PERSONAL HEALTH INFORMATION MANAGEMENT IN DIABETES

by

SI SUN

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Nicholas J. Belkin

And approved by

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ABSTRACT OF THE DISSERTATION

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Dissertation Director:

Professor Nicholas J. Belkin

This study aims to explore how patients with type 1 or type 2 diabetes manage their daily personal health information, including (a) the motivators that lead patients to engage in personal health information management (PHIM), (b) the PHIM activities, and (c) affective processes that accompany PHIM activities. These three aspects are integrated into a comprehensive model of PHIM in diabetes and design principles for future interventions are proposed.

Thirty people living with type 1 or type 2 diabetes are recruited for this study through snowball sampling and participated in semi-structured one-on-one interviews and photo-documentation. These methods offer rich data that is suitable for this exploratory study. The data from the interviews are transcribed and coded with a framework adopted from the literature and the detailed codes are developed through latent content analysis.

The findings reveal 39 categories of motivators, 22 activities, and 12 affective processes that are threaded together by the feedback loop between motivators, activities and affective processes as well as various information items. These findings come

together as a comprehensive model of PHIM processes in diabetes and offer a patients'

perspective toward PHIM and its impact on diabetes management. The findings show

how PHIM processes in diabetes may connect to and differ from the personal information

management processes. Based on the findings, 5 implications for design are proposed to

address some of the key issues faced by diabetes patients as they navigate their personal

health.

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CHAPTER 1 INTRODUCTION

Chronic conditions, in contrast to acute diseases, are on-going illnesses that cannot be cured (Holman & Lorig, 2004) and may require great efforts and plenty of resources for long-term control (Strauss, 1997). Chronic conditions affect117million people (Ward, Schiller, & Goodman, 2014) in the United States and account for84% of health care expenditure (Robert Wood Johnson Foundation, 2010). These chronic conditions affect the quality of people's everyday lives, causing disabilities and inconveniences in social interactions. For example, diabetes can lead to complications like necrosis in the limbs, kidney failure, blindness, and heart disease (Centers for Disease Control and Prevention, 2011). If not managed properly, chronic conditions can even lead to death. In fact, non-communicable chronic diseases cause about 63% of all deaths worldwide (World Health Organization, 2011) and about 70% of those in the US (Kung, Hoyert, Xu, & Murphy, 2008).

This study explores an important aspect of the treatments for people with chronic illnesses – personal health information management (PHIM), including the reasons why patients do or do not engage in PHIM, as well as the various activities and processes involved in patients' management of health information in every day settings. The next two subsections bring this field to focus by first explaining self-management of chronic conditions as an important venue to control the development of these illnesses, and then introducing personal health information management as a crucial component of self-management.

1.1 Self-Management in Chronic Conditions

Although chronic conditions can have various levels of negative effects on patients, there is an increasing amount of evidence suggesting that they can be controlled and perhaps alleviated through carefully carrying out healthful activities on a daily basis (Bodenheimer, 2002; Glasgow, Kurz, et al., 2012; Lorig et al., 2001; Ory et al., 2013). Usually referred to as patient *self-management*, these activities extend beyond the clinical environment and are increasingly carried out in everyday settings(Gallant, 2003). The transition of health management for patients with chronic conditions from clinical environments to the home is in part due to the increased number of patients (Wu & Greene, 2000) and the limited resources in face-to-face clinical visits such as time, availability of physicians, and restricted amount of expenditures (Funnell & Anderson, 2004). Also, patients are experts on issues regarding themselves. They have a better understanding of their own preferences toward life-styles and have more control of their health-related activities outside the hospital compared to that of their health care team (Deber, 1994).

Playing an increasingly important part in patients' daily lives, self-management has yielded promising outcomes. Studies have found that efforts in self-management can enhance patients' understanding of their conditions (Kralik, Koch, Price, & Howard, 2004)and boost their self-efficacy in solving problems related to their conditions (Bodenheimer, 2002; Strecher, McEvoy DeVellis, Becker, & Rosenstock, 1986). These benefits encourage behavior change toward more healthful lifestyles (Strecher et al., 1986), and in turn, lead to better health outcomes (King et al., 2010), fewer clinical visits (Baker et al., 2005), as well as reduced health care costs (DeMonaco & von Hippel,

2007). Interestingly, research has also noted patients reporting chronic conditions as a blessing, because it pressures patients into healthier lifestyle, leading to their longevity (Anderson, 1986).

Research has also reported the manifold barriers to the self-management of chronic conditions, such as (a) physical discomfort, especially when patients live with co-morbid chronic conditions (Bayliss, 2003); (b) lack of knowledge regarding the condition, treatments, and regimen (Bayliss, 2003; Nagelkerk, Reick, & Meengs, 2006; Nam, Chesla, Stotts, Kroon, & Janson, 2011); (c) lack of control of the health condition (Nagelkerk et al., 2006); (d) certain patients' attitudes toward the health condition and its treatments (Nam et al., 2011); (e) low levels of self-efficacy (Glasgow, Toobert, & Gillette, 2001); (f) insufficient emotional support (Bayliss, 2003); etc. These barriers may impact multiple aspects of the chronic condition. For example, type 1 and type 2 diabetes patients may experience barriers with information collection (e.g., blood glucose testing), exercises, diet, medication, and traveling (Glasgow, Hampson, Strycker, & Ruggiero, 1997). Failure to overcome some of these barriers may lead to worse health outcomes (Glasgow et al., 2001).

Furthermore, the action of self-management may impose negative consequences on some patients. For example, patients with multiple chronic conditions can consider health tracking activities as work and be reminded of their chronic conditions, especially if the health indicators they collect do not reflect good health (Ancker et al., 2015). Over time, patients and their family members can have difficulties understanding patients' health information and using it to draw connections and identify issues (Barbarin, Klasnja, & Veinot, 2016). Also, patients with diabetes can perceive lower levels of support from

their family members when they engage in higher levels of collaborative activities concerning the patient's health information (Veinot, Kim, & Meadowbrooke, 2011).

To overcome the barriers of self-management and address the potential negative consequences of self-management, some patients rely on the careful administering of a wide range of health-related self-management activities, such as framing the illnesses in a way that motivates actions (Holman & Lorig, 2004), solving problems (Hill-Briggs, 2003; Lorig & Holman, 2003), making illness-related decisions (Thorne, Paterson, & Russell, 2003), making agendas (Lorig & Holman, 2003), managing relationships with health care providers (Nagelkerk et al., 2006) and those with others (Hill-Briggs, 2003), and personalizing activities (Lorig & Holman, 2003).

Many of these activities require intense and continuous navigation of health resources, which presents challenges to patients on various levels. Framing the illness, or seeking meaning in a chronic health condition, requires patients to formulate a positive sense when dealing with the frustration of mixed cues associated with the illness, such as treatment not resulting in anticipated outcomes and sudden change of health conditions when patient maintain their usual self-management behaviors (Öhman, Söderberg, & Lundman, 2003). Also, the rollercoaster of chronic illness development patterns (e.g., many diabetes patients experience periods of hypoglycemia when they are asleep, an extremely dangerous condition that can cause deaths) usually requires patients to constantly re-adjust their perspectives toward their conditions in order to maintain this positive sense and the meanings of living with chronic illnesses(Paterson, 2001). These constant shifts in mindsets can happen in parallel with the on-going physical discomfort and emotional suffering that accompany chronic illnesses (Öhman et al., 2003). Further,

the mindset adjustments can also result in the emergence of patients' preferences toward different, and sometimes harmful, self-management activities (Paterson, 2001).

Problem-solving is also an important aspect of self-management that can be carried out on a daily basis. If patients encounter a problem when engaging in self-management, they may try to find out about possible solutions through measurements such as defining the problem, consulting health care professionals and their social networks, and testing various solutions through trial and error (Hill-Briggs, 2003; Lorig & Holman, 2003). Results of problem-solving are often used for decision-making. For example, a diabetes patient may find that having two sugar free cookies before bed can relief her life-threatening hypoglycemia symptoms during sleep. This patient then decides to go against her dentist's advice of no food for at least two hours before sleep and have the cookies instead.

As an activity closely related to problem-solving, decision-making covers topics concerning many aspects of patients' lives, such as lifestyle changes, medication choices and adherence, treatment options, daily regimen, and help seeking (Thorne et al., 2003). To make suitable decisions, patients may utilize a wide range of resources, such as information and expertise (Paterson, Thorne, & Russell, 2002). Recently, decision-making has increasingly become an activity that involves both patients and their health care providers (Charles, Gafni, & Whelan, 1997). This shift to shared decision-making may add requirements for effective communication (e.g., patient-doctor health communication that increases patients' understanding of their health conditions and doctors' medical advice) on top of those for patients' skillful use of resources.

After patients decide to carry out certain decisions, they often make an agenda for self-management (Lorig & Holman, 2003). To make effective agendas, patients would need to be knowledgeable about the types of plans that would work best with their particular situation, the time frame of such plans, and how to carry out these plans (Lorig & Holman, 2003). All of these activities can require patients to have a rather solid knowledge about their conditions and illness management.

Many of the activities above involve interactions with health care providers and patients' social networks. The role of healthcare providers gradually shifted from the leader in patient-provider relationships to a collaborator and educator that shares a balanced role with their patients (Deber, 1994; Holman, 2000).Good patient-provider relationships can be established through equipping patients with abundant information and skills needed for decision-making, problem-solving, and other related activities (Funnell & Anderson, 2004). Successfully establishing such partner relationships can empower patients to overcome obstacles and develop higher levels of engagement in self-care (Funnell & Anderson, 2004). Also, patients' social networks are a commonly used resource for social support that can assist patients with information, emotional support, and on many other levels (Lorig & Holman, 2003).These social interactions can also be a barrier for self-management, such as when patients experiencing stigma perceive low levels of self-worth(Kato et al., 2016)and when patients encounter family conflicts regarding self-management activities (Noser, Huffhines, Clements, & Patton, 2016).

The multiplicity of chronic illness management activities described above can be further complicated by the requirements of self-management that are specific to various diseases and patient experiences (Lorig & Holman, 2003). These differences usually

originate from the complex and unpredictable patterns of illness development and patients' preferences regarding self-management activities, which may prompt patients to move away from the text book formulas of self-management and establish their own rules of control (Thorne et al., 2003).

There is one element, however, that can penetrate many activities and issues of self-management and enables patients to make meaningful connections among these activities. This element is personal health information management, which has only recently been recognized as a key factor that can facilitate patients' self-management when dealing with chronic conditions. The next section briefly introduces the role that information management plays in self-management and the difficulties experienced by patients when performing information management activities.

1.2 Importance of Information Management in Self-Management

The Chronic Care Model suggests that informing and activating patients to help them engage in effective self-management are more successful in achieving better health outcomes compared to traditional measurements of patient education (Wagner et al., 2001).The benefits of staying informed and active manifest through a number of different aspects. When patients prepare to engage in self-management through establishing positive meanings for their conditions, they can use new information to help interpret and frame the disease (Berger & Calabrese, 1975). Although establishing positive meanings does not necessarily involve the utilization of information, attempts to and preparations for engaging in self-management are usually connected to interacting with information

about one's health conditions and related subjects (Babrow, Kasch, & Ford, 1998; Mishel, 1988).

Problem-solving, decision-making, and planning are three self-management activities that are highly dependent on patients' cognitive processing of information. These activities usually require patients to be knowledgeable about the diseases they are living with (Stinson et al., 2012) and their own data on past illness episodes (Hill-Briggs, 2003). Also, patients would need to evaluate the information at hand (Thorne et al., 2003) – judge its usefulness, relevance, quality, and applicability. Further, patients would need to be capable of connecting information about the disease and themselves in order to make meaningful inferences about the development of their conditions, and decide what to do next and how to carry out the treatment and regimen plans (Thorne et al., 2003).

Similarly, when patients establish relationships with their providers and utilize resources generated by their networks, they would need to present their health information for easy understanding in order to elicit desired information from others in the form of raw data, news, advice, and so on. Therefore, being able to extract relevant information from patients' personal information collection, deciding what information to share and obtain, and considering how to present and store information for sharing may also play an important part in self-management (Charles et al., 1997). Research suggests that staying informed and effectively using health information to communicate with patients' health care team, is a key to better long term health outcomes (Wagner et al., 2001).

Indeed, interactions with health information is a major component in the endeavor to improve outcomes in chronic conditions through evidence-based, planned care (Wagner, Austin, & Von Korff, 1996).

1.3 Information Management as a Potential Barrier for Self-Management

As such an important factor in self-management, however, information management presents many challenges for patients (Holman & Lorig, 2004). To start with, the abundance of information from multiple sources can lead to patients' disorientation from information overload (Sommerhalder, Abraham, Zufferey, Barth, & Abel, 2009). To monitor one's health conditions for the purpose of problem and solution identification, decision-making, and agenda planning, patients would need to gather information regarding the specific illness, possible treatment and regimen options, their own physical conditions, and preferences with possible options. Further, patients may receive a vast amount of information passively from external environments such as various mass media and one's social networks (Kobsa, Chen, & Wang, 2012). Although accessibility has stopped many patients from obtaining enough information, many patients (Eysenbach & Diepgen, 1999) and their health providers (Hall & Walton, 2004) alike are drowning in the information explosion brought forth by the consumer-oriented content on the Internet and the clinical data made available through hospitals' electronic interfaces (e.g., patient portal systems that enable patients to access clinical information such as their health records, laboratory test results, and educational materials). In this case, patients may experience difficulties digesting the information (Nagler et al., 2010), making it hard to use the collected information when needed.

Studies have also found that information overload can contribute to cognitive inactivity as well as physical and psychiatric distress (Fava & Guidi, 2007), which can negatively influence patients' engagement in self-management activities and their health conditions.

Further complicating the problem, information can be highly fragmented (Jones, 2007),offered by multiple sources in various contexts, such as health care professionals from the hospital; family, friends, and acquaintances from home settings; colleagues, collaborators, and clients from work; and insurance-related parties (Pratt, Unruh, Civan, & Skeels, 2006). Information can also be delivered through different channels, such as face-to-face (i.e., interpersonal communication), the Internet, and telephone, and paper mail (i.e., mediated communication). Some information from different sources and channels may be irrelevant, of uncertain quality, and even contradict each other (Eysenbach, 2002; Kobsa et al., 2012; Shepperd, Charnock, & Gann, 1999). Also, the heterogeneous format of the information collected, such as patient records, medical bills, online chat log, emails, and educational materials (Civan et al., 2006; Mamykina, Mynatt, & Kaufman, 2006), increases the difficulties of keeping a coherent record over time. Some patients may keep up to 300 different types of disease-specific objects for information storage and related purposes. This accounts for about forty percent of the total number of items kept for information management activities in all aspects of everyday lives (Whetstone, 2013). Further, the adoption of technologies and the prevalence of the Internet offers numerous applications that, to some degree, aggravates the problem of information fragmentation (Tungare, 2007).To counter this problem, patients would need to integrate the information from various sources and in diverse formats to enhance their control over the information and prepare for future use (Civan et

al., 2006). However, challenges in gleaning scattered information can lie not only in the difficulties of identifying ways for integration, but also in obtaining the information that is missing from a collection (Civan et al., 2006). For example, patients who collect copies of their health records may prefer to obtain all records that describe the complete trajectory of their illness development. This connects to the next difficulty of information management – the longitudinal maintenance of health information.

Everyday health information can also be ephemeral. As Bernstein, Van Kleek, Karger, and Schraefel (2008) noted, some information may be recorded in temporary forms at place such as post-it notes or a corner of a piece of paper, which people may lose track of very quickly. However, keeping health information over the long term and in consistent forms can be important for retrospective evaluation of the connections between health behaviors and health outcomes and also for the prediction of future illness developments (Albisser, Sakkal, & Wright, 2005). For example, daily monitoring of blood glucose level is recommended to help diabetes patients understand their conditions and make informed decisions. Nevertheless, if there is a considerable amount of missing data in such records, their usefulness for predicting future trajectories, which usually builds on regularly gathered data, would be compromised. As a major component of patients' self-monitoring and motivator of self-management (Kanfer, 1970), the long-term gathering of health data can be just as challenging as the adherence to health regimen and lifestyle changes (Harris, Cowie, & Howie, 1993).

Further, even if a complete collection of abundant health information is available, patients may still experience difficulties when using it for activities such as problem-solving, decision-making, planning, and sharing. This problem may partially originate

from patients' inadequate knowledge regarding the health condition and related issues. Also, patients may have difficulties finding information relevant to their self-management needs within the health information they have kept (Civan et al., 2006; Longo et al., 2010; Pratt et al., 2006).Further, the complexity of illness development, often yielding inconsistent and counter-intuitive results, makes it hard for patients to find meaning in the information collected and can be counterproductive for patients' self-management (Peel, Parry, Douglas, & Lawton, 2004).In other words, patients need sufficient and proper information as the premise of effective information use. However, even with an abundant collection of information, patients may not understand how to arrange the information in a form that can be meaningful for self-management.

In sum, information management is a crucial element underlying many activities of patients' self-management. However, it also holds many challenges originating from the complexity of the illnesses, characteristics of chronic health information, and patients' capacity in managing and processing information. Therefore, in order to facilitate patients' self-management, it is important to understand why patients use or not use some information management tactics, how patients experience on-uses with various aspects of information management, and how these experiences can be enhanced or diminished and made more effective for facilitating self-management.

CHAPTER 2 LITERATURE REVIEW

Personal health information management (PHIM) lies in between the fields of personal information management and chronic disease self-management. As mentioned in the introduction, information management is an important activity that is present in many processes of self-management for chronic conditions. This study considers health self-management as the context in which personal health information management takes place. The rest of this section briefly introduces the development and related fields of personal health information management. Figure 1 illustrates how the various fields discussed relate to Personal Health Information Management (PHIM).

2.1 Personal Knowledge Management

Knowledge management (KM) originates from organizational studies. Established as a discipline in the early 1990s, knowledge management examines how members of an organization collect, advance, share, and effectively use knowledge in an organization (Davenport, 1994). This concept is commonly used on the organizational level and sometimes referred to as the top-down approach toward knowledge management (Pollard, 2008). This knowledge management perspective considers knowledge a collective property, and its values are generated in the process of locating and sharing knowledge within an organization. As Atwood (2009, p. 2) mentioned, "(m)anaging knowledge is identifying useful knowledge that exists in the organization and making it available to others to use or build on".

Recently a new area of knowledge management studies – personal knowledge management (PKM) – brings the focus to individuals as knowledge workers in an

organization. This individual level knowledge management perspective believes that a

focus on individuals is necessary because they are most familiar with specific contexts

and know how to efficiently and effectively manage knowledge in their control (Pollard,

2008). Also, increased burdens from information overload and information chaos makes

it difficult to formulate organizational level
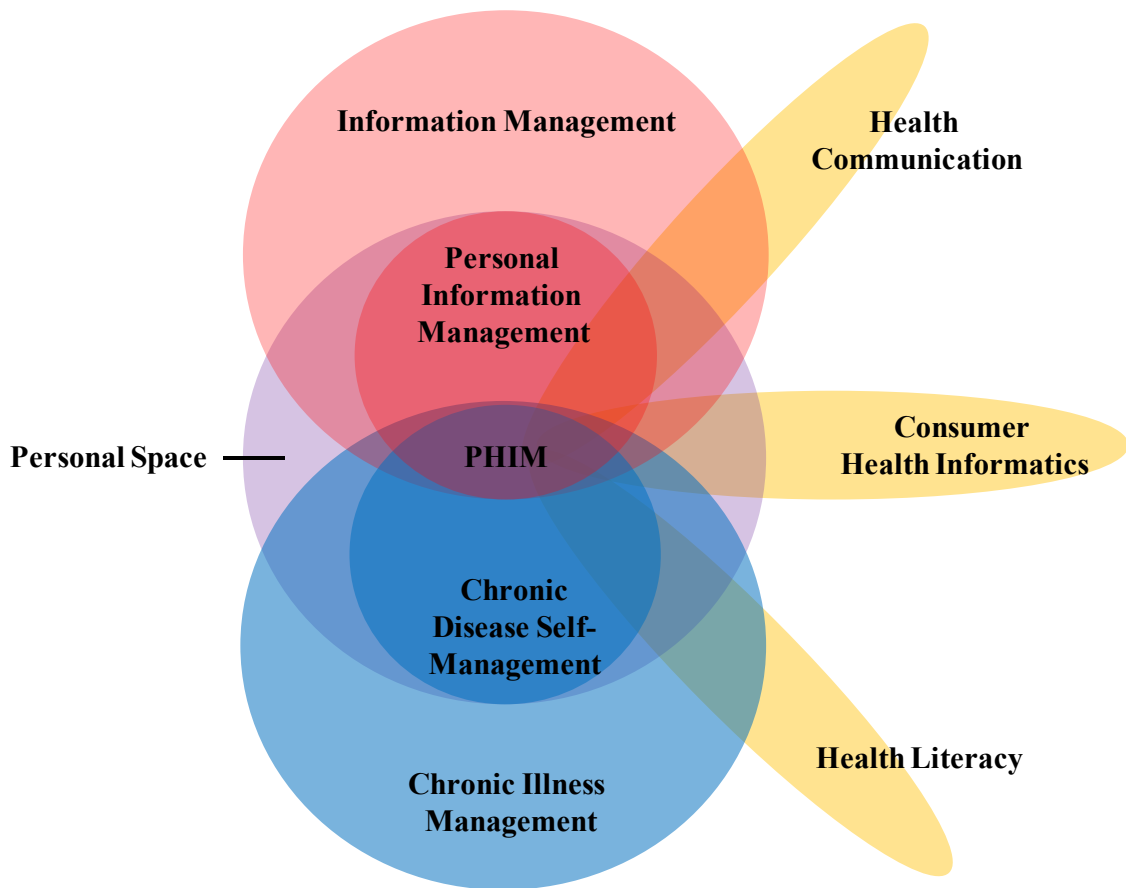
Figure 1. Fields Related to Personal Health Information Management (PHIM)

knowledge without extensive efforts at the individual level (Frand & Hixson, 1998).

Therefore, individuals are the creators, managers, and users of knowledge and

information, and the success of PKM is a crucial corner stone of KM at the organizational level.

KM and PKM are essentially connected. Both KM and PKM consider *knowledge* as the product of human intelligence and experiences regarding various aspects of an organization (Atwood, 2009). It can be verifiable scientific knowledge, recorded history, or personal experiences (Mertins, Heisig, & Vorbeck, 2003). Some studies in KM argue that knowledge differs from data, information, and wisdom (Ahsan & Shan, 2006; Bellinger, Castro, & Mills, 1997; Davenport & Prusak, 2000), where data is signs that people assign to certain objects, their properties, and their relationships with other objects; information is data that is useful for certain purposes; knowledge is processed information that reflects people's understandings; and wisdom is collections of knowledge that solves problems. This classification and relationships between the knowledge categories vary according to field of study (Ahsan & Shan, 2006; Mertins et al., 2003), but the emphasis on knowledge as processed and useful information is commonly agreed upon in the knowledge management literature (Mertins et al., 2003).

Information and knowledge can be conceptually different and they are transformable between each other. Nonaka's (1991) SECI theory suggests there are two types of knowledge, including (a) "explicit" knowledge that are "formal and systematic" (Nonaka, 1991, p.98) and ready for sharing between people and (b) "tacit" knowledge so personal and internalized that it is not easily expressed in words. When the explicit knowledge and tacit knowledge transform between and within each other, new knowledge can be created. According to Nonaka (1991), tacit knowledge can be transferred to another person (i.e., socialization); a person can translate tacit knowledge

into explicit knowledge that can be shared (i.e., articulation); this explicit knowledge can be standardized and utilized (i.e., combination); and utilizing the explicit knowledge enriches the tacit knowledge of people performing the steps of this knowledge transfer process (i.e., internalization). These steps of transferring go in an upward spiral of knowledge creation (Nonaka, 1991).

In the SECI theory, information is similar to the concept of explicit knowledge. Information can be recorded and can be communicated with others. On the one hand, the communication of information can lead to the different developments of tacit knowledge in various people due to differences in each person's internalization process. On the other hand, information is the manifestation and expression of tacit knowledge that can be standardized to facilitate the application or utilization of this information across contexts. The transfer between knowledge and information in KM is also captured in the literature of PKM.

Research in the fields of KM and PKM realizes tight connections between knowledge and information. For example, McInerney (2002) suggests that knowledge is information that is enriched by personal experiences and can be dynamically transferred between people through learning. Knowledge management occurs though the management of knowledge artifacts (i.e., the items that store the representations of knowledge) and encompasses information as well as the transfer of information (McInerney, 2002). Frand and Hixson (1998) examined the processes of PKM and identified five PKM activities, including searching/finding, categorizing/classifying, naming things/making distinctions, evaluating/assessing, and integrating/relating. Each of these five activities can include multiple components of the SECI theory. For instance,

when people engage in the searching/finding activity, they would start with articulating their information needs. Then, the searching/finding process can be a type of socialization where people communicate with authors of the written materials through reading. After that, people may use the information they found on certain tasks or advance their understandings on certain issues, which is the combination process. Last but not least, the person carrying out the above activities may internalize her experiences during this process and expand her tacit knowledge. Similarly, categorizing/classifying can involve the articulation of categories or socialization of existing categories, the combination of new categories or new items in some categories into the standardized company regulations, and the internalization of the knowledge on how items can be categorized in the future. The other three activities can include elements of the SECI model in similar manners.

