused payment – in these cases a $20 donation was made to the Juvenile Diabetes Research Foundation (jdrf.org). Additionally, some participants volunteered (unsolicited) additional information via email after the interview session, and several volunteered their time for follow up conversations with the researcher.

3.4 Interview Session
Data was collected in a one-time interview session. Each interview lasted approximately one hour, and followed the format:

1. Greeting and Introduction (5 minutes)
2. Diabetes Knowledge Test (DKT) and eHeals questionnaires (10 minutes)
3. Interview (40 minutes)
4. Wrap up and remuneration (5 minutes)
3.4.1 Greeting and Introduction

Each session began with a short introduction by the researcher where study was described and consent was asked for recording the conversation. Participants were given the opportunity to ask questions at any point in the session, or to decline to participate in any activity. Following the introduction, the participant answered 11 demographic questions (Table 5) common to research in the consumer health domain (Atkinson et al., 2009; Fox & Purcell, 2010; Xie, Wang, & Feldman, 2011).

Table 5. Demographic questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>When were you first diagnosed with diabetes?</td>
<td>Year:</td>
</tr>
<tr>
<td>What type of diabetes do you have?</td>
<td></td>
</tr>
<tr>
<td>About how often do you use the Internet?</td>
<td></td>
</tr>
<tr>
<td>About how long have you been using the Web? ___ years</td>
<td></td>
</tr>
<tr>
<td>In the past 12 months, when have you used the Internet to look for health or medical information online?</td>
<td></td>
</tr>
<tr>
<td>How is your home connected to the Internet?</td>
<td></td>
</tr>
<tr>
<td>Where do you usually access the Internet?</td>
<td></td>
</tr>
<tr>
<td>What is your level of education?</td>
<td></td>
</tr>
<tr>
<td>About what is your annual income?</td>
<td></td>
</tr>
<tr>
<td>What is your age? _________</td>
<td></td>
</tr>
</tbody>
</table>

3.4.2 Diabetes Knowledge and eHeals

Individuals participating in the study might have varying levels of knowledge about diabetes. In order to assess each participant’s knowledge in this area we next administered the 14 question Diabetes Knowledge Test (DKT) by either having participants to complete an online version, or answering the questions over the
phone This test was originally developed by researchers at the University of Michigan (Fitzgerald et al., 1998), and has been validated in previous research studies. The DKT can be accessed online at: http://www.med.umich.edu/mdrtc/profs/survey.html#dkt

Knowledge of diabetes is important for effective self-management, as is e-health literacy in the context of using OHRs. In order to determine if our participants show any significant differences in their ability to utilize health information, each participant completed the eight-question eHeals scale (Norman & Skinner, 2006a) to measure their e-health literacy. As with the DKT, questions were completed using an online form, or were answered over the phone. The eHeals scale can be accessed online at: http://www.jmir.org/article/viewFile/507/1/2977

These questionnaires were originally intended to provide data useful for characterizing members of our study. However the data collected was not found to be as useful as we hoped. We present it here to confirm the population and provide insight into our participants’ diabetes knowledge and e-health literacy.

3.4.3 Interview

After completing the DKT and eHeals questionnaires, we then conducted a one on one semi-structured interview with participants about their use of OHRs in their diabetes self-management practices. The protocol contains themes to be explored, and interesting leads were followed in the course of the conversation (Table 6).
Questions were in part derived from Siegel et al. (1991) and Hughes et al. (2007) who investigated professional health information searching.

The protocol was used to elicit situations from participants that included going online to find diabetes-related information. During the pilot study, the interviews worked best when they began with brainstorming for situations (question one) to produce a list of events that were then explored in questions two through ten. Thus, we followed this format in the remainder of the study. The pilot study showed that participants often provided answers to questions in the course of the conversation before they were directly asked, necessitating a semi-structured protocol. For example, when asked what information resources were used (question 4), the use of these resources might also be described (question 5). In these instances the previously answered question was not directly asked, rather answers were clarified if needed and we followed up on any incomplete answers.

During the course of the interview, the researcher took handwritten notes to support revisiting topics discussed for follow up, and to record thoughts for use in later data analysis. This helped the researcher “work with concepts rather than raw data” and was beneficial later in the analysis in “stimulating new insights into data” (Corbin & Strauss, 2008, p. 120).

3.4.4 Interview Protocol

Semi-structured interviews were guided by the interview protocol reproduced in Table 6. As the interview progressed, the investigator took notes and probed for
additional details and asked for clarification if needed. At the end of the interview participants were given the opportunity to ask questions or offer any additional comments.

Table 6. Semi-structured interview protocol used in participant interviews

* Prompts intended to guide the interview are in italics.

Can you think about instances or incidents that led you to look for information about diabetes? Examples might be when you were diagnosed, when there was a change in your health, when you were visiting your doctor

1. What are situations or events that led you to do search for information?
   - Examples might include diagnosis or changes in your health. Let’s brainstorm some situations, and then we can go into more detail for each.

2. When did the situation occur?

3. What specific information were you seeking?
   - What search terms did you use?

4. What resources did you use to search for this information?
   - What search engines or websites? Google?
   - Did you use social media like Facebook, or a patient forum?
   - Did you read comments or other information created by other patients?

5. How did you use these information resources? What did you find hard/easy about using online resources and tools? Why?
   - How did you evaluate these resources

6. What information did you obtain as a result of this search?

7. In what specific ways was this information helpful?
   - What did you do (differently) as a result of what you learned?

8. What was the impact on the situation of having this information?
   - How did it affect what happened? What might have happened otherwise?

9. Was the Internet an important source of information?

10. What was the outcome of the situation?
During the interviews, the participant’s actions, thoughts, and experiences were explored in relation to their use of online health resources in diabetes self-management. For question one participants thought of times where they went online to find health information. The goal of this question was to provide the context of their information behaviors, which we would discuss in-depth in the following questions. Question two was intended to capture the timeframe in which the behavior occurred, so that we might organize the data in a chronology during the analysis. Questions three and four sought to prompt the participant to discuss the information they desired, and the resources used to access that information. Question five was designed to capture the participant’s experience using information resources. The goal was to collect their interactions with the site (i.e., by clicking) and reading content, and also to collect thoughts and ideas about the characteristics (both heuristic cues, and the within-the-mind knowledge) used to evaluate the resources. Questions seven, eight, and nine were used to capture the helpfulness, importance, and impact of online information in the context of the participant’s health concern. Finally, question ten asked the outcome of the situation, if there was there a consequence to using OHRs in the context of the health concern.

Each interviewee was unique and every session provided useful data. Participants ranged from somewhat reserved, requiring prompting to elaborate on answers, to extremely engaged in the process. During interviews with more reserved participants, the researcher prompted the participant to share more information
and provide more detail to their answers. Generally, as the interviews proceeded reserved participants opened up and freely shared their experiences. Engaged participants volunteered a wealth of information, often without waiting for questions. They also engaged in extra activities during the session, for example looking up histories in web browsers and revisiting websites discussed in the interview.

3.4.5 Pilot Study

The data collection procedure was piloted with seven participants in the initial phase of the study. The pilot confirmed that questions in the protocol adequately addressed the research questions. Minor changes were made to the protocol after the study, most notably the researcher’s prompt asking that the participant brainstorm several incidents in question one, and explaining that each would be explored in depth. Web searching, particularly using Google, was something few participants thought to mention, requiring prompts from the research asking if a search engine was used to find resources – often search was used as a first step towards accessing resources, conforming to previous findings.

The pilot study showed that participants often provided answers to questions in the course of the conversation before they were directly asked, necessitating the semi-structured protocol. For example, when asked what information resources were used (question 4), the use of these resources might also be described (question 5). In these instances the previously answered question was not directly asked, rather
answers were clarified if needed and we followed up on any incomplete answers. Data collected in the pilot are included in the final results.

3.5 Data Preparation and Analysis

Interview recordings were transcribed to text and imported into Atlas.ti qualitative analysis software (version 6.2.28) for coding in order to identify themes within the data. A professional transcriptionist transcribed two interviews, and the researcher transcribed the remaining 28. Using Atlas.ti, codes were assigned to the text with the minimum unit of analysis being a sentence or long phrase. As iterative coding continued changes to the coding scheme, like new codes or combining codes, were recorded. The software also served as a useful data management tool, providing an easy view of codes and their connections, and fast export of all codes and associated quotes. Notes taken during the interview supported coding, and literature used in the development of the conceptual model was consulted for possible concepts to be aware of in data analysis (Marshall & Rossman, 2011).

In addition to thematic data, chronological data was also recorded in the interviews – either volunteered by the participant or in response to the question when did the situation occur in the protocol. Reports of situations were arranged chronologically in text files, allowing us to view the use of information resources over time. For example, our participant P29 was diagnosed in 2009, and at the time of diagnosis was “curious about what was going on.” This led to visiting WebMD and the American Diabetes Association website. Later, in 2010 a change in life resulted in
looking for information on how long he could store insulin before it expired, in case he needed to use older insulin during a possible gap in his insurance coverage. Most recently, in 2013 P29 acquired a new insulin pump and used OHRs to learn about features of different models.

We followed an iterative coding procedure, where reviews of data, coding, and field notes or memos informed subsequent data collection and analysis. First we coded interview transcripts using open-coding where categories and themes are discovered in the data. Next, we examined the codes for categories that could be eliminated or combined with other codes. We performed axial coding, where categories were grouped together and sub-categories were placed in a hierarchy under more broad subjects. Finally, we performed selective coding where the categories were refined and the overall theoretical concepts were formed.

Memos were used to record thoughts and ideas in the course of the study. Two type of memos were used in this analysis, thematic and methodological (Marshall & Rossman, 2011), to guide the analysis of data collected and the methods used as the study progressed. Thematic memos were used by the researcher to keep track of themes arising from the data over the course of data collection. In these memos, the researcher’s thoughts on connections between themes were recorded to aid the development of the final model and guide data collection in areas that needed further development. Methodological memos were used to record the researcher’s thoughts towards changing aspects of data collection.
Saturation is a point at which “little more can be gained by further data collection” (Marshall & Rossman, 2011, p. 220) and when information collected becomes redundant. Saturation occurred relatively quickly for themes such as diet and exercise or search engine use (saturation occurred within the first seven interviews), and affective support. However, the investigation of other themes such as insurance and information monitoring took longer to develop. The IRB approved 30 participants for this study, per Creswell’s recommendation (1998) all 30 were conducted to confirm and corroborate the themes and concepts that emerged in previous interviews.
4 Chapter 4. Results

4.1 Participant Demographics and Characteristics

Thirty e-patients participated in our study. Twenty-seven participants were from the United States, and one each was from Australia, Canada, and The Netherlands (all communicated in English). Table 7 provides a summary of participants' demographic information. Participants were diverse in many criteria. Age ranged from 22 to 64, with an average age of 36. Twenty-nine of the 30 participants have at least some education beyond high school, and we had seven participants volunteer who are current students. One participant declined to provide an income, and one participant had no income.

4.1.1 Internet Use

Participants overall were active and experienced Web users, who accessed online information for a multitude of reasons. This result is not surprising as our criteria asked for participants with at least three years of Web use, and use of the Web for health information within the past 12 months. Table 8 summarizes our participants' Internet use.
Table 7. Participant demographics

<table>
<thead>
<tr>
<th>Criteria</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>22 – 25</td>
<td>6</td>
</tr>
<tr>
<td>26 – 29</td>
<td>9</td>
</tr>
<tr>
<td>35 – 44</td>
<td>9</td>
</tr>
<tr>
<td>46 – 64</td>
<td>6</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>13</td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>1</td>
</tr>
<tr>
<td>Some College</td>
<td>7</td>
</tr>
<tr>
<td>Associates Degree</td>
<td>2</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>11</td>
</tr>
<tr>
<td>Graduate</td>
<td>2</td>
</tr>
<tr>
<td>Current Undergrad student</td>
<td>5</td>
</tr>
<tr>
<td>Current Grad student</td>
<td>2</td>
</tr>
<tr>
<td><strong>Self-Reported Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>24</td>
</tr>
<tr>
<td>African American</td>
<td>3</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
</tr>
<tr>
<td>South Asian</td>
<td>1</td>
</tr>
<tr>
<td><strong>Income USD</strong></td>
<td></td>
</tr>
<tr>
<td>$0 – 25,000</td>
<td>9</td>
</tr>
<tr>
<td>$26,000 – $48,000</td>
<td>7</td>
</tr>
<tr>
<td>$49,000 – $81,000</td>
<td>7</td>
</tr>
<tr>
<td>$90,000 – $160,000</td>
<td>6</td>
</tr>
</tbody>
</table>
All of our participants reported using the Internet several times a day for any reason and have been using the Internet for at least six years. Many participants found the question about length of time they have been using the Web humorous, as they tried to recall when and where they first started using the Web. Recollections led participants to think about how different their information behaviors were in the time prior to gaining online access. Participants accessed the Internet from several locations, with all but one participant having a home Internet connection. The one participant without a home connection lives in a large city in the United States, and utilizes Wi-Fi networks available from coffee shops and convenient locations for online access.

<table>
<thead>
<tr>
<th>General Internet Use</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Several Times per Day</td>
<td>30</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years Using the Web / Internet</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6 – 12</td>
<td>5</td>
</tr>
<tr>
<td>13 – 17</td>
<td>16</td>
</tr>
<tr>
<td>18 – 25</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Web Use for Health Information</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Within the past week</td>
<td>22</td>
</tr>
<tr>
<td>Within past month</td>
<td>6</td>
</tr>
<tr>
<td>Within the past 3 months</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Home Internet Connection</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>High Speed (Cable or Fiber Optic)</td>
<td>26</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Wireless network on college campus</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Internet Access Locations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>28</td>
</tr>
<tr>
<td>Work or School</td>
<td>19</td>
</tr>
<tr>
<td>Mobile</td>
<td>23</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>
4.1.2 Diabetes History

Our participants have a broad range of experience with diabetes (Table 9). Participants’ length of time being diagnosed with diabetes at the time of our interviews ranged from 41 years to just a few months, with an average of 13 years since diagnosis. Age at diagnosis ranged from two years old to 56 years old, with an average age of 23 years old. While at the time of the study all were active users of OHRs in their self-management, two types of participants did not access the Internet when they were diagnosed: participants who were diagnosed before the Internet was widely available to the general public (for example, a participant first diagnosed in 1972), and participants who were young children when first diagnosed (for example, a person diagnosed at age 5).

<table>
<thead>
<tr>
<th>Year First Diagnosed</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1972 – 1984</td>
<td>5</td>
</tr>
<tr>
<td>1991 – 1998</td>
<td>8</td>
</tr>
<tr>
<td>2001 – 2009</td>
<td>7</td>
</tr>
<tr>
<td>2010 – 2012</td>
<td>6</td>
</tr>
<tr>
<td>2013</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age When Diagnosed</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2 – 8</td>
<td>8</td>
</tr>
<tr>
<td>9 – 19</td>
<td>7</td>
</tr>
<tr>
<td>24 – 36</td>
<td>9</td>
</tr>
<tr>
<td>39 – 56</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Condition</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Type I Diabetes</td>
<td>19</td>
</tr>
<tr>
<td>Type II Diabetes</td>
<td>11</td>
</tr>
</tbody>
</table>
The range of ages and length of time living with diabetes allows us to collect reports of e-patient behaviors along many stages in the chronic disease trajectory. Recently diagnosed people are able to provide detailed insight into their activities, which happened just a short time ago. Those diagnosed in the past are able to provide reports of recent activities by experienced e-patients, while also relating incidents that happened in the more distant past.