Many PKM models depict the traversing of knowledge information transformation throughout the PKM activities, similar to Frand and Hixson's (1998) five activity model. Among these studies, Pollard's (2003) model of personal knowledge effectiveness integrates social activities into the personal sphere of information management and highlights activities such as finding information, keeping a collection of information sources, retrieving information, analyzing and interpreting information, and sharing information. A very and colleagues' (2001) seven-skill PKM framework includes activities of retrieving, evaluating, organizing, collaborating around, presenting, and securing information. Grundspenkis's (2007) agent-based approach for organization and personal knowledge includes identifying, creating, acquiring, interfering, generating, storing, aggregation, access, analysis, use and reuse, distribution, sharing, and consulting

about knowledge. Wright's (2005) emergent PKM framework includes activities such as accessing, searching, storing, and organizing information. Because the different processes of knowledge and information transformation span over each activity described above, these PKM models paint a vivid picture of the inseparableness of knowledge and information and the importance of the knowledge and information transformation to personal and organizational learning and growth. This necessary entanglement of knowledge and information is also highly valued in the personal information management literature, which focuses on issues concerning information, or explicit knowledge.

2.2 Personal Information Management

PIM examines information as thing that can be interacted with, compared to knowledge that cannot be directly experienced or examined (Jones, 2010).PIM is connected with PKM in the sense that PKM examines the elicitation of knowledge in the form of information and the internalization of information as knowledge (Jones, 2010).The personal information emphasized by PIM includes information kept for personal use, information about and controlled by the person, and information out of personal control but experienced by the person (Jones, 2007).

One of the pioneering works in personal information management (PIM) is Barreau's (1995) investigation on the storage, organization, and retrieval of information by seven managers. Barreau identified five PIM activities including the acquisition, organization and storage, maintenance, retrieval, and output of information. When comparing the PIM activities of users accustomed to different computer operation

systems, Barreau and Nardi (1995) found that searching and reminding are two major activities in PIM that are similar across the information activities performed by users of different systems.

Jones (2007) argued that PIM encompasses many activities that are concerned with the direct interaction with an individual's personal collection of information. These activities include finding/refinding, keeping, and meta-level activities. Finding/refinding information is concerned with seeking information either within or out of the boundaries of one's personal information collection. The need to successfully find information can prompt people to try to improve their information management activities. A critical step in this process is to remember to look for information and remember what information is available. To facilitate information finding/refinding, especially that within one's personal information collection, skillful information keeping is crucial. Information finding/refinding and information keeping are connected to each other through meta-level information management activities, such as the maintenance and organization of information as well as interpreting and evaluating information. Jones (2007) argued that these meta-level activities are a critical component of PIM. Therefore, PIM includes the intellectual processing of personal information at least in the form of sense making and evaluation that are also examined in PKM.

While PKM originated from organizational studies and considers individual level knowledge management a component that serves for organizational development, personal information management (PIM) focuses on the individuals. For example, PIM does not consider the standardization of information for communication within an organization. However, this personal information may be used to communicate with

others, such as when patients share their personal health diary with their health care team or with their family in order to solve a health problem. Therefore, a key difference between PKM and PIM is the purpose of performing the knowledge or information management activities: while the former aims at organizational growth, the later focuses on personal progress.

Further, PKM can be conceptually different from PIM in that the former is mainly concerned with the management of knowledge or processed information, and the latter focuses on the organization of information or explicit knowledge. However, the theories and models of PKM and PIM examine very similar activities and processes that involve the transformation between tacit knowledge and information. In organizations and in people's daily activities, this transformation is a process of knowledge creation and information production. The transformation requires the examination of both knowledge and information to reveal the secret of growth, productivity, effectiveness, and many of its other effects on the organization and the person.

2.3 Personal Informatics

Personal informatics examines the application of information technologies to support personal information management activities. This is an emergent concept that has only been developed for less than a decade. Li, Dey, and Forlizzi (2010) brought the area to attention by their five stage process model, including the preparation, collection, integration, reflection, and action on information. The *preparation* stage is where people develop motivation to collect information. During the *collection* stage, people collect information about themselves at different frequencies. The *integration* stage includes

multiple activities such as preparing, combining, and transforming information. During the *reflection* stage, people reflect on their personal information before acting on it. Activities in this stage may include information browsing, visualization, and so on. The reflection stage allows people to gain new understandings about themselves, so that they can react to this new understanding in the *action* stage. These stages do not develop in a linear manner, but are interactive. They may also incorporate one or multiple facets of people's lives, and may be motivated either by people's information needs or by the systems that anticipate these needs and perform the information management activities for people.

Later, Li and colleagues (Li, Dey, et al., 2010; Li, Dey, Forlizzi, Höök, & Medynskiy, 2011; Li, Dey, & Forlizzi, 2011; Li, Forlizzi, & Dey, 2010) used the five stage model to guide the design of technologies and have noted considerable improvements in personal productivity. Li and colleagues also examined personal informatics in the context of personal wellness, and explicated the connections between information management and health (Li, Dey, & Forlizzi, 2012; Li, Froehlich, Larsen, Grevet, & Ramirez, 2013; Li, Medynskiy, Froehlich, & Larsen, 2012).

The studies above seem to support that personal informatics has integrated PIM and PKM in its pursuit for better systems to support people's interaction with information. In particular, the preparation, integration, reflection, and action stages all require people's active input that can lead to the production of knowledge. In the next section, an introduction to personal health information management suggests more of such integration, where every PIM activity is connected with and is examined in relation to the inevitable involvement of active information processing.

2.4 Personal Health Information Management

Personal health information management (PHIM) is the adaptation of personal information management to the health care domain. This field originated from health informatics, which is a field that studies the use of information technologies to help with health care. Recently, however, scholars noted that PHIM is a bottle neck in health information systems design (Civan et al., 2006), and our limited understandings in how patients manage their daily health information has restricted our abilities to help patients with their endeavor toward successful PHIM.

Research on PHIM focus on two issues: Personal Health Record (PHR) systems (e.g., Kim, 2012) and the processes of managing personal health information, with or without the support of PHR. This dissertation focuses on the latter. As conceptualized by Pratt et al. (2006), PHIM is the collection of information activities related to self-management, including a wide variety of activities ranging from information seeking, collection, storage and organization, to information finding and using. Each of these activities has a definition that is unique to the situation of health care. For example, Civan et al. (2006) noted that PHIM consists of a number of information management activities, such as (a) monitoring and assessing health through constructing a personal health history and later reconstructing the history to suit the health issue at hand; (b) making health-related decisions and plans by creating lists and clusters of information; and (c) facilitating health-related actions through activities such as setting reminders. Similar PHIM activities are also observed by Zayas-Cabán (2012) in units of families. Zayas-Cabán identified 69 tasks concerning health information management that scatter across locations and information items. These tasks include health record keeping, health

planning, interacting with health information with specific concerns in mind, coordinating activities, and storing health devices.

From a clinical perspective, Rassin et al. (2007) examined how patients manage medical documents without the help of health information management system. Rassin and colleagues found that most patients keep a personal information collection for medical records though the hospital already has such a collection. Patients who keep such records use them to communicate with others and keep them for potential future uses. Importantly, patients feel empowered when making decisions about ways to manage these records.

Many of the above activities not only involve the collection, organization, and retrieval of health information, but also the mental processes that accompany these activities with a deeper concern for current and future information use. For example, making health related decisions requires patients to have considerable knowledge about their current health conditions, the health information available, the prospect of possible outcomes, and how to integrate and process the health information in order to achieve the best outcomes. Further, these PHIM activities may also be connected to patients' emotions that commonly emerge when they are dealing with chronic illnesses (Whetstone, 2013).

Although there are differences in terminologies used in PHIM and PIM research, these two areas are essentially connected. For example, Civan et al. (2006) defined PHIM activities in tight connections with health specific activities that patients carry out. The PHIM activity of making health-related decisions and plans by creating lists and clusters of information, as mentioned by Civan et al. (2006), can be connected to the *keeping*

activity noted by Jones (2007). Similarly, setting reminders for health-related activities in Civan et al. (2006) is one of the *refinding* activities defined by Jones (2007). In this dissertation, previous research from both PHIM and PIM are used to construct a comprehensive model. In a preliminary version of this model (Figure 2), concepts from PIM are used for the major components. However, PHIM literature will be referred to with higher intensity when the "meat" of the structure (i.e., the detailed items of the PHIM components) is compiled, because of the more context specific concepts characterized in the PHIM literature.

To sum up, PHIM encompasses a wide variety of issues related to information management when patients engage in everyday health-related self-management activities. The goal of PHIM research is to design better health information management strategies and systems that offer more powerful support for patients' daily health information activities. These activities are crucial for improving patients' health outcomes both directly and indirectly. However, multiple fields related to this area all have relatively short histories, and not enough studies have explored the nature, potentials, and problems of PHIM. This study attempts to discover and develop ways to support PHIM by gaining a more comprehensive and in-depth understanding of patients' PHIM activities and related processes.

With a better understanding of PHIM, we can design more effective interventions to solve PHIM issues, support PHIM activities, and motivate more frequent and higher levels of engagement in PHIM for the ultimate purpose of improving health care outcomes.

Further, the specific population observed in this research can offer unique insights for information management in general. Many patients living with chronic conditions manage health information with great intensity to achieve optimum health outcomes and maintain a normal life. This endeavor potentially makes them experts of information management and a suitable population to learn from.

CHAPTER 3 THEORETICAL FRAMEWORK

The limited amount of research on PHIM draws a rough roadmap toward

elements to examine, including motivators toward information management, information

items, PHIM activities specific to various information items, and the cognitive and

affective processes that characterize these PHIM activities. Figure 2 represents a

preliminary model of PHIM activities, based on the literature relevant to PHIM. In the

rest of this section, the researcher reviews studies that support the conceptualization of

each element of this model, and their relationships to one another.

3.1 Motivators

Similar to other information activities, such as information seeking, PHIM

activities are motivated by information needs in many circumstances, but the need for

information itself is not the ultimate or underlying need for health information

management in many cases. As noted by Taylor's (1967) concept of visceral information

needs, Belkin et al.'s (1982) anomalous state of knowledge, and Dervin's (1983) sense-

making model, people's direct information needs may not be readily articulated, but may

rise from the deeper underlying real-life problems that require solutions though

information seeking. These underlying problems are also referred to as situational

relevance from the perspective of technology design. For example, patients may need to

make a decision on whether to switch a treatment plan. In order to make the right choice,

they would perhaps need to integrate information offered by their health care providers,

their social networks, the Internet, and their experiences of living with the chronic

condition. In this regard, patients may consider decision-making, rather than information
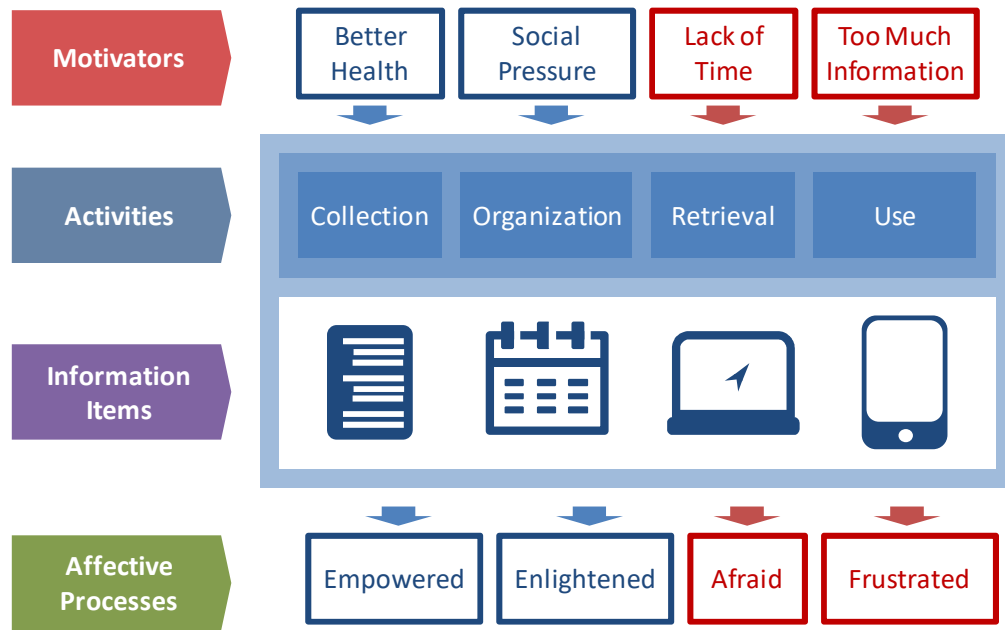
Figure 2. A Research Framework of Personal Health Information Management by People Living with Chronic Conditions.

integration, as the motivator for them to keep a personal health record.

Intuitively, the overall goal of PHIM is to improve health outcomes, but there may be more specific motivators for performing each activity and also the transitions between activities. For example, the motivator for collecting data on one's health indicators is perhaps for monitoring health conditions, but that for recording such data over long term may also be motivated by patients' need for using such data to make decisions on updating treatment plans. Although many studies implicitly mention motivators for patients' to perform PHIM (e.g., Ancker et al., 2015; Whetstone, 2013), they often integrate the motivators with actual PHIM activities, making them less distinguishable (e.g., Civan et al., 2006). Examining PHIM motivators separately from activities, however, offers a crucial channel for understanding barriers toward performing PHIM activities and for developing interventions to motivate these activities. Therefore,

this study considers motivators for PHIM as a distinct element and examines them in relation to the aforementioned PHIM activities.

Further, research on the motivation of people engaging in behavior changes investigated a large number of factors influencing people's behaviors, but this type of research tend to focus on people's individual characteristics, not the specific issues they encounter. For example, Health Belief Model (Janz & Becker, 1984) measures people's perceived susceptibility to a health condition, perceived severity of that health condition, perceived benefits of carrying out healthful behaviors, and perceived barriers toward behavior change. This model examines individual differences in psychological status regarding a certain health issue rather than the different influences that various health activities have on a person.

Studies in information science also point to predictors of information seeking behaviors. For example, the Comprehensive Model of Information Seeking (Johnson, Donohue, Atkin, & Johnson, 1995) measures demographics, people's direct experiences with behavior change, salience or the applicability of behavior change, and personal beliefs. Aside from demographics, most of these elements are based on the feelings, understandings, mindsets, and other factors regarding a person's psychological status. This model is more relevant to aspects of information seeking actions, such as the scope and depth of these actions and information sources. The model seems to be less relevant to what type of information people seek and the specific purposes of information seeking. Furthermore, the focus of CMIS on information seeking makes it potentially less applicable to this study, which focuses on processes after information seeking.

Although previous research has examined issues related to motivations of performing or not performing PHIM activities, motivations specific to various health issues are usually either not the focus or are reported in ways that make them less distinguishable from PHIM activities. This dissertation will contribute to the literature by investigating PHIM motivations from this less explored perspective.

3.2 Activities

The core of the above framework is the PHIM activities, defined as the actions that patients take when conducting health-related information management. In an early effort to conceptualize personal information management (PIM), Barreau and Nardi (1995) identified two activities: searching and reminding of the existence of certain information. While the former is concerned with obtaining information for current and future use, the latter is a trigger for current information use.

Barreau and Nardi's PIM activities are of a smaller scope compared to those investigated in later studies. For example, Jones (2004, 2007, 2008) stresses three activities, namely finding and refinding, keeping, and meta-level activities. Jones pointed out that finding information is also known as information seeking and refinding information is also referred to as information retrieval. These two activities are motivated by information needs. In contrast, people also keep information when they do not have an immediate information need but are anticipating possible future uses. Connecting activities motivated by and anticipating information uses is the third type of information activities: meta-level activities, which involve maintaining the organization of information and evaluating and interpreting the information. In other words, Jones's

concept of PIM includes not only information organization and retrieval, but also information seeking and information use.

Many later studies used Jones's categorization of PIM activities. For example, Diekema and Olsen (2011) examined the information sources, information items, sorting, and storage behaviors of teachers; and Pikas (2008)investigated the information organization, keeping, preservation, and retrieval activities of engineers. Specific to the health context, Civan et al. (2006) found that patients seek information from a wide variety of sources, keep them in different forms, construct personal health history across information items, remind themselves about health activities, and use health information for decision-making and planning. In addition, Eschler et al. (2015) found that patients who use different types of calendars for health information management may either push (i.e., set reminders) or pull (i.e., browse information), as methods of information retrieval.

In sum, previous research has conceptualized PIM in different senses, but the core elements are very similar: either motivated by explicit or potential information needs, people engage in information management activities including information seeking, information organization (include activities such as keeping, maintaining, evaluating, interpreting, and other activities), information retrieval (include activities such as finding, refinding, memory triggers and other activities), and information use. Among these activities, information seeking involves the choice and evaluation of information sources; information organization encompasses issues such as filing information into different categories, ranking information, maintaining information with anticipated future information needs in mind, evaluating the usefulness and relevance of information, and interpreting the meaning of the information in relation to oneself; information retrieval

can take the form of searching and use memory triggers for recall; and information use builds on the premise of making sense of information and matching the desired information with specific needs. Research on PHIM has not offered a systematic categorization of information management activities *per se*, but has identified some activities that are distinctive to PIM in the health context. In the current study, the researcher categorizes PHIM activities based on the general PIM activities reviewed above, while accommodating to the context of health.

3.3 Information Items

Information items are packages of information (Jones, 2007). They may take diverse forms, such as human memory, paper-based items (e.g., note books, calendars, letters, and paper health reports), devise-based items (e.g., blood glucose meters, pedometers, and cell phones), web-based items (e.g., e-mails and specialized web pages), and information scraps (e.g., post-it notes and messages jotted down on a corner of a random piece of paper). PIM research has explored ways to support information management through integrating information items and reducing information fragmentation using electronic devices and web-based applications since the 1990s (e.g., Herrmann, Brubaker, Yoder, Sheets, & Tio, 1999; Williamson, 1998). Also, in the clinical environments, EMR[1] and CPOE[2] systems support the integration of patient health and medical order information and access to this information throughout the hospital for

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[1] Electronic Medical Records (EMR) are electronic clinical systems that integrate patient information such as demographics, health history, health status, lab test results, and billing information, and make the information accessible to authorized personnel through electronic devices in a hospital.

[2] Computerized Provider Order Entry (CPOE) systems are similar to EMRs but are more focused on in-patient information and support with medical order completion and delivery.

physicians. In contrast, less is done to support information management in everyday self-care settings (Whetstone, 2013). However, it is in this very personal health management setting where patients use a wide variety of information items to assist their self-management activities on a daily basis. In fact, of the about 700 personal information items, about 300 are used by patients in their PHIM activities (Whetstone, 2013), pushing the risk in information fragmentation to an even higher level. Therefore, PHIM urgently needs the same level of support as information management receives in work settings and clinical environments.

Furthermore, little is known about how PHIM activities differ for various categories of information items, although research has pointed to the complexity associated with certain information items. For example, human memory is widely reported as a commonly used item for keeping health information, but is also reported as highly unreliable (Civan et al., 2006). Also, Eschler and colleagues (2015) examined how shared calendars are used in the home by diabetes patients and mothers of children with asthma, as a tool for information storage and reminder for actions.

Investigating information items in terms of their utilities and potential problems when applied in different PHIM activities may shed some light on how PHIM can be better supported by taking advantage of certain aspects of some information item categories and avoiding some others.

3.4 Affective Processes

Research on human information behaviors noted that these behaviors can be accompanied by emotions. For example, Kuhlthau's (1993)Information Search Process

(ISP) model suggests that the process of searching for information may consist of six stages. Each of these stages can be accompanied by three types of experiences, namely: the physical activities, the cognitive thoughts, and the affective feelings. Nahl's (2005)affective load theory poses that affective load, including uncertainty (i.e., irritation, frustration, anxiety and rage) and felt time pressure accompany information search behavior and sometimes people may use affective coping strategies to address uncertainty. Also, the Cognitive-Social Health Information-Processing (C-SHIP) model supports that patients process health information both cognitively and affectively (Miller & Diefenbach, 1998). In addition, patients with HIV/AIDS who receive information support from other people tend to also receive emotional support in the same interaction, and this emotional support can be tightly interwoven with informational support (Veinot, 2010).

Research on PHIM also supported that people experience different emotions as they manage their personal health information. For example, using health records to make decisions about treatment changes may elicit emotions expressed in ways such as "afraid" (Middleton, LaVoie, & Brown, 2012, p.594), "disappointment" (Middleton, LaVoie, & Brown, 2012, p.595), and "frustration" (Civan et al., 2006, p. 159). Although none of the cited studies on health related information management explicitly examined the affective aspect, the above quotes from patients and the authors' analyses included phrases that are highly emotional.

It is only recently that studies in PHIM examined emotion as a key element that is woven with information management activities and can potentially motivate certain PHIM activities. For example, the perceived heavy workload of PHIM can lead to frustration and discouragement in patients, which can affect patients' activeness in health

information use (Unruh & Pratt, 2008). The complexity of the information search process can also cause patients to feel confused and fearful (Lauckner & Hsieh, 2013). Patients may also experience positive emotions when managing their health information. For example, some diabetes patients reported that they feel confident when actively monitoring their blood glucose levels (Owen, Buchanan, & Thimbleby, 2012).

Given the importance of the affective aspect that previous research point to, it is necessary to explore the affective processes in conjunction with the other elements to build a comprehensive framework of PHIM.

In this dissertation, the researcher examines both affect and emotions. Affect refers to a spectrum of positive and negative emotions or moods experienced and expressed by people (Watson, Clark, & Tellegen, 1988). Affect examines the levels of activation and pleasure felt by people (Watson et al., 1988). Emotion refers to cognitive functions or somatic components of behaviors (Lopatovska & Arapakis, 2011). Because this dissertation examines PHIM as a cognitive process manifested in behavior, the exploration of emotion focuses on cognition rather than its somatic aspect. Affect is incorporated to organize different emotions into categories (i.e., positive, negative, and neutral). The concept of affect suggests that emotions may fall somewhere on a spectrum of activation and pleasure scales, which means the categorization of emotions into the aforementioned three categories is not necessarily rigid. This exploratory study does not examine the exact location where each emotional term reported by participants fall in the affective space (i.e., with two dimensions, including activation and pleasure). Rather, the categorization (i.e., positive, negative and neutral emotions) is broad and reported by participants. This is because the study examines multiple aspects of PHIM (i.e.,

motivators, activities, affect and information items) and their relationships, which can be highly complex, and navigating the different dimensions of affect may reduce the clarity of the report.

In all, this study explores patients' various PHIM activities and the cognitive and affective processes that accompany these activities. Investigations will also be made in connection to the motivators of each process and the potential differences between information items. The next section introduces these research objectives in details.

3.5 Research Objectives

This study aims to investigate the daily health-related information management behaviors of people living with chronic conditions, such as the PHIM activities, the dynamics of transition between activities, the cognitive and affective processes accompanying the activities, the elements that motivate the activities, and the relationships between information management activities, processes, and motivators. Specifically, the study is driven by the following research questions:

RQ1: Why do patients with chronic conditions engage or not engage in PHIM activities?

As mentioned before, the motivators for patients to manage their daily information are the underlying real-life problems that give rise to information needs. As a result, the concept of *motivators* examined in this study assumes that patients *make decisions* as to whether or not to manage information. For example, some patients may be concerned about high blood glucose level and the adverse effects of hypoglycemia at the

same time (i.e., underlying problems). These patients may desire to collect information related to diets that can help maintain a stable blood glucose level (i.e., information need). On the contrary, patients' *age* may also influence their information needs (Jenkins, Fallowfield, & Saul, 2001), but this influence does not involve patients' judgments. Thus factors like age, although they can influence patients' preferences toward PHIM, will not be considered as motivators, since they are intrinsic to the person, and not judgments by the person.

Therefore, the motivators of information management mainly include issues that are perceived, understood, interpreted, and evaluated by patients. Some of these issues may not be recorded in clinical health records (Glasgow, Kaplan, Ockene, Fisher, & Emmons, 2012), and some patients may be selective when sharing information publicly (e.g., on the Internet) because of privacy concerns (Ancker et al., 2015). These constraints point to the necessity of collecting data directly from participants, not through various mass media or existing records.

RQ2: How do the PHIM activities patients engage in interact to assist self-management?