4.1.3 Diabetes Knowledge and eHealth Literacy

A large part of diabetes self-management is having a level of diabetes knowledge sufficient to understand basic health information. eHealth literacy is a concept that helps describe an e-patient’s ability to successfully find and use OHRs when making health decisions. In order to gauge our participants’ diabetes knowledge and eHealth literacy, we administered the DKT (Fitzgerald et al., 1998) and eHeals (Norman & Skinner, 2006a). Scores from the DKT and eHeals indicate a high level of diabetes knowledge and eHealth literacy among participants in our study (Table 10). We scored the DKT by counting a 1 for each correct answer and a 0 for each incorrect answer. Results from the DKT suggest most of our participants have an overall high level of diabetes knowledge, correctly answering 12 of 14 questions on average.
Table 10. Aggregate DKT and eHeals score per user

<table>
<thead>
<tr>
<th>User</th>
<th>DKT Score</th>
<th>eHeals Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>14</td>
<td>32</td>
</tr>
<tr>
<td>P2</td>
<td>13</td>
<td>40</td>
</tr>
<tr>
<td>P3</td>
<td>7</td>
<td>33</td>
</tr>
<tr>
<td>P4</td>
<td>13</td>
<td>37</td>
</tr>
<tr>
<td>P5</td>
<td>13</td>
<td>40</td>
</tr>
<tr>
<td>P6</td>
<td>14</td>
<td>38</td>
</tr>
<tr>
<td>P7</td>
<td>14</td>
<td>37</td>
</tr>
<tr>
<td>P8</td>
<td>14</td>
<td>38</td>
</tr>
<tr>
<td>P9</td>
<td>14</td>
<td>31</td>
</tr>
<tr>
<td>P10</td>
<td>12</td>
<td>35</td>
</tr>
<tr>
<td>P11</td>
<td>13</td>
<td>24</td>
</tr>
<tr>
<td>P12</td>
<td>12</td>
<td>32</td>
</tr>
<tr>
<td>P13</td>
<td>14</td>
<td>31</td>
</tr>
<tr>
<td>P14</td>
<td>7</td>
<td>31</td>
</tr>
<tr>
<td>P15</td>
<td>11</td>
<td>32</td>
</tr>
<tr>
<td>P16</td>
<td>14</td>
<td>40</td>
</tr>
<tr>
<td>P17</td>
<td>13</td>
<td>30</td>
</tr>
<tr>
<td>P18</td>
<td>10</td>
<td>31</td>
</tr>
<tr>
<td>P19</td>
<td>12</td>
<td>34</td>
</tr>
<tr>
<td>P20</td>
<td>14</td>
<td>40</td>
</tr>
<tr>
<td>P21</td>
<td>11</td>
<td>40</td>
</tr>
<tr>
<td>P22</td>
<td>13</td>
<td>36</td>
</tr>
<tr>
<td>P23</td>
<td>13</td>
<td>31</td>
</tr>
<tr>
<td>P24</td>
<td>11</td>
<td>35</td>
</tr>
<tr>
<td>P25</td>
<td>13</td>
<td>30</td>
</tr>
<tr>
<td>P26</td>
<td>7</td>
<td>26</td>
</tr>
<tr>
<td>P27</td>
<td>13</td>
<td>34</td>
</tr>
<tr>
<td>P28</td>
<td>13</td>
<td>39</td>
</tr>
<tr>
<td>P29</td>
<td>12</td>
<td>32</td>
</tr>
<tr>
<td>P30</td>
<td>14</td>
<td>35</td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td><strong>12.26</strong></td>
<td><strong>34.13</strong></td>
</tr>
<tr>
<td><strong>Standard Deviation</strong></td>
<td><strong>2.08</strong></td>
<td><strong>4.23</strong></td>
</tr>
</tbody>
</table>

The eHeals scale is scored by assigning one point to a response of “strongly disagree” up to five points for a response of “strongly agree” for a highest possible
score of 40 for the eight questions. eHeals scores ranged from 26 to 40, averaging 34 points. This result indicates a high level of self-reported ehealth literacy among our participants, which is not surprising considering the population we recruited active users of online health information.

DKT and eHeals results suggest that our participants are knowledgeable about the disease, believe OHRs are useful, and perceive they have the ability to successfully use OHRs in their diabetes management. Two supplemental eHeals questions reveal that participants find OHRs both useful and important in their disease management. Insight into the participants’ diabetes knowledge and eHealth literacy are useful in our study because knowledge and ability are important dimensions of online health information behaviors.

4.1.4 Participant Summary
Summarizing our participant characteristics from the responses above, participants in our study are active Web users, with all accessing the Web several times each day. Participants average 16 years of experience using the Internet and all have accessed the Web for health information within the past three months. Our participants have a wide range of experience with the disease. On average, participants were diagnosed 13 years ago, ranging from less than a year to 41 years ago. Data from the DKT and eHeals suggests our participants are knowledgeable about diabetes, and believe they have the ability to successfully find, evaluate, and use online health
resources. We believe this population of respondents enables us to gain broad insight into online health behaviors in the chronic disease trajectory.

4.2 Interview Data

In this section, we present the data collected in participant interviews. Searching and learning on the Web is a substantial part of self-management for participants in our study. Websites from medical authorities and social media were reported to be essential throughout the chronic disease trajectory. Uses of OHR in self-management include guiding health and lifestyle decisions, providing topics for conversations with health professionals, and giving affective support. Online health information behaviors evolve over the chronic disease trajectory as e-patients move from a relatively naïve state at diagnosis to one of relative expertise.

Diabetics must be active and involved in their care, taking charge of medical decisions with the goal of controlling the disease and reducing its impact (Clark et al., 1991). Diabetes is a condition with potentially serious impact on the e-patient’s health and life. Complications of diabetes reported by participants in our study include foot neuropathy, reduced vision, and unsuccessful pregnancy. Our participants used routinely OHR as a means to address the information gap in self-management, searching for information in response to health concerns. Participant reports included using OHR to support their decision to change medications that caused severe side-effects and advocating for extra medical testing. While
complications cannot always be avoided, appropriate self-management practices can substantially influence health outcomes.

When first diagnosed, there is a burst of intense information seeking and Web use. As the e-patient gains experience with their disease, and begins to understand their individual experiences with the disease information behaviors start to be tailored to their unique situations. Over time, a collection of resources and procedures to find and evaluate information become a part of the e-patient’s self-management practices. For example, some e-patients may find that web forums like tudiabetes.com work well for their needs, while others may prefer sites like MayoClinic.com to address their concerns. Needs and sources are context dependent – an e-patient seeking affective support is likely to find what they need in a social media source, while general biomedical information needs may be better satisfied on medical authority sites.

Information behaviors in diabetes self-management reported by our participants include actively seeking information while responding to events or managing ongoing persistent concerns, monitoring sources to stay up to date, contributing new material to social media, and encountering diabetes related information in daily life. Participants for much of their lives remain in good control, where daily life goes on as normal and a nominal amount of information is needed. During this stable period OHR are used to maintain good health by satisfying persistent needs of diet and exercise or affective support, and monitoring resources, like Web forums or mass
media sites, that are periodically updated for new information about diabetes. Less common, though mentioned by participants, is posting to social media which follows previous findings (Fox & Purcell, 2010; van Mierlo, 2014) that fewer e-patients post to social media than read it.

On occasion events occur that disrupt, or threaten to disrupt the state of good control, and prompt the e-patient to actively look online. These events are often marked by changes in health, but not always. Because diabetes intrudes on e-patients lives in many ways (Hayes & Aspray, 2010, p. 83), events may be otherwise seeming innocuous events, such as getting a tattoo:

*I was getting a tattoo about half a year ago and I didn't know about any health risks. I didn't think there were any but I did ask the question.* [P25]

When an event occurs in the life of the e-patient that triggers a need to find specific information about their condition, they then engage in event-driven information behaviors. Types of events include diagnosis, comorbidity, life changes, and following up on encountered information that is felt to require more investigation. They may also include additional needs like planning for future life situations such as pregnancy or leaving home for college, or preparing questions for an appointment with a doctor. Unique to health is that an event may be triggered by the e-patient responding to cues from their own body.
With the exception of trajectory onset (diagnosis), some events may re-occur at intervals in the chronic disease trajectory, however the circumstances and context will be unique each time due to changes in the e-patient’s health, experience and cognitive abilities, and resources available. For example, a diabetic may change medicine dosages several times, but each time the e-patient may look for information related to the present circumstance. Their behaviors will likely change each time, as they will have more knowledge of diabetes in general, their body’s reaction to the drug, and the information resources available.

The intensity of information behaviors ebbs and flows as participants move through the disease trajectory. E-patients have changing information needs at different times in their lives. Most participants in our study spend much of their lives in good-control following the initial diagnosis. Their information needs, and thus information behaviors may be relatively little. However, e-patients with complications or hard to control diabetes actively work to manage their health, with OHRs as a vital part of this effort:

*We’re working extremely hard to maintain/keep our blood sugars in good control. It is probably a small point, but it really does require work and dedication to maintain really good control and that’s why using online health resources is a vital part in maintaining that control.* [P1]

In this section we present the data collected during our interview sessions that resulted in the codes found in Table 11. These codes are grouped into four thematic
categories, events, information types and purposes, online information resources, and evaluation, which serve as the basis for developing a conceptual model of online information behaviors.

Table 11. Codes resulting from the analysis of data collected in participant interviews

<table>
<thead>
<tr>
<th>1. Events</th>
<th>2. Information Types and Purposes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1. Diagnosis</td>
<td>2.1. Affective</td>
</tr>
<tr>
<td>1.2. Doctor or Clinician Interaction</td>
<td>2.2. Empowered</td>
</tr>
<tr>
<td>1.3. Life Change</td>
<td>2.3. Diet and exercise</td>
</tr>
<tr>
<td>1.4. Symptom Checking and Comorbidity</td>
<td>2.4. Insurance</td>
</tr>
<tr>
<td>1.5. Symptom Checking and Comorbidity</td>
<td>2.5. Medical Information</td>
</tr>
<tr>
<td>1.6. Symptom Checking and Comorbidity</td>
<td>2.6. Medications</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Online Information Resources</th>
<th>4. Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1. Information Sources</td>
<td>4.1. Source Evaluation</td>
</tr>
<tr>
<td>3.1.1. Authority Website</td>
<td>4.2. Using Own Expertise</td>
</tr>
<tr>
<td>3.1.2. Social Media</td>
<td></td>
</tr>
<tr>
<td>3.1.2.1. Patient Stories</td>
<td></td>
</tr>
<tr>
<td>3.2. Online Information Access</td>
<td></td>
</tr>
<tr>
<td>3.2.1. Apps and Mobile</td>
<td></td>
</tr>
<tr>
<td>3.2.2. Monitoring</td>
<td></td>
</tr>
<tr>
<td>3.2.3. Search Engine</td>
<td></td>
</tr>
</tbody>
</table>

1. Events: What prompts information behaviors?

E-patients in our study reported several types of events that led them to look online for health information (Table 12). Events, as discussed above, prompt an e-patient to look online to find information. In addition to events like appearance of new symptoms or comorbidity, diagnosis, and doctor’s visits there are other circumstances that require the e-patient to become informed. E-patients in our study reported planning for future events, researching new treatment technologies,
and investigating activities that may cause problems for diabetics. Below, we provide examples where e-patients seek information for events that occur in their lives.

Table 12. Events

<table>
<thead>
<tr>
<th>1.1. Diagnosis</th>
<th>Diagnosis with diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“I started looking into just random things about diabetes to see if there’s anything new or anything different that I could learn.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1.2. Doctor or Clinician Interaction</th>
<th>Related to interactions with a physician, visits to the doctor’s office.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“In my experience you have to be a pretty strong self advocate in the medical system and it helps in that way. The doctor understands that you are informed and understand it’s also much easier to work effectively with the doctor as a partner.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1.3. Life Change</th>
<th>A changing condition or event in the life of an e-patient that leads to OHRs use.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“I remember specifically asking, I'm going to Penn State, I was kind of a goodie goodie in high school I didn't drink or anything and I'm going to go to college and there're going to be parties and I want to have fun. What's the safe way to do this?”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1.4. Symptom Checking and Comorbidity</th>
<th>Investigating symptoms of diabetes, or an illness or other health concern of the e-patient co-occurring with diabetes.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“Search for conditions that are associated with diabetes like Celiac disease, and I think that because that disease is highly associated with diabetes I had to go through a lot of diabetes websites to find more information on it.”</td>
</tr>
</tbody>
</table>
1.2. Diagnosis

*It’s a whole new world.* [P4]

Diagnosis is obviously a significant event in our participants’ lives, entailing a need to make substantial changes in their lifestyle if they wish to remain in good health. Knowledge of the disease whose treatment was to become a daily presence in participants’ lives was often quite limited, “I thought I was too old for it, I had no idea what it entailed, I naively thought it was something people managed so it’s got to be you can just take a pill once a day or something and it’s fine” [P2]. As participants began coming to terms with diagnosis, they learn the basics about diabetes and steps they can take to control the effects, “at the beginning it was mostly about basically trying to understand what it was” [P13].

*I did go online pretty quickly, and I think a lot of the stuff I did initially was pretty morbid. Like about life expectancy stuff. But once I was noticing trends on blood sugar and stuff that’s when I started to get more specific and try to figure out, like what’s a normal dose of insulin. What should I expect as my disease progresses over the next few months... I definitely went to the Internet pretty quickly after I left the hospital.* [P19]

The experience of being diagnosed may be shocking; “yeah it was a pretty major event for me. I’m still getting used to it a little bit” [P7â]. Diagnosis may be unexpected and in these circumstances, information retention at the time of diagnosis was reported to be poor: “my doctor didn’t give me a lot of information, she said I wasn’t going to remember it anyway - which is true. I don’t remember a lot of what she said after that because I was just really really surprised” [P7]. The
scenario shared by participant P19 below illustrates the unsettled circumstances that may accompany diagnosis:

*I was actually in diabetic ketoacidosis so he called me at 6 o’clock on a Friday. And he told me to go to the ER. I actually was given most of my information from the ER doctor. And then I was admitted to the hospital, I spent about a weekend in the hospital. Three days in the hospital, so they gave me a good amount of information. But still, it was all pretty hectic and sudden. You know, I knew a little bit about diabetes. I knew more about type two. I wasn’t as knowledgeable about type one. I didn’t really know what it meant. I had done a little bit of research beforehand looking at the symptoms... so they gave me information but it was a lot to handle at first. I don’t know how much of it I took him. I actually felt after I left the hospital that I still didn’t know what was going on. And I don’t know if that’s normal or what. But I think that I was still limited in my knowledge at that point. [P19]*

This data demonstrates the importance of OHRs for newly diagnosed e-patients, as information provided at the time of diagnosis is likely to not be retained. The need for basic information and the lack of information retention leads e-patients to go online, “I totally Googled it to death” [P7]. Basic medical information and the impact on day-to-day living are prevalent as e-patients come to terms with their new situation in life.

*So I really didn’t have much of an idea after I left the hospital after an hour or two. And yea, pretty much my first resource I went to was the Internet - just to find out more, how common it was for people to get diagnosed at my age and just basically what the issue was and how my life was going to change kind of a thing. [P2]*

### 1.2. Doctor or Clinician Interaction
Managing a chronic disease requires collaboration between doctor and patient. While much of the focus in our study is on e-patient self-management, doctors and other health professionals are required for effective treatment. The collaborative nature of chronic disease management highlights opportunities and limitations in the exchange of information between doctor and patient. Participants report that having well-informed conversations with doctors and the ability to ask insightful questions about their disease are important. OHRs are used to prepare questions for future interactions and also to follow-up, investigate, or interpret information and instructions provided in an appointment with a health professional.

*My doctor seems to be quite open. He is a skeptic though, because he is the person that the scientific literature and I usually bounce to user reviews or quotes, taken out of context. But he will definitely listen to me and get what I say or think something is like - and he’ll correct me if something is not the case. Usually he’s a good listener and he knows what he’s talking about.* [P25]

E-patients in our study were certainly empowered by the information found online, which helped them “*work effectively with the doctor as a partner*” [P27]. Bringing information found online to the doctor can be a positive experience for some e-patients, provided they have a receptive audience when talking with their doctor:

*Yeah that actually made me feel really good, because most of the time I’m at the doctor I kind of feel out of my depth. Which is not what I’m used to, so it felt really good to go in there, and she said well that’s actually a really good question. And I was like-oh good. My doctor was kind of surly when I first met her and she kind of warmed up-so that was really comforting.* [P7]
However, there are often limitations on the time doctors have for conversation with patients, leading participants to go online:

*I think our health system, in terms of doctor’s appointments, is not really structured to give people information. So that’s why I tried to use the Internet to compensate or even decode the information I’m getting from a 5 minute doctor’s appointment.* [P13]

In part, the need for support from OHRs comes from the limitation that health professionals have little time to engage in “information work” with patients. As shown above, a common theme among interviewees was the short time doctor and patients have together for information work, as opposed to a medical examination;

“I talked to my doctors, but my doctor’s appointments are 20 to 30 minutes max. So for that essential health information the Internet is probably the main resource I use” [P6]. Because of the time limits imposed, many participants reported minimal information transfer from doctor to e-patient. In particular one participant (P1) reported leaving a doctor’s office in tears because the doctor would not answer any more of her questions, as she had exceeded the time allotment of their appointment and many more patients were waiting.

With limitations in mind, e-patients use OHRs to prepare for doctor’s appointments so that they may maximize the time available to them, “I’ve definitely brought ideas in that I’ve learned online - like hey what about this or what about that, or - is this is problem because I’ve read that this could be a problem. And I guess for the most part
I’ve had pretty great doctors and they’ve been willing to answer my questions” [P23].

Doctors were also seen as imperfect in some cases, and OHRs were used to investigate and learn about doctor’s decisions, “I was the only type 1 he was treating so I didn’t exactly trust his judgment when it came to what his plan of care was for me” [P5].