Health information activities are defined in this study as patients' visible health-related information management actions. Following the literature that guided the development of the theoretical framework for this study, PHIM activities examined in this dissertation include information collection (e.g., blood sugar testing), organization (e.g., filing doctor's notes into folders), retrieval (e.g., browsing for an article previously seen in a collection of magazines) and use (e.g., sharing diabetes-related information with

other people). These activities are often integrated in patients' everyday lives and span a wide period of time. This is especially typical for patients with chronic conditions. For example, type 2 diabetes patients' treatments include medication, diet, exercise, psychological adjustments, and so on. When engaging in self-management, patients may record details about the self-management activities, outcomes, and perhaps reminders for sharing this information with their physicians at the next clinical visit. To compile a record, patients may write a diary at the end of the day or keep a scrap of paper in their pockets and jot down their activities right after. They may create these records in a clinic, at home, at work, or at social events. In all, the large diversity of conditions in which health information management activities can take place makes methods involving controlled conditions (e.g., experiments and interventions) a sub-optimal venue to collect data for this exploratory study.

RQ3: What are the affective processes that accompany patients' PHIM activities?

While patients' information management activities are visible, the affective processes may be less observable. For example, patients may feel confused, frustrated, and even angered or frightened (Guadagnoli & Ward, 1998)because the changes in their health conditions may fluctuate unexpectedly regardless of the treatment they pick, making it highly challenging to understand their conditions, not to mention making health decisions based on these understandings. Without patients' descriptions of these processes, it would be hard to observe the affective processes as outsiders. In fact, elements related to people's affective processes in information behaviors are usually measured through interviews (e.g., Foster & Ford, 2003 and Savolainen, 1995) and

surveys (e.g., Dervin & Nilan, 1986 and Ford, Wilson, Foster, Ellis, & Spink, 2002). Also, studies have suggested that people's expression of affective issues is easily susceptible to misunderstanding (Condon, 2008; Pfeil & Zaphiris, 2007), which calls for means to confirm with patients when collecting data on the affective processes.

Affective processes can potentially be observed online, such as in online health communities (e.g., Maloney-Krichmar & Preece, 2002) and through clinical online communication tools (Sun, Zhou, Denny, Rosenbloom, & Xu, 2013). However, patients may only selectively present information about themselves in a mediated or publicly observable environment (Diaz et al., 2002). Therefore, observations or analysis of records though mediated communication tools may not grant the level of completeness in data gathered compared to methods directly involving patients.

Information items mentioned in the research framework will also be examined in this study. However, these items are investigated extensively in previous research (e.g., Whetstone, 2013). Therefore, this dissertation will not focus on categorizing health information items, but will explore how different information items are used in patients various PHIM activities. In other words, information items are considered contexts of PHIM activities, rather than a major research objective.

Health outcomes are also not a focus of this dissertation. Although outcome related data could be used to enrich findings regarding PHIM processes, the overall long term outcomes are hard to measure in a chronic condition that can influence many different aspects of a person's life and when patients' everyday activities cannot be effectively control for fair comparison. Rather, this dissertation attempts to build a part of the foundation for future endeavors to measure these outcomes. It examines various

components of PHIM and how these components interact to impact patients' self-management agenda, potentially touching on issues related to health outcomes, such as behavior adherence/engagement, patient satisfaction, and patients' self-efficacy.

To sum up, this is an exploratory study that investigates how patients manage their everyday personal health information, including elements such as motivators, activities, and affective processes. The characteristics of the specific elements examined and the exploratory nature of this study suggests the adoption of methods that (a) have few restrictions on the data collection environment, (b) directly involve patients and are not limited to only the analysis of existing records, and (c) allow the gathering of patients' feedback during or after data collection for confirmation purposes. The next section presents a brief review of selected research methods commonly used in studies on people's information management and patients' information behavior related issues.

CHAPTER 4 RESEARCH METHODS

4.1 Research Methods in Previous Work

While the previous section introduces this study's research questions, this section briefly reviews some of the commonly used methods in previous studies on health information behaviors and personal information behaviors, with a preferred selection of studies that examine information behaviors for the purpose of guiding systems design.

4.1.1 Semi-Structured One-on-One Interview

Interviews are commonly used to acquire in-depth data about participants though purposeful conversations (Bingham & Moore, 1959). This method is valued for its ability to elicit information on subjective perception of experiences without being as intrusive as observation or as constraining as surveys. Also, data gathered from interviews may cover issues not readily visible through observations (Lindlof, 2011).

Semi-structured interviewing is a style of interview where the process of the interview is highly flexible for both the researcher and the participants. Therefore, this interview style is especially suitable for exploratory studies where the structure of an issue or event is unclear. One-on-one interviews allow every interview participant's voice to be heard and can avoid participants' influences on each other. Semi-structured one-on-one interviews are widely used in both health information management and self-care research. For example, Dee and Blazek (1993) used this method to generate data on physicians' feelings regarding their information needs in a rural environment. Barrie and Ward (1997) conducted interviews on 27 general practitioners concerning their likelihood

to adopt evidence based medicine in relation to their questioning behaviors during patients' clinical visits.

As an example in the consumer health area, Gardner and colleagues (2005) examined patients' experiences with clinical health care following a major heart surgery through semi-structured one-on-one interviews with eight patients (p.243-244). This type of interview is also used to find out about user preferences to guide systems design. For example, Ash, Marc, and Coiera (2003) investigated errors related to several information systems designed to support patient health care by interviewing stakeholders at different clinical sites using a semi-structured guide.

4.1.2 Focus Group Interview

Focus group interviews are different from one-on-one interviews in that the former are conducted with multiple participants in the same space and interacting with one another, while the latter usually refer to one-on-one interviews. This interactive nature of focus group interviews offers data that individual interviews would otherwise miss and the interviewing process can be less time-consuming (Kitzinger, 1994). However, focus group interviews can be more costly in terms of schedule arrangement and space. More importantly, focus group interviews require that participants are comfortable with self-disclosure within the focus group. Therefore, more time and resources are needed in the preparation phase to find members for or cultivate such a group (Rabiee, 2004). This challenge can perhaps be more prominent when the interviews concern health-related issues.

This method is also commonly used in research on various aspects of health information management. Skinner and colleagues (2003) explored 210 adolescents' needs for health information and social support, and their opinions as to how technology influences these needs through 27 focus group interviews. The interview sessions were90 minutes each and were monitored by a team of a researcher and a facilitator previously known to the participants. In a slightly different way, Cossrow, Jeffery, and McGuire (2001) conducted a focus group study on a group of adults to investigate their experiences with weight-related stigma. In total, six focus groups involving 31 adults were each monitored by two researchers. In addition, each focus group either has only man or woman, perhaps to avoid gender-related stigmas that could further complicate the results. Compared to semi-structured interviews, focus group interviews seem to be more commonly used with consumers rather than with health care practitioners, perhaps due to the latter's extremely tight schedules and long work hours.

4.1.3 Survey

Survey and structured interview are methods used to collect structured data, commonly used for quantitative and sometimes statistical analysis. Compared to interviews, surveys are relatively easy to conduct, can be widely distributed at large numbers with low cost, yield data that requires less processing before analysis, and are subject to fewer types of errors (e.g., errors originating from researchers' interpretation of participants answers). In particular, online surveys also have the advantage of reaching unique populations (Wright, Frey, Scherer, & Hilton, 2006). However, surveys' answer rates and qualities (e.g., incomplete answers and problematic responses due to

misinterpretation of survey questions) are less insured when not administered by researchers directly.

Surveys are one of the most often used methods in research concerning people's interaction with health information. Existing research has adopted surveys to investigate topics such as health information sources (Hesse et al., 2005), evaluation of information sources (Kunst, Groot, Latthe, Latthe, & Khan, 2002), consumer perspectives about health (Dutta-Bergman, 2004), health information technology adoption (Shields et al., 2007), and so on. Many such surveys are based on a regional or national sample including thousands of participants, which is a number that is nearly impossible to reach with interview studies.

Surveys are also commonly used with interviews for complementary data gathering, triangulation, and confirmation purposes. For example, Leydon et al. (2000) included a short survey for demographic information before an in-depth interview when investigating the information needs and information seeking behaviors of cancer patients. Beisecker and Beisecker (1990) distributed a survey with 106 adult patients regarding their opinions on seeking information from their doctors 10 to 14 days after an interview on the same topic.

In addition, surveys can also be mixed with other methods to satisfy unique needs for data collection. For example, Civan and colleagues (2006) investigated patients' PHIM activities through a series of structured focus group activities, called nominal group technique, where participants write down a list of PHIM activities on their own and discuss about their lists in the group.

However, the researcher has less control of the survey answering process compared to the data gathering process of interviews and observation. In this circumstance, participants may feel less encouraged to provide complete and honest answers, and may receive less guidance to accurately fill out the questionnaires. Further, surveys are less flexible compared to interviews because the participants respond to a fixed set of questions and there is no opportunity to adjust these questions to elicit answers of better quality. In addition, online surveys may yield a biased sample, only reaching people with Internet connections.

4.1.4 Observation

Observations are a type of method through which researchers investigate participants in their natural settings where the activities monitored are usually carried out. This approach allows the gathering of rich data about certain phenomena and enables researchers to identify issues not apparent to the participants, which are hard to elicit through interviews or surveys. However, observation only helps to answer the "how" questions, but not the "whys", at least not without assumptions. Because of this limitation, many studies adopting this method also incorporated other methods that can explain observed phenomena. For example, Eysenbach and Köhler (2002) combined observation with focus group interviews and in-depth interviews when investigating 21 consumers' information search and evaluation behaviors. Ash et al.'s (2003) study on unintended consequences relating to clinical health information systems adopted interviews and observation on all three research sites they investigated.

In addition, observation has the risk that the presence of researchers can lead to changes in participants' natural behaviors, perhaps because participants attempt to satisfy researchers or evade possible negative consequences with self-disclosure.

4.1.5 Photo-Documentation

Photo-documentation uses photographs as a substitute or supplement to note-taking and assumes that photographs are accurate records of a phenomenon (Rose, 2012). This method is commonly used in exploratory studies concerning personal information management. For example, Ducheneaut and Bellotti (2001) combined photo-documentation, video-recording, and interviews to explore how people use e-mails to manage personal information in work settings. Photo-documentation is also one of the major methods used in health community-oriented studies. For example, Fitzpatrick and colleagues (2009) used photos to illustrate 23 Asian immigrants' perceptions of cardiovascular health. During this study, participants received cameras and completed the documentation on their own. This method is also widely used in research on clinical information technology placement to illustrate patients' and physician's work sites. For example, Klasnja and colleagues (2010) recorded patients' information items and information activities in everyday settings. Compared to Fitzpatrick et al.'s (2009) study, Ducheneaut and Bellotti (2001) and Klasnja and colleagues (2010) did not ask participants to do the recording, but the researchers conducted the recording themselves.

Compared to naturalistic observation and participant-administered journaling that use written notes, the unique advantage of photo-documentation is that images can (a) capture rich and detailed evidence that would otherwise stay unnoticed or unreported

through interviews, and (b) describe items or conditions that words cannot (Rose, 2012, p.326). An example for the first advantage is that some patients may easily identify the calendar as an important information item when managing their illnesses. However, they may not consider the health notes that they jotted down at the edge of the calendar when calling their doctors something that is worth mentioning at an interview or when writing a journal. In the latter scenario, the calendar is no longer merely an information item for time arrangement and reminder, but has also become a location for information recording and integration. Another example illustrating the second advantage is that the study may find some patients use the physical desktop as a platform for information integration. On such a desktop, many information items are arranged in ways that support patients' understanding of the connection between incidents and provide visual cues for memory triggers. Although verbal description of such a complex desktop is possible, an image would be more directly perceivable by readers. Indeed, photo-documentation can serve as a powerful means to provide rich evidence that can develop, support, or supplement research findings that are expressed in words (Rose, 2012, p.326) and triangulate research methods that enable the collection of verbal or text data.

4.1.6 Journaling

Some studies also ask participants to record certain activities of interest in the form of journals. Compared to observations and photo-documentation, journaling is perhaps less intrusive because participants have full control over what to record and what not to record. However, sometimes what is not recorded in participant-administered journals is not a choice but a miss. Participants may not notice the importance of a certain

event because they are too used to its presence or occurrence. Using the same example as the one in photo-documentation, patients may consider calendar an important information item, but may not notice the importance of the notes on doctors' instructions that they jotted down at the edge of a calendar. Because of this, patients may mention the calendar in their journals but may miss the note on the edge, while a photo will capture all elements present on the calendar. Therefore, when choosing between observation, photo-documentation, and journaling, a balance between intrusiveness, richness, and completeness of data is crucial.

Further, similar to observation and photo-documentation, journaling also does not answer the "why" question and needs to be paired up with other methods when the cause of an act needs to be investigated. One thing worth noting is that journaling is also a new subject of observation in the area of technologies that supports patients' self-management. These studies may ask patients to write down their daily experiences in the form of journals and examine the impact of journaling on people's health conditions (e.g., Grimes, Tan, & Morris, 2009), which is different from the approach to use journaling as tool for data collection.

4.1.7 Participatory Design

From a consumer information system's perspective, participatory design aims at developing products that suit user needs well and have high levels of usability by actively involving users in every step of the design process. Commonly used in the human computer interaction field, participatory design is a step between concept formulation and product development, and can be used to reduce development costs. For example, Civan

et al. (2006) developed a number of design principles for PHIM systems through discussions between researchers and participants regarding PHIM activities and supporting technology design. The application of this method is limited, however, in the sense that studies adopting this system should aim at developing a system or at least the guidelines for developing a system.

4.1.8 Summary

When matching the advantages of each selected research method with the requirements on data discussed in the previous section, it is easy to see that some research methods may be more suitable to specific research questions compared to others. Specifically, while semi-structured interviews, focus group interviews, and open ended surveys would fit all research questions, observation, photo-documentation, and journal would only be suitable for some of the questions. However, the unique advantages of the last three methods in acquiring rich data, especially for exploratory studies, makes them valuable choices even for a narrower scope of application.

For research questions one and three, semi-structured interviews, focus group interviews, and open ended surveys are potential choices. However, open ended surveys pose the risk of having relatively lower answer rate and eliciting lower quality responses because of a lower level of researcher involvement. This issue can lead to suboptimal findings in the three research questions mentioned above when using open ended survey alone for data gathering. Compared to open ended survey, semi-structured interview and focus group are more likely to have higher response rate and produce data of higher quality. However, a focus group interview has the risk of discouraging self-disclosure,

although it has the potential to offer more in-depth data. Also, it is relatively harder to administer and is very costly in terms of team building and arranging the time and resources for gathering. Therefore, semi-structured interview appears to be a better choice than open-ended surveys and focus group interviews for answering research questions one and three due to its ability to collect higher quality rich data with higher response rate from potential participants at a lower overall cost.

Observation, photo-documentation, and journaling are possible candidates for research question two, in addition to the three methods that are also possible choices for answering research questions one and three. As mentioned before, observation, photo-documentation, and journaling all offer rich data, but similar to data collected from interviews and surveys, that from journaling reflects more subjective thoughts and judgments from the participants. Also, observation is relatively more intrusive and could potentially change participants' behaviors. In contrast, photo-documentation allows participants and researchers to negotiate the amount and depth of data gathered, and can be less intrusive while still offering some unique advantages of objectivity in the data collected. Further, photo-documentation can help present the data with considerable richness when used as a supplement to verbal narrations (Rose, 2012). Indeed,

Table 1

The Advantages and Disadvantages of Selected Research Methods

Methods	Advantages	Disadvantages
Semi-Structured Interview	- Offers in-depth data - Less intrusive - Flexible, suitable for exploring - Answer the "why" question	- Expensive in time and other resources - Hard to administer
Focus Group Interview	- Offers more in-depth data than semi-structured interview - Less intrusive	- More expensive in terms of schedule and space arrangement as

	- Flexible, suitable for exploring
	- Answers the "why" question
	- Less time-consuming than semi-
	  structured interview
		well as assuring a trusting
		group dynamic.
		- Harder to administer than
		semi-
		  structured interviews

Survey	- Offers structured data for easy processing - Easier to administer - Can be of lower cost - Can reach unique populations more easily - Subject to fewer types of errors - Can answer the "why" question	- Less reliable answer rate and quality
Observation	- Offers very rich and detailed data - Highly flexible - Easy to administer - Can be controlled by researchers	- Does not answer the "why" question - Potentially change participants' behaviors - Expensive in time and other resources
Photo- Documentation	- Offers rich and detailed data - Can be less intrusive than observation - Highly flexible - Easy to administer	- Does not answer the "why" question - Potentially change participants' behaviors - Expensive in time and other resources
Journaling	- Offers rich data - Can be less intrusive than observation - Highly flexible - Easy to administer	- Does not answer the "why" question - Potentially change participants' behaviors - Expensive in time - Cannot be controlled by researchers
Participatory Design	- Offer specialized design-related data	- Does not offer the broad data available from above methods other than close-ended surveys

Table 2

The Requirements of Research Questions on Data and Potential Methods

Research Questions	Data Required	Potential Methods
RQ1 Motivators of PHIM RQ3Affective aspects of PHIM	- Patients' opinions and understandings - Rich data	- Semi-Structured Interview - Focus Group Interview - Open-Ended Survey
RQ2 Activities of PHIM	- Patients' observable actions - Rich data - Data from natural settings	- Semi-Structured Interview - Focus Group Interview - Open-Ended Survey - Observation - Photo-documentation - Journaling

compared to journaling and naturalistic observation, photo-documentation offers a compromise between the richness and comprehensiveness of data collected, and the intrusiveness during the data collection process. However, same as observation and journaling, photo-documentation does not offer explanations as to why the observed behaviors are conducted, and would be better used in combination with methods that enable the collection of data on participant opinions, such as interviews and surveys. As argued above, semi-structured interviews allow the collection of rich and high quality data at a relatively low cost. Therefore, this study attempts to take the advantages of combining photo-documentation and semi-structured interviews to answer research questions one and three. Table 1 presents an overview of the advantages and disadvantages of the various methods of data collection relevant to this study and its research questions; Table 2 shows which of these methods have been chosen for the study, and the research questions which they will help to answer.

In all, a comprehensive view across requirements for understanding patients' perceptions and opinions, patients' observable actions in natural settings, as well as

richness of data, effectiveness of cost, researcher's level of control, and quality of data is necessary. After comparing and contrasting as well as mixing and matching various selected methods, an approach consists of semi-structured interviews and photo-documentation for gathering rich data with triangulation and confirmation is chosen. The next section describes the detailed processes of implementing these methods in this study.

4.2 Sources of Data

This study adopts two research methods to answer the research questions, with semi-structured, one-on-one interview as a primary method, and uses photo-documentation to confirm and enhance data collected from the interviews. The integration of these methods could compensate for each other's weaknesses and elicit a powerful combination of rich, in-depth, and high quality data in a relatively cost-effective way.

4.2.1 Semi-Structured One-on-One Interview

Semi-structured, one-on-one interviews are the primary method used to guide participants in their narratives concerning all three personal health information management processes. These interviews produce a large amount of rich data suitable for theory development in this exploratory study.

Two rounds of interviews are carried out. The first interview explores all four aspects of PHIM. The interview guide was tested and revised iteratively during a pilot study with 30 people living with type 1 or type 2 diabetes. For example, the original interview guide began by asking the pilot study participants what they do with the health

information they collect. These participants find it hard to recall instances where they performed actions on their health information. As a result, the revised interview guide began by asking participants what sources they use to collect health information; then proceed by asking what actions participants performed on that information. The interview guides are attached as Appendix (4-6).

During the first interview, the researcher may pursue questions that are not included in the interview guide but are inspired by participants' narratives on issues that may relate to PHIM. In this way, not only the core PHIM issues extracted from the theories can be investigated in detail, but also those that are not explicit in previous studies can potentially be identified and explored. During the interview, the researcher takes detailed notes. Also, the interviews are voice-recorded with written consent from participants.

The first interview may be accompanied by photo-documentation, where pictures are captured to enhance the findings of the first interview. A second interview may be carried out if the researcher needs clarifications on the pictures. For example, a participant may submit a photo of her insulin pump, which does not show any information explicitly. During the second interview, the participant may mention that this insulin pump stores data on multiple health indicators, and while doctors can acquire this data during hospital visits, the participant has to go through complicated requesting processes to access it. This would indicate very rich and specific difficulties in PHIM, which can be connected to a lower level motivator toward PHIM and consequent affective distress. The second interview may occur over emails, text messages, or in face-to-face contexts, depending on participants' preferences and availability.

After the second interview, the researcher has a large collection of stories on PHIM processes with highly context-rich narratives and images that support the development of the preliminary model of PHIM.

4.2.2 Photo-Documentation

Before the first interview starts, participants were asked if they would like to participate in photo-documentation in addition to the interview. The purpose of photo-documentation is twofold: (a) it is used for confirmation and help support findings from the first interview, and (b) it is also used for theory generation and can potentially identify issues that have escaped the first interview. An example for this twofold purpose is that a patient may use a calendar to record appointment schedules, but may also jot down notes during a phone call with her doctor. During the interview, the patient may mention the calendar as an important information item, but may forget the notes she jotted down during the phone call or consider them an unimportant detail. On the other hand, the photos taken by the patient may show such notes from phone calls and based on this may classify the calendar as a medium for documenting ephemeral information (i.e., the phone call notes) as well as a reminder system (i.e., appointment time reminder). Given this unique two fold purpose served by photo-documentation, this method is of crucial importance to assure the richness and preciseness of the study.

Photo-documentation is offered as an optional portion of the study because it requires extra work and can be perceived by some participants as a method that can jeopardize their privacy. For those who agree to participate in photo-documentation, the

researcher collaborates with participants to take photos of their PHIM activities and the corresponding information items.

The photo-documentation process can occur either during the first interview or within a week after the first interview. The first situation applies when the first interview was conducted in participants' homes or if the interview was conducted at another location (e.g., work place, hospital, or restaurant) and the participant brought all the items that they use to carry health information (e.g., note books, blood glucose meters, and smart phones). In this case, the researcher takes photos with participants' oral consent for each picture. The second situation applies when the interview was not conducted face-to-face, or if some important items were not present during the first interview. After the first interview, the researcher sends participants an email or text message, depending on the participant's preferences, with a list of items and activities mentioned during the interview and participants may take up to a week to respond with the requested photos and other relevant items as email attachments or multimedia text messages.

To reassure participants' privacy, before any photos are used, the researcher sends a copy of the redacted version of all photos processes by blurring or blocking identifiable information. This process is still completed when participants noted that this is unnecessary.

When analyzing the pictures collected, the researcher goes back to the interview transcripts and connects the photos with relevant segments in the transcripts. In this way, photo-documentation can provide meaningful support for the interview data and can potentially manifest new issues that are not present in data from the interviews.

4.3 Participants

In this section, some key issues regarding participants in this study are explicated. These issues include criteria for sampling and procedures of recruitment.

4.3.1 Recruitment Criteria

Thirty adult patients were recruited for the interviews and photo-documentation. All participants contributed to both the interviews and photo-documentation. All participants were recruited from the United States and are living with type 1 or type 2 diabetes mellitus. Diabetes is chosen among all chronic conditions because of its prevalence in the United States (11.9% adults were living with the condition in 2010 according to the Centers for Disease Control and Prevention) and among many other countries in the world (e.g., 11.6% adults in China were living with diabetes in 2013 according to Xu and colleagues' study in the same year). Also, diabetes is a chronic condition that can be managed through long term self-management, which makes PHIM an inevitable part of diabetes patients' lives. Only diabetes is chosen in order to prevent over complexity with the analysis in this exploratory study. However, type 1 and type 2 diabetes are included to account for the possibility of differences between two closely related health conditions and to lay a foundation for possible future research that examines inter-condition differences.

The researcher attempted to stratify participants for their years of experiences with diabetes and their levels of engagement in PHIM, so that the motivators for not managing health information and the difficulties of PHIM can also be examined. However, the recruitment of a potentially vulnerable population (i.e., diabetes patients),

the investigation of a sensitive problem (i.e., health information management) and the relative intrusiveness of the chosen research methods (i.e., interview and photo-documentation) makes it difficult to stratify participants when accessing the target population poses many barriers. Section 6.1.2 describes these barriers in details.

4.3.2 Recruitment Procedure

The interview and photo-documentation participants were recruited through snowball sampling, an economical, efficient, and effective way often used in interview studies to access populations that are potentially vulnerable or stigmatized (Atkinson & Flint, 2001). Also, snowball sampling makes it easier to recruit patients from a certain geographical location, which facilitates face-to-face interviews and photo-documentation. However, snowball sampling is subject to sampling bias (Rankin & Bhopal, 2001), which can also be present in other commonly used sampling methods such as simple random sampling for interviews (Herzog & Rodgers, 1988). Section 6.1.2 explicates the issue of sampling bias in the population recruited for this study.

Before the recruitment process, the researcher spent about a year conducting ethnographic work in a face-to-face type 1 diabetes patient support group based in New York City, and three online type 1 and type 2 diabetes communities. The researcher is familiar with the culture at the various groups and many of the community members are familiar with the researcher (face-to-face) or her online ID (online community).

When conducting snowball sampling, the researcher first started from her personal network, including the face-to-face and online diabetes support groups and connections from family and friends. Then, the researcher asked participants recruited

from the initial personal network to refer other potential participants that satisfy the

recruitment criteria. In this way, the researcher was able to gain easier access to the target

population. However, snowball sampling gives the researcher little control over the

stratification of the sample in age, gender, ethnicity, and other areas.

CHAPTER 5 DATA ANALYSIS

The data collected through interviews is analyzed with content analysis and that

via photo-documentation is used to tag categories in content analysis.

5.1 Data Processing

Before diving into the data analysis, the data collected from all three methods are

processed: (a) the audio recordings are transcribed, with thematic segments marked out;

and (b) the photos are screened to blur any content that may jeopardize participants'

privacy.

5.2 Content Analysis

Content analysis is adapted to the data collected from the interviews and the

photo-documentation with the help of Microsoft Excel spreadsheets. Content analysis

allows considerable flexibility and can preserve the richness of the data collected. Data

on each participant are analyzed separately to assure consistency in meaning across data

collected through different methods. The researcher started from analyzing transcripts

from the first interview and then used the photos and data from the second interview to

support or argue with findings from the first interview.

Latent content analysis (Graneheim & Lundman, 2004) is adopted to analyze data

from interviews and photo-documentation. This content analysis method examines the

meanings underlying the surface of the text, while its counterpart, manifest content

analysis, investigates the visible components in the respondents' answers (Graneheim &

Lundman, 2004). Latent content analysis is chosen to suit the needs of analyzing less

visible, less separable, and not readily classifiable issues focused in this dissertation, including motivation, activities, and cognitive and affective process related to patients' PHIM. An example of this need is when analyzing the use of a calendar. This item can be used as a trigger for memory, a memo for everyday information recording, or a location for information integration. These functions that support different information activities may not be clearly visible by just categorizing concepts, but need more in depth analysis in order to manifest the meanings of patients' actions.

Before the content analysis, data collected from photo-documentation are inserted into corresponding locations in the Microsoft Excel spreadsheets, where the situations depicted in the pictures correspond to the interview conversations. The same picture can be inserted multiple times throughout an interview if the pictures are relevant to multiple conversations. During the coding process, if the pictures suggest new codes that are not mentioned in the interview, a new code is assigned to the picture although there may not be a corresponding conversation. The pictures collected in this dissertation did not result in new codes, but contributed to nuances of the codes, some of which are contradictory to what participants mentioned during the interviews. The portions of the transcript that are not related to PHIM (e.g., participant commenting on the election and explaining the process of blogging) are excluded from the coding process.

Because of the importance of context in the text, thematic units instead of line-by-line coding is used (Burla et al., 2008). The process of the content analysis is as follows: First, the researcher codes all thematic units for an interview (A) and created a code book (A') with necessary nesting structures. Second, the researcher collects feedback about the coding scheme from colleagues and revises it. Third, the researcher recodes interview (A)

using the revised coding scheme (B') and codes all thematic units for a second interview (B) using the revised coding scheme. Fourth, steps 2 and 3 are repeated until the code book is no longer updated. In total, steps 2 and 3 are repeated 8 times on 8 different interviews to achieve the code book used for data analysis in this dissertation. Fifth, the researcher finished coding all 30 interviews. Sixth, a second coder codes 5 of the 30 interviews. Sixth, inter-coder reliability using percent agreement, Cohen's Kappa, and Krippendorff's Alpha are calculated and compared. This process is accomplished using Microsoft Excel spreadsheets.

The second coder underwent training before starting with coding. The training process was as follows. First, the researcher shared the code book with the second coder and explained the structure of the codes and the transcript to the second coder. Second, the second coder studied the codes and their definitions in the code book and independently reviewed some examples previously coded by the researcher. Third, the researcher and the second coder reviewed some examples previously coded by the researcher together, and the researcher clarified the definitions of some codes (e.g., differences between evaluation, problem solving, and decision making) during the review process. Fourth, when the second coder coded the 5 allocated interviews, she asked the researcher for further clarifications on some codes in the code book (e.g., whether the code "Continuity of Existing Behaviors" include two different scenarios, including continuing existing PHIM activities and continuing other everyday activities that PHIM activities may disrupt).

The three indices of inter-coder reliability measurements are chosen based on their reliability, complexity, and applicability. The various types of percept agreement are

the most commonly used in social science, Cohen's Kappa is more reliable than percept agreement measure but is less applicable, and Krippendorff's Alpha is the most reliable and applicable, but also the most complex. Table 3 summarizes the reliability, complexity, and applicability of the three inter-coder reliability indices selected for this study, including Percentage Agreement, Cohen's Kappa, and Krippendorff's Alpha.

Table 3
Characteristics of the Three Selected Inter-Coder Reliability Indices
(Lombard, Snyder-Duch, & Bracken, 2002).

	Percent Agreement	**Cohen's Kappa**	**Krippendorff's Alpha**
Reliability	- Does not consider chance agreement.	- Considers chance agreement.	- Considers chance agreement.
	- Does not account for distribution of variables.	- Account for distribution of variables.	- Account for distribution of variables.
Complexity	- Simple.	- Complex.	- Highly complex.
Applicability	- Most commonly used in marketing research.	- Used largely for nominal level variables.	- Used for variables from nominal to ratio levels.
		- Commonly used to code content on human behavior	- Applicable to analysis by any number of coders.

The five transcripts coded by the researcher and a second coder (a Rutgers University PhD Candidate) include 391 conversations. A conversation is communications around a coherent topic, usually with the researcher asking a question and the participant providing an answer. A conversation may sometimes include multiple questions asked by the researcher followed by multiple answers when all communication is on the same

topic. For example, the following conversation is on a coherent topic but the researcher asked two different questions. "*Researcher: What about other patients? Did you receive any useful information from other diabetes patients? Participant: Sometimes yeah. Researcher: Could you give me some examples of this? Participant: Um hum. On the internet, I started a group called [group's name] on Facebook, and then I have a lot of friends on Facebook, who are people with type 1 diabetes and type 2....*"Within each conversation, there may be one or multiple thematic units. The conversation above has one thematic unit. Longer conversations with the researcher asking a question and the participant providing a long answer may include more than one thematic unit as the conversation carries on.

Coding is done on thematic units, not on conversations. Each thematic unit may have more than 1 code. In total, 891 codes are applied to the 391 conversations in the 5 samples. There are cases where one coder assigned a code to a thematic unit and the other coder did not assign a corresponding code. This situation counts as coders disagreeing with each other.

The inter-coder reliability indices are calculated following the processes demonstrated in Cohen (1960) and Krippendorff (2011) using Microsoft Excel spreadsheets. The indices are calculated separately for each research question, on motivators, activities, and affects. (Table 4).

Codes for motivators have the lowest level agreement, while those for activities and affective processes are higher. This phenomenon is potentially caused by the larger number of codes to manage for motivators (39 codes) versus those for activities (23 codes) and affective processes (15 codes). Coding for all three research questions and all three

Table 4
Inter-Coder Reliability Results

	Number of Thematic Units	Percent Agreement	Cohen's Kappa	Krippendorff's Alpha
Motivators	349	0.7218	0.7060	0.7054
Activities	440	0.8317	0.8175	0.8174
Affective Processes	116	0.8790	0.8548	0.8547

inter-coder reliability indices show moderate to substantial levels of agreement between two coders (Leech, Barrett, & Morgan, 2011).

5.4 Connecting Data Analysis and Research Questions

The researcher keeps the research questions and the overall purpose of this study in mind when conducting data analysis. This strategy is especially prominent in the coding scheme development process and the coding process while performing content analysis.

As mentioned before, data from semi-structured interviews can provide support for all three research questions. To reassure that all aspects of each research question are addressed in an in-depth and comprehensive manner, content analysis for each research question is conducted separately. For example, when analyzing data from the interviews, a coding scheme to answer RQ1 (i.e., motivators for patients to engage in or not in PHIM activities) is developed first. After that, another coding scheme to answer RQ2 (i.e., types of PHIM activities) is developed. This process is repeated for the third research question as well, until codes have been developed for all research questions. Then, each coding

scheme will be adjusted separately for each research question. Similarly, the coding processes are carried out separately for each question, and all discussions and further adjustments are carried out in a similar manner. In other words, data analysis for each research question is conceptually connected, but independent in the execution processes. Therefore, it is possible that the analysis aiming to answer each research question is not carried out at the same time, and each analysis process will only focus on one research question to assure the quality of analysis.

This exploratory study investigates the complexity of patients' PHIM, requiring the collection of rich data directly from patients. This rich data is collected through semi-structured interviews that not only offer rich and in-depth data, but also offer it in a cost effective way. The rich data from semi-structured interviews is further supported and supplemented by images collected from photo-documentation, which can also illustrate the findings in a more intuitive way.

The findings from data analysis is presented in a manner that not only clearly answers each research question, but also effectively draws connections between research questions for theory development. Findings for different research questions are described in detail in the sequence in which the research questions are listed. Findings of the relationships between those of various research questions are explicated to reflect connections between PHIM elements. Based on the finding, the theoretical framework depicted in Figure 2is reconstructed to a new model that reflects the structure of the research questions and the empirical evidences. The model is discussed in relation to existing studies on PHIM and other similar issues, and also in terms of the contributions

that can potentially address the gaps in theories and methodologies in PHIM as well as that in the self-management and information management literature.

To sum up, all steps of data analysis reflect the focus on understanding patients' PHIM related issues, although the analysis for different research questions has a more specialized focus of their own. Answering each research question with such an overall focus in mind contributes to the development of a comprehensive model of patients' PHIM processes. The construction and refinement of such a model aims to inform the design of interventions to help patients engage in and enjoy the advantages of effective PHIM, and have theoretical and practical contributions to the research area.

5.6 Summary

This study examines the motivators for patients to engage in or not engage in personal health information management (PHIM) practices, types of patients' PHIM activities, information items used in various PHIM activities, and the affective processes that accompany the PHIM activities. An in-depth and comprehensive understanding of patients' PHIM practices and difficulties may pave the way toward solutions for issues such as information overload, information fragmentation, and the loss of critical health information in personal health records. This study can also serve as a step toward equipping patients with better health-related problem-solving, decision-making, planning, and information sharing skills, potentially leading to better health outcomes.

To explore a wide range of elements in PHIM, an approach encompassing semi-structured interviews and photo-documentation is employed. Semi-structured interview is chosen for its balance between data quality, richness, cost, and difficulty for data

collection; photo-documentation is an important supplement to semi-structured interviews that can collect and present data not easily captured and expressed by text.

Content analysis is employed for data analysis. The data collected through interviews is analyzed through content analysis with the images collected from photo-documentation as illustrations and supplements for text descriptions. During the whole analysis process, the researcher keeps in mind the overall focus of understanding patients' PHIM practices while also having specialized focus when attempting to answer different research questions. The analysis leads to the development of a comprehensive model of patients' PHIM and can potentially contribute to the field of PHIM in terms of theoretical and methodological developments.

CHAPTER 6 FINDINGS

In this chapter, findings from this study are reported, including an overview of information on participant recruitment results and participants, and data analysis results that answer the three research questions on PHIM motivators, activities, and affective processes respectively.

6.1 Participants

Recruitment for this study started in October 2014 and ended in September 2015 when the planned 30 participants were successfully recruited. In this section, information on the participants' background and discussions on the recruitment methods are presented.

6.1.1 Participants' Background

Participants in this research reported the type of diabetes they are living with, the number of years since their diagnosis of diabetes, age, sex, and occupation at the beginning of the first interview with each participant. The distributions of the first four parameters are illustrated in Tables 5-8. Participant's occupations are listed in Table 9.

Some of the participants are on disability insurance but intend to return to their jobs before the incident if their health condition allows. In this situation, their occupation before the incident is reported in Table 9.

Table 5
Distribution of Participants: Health Condition

Health Condition	Number of Participants
Type 1	26
Type 2	4

Table 6
Distribution of Participants: Sex

Sex	Number of Participants
Female	22
Male	8

Table 7
Distribution of Participants: Age

Age	Number of Participants
18-24	1
25-44	8
45-64	15
65+	6

Table 8
Distribution of Participants: Number of Years since Diagnosis of Diabetes

Number of years since diagnosis of diabetes	Number of Participants
2-	4
3-19	9
20-49	15
50+	2

Table 9
Participant's Occupations

Occupations	Number of Participants
Health Care Provider	6
Artist	4
Business Administrator	3
Student	3
Lawyer	2
Educator	2
Engineer	2
Writer	1
Accountant	1
Retired	6

In terms of the location of participants, a majority of them (26) were based in New York City, NY, USA. Four participants were based in other regions of USA. The specific locations are not reported in order to protect participants' privacy.

Participants in this dissertation reported diverse backgrounds, especially with occupation, age, and years living with diabetes. However, participants in this dissertation are not a perfect representation of the current population in the United States living with type 1 or type 2 diabetes. First, the number of participants with type 1 diabetes is much higher than those with type 2 diabetes, but according to the American Diabetes Association (2016), the US population with type 1 diabetes only account for 5% of the US population diagnosed with diabetes. Second, participants tend to be older in age and have more years of experiences with diabetes. This is interesting because type 1 diabetes is usually diagnosed relatively early compared to type 2 diabetes (American Diabetes Association, 2016). With the majority of the participants being diagnosed with type 1 diabetes, the younger age group recruited in this dissertation can be larger, contributing to fewer years of experiences with diabetes. Also, this phenomenon goes against what previous research has found about response rate (e.g., Herzog & Rodgers, 1988)

6.1.2 Sampling Bias

The characteristics of the sample in this dissertation noted in the section above makes it necessary to interpret the results of this study with some levels of caution. First, all participants are relatively active with caring for their health condition and have the willingness and the condition to participate in this research. There were cases where patients voiced that they were brought to the support groups by caregivers against their

own will. These patients rejected participation in this study. Also, there were potential

participants who are too physically challenged or engaged in treatments and were not

able to find a chance to participate. Because of this, the results reported in this

dissertation do not provide enough information on the perspectives of this population,

who may have different experiences and requirements compared to the participants in this

study.

Second, all participants were recruited from connections originating from a face-

to-face support group, missing the perspectives from people who do not attend face-to-

face support groups. There may be patients who attend online support groups only or do

not attend support groups. However, some of the participants reported attendance at

online support groups and communicate with other patients who do not attend any

support groups. We can have a glimpse into the perspectives of the other population

through the lenses of the participants.

This dissertation aims to recruit participants from sources other than support

groups, such as Rutgers University listservs, online health communities, local community

centers and those in New York City, and bulletin boards in the researcher's school. The

result is unsatisfactory. The researcher received an inquiry from a potential participant

who learned the study from a Rutgers listserv, but there is no further response after the

researcher shared the full version of the recruitment advertisement (Appendix 1). The

advertisements posted at a number of large online diabetes communities are either moved

to the advertisements section or were disregarded by community members who voiced

concerns over the purpose of data collection. In particular, some community members

pointed out that the IRB approved and stamped advertisements and information about the

researcher (e.g., name, email, position, and link to the researcher's page on the Rutgers official website) can be easily fabricated. The request for photo-documentation raised more concerns than the interviews. People who responded to the researcher's advertisement in online communities also noted that they see research advertisements on a daily basis and some of them have participated but never heard from the researchers afterwards, leaving them wondering what has happened to the information they shared and whether their contributions have made a difference to their community, an issue noted in previous research on vulnerable communities (Smith, 2012). Similar concerns were expressed by a leader of a face-to-face support group, who originally had doubts about the researcher's purpose for attending the group, but participated in the study a year after the researcher's joining. During the interview, the participant expressed that prior researchers and doctors joined the group in order to sell products and services, not to genuinely help the community.

Given the distrust of the patient community, difficulties in recruiting participants for research using ethnographic methods, especially those like photo-documentation, that can jeopardize participants' identity if not conducted rigorously can be highly challenging. Nevertheless, with the help of snowball sampling, 30 participants contributed to the study. Further, the original goal of having 20 participants for photo-documentation is far exceeded, with all 30 participants consenting to both interview and photo-documentation. To gather rich and high quality data in the context of this study, it seems that sacrificing generalizability is inevitable and can be compensated through further research using other methods, such as survey, in order to acquire larger and more balanced samples. However, this exploratory study does not focus on the generalizability

of its findings. Rather, it creates a *thick description* (Geertz, 1973) of the context in which the findings may apply and builds the foundation for *transferability*(Lincoln & Guba, 1985) of some of the findings to contexts other than type 1 and type 2 diabetes patients.

6.2 Motivators for Engaging or Not Engaging in PHIM Activities

Motivators in this dissertation are defined as reasons that cause people to manage or not manage their personal health information. In this dissertation, the scope of health information mainly focuses on diabetes-related information. However, in the case that other health information may have an impact on diabetes management, such information is also considered in the analysis. For example, P26 is navigating her health care between diabetes, lupus, high blood pressure and other chronic conditions. She explained that a treatment for lupus involves the ingestion of steroid based medications, which drives her blood sugar uncontrollably high. In this case, information on lupus managed by P26 is also examined because it interacts with her diabetes management.

Motivators for diabetes management activities that are not related to personal health information management are not coded.

Seven categories of motivators are identified. These categories and their definitions are reported in Table 10. In the rest of this section, motivators that fall into each of these categories are introduced in detail.

Table 10
PHIM Motivators

Motivator Categories	Definition
Information	The attributes of health information received or managed by the

Attributes Motivators	participants, whether it is information about patients themselves (e.g., blood sugar levels) or information on diabetes from external sources (e.g., a news article on new treatments for diabetes). These attributes may have different meanings and significance for different people, but they are all related to the health information they acquire.
Medical Motivators	The motivating factors for PHIM activities that originates from medical issues or concerns.
Behavioral Motivators	Motivators emerging from the interactions between PHIM activities and participants' daily diabetes management activities.
Social Motivators	Social factors that motivate or discourage PHIM activities.
Personal Motivators	Factors personal to the participant and can influence the performance of PHIM activities, such as different preferences, beliefs, lifestyles, habits, etc.
Financial Motivators	Monetary costs associated with PHIM tools and processes and the difficulties related to reimbursement of these costs (e.g., health insurance and the cost of medical equipment, such as continuous glucose monitors, pumps, and glucose meter strips).
Environmental Motivators	Natural environmental factors, such as weather, that can facilitate or discourage PHIM activities.

6.2.1 Information Attributes Motivators

Information attributes motivators include 10 subcategories, as shown in Table11. In the rest of this section, findings on each information attributes motivator are introduced in detail.

Table 11.
Information Attributes Motivators.

Information Attributes Motivators	Definition	Examples
Information Availability	Whether health information is perceived as readily available and is visible to patients.	*"The doctor gave me a brochure, so I read it."*
Information Abundance	The volume of health information available as perceived by patients.	*"There is just too much information for me to manage."*
Information Credibility	The credibility of the information sources and the health information as perceived by patients.	*"I got this information from a TV commercial, so you have to take it with a grain of salt."* (information sources) *"The so-called experts, they all claim to cure diabetes. I don't believe it."* (health information)
Information Accuracy	The accuracy of health information as perceived by patients.	*"I doubt if the blood glucose meter's readings are accurate."*
Information Consistency	Whether the health information patients collect about themselves and from external environment agrees with each other.	*"I just hope there is one consistent guide about how to manage diabetes."*
Information Timeliness	How up-to-date the information is and the timing that the information reaches the patient.	*"When you think of going back to the files, they are already obsolete."* (up-to-date) *"...if I see something that I would use immediately or I need to start implementing this in my lifestyle, that's urgently relevant."* (timing)
Information	How subjectively useful the information is to patients. This usefulness can be immediate or	*"In case I'm in critical condition, my family can*

Usefulness	anticipated usefulness in the future. It can be for participants or for others.	*have the records to show doctors.”*
Information Process Level	To what extent the health information is processed by patients, other related parties, or information management tools.	*“The integrated information is some extra motivation because you see all the efforts put together.”*
Information Presentation Style	The ways in which patients' health information is presented visually.	*“I don't read newspapers … because the words are too small.”*
Information-Elicited Emotions	The emotions that patients experience when interacting with their personal health information.	*“I love recording all these numbers and going back to them because I feel I'm in control.”*

6.2.1.1 Information Availability

Whether a piece of health information is readily available can have a great influence on whether patients collect and organize it. For example, P17 reported that one of her previous health care teams did not offer her enough information about diabetes management in the home when she was first diagnosed. She had to bring up basic questions with her doctor during clinical visits. Questions like "*What is the range of normal blood sugar levels?*" "*What can I eat?*" and "*Do I need to record any numbers?*" are asked by some participants during clinical visits because some doctors seem to be "*making it a secret*".

Other participants reported that they do not keep diabetes-related information they found from mass media, such as TV, radio, newspapers, and the Internet, because the information is irrelevant or repetitive. In other words, new information is not available. Participants complained that most of the information they found are for type 2 diabetes,

which is not completely applicable to patients with type 1 diabetes. Also, P28 explained

the issue with the lack of new information, "*I mean there are stuff out there. I'm not*

blocking everything. But I'm just saying yes I pay attention, but I already know everything

that I need to know. I'm not against learning new things, but there's not a whole lot of

new things to learn."

On the other hand, having information available can motivate patients to manage

it. For example, P13 said that one of the reasons that she downloads and keeps videos that

her friends send her is that they are available for download. "*I don't know maybe they'll*

take it down from YouTube or whatever, it's lost. If I can download the video, I will

always download it." P13 seems to be also concerned about how long the videos are

going to be available. She anticipated the lack of access to the videos in the future made

her eager to keep it.

6.2.1.2 Information Abundance

When health information is available, its volume can also motivate or discourage

patients from performing PHIM. For example, P5 mentioned that she sometimes gives up

on information management with her emails, which include newsletters on diabetes

management, because there is too much information. She said, "*…sometimes just*

because of y'know, the overload of the email. Sometimes I leave it and just never get back

to it. …I often won't delete it especially if I've skimmed it or if I haven't looked at it at all.

I usually keep it, but that's why I have over 10,000 unread emails in my inbox."

On the other hand, having a small amount of information can also be a reason that

patients do not carry out PHIM activities. P4 mentioned that she does not organize the

articles that she keeps to facilitate information retrieval, because she does not have a

large collection of these articles. "*I don't really have many. I would say maybe like 10,*

maybe like 12... So if I were to need something, I only have a few sheets of paper to look

through. I don't have a vast collection." The low volume of information that P4 keeps in

the form of printed articles seems to not warrant the effort of organizing them, because

browsing through the whole collection is easy.

It seems that there is a balance point in the volume of information where patients

may be encouraged to perform PHIM. This point may be related to the types of

information items used and the PHIM activities required. Email used by P5 is an

electronic information item that automatically receives and keeps information, requiring

no effort on the person's part, but requires work on deleting and organizing information.

In contrast, the printed articles kept by P4 seem to require more effort in keeping

compared to deleting and organizing information, leading to a lower volume of

information to work with, and a lower level of necessity for information management.

6.2.1.3 Information Credibility

When patients have access to the health information they need, they may not

collect this information because of credibility issues. Some patients evaluate information

credibility based on its source. For example, P3 voiced her trust in advice from doctors

who have diabetes themselves, "*Dr. [name is removed] has diabetes himself, so he knows*

what it's like and he gives really good suggestions."It is common for participants in this

study to actively seek health care professionals who are living with the same type of

diabetes as the participants, because those health professionals not only understand the

medical side of the disease but also the nuances of everyday diabetes management, and can provide not only useful but also practical information.

Other patients noted that looking at the source alone does not warrant the credibility of information. P7 mentioned Dr. Oz's morning show on TV as an example and explained that the show has increasingly become a place for problematic advertisements despite Dr. Oz's reputation as a competent and caring physician. It seems that the context of an information source can affect its credibility. The perceptions that P7 has regarding Dr. Oz's morning show led her to stop using this show as an information source.

However, sometimes participants do not share judgments on the credibility of a piece of health information. For example, a new drug called Farxiga is FDA approved for people living type 2 diabetes. Two participants living with type 1 diabetes tried it and had different opinions. P17 finds it very effective, but P7 finds its side effects are more significant than its health benefits and started doubting whether the drug is legitimate. "*I saw an ad for this drug on TV – I shouldn't have trusted a TV ad.*"

6.2.1.4 Information Accuracy

Participants have questions about the accuracy of information from external sources. For example, P15 used to have an app on her phone called Calorie King. She used it to keep track of her calorie intake but she found the information on calories of foods confusing, "*…it's not always so accurate. You have so many- a range of different things, I really don't know what the accurate thing is, so I'm like, oh I'll just Google it.*"

P15 stopped using Calorie King as an information source because of concerns for information accuracy.

Participants also reported that self-generated information can be inaccurate too. This lack of accuracy may prompt participants to triangulate the collection of self-generated information, instead of causing them to stop using certain information items. For example, P11 noted that "*I try not to do extra finger sticks just for the CGM[3], but sometimes when the CGM gives me a reading or an alarm, I don't necessarily feel the way that the alarm says I should feel, then I'll do a finger stick to confirm.*"

6.2.1.5 Information Consistency

The consistency of information also affects whether patients will manage it. Participants reported testing their blood sugar levels more frequently when they see a "ridiculous" number, in order to have a better estimation of their health condition and to monitor the effects of subsequent adjustment actions (e.g., taking insulin or medication for high blood sugar levels and taking juice or candies for low blood sugar levels).