These results highlight the role OHRs play in the doctor-patient relationship. While doctors are ultimately the decision makers in terms of prescribing treatments and providing diagnoses, OHRs can help address limitations on information sharing that is a part of our current healthcare system. Productive and positive interactions with health professionals are a central concern and OHRs help participants prepare for appointments. Previous health informatics research described the doctor-patient relationship as a “partnership rather than a process of one-way information provision”, with e-patients “empowered” by the Internet (Broom, 2005, p. 326). Findings from our study were consistent with the sentiment of this prior work.

1.3. Life Change

Life changes occur when some event, in the present or anticipated in the future will have result in a substantial change in the e-patient’s health or lifestyle. Life changes may involve using a new treatment technology or planning for future events that may impact diabetes management. Here we present three examples where OHRs
were used to help plan for a life change, acquiring an insulin pump and planning pregnancy, and going away to college.

**Life Change Example 1: Acquiring a new insulin pump**

Insulin pumps are an important care technology for many respondents. Acquiring an insulin pump brings together many parts of the diabetic experience; doctor suggestions, investigating new technologies, determining insurance coverage, and considering future lifestyles. Participant reports of seeking information for a new pump contain rich descriptions of the interaction between many self-management resources. Pumps are worn continuously and deliver insulin to the diabetic without requiring an injection with a syringe. Deciding on a new pump is an important life decision, as the e-patient will likely use it for several years. And much like purchasing any piece of technology there are several vendors and options available, requiring thorough research: “*well the first thing I was seeking is just what are the different vendor options available and then people’s experiences with the different ones*” [P15].
Similar to shopping on an e-commerce site, ratings and reviews can be an important part of the decision, leading participants to investigate other e-patient experiences with the devices:

“I’d like to read more about [insulin pumps] because my doctor has little time and I can spend all day researching about reading reviews and comparing them - on whatever- the usefulness, how long the battery life is, how easy it is to use, and I’m not sure my doctor can tell me that because he’s a non-diabetic. So he doesn’t have to live with it every day and use the pump everyday. Looking on the Internet for easiness and usefulness of a pump - I got really good reviews. [P25]

The impact of wearing a pump is a primary concern for our participants in their investigations. In addition to the medical need of delivering insulin, this technology is evaluated based on its usability in the e-patient’s life. For example, athletes want a pump that can handle the rigors of their sport and provide care despite possible rough treatment:
I was mainly looking for which insulin pumps were the best for someone who's active. I like to play basketball, so I wanted to make sure I did not get one that would get broken if I tried to play basketball with it. So that was the main thing. [P20]

In addition to the durability, some are concerned with “cosmetic” issues of wearing a device. While this concern may not be strictly medical in nature, it can impact the day-to-day life of an e-patient.

Some of the different pumps are worn directly on the skin so it's a cosmetic thing, that you always have to live with having this thing stuck to you. So just thinking about that. Some of these are just a Google search - an image search - like seeing how other people wear them and how it looks with their clothes. Probably cosmetic issues, I mean when you wear something 24/7 it's definitely something to consider when making a decision. [P9]

Life Change Example 2: Planning for Pregnancy
Diabetics may have concerns in their lives that may not be problematic for non-diabetics. For this reason, it is sometimes necessary to find information to help plan ahead or respond to life events in ways that may not be obvious to non-diabetics:

Even to dating and stuff, and how do you tell you someone 'oh I can't have that second beer', I carry a syringe and insulin in my purse' - that's not something that you throw out there. [P1]

Planning for future changes in life is an important part of many participants’ self-management. Many participants desire “an idea about what kind of questions at this point in my life I should be asking. Or what’s going to be coming up” [P6]. Pregnancy in particular was a concern for the future, as diabetic pregnancies can be high risk:
And also another thing I can think of is I started looking up a little while ago just because it started to be of interest to me, not that I am start a family anytime soon, but I wanted to look into what complications could come up from trying to get pregnant for being pregnant. You know if it was much more difficult or if there were—because you know I had heard random snippets of information but again this was a medical site it was both actually because I looked on medical sites and they were saying that—there was mostly reassuring stuff there I think that it’s actually not very much harder and that it’s high probability that you will have a very safe and healthy pregnancy and that everything will go okay. [P2]

Life Change Example 3: Going Away to College
Leaving home for college was another major event for some participants.

Participants in this situation looked for practical information that could be used to help them transition and be successful in their new situation:

Definitely used it before I went to college just kind of seeing what other people have done… I remember reading how to tell your roommate you have diabetes. And how to deal with a change in schedule. Sometimes diabetics try to be flexible but some things have to be scheduled at a certain time. A lot of the things they said like when you’re scheduling your classes he probably can’t schedule a day where there’s no break for lunch. You’re going to need an hour to a half hour to get something to eat. Or, if you have a longer exam to make sure that blood sugar is at the right level. Kind of practical tips of how to deal with it. [P6]

1.4. Symptom Checking and Comorbidity

Just because you have diabetes doesn’t mean you also don’t have cancer or don’t have something else. [P20]

OHRs may be used to find information about health concerns that are part of, or co-occur with, diabetes. Periodically e-patients experience health conditions that must
be addressed in addition to their normal management routine. These conditions can be issues related to diabetes like foot conditions or hypoglycemia, or unrelated issues like the flu that are thought by participants to impact their diabetes (such as by raising or lower blood sugar). When a condition arises, participants turned to the Web to learn about the medical the condition:

*I often search for what to do about hypoglycemia. At first I didn't know what foods to eat to help get the blood sugar back up but without making it go too high.* [P13]

*I noticed myself getting tired last fall, and I know that celiac disease is associated with diabetes. So I started doing some research on celiac disease - looking up like symptoms and things like that. And what types of blood tests are needed. So when I went to my next doctor's appointment I could bring up my concerns about this. And so they could issue the blood test for me turns out that I could not have it. But, I was just curious of looking into some of the symptoms like I was tired - I think that a lot of the ones I came across I was like, oh my gosh I definitely have this disease.* [P9]

### 4.3 Information Types: What information is sought and used?

Many types of information are accessed and used by e-patients in the chronic disease trajectory (Table 13). These include information about the causes and effects of the disease, diet and exercise, and medications. Affective information, which is used for emotional support, is commonly sought, as is information that helps empower the e-patient to take charge of their own care. Other patient stories are reported to be important for reading about how other e-patients approached situation similar to those facing our participants.
Table 13. Information types and purposes

<table>
<thead>
<tr>
<th>Information Type</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>2.1. Affective</td>
<td>Information resulting in improved emotional well-being. “I’m kind of freaked out about this process in general but again knowing that someone has done it and made it through and lived document the entire experience is kind of comforting.”</td>
</tr>
<tr>
<td>2.2. Empowered</td>
<td>Information that leads to the e-patient feeling more in control of their care. “I may look at it one way which could be the right way, but when somebody else talks about the way they handle it that's a totally different way to look at it and it may be more helpful to me so I look at it like that, it's definitely empowering.”</td>
</tr>
<tr>
<td>2.3. Diet and exercise</td>
<td>Information for food and diet (such as recipes) and exercise. “I started looking up diabetic recipes because I love to cook.”</td>
</tr>
<tr>
<td>2.4. Insurance</td>
<td>Accessing information related to insurance or payment/provision of care related concerns. “Pretty much you want to start understanding it costs associated with health and the health care system in general.”</td>
</tr>
<tr>
<td>2.5. Medical Information</td>
<td>Accessing information to learn about the causes, effects and treatment of the condition. “I had no idea how alcohol would affect diabetes. It’s actually a really, not complication, but it can have serious effects if you’re not taking care of yourself. So just learning about what it can do to your blood sugar, and what signs you and your friends should look out for - beyond just drinking but also diabetes and drinking.”</td>
</tr>
<tr>
<td>2.6. Medications</td>
<td>Information about a specific medication, including side effects. “If I’m looking for a particular medicine I’m looking for side effects and things especially if I was experiencing any.”</td>
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</table>

2.1. Affective

Affective, or emotional, support, provided by OHRs is vital for many participants. Staying positive was described as a “battle” by our participant P10. Several
participants reported affective support as their primary reason for using OHRs in diabetes self-management, “I do use the Internet for seeking out scientific information, but more of the things I’m looking for online when it comes to my diabetes management are more like support” [P8].

E-patients reach others online synchronously and asynchronously for affective support through social media. Near-synchronous support can come from behaviors like “tagging” a post in Facebook with a contact’s username in an attempt to elicit a fast response or using an online chat system. Asynchronous support can come from reading about other e-patient experiences, such as a person’s blog post, or visiting diabetes Web forums.

Affective needs are largely addressed by accessing information that lends emotional support. Most frequently participants received affective support by reading social media resources.

In the year I’ve started reading blogs by people with diabetes. I don’t know how helpful it is but I think that social support, all the emotional things that come with having a chronic disease, I’m sure that people with diabetes, not just me, do searches to find emotional support. I’ve definitely started subscribing to several blogs within the past year. I check them pretty often to read the updates. [P9]

In other cases, participants posted on social media with the intent of receiving responses from others:
Facebook or Instagram, I've posted if I've had a couple days where my blood sugar has been crazy low so I'll post a picture... and be like 'what the hell is going on with today' something like that. [P5]

2.2. Empowered

*Knowledge is power* [P17, P12]

Empowering information supports the person feeling in control of their care, that they have the information needed to make the correct decisions, “I know the more I feel informed, the better decisions I can make as far as what I am going to do” [P29].

A part of feeling empowered is the knowledge that e-patients have the warrant to take actions on their own, without first getting approval from a doctor or health professional:

And that was one of the first times that I first started to realize if I don't do something and wait for someone's permission that could have a pretty big adverse effect on my life or my health. So even since then I've had to make minor adjustments. My insulin dosage, or what I'm eating. And I think a lot of those decisions - if people feel they have to wait for permission from a doctor or something, and they can get themselves in trouble. [P19]

Participant P6 provides another view of empowering information, “knowing that someone has done it and made it through and lived to document the entire experience.”
2.3. Diet and exercise

Diet and exercise is an important concern for diabetics as choices in this area can have a major effect on the development of the disease. E-patients in our study frequently look for diet and exercise information on an persistent basis. For example, when eating out at a restaurant, information is often sought on a smartphone or mobile device, “if I’m out at a restaurant and I have no idea how to estimate the grams of carbohydrate in what’s in front of me... I type in whatever restaurant I’m in and nutritional information in Google-that almost always comes up” [P8]. When cooking at home, two concerns arise. First, a need to know the nutritional information of food being prepared, which can be found in some recipe websites or by searching for ingredients. Second, diabetics can get bored with limited diet choices and go online for find new ideas, “yea that’s pretty much constant, you get tired of the low carb options - you’ve got to find new ones for the next time you want to make dinner, ha!”[P5]. As our participant P26 points out, finding healthy and diabetic friendly recipes is important because he recognizes the positive and negative effects diet can have:

\[
I
definitely have looked online for healthy recipes. That’s one of the things that I pride myself on is my diet. I eat comparatively way more healthy than most. I eat a lot of vegetables I eat a lot of fruits that have so many nutrients in them. I pay attention to what I eat because I realize that not only things like alcohol or tobacco or drug consumption - food can also kill. [P26]
\]

Along with diet, exercise is important for diabetics, and is a topic for participants, “I think most of the stuff I’ve been looking up is about habits. Things like exercise and
still learning what exercise does for me” [P19]. Along with learning the positive side of exercise, diabetics must also be aware of potential complications:

I also really enjoy exercising and running a lot so, a lot of the male blogs will be about exercising. Like, a lot of really intense exercise people like marathoners or people who bike across country - they’ll be type 1 diabetics and they’ll blog about their experiences. So, read those too because when I exercise I go through a lot of the same issues that they have to handle with all of their intense training. [P9]

2.4. Insurance

Insurance companies play an important role in the provision of health care for e-patients. Occasionally, issues related to how insurance will pay for the care of diabetes needed attention by some participants, “the supplies that come with the pump are out of network for me, so I had to go through my insurance company to figure out what pharmacy does carry the Omnipod supplies and I used their website to do that” [P9]. Insurance information can be an important part of coordinating self-management activities.

2.5. Medical Information

We use the code medical information to describe instances where e-patients sought medical information about the causes and effects of the disease. Medical information can be used to investigate a present health concern, “I was passing ketones, so I wanted to make sure that I wasn't hurting myself” [P20], and can include questions about symptoms or complications e-patients may face, “what does
this mean for me, am I going to have a shorter lifespan, am I going to have trouble with joint problems or anything like that” [P2]. E-patients also use medical information found online to help make guide adjustments in their daily self-care practices, such as choosing an insulin injection site: “I started noticing I was getting more resistance and wear- at that time I was using my belly as my infusion site so what I started doing was looking to alternatives to a belly as an infusion site” [P22].

E-patients also use medical information to confirm information from health professionals:

that is one thing that the Internet was going about, was telling me what the diagnostic criteria for type one was. When I went into my doctor for the last time I said are you sure we should not check because I knew that just because I was over 18 did not mean I didn't have it. I'm still pretty young so asked and I got her full reasoning for why that's probably not it I think that was actually pretty concrete thing the Internet gave me as far as my health care. Just being able to evaluate her reasons, and say that's actually pretty solid. [P7]

2.5. Medications

This code refers to information about medications they have been prescribed.

Participants often reported medication in combination with their side effects, or investigating potential side effects, “the doctor may prescribe it but they won't spend the amount of time I can spend on Google finding all the side effects” [P15].

In the past I had been prescribed steroids that affected my blood sugar, it made my blood sugar spike and I’m a little skeptical whenever I get prescribed medication. Not that I think my doctoral forget that I have diabetes, but maybe they do not realize that that medication is going to affect my blood sugar so I take it into my own hands to research it and make sure. [P8]
3. Online Information Resources: Where and how do e-Patients find Information?

Online information resources provide e-patients with the content they need to self-manage their condition. We divided this coding into two thematic categories, information sources and information activities. Information sources are the locations visited online where informative content is found, while online information access encompasses the ways e-patients access these resources.

3.1. Information Sources

These codes pertain to the sources where information was found (Table 14). In this work we differentiate between social media and authority resources. Social media consists of resources that contain primarily peer-produced content, while authority resources contain information produced by people or organizations recognized as medical authorities. On social media sites, participants sometimes found information useful for their self-management within stories shared by other e-patients.
Table 14. Online information sources

<table>
<thead>
<tr>
<th>3.1.1. Authority Website</th>
<th>Accessing resources from an organization perceived to have medical authority. “Their website [JDRF] is really great”</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1.2. Social Media</td>
<td>Accessing peer-produced health-related content, including forums, blogs, Facebook and YouTube. “I get a lot from the blogs. With people that are having similar issues with their insulin pump sites, and their trial and error- I can learn from that.”</td>
</tr>
<tr>
<td>3.1.2.1. Patient Stories</td>
<td>A child of social media, reading or viewing another e-patient’s experience with a condition or situation, similar to the participant’s. “It’s basically reading someone else’s experience living life with diabetes. Facing the same challenges that I face every single day.”</td>
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3.1.1. Authority sites

Authority websites are those provided by organizations expected to have content maintained by medical professionals, like the Mayo Clinic or WebMD.

*Obviously when you're a reputable establishment like Mayo Clinic or even WebMD you have a reasonable amount of assurance that the people publishing information are, you know they got the information from doctors and reputable studies.* [P30]

We also include here vendor websites, like Medtronic, a company that produces and sells insulin pumps. These sites are often reported to be useful for finding biomedical information, but are sometimes viewed with caution because of advertising or other financial concerns that may bias the information found there.

*I like to read the official information from the manufacturer... you know they are only going to show you the best parts they're not going to show you the bad parts. But I, I don't know I guess I like to get a sense of what the manufacturer is saying and see it from their perspective.* [P1]
3.1.2. Social Media

Participant P30 who works in the information technology field described his use of authority and social media sites:

*I use them all equally but I use the information differently. Obviously when you’re a reputable establishment like Mayo Clinic or even WebMD you have a reasonable amount of assurance that the people publishing information are, you know they got the information from doctors and reputable studies.

You know the forums obviously can be anyone so you have to increase your censor so to speak because people go on and really have no idea what they’re doing obviously. Then there is consensus where you have 20 or 30 people discussing things that seem to be having an effect well that probably increases the credibility of that.* [P30]

Social media sites are OHRs consisting of information created by fellow e-patients.

Often the creator of the information is unknown to the reader, or may be identifiable only by a username. Social media sites reported by participants include YouTube, Facebook, and Twitter, along with blogs and diabetes specific forums like tudiabetes.com:

*When I checked read it, it seems like on the diabetes forum, that everybody there seems to have diabetes so it's really easy to figure out who knows what they're talking about and who doesn't in general by the questions that they ask or the response that they've given.* [P22]

*And I’ll tell you, some of these - I mean a lot of them are on YouTube - these guys shooting video of how they put it on so it’s like it’s really amazing just to see what like everybody’s - you kind of think you’re unique, but you’re really not.* [P17]
3.1.2.1. Patient Stories

Accessing information written by other e-patients was reported to be a common and important behavior. Patient stories can provide a reader with medical information, affective support, and can be empowering and are shared on social media sites.

Stories can have a positive effect:

> It’s basically reading someone else’s experience living life with diabetes. Facing the same challenges that I face every single day. Have a deal with it, how they dealt with it what works, how it makes them feel... And that information is just as important as the scientific perception. [P8]

From the reader’s perspective provided by participants, e-patients look for stories where they share personal characteristics with the author (for example, type of diabetes, gender, or age). “This is going to sound mean, I really don’t like type 2’s, ha!” [P6]

3.2. Online Information Access

Codes here concern activities reported by participants while finding and using online information (Table 15). Apps and Mobile devices are often used for checking nutritional information away from home. Monitoring may include information resources like blogs or forums with content that is updated on a regular basis. Finally use of search engines a ubiquitous participant action.
### 3.2.1. Apps and Mobile

Using mobile apps, or a mobile web browser to access information.

“I even have an app for my phone for when I'm out I can search foods and get automatic numbers for that. That's immensely helpful.”

### 3.2.2. Monitoring

Periodically visiting a source where new information may be found.

“I've definitely started subscribing to several blogs within the past year. I check them pretty often to read the updates.”

### 3.2.2. Search Engine

Using search engines like Google or Bing, or onsite searches (for example, searching WebMD).

“So I just looked it up online. Just Googled it.”

---

#### 3.2.1. Apps and mobile

Mobile devices, like a smartphone, and mobile apps were reported to be used for two primary purposes. First, to look up nutritional information for purposes such as carb counting or checking on ingredients when eating in a restaurant:

*Whenever I’m at work and having lunch or something, I can just go to calorie counter-or calorie King, or whatever and instantly find all of these different foods. I can even find exactly the grams the exact amount of ingredients in it. It’s amazing* [P2].

Second, mobile apps were used to track diet and exercise information; “*I've used an iPhone app to track my blood sugar all day and to track what I'm eating, and to track my exercise*” [P19].
3.2.2. Monitoring

Some participants regularly revisited OHRs with the hopes of finding new diabetes-related materials. Medical authority and social media sites were reported to be monitored and periodically revisited, “so as I see different leads on things I kind of tuck them away and bookmark them and look at them every once in a while.” [P23]

3.2.3. Search Engine

Search is a ubiquitous part of the e-patient experience. Our participants report using a search engine, like Google or Bing, to be a major part of their online experience, “Google. That’s pretty much my main way of looking up stuff, I Google everything” [P29]. However, search is not seen as a destination, rather as a path to reach the information desired, “I use Google to get to all of those places, that’s the biggest navigator that I use” [P23]. Search is also seen as a starting point for research, as a tool to discover new resources, “a lot of times I’ll just start with a Google question will put it to Google, you know. That’s typically how I do it” [P12].

4. Evaluation: How do e-patients assess resources?

E-patients evaluate information resources they use in their self-management by assessing the source (for example, the author of a blog post), and examining the content (Table 16). Evaluation occurs on both authority and social media resources. For example, our participant P6 shared the method she used to evaluate her Facebook friend as a source of diabetes information:
The reason I go to her is she has had diabetes longer than I have, I know she is in really good control with her own management, and she is the one friend who is always posting about new research for sharing the new technology. She always has the newest pump or the newest glucose monitor. So I feel like she is a good source, she is on top of her stuff.

In addition to systematically evaluating the content and heuristically evaluating the source, e-patients will sometimes “triangulate” resources, checking and verifying the information they find:

Just last week I was put on an antibiotic and it was not one I had taken in my patient history so I wasn’t sure if it would affect my blood sugar in anyway. So I Googled it and it turns out that it has no effect. From looking - I used a couple of different sources. Not every site gave me the same information so I made sure I was reading the same thing across several sites [P8].

<table>
<thead>
<tr>
<th>Table 16. OHRs evaluation</th>
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</table>
| **4.1. Source evaluation** | Evaluating the source of information based on heuristic cues  
“Well, it’s commercial, and so I’m not sure if the information given is based on medicine that is proven, research based medicine.” |
| **4.2. Using Own Expertise** | Comparing information to previously held knowledge.  
“I take the knowledge that I already have... my best guess, and if what I am reading kind of lines up with that then I know it’s pretty spot on.” |

4.1. Source Evaluation

Information from online sources, both medical authorities and social media is evaluated by e-patients before it is used. Websites like WebMD that have advertising, and technology vendors are scrutinized for potential conflicts of
interest. The content and tone of websites is also a factor. For example, WebMD in particular is singled out for its sometimes drastic suggestions, “WebMD assumes you have cancer no matter what your problem is, ha!” [P10]. Information from social media is evaluated on source levels (is the person someone like me?), characteristics of the post (are there misspellings?), and personal relevance (is this material relevant to my situation?). In many cases participants utilized several sources of information in order to strengthen their confidence in a position.

Participants used heuristic cues to evaluate the source, or carrier, of information they find online. Advertising, sponsorship, and overall design and tone of authority websites were considered, “I figure if they haven’t managed to put up a good website they don’t care about their product” [P27]. Authority websites are sometimes under particular scrutiny, as shown by comments like “I know you have to follow the money trail” [P13]. Participants realize there is a financial incentive for companies to promote their products and are cautious to accept claims without verification. Social media sources were evaluated primarily on the tone of the other e-patient’s postings, and the similarity in context and situation, “we share the same pump, she’s the same age range - the similarities, whatever I’m going through she’s probably dealt with it as well” [P6].

4.2. Using Own Expertise

E-patients realize that “there’s a lot of crap on the Internet” [P19] and also use their own expertise and experience to evaluate the content of OHRs they visit. Learning
how to “separate the wheat from the chaff” [P22] is a skill that develops over time, “you have to learn how to read it, not to overreact because there are so many causes for things” [P20]. Participants used experience and knowledge they acquired to evaluate resources. Part of this experience entails understanding how their body reacts to certain actions or situations they may read about online. Making personal health decisions based entails some risk, and e-patients in our study balance that risk against the potential rewards within the context of their own.

4.4 Summary of Interview Data

Participants in our study endeavor to achieve and remain in good control. They are active and involved in their care, taking charge of many medical decisions. When first diagnosed, there is a burst of intense information seeking and Web use. As the e-patient gains experience with their disease, and begins to understand their individual experiences with the disease, information behaviors start to be tailored to their unique situations. Over time, a collection of resources and procedures to find and evaluate information become a part of the e-patient’s self-management practices. For example, some e-patients may find that forums like tudiabetes.com work well for their needs, while others may prefer sites like MayoClinic.com to address their concerns. Needs and sources are context dependent – an e-patient seeking affective support is likely to find what they need in a social media source, while basic medical information may be found more readily on medical authority sites.
4.5 Offline Information Sources

While we focus on information sources found online, during interviews participants also reported using offline resources as well. Friends and family members are information sources, particularly for those with people close to them who have diabetes. However, the personal nature of the disease may limit the effectiveness of advice from people dissimilar to the e-patient. For example, a participant reported that while he knows other diabetics quite well, their differences can mean that often advice or best practices may not carry through from one generation to the next, “my girlfriend's father's type one diabetic, my best friend's father's type one diabetic. I have those two people-two people I'm very close with, but they are 50, 55 years old, 60 years old” [P19]. Books and magazines remain sources for some, especially those who were diagnosed prior to the popular adoption of the Internet in the 1990’s. Diabetes camps for children were reported to be a part of several participants’ experiences for those diagnosed in their youth. Diabetes education classes, which teach self-management practices, are offered by health organizations. These classes generally occur over the course of several sessions and are usually taken near the time of diagnosis. We recognize these all of these and more are potentially important information sources that are not addressed in our investigation of online health behaviors.

4.6 Data Validity

In this section we describe two methods used to validate our data; intercoder reliability and member checking. Both methods are commonly used in qualitative
research to validate codings and the investigator’s interpretation of the data (Marshall & Rossman, 2011).

4.6.1 Intercoder Reliability

“Intercoder reliability is the widely used term for the extent to which independent coders evaluate a characteristic of a message or artifact and reach the same conclusion” (Lombard, Snyder-Duch, & Bracken, 2004, p. np). An additional coder (an advanced Ph.D. candidate) was used to assess the reliability of the coding developed by the researcher. Following previous researcher’s methods (Burla et al., 2008; Carey, Morgan, & Oxtoby, 1996; Lombard et al., 2004) an intercoder procedure was developed for the present work (Figure 10). Intercoder reliability was checked late in the study after the primary themes and codes were well developed. Codes that “address substantive issues related to the research question” (Burla et al., 2008, p. 115) were used in this process.

Two rounds of coding were conducted, with a period of conversation and negotiation in the interim (Lombard et al., 2004). Prior to the coding, the study and codes were explained to the additional coder. The coder was given a codebook and printed worksheet with random sample of 30 coded passages selected from the data. The coder was instructed to apply one code per passage (Burla et al., 2008), and to note passages where they had questions. After comparing coding in the first round and calculating agreement, the researcher and coder discussed areas of disagreement. In the second round, a random sample of 49 codes was selected from
the data. Again the coder independently coded the data and the results were compared. Areas of disagreement were discussed and while no serious matters arose, the coder offered suggestions to improve the code definitions.

Cohen’s Kappa was used to determine intercoder reliability. After round one, Cohen’s K was .778. After round 2 this improved to .886 indicating a high level of agreement. Both round one and round two levels are sufficient to support agreement between the coders, suggesting that coding of the data is reliable (Tables 17, 18).

Figure 11. Intercoder process used in the study
### Table 17. Round 1 - Cohen’s Kappa

**Symmetric Measures**

<table>
<thead>
<tr>
<th>Measure of Agreement</th>
<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kappa</td>
<td>.778</td>
<td>.081</td>
<td>13.311</td>
<td>.000</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>30</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

### Table 18. Round 2 - Cohen’s Kappa

**Symmetric Measures**

<table>
<thead>
<tr>
<th>Measure of Agreement</th>
<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kappa</td>
<td>.886</td>
<td>.048</td>
<td>18.584</td>
<td>.000</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

### Table 19. Codes used for intercoder reliability

<table>
<thead>
<tr>
<th>Code</th>
<th>Code</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective</td>
<td>Apps</td>
<td>Authority Websites</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>Diagnosis</td>
<td>Diet and Exercise</td>
</tr>
<tr>
<td>Doctor Interaction</td>
<td>Empowered</td>
<td>Insurance</td>
</tr>
<tr>
<td>Self-Expertise</td>
<td>Other Patient Experience</td>
<td>Search</td>
</tr>
<tr>
<td>Social Media</td>
<td>Source Evaluation</td>
<td>Symptom Checking</td>
</tr>
</tbody>
</table>
4.6.2 Member Check

The results of qualitative research using a grounded theory approach can be “validated by comparing it to raw data or by presenting it to respondents for their reactions…. [It] should be recognizable to participants and the larger concepts should apply to each case even if some of the details specific to their case are missing or don’t seem to fit” (Corbin & Strauss, 2008, p. 115). Following the analysis phase an email (Appendix E) was sent to six participants who volunteered their time for a follow up, asking them to read a short summary and comment on the findings. Three participants responded, submitting their comments via return email and a follow up (approximately 10 – 15 minute) phone call. The participants were given a summary of the study, including an explanation of the three stages (at the time labeled Diagnosis, Intermediate, and Advanced) in the model. All respondents agreed the model represented their experiences with only minor wording changes suggested. These responses suggest the researcher has successfully interpreted the data so that it matches the real world information behaviors of participants.

“I found your summary to be straightforward and accurate.” [P1]

While confirming the transition between the Forming Ability and Established Ability phases in our model, our participant P22 stated its nature, from a lack of control to a state where “diabetes doesn’t manage you, you manage diabetes.” Further, P22 shared that although he could not state definitively how or when the transition
happened, “I don’t know how it happened, it just happened” – he agreed that there are “definitely” [P22] three unique stages. Similarly, P1 confirmed the definition of the three stages, stating, “I definitely agree with that.”
5 Chapter 5: Conceptual Model and Discussion

The most intensive period of online research was at the very beginning and then it’s been more around specific questions. [P13]

In this section we introduce and discuss the model of information behavior in the chronic disease trajectory. We then describe the emergence of the model from the data. Finally we discuss our contribution to research in the health and information sciences.

Over many years of experience with a chronic disease, e-patients learn and gain expertise and ability self-managing their condition. In terms of using OHRs, this increased ability has several components. First, e-patients build a store of basic knowledge, which results in reduced need to access general or basic information as time goes on. Second, e-patients gain procedural abilities, developing an informal collection of OHRs that are useful in their self-management. Finally, as e-patients cope with their unique circumstances they actively seek information that is relevant to their personal situation. All of this activity takes place within the community, health system, and self-management support described by the CCM (Bodenheimer, Wagner, et al., 2002; Bodenheimer T, 2002; Wagner, 1998; Wagner et al., 2001). Our model contributes an understanding of the place of OHRs in the chronic disease trajectory. The “trajectory” of a chronic illness has been described as:

the illness/chronic condition course requires the combined efforts of the affected individual, family, and health care practitioners in order to shape it. That is, to determine its eventual outcome, manage any symptoms, and
handle associated disability. Trajectories are often uncertain. They can be graphed, but only in retrospect. For although each illness has a potential course, its details cannot be fully determined ahead of time. Much depends upon the individual, the action taken to shape that course, and the turn of events that occur. (Corbin & Strauss, 1991, p. 162)

5.1 Conceptual Model

Our model represents e-patients’ online information behaviors in the chronic disease trajectory (Table 20). The stages in this model are cumulative. For example, e-patients do not stop visiting OHRs from medical authorities as they advance. Rather, due to increased understanding of basic concepts in the disease their information needs develop towards information they can use in their own personal experiences with the condition. Over time, e-patients gain expertise and ability in self-managing their condition that influences an evolving use of OHRs.

Based on participant reports, the progression of e-patients’ online information behaviors in the chronic disease trajectory was organized into three stages:

1. **Diagnosis with the Disease**: Behaviors close to the time of diagnosis where the e-patient has many basic information needs related to the disease, the trajectory onset phase of diabetes.

2. **Forming Ability**: After the e-patient leaves the trajectory onset phase and is actively self-managing their diabetes. OHRs are used to help form and guide self-management as the patient experiments with practices, with the goal of reaching and maintaining stability.

3. **Established Ability**: When the e-patient has had substantial experience self-managing their diabetes through the trajectory, which may include the periods of stability and instability. The e-patient has learned techniques and practices that result in effective self-management for their personal condition.
Table 20. Stages of the conceptual model. For each stage we provide detailed characterizations and detailed information about the kinds of behaviors that occurred. Stages are cumulative and build towards highly advanced abilities in the use of online information resources. Information Needs: bullet points the types of information sought by the e-patient in each stage
Actions: bullet points indicate the primary actions take to find information in each stage
Resources: bullet points indicate the online resources used in each stage
Evaluation: bullet points indicate the primary ways e-patients evaluate information in each stage

<table>
<thead>
<tr>
<th>Information Needs</th>
<th>Stage 1: Diagnosis with the Disease</th>
<th>Stage 2: Forming of Ability</th>
<th>Stage 3: Established Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fact-based</td>
<td>Medical information</td>
<td>Empowering</td>
<td>What's New</td>
</tr>
<tr>
<td>- Diet and exercise</td>
<td>- How life will be affected</td>
<td>- Symptom checking</td>
<td>- Personalized medical</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Insurance</td>
<td>information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Medications</td>
<td>- New treatments</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Affective support</td>
<td>- Future plans</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Actions</th>
<th>Stage 1: Diagnosis with the Disease</th>
<th>Stage 2: Forming of Ability</th>
<th>Stage 3: Established Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding</td>
<td></td>
<td>Interpreting</td>
<td>Discovering</td>
</tr>
<tr>
<td>- Exploratory Search</td>
<td></td>
<td>- Event search</td>
<td>- Discovery search</td>
</tr>
<tr>
<td>- Understanding the impact of the disease on life</td>
<td></td>
<td>- Responding to events</td>
<td>- Monitoring</td>
</tr>
<tr>
<td>- Understanding the cause</td>
<td></td>
<td>- Interacting with doctors and clinicians</td>
<td>- Using procedural knowledge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Reading other patient experiences</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Resources</th>
<th>Stage 1: Diagnosis with the Disease</th>
<th>Stage 2: Forming of Ability</th>
<th>Stage 3: Established Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trusted resources</td>
<td></td>
<td>Expanded resources</td>
<td>Familiar resources</td>
</tr>
<tr>
<td>- Medical authority sites</td>
<td></td>
<td>- Health-related social media</td>
<td>- Utilize a collection of recognized resources</td>
</tr>
<tr>
<td>- Search</td>
<td></td>
<td>- Mobile Apps</td>
<td></td>
</tr>
<tr>
<td>- Known social media</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Stage 1: Diagnosis with the Disease</th>
<th>Stage 2: Forming of Ability</th>
<th>Stage 3: Established Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heuristic Knowledge</td>
<td></td>
<td>Domain knowledge</td>
<td>Personal knowledge</td>
</tr>
<tr>
<td>- Source evaluation</td>
<td></td>
<td>- Using expertise</td>
<td>- Comparison to own unique situation</td>
</tr>
</tbody>
</table>

The e-patients interviewed in this work spend much of their lives in a stable condition. Accessing online information is reported for responding to events and circumstances that arise in the course of the disease, and for addressing persistent needs. Examples of events include situations such as investigating potential side
effects of a new drug or finding user reviews of diabetes treatment technologies.