Inconsistency can also come from external information sources. For example, P13 reported that she talks to her doctor if she has doubts about the information she collects from external sources. In order to do this, she performs PHIM activities, such as entering the information in a to-do list on her smart phone. Consistent information seems to lead participants to perform PHIM activities less frequently, vice versa.

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[3]CGM: A device that measures and displays real-time blood sugar levels with about 15minutes' delay. It also shows the direction at which the blood sugar levels are heading and the speed at which the changes are occurring.

6.2.1.6 Information Timeliness

Newly generated information is sometimes valued. P7 reported that the information in books can become obsolete by the time they are published. That is why she prefers reading articles found on the Internet. P7 also believes that information is worth more attention when it is freshly generated, either by herself or by other information sources (e.g., the Internet and magazines), because recent information provides immediate utility but its future utility becomes indefinite after some time. As a result, P7 does not keep much health information related to her condition.

The timing at which a piece of information is encountered by patients can also be a motivating factor for PHIM activities, no matter when this information is generated. P11 explained how she judges whether a piece of health information is timely, "…*if I see something that I would use immediately or I need to start implementing this in my lifestyle, that's urgently relevant. If it's like a touchy feel good story about somebody else that's successfully pursuing a particular lifestyle with diabetes, that's great and I like hearing these stories, but I don't necessarily have to retain that information. It's not like it's going to affect me greatly.*" Similar to P11, our other participants reported that different types of information that may help with their diabetes management at different points in time. When participants were newly diagnosed, any information seems to be worth keeping. However, as participants' conditions and their familiarity with diabetes management develop, they may discard information that no longer suits their needs and keep timely information that addresses their current issues.

6.2.1.7 Information Usefulness

A major motivator for participants to perform PHIM is whether they consider the health information useful to themselves and others. Participants reported that recorded health information can help them make self-management decisions and solve problems. For example, P24 measures her blood glucose levels to determine how much she will have for the next few meals. Some participants also use information to make long term adjustments. P2 keeps extensive records of his blood sugar levels, insulin intake, diet, and other contextual information, and integrates this information on a weekly, monthly, and yearly basis in order to identify patterns to guide behavioral adjustments on a strategic level over long periods of time. As P2 commented, "*I have been doing this* [i.e., keeping self-generated health records] *for a number of years. I would say 10, 15 years at least… One day, I would pick up a sheet, look at it, and see a pattern. Patterns determine possibilities.*"

Some participants benefit indirectly through managing their personal health records, mainly by sharing these records with their health care team. For instance, P16 keeps records of his blood sugar levels diligently and would print these records out when he encounters questions about the numbers and tries to seek answers. P16 mentioned, "*If it's something that I'm going to say to my doctor or share with others, I would print it out and look at it with my- To find out what could cause my A1C to become more elevated.*"

Not only would the benefits for oneself motivate participants to perform PHIM activities, but the anticipated utility of information for others would also have similar effects. Several participants are A1C Champions[4] and they keep information from

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[4]The A1C Champions Program is a peer-led education program offered by sanofi-aventis U.S. LLC for people living with diabetes. The A1C Champions are diabetes patients with

sources other than themselves to "*help others and help themselves*". For example, P12 mentioned that most of the external information he searched for and kept was for other patients he helped. When he finds an article or a brochure, he considers if it would be useful for himself and for other patients, then decides if he will keep it.

Participants may also keep health information to help others indirectly, such as through contributing to research projects. For example, P16 uses a Medtronic insulin pump, which records his blood sugar levels and insulin dosages. P16 uploads this information to Medtronic because "…*it's possibly something that maybe keep track of all people that are using their product and see if it's really helping them manage their diabetes better than what they're doing before*."

Keeping family members and caregivers informed may also be a motivating factor for some patients. For example, P8 sets up her phone to allow her husband to have access to her location in real-time, so he would not be concerned, when she is off schedule, about issues such as medical emergencies caused by her low blood sugar episodes.

Participants also recorded that information that they do not record information perceived as useless. P5, for example, expressed her frustration with useless information from family members, "*They know just a very little bit about diabetes and it's probably from 2008. Y'know, I don't expect them to follow it closely but it's just that 'Oh, you shouldn't eat sugar'. 'Oh, you're acting funny, your blood sugar must be low.'*" P5 does not keep information from family members because such information has little use to her.

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well controlled A1C levels. One of their major tasks is to give talks to fellow diabetes patients to educate and motivate them on diabetes management.

6.2.1.8 Information Process Level

Much of the information patients gather on a daily basis is raw data with low levels of processing. For example, participants reported recording their blood sugar levels and medication usage, which are sets of data that are not connected to each other in their natural status. Some participants also keep articles they found online, which can be about specific topics that do not reflect much about personalized health care strategies for individual patients. Participants reported that more processed (e.g., integrated, connected, and annotated) information can show meaningful patterns and point to possible solutions to their personal health problems. Therefore, these participants were more encouraged to organize their highly processed health information compared to its less processed counterparts.

For example, P11 organizes information about her caloric intake and exercises using two smartphone apps. These apps communicate with one another and "*translate how much exercise I've done into calorie burning*". On the other hand, the lack of integration of the other data she could keep, such as blood sugar levels and insulin intake, has discouraged her from organizing this information. P11 explained, "*if I could get my blood sugar levels and my carb counts and my insulin usage and my activity levels, and all of these things were integrated together, I would have a much greater understanding of what's going on and how things are affecting my body.*" P11 still uses the smartphone apps she mentioned sporadically but she does not perform further information management activities using information from these apps (e.g., download or transcribe records and solve mysteries regarding blood sugar level changes) due to their limited functionality.

6.2.1.9 Information Presentation Style

How information is presented to patients can also affect whether they perform PHIM activities. A few participants reported that they enjoyed reading information displayed on their continuous glucose monitor or CGM. This is partly because the device allows them to set an interval for their desired blood sugar levels and display multiple historic records of these levels at the same time, enabling them to estimate their condition over time at a glance. As P18 mentioned, her CGM can be connected to her computer and show color-coded data on highs and lows, and features like this have prompted her to keep a closer eye on her condition and save copies of this information for herself.

On the other hand, some ways of presenting health information may not be well accepted by patients with specific needs. For example, P17 reported that the reason she does not read books or feel a desire to keep them is because books take too long to get to the point in their usual writing style. Books tend to try to engage readers by using stories, examples and analogies in their introductions, but for P17, succinctly presented information is more desirable for efficiency.

6.2.1.10 Information-Elicited Emotions

When participants are exposed to diabetes-related information, they may avoid it if it brings unpleasant emotions. For example, P25 reported that he never record diabetes-related information that he comes across from TV, because "*Most of the television things are very depressing you know, I actually - my only personal feeling is I really wish they would ban the pharmaceutical industry from television advertising because it just is so unpleasant…* " P8 agreed and went further to explain that the negative information we

find from external information sources is amplified because people's "*tendency is to go to the awful prognosis at first*".

The negative emotions led participants to abandon some information sources altogether. P13 explains the reason that she avoids certain websites, "*If it's a freak-me-out article, I won't read it. And I try not to get on WebMD and all of these websites, because I think they just- it would scare me.*"

Similarly, participants' self-generated information with negative implications can also cause participants to avoid certain PHIM activities. For example, P11 does not feel appropriate to share her real time health information with others because the lack of contextual information may lead to unnecessary concerns, "*It's creating anxiety for the sake of anxiety and for instance, if … my sensor came out accidentally, I might get a fake alarm, but I know that the sensor came out. Other people may not know, so it's a complicated issue.*"

On the other hand, positive emotional reactions to information may encourage PHIM activities. For example, P2 mentioned that keeping information about himself makes him feel a sense of control no matter what the information may show. If the numbers are in range, he feels happy that things are going fine; if the numbers are out of range, he knows how to fix it and feel relieved that he has caught a problem. This sense of control is one of the motivating factors that drove P2 to carry on the work of keeping extensive records about himself.

6.2.2 Medical Motivators

Medical motivators include 6 subcategories, as shown in Table 12. The rest of this

section includes explanations and examples for each medical motivator.

Table 12
Medical Motivators

Medical Motivators	Definition	Examples
Symptom Notability	The notability of the symptoms of the health condition experienced by participants.	*"When I feel uncomfortable, I test and record my blood glucose levels."*
Symptom Consistency	Whether the symptoms are stable under certain conditions, such as when given the same treatment, at the same time of day, when the patient performed the same daily activities, etc.	*"If my numbers are normal over some time, I test less frequently."*
Condition Severity	How severe the health condition is, as perceived by participants.	*"Only those with continuous bad numbers need to test frequently."*
Discomfort Prohibiting Information Management	Health conditions that prohibit information management activities. These conditions may relate or not relate to diabetes.	*"My hands are shaky; it's hard to write down anything."*
Discomfort Caused by Information Management	Discomfort caused by performing health information management activities.	*"Pricking fingers seven times a day is too painful for me."*
Anticipated Health Outcomes	Patients may be motivated to perform PHIM activities if they believe these activities can bring about better health outcomes.	*"I get more information so I can have better numbers."*

6.2.2.1 Symptom Notability

How noticeable the symptoms are can motivate participants to perform or not perform PHIM activities. Participants reported that if their symptoms are noticeable, they would be more motivated to manage their diabetes-related information. For example, hypoglycemia episodes are particularly dangerous to diabetes patients who are insulin dependent because they can lead to impaired cognitive functions, seizures, and death (Cryer, 1999). Participants reported that when they "*feel a low* [blood sugar]", they would measure their blood sugar levels to confirm and take actions to raise their blood sugar if necessary. The symptom of a low blood sugar can be very unpleasant, prompting participants to collect their health vitals more frequently. P30 complained that "*the worst feeling in the world is when your glucose starts to drop. When it starts to get to 70 and below, the last thing you want to do is eat, you want to just crawl into a hole and die, …but the cure is to eat or drink something like orange juice or milk or apple juice, something that will elevate your glucose. But it doesn't happen right away. It takes a good 15 to 20 minutes for you to start to feel a little better. So before I go on the treadmill or on the bicycle, I always check my glucose, and I suspend my pump if I have to*."

On the other hand, when symptoms are not noticeable, participants may reduce the frequency of PHIM activities. P12 suspects that type 2 diabetes is on the rise because the symptoms are not noticeable enough, at least over the short term, and this is causing people with type 2 diabetes to not appropriately manage information they collect from their doctors. "*You went out and had too much to drink today and tomorrow get a hangover, cause and effect is pretty obvious; but what you do today with your diabetes*

does not show up tomorrow morning, it's further down the road, and if you've done some

damage and caused some of these complications, for the most part, you're not going to be

able to reverse the circumstance. ...And it's like, why didn't you tell me? Well, they did

tell you, you just didn't pay attention. You didn't take it seriously."

Participants also reported cases where they feel insecure when their symptoms are not noticeable enough and may collect information about themselves more frequently as a result. For example, P7 noted that frequent testing of her blood sugar levels is important because it allows her to notice problems even when her body does not feel it. "*The numbers are supposed to register what's going on in your body. But in my head, like now, I feel great. ... I don't feel I'm going down from this number. So it's very hard to really tell. ... They call it now diabetes unawareness. Whereas the beginning, I used to be able to tell right away. Now I get different symptoms, and until I stick myself, I go, 'Oh, I'm low, mmm...' So everything changes, because your body gets used to certain things.*"

Hypoglycemia unawareness is a type of "diabetes unawareness" as mentioned by P7. It is a phenomenon where insulin dependent diabetes patients used to but no longer feel an imminent hypoglycemia episode, thus failing to take actions to avoid it (Cryer, 1999). Participants reported concerns about experiencing hypoglycemia unawareness during the night and not being able to react while asleep. To counter this problem, P10 developed strategies to make sure that she wakes up every night to test her blood sugar. She mentioned that she drink plenty of fluids before sleep because "*[y]ou wake up before you're going to pee in your own bed, and so it starts to irritate you awhile before it gets so bad that you have to go. ...So I figured that I live alone and if you die you're going to*

be anyway,... might as well try and see if that's going to keep you alive to go to the bathroom."

6.2.2.2 Symptom Consistency

When participants' symptoms with diabetes are more consistent, they tend to manage their personal health information less actively. For example, P13 introduced the development of her PHIM activities over time, "*you know six months ago, even three months ago, I was much more diligent about it* [i.e., recording blood sugar levels]. *Then I think it's just for me at this point, I've gotten to where I am pretty controlled in management it. And so I don't- maybe that's what it is.*"

While some participants agree that experiences with diabetes management lead to confidence in consistent symptoms and lower frequencies of PHIM activities, others maintain PHIM same levels of activities in case of occasional inconsistencies in their symptoms. P12 described the seasonal pattern in which he experiences inconsistent blood sugar levels, "*...there seems to be almost a cyclical effect. I, once or twice during each winter season, will have a period of anywhere between three to five days, where no matter what I do, no matter how much insulin I use. I'll have elevated blood sugars for no reason whatsoever. ...And so if I were type 1, ... I'd have consistent results with the same amount of insulin, with the same amount of carbs. But as a type 2, I have some days a greater resistance factor to the effects of insulin than other days. Gee, my pancreas will kick in a little bit more than I expected and so in many ways, it's kind of a crap shoot as to exactly what thing results. That's why I feel CGM is so critical to keeping you within reasonable balance.*" Although P12 imagined that people with type 1 diabetes may have

more consistent symptoms, participants with type 1 diabetes disagree. P1 mentioned that, despite her consistent and healthy lifestyle, her morning blood sugar levels are highly unpredictable. P1 said, "*I try, as soon as I wake up, to check my blood sugar, and see where it is, because it can be anywhere, from like 80 to 140 and if it's past 100, then I take 1 unit of my meal time insulin to stop the rise.*"

6.2.2.3 Condition Severity

Participants' perceived severity of their health conditions can also impact whether they perform PHIM activities. Unsurprisingly, when participants perceive that their condition is more severe, they perform PHIM more often, vice versa.

Perceived condition severity, however, can vary between participants, because of factors such as physiological characteristics, interactions between diabetes and other conditions, medication side effects, etc. For example, P30 has type 1 diabetes and heart conditions. Her doctor suggests that she maintains a higher blood sugar level compared to what is recommended for other type 1 diabetes patients, because a hypoglycemia episode can be detrimental to her heart. In this case, P30 does not actively monitor or keep information on her blood sugar levels because elevated blood sugar levels are considered less severe compared to other diabetes patients.

6.2.2.4 Discomfort Prohibiting Information Management

Participants reported that discomfort caused pre-existing conditions such as diabetes, cancer, gout, trauma, and the interactions between multiple health conditions can discourage them from managing diabetes-related information and create tremendous

hurdles for such activities. For example, P18 is taking medications to manage cancer and one of the side effects of a medication is extreme fatigue, which prohibits her from performing PHIM activities, such as testing her blood sugar and making records of it. She explained the constant struggle and misunderstandings associated with this difficulty, "*The doctors wouldn't understand, 'but you just get up and do it'. If I could do that I wouldn't be in the position I'm in. I mean there was one day I missed work because I was trying to do a finger stick. It took me like 4 hours and I keep falling the slips between, just kept on passing out practically. Because I just could not keep my eyes open.*" Much of this difficulty is invisible to others, including P18's health care providers, who sent her to multiple specialists to solve the mystery of her fatigue, such as checking her thyroid functions. It was not until a year later that P18 found out about the medication's side effect and identified ways to cope with it.

6.2.2.5 Discomfort Caused by Information Management

Some participant voiced that performing PHIM activities can bring discomforts, such as pain and stress, and these discomforts can discourage them from continuing these activities. Participants noted physical discomforts, such as pain and disturbance associated with finger sticks for blood sugar testing, irritations on the skin caused by tapes used to hold sensors on a CGM in place, and bulkiness of CGM and insulin pumps that interfere with sleep and physical activities.

Some of these physical discomforts extend beyond the body. P10 explained how testing blood sugar with a glucose meter has interfered with her hobby, "*[l]ike the canvas here. I needle pointed that. So I did that many many many years ago, well before I was*

diagnosed. I have a canvas there, you see on all my walls. …When you do this kind of needlework, one of the enjoyable part is the feel of the wall, the physical touch. From sticking your fingers, tens of thousands of times, …you really lose some of the sensation in your fingertips. And your fingertips are rough. So it takes away that small pleasure." P10 still tests her blood sugar levels frequently for her health but does not record these numbers, because "*it would probably piss me off… Because … the theory of karma, goes around comes around. It's like what have I done to deserve this? Okay?*" The physical discomfort from PHIM activities experienced by P10 can be amplified when she makes records of her health vitals, reminding her of the work she put into the activities and the discomfort she has suffered.

Other participants noted that PHIM activities can also bring psychological stress. Similar to P10, P7 also tests her blood sugar levels frequently but does not make records of these test results. P7 argued that the extra work on top of active blood sugar monitoring can add to the stress she is experiencing, which can worsen her physical condition.

6.2.2.6 Anticipated Health Outcomes

Participants agree that a goal of performing PHIM activities is to strive for better health outcomes, such as avoiding the short term symptoms brought by out-of-range blood sugar levels, longevity, delayed complications, and the ability to live a normal life. Intuitively, this motivator would be a primary motivator for PHIM activities, but the results show that many other motivators interact to shape participants' PHIM activities and experiences.

6.2.3 Behavioral Motivators

Four subcategories of behavioral motivators were identified and reported in Table 13.

Table 13
Behavioral Motivators

Behavioral Motivators	Definition	Example
Continuity of Existing Behaviors	Whether PHIM activities are a part of participants' existing behaviors and allow the continuation of existing behaviors, or cause disruptions in these behaviors.	"…it's being like a routine thing to just get them on my spreadsheet instead of having them take my pump and like print it out and stuff."
Ease of Information Management Processes	How easy it is to perform PHIM activities as perceived by participants.	"It is just too much trouble – having to do it multiple times a day and constantly thinking about it."
Availability of Information Management Tools	Whether desirable health information management tools and functionalities are available as perceived by participants.	"The blood glucose meter comes with a notebook. I use it to record my numbers."
Ease-of-Use of Information Management Tools	How easy it is for the participant to use the PHIM tools as perceived by participants.	"It is very easy to enter numbers in the table."

6.2.3.1 Continuity of Existing Behaviors

Participants reported the routines are an important part of their diabetes

management and whether they perform certain PHIM activities depends on whether these

activities are a part of their daily routine and how these activities interact with their daily routine.

Participants found it easier to continue performing PHIM activities when these activities are integrated into their daily routine. P25, for example, remembers the effectiveness of a diabetes patients training program he participated, "*I had to stay in a hotel in Boston. And then they treat you, ... so the doctor tells you how you should count all the carbs and they made the - the correction ratio and my carbs I'm taking.*" P25 carried on with what he learned from the program after he left and he stressed the importance of maintaining healthy routines, "*Everything I think about managing diabetes deals with habits and good habits. ...Writing down what you eat, shooting before you eat, noting how much carbs you're going to eat and then calculating the amount of insulin to take for the amount of carbs you're going to ingest. ...if something is a habit if it is habitual, you don't always think about it, you just do it.*"

The ways in which PHIM activities facilitate or cumber the continuity of other daily routines can also have different motivating effects for participants to perform these PHIM activities. P15 describes how testing her blood sugar levels has disrupted her everyday life and caused her to not actively record her test results, "*So is like every time I test my blood sugar, ...it's like 4 times a day. ...I know it doesn't sound so bad, but like you're getting up in the morning and you gotta run. I'm sending my daughter to school, and I'm putting the information in a few devices. And when I'm hungry I want to eat lunch. ... Everyone sitting down at the table and I'm like oh shoot, I gotta test myself before I can eat. ... It's like all these extra steps. ... It's getting in the way of normal life, thinking about blood sugar all day.*"

6.2.3.2 Ease of Information Management Processes

Participants reported more likely to perform certain PHIM activities when they perceive these activities as easy to accomplish. P16 describes how PHIM activities for diabetes management have been an easy task for him, "*It's not hard… this is an ordinary thing, it's like everything else. … In a day I'd say, three meals, maybe 15 minutes total for all three meals. … It's seconds to take- you wanted to take the test strip out, and to take a finger stick test, and get ready for breakfast, maybe a minute. Counting my carbohydrates, maybe 30 seconds or so, and insulin injections and that is just- get the number of carbohydrates I need, I'll push a few buttons on my pump and it's done. Gosh I'd say, to be honest, maybe 3 minutes for managing diabetes. Not the whole process, for each process. 3 minutes for breakfast, for lunch, for dinner. So whole day maybe max 9 minutes. Sometimes for example, I need to change the battery and the pump, but that doesn't happen every day.*" P16 manages his self-generated information on a daily basis, partially because this process is not considered hard for him.

In contrast, P22 found it challenging to perform PHIM activities. She reported difficulties with portion size and carbohydrate counting and why she is not collecting and using information on her carbohydrate intake. "*I don't know the size of what I'm eating. Like one portion. …Like an apple. I eat an apple, right? But this size apple, this size is way different than a big size, right? So what do I know? I just dope up my carbs in for an apple.…I can't to grams. Where am I going to weigh it? …I don't eat packaged food. I don't need anything that's packaged. But they should have a way.*"

Participants also reported that they perform PHIM activities when these activities make other subsequent PHIM activities easier. For example, P13 keeps a collection of

emailed newsletters that involve diabetes management information. She explained that she can search the emails, but putting emails in different email folders "*will break it down much faster at search, so it takes less time.*"

6.2.3.3 Availability of Information Management Tools

Some participants believe that some information management tools can help them with PHIM activities and lack of these tools has kept them away from managing certain diabetes-related information. For example, P22 found it hard to understand carbohydrate counting but smartphone apps can help her overcome these difficulties. "*I don't have a smartphone. I don't have any apps or anything like that, but I'm going to get one. ... I heard there is a way that you will be able to, you take a picture of what you're eating, and they can tell you how many carbs it is. That would make me happy. That's what I need.*"

Other participants reported that having access to information management tools have motivated them to manage their health information. For example, P11 uses a smartphone app named S Health to record her health information because the app is built in on her smartphone.

Not having access to desired information management tools can also prompt participants to build their own tools. For example, P2 designed a paper form to incorporate all the contextual information that the booklets provided by his health care providers do not have space for. Also, P20 uses an electronic spreadsheet to record his self-generated information and build statistic models because no paper forms or smartphone apps he know has the same functionality.

6.2.3.4 Ease-of-Use of Information Management Tools

When participants have access to information management tools, how easy it is to use these tools can also motivate participants to manage or not manage their health information. For example, P1 found it a challenging task to remember if she has taken insulin and sometimes she risk injecting insulin twice if she does not remember the first injection. This can cause hypoglycemia with serious health consequences. She has considered using calendar reminders and alarms but she would forget to set these alarms or forget if she has acted upon the alarms if interrupted in the process. P1 is now using a timer device that is attached to the insulin pen, which resets the timer whenever an injection has occurred. In this way, P1 is able to keep track of her injection schedule without much difficulty.

On the other hand, difficulties with using certain tools can discourage information management activities. For example, P15 does not download information from her CGM or input contextual information (e.g., carbohydrate intake) into her CGM because she does not know how to perform these tasks. She said, "*honestly I could plug my CGM in and save the information but have never done that. I never got comfortable with it, which I really should, because I was getting much better- and then again, it doesn't always- cuz actually, I think there is a way to put what* [and]*when you eat into the CGM, but also I haven't done that. They never really showed me how to do all the extra stuff on it, so I never used it for that, but I think you could actually do it, it would be more helpful I guess.* "

6.2.4 Social Motivators

A variety of social factors can have different motivating effects on participants'

PHIM activities. Table 14 shows a list of social motivators and their corresponding

examples.

Table 14
Social Motivators

Social Motivators	Definition	Example
Social Identity	How participants position and perceive themselves in their social environment in relation to other people.	*"Type 2s are very different. They don't have to take medicine. They can manage diabetes by taking better care of themselves. I don't think they understand what it's like to be a type 1, so I don't talk to them about diabetes."*
Exclusiveness of Benefits	Whether performing certain PHIM activities would benefit others.	*"These magazines I bought were all taken and never returned, so I don't buy them again."*
Expectations from Others	The expectations that others hold for the participants' information management activities can affect whether participants perform these activities.	*"The doctor asked me to write down all the numbers."*
Reactions from Others	How other people react to the participant's PHIM activities can influence whether participants perform these activities.	*"The doctor does not look at these records, so I stopped recording."*
Exemplars	People who have similar health conditions may have experiences and outcomes from performing or not performing PHIM activities that are known to the participant and motivated the participant to perform or not perform	*"My brother manages diabetes very diligently, keeping all these records and being conscious about what he eats, but he died before me. I don't think any effort*

	certain PHIM activities.	*will make a difference."*
Social Significance of Information Items	The meaning of certain information items in relation to the participant's social network.	*"I keep these books because they are all gifts."*
Stigma	The association of stereotypes of diabetes patients with negative ideas.	*"I don't talk to people about my diabetes because they assume people with diabetes don't take care of themselves."*
Social Norms	How social norms can facilitate or discourage the performance of certain PHIM activities.	*"You are not supposed to be doing an injection or stick a needle in your finger in public."*
Social Relations	Participant's relationships with others can have an effect on whether the participant performs PHIM activities.	*"The Twitter support group is particularly helpful and I know that I have done a much better job of taking care of myself, the more involved that I got with a diabetes community."*

6.2.4.1 Social Identity

Participants' perceived social identity for themselves may motivate them to perform PHIM activities in different ways. Participants disagree on whether diabetes is a part of their social identity. P19 reported that his earlier unwillingness to be associated with the identity of being a person living with type 1 diabetes has made it difficult for him to collect any information related to his health condition.