Persistent needs are those that occur frequently in the course of self-management and include diet information and affective support. E-patients access websites from medical authorities and social media, which are evaluated for usefulness in the current situation and trustworthiness.

### Table 21. Overview of e-patient experiences in the three stages of our conceptual model.

<table>
<thead>
<tr>
<th></th>
<th>Stage 1: Diagnosis with the Disease</th>
<th>Stage 2: Forming of Ability</th>
<th>Stage 3: Established Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What information is wanted</strong></td>
<td>Basic information about the disease diabetes, what it is, and how lifestyle/health status may change.</td>
<td>As e-patients begin learning about their unique experience with the condition, they access material relevant to their personal situation.</td>
<td>Information that is personally relevant and helps maintain a healthy and enjoyable lifestyle.</td>
</tr>
<tr>
<td><strong>What information resources are utilized</strong></td>
<td>E-patients primarily want information from trustworthy websites, often those with information from medical experts.</td>
<td>E-patients look towards information from other patients with similar conditions and circumstances. Social media sources rise in use.</td>
<td>E-patients use both authorities and “patients like me” – often drawing from a collection of resources known to them.</td>
</tr>
<tr>
<td><strong>How information is evaluated</strong></td>
<td>E-patients look towards heuristic cues to find trustworthy information sources.</td>
<td>E-patients begin using their knowledge of diabetes to judge information.</td>
<td>E-patients compare information found online to their personal situation or experiences.</td>
</tr>
<tr>
<td><strong>Why information is wanted</strong></td>
<td>E-patients want to learn about their condition, how it will affect their lives, and what they should do to begin living with changed circumstances</td>
<td>In order to respond to events and find affective support, while interpreting responses to changes in the condition.</td>
<td>In order to maintain a high quality of life and plan for the future.</td>
</tr>
</tbody>
</table>
5.2 Development of the Model

The experiences of e-patients in our study are characterized in three stages, Diagnosis with the Disease, Forming of Ability, and Established Ability. In this section we present and discuss data that informed the building of our model. Table 21 summarizes the three stages of our model, and in the following section we explore the development of our model using examples from our data.

5.3 Stage 1: Diagnosis with the Disease

5.3.1 Fact-Based Information

The diagnosis stage of our model includes the time after diagnosis, as the e-patient comes to terms with their condition, and researches the disease and changes in their lives. In addition, our model includes the pre-trajectory phase for e-patients who research diabetes in the time shortly before diagnosis by a doctor. The time around diagnosis is challenging as the causes and effects of diabetes begin to be understood. OHRs play an important role in the helping e-patients learn about the medical components of their disease.

*If I could get out of it somewhat... that was something I wanted to know. If, you know, if I work out hard enough, if I lost enough weight, changed my diet quickly, could I get over this disease, quickly... And so far I haven’t found a really good answer for that yet. Except that it does look like that I could at least help my diabetes a lot more. [P4]*

Information retention among participants was reported to be difficult at diagnosis, making later online searching an important component of coming to terms with the
condition, “when I was diagnosed I didn't know what kind of doctors, how long I would have to be in treatment” [P14]. E-patients turned to the Web to start researching and learning about their condition, often utilizing resources from recognized medical authorities, “so I looked into it and the first thing that popped up was ADA American diabetes Association” [P29]. OHRs, particularly search engines and results from large medical sites like WebMD and Mayo Clinic were reported a primary source of basic medical information shortly after participants were diagnosed.

Websites from authorities were important sources for our participants near diagnosis, “I started looking into just random things about diabetes to see if there’s anything new or anything different that I could learn that I haven’t been told by my doctor. Everything was like ADA, WebMD” [P29]. However, an unexpected finding is that some participants who were very experienced social media users when diagnosed made use of these known-to-them resources as a natural part of their beginning self-management practices,

*I'm pretty obviously biased towards the social media...I grew up with the Internet, and I'm pretty versatile taking things with a grain of salt. So I can weed out kind of the good information from the bad... So that works for me. But if it happened to my dad I would probably recommend sticking with the authorities.* [P7]

A key component of the diagnosis stage is the e-patient investigates the medical aspects of diabetes, and how to begin self-managing the condition. Over the
following stages self-management practices are refined as the e-patient gains experience. During diagnosis, the e-patient desires to learn about the disease, discover OHRs that are helpful, and begin to form behaviors that will support their needs down the road. Learning about the disease, their personal context, and the resources available to assist in self-management lead the e-patient into the next stage of our model.

Certainly at the beginning it was mostly about basically trying to understand what it was, what kind of lifestyle one would have to have in order to manage it, what kind of diet and those sorts of things.

Definitely within the first 3 months I did a lot of searching just to find out who were reputable sources and see if there were differences in what the reputable sources were saying. [P13]

Diagnosis Experience
Participants in our study had vastly different experiences at the time they were diagnosed. Among participants who reported using online information at diagnosis three distinct groups emerged. 2 The first group was surprised by their diagnosis, not suspecting they had the disease. This finding follows that of previous researchers (Paterson & Thorne, 2000), that many diabetics are shocked and “reeling” at diagnosis. The next group experienced symptoms prior to diagnosis and through online research suspected they may have diabetes. Finally some participants had a family history of the disease and felt it was only a matter of time before they were diagnosed. Participants who did not have Internet access when they were diagnosed were either diagnosed prior to broad availability of the Internet, or diagnosed as young children.

2 Participants who did not have Internet access when they were diagnosed were either diagnosed prior to broad availability of the Internet, or diagnosed as young children.
diagnosed. Despite these three unique experiences, all participants in these three groups felt OHRs were important as they began self-managing their own disease.

**Diagnosis Experience 1: Unsuspected**

_I went to a walk in clinic because I wasn't feeling well and they sent me to the emergency room of the hospital. So I went in there and they're like 'you're diabetic it's probably type 1, and you're going to give yourself injections with a needle for a while, and we'll set up another appointment'. So it was just really weird for me and I had no idea about the disease._ [P2]

The participants who reported diagnosis with diabetes as a surprising or shocking event had no prior experience with the disease and were initially unprepared for the demands of self-management. These participants felt the experience was overwhelming, and retained little information given to them at the time they were diagnosed. OHRs were used to fill in the blanks and start to gain an understanding of the disease after the initial shock wore off.

**Diagnosis Experience 2: Suspecting**

Participants who reported experiencing symptoms often researched them online, prior to meeting a doctor, were better prepared to accept the diagnosis than those with no suspicions:

_I was in college at the time and having symptoms... after a few months I came to the realization that something might be going on here. And I think I set up an appointment to go in and have my blood work done. But in the meantime I looked it up on WebMD and found that those were the symptoms and kind of in my mind realize that's probably what I have, a couple of weeks before actually finding out it kind of helps me realize, get a grasp I guess, and kind of_
helps me react when I did find out the actual diagnosis I wasn’t so blown away by it. [P16]

Despite the thought that they may have diabetes, this group nonetheless also had little knowledge about self-management and struggled absorbing new knowledge:

So they gave me information but it was a lot to handle at first. I don’t know how much of it I took him. I actually felt after I left the hospital that I still didn’t know what was going on. And I don’t know if that’s normal or what. But I think that I was still limited in my knowledge at that point. [P19]

**Group Experience 3: Expecting**

Some participants, particularly those who had a family history with diabetes, felt a strong likelihood they would eventually diabetic and therefore were not surprised when they were diagnosed:

I knew, I had a good feeling that I would be diagnosed with it because it runs in my family, so I was like - But I kind of like knew how to manage it before I had it because I was so used to being around it and watching it. [P21]

However, even with prior experience, substantial effort was needed to find self-management practices that worked for their unique circumstance. The personal nature of the disease means each person’s experience is unique. Even participant P21, who grew up “surrounded by it” started his experience with diabetes needing to learn about the effects in his personal circumstances, “I tried to apply my knowledge... but that didn’t work.” While P21 at diagnosis knew what diabetes was
and general information about the disease, he did not know how self-management would work in the context of his own care.

5.3.2 Adjusting to the Impact of the Disease

E-patients who are newly diagnosed often seek information about the impact of diabetes on their lives. For example, participant P2 first learned basic medical information, “at first I was really looking for medical information, what does this mean for me” and next tried to make sense of her condition “I was finding sort of different conflicting things... and I didn't know how to actually implement it in my life”. P2 wanted to know straightforward facts, like complications and lifespan, in order to understand the impact diabetes may have on her life:

*When I first got diagnosed and I was looking, I was looking at expected lifespan and expected complications, and that sort of thing. I looked on all sorts of different websites and it kind of freaked me out, I was like oh I'm going to lose all of my limbs and die when I'm 35, and everything like that. And then it might've been a link from the Mayo Clinic or American Diabetes Association, something like that I think it was just saying that a lot of the studies were conducted back 20 or 30 years ago and talked about all of the different changes that diabetes care I'm going through in the past 30 or 40 years. And just saying that the advances in care that we've got going from injections once a week or once a day, and now there is so much better monitoring, that really helps... That was a huge relief for me to read that actual kind of medical information about the possible detriments to my health with having diabetes. [P2]*

5.4 Stage 2: Forming Ability

This stage was described as, “living with diabetes” [P24]. Unlike Diagnosis with the Disease, there is no single event that marks a person’s move into the forming phase.
Rather the forming stage is an accumulation of knowledge and experience that marks the person’s switch, as our participant P24 relates, from being diagnosed with diabetes to learning the abilities needed to use OHRs as part gaining control and living a full and an healthy life with the disease:

*Because at that point I think my mind switched from being diagnosed with diabetes to living with diabetes. And that was like a totally different focus. Because then it wasn’t about damage control and like, the quick fix. It was about...God willing I’ll be alive for like another forty or fifty years what am I going to do to address this on a daily basis? [P24]*

### 5.4.1 Empowered E-patients

Participants in the forming stage of our model begin feeling empowered to make changes in their treatments and lifestyles. Part of the helpfulness of OHRs is that the information they find empowers them to make decisions, or feel more in control of their care. For example, our participant P24 reported that he “panicked” when he was diagnosed. Over time, P24 became an active e-patient and began using online resources. Part of this process was learning which OHRs to utilize, and which to reject, “*I’ve really had to learn to filter which sites are reputable*”. The empowered P24 put the information he found online to use when he had a medical condition, which caused a change in his blood sugar levels:

*Last summer I had an emergency appendectomy. Was in hospital for a few days and so my blood sugar was really high because of the surgery. I wasn’t really stressed about it. They were giving insulin in the hospital because it was high. But because I had already done the research I already knew that surgery concentrated blood sugar up very high so it wasn’t a concern. Things that would have maybe frightened me... that information I feel like I’ve*
already digested... That was just something that I had already read my searches on these websites. That was information I already absorbed.

Compare the newly diagnosed P24, who panicked, to the e-patient armed with the ability to find online information. After researching and learning about how surgery may affect blood sugar, P24 knew to not be concerned that his numbers changed. Experience with the disease, and information gathered online, let P24 to remain calm in the face of abnormal blood sugar readings.

5.4.2 Interpreting

E-patients in the Forming Ability stage possess basic knowledge about diabetes (gained in the Diagnosis stage) and now begin using OHRs for additional purposes, including support for self-directed changes in treatment (like modifying blood testing schedules). This period includes trial and error as the e-patient tries to find routines that are effective. OHRs are used to both guide these routines and to interpret the results of changes. As the e-patient learns to live with diabetes, they will form their own online information behaviors distinct from others’. Each e-patient has a unique context of self-management and online information use due to their health status and desire to investigate the disease. For example, different types of OHRs may be used:

I think Webmd is good for like little things - like oh I have this weird rash or something like that - but for serious things - I don’t know if I will get WebMD for diabetes stuff, or for symptoms these days. [P16]
OHRs help guide and interpret the results of self-management decisions. Because e-patients in the Forming Ability stage have learned basic information about their condition, they now respond to incidents or events that cause a need for information, and look for persistent needs like diet and exercise, and affective support. Events become a primary trigger for e-patients to seek out information online in the intermediate stage. In the example below, P13 is looking for information about a reoccurring health concern and how she can adjust her diet to manage blood sugar levels:

*Right now the main issue is that I am getting very, very frequent low blood sugar so that is what I am trying to learn about – I often search for what to do about hypoglycemia. At first I didn’t know what foods to eat to help get the blood sugar back up but without making it go too high.* [P13]

**Event Search and Responding to Events**
E-patient online information behavior through the chronic disease trajectory consists of peaks and valleys, periods of intense information seeking and periods where little active information seeking occurs. Because events may require knowledge that an e-patient might not already possess, even e-patients with established abilities can find themselves lacking information needed to guide health decisions. Following the conclusions of Kralik, Koch, Price, and Howard (2004) our results suggest that OHRs serve an important role when responding to an event or crisis, OHRs serve a substantial role.
Unique to the health domain that is the patient’s body serves as an important information source. E-patients receive information in the form of results from blood testing and other procedures, and feelings from their body indicating the current state of health. Interpretations of these signals may provide feedback on the effectiveness of self-management practices, and may act as an event, leading the e-patient to go online to look for health information, “my blood sugars are always seem to be fluctuating so just trying to get some recipes or ideas” [P1]. This “body listening” has been described as a “central and critical source of information” (Price, 1993, p. 45) that must be learned over time. Particularly for e-patients early in their self-management, there may be a “gap” between their state of knowledge and what knowledge of what, if anything, they should do. OHRs help fill this gap in knowledge by providing access to resources that can be used to interpret messages from body listening.

Other Patient Experiences
Participants find both medical information and affective support in stories shared by other e-patients. This leads to looking for anecdotes or stories about successful plans and practices that others have implemented in their self-management. Participant P2, who transitioned from knowing nothing about diabetes when diagnosed to the intermediate forming stage, reported relying more on social media as time went by, “when I go looking for information I'm looking for anecdotes, I'm looking for blog posts that resonate with me. I'm going to be looking more for people who-I guess I'm going to be looking for people more with a lifestyle like mine” [P2].
These anecdotes from others provide the biomedical information and affective support that was reported to be very important.

P2’s experience moving from diagnosis to forming helps illustrate the desire and need to find others with similar circumstances, and the critical role OHRs can play in the process. Because she was diagnosed later in life with Type I, while most Type I diagnosis occur when the e-patient is a child, P2 at first felt isolated. There were few areas where she could turn to for support, as much of what she could find was targeted towards those who were diagnosed early in life. Using OHRs, P2 was able to find stories and posts that help:

And it’s made me feel a lot less alone in my reality of life. I don’t know anybody with diabetes and I would’ve felt really alone and a lot of the, even on the Internet a lot of the stuff out there is geared at juveniles like actual children with diabetes, or once you’re dealing with adults with type one you’re dealing with people who had a long time. Or you’re dealing with type two, and none of those categories apply to me. So to be able to have resources like the Internet where so many people can be a part of it, you’re eventually going to find somebody who rings true to you and you can share experiences.

5.5 Stage 3: Established Ability

Diabetes doesn’t manage you, you manage diabetes [P22]

In this advanced stage, e-patients have substantial experience with the disease and have established self-management practices and online information behaviors that address their unique wants and needs. Like the move from diagnosis to forming
ability, there is no single event that signifies a change. Rather, it is a change to where the e-patient has command of their situation, likely having successfully faced several health challenges in the past. E-patients in this stage give importance to looking for information related to their unique circumstances. They have come to terms with their condition and use OHRs to maintain a stable condition and healthy lifestyle.

As P10, who has managed diabetes for 22 years, succinctly describes her level of experience, “yeah, I've been around.” E-patients in this stage bring to bear their domain knowledge and experience with OHRs, “being diabetic for 30 years, there are certain things that I know” [P15]. An information behavior in this stage is to find and use resources that provide personally relevant information as opposed to general medical information; “you got to just kind of relate it to yourself and your situation” [P16]. Finding information online to use in self-management is a “research” process that includes comparing others’ experiences to their own situation.

Part of research information that you find from laymen online, you got to research that their experience is not necessarily going to be the same as mine. While our needs might be very similar our needs aren’t going to be exactly the same. [P22]

Much of the personally relevant material can be found on social media websites, where e-patients can find others with similar circumstances and experiences. For example, our Participant P17 needed a new insulin pump, and had lifestyle requirements based on his previous experiences: “what was difficult was... that the
tubing would all get caught up on stuff but now the pump I’m on currently I did a lot of research online.” Representatives of an insulin pump vendor introduced Jim to the pump he currently uses. However, Jim was already very knowledgeable about pump operation, having used one in the past for many years, and was most interested in how the pump works with his lifestyle. Therefore, Jim ignored the vendor’s website and instead turned to YouTube and viewed videos of others:

*These guys shooting video of how they put it on so it’s like it’s really amazing just to see what like everybody’s – you kind of think you’re unique, but you’re really not, like it’s – people are having just as many problems as you and how they deal with it sometimes it really helps because there are items you would have never thought of. Like oh my God, I’ll do that, you know, that makes sense.* [P17]

Similarly, Participant P15 looked on YouTube to find information. His experience with a technology vendor included a situation where he researched the vendor online and discovered they were less than truthful in its dealing with the public. This led David to consider them “dead to me.” He then turned to social media to find information from what he considered a less biased source:

*I spent a lot of time searching on people’s experiences with which brands they prefer and then how people actually use it instead of what the manufacturer says is the recommended approach. There were some YouTube videos about applying the sensor that were incredibly helpful.* [P15]

Use of social media sources can be risky, as there is no quality control on the information posted. However, the experiences and knowledge of an e-patient in the
established stage helps them “separate the wheat from the chaff” [Brent]. Over time, however, e-patients develop their own strategies for evaluation of resources:

> Even the vendors sometimes don't present things objectively. So everybody's got a bias. You've just got to figure out what the bias is. They could be totally biased and also say something that is true, so you know. That's a real challenge. [15]

### 5.5.1 Examples of OHR Use

Participant reports of interactions with doctors provide detailed insight into e-patient use of OHRs and their diabetes knowledge in the Established Ability stage. Here, we present two scenarios where e-patients use OHRs to double check their doctor's decisions or correct the decision of a health professional, based in large part on information found online. Advanced e-patients have high level of expertise managing their condition, and use OHR to help make decisions. The following two scenarios describe instances where e-patients in our study made critical care decisions supported by OHRs.

**Scenario 1**

First, P28, who was diagnosed in 1977 and suffers from other several serious conditions, in addition to diabetes. P28 was denied a prescription critical to his care due to an automated alert system in his local pharmacy:

> The drugs that I’ve been prescribed, there's actually a risk of complications... the pharmacy was actually the one that made this a very big issue because they were refusing to prescribe me a medicine, and without the Metoclopramide for my stomach I would continue to vomit. So it was a case of regardless of the side effects, I needed the medications. And I had to deal
with the pharmacy, my doctor, and the web because when the pharmacy denied me the drug I came home and researched why they were denying it.

P28 was denied needed medication by a health professional. Rather than accept their expertise and submit to their judgment, he used OHRs to research the situation, and form his own evaluation.

I think it was a case of a flash on their screen, a warning sign on their end computer wise because they had no person, the pharmacist just said we can't combine this drug with the drugs that you are already taking and they said well it's a bad combination. They just generalized it. So I came home and plugged it in and established that there was a complication that they were concerned about. They actually had to get a hold of my doctor while I went back. And I actually went back with the information and said, look we are dealing with a digestive issue that is life or death. I will have to go in and get a gastric bypass insert.

After using OHRs to research the medication interactions, P28 was able to reach his doctor by telephone and have the situation resolved. When asked how online resources helped, P28 was adamant:

I would not know how to fight the battle. I would have gone by the professional. I would not have had the resources to establish what the problem was, and how to resolve it.

Scenario 2
Next we look at an event with participant P5, who was diagnosed in 1997. P5 decided in 2009, without speaking with her doctor but with support from online
resources, to stop a course of medications with side effects that she felt were making her seriously ill:

I stopped. I knew, based on what had I found, how long it would take for me to end up having the negative side effects. And then, I had decided that if they showed up in full force I would stop it. I stopped it. It also, I didn't feel like there was enough benefit to it based on how sick it was making me feel so I stopped it.

When asked if she would have stopped without have access to online resources, P5 answered:

I probably would have stuck with it longer. I would have thought that okay maybe I'm just getting used to it. Maybe I just have to wait a little bit longer and the side effects will fade. But I had seen that the side effects kind of show up and stick with you if you got them and would go away if didn't get them.

Next, P5 explained that she made this decision to stop the medication without first asking her doctor because she did not hold great trust in his judgment:

No, I just stopped right away. I didn't want to use them in the first place and he knew - and I was the only type 1 he was treating so I didn't exactly trust his judgment when it came to what his plan of care was for me.

P5 related what happened when she explained her decision to her doctor, and how she had learned “typical side effects” from online information:

He was disappointed and asked why I had stopped, and he hadn't given me information about the side effects or how strong the side effects were going
to be. So I told him that - I actually ended up getting violently ill while taking these - so I told him I ended up finding out that the side effects I was experiencing were the typical side effects of the medication for some people and my quality of life was crap so I stopped taking them, and he understood. Has was disappointed but I don’t know, if he had given me all of that information as he prescribed them, I don’t think I would have even started the course.

These two scenarios illustrate how advanced e-patients take a very active role putting their knowledge to use making critical care decisions. In P28’s case, he would have deferred to the professional, with potentially serious consequences. The use of OHRs gave him the information he needed to question the professionals and make an informed decision. P5’s case illustrates a situation where an e-patient used information found online as part of the decision making process to stop taking a prescribed drug causing substantial side effects, without a doctor’s instruction. In both cases, the participants point directly to OHRs as an important component in the scenario, and without OHRs there could have been different and potentially life altering consequences.

5.5.2 Summary of Stages

As e-patients move through the chronic disease trajectory their information needs and behaviors evolve. Near diagnosis, e-patients look for information about what diabetes is, and what it means in their lives. These questions often lead to WebMD, MayoClinic, and other highly ranked (by search engines) medical websites. In addition to the medical information found on these sites, participants report
accessing social media resources, to investigate how other people with the disease have approached their self-management.

In Diagnosis with the Disease stage, participants has relatively low levels of experience and ability related to utilizing OHRs while self-managing the disease. With experience, the e-patient gains ability and expertise in using OHRs as part of their self-management practices. In the Forming of Ability stage, they begin utilizing OHRs to respond to events arise in their self-management, such as symptom checking, determining insurance coverage, and investigating symptoms. In the final Established Ability stage, e-patients turn towards materials that address their personal needs and circumstances in the later stages, which often includes the use of social media like blogs and online forums in order to learn from other e-patient experiences. Along their journey, events or incidents may occur that prompt the e-patient to seek out information for a specific need, or they may access information from medical authorities and social media for the persistent needs of diet and exercise, and affective support.

This study investigates e-patient’s online information behaviors in the chronic disease trajectory, as they use online health resources to learn about diabetes and their own personal experiences with the condition. We have identified several themes that describe e-patients’ evolving online health information behaviors in the chronic disease trajectory. Over time, as an e-patient gains experience in the
information work of self-management, they also gain expertise finding, interpreting, evaluating, and using materials found online (Figure 12).

![Figure 12. Stages of our model and growing expertise in the chronic disease trajectory. E-patients may revert to an earlier stage when responding to events or situations where they have yet to form ability.](image)

Recognized medical authorities and peer sources on social media are reported to be important and complementary information sources. These materials inform self-management practices and support learning about the disease, lifestyle maintenance, and a healthy emotional attitude toward the chronic disease. E-patients in our study spend most of their time in a stable condition, utilizing OHRs for diet and exercise information and affective support, and while responding to events or situations that may disrupt stability. Additionally, participants recognize that they need to be motivated and in control of their care:

*A different generation is coming to the new horizon, and when I grew up you did whatever the doctor said you should do. And you took whatever pill they told you to take. And you accepted their diagnosis. And as a young adult that started to change, and in my young adulthood that started to change. You*
know 5 years, a decade - it started to reverse, the way people do things started to reverse and we had to be our own advocate, and now it's very sharp that direction of you have to be your own advocate - you don't just accept what the doctor said. Even if they want you to, you need to do your own research, you can't rely on any one source. And, you have to ask questions and look for things on your own. [P18]

Findings from this study provide important and novel contributions to our understanding of online health information behaviors. Online information behaviors augment behaviors that existed prior to the popular adoption of OHRs in the chronic disease trajectory, like monitoring health status and receiving information from health professionals. The importance of education and an informed patient have long been known in healthcare and diabetes management (Haas et al., 2012; Broom, 2009; Clark et al., 1991; Ellison & Rayman, 1998; Paterson & Thorne, 2000; Price, 1993). Less well known has been the use and impact of OHRs in the chronic disease trajectory. Our research found OHRs are a critical part of self-management and are seen by e-patients as very helpful and empowering. E-patients use OHRs to help them become better informed and to help them become more skilled self-managers. OHRs even offer virtual second opinions that help e-patients determine courses of action, “like they say two heads are better than one” [P21].

Reaching information online appears to require less effort than going to a doctor or using print material to find information for people who have access, “without the web it would’ve been a whole lot harder. Before the web, or without the web there was a health book that I would refer to. I had some books from prevention magazine,
Rodale press or whatever. But I might go in, use it as a reference, look up whatever
what's going on, that way - but how limited is that” [P12]. This quick and relatively
easy access to information provided by the Web, follows the principle of least effort
(Zipf, 1949) and makes it a first stop for many (Hesse et al., 2005). The relatively
lower level of effort felt by e-patients in our study may influence people to access
more information than is otherwise possible, as the need to manage diabetes is
constant.

Diabetes has been described as a “ubiquitous” disease that imposes a substantial
burden, where “patients never get away from it. The demand for diabetes
management intrudes on patients several times a day” (Hayes & Aspray, 2010, p.
83). Our study suggests that use of OHRs can help alleviate the burden on e-patients,
by providing readily accessible information and materials to help e-patients
research, learn, and make decisions about their care:

I wouldn’t know what to do without the Internet for diabetes. I wouldn’t know
what to do. You can get information when you go to the doctor, you can get
pamphlets and stuff like that, but I think the Internet is the best, to me, is the
best resource for diabetes. [P3]

5.6 Discussion

In this work we model online information behaviors in the chronic disease
trajectory, characterizing the role of online health resources, and describe the
changes that take place in their use over time. Our study makes several
contributions towards understanding how and why people use information over
time in a trajectory. We identify three stages of emerging abilities to use resources in a domain that is heavily reliant on information, chronic disease self-management. We describe the online information needs inherent in each stage, as e-patients move from fact-based information towards information targeted to their personalized needs. We also describe the actions e-patients undertake, and resources utilized, in order to understand, interpret, and discover, information related to chronic disease self-management.

Our primary contribution is identifying three stages of online information behaviors and characterizing the changing online information needs, actions, resources, and evaluation activities characteristic of each stage. We found that e-patients information behaviors change as they gain ability, and move from seeking basic medical information about their condition to seeking personalized information that is relevant to their unique condition. Our study also expands our understanding of the role of OHRs, the websites and social media that are used by e-patients as integral parts of their chronic disease self-management practices. Our results show how the use of OHRs helps e-patients successfully self-manage their disease, which includes empowering them to make critical healthcare decisions independently, without the intervention or approval of a health professional. With growing abilities over time, e-patients make an increasing number of health decisions, utilizing trusted OHRs to provide information, opinions, and advice.
The identification and characterization of online health behaviors in the chronic disease trajectory is an important and novel contribution to the health sciences and information sciences. While research from the information sciences has studied how people find, access, and use information; and research in the health sciences has described the development of patient expertise, our documentation of stages of online information behaviors furthers the understanding of how e-patients are using the increasingly important online health resources to manage their condition. The model developed in this study may be used to further investigate stages in long term information behaviors in the health sciences and other domains, and examine the concepts of exploratory search and searching and learning over time.

5.6.1 Stages of Ability

Time is an important component in many theories of information behavior in the library and information sciences (Jansen & Rieh, 2010). Findings from this study confirm the place of time in the online information behaviors of e-patients with a chronic disease, which changed during a progression through several stages of self-management. E-patients’ evolving behaviors and information needs reflect their growing experience and expertise in the context of self-managing diabetes. Over a lifetime of self-management, people learn about the disease, respond to events by actively seeking information to help make critical decisions, helping them take charge of their disease management. At the time of diagnosis, our participants knew
little about the impact of the disease on their lives and had a desire for information, similar to previous findings (Peel et al., 2004).

We found that participants quickly turn to OHRs and start self-directed searching and browsing as a way to learn about and begin understanding diabetes and its impact on their lives. E-patients begin to rely on their own experience and knowledge as they progress through the chronic disease trajectory. In turn they gain the ability to evaluate and use an expanding array of sources. Findings from this study show that e-patients with a chronic disease progress through several stages of online behaviors, reflecting their growing experience and abilities in the context of self-managing diabetes. Over a lifetime of self-management, people learn about their disease, respond to events by actively seeking information to help make critical decisions, aided in large part by OHRs.

**Evolving Use Online Information Resources**

Previous models of progression in diabetes ability and expertise discuss the experiences and roles of patient self-managers, including developing expertise, but they do not discuss the role of online resources (Table 22). Our study of online information behaviors is consistent with these previous characterizations of chronic disease patients, in that we identified a series of stages describing the OHRs accessed by e-patients. However, where those studies investigated how patients learn to manage diabetes in an offline environment, our focus is in the growing area of online information. Our work expands the understanding of patient behaviors to include the use of OHRs, such as websites and social media sites that are reported to
be very important in the support of self-management practices in our study, over defined stages.

Over time, as e-patients progress with their self-management, they become expert self-managers (Ellison & Rayman, 1998; Paterson & Thorne, 2000; Price, 1993; J. Wilson, 1999). The progression from diagnosis to established is neither linear nor the same for all (Paterson & Thorne, 2000). E-patients who are active in self-management learn about the disease and resources relevant to their situation, as they become expert self-managers. Online information behaviors appear to evolve along with the e-patient’s expertise and ability managing their condition.

<table>
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<tr>
<th>Table 22. Comparison of the present model of online behaviors to previous (offline) models of progressing ability in diabetes self-management</th>
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<tr>
<td>Diagnosis with the Disease</td>
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<td>Forming of Ability</td>
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<td>Established Ability</td>
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5.6.2 Exploratory Search in Self-Management

Exploratory searchers utilize a combination of searching and browsing behavior to navigate through (and to) information that helps them develop
powerful cognitive capabilities and leverage their newly acquired skills to address open-ended, persistent, and multifaceted problems. Searching to learn includes decision making, and professional and life-long learning. (White & Roth, 2009, p. 10)

Exploratory search emphasizes that search is not a simple query and answer process, rather people search (and browse) over time, with learning occurring during this process (Marchionini, 2006; White & Roth, 2009). “Search” sessions, which include searching, browsing, and reflection, entail several iterations that can occur over many weeks or even months. People engaged in exploratory search and learn as they engage with information resources (Marchionini, 2006). Exploratory searchers use what they have learned to guide future information seeking activities. Movement through resources can follow a berrypicking path (Bates, 1989), with searchers learning and changing needs as they move through a series of information resources.

Participants in our study reported using a variety of sources when learning about diabetes, investigating questions, or responding to problems that arose. As they searched, they learned from resource they accessed, and this new knowledge informed subsequent online information behaviors. Exploratory search behaviors were reported in the chronic disease trajectory, moving among an assortment of sources when learning about diabetes, investigating questions, or responding to problems that arose. As they searched, they learned from resources they accessed and this new knowledge informed subsequent online information behaviors.
Our work may be able to expand investigations of exploratory search in two ways. First, we show that e-patients in the chronic disease trajectory engage in exploratory search behaviors; searching and learning over time. As they gain ability and learn, their information behaviors evolve to reflect their changed condition. Further investigations may provide additional insight in this domain, resulting in more detailed characterizations of exploratory search in chronic disease self-management.

Second, we introduce a staged model of information behaviors that may be useful for future representations of exploratory search behaviors. As information searchers form new abilities and expertise, it is possible exploratory search behaviors for many domains may be described in definable stages as we have done in this study. While our stages are now at a high conceptual level, further investigation may also lead to more nuanced phases of exploratory search in health and other domains. For example, determining the specific influences of social media and other patient experiences in the exploratory search behaviors of e-patients.