On the contrary, P20 prefers to inform people around him about his condition so he can more comfortably manage his diabetes-related information in a social environment.

For example, P20 informed his co-workers about his need for frequent blood sugar tests and potential medical emergency situations. He even jokes about guarding his co-workers' specialty chocolate because he is not interested in having any due to his health condition. P7 adds that although she accepts her diagnosis, she will not let being a diabetes patient become her major identity.

For participants who have careers related to diabetes (e.g., P1 is a writer who focuses diabetes-related topics and an A1C champion; P14 is the CEO of a start-up company for type 1 diabetes patients), they embrace their health condition as one of their major identities and they are more motivated to perform PHIM activities because of this.

The identity of being a person with diabetes seems to have encouraged participants to avoid communicating diabetes-related information with people who do not have diabetes. A major reason is that people without diabetes would not understand the nuances experienced by diabetes patients, and may pass judgments on patients or provide unsolicited advice to these patients. This concern has led some participants to seek out health care providers that are also living with diabetes in an attempt to promote mutual understanding.

Participants also do not agree on whether people living with type 1 diabetes and those with type 2 diabetes should share the same identity when it comes to information management. P7 argues that both conditions, albeit different in physiology, would require similar information management processes. Therefore, she organizes support groups where people living with either condition can attend and share their experiences or seek help. P7 is living with type 1 diabetes and she recalls connecting with a waiter who has type 2 diabetes when the waiter saw her test her blood sugar at the dinner table. She said,

"it's like another language. It's like you are meeting someone from a foreign country that knows your whole background. So it's like a society within."

P26 disagrees and supports that type 2 diabetes patients *"really don't have all that hassle to deal with. It's probably kind of judgmental, but I don't really like to look at them like real diabetics. They are like light to diabetics, and we're like hardcore diabetics, we are like the real troopers."* As a type 1 diabetes patient, P26 does not seek information from patients with type 2 diabetes.

6.2.4.2 Exclusiveness of Benefits

Participants may be motivated to manage diabetes-related information depending on whether this work may benefit others. Participants reported managing health information that has minimal use for themselves in case this information can help others. As P9 mentioned, *"You help yourself by motivating others, motivated by motivating."* Participants reported activities such as sharing articles at support groups to help newly diagnosed patients, uploading self-generated information to services in the cloud in case it is useful to others, and building online repositories of articles to share with others.

6.2.4.3 Expectations from Others

If certain PHIM activities are expected or required by other people, participants may be more motivated to perform these activities. For example, P30 noted the reason that she keeps short term records of her blood sugar numbers, *"I did that only when I went to the doctor. I did it for them. They asked me to do it for a week. So I was going to*

the doctor on Friday, so I start to keep it on the previous Friday for the whole week, and then I give her the sheets."

Interestingly, P3 reported that she keeps records of her diabetes-related information at work because a part of the information is pertinent to her company's policy of "*encouraging employees to follow up healthy diet and things like that*". P3 searches health-related information on her work computer and keeps it in a flash drive when she is free.

In contrast, no expectation from others can lead participants to not perform certain PHIM activities. For example, P17 mentioned that a reason that she does not keep self-generated information is that, "[n]*obody ever told me to do it more than the test and control. So I don't do it.*"

6.2.4.4 Reactions from Others

Other people's reactions toward participants' PHIM activities may lead them to carry on or discontinue these activities. For example, P1 reported positive experiences when she shared diabetes-related information with peers, which motivated her to continue sharing. "*They* [i.e., patients]*are still grappling with the basics, but it's just very rewarding to help them out, you know, and then they'll come up afterwards and they'll ask me questions or thank me for something I said that made a difference for them. It's fun.*"

In contrast, some participants stopped performing certain PHIM activities when facing negative reactions from others. For example, P8 stopped recording her insulin intake because her doctor does not seem to care. She said, "*I don't think it would be that*

helpful… In fact, when I take these printouts from a diabetologist, he never really asked me what's, you know- he just asks me- he goes over what's the scale. So I get a feeling that it isn't going to do that much for me."

6.2.4.5 Exemplars

Exemplars may have motivating or discouraging effects whether they are successful or unsuccessful in managing diabetes. Intuitively, exemplars with positive health outcomes may motivate PHIM activities. Participants reported that interacting with peers at support groups who have lived with diabetes for more than 50 years with no complications has been very inspiring and encouraging. At the same time, negative examples from participants' social networks have warned participants about the potential consequences of not performing enough PHIM activities. For example, P20 was devastated by his sister's death resulted from complications from type 1 diabetes. He was struck by how fast the condition progressed without proper care and this experience is a reason that he is diligently keeping records of his self-generated information and building time-series models around it.

On the contrary, successful exemplars can motivate people to perform fewer PHIM activities because such activities may reduce quality of life aspects other than diabetes-related complications. For example, P7 tests her blood sugar diligently and uses a CGM to monitor her status but does not keep records of these tests results over the long term, partially because an overload of such work is unnecessary and it negatively impacts the quality of life. P7 mentioned, "*I have some friends who make themselves crazy. They'll test every finger to see if this hand is better than this hand. I mean you can't let it control your life. This guy he was on a meter, he was on a CGM, he wrote out every*

number, he wrote down what he ate. He was doing the same thing that I was doing 10

years ago, and it continues."

6.2.4.6 Social Significance of Information Items

Participants reported keeping some information items not because of the

information it provides, but because of the meaning of these items for the participant's

social life. For example, the diabetes-related books that P9 keeps are all gifts from people

in her social network. She kept these books for a long period of time although she rarely

keeps other printed media such as magazines.

Also, P24 keeps the schedule from a diabetes-related meeting to remind her of the

time spent there and the people she met. She recalls, "*I kept the handouts and the*

schedule of meetings and this list of speakers and things like that. Just maybe even for

prosperity. I really enjoyed myself and it was like coming back from a great trip and

bringing back postcards or something like that. That's how I felt. I wanna remember this

stuff, I mean we were given some really cheesy costumes. Well, there was a banquet and

we had to dress up a little bit and so they had headbands with snowflakes on them for like

Disney's Frozen you know? They like lit up. I will never wear that, but like it just makes

me think of the great time I had and all the people that I met. Yeah. I will keep my glow in

the dark light up headband."

6.2.4.7 Stigma

Perceived stigma can discourage participants from performing PHIM activities in

public. Some participants with type 1 diabetes stress that they have juvenile diabetes

when asked by others. This is to assure that other people do not consider them as lack of self-control, which participants report is a quality associated with type 2 diabetes. One the other hand, participants reported that type 1 diabetes is usually considered more serious and easier to pass on the next generation. Both conditions seem to suffer from some level of perceived stigma, which leads to hesitations with diabetes-related PHIM activities in social contexts.

6.2.4.8 Social Norms

Participants reported that accommodating to social norms can be an important factor when they make decisions on whether to perform PHIM activities in social environments. Participants complained that people do not feel comfortable when they see blood in social context and they had to refrain from testing with glucose meters in public. P22 mentioned that one of her friends at a support group she frequented would not test her blood glucose in public, because she once tested in a restaurant and was asked to leave by the waiter and other customers. One of the customers was breast feeding her child and nobody complained, perhaps because people have a better acceptance of breast feeding over the view of blood in a dinning environment.

There are also participants who challenged the norm in certain contexts and carried on PHIM activities because diabetes information management has become the new norm. For example, P7 recalled testing her blood glucose levels in her office while her colleagues visited. They were curious of the devices and supplies and P7 would educate them, while demonstrating how the devices are used. P7's openness also enabled her to help one of her colleagues with a quick diagnosis. The story is, "*I had one boss*

who had one kidney and came into my office and say to me, 'I'm really feeling crappy today.' So I said, 'Do you want me to test you?' So he said, 'Would you mind?' I said, 'No.' [Author note: Participant acted out the motion of blood glucose testing] *I said 'Go down to see the doctor. You are too high, you are not normal.' And he was put in hospital.*" In a way, P7 has made her office environment into a blood-sugar-testing-friendly one through actively educating her colleagues and offering help.

6.2.4.9 Social Relations

For some participants, a good social relationship with others can prompt them to manage health information related to the other party. P6 described his bond with his endocrinologist, "*She's really nice and she cared. She cared about condition. The other thing is that her father is a pathologist so we bonded on that basis. I've heard a lot of stories where, I mean, friends of mine have emailed me about problems they are having with their doctors. My advice is get another doctor. Honestly if they are having the problems relating to their physicians, they don't have to put up with that. I feel very lucky that I've got such a good physician…. I think when you have someone who is very important in your care that you do a little more in trying to please them.*" P6's good relationship with his doctor prompted him to record his self-generated health information more diligently and also actively share it with his doctor.

6.2.5 Personal Motivators

Some personal preferences and attributes can motivate participants to perform PHIM activities differently. Table 15 shows 8 personal motivators reported by participants.

Table 15.
Personal Motivators.

Personal Motivators	Definition	Example
Outlook On Life	The participants' anticipation of their future life, such as quality-of-life and social networks, can motivate participants to perform or not perform PHIM activities.	*"What the doctor said really makes me feel hopeful of what the future is. I see that I can still have a normal life and that completely changed my mind set."*
Interest in the Activities	How interested the participants are in PHIM activities can affect how they perform these activities.	*"I manage my daily health information as a hobby."*
Interest in the Information	How interested the participants are in the health information can affect how they manage this information.	*"I personally want to know my numbers, probably because of curiosity."*
Location of Responsibility	The participants' perception of who is responsible for diabetes management and related PHIM activities can influence whether they perform these activities.	*"Doctors don't have the time and they don't know what's going on in my day-to-day life. So I have to be proactive in my own care."*
Abundance of Time	How much time the participants can allocate for PHIM activities can determine the intensity of the PHIM activities they perform.	*"I have a very busy schedule. I don't have time to test my blood sugar all the time and write down the numbers."*
Abundance of Space	How much space the participant can allocate for information items used for PHIM activities can affect the ways in	*"I try not to keep any physical copies because it takes up too much space."*

	which participants carry out PHIM activities.	
Confidence in Memory	How much trust the participants have in their memories can influence what PHIM activities are performed.	*"I don't remember. That's why I keep the records."*
Secure Information	Participants may feel insecure about their information because of the possibility of losing it.	*"...my sketch book is often for sketching but I have things that I have to write in there. This is for insurance."*

6.2.5.1 Outlook on Life

Patients' perspectives on what their future would be like and what they hope to accomplish can have a great impact on how motivated they are in PHIM activities. Compared to living a long life, living a quality life seems to have stronger motivating powers. P10 mentioned that dealing with diabetes "*is not a game of who lives longest, but who lives the longest while still enjoying life.*" What constitutes a quality life, however, differs between people.

Participants reported that they hope to live a long and healthy life in order to achieving personal goals. As a painter, P25 values his talent in and devotion to painting more than anything else when it comes to motivating himself to manage diabetes-related information. He said, "*Life could be long and fruitful …. The thing is with an artist, when you die, all you do is you try to sell as many paintings as you can in your life time. You put them out in the world so that people can enjoy them…. If I get to be 86 years old, I'm going to have another 20 years of pictures …. I enjoy my work, it's not always easy, but it's mine.*" P25 lost his toe due to diabetes-related complications, and in his attempt to

gain better control of his blood glucose levels, he fainted in the street due to hypoglycemia episodes and was admitted to the hospital a few times. These events made him ponder on what he wants to achieve as an artist and how he could assure his condition does not get in the way. After consulting his doctors, P25 started maintaining a log book where he records his daily health-related activities and data.

Participants also mentioned that being able to spend quality time with family and friends also motivated them to perform PHIM activities. For example, P1 recalls that she used to have minimal motivation to measure her blood glucose levels, but everything changed as she welcomed a major transition in her life. She says, "*I was 48, I was getting married for the first time, so I decided I wanted to be as healthy as I could be, for as long as I could be.*" P1 is now an A1C Champion with a rigid daily routine and regular blood glucose levels. For P1, being healthy for her marriage seemed to be more motivating than being healthy solely for herself. Our participants also reported that they do not want their family members to worry about them (e.g., P26), want to be able to look after their young children (e.g., P15), do not want to add burdens to their grown children (e.g., P8), and hope to spend more time with friends (e.g., P16). As P16 mentioned, diabetes information management is "*a labor of love*". He is diligent with PHIM activities because "*I have family and friends and I want to spend time with them, not to be a burden to anyone.*"

6.2.5.2 Interest in the Activities

Participants reported that their pre-existing interest with information management is related to how they manage diabetes-related information. P13, for example, finds pleasure in organizing anything, including her health information. She is especially

interested in labeling and categorizing information items, such as books and web pages. P13 expresses her interest for information management, "*Honestly if you have questions about how to organize something, like a spreadsheet, pick my brain. It's like my crack, I call it.*"

On the other hand, some participants found managing diabetes-related information a difficult chore because of their lack of interest in managing any information. As P17 puts it, "*I don't have great interest for inspection regarding my diabetes. I want to find out where it came from how I got it and how to get rid of it.*"

6.2.5.3 Interest in the Information

Participants also mentioned that they manage certain diabetes-related information because they are interested in the information and curiosity drives them to learn more. For example, P8 keeps information on medical research that she ran into at the hospital she is volunteering. She explains that a reason for her to keep this information is "*It's general knowledge. General advanced knowledge. And I'm just fascinated by things, like diabetes in the hospital and how they manage it.*" P16 adds, "*I like to research information, new information, you know, I have a desire to find out about it*", which is a reason for him to periodically search for new information online.

6.2.5.4 Location of Responsibility

Participants disagree on who is responsible for PHIM activities. Some participants believe that PHIM activities are patients' responsibilities and they are more active in performing these activities. For example, P7 describes a reason that she makes notes of

what she needs to talk to her doctor before her regular check-ups, "*I'll jot it down and if I see like one word of it, I know what I want to say... they [i.e., doctors] have limited time, in and all, that's also money related.*" P7 also mentioned that this responsibility persists when she leaves the home environment and enters a non-diabetes-related in-patient setting. During a surgery, P7 insisted on bringing her blood sugar testing tools with her and said to her health care team, "*I will do my own testing. I will tell you what my numbers are but you are not to come near me unless I can't talk.*" P7 was concerned that because the surgery team does not have the responsibility or the expertise in diabetes care, her needs for maintaining stable blood sugar levels may be perturbed during her stay at the hospital. P8 also mentioned that she takes full responsibility of her PHIM activities because "*nobody is going to be as interested in me as I am*".

Participants may also perceive PHIM activities a responsibility of others and therefore do not manage their diabetes-related information. For example, P22 answered a question on the ways in which she uses her self-generated health information to guide her diabetes management activities, "*He does that. My doctor does it. I don't know.*"

6.2.5.5 Abundance of Time

Participants reported time is an important resource. While they agree that blood sugar testing does not take much time, they do not have enough time for other PHIM activities such as search for extra information related to diabetes management and make detailed records of their health condition.

Participants appreciate tools that can help them with PHIM activities and save time. P13 often finds interesting articles online when she is using scraps of time to

browse the web. Because the devices she uses when she is on the go do not share browser bookmarks, she has to email the web links to herself as a quick fix and hope to bookmark the links when she goes back home. However, "*sometimes I wouldn't have time to go back and bookmark. And it felt overwhelming*". P13 now uses an Excel Spreadsheet and Pinterest (i.e., an online bookmarking website) to manage her web links because "*it's being a time-saver, which is really great*".

6.2.5.6 Abundance of Space

Lack of space is a common theme for participants who live around New York City. For these participants, accumulating paper materials is not an option because of the limited space in their home. P24 complained "*I don't have a lot of room. I live in New York City so I don't have a lot of shelf space*" when asked about the reason that she is not keeping a copy of the paper materials she received.

Some participants reported that they may have the space to accommodate paper materials, but they prefer not to in order to "*de-clutter*", as a way to make their living space more pleasant.

To resolve the issue of lack of space, participants resort to digitizing paper materials and keeping digital items only. For example, P14 mentions, "*It just seems less and less relevant to really have the hard copy and so environmentally is paper. I don't also have the space, since I live in New York City in storage. I just prefer to try to use things more digitally. Fact is sometimes it's annoying. When I have found something in the physical form, and I really wish I just had it already in digital form.*"

6.2.5.7 Confidence in Memory

Participants report that if they have confidence in their memory, they tend to perform other PHIM activities, such as recording and organizing diabetes related information, less frequently. P30 mentions that she does not keep diabetes-related information, "*I don't keep it in a file or anything. It's just up here. And also I've been doing most of this for so long, it's kind of second nature to me now. I do have a good memory.*" However, the confidence in memory does not necessarily apply to all health information. During the photo-documentation phase of the interview, P30 found a notebook where she keeps written notes when she goes to doctor's visits. P30 forgot about the notes during the interview, but the visual cue of the notes reminded her of its existence.

6.2.5.8 Secure Information

Participants may perform PHIM activities because they want to secure the information, in the sense that it will not be lost. For example, P17 keeps a paper copy of her electronic files because "*I don't trust computers, I don't like the internet. I'm the classic older person who didn't grow up with them, so I print everything that I'm interested in.*" Duplicating information items in different formats is a common failsafe for participants who feel insecure about their diabetes-related information.

6.2.6 Financial Motivators

Participants find the costs of diabetes treatments are high. For example, modern blood glucose meters consume testing strips with each test. Participants living with type 1

diabetes test between 4 and 11 times a day. Over time, the large consumption of strips and the limited supplies that patients' insurance covers adds stress to patients' ability to maintain their preferred levels of information work.

For items that are covered by insurance, the supply is shrinking. Participants reported that their insurance companies used to provide around 300 strips a month, but that number was cut down to around 100, which was barely enough to sustain the least volume of consumption reported by participants.

Similar situations exist for continuous glucose monitors (CGM), which are devices that enable almost real-time monitoring of blood sugar levels. CGMs have sensors that are attached to patients' body to collect information on blood sugar levels. Participants reported while the device itself can last a year or two, the sensors last a week and can cost around $70 each out of pocket. Participants' insurance covers some types of CGM and the coverage can change over time.

Participants also mention that because of the limited time they have with doctors, they may need to go to dietitians and nutritionists to acquire more information, but these professionals charge by the hour and the cost of information makes participants hesitant to acquire their services.

When facing the high cost of PHIM tools for personal information collection, some participants had to strategize the acquisition and use of these tools. They either rely on less costly tools or collect information about themselves at a lower frequency.

6.2.7 Environmental Motivators

Natural environment can provide barriers to certain PHIM activities as well. Participant report cold weather can hinder activities, such as blood sugar testing, when they are in outdoor environments. However, participants do not report indoor environmental factors that can facilitate or hinder PHIM activities..

<div align="center">

6.3 PHIM Activities

</div>

PHIM activities are the observable actions that people take when managing their health information. Four major PHIM activities are extracted from the literature, including collection, organization, retrieval and use. Participants in this study reported a wide spectrum of activities for each of the 4 major PHIM activities listed above. Figure 3 shows a list of all sub-categories of PHIM activities identified. In the rest of this section, all PHIM activities are introduced with relevant examples.

6.3.1 Collection

Collection is the process of locating information and adding a piece of health information to a personal information collection. This process may include how people locate information sources and extract information from it. Table 16 introduces the 7 information collection activities identified in this study.

6.3.1.1 Consulting

Consulting occurs when people actively pose questions to others, either in face-to-face communication or with the support of medicated communication tools. People who consult others always have specific purposes in mind.
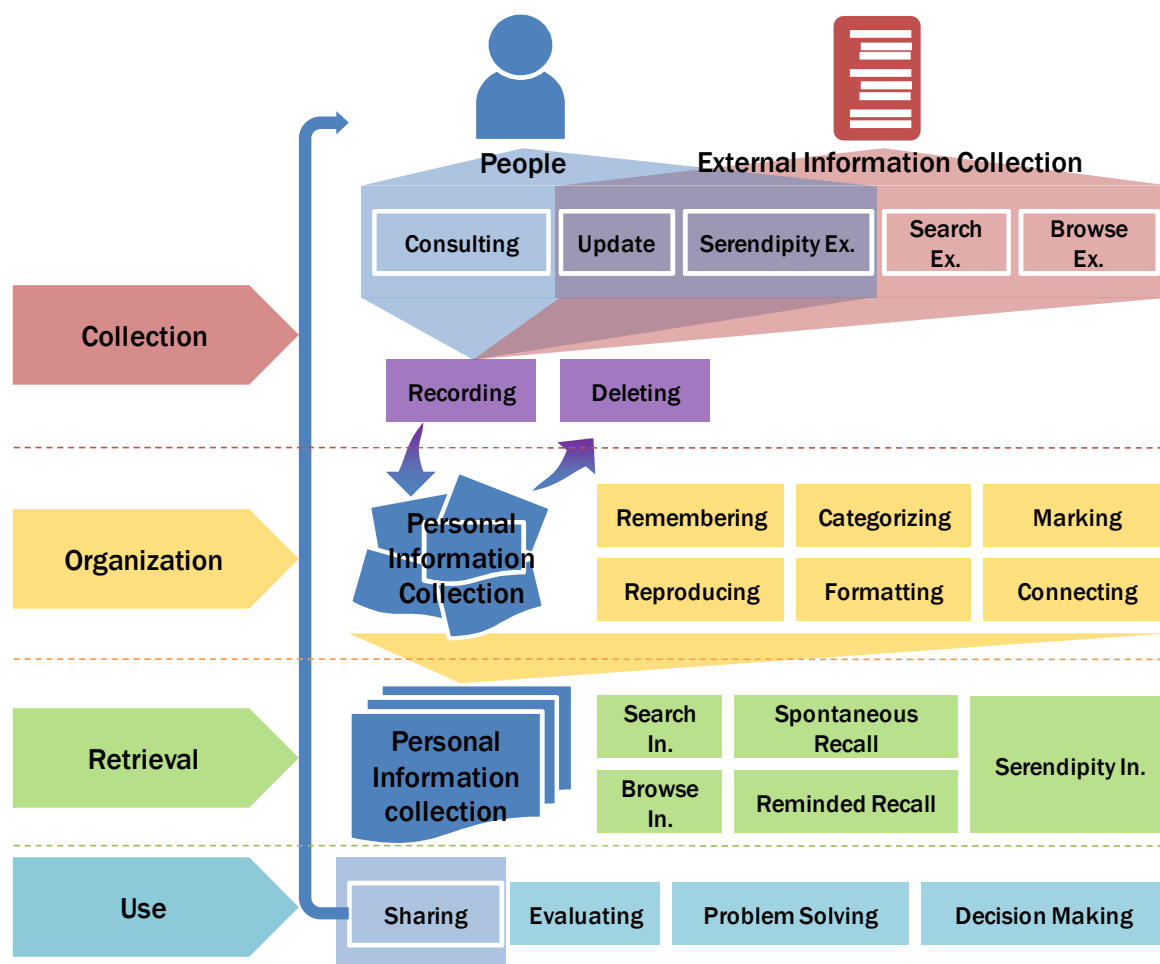
Ex. = External information sources   In. = Internal information sources

Figure 3.Personal Health Information Management Activities

Table 16
Information Collection Activities

Collection Activities	Definition	Example
Consulting	The activity of people actively looking for information by asking other people.	*"I bring up questions I have when I go to support groups."*
Updating	The activity of people going back to a previous	*"I set Google alert for diabetes and it sends me new web pages every*

	information collection and see what is new.	*day.”*
Serendipity Encounter in External Information Sources	The activity of people unintentionally acquiring a piece of information from external sources.	*“I was watching TV and I saw this ad about a pill that let you pee out the sugar.”*
Searching External Information Sources	The activity of people actively looking for information from external sources by looking through an indexed paper system, such as a catalog or using a search engine in a digital environment.	*“For a particular question, I search for it online ... Yes, using Google.”*
Browsing External Information Sources	The activity of people looking through an external information collection by examining the information items one by one.	*“I was in the waiting room and I started reading all the magazines and brochures.”*
Recording	The activity of storing a piece of information in media or keeping an information item.	*“After I measure my blood sugar, I write it down in the log book.”*
Deleting	The activity of deleting pieces of information from one’s personal information collection.	*“I will keep track of it, eventually a piece of paper gets thrown out.”*

Health Care Team. Participants reported consulting their health care team and

other people who are living with the same health condition. The health care team of

patients with either type of diabetes includes an endocrinologist and nurses in the same

clinic, and may include a primary physician, a nutritionist or dietitian, a diabetes educator,

and a trainer for everyday consulting, as well as an ophthalmologist, a podiatrist, a neurologist, and other specialist for potential or ongoing complications. Participants reported seeing their health care team periodically but at different frequencies. For example, some participants see their primary doctors more frequently than meeting with their endocrinologists. During clinical visits, participants may bring up specific questions about diabetes management.