As suggested by White and Roth (2009) above, life-long learning is a characteristic of exploratory search. Similarly, diabetics manage a disease for a lifetime and encounter a series of learning situations along the way. These needs lead e-patients to search and learn to fill the information gap, in support of their self-management practices. As they progress search strategies, tactics, and cognitive abilities evolve (Bates, 1989; Marchionini, 1995, 2006) reflecting changing circumstances and contexts (Ellis, 1989; T. D. Wilson, 1997).
Ellis (1989) studied the information behaviors of academic social scientists, describing a series of actions in information seeking: starting, chaining, browsing, differentiating, monitoring, and extracting. Although conducted in an academic library domain, his findings parallel many of our observations of self-management practices. In both contexts, people gain knowledge and ability over time. Social scientists, as they engage in research develop specializations and expertise their area of study. Likewise e-patients develop expertise managing information needs for their disease, specializing in the domain of diabetes self-management. Similar to those shown in our study, Ellis found information seeking patterns “will depend on the unique circumstances of the information seeking activities of the person concerned at that particular point in time” (1989, p. 178). Our participants’ information seeking and behaviors similarly depend on the circumstances of the need. E-patients use multiple sources, and follow citations (Ellis, 1989), which online are in the form of hyperlinks, to supporting information. Participant P24 demonstrates these concepts; showing well developed information seeking practices: "when I do WebMD I tend to click the links that the research is drawn from... so where they draw their research from."

Marchionini’s (1995) model of information seeking in electronic environments shares factors with Ellis (1989), although it does not delve into as much detail of the searchers individual actions. Marchionini’s model includes a process of the information seeker first recognizing and defining a problem, then selecting and querying a source. Next the searcher examines results, extracts and reflects on the
information. This process can continue iteratively with the searcher transitioning back to previous stages along the way. Our participants follow similar paths, first recognizing a need, possibly due to some event. Sources are then selected for searching and browsing, depending on the type of need. Finally information is extracted and the e-patient decides to continue searching or cease. All of these activities happen within the context of the person’s medical situation.

T.D. Wilson’s (1997) revised general model of information behavior places an emphasis on the “person in context” which we found to be an important component of information behaviors in our study. The context of an information need had a substantial influence on participant’s information seeking activities. Context can be defined as the e-patient’s experience with self-management, their place in the model (Diagnosis with the Disease, Forming of Ability, or Established Ability) and the novelty or type of need that causes them to seek information. E-patients then make a decision to actively seek information, selecting the sources thought to be most appropriate. As they explore resources, they examine and evaluate results. This leads to gaining knowledge, which can then be used to address the situation. As shown in Figure 13, e-patients can revert back to previous steps and the process is iterative, it may be repeated several times. However, each time the cycle repeats, the e-patient has a changed context even if only very slightly different from the previous iteration.
5.6.3 Emerging Expertise

Previous research suggests expertise can impact the way people look for information, resulting in medical experts and non-experts exhibiting different search behaviors (White, Dumais, & Teevan, 2008). An investigation of experts across several domains, including the medical domain, found “experts search differently than non-experts in terms of the sites they visit, the query vocabulary they use, their patterns of search behavior, and their search success” (White et al., 2009). Similarly, our model shows changing information behaviors of e-patients as they gain ability and become more expert. E-patients who have spent considerable time managing a disease can become an “experiential expert” (Thorne et al., 2003) in their condition. E-patients in each of the stages of our model have changed needs and abilities that lead to the use of more general information early in the disease trajectory, and later use of resources with more personal relevance.
Expertise in the use of OHRs includes several components such as knowledge of online resources available, the ability to connect and use online resources, the ability to evaluate online resources, and knowledge of personal circumstances and biomedical information. We found that e-patients develop an understanding of resources available to them, and utilize them for purposes. Bhavnani (2001) described this knowledge as “declarative components” of expertise for health professionals, which consists of knowing what types of websites exist in a domain, their locations, and knowledge of the content on these sites. Similar expertise or ability is part of the e-patient’s context in information behaviors.

E-patients have individual experiences with their conditions, and each follows their own unique path. While e-patient expertise generally trends upwards as they gain experience, a person’s health condition may become unstable and require learning about a new aspect of diabetes management. Examples of this may include progression of comorbidity like foot neuropathy or major life changes where the e-patient will have a substantially different lifestyle (like going away to college). While an experienced e-patient may not have expertise with the biomedical information for these specific events, they will likely have “procedural” expertise (Bhavnani, 2001) to draw on and guide them to useful resources.

5.6.4 Intermediaries in the use of OHRs

While participants in our study moved through several information sources, they did not report the use of authoritative information intermediaries, like doctors or
nurses, in their use of OHRs. Prior to the popular use of the Web, intermediaries like librarians, nurses, doctors, and other professionals were gatekeepers who controlled access to information (Eysenbach, 2007). Today, these gatekeepers appear to be absent. In their place, e-patients pursue self-directed information seeking using search engines and social media as guides to health information. Lost, however, in the move to self-directed information behaviors are the systematic and heuristic processing skills of professionals with expertise in the health domain or use of information systems that were “old hat to reference librarians” (Belkin et al., 1982, p. 68). As predicted by Belkin, Brooks, and Daniels, today computer-based systems “need to perform at least some the functions that human intermediaries perform” (1987, p. 127).

Search and social media often fill the role of intermediary today. Search, the use of Google in particular, is so ingrained in the information behaviors of our participants that they needed prompting to discuss its use. However, Google is not a destination rather as a (seemingly forgettable) tool to find OHR. While not a memorable experience, Google searches appear to be a central tool in finding information, “I figure if Google can’t find it nobody can” [P8]. Social media too, is a useful tool helping e-patients find information. Posts from fellow e-patients might guide others to useful OHR, “I feel like she is a good source, she is on top of her stuff” [P6]. These types of guides are labeled “apomediaries” by Eysenbach (2007, 2008). While not required for access to health materials, they “are agents (people, tools) which ‘stand by’...to guide a consumer to high quality information and services without being a
prerequisite to obtain that information or service in the first place, and with limited individual power to alter or select the information that is being brokered” (Eysenbach, 2008, np). Our findings support Eysenbach’s model; guides in the form of search engines and social media provide substantial assistance to the e-patients in our study and a critical information resources.

5.6.5 Information “Work,” Evaluation and Self-Management

The “work” of managing diabetes must be learned (Corbin & Strauss, 1985; Souden, 2009). Using OHRs is a large part of the information work in self-management for e-patients. The information work required by a self-manager includes finding, evaluating, comparing, and acting upon (using) the information they retrieve. With the wealth of resources available on the Web e-patients must decide to accept or reject information they find, often without outside assistance (Eysenbach, 2007; Belkin et al., 1982). There are two major challenges here. First, the e-patient may accept some information that is unsafe, potentially causing damage to one’s health. Second, an e-patient may reject information that is helpful, thereby not receiving the benefits of information they have encountered. Reports our participants indicate a variety of methods are used to evaluate OHRs before using the information found in self-management decision-making.

E-patients in our study employed heuristic and systematic processing in order to evaluate online sources of health information. Heuristics included accepting the information found on recognized medial websites, “some sources that were
obviously medical institutions I had heard of in the past like Mayo Clinic so they were definitely clearly ones that I believed and trusted” [P13]. E-patients also use their own knowledge to systematically evaluate resources, particularly in later stages when they can compare what they find, particularly postings from others on social media, to their own experiences and knowledge, “one of the things you find in forums that you have to read everything with the knowledge of skepticism” [P19].

These findings are consistent with the principles of dual-process theory that posits people evaluate informative resources via dual channels. People with greater ability, like experienced e-patients, can evaluate content based on its own merits while comparing it to existing knowledge. Those with lesser abilities, like a newly diagnosed e-patient, are more likely to rely on heuristic cues to evaluate OHRs.

Corroboration between multiple OHR, strengthens an e-patient’s trust and confidence in the content they find, providing “validation for what I was thinking and knowing” [P6]. Nicholas et al. (Nicholas et al., 2006) found that people visit many sites in health information seeking, an indicator of exploratory search behaviors. Overall, our participants looked for confirming information evidence to help them reduce the risk that they use unsafe or untrue information, “the more it's confirmed, or there is further agreement then for me it seems more likely that this might be real or true or accurate” [P12].
**Unexpected Findings in Social Media**
Two unexpected findings related to social media came out of our data analysis. Our expectation was that social media use would not be a part of e-patients’ behaviors until after they moved out of first stage. Yet, some e-patients reported using social media during the Diagnosis with Diabetes stage. We also did not anticipate that social media would be used to find biomedical information, given the wealth of medical websites available today. Findings from our study show that social media resources were used in all stages of our model, and were used to find biomedical information.

We expected that social media would be used in later stages of our model, because 1) e-patients would have knowledge of the medical aspects of diabetes, and 2) because e-patients would have better abilities to evaluate social media, where validation would be harder to come by due to lack of external cues. Participant reports in our study show that e-patients use social media in all stages of our model.

The use of trusted authorities in diagnosis, and social media in later stages, was expected as e-patients were anticipated to rely on heuristics (Chaiken et al., 1989) near diagnosis and systematic processing of content, due to their increased ability, after they have became experienced self-managers. This expectation was based on dual-processing theory that holds a human information processor relies more on heuristic evaluations when they have little ability in a domain, and more on systematic processing when they have greater ability (Chaiken et al., 1989; Petty &
Cacioppo, 1986). However, several e-patients reported using social media in the diagnosis stage, which required further exploration.

Our data suggest this is due to participants’ pre-existing experiences with social media resources in non-diabetic Web use. Many participants were highly experienced using social media in other aspects of their lives, using it for health-related matters was a natural transition. In this case, they had the knowledge of resources available, that helps mark expertise in a domain (Bhavnani, 2001; Johnson, Case, Andrews, Allard, & Johnson, 2006).

“I’m real comfortable with the Internet” [P21].

Social media is also an important source of information where an e-patient can learn from the expertise and experiences of others. Other “patients-like-me” provide medical information, along with lifestyle and affective support that may be difficult to find through other channels. Previous work holds that social media can help e-patients find information that confirms or complements that provided by authorities (Hartzler & Pratt, 2011). Our work suggests social media functions as a somewhat personalized resources by a collection of resources with material authored by patients with similar conditions and experiences and can serve as a primary source of medical information.

5.6.6 Community

There is a huge online diabetes community [P8]
Community, a component of the CCM (Bodenheimer, Wagner, et al., 2002; Bodenheimer T, 2002; Wagner, 1998; Wagner et al., 2001), is a part of self-management reported by our participants. Unlike the CCM which describes community as “exercise programs, senior centers, and self-help groups” in our model of online information behaviors, community is formed on social media websites. Participants reported they “build up a camaraderie with other diabetics” and form an “online relationship” with others [P30].

A challenge is finding ways to drive more participation in the online community, what Preece and Schneiderman (2009) call the “reader to leader” framework, an approach intended drive participation in social sites. E-patients appear to be motivated to make contributions to health social media sites in large part by factors like altruism while less so by factors like personal gain (Oh, 2012). Participants in our study related feeling good about helping others and a sense of contributing to other’s well being, just as they may have been helped in the past. Yet, few participants reported posting in relation to the number who reported visiting social media sites.

Community seems to occur even when the e-patient is not an active contributor to social media: having a diabetes community even if I don’t comment - I like reading other peoples experiences.” [P7]. This sentiment is consistent with previous findings that these so called “lurkers” can feel a sense of community and gain benefits from their read-only participation (Preece, Nonnecke, & Andrews, 2004). Reasons for not
contributing can include only needing information, wanting to be helpful by not posting (thinking their posts may not be useful to the community), and needing to find out more about a group (Preece et al., 2004).

Our results follow these previous findings, indicating that some e-patients feel they may not have much to contribute, yet feel a part of the community just by reading what others have written. However, triangulation and confirmation across several OHRs and postings on social media was shown to be a method of determining information evaluation by participants in this study, indicating that even posts, which appear to repeat previous material, may be helpful although on their face they appear repetitive. E-patients should be encouraged to post and share their experiences, so that others may use them to learn and confirm self-management decisions.
6 Chapter 6: Conclusion

In this work we model online health behaviors in the chronic disease trajectory in three stages. First, the Diagnosis with the Disease stage where e-patients use OHRs to understand the medical basis of diabetes and its impact on their life. Next, the Forming of Ability stage where e-patients are empowered to utilize expanded resources as effective self-management practices are tested and developed. E-patients begin to focus on improving their lifestyle and developing ways to remain in good health. They recognize that they have an experience with diabetes unique from others, which leads to a desire for situationally relevant material (P. Wilson, 1973). Finally in the Established Ability stage, e-patients have become successful managers of their disease, and use OHRs to find new developments and personalized information in order to maintain a stable condition and respond to events. Like in other models of self-management, the path through these three stages is not always linear or guaranteed. E-patients have individual experiences with their conditions, may revert to a previous stage when they encounter new events or circumstances, and not all are guaranteed to reach the final stage.

Our model is a novel contribution in that it provides a staged view of emerging abilities, as a patient-searcher moves from a state of low ability to one of high ability. These stages show how e-patients begin their information journey by trying to understand the new domain in which they find themselves. They next form ability to use online information through experience searching and learning from the
resources they visit. Finally a state of high ability can be reached where resources are known to the searcher, and material relevant to the searcher’s unique needs are sought.

While e-patient expertise generally trends upwards as they gain experience, a person’s health condition may become unstable and require learning about a new aspect of diabetes management. Examples of this may include progression of comorbidity like foot neuropathy or major life changes where the e-patient will have a substantially different lifestyle (like going away to college). While an experienced e-patient may not have expertise with the biomedical information for these specific events, they will likely have “procedural” expertise (Bhavnani, 2001) to draw on and guide them to useful resources.

E-patients in our study generally are in good control of their diabetes, and spend much of their time in a stable condition. During these periods of stability, active searching for new information may wane, although behaviors related to diet and exercise and affective support continue, along with monitoring for new diabetes-related discoveries. Mass media, like newspaper websites may also provide news on diabetes. Encountering a piece of news, like a new treatment option, may spurs further purposeful information gathering. Events can change, or threaten to change the e-patient’s state of health. Events that disrupt stability trigger purposeful information seeking. OHRs are used to find information that helps guide e-patients
through actions to affect health implications, or to help plan for future events or needs.

Finally, e-patients have two persistent information needs that are satisfied by OHRs. First, diet and exercise is a primary influence on health in diabetics, and participants used OHRs, including mobile devices and apps, to help manage these lifestyle needs. One simple reason for going online is to find new and interesting recipes, as the diabetic diet can restrict options, potentially making meals repetitive. While dining out in restaurants control of ingredients is outside of the e-patient’s control. Mobile resources are used in these cases to help determine the nutritional information, like carbohydrate count, and plan accordingly. Second, e-patients use OHRs to find affective support from others on social media. This emotional encouragement was reported by some to be a large part of their online health activities and served as a way to help face day to day challenges or difficult events.

Since the time electronically available health resources were first made available there has been steady progress towards publicly accessible health information delivered online. Along with the benefits of accessibility comes a threat – the potential for people accessing health information to harm themselves due to something they have read online. However, this threat appears to be minimal, as just 2% of respondents with a chronic disease in a 2010 Pew study report being harmed by information they found online (2010). The same study reports 36% of people with a chronic disease report being helped by online health information.
Participants in our study reported OHRs to be helpful in their self-management, however we also recognize the potential for harm that exists when e-patients act on information found online. As expertise and confidence grows, a wider range of resources opens up due to careful experimentation with information resources and treatment regimens. Along the way, e-patients report strategies like triangulation and checking with health professionals or other diabetics, in order to determine the value and safety of information.

6.1 Limitations

This study has the limitations inherent in many qualitative research studies. While qualitative methods do not produce results that are generalizable, as thought of in quantitative research, the results from this study should be transferable to a similar population of e-patients. The researcher interpreted the data, which may reflect bias arising from the researcher’s past experience. We used intercoder reliability and member checks as methods to counteract personal bias or perspective that may be injected into the analysis. We recruited participants on a university campus and online, therefore we make no claims that our respondents are representative of the entire diabetic population. Our participants had high e-health literacy and self-selected suggesting they are more motivated than those who did not respond. Additionally, we only examined the behaviors of patients themselves. Caregivers are an important part of chronic disease care, and perform many online health activities (Fox, Duggan, & Purcell, 2013). We do not investigate the behaviors of caregivers in
this study and recognize that the caregiver population requires examination in future works.

Data collection in semi-structured interviews depended on the interviewees’ ability to faithfully recall events or incidents and accurately express their thoughts. In future works, longitudinal investigations using Web log data and detailed diary reports by e-patients may be used to further investigate online information behaviors. Despite these limitations, we feel the data collected in this study is sufficient to support our analysis and conclusions.

6.2 Implications
Successful self-management requires “master[ing] three separate but related categories of activities” (Clark et al., 1991, p. 6), including: knowledge about the condition and treatment, working to manage the condition, and maintaining psychosocial functions. In our study OHRs are used to address these concerns, helping people make informed medical and lifestyle decisions, and receive affective support from a community of people with similar conditions. The frequent use of OHRs and their primary place in e-patient’s information behaviors have several implications for the health sciences and information sciences domains.

Our main contribution is a model of online information behaviors over a progression from a state of low ability when introduced into a domain, to a state of high ability after substantial experience using online resources in this topic area. While it was previously known accessing health information found online is a common behavior,
and that people managing a chronic disease develop expertise over time, there has been a gap in understanding the influence and use of domain-specific health resources over this progression from low ability at diagnosis to a high ability self-manager as the e-patient interacts with health resources.