Participants also noted that they do not have specific questions but they have specific goals in mind when consulting their health care team. For example, P11 visited "*a diabetes educator once in the last 3, 4 years, and it was for a particular needs, so I was looking for a new insulin pump. I had to meet with a diabetes educator just to hear about all the different options and whether they are available to try them out, to physically see them, and discuss the pros and cons.*"

Peers. Participants expressed that they often consult other people who are living with the same condition or other types of diabetes. They visit face-to-face and online patient support groups and seek out other patients from their social networks in order to acquire information. Participants reported that peers are usually more knowledgeable than their health care providers when it comes to questions on everyday diabetes management, such as ways to counter irritation from devices attached to the body, bleeding from insertions, how often to change insertion sets, whether to mix different types of insulin, the best type of carbohydrate to fight hypoglycemia episodes, and how to pack these carbohydrates. Participants found they cannot acquire answers to these questions from their health care teams and their device and medication providers because

they either do not have the answer or are concerned about the potential liability when answering these questions.

Others. Participants recall that they do not consult family, friends, colleagues, and other people for diabetes-related issues because these people do not have the knowledge to answer their questions.

6.3.1.2 Updating

Participants may revisit information sources without specific goals or questions in mind, just to see what is new. Participants reported updating when they communicate with people and interact with various media.

Patient Support Groups. Patient support groups are common places for updating. Participants voiced that sometimes they attend these support groups to see what other attendees may bring to the table.

Health Care Teams. Participants were informed by their health care team that they should visit their endocrinologist once every three months to test their hemoglobin A1c[5]. During these visits, participants receive updates on their health outcomes and news on research and developments on diabetes.

Devices and Sensors. Various devices with sensors are used by participants. Some examples include CGM and pedometer on a smartphone. These devices send updates to their wearers at certain intervals or collect and offer information in real time. Participants may receive notifications from these devices when attention is acquired and check these devices to acquire updates on their health condition.

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[5] hemoglobin A1c: A blood test that reflects an average blood sugar level over the past 2-3 months (American Diabetes Association (ADA), 2014).

News and Social Media. Participants reported signing up for newsletters from various diabetes-related websites, such as DLife. They receive periodical emails from these websites on the latest news articles available. Participants also receive diabetes-related information from sources such as podcasts that can push notifications through mobile devices.

Social media is used by some participants for updates from peers who visit online support groups. For example, P27 follows her friends who also have diabetes on Facebook and she receives updates when her friends share links on diabetes-related news articles or stories about themselves.

6.3.1.3 Serendipity Encounter in External Information Sources

Compared to updating, where people actively look for information, serendipity encounter is where people do not have an information seeking objective in mind, but accidentally acquired a piece of desired information. Serendipity encounters can happen when participants are communicating with people or interacting with other external information sources. For example, P9 is an A1C Champion and one of her responsibilities is to give talks at hospitals to help other patients. At these talks, P9 expects to share and not acquire information because her audience is usually newly diagnosed patients who find it difficult to engage in self-management regimens. However, P9 encountered circumstances where her audience raises good questions and point out alternative solutions. P9 mentions, "*When I'm giving my presentations, usually during the question answering period, there are sometimes someone will have something that's useful. It's not often, but every once in a while they will tell me they are doing this and*

how it serves them well that I haven't thought of before. It becomes helpful for me that I have either adopted it or accepted it as well."

Participants also reported serendipity encounters with other information sources, such as TV, websites, and newspapers. For example, P5 describes her experiences with books, "*If I was at a Barnes and Noble and I walked by a book that has topic about diabetes, I definitely would pick it up.*" However, P5 adds that "*I may not buy it because I tend to believe that the information I'm going to get that I can get online and I can get it more up to date.*" In this case, serendipity encounters seem to serve as a starting point for other types of information collection activities.

6.3.1.4 Searching External Information Sources

Participants reported using online search engines for the indexed Internet (e.g., Google), social media (e.g., Facebook), and scholarly databases (e.g., PubMed)frequently when they aim to look for health information. Participants with smart phones also mentioned that they use apps on their phones (e.g., CalorieKing) when they need specific information.

With a large or unlimited data plan and the easy access to free WiFi in the New York City area, participants search for information right before it is consumed. For example, P15 mentions that she searches for carbohydrate information on her smart phone when she is about to eat, "*usually I'm like somewhere, then I want to eat. I don't have my computer next to me.*"

In addition, P5who used to be a librarian also searched library catalogs for diabetes-related information.

6.3.1.5 Browsing External Information Sources

Sometimes, participants have in mind what information they are looking for but are not sure where it is located. In this case, they browse through information collections (e.g., magazines at clinic waiting area, brochures, websites, and social media), hoping to find relevant information. For example, P17 hopes to find information on new treatments and she browsed through "*all the materials in the book clubs*" at a medical center, including brochures, magazines and books.

Participants may also browse through electronic information sources, such as visiting the American Diabetes Association website and read articles on diabetes and diabetes management.

Overall participants reported more search activities on electronic information sources and more browse activities on paper-based information sources.

6.3.1.6 Recording

Recording is the activity of storing a piece of information in media or keeping an information item. Participants may record the information through (a) allowing it to be automatically saved by a device or a service, (b) manually keeping it on a device or a service, (c) manually writing it down on paper, or (d) keeping a paper-based information item.

Automatically Saved by a Device or a Service. Participants reported using CGM and glucose meters to test their blood sugar. These devices automatically save the testing results for a period of time ranging from a few weeks to a few months, depending on the brands of these devices. After this period of time, the devices delete information

starting from the oldest test results. Participants also reported receiving updates through

emails from newsletters that they subscribed to. These emails are automatically kept in

participants' emails. P5, for example, has over 10 thousand unread emails automatically

saved in her email that she did not have the chance to read.

Manually Keep in a Device or a Service. Participants mentioned that when they

find information online, they may record key information in their computer, or

smartphone notes to share with their health care providers. They may also record

information that they acquire from health care providers, peers and other parties in their

computer or smartphone notes. A number of different applications are used by

participants for recording, such as memo apps that come with different smart phones (e.g.,

Figure 4), emails, calendars that synchronize between devices, and participants' social

media accounts.
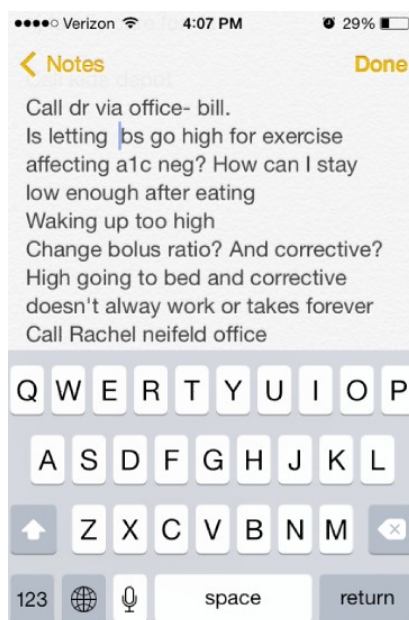
Figure 4. P15's notes on questions to ask during clinical visits recorded in her smartphone

Manually Write Down on Paper. The same self-generated information and information from people and other external information sources that some participants keep in electronic devices or services, they may also write down the information on a piece of paper. Figure 5 shows written notes that P22 kept from one of her clinical visits. The notes are on the carbohydrate content of different breakfast food combinations and the total carbohydrate counts are marked out in read parentheses.

```
EGG SAND   19          OATMEAL    54
Orange     15          1/2 BANANA  7
          (34)                   (61)

Bran Muffin 19         Cheerios   12
Orange     15          milk        8
          (34)         1/2 BANANA  7
                                 (27)
1/2 Bran   26
orange     15
          (41)
```
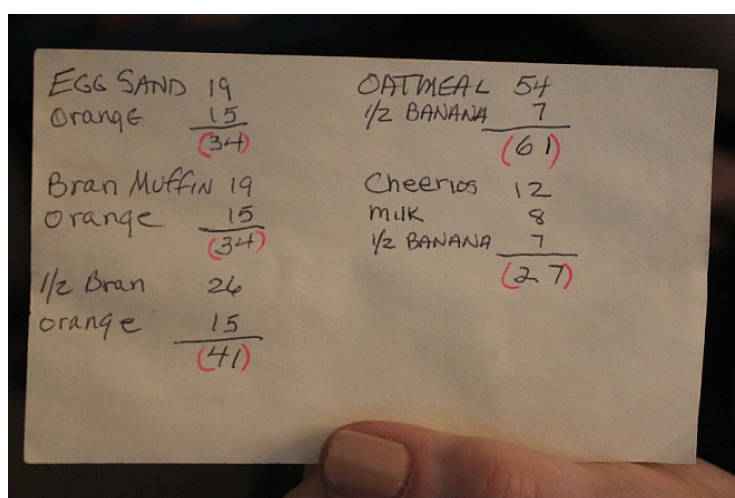
Figure 5. P22's note on carbohydrate counting from clinical visits

Keep Paper-Based Information Items. Participants may receive or find paper-based information items that already carry the information they need, such as books, magazines, brochures, and doctors' notes from clinical visits. They may keep these information items as they are.

Figure 6. Paper-based information items kept by participants. (a) P14's reference library bookshelf and (b) P28's medical bills received through snail mail

6.3.1.7 Deleting

Participants reported 3 different ways in which they delete information from their personal information collections, which I have named (a) timed old item deletion, (b) mastery desertion, and (c) disruption dumping.

Timed Old Item Deletion. Some participants reported that they clean up their collection once in a while, such as during the spring when the New Year starts. During the clean-up, participants usually delete the older information items that they keep. For example, P2 retains 10 years' worth of his own hand-written health records. Because of limited space in his cabinet, he has to discard the older records.

Mastery Desertion. Mastery desertion was the behavior of discarding a specific type of information because of high levels of familiarity with that information. For example, P1 stopped keeping log books over the long-term because her condition was very predictable and the information she put in the log books became increasingly homogeneous over time.

Disruption Dumping. Disruption dumping may happen when there is a major disruption in a person's life, such as moving and getting married. For example, P4 kept paper files on diabetes management before she went to college. When it was time to leave home for college, she left her paper files at home and started using Google Docs to keep her health information instead.

6.3.2 Organization

Information organization occurs after people add a piece of information to their collection and before they retrieve it. During this process, participants may process the information and make it look different in form and meaning to prepare for its use. Some people may skip this process when they use the information they collect in real time (e.g., monitoring). Table 17 shows a list of information organization activities arranged according to the amount of changes done to the information items, from the lowest to the highest.

Table 17
Information Organization Activities

Organization Activities	Definition	Example
Remembering	The activity of storing a piece of information in one's memory.	*"I'll remember key work in a journal or key word or two and author… If I can remember enough to put into Google to use my search skills, it works out."*
Categorizing	The activity of dividing up information items or putting them in order according to	*"I arrange my medical records according to time."*

		continuous (e.g., time) or discrete classification methods (e.g., type, purpose, source).	
Marking	The activity of making marks on an information item.	*"I fold the pages that I want to come back later."*
Reproducing	The activity of changing the media carrying the information.	*"I save the article in PDF…"*
Formatting	The activity of presenting the information in an information item in ways different from the original information item.	*"I make graphs in Excel using my own data."*
Connecting	The activity of establishing connections between information items.	*"MyFitnessPal gets my calorie intake from what I put in my pump. It also tracks the exercises I do every day and tells me how much my calorie balance is for the day."*

6.3.2.1 Remembering

All participants relied on their memory to manage certain health information. Remembering can be a substitution or a supplement to other information organization activities. Participants reported remembering information that they encountered, including but not limited to (a) experiences; (b) diabetes-related vitals and regimen; and (c) information from external information sources.

Experiences. Participants recall vividly the experiences and feeling they had when they were diagnosed with diabetes, at certain milestones directly or indirectly related to the illness, and acute episodes. For example, P20 recalls two events where he experienced episodes of uncontrollable blood sugar levels due to extreme emotional

turmoil during traumatic events, once was when he saw the falling of the World Trade Center from across the street and another time when his sister passed away. Participants report that although they prefer to not remember these events, these memories nonetheless stay with them.

Diabetes-related vitals and regimen. To different extents, participants can remember the details of their blood sugar test results, insulin dosage, diet, exercise and other self-generated health information. Some participants use memory to hold on to a piece of information before they have the opportunity to record it; some participants remember the information and do not see the need to record it.

Information from external information sources. When participants encounter a piece of information from their social networks or the mass media, they found the information easy to remember. They may record the information during the social interactions or mass media exposure, afterwards, or keep the information in their memory.

Participants explain for information diabetes-related vitals, regimen, and information from external information sources, if the information is immediately applicable to their situation, they consume the information to update their regimen. In this situation, short term memory is sufficient.

For information that can have long term value, participants found repeated exposure to similar information can help them strengthen the memory. For example, P14 does not record the content of her diet because "*I have a real routine of what I eat. So I have just internally memorized.*"

However, memory is not always reliable. The motivator "confidence in memory" points to the issue that participants may not fully rely on memory depending on their

perception of how well their memory works. Participants reported forgetting the content of an information item (e.g., P26), the existence of an information item (e.g., P30), and the various categories for information items (e.g., P1).

6.3.2.2 Categorizing

Participants categorize information in their personal health information collections using either continuous, discrete, or both categorization methods. An information item may have properties (e.g., date, topic, creator and subjective values) that can function as readily available categories. Participants reported using these properties to categorize their diabetes information.

Discrete ordering. Participants reported three types of discrete ordering methods for diabetes-related information, including categorizing according to (a) purposes, (b) topics, and (c) locations. For example, Figure 7 shows that P9 keeps her diabetes-related information for personal use and for work in two separate piles. Figure 9 depicts the ways in which P13 categorizes her health information according to different topics by using plain tags or color coded tags that provide visual cues on the change of topics.

(a)   (b)

Figure 7. P9's health information for personal use (a) and for work (b)is kept separately

Information items can also be organized according to locations. For example, P12 receives doctors' notes when he returns from clinical visits and he places these records at locations where these notes are pertinent to. P12 explains, "*As soon as I get home, I read that all over and depending upon if it deals with medications or ... efforts. Then I put it with that activity, I guess is the way to say it, that has to do with the medication or goes with the medication or some actions. It goes with taking that action.*" These notes are not placed in folders and only one note is kept at each location to facilitate information use. P7 reports a similar activity of placing blood sugar meters at different locations in the home to facilitate information collection (Figure 8).

(a) (b) (c)

(d) (e)
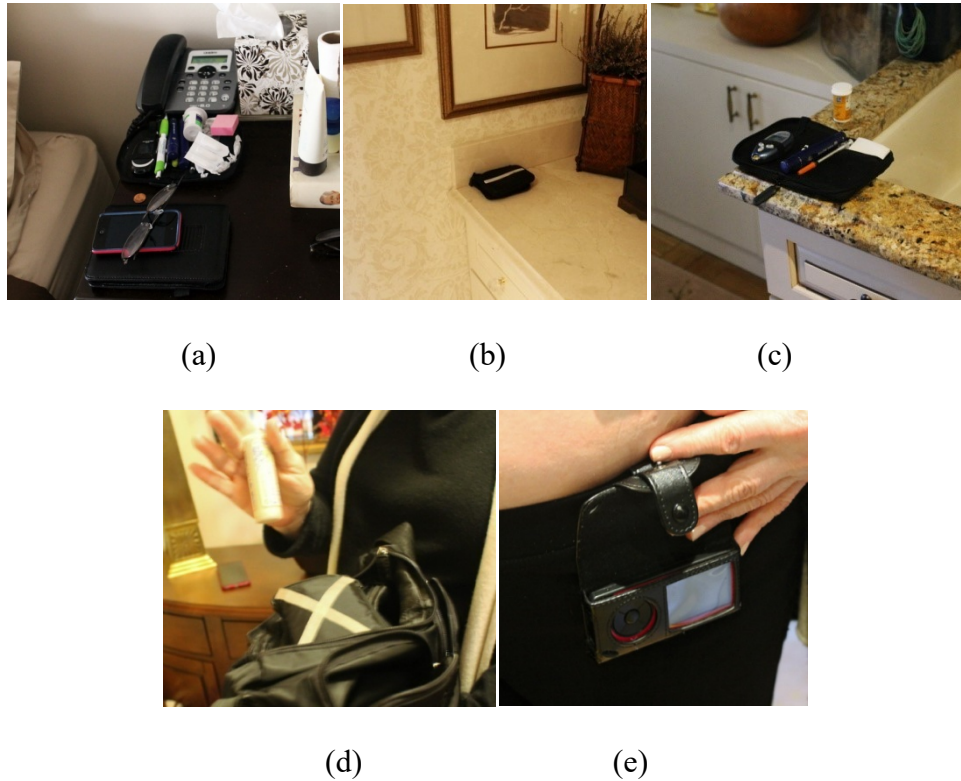
Figure 8. P7 places blood glucose meters and a CGM at different locations around home to facilitate information collection: (a) nightstand in bedroom, (b) bathroom counter, (c) kitchen sink, (d) bag for trips, and (e) on the body

Continuous ordering. Participants reported continuous ordering information items after they have been sufficiently categorized using discrete ordering. Figure 9 (a) shows the ways in which P13 categorizes her diabetes-related information. Each of the folders in Figure 9 (a) is a different discrete category. The documents in each folder are organized according to the time when they were added to the collection.

(a)   (b)
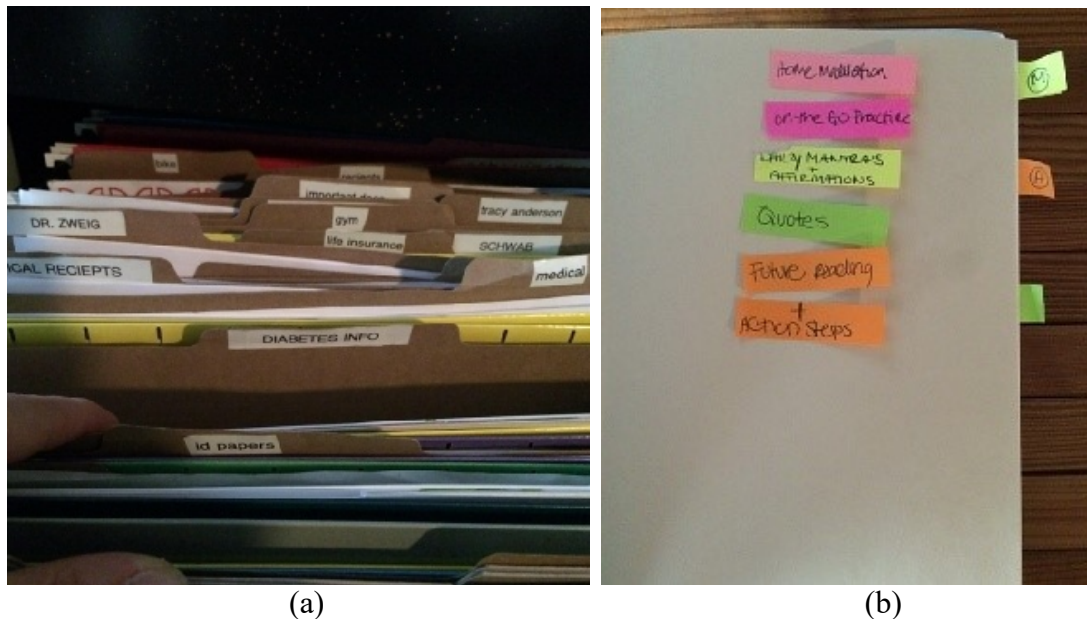
Figure 9. P13's categorized health information: (a) plain tabs, and (b) color coded tabs

Participants reported that a major difficulty to maintain the organization structure of information items ordered continuously is that the structure can be disturbed during information collection and retrieval processes. For example, P25 is a painter and he keeps his health information in the sketchbooks, between the pages. When the sketchbooks are used up, P25 marks the year in which they are completed on their binders and put them on the bookshelves in his office. However, P25 does not arrange those sketchbooks

according to time. This was because, as a painter, serendipitous encounters with his

previous work were more important. In an attempt to arrange his sketchbooks, P25 once

had an intern put his sketchbooks in time order, but the shelf soon reverted back to

randomness due to his professional needs. Figure 10 shows a collection of P25's

sketchbooks on the floor with health information held between their pages.

Figure 10. P25 finds it difficult to keep information items in time order

In contrast, keeping information within information items in a continuous manner

is common practice among all participants and the information organization process

seems to face fewer challenges compared to categorizing information items. For example,

all participants reported testing their blood sugar levels and recording the test results

either automatically in their blood glucose meter and pump, or manually in apps and note

books. These test results are arranged according to time and participants did not report

difficulties associated with keeping the information organized in time order. This is

potentially because the two issues with organizing information items (i.e., the items used

to carry information) do not apply to organizing information within the same information item (e.g., multiple blood glucose test results stored in a glucose meter). (a) During information collection processes, new information (e.g., test results and questions to health care providers) is usually added to the beginning or the end of the existing information collection. There seems to be fewer chances for confusions compared to adding a new information item to an information collection (e.g., adding a new book to a library that is ordered alphabetically), where a decision is necessary regarding where to insert the new item. (b) During the information retrieval processes, retrieving a piece of information from an information item does not disturb how the information is positioned within the information item. However, when retrieving a paper-based information item from a collection of paper-based information items, the information item is taken out of the collection and has to be categorized again when placed back into the collection. Electronic information items do not pose the second challenge when being categorized.

Combined ordering. The information categorization methods used by participants are diverse and are usually a combination of discrete and continuous categorizing. For example, P9's diabetes-related personal files and work files are organized according to topics and by time within each topic. Also, each of P7's blood glucose meters places around her apartment arrange the blood sugar test results by time.

Participants complain that categorizing their health information and maintaining the categorization scheme are difficult. For example, P1 is an A1c Champion who is motivated with diabetes management and organized with the relevant supplies but she found organizing information, especially over the long term, particularly challenging. She describes the difficulties she experienced with maintaining the categorization scheme for

her electronic information, "*I'll name a folder, 'diabetes research', and I'll throw stuff in it, and then I will forget I already stored that folder and I read an article and I want to save it. And if it's about time management, then I'll start another folder and say 'time management', and then I get folders here and folders there and you know. If it's like paper, in a file cabinet, I could go through it and see everything I have and throw things away, and read, cluster, but it's file folders on my computer, it's just a mess.*" In this case, paper files seem to be easier to categorize compared to electronic files, potentially because the visual cues offered by paper files promote frequent maintenance, so that work is more piecemeal.

6.3.2.3 Marking

Participants may mark information to provide cues of the existence, location, and content of a piece of information.

When marking paper information items, participants reported activities such as underlining texts and folding the corner of a page (Figure 11).

Figure 11. P23 folded a corner of a recipe book for quick future reference

When marking electronic information items, participants may use functions embedded in the information items or use another application to assist the process. Services such as emails and browsers have built-in functions for marking. Participants reported marking read emails as unread and giving important emails a star or other marks to indicate their importance and a necessity to revisit them. Participants also use browsers to manage the web pages they visited by bookmarking certain web pages on the browsers to facilitate future revisiting.