Our work has several practical implications for the development of future health information systems. E-patients appear to learn about circumstances in their condition in part by reading the accounts of others on social media. While e-patients are able to connect online, there appears to be little guidance from health professionals in the relationships that are formed. Paterson and Thorne (2000) suggested a mentoring program where newly diagnosed are matched with self-management experts. This appears to be occurring in social media, however without a formal mentoring program being implemented. Participants looked online for those reporting successful outcomes and with whom they share characteristics. Given the popularity of this behavior, it seems possible that online forums and other social media could implement formal mentoring programs; leveraging e-patients comfort using online resources.

Doctors were identified as a primary partner in our study, yet the relationship in terms of information sharing was not always satisfactory for participants. For example, our participant P1 described the lengthy process she went through to find doctors, specifically a team of doctors, who would spend the necessary time to answer questions and share information with her. While others in our study
reported experiences where information interactions with doctors fell short of needs or expectations, several participants reported that OHRs helped them have productive information interactions with their doctors. OHRs were used primarily to prepare questions for a previous office visit or to interpret information provided in a past visit. Health professionals are often extremely busy, however these results imply that OHRs could be used to improve the information interactions between doctors and patients.

Our results will be useful for helping guide future research into the relationships between new health tools or information systems and others used by e-patients. Munson (2013) asks, "When is an ecosystem of tools better than attempting to build an integrated tool? When an ecosystem of tools exists, how can systems or other processes guide individuals to the right tool or tools to support their goal (or subgoal)?" Many research projects investigating Web use by those with a chronic disease focus on specific interventions; such as building a system and measuring its effect on a population. However, in the real world e-patients use an “ecosystem” of websites, moving between them to find and use health information. Our model is well suited to guide such investigations of Web ecosystems.

Similarly, chronic disease self-management models do not yet appear to have a place for OHRs and their relationship to patient behaviors. Our model can extend previous models of chronic care to include the place of online health resources that seem so important to our participants. Models of chronic care and self-management
are not static, they must adapt to changes in technology and society. The Chronic Care Model (Bodenheimer, Wagner, et al., 2002; Bodenheimer T, 2002; Wagner, 1998; Wagner et al., 2001) and Chronic Illness Trajectory Framework (Corbin, 1998; Corbin & Strauss, 1991) are both dynamic structures that have been updated over time. However, as of yet, the place of OHRs have not been incorporated. Similarly, chronic disease self-management models (Price, 1993; Ellison & Rayman, 1998; Paterson & Thorne, 2000) do not yet appear to have a place for OHRs in e-patient behaviors. These models were developed before, or near when the Web first became popular source of health information. Our findings highlighting the unique and important place OHRs hold in chronic disease self-management would likely be useful to inform future updates to these and similar descriptions the chronic disease experience.

6.3 Future Work

This study describes e-patient online information behaviors in the chronic disease trajectory. The issues found in this work point towards several areas of future work. While our findings align with previous frameworks, additional study is needed to further explore our model. Quantitative work, like web log analysis of the online information behaviors of diabetics may provide additional insight. While in our work participants recalled past behaviors, log data would provide detailed data on areas like search terminology, URLs visited, and sequence of visits. Diary studies, a method explored for this work, may also prove useful in future research. These studies would provide detailed data for an e-patient’s web use (and non-web information
use). Additional, in-depth investigations of individual stages or unique events (such as acquiring an insulin pump) may allow us to model e-patients’ online behaviors at a more detailed level.

Our work investigated people who are active Web users, and does not delve into questions regarding avoiding Web resources in chronic diseases. Information avoidance can be a problem in chronic disease management and while our findings show the people in our study think they are helpful, we offer no insight into how OHRs might be made to appeal to current non-users. Additionally, caregivers are an important component of chronic disease care. It is likely their online information behaviors have several parallels to those of e-patients, and their needs would make a worthy future investigation.

6.4 Concluding Statement

The Internet kind of filled the void for me. [P7]

The e-patients in our study recognize that they have a powerful responsibility to be active and engaged in the management of their chronic condition, which mirrors the conclusions of the American Diabetes Association (2012, p. S17). “Active” patients are thought to have better outcomes than passive patients (Broom, 2009), and are expected to take a primary role in their care (Goldman & Schafer, 2011). Participants in the present study actively manage their condition, relying heavily on OHRs to advise their practices and diabetic care decisions. The results from our study suggest
online resources are a critical part of the self-management process for e-patients managing a chronic condition.

A central topic throughout this study is the importance of information found online to guide and inform self-management of a chronic disease. Resources from medical authorities and social media are used together to help e-patients form effective and personalized self-management practices that support a healthy lifestyle within the limitations of diabetes. E-patients in the chronic disease trajectory have evolving online information behaviors that reflect their changing expertise and information needs. Effective self-management of chronic conditions requires informed and active e-patients. As this study shows, online health resources are critical resources, playing a leading role for the informed and active self-manager throughout the chronic disease trajectory.
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8 Appendices
## 8.1 Appendix A: Preliminary Model

<table>
<thead>
<tr>
<th></th>
<th>Stage 1: Diagnosis</th>
<th>Stage 2: Intermediate</th>
<th>Stage 3: Advanced</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What information is wanted</strong></td>
<td>Basic information about the disease diabetes, including necessary changes to diet and exercise.</td>
<td>Information about events, diet and exercise, and affective support.</td>
<td>Information for affective support is prominent, information about the e-patient’s unique circumstances.</td>
</tr>
<tr>
<td><strong>Why information is wanted</strong></td>
<td>E-patients want to learn about their condition, how it will affect their lives, and what they should do to begin managing it.</td>
<td>In order to respond to events, persistent needs like diet and exercise, affective support.</td>
<td>In order to maintain a high quality of life, feel empowered, and plan for the future.</td>
</tr>
<tr>
<td><strong>What information resources are utilized</strong></td>
<td>E-patients want information primarily from medical experts, on websites operated by entities considered medical authorities.</td>
<td>E-patients look towards information from other patients with similar conditions and circumstances. Social media sources rise in use.</td>
<td>E-patients use both authorities and “patients like me”, with the later more heavily utilized.</td>
</tr>
<tr>
<td><strong>How information is evaluated</strong></td>
<td>E-patients tend to visit known medical authorities.</td>
<td>E-patients begin using their knowledge of diabetes to judge information, and visit harder to evaluate sources.</td>
<td>E-patients compare information found online to their personal situation or experiences.</td>
</tr>
</tbody>
</table>
## Appendix B: Early Version of the Code Book

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
</table>
| Diagnosis | Diagnosis with diabetes  
“I started looking into just random things about diabetes to see if there’s anything new or anything different that I could learn that I haven’t been told by my doctor.” |
| Comorbidity | An illness or other health concern of the e-patient, in addition to diabetes.  
“Search for conditions that are associated with diabetes like Celiac disease, and I think that because that disease is highly associated with diabetes I had to go through a lot of diabetes websites to find more information on it.” |
| Planning | Planning for future events or lifestyle changes.  
On researching the transition from high school to college: “how to tell your roommate, the lifestyle that you will experience, drinking and diabetes because that comes up in college.” |
| Insurance | Accessing information related to insurance concerns.  
On investigating insurance plans to cover diabetes: “Pretty much you want to start understanding it costs associated with health and the health care system in general. It really puts that into your mind how important your health really is.” |
| Medications | Medication information, including side effects  
“If I’m looking for a particular medicine I’m looking for side effects and things especially if I was experiencing any.” |
| Symptom Checking | Investigating symptoms.  
“I totally wouldn’t do a search with a broad symptom like I’m tired because you get anything from that search. If I ever had something like I had a rash on my arm or something I think that I would go to WebMD - the symptom checker to look it up.” |
| Doctor Interaction | Related to interactions with a physician, visits to the doctor’s office.  
“In my experience you have to be a pretty strong self advocate in the medical system and it helps in that way. The doctor understands that you are informed and understand it’s also much easier to work effectively with the doctor as a partner.” |
| Affective | Information resulting in improved emotional well-being.  
“I’m kind of freaked out about this process in general but again knowing that someone has done it and made it through and lived document the entire experience is kind of comforting.” |
| Diet and Exercise | Information for food and diet (such as recipes) and exercise.  
“I started looking up diabetic recipes because I love to cook.” |
| Authority Resource | Web resources from an organization perceived to have medical authority.  
“Their website [JDRF] is really great” |
| Social Media | Accessing peer-produced health-related content, including forums, blogs, Facebook and YouTube.  
“It’s basically reading someone else’s experience living with diabetes. Facing the same challenges that I case every single day.” |
| Search | Using search engines like Google or Bing, or onsite searches (for example, searching WebMD). |
| Blog | Visiting a blog written by another e-patient.  
“It’s basically reading someone else’s experience living with diabetes. Facing the same challenges that I case every single day.” |
| Facebook | Accessing Facebook for health information.  
“I think I just posted on Facebook ‘which pump do you have, what do you like better, I’m thinking about getting this one’ and kind of going from there.” |
| Social Media | Accessing peer-produced health-related content on sites other than blogs, Facebook or YouTube.  
“I just kind of go to the different pumps websites to kind of look at what other people have said about them. A lot of times people will post reviews of the pump and what they like about it and what they don’t like about it.” |
| YouTube | Accessing YouTube for health information  
“A lot of them are on YouTube - these guys shooting video of how they put [the insulin pump] on so it’s like it’s really amazing.” |
| Apps | Using mobile apps, or a mobile web browser to access information.
<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Evaluating Web content</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“Well, it’s commercial, and so I’m not sure if the information given is based on medicine</td>
</tr>
<tr>
<td></td>
<td>that is proven, research based medicine.”</td>
</tr>
<tr>
<td>Patient Knowledge</td>
<td>Using existing knowledge to help make a judgment.</td>
</tr>
<tr>
<td></td>
<td>“I take the knowledge that I already have… my best guess, and if what I am reading kind</td>
</tr>
<tr>
<td></td>
<td>of lines up with that then I know it’s pretty spot on.”</td>
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</tbody>
</table>
8.3 Appendix C: Recruiting Flyer

Have you been diagnosed with diabetes, and do you use the Web to find health information?

You may qualify for a research study to help develop future Web-based health information resources.

Research Objectives:
We are researching how people search the Web to find health information. The purpose of the work is to develop better Web-based information resources. Your participation will consist of a one-time interview where you will answer questions about when and how you searched for diabetes information on the Web. The study will take about one hour to complete. Your participation will remain confidential.

Eligibility:
You can participate if you are 21-65 years old, are fluent in English, and have been diagnosed by a doctor or other health professional with diabetes or pre-diabetes. You must have looked for diabetes-related information on the Web within the past 12 months, and have experience using the Web to find information (for any reason) for at least the past three years.

Interviews will be conducted remotely by telephone and computer, or in person on the Drexel University campus. We are recruiting up to 30 people for this study on a first-come-first-serve basis.

Remuneration:
Participants will be paid $20 for participation in this study.

If you are interested in participating, please contact:

Michael Zarro
mzarro@drexel.edu
8.4 Appendix D: IRB Approval

December 6, 2012

Xin Lin, Ph.D.
College of Information Sciences and Technology
Mailstop: Drexel University

Dear Dr. Lin,

On December 6, 2012 the IRB reviewed the following protocol:

<table>
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<th>Type of Review:</th>
<th>Initial</th>
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<tbody>
<tr>
<td>Title:</td>
<td>Characterizing and Enhancing Dual-Process Exploratory Search</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Xin Lin, Ph.D.</td>
</tr>
<tr>
<td>IRB ID:</td>
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<td>Funding:</td>
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<td>IND, IDE or HDE:</td>
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</tr>
<tr>
<td>Documents Reviewed:</td>
<td>Application Form, Data Collection Tools, Flyer and Proposal</td>
</tr>
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</table>

According to 45 CFR 46.101(b) (2)), the IRB approved the IRB approved the protocol on December 6, 2012. The protocol is approved Exempt Category 2, this study will enroll 30 subjects recruited from Drexel University and the surrounding community to complete questionnaires and interviews.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL.

Sincerely,

Danyelle S. Gibson

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www.research.drexel.edu • www.drexelmcd.edu

In the tradition of Woman's Medical College of Pennsylvania and Hahnemann Medical College®
Philadelphia College of Osteopathic Medicine is a campus of Drexel University College of Medicine. Philadelphia University College of Osteopathic Medicine is an independent college in Philadelphia.
8.5 Appendix E: Follow up questionnaire / email text

Thank you again for participating in my academic research study on Web information for diabetes a few months ago. I really appreciate you volunteering your time to help me with my research, which is now just about completed. When we talked, you mentioned that you are available for a follow up.

I’m writing to ask for your comments on the findings that have come out of my study. Your thoughts will help me accurately report the results, and should help us improve future online health resources. Could you please take a few minutes to read a short summary below and answer a few questions?

Summary:
People diagnosed with diabetes use online information to help them manage the disease over a lifetime. They look for information from both doctors/medical experts (on sites like WebMD or MayoClinic), and other people with diabetes (on social media like blogs or web forums). Information from medical experts is consulted for topics like investigating symptoms and treatments. Information from other diabetics helps people learn from the experiences of others, in areas like finding new recipes or learning about how others have handled diabetes-related situations. Having access to online resources and reading the experiences of others often gives people a positive feeling, and can help people feel like they are more in control of their diabetes management.

Many people with diabetes spend most of their time in good control, and turn to online information when an event occurs that requires them to learn something new about diabetes - for example, a change in health or needing a new insulin pump. People also periodically visit sites (like news websites or online forums) where they may run across topics of interest. When using information found online, people often use more than one website to answer a question, and try to find answers or ideas that are common across several sites. Finally, people with diabetes use the information they find online to help collaborate with their doctors, giving them ideas for questions to ask or topics to discuss during doctor’s visits.

Generally speaking, people’s experience using online resources in the management of diabetes can be described in three stages of time- from diagnosis to advanced:

1. Diagnosis stage, and shortly after

When diagnosed, there is a lot of information to absorb - people may experience "information overload."

People want to find out what diabetes is, and general information about how it may impact their lives.

People generally use websites from recognized medical organizations, like WebMD, MayoClinic, and the American Diabetes Association.

2. Intermediate stage

After learning about diabetes in the diagnosis stage, people now generally begin to focus more on lifestyle management issues like diet and exercise.

Having learned some things about diabetes, people generally feel more able to evaluate information they read on the Web for its accuracy.
People use social media websites more often, like forums and blogs, to read the experiences of other diabetics and see how their experiences compare to others.

3. Advanced Stage

People use information they find to maintain a high quality of life, and plan for the future.

As a person becomes experienced managing diabetes, they feel comfortable using their own knowledge or expertise to judge the information they find online and compare it to their own experiences.

People tend to look for information from others who share similar characteristics, so they can find information that is directly relevant to their situation.

Please answer the following questions:

1. Did you find any of the content of the summary noteworthy or confusing?
   -- If yes, could you please explain?

2. Did you find any information in the summary inaccurate and should be changed?
   -- If yes, could you please explain?

3. Is there anything you feel needs to be added to the summary?
   -- If yes, could you please explain?

4. Do you have any other comments or ideas.

Thank you again for taking part in the study. I really appreciate your time and willingness to share your experiences.

Sincerely,

Mike

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Michael Zarro
Ph.D. Candidate
8.6 Appendix F: Memo Example

Merged the code ‘Google’ into the code ‘search’ - which itself is composed of the original ‘search’ and ‘search reformulation’ codes... originally based on the Pew research (and others) that many/most health care information sessions begin with search, I thought this would be a multifaceted area with many facets to explore. In reality, participants don’t seem to recall so much about search - it’s a means to an end, and the parts that matter to them are the interactions with resources. Google is synonymous with search, and participants do not even mention search many times without prompting (except in passing). It seems like search is like the highway that gets them to the place they want to be (a health resource) and like in the real world you may not think about the road you took to a location many years ago, people don’t really think about search.

Merged ADA and JDRF into ‘authority website’ - want to represent that ADA, JDRF, and similar sites are seen as written by medical authorities.
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Education
2014:  Ph.D., Drexel University, Information Studies
2007:  MS, Drexel University, Library and Information Science
1996:  BA, The George Washington University, History

Publications

Teaching Experience
Instructor for graduate courses: Digital Libraries (INFO653), Digital Library Technologies (INFO657), and Information Architecture (INFO658)

Select Professional Experience
2009 – 2014:  Research Assistant and Instructor, Drexel University
05/2013 – 11/2013: User Experience Researcher, SAP
2004 – 2007: Web Applications Developer, Bryn Mawr College

Select Awards
2014 Upsilon Pi Epsilon, Honor Society for Computing and Information Disciplines
2010 – 2011 Fellowship, Institute of Museum and Library Services
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