A third-party application may also be used to mark electronic information. P13 reports using Pinterest and Microsoft Excel Spreadsheet to mark certain web pages. P27 saves articles on Facebook as a way to bookmark the articles (Figure 12).
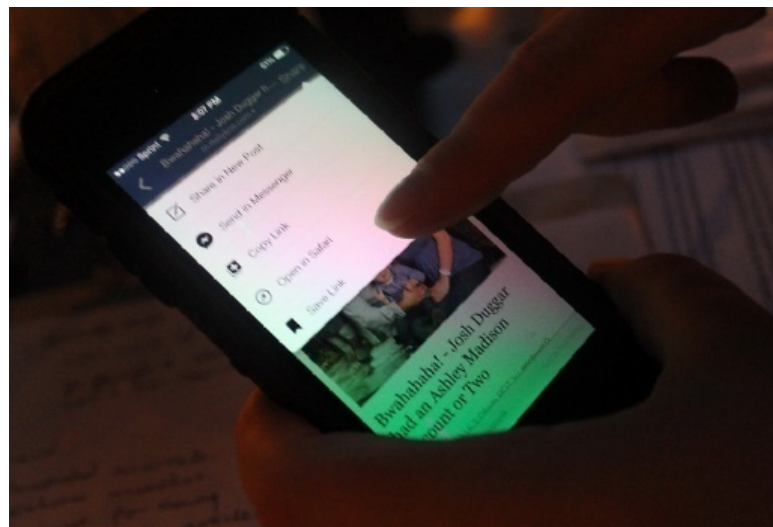
Figure 12. P27's smart phone screen for saving an article on Facebook

Participants mentioned color coding as a popular way to stress important information. For example, a CGM used by P11 marks out-of-range numbers with yellow, indicating a potential need to take actions (Figure 13).
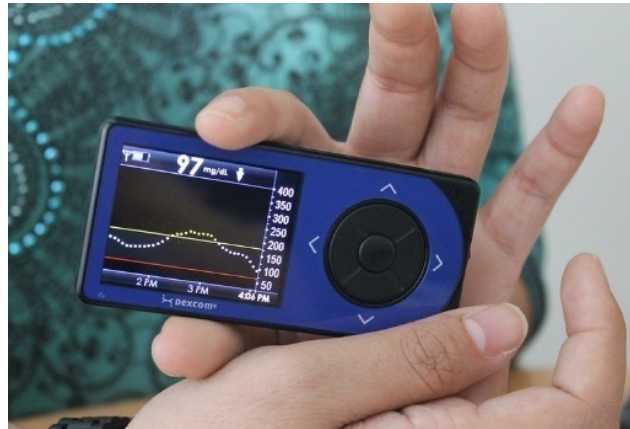
Figure 13. Color-coded blood sugar readings on a CGM

While the marking activities mentioned above are all binary (i.e., important or unimportant), color coding also enables the marking of different degrees of importance. For example, P2 color-codes his blood sugar test results to indicate the gradations of his blood sugar levels according to his health condition and his preferences. As illustrated in Figure 14, P2 marks his blood sugar test results into very high (purple), high (red), and normal (green) ranges. The color-coded blood sugar test results allow P2 to be more aware of cases where he had higher levels of blood sugar and make long term plans accordingly. Participants report that color coding help them understand the information better and faster, and can assist them with retrieving relevant information marked with certain colors by indicating its existence, location, and content.

There are also items that feature marking in a dynamic manner. For example, P1 uses a set of various tools to mark (a) when a diabetes management action is last taken, (b)

whether the action is taken at a given time, and (c) agendas for taking the action. These

tools give her real time guidance on diabetes management. To mark whether insulin is

taken, P1 uses Timesulin (i.e., a device that shows that time since last insulin injection)
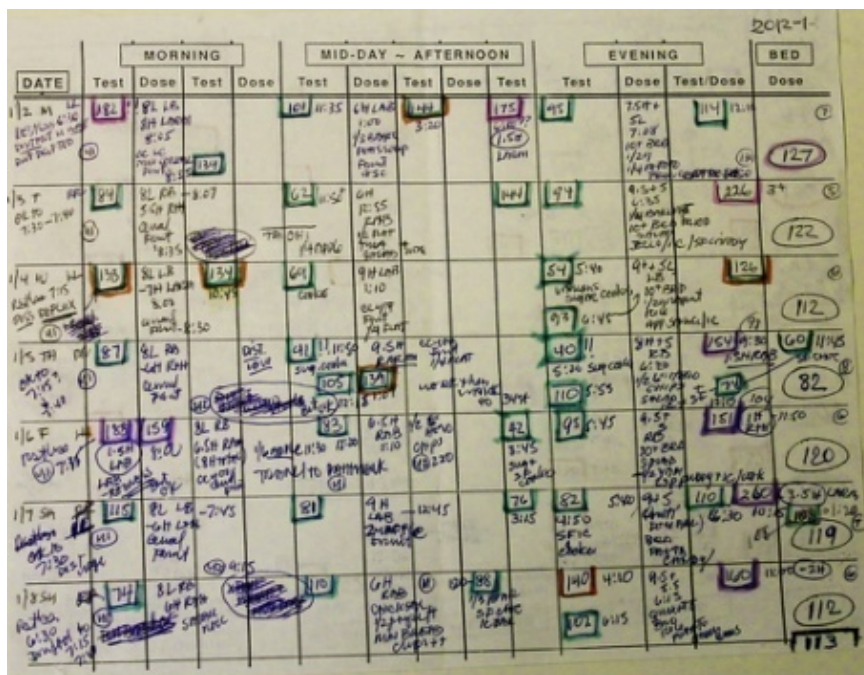
Figure 14. P2's color-coded blood sugar test results

and a rubber band to mark whether she has taken insulin. When P1 is at home, she looks

at Timesulin (Figure 15, a) whenever she remembers to take insulin, and the timer

indicates that she has not taken her insulin if the time lapse is great. When P1 travels, she

wears a rubber band (Figure 15, b) to indicate that she has not taken her insulin. She takes

the rubber band off once she completes the injection and puts it back on when the

window for injection has passed. P1's calendar shows the time windows for insulin

injection (Figure 15, c), which gives P1 an overall guidance on injections.

6.3.2.4 Reproducing

Participants reproduce diabetes-related information items by keeping the content and

formatting of the information but changing the media that carry it. Participants

(a)   (b)   (c)
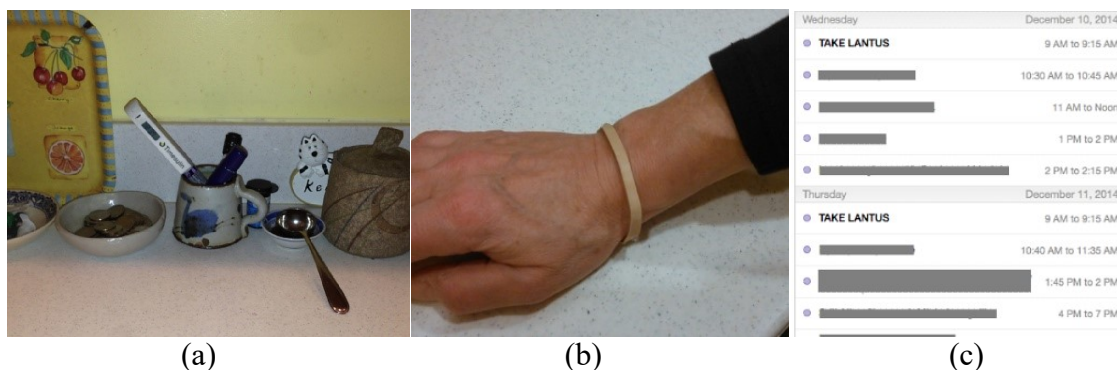
Figure 15. P1 marks information in a variety of ways: (a) a timer indicating last insulin injection time; (b) a rubber band indicating whether an injection is taken; and (c) a calendar to mark injection agenda

reported reproducing information items by transforming them between paper and

electronic media and copying between paper media or between electronic media.

Transforming between paper and electronic media. Participants scan paper

documents as a way to secure the information they keep or save space that paper takes up.

Participants print out electronic information items to secure the electronic information,

facilitate sharing, or enable hand-writing on paper.

Copying between paper media. Participants make paper copies of their paper-

based information items to share the duplicate items with others. For example, P2 copied

his paper forms for self-generated information management (Figure 14) in order to share

with peers at a face-to-face patient support group and with the researcher.

Copying between electronic media. Participants back up their diabetes-related

information in the cloud (e.g., using Dropbox) to secure the information. They also copy

the information to flash drives in order to bring this information to other locations and make changes to it.

6.3.2.5 Formatting

When formatting information items, participants make changes to the information items to produce meaning. Participants reported different levels of formatting activities, including (a) cosmetic formatting, (b) inference formatting, and (c) genre formatting.

Cosmetic formatting. Participants reported changing the fonts and sizes of words when formatting information items with their diabetes information, such as an information sheet with medical history and documents on a smart phone. For example, P14 reformatted a food list that includes two types of foods (Figure 16). She wrote the list of foods that are good for diabetes patients in her preferred colors – pink and blue, while she formatted the list of undesirable foods in an alarming red color.

Inference formatting. Participants format information items to make inferences for the goal of better understanding their health conditions. For example, P20 records his blood sugar levels on a Microsoft Excel Spreadsheet and he used the information to build time series models (Figure 17). These models show the seasonal changes and various repeated patterns in his blood sugar levels. P20 used to be frustrated during the last few weeks of the year because no matter what he did, his blood sugar levels stayed higher than he preferred. The time series models made him speculate that the uncontrollable blood sugar was a seasonal effect, which was later confirmed by his doctor.

Genre formatting. Participants can also completely change the ways information is presented by their information items. For example, P14 uses picture diaries to replace
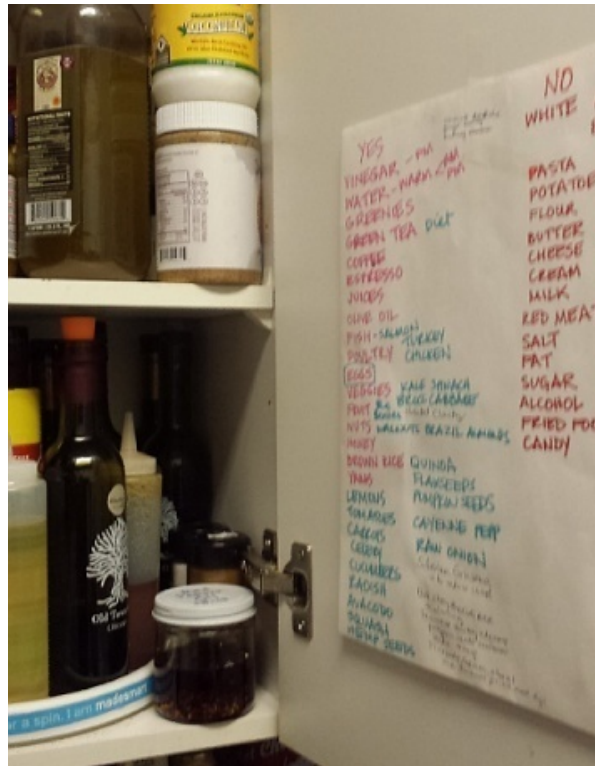
Figure 16. P14's food list on a pantry door
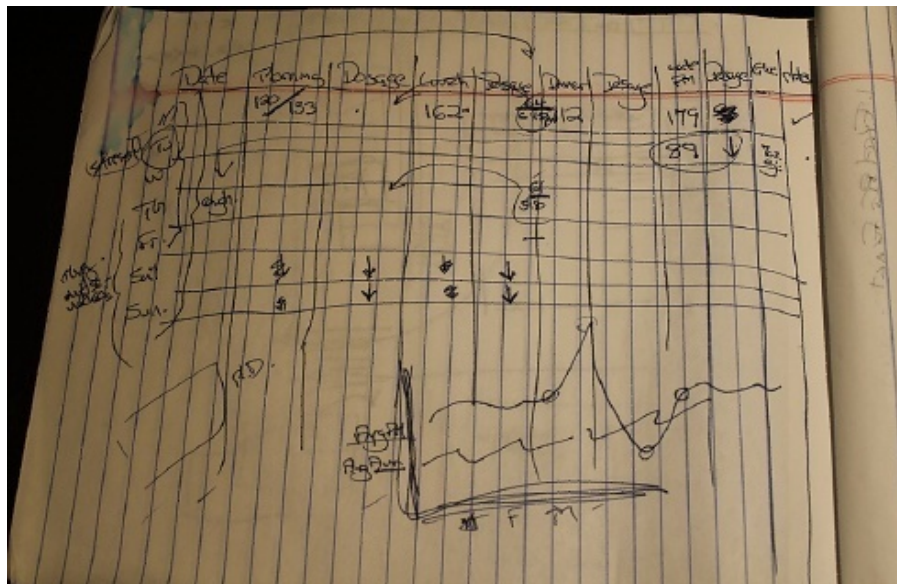
Figure 17. P20's illustration of a spreadsheet for time series models based on blood sugar test results

the table-formatted diabetes records she received from her health care providers (Figure 18). In comparison to the table-formatted records, which use numbers to record facts in structured ways, the picture diary uses picture and text narratives to enable story-telling and record more rich information.

(a)   (b)
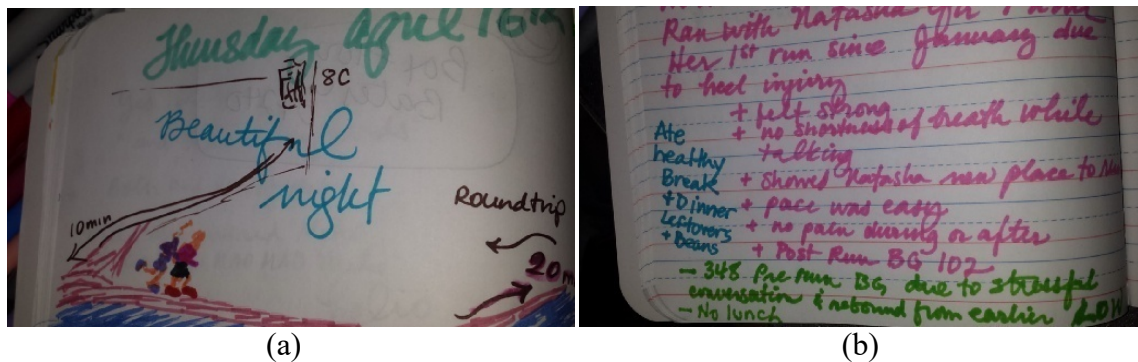
Figure 18. P14's picture diaries: (a) picture, and (b) corresponding diary

6.3.2.6 Connecting

Participants reported connecting multiple information items to help gain a better understanding of their health condition. During this process, patients combine the information from two or more information items and may store it in another information item. Connecting differs from reproducing and formatting in that it involves more than one information item and requires people to actively connect information items to create new meanings.

Among participants who use CGM to test their blood sugar levels, a common practice recommended by their health care providers is to use blood glucose meters to perform regular finger sticks and use the finger stick results to calibrate the CGM by entering the test results into the corresponding locations in the CGM. Participants also reported using finger sticks to validate the blood sugar test results provided by the CGM

because the latter differs from what they expect or how they feel. For example, P12 recalls, "*There might be a meter reading that was before breakfast and a meter reading after breakfast. And if I noticed that my CGM was accelerating faster, higher than I expected, I might calibrate that again or cross check...to see that it really was elevating that rapidly and I might need to do a corrective dose of insulin between meals.*"

Participants also report attempts to build connections between cause and effect to guide future activities. For example, P2 has a collection of blood sugar worksheets in the form of paper cards, where he infers if his blood sugar is at a certain level, and what actions can result in the blood sugar reaching certain levels in the future (Figure 19, d). P2 explains, "*…this shows the pattern that I had over a certain period of time. So if I'm 50-70 in the morning I will take one third of a sugar cookie like I just did. I'll take 6 units of Humalog, have my breakfast. This tells me where I'm at lunch time. So from 50-70, I was 58, I took some sugar cookie, I took 6 units of Humalog. At lunch time I was 94. At lunch time I was 147. So it varies.*"P2 created this worksheet from his collection of weekly blood sugar records (Figure 19, c) that includes health outcome information (i.e., blood sugar levels), treatment information (i.e., types of insulin, insulin dosage, and injection time), and contextual information (e.g., diet and blood sugar test location). P2 also keeps yearly blood sugar records (Figure 19, e), where he brings together daily average blood sugar readings from the last column in his weekly records and uses these records to calculate A1c – a three months average blood sugar level. With what he learned from all the records he keeps, P2 compiled an instruction sheet that he keeps in his wallet (Figure 19, f). This piece of paper includes information on how to treat P2 in case of emergencies (e.g., P2 collapses in the street due to a hypoglycemia episode).

Another example is P20's inventory tracking spreadsheet. P20 uses Excel to track his diabetes supplies, such as insulin and blood sugar test strips, by recording the volume of the supply in his storage and the anticipated date for reordering. He keeps this inventory tracking spreadsheet on a different tab of the same Excel file, where he logs blood sugar levels (Figure 19), in order for him to keep an eye on the inventory. With every shipment of supplies P20 receives, he updates the inventory tracking spreadsheet. At the same time, he updates his calendar, which sends him reminders when the next anticipated prescription refill date approaches.

Information connection activities are usually built on top of other information management activities. Take the personal blood sugar records developed by P2 for an example. His blood sugar worksheet that is used to connect causes and effects between treatments, daily activities, and blood sugar levels (Figure 19, d) is built on a collection of his weekly records (Figure 19, c). These weekly records are compiled from two other records, including (a) a scrap of paper that P2 keeps in his wallet to record any diabetes-related information that he encounters on a daily basis, such as blood sugar levels, blood sugar test location, insulin dosage, and diet (Figure 19, a); and (b) a test site worksheet that P2 keeps in his bathroom to record blood sugar test locations and some test results (Figure 19, b). When compiling these records, P2 administered at least 5 PHIM activities, including updating (e.g., test blood sugar), recording (e.g., writing down blood sugar test results), reproducing (e.g., printing out blank weekly records), marking (e.g., color coding weekly records), and connecting. Without the foundations laid out by the other PHIM activities, it would be difficult to connect information items and make inferences in a sophisticated way as P2 does.

(a)

(b)

(c)

(d)

(e)

(f)

Figure 19. P2's blood sugar records: (a) a scrap of record in P2's wallet; (b) a test site worksheet kept in P2's bathroom; (c) P2's weekly records; (d) a snippet of P2's blood sugar worksheet based on his weekly blood sugar records; (e) P2's yearly blood sugar records; (f) P2's emergency reaction instructions kept in his wallet

6.3.3 Retrieval

Information retrieval, in this study, refers to the process of people extracting information from their information collection. Some people may skip this process when they use the information they collect immediately (e.g., monitoring). Table 18 includes 6 information retrieval activities reported by participants.

Table 18
Information Retrieval Activities

Retrieval Activities	Definition	Example
Search in Personal Information Collection	The activity of searching in a categorized or indexed personal information collection.	*"If I need to find an article by an author, I just go to my browser and click on the book mark with her name on it… The book marks are automatically sorted by names."*
Browse in Personal Information Collection	The activity of checking the information items in a personal information collection one by	*"The magazines are not organized … I go through them one by one until I find the*

	one for a piece of information.	*article."*
Spontaneous Recall	The activity of remembering the existence and content of a piece of information without the help of any information items.	*"I just remember it."*
Reminded Recall	The activity of remembering the existence or content of a piece of information with the help of information items.	*"My calendar sends a reminder on my phone when it's time for testing."*
Serendipity Encounter in Personal Information Collection	The activity of people unintentionally revisiting a piece of information in their personal information collection.	*"I put information about different diseases together. Sometimes, when I check the information about other conditions, I accidentally see the diabetes folder and I'll read through it with a new mind."*
Refinding in External Information Collection	The activity of retrieving previously found information from external information collection.	*"If I need an article I read a while ago, I can just go online and search for it."*

6.3.3.1 Search in Personal Information Collection

Participants report that they search in paper and electronic information collections. Some examples of indexed paper collections used by participants include magazines, books, and medical records. Some of these information items, such as magazines and books have their own indices aside from the orders in which participants arrange them. For example, P12 arranges his Diabetes Self-Management magazines in reverse time order. In order to revisit a specific article, P12 has to remember the rough time frame

during which the article is published, and then he reads the indices of the magazines published during the time frame to locate the article.

When searching electronic information collections, participants reported using various search engines for information items such as file managers on computers, electronic documents, and email. To initiate the search process, participants recall that they specify search terms, usually when they remember that they have the information in their collection.

Interestingly, participants report a preference of refinding in external information collections by using open web search engines like Google to searching in their personal information collection, even if they are aware that they have collected the information. For example, P5 notes, "[it] *depends on how lazy I felt. If I didn't want to go get into my email. I'd probably just Google some keywords for it and see if I can find it that way. And then if I couldn't and it was something pretty specific, I remembered getting it in email. Then I would go into my mail on my outies.*"

None of the participants mentioned searching their collection of self-generated information, although participants like P11 and P20 have electronic collections of self-generated information accompanied by contextual information recorded in the form of free text, such as diet.

6.3.3.2 Browse in Personal Information Collection

When participants try to retrieve information from a personal information collection that is not indexed, they browse through the information items in the collection until they locate the specific piece of information they look for. Participants complained

that browsing can be time consuming. For example, P1 keeps a large collection of diabetes information in her computer. She describes her experiences of browsing her information collection when she looks for a specific piece of information, "*I will spend a day looking for it. Very inefficient. ...Some times, I'll use a word or something to do a search but I don't have very good computer skills...*"

Other participants find browsing an easy task, especially when the information collection is small, or if the need for browsing is scarce, or both. For example, P25 maintains a collection of diabetes information, including notes from clinical visits and records of his self-generated information. This information is written down or kept between pages in his sketchbooks (Figure 10) as a part of his work as a portrait painter. P25 fills about 6 sketch books every year. When he looks for a piece of information kept in the sketch book, he remembers the year and browses the 6 sketchbooks completed during the year. P25 explains although "*it's quite a stack*" there were very few instances where he needed to retrieve information from the sketchbooks.

6.3.3.3 Spontaneous Recall

All participants report instances of spontaneous recall without going to an information collection or being reminded. Participants recalled information in their memory, external information in their information collections, self-generated information, and PHIM activities.

Recall information in memory. Some participants keep certain diabetes-related information in their memory and they are able to recall the information later. This information can be external or self-generated information. For both types of information,

participants sometimes recall it in order to record it. In this case memory functions as a transition between encountering information and recording it, for the purpose of information collection. Participants report that they also recall information for information use, such as recall the carbohydrate content of a type of foods to determine insulin dosage and recall blood sugar levels from the previous day to judge whether to change insulin dosage.

Recall external information. Participants keep external information in their personal information collection and they sometimes recall this information without reviewing the information item, such as recalling a piece of medical advice in a doctor's note.

Recall self-generated information. Participants found it difficult to recall their self-generated information collected on a day-to-day basis, such as a blood sugar test result on the same day two years ago, but they can recall information that is recently generated or certain information associated with milestones or key events. For example, P13 recalls her recent A1c levels, "*I've been able to maintain you know 5.1, 5.5, that was my last A1C, it was 5.1.*"

Recalling the existence of a piece of information can be helpful when retrieving information from a personal information collection. For example, before P25 browses his information collection, he recalls when the information was kept, which helps him narrow down the scope of browsing.

Recall PHIM activities. Participants report difficulties in recalling PHIM activities compared to recalling information. When asked about their long term information management activities, participants diagnosed over 10 years ago cannot

recall details of their PHIM activities, although some of them recall their blood sugar test results and the date of diagnosis. For example, P2 responds to the question on how long he has been keeping up with his current PHIM activities (Figure 19), "*I don't remember, I've been doing this for a number of years. I would say 10, 15 years at least. Before that, I mean. I'm sure I was keeping records, but probably notes that a lot of people do.*"

6.3.3.4 Reminded Recall

Participants also recall information when reminded. Marked information items remind participants of the existence, location, and content of health information. For example, folded book pages remind P23 of the existence of recipes that she intends to try as well as the location of the recipes in the book (Figure 11). Bookmarked web pages remind P13 of the existence, location, and content of these web pages. An insulin pen cap can remind P1 of the time when the previous injection was taken (Figure 15, a).

6.3.3.5 Serendipity Encounter in Personal Information Collection

Participants experienced circumstances where they retrieved desired health information from their personal information collection when they were not expecting it. P5 describes her instances of serendipity encounter, "*I wouldn't say that it happens constantly, but I've gone back and looked at a file and said where did I get this article? I don't remember seeing this. Like that kind of thing. Wow I wish I had known this was here because this would have been useful three months ago.*" In this case, recorded information that is not remembered seems to be a precondition to experiencing serendipity encounter in personal information collection.

6.3.3.6 Refinding in External Information Collection

Participants who have encountered certain health information from external information sources but did not record such information may retrieve this information by attempting to refind it from external information sources. This activity only applies to external information and not to self-generated information. The activity is included in the scope of this study although it does not only retrieve information from personal information collections. However, because participants are aware of the existence and location of the information they previously found, the previously located information, in some sense, takes a middle ground between personal information and external information. Thus, the activity of refinding in external information collection is included in the analysis.

Participants report that they retrace the steps they took when they first encountered the health information in order to refind it from external information sources. Consulting social networks and searching external information sources are reported as the primary methods for refinding.

Consulting. Participants reported returning to the same members of their social network from whom they originally acquired information to refind the same information. For example, P3 describes a piece of information that she forgot, "…*information about, let me think of the name in English, I cannot remember, I don't remember, but people in Brazil, they try to do natural, they tried to process natural plants, process means like do the flour of, what fruit was that, they make kind of flour out of, it's not a pomegranate, see the memory problem? Now I don't remember. It cannot come from the memory.*" When

asked how she would find out about the name of the plant, P3 says, "*You know I can call somebody in Brazil and ask.*"

Searching external information collection. When the health information previous acquired is located through searching, participants resort to searching external information sources to refind the information. For example, P17 does not record information she acquired from external sources because she refinds the information through new searches, "*These are always online so I know how to go back to it.*"

Searching external information collection is sometimes preferred over searching or browsing personal information collection when the participants are aware that the same information exists in both information collections. For example, P5 describes how she refinds a specific piece of information, "*Usually my first step is always to Google and see if I can find it. Even if I know it was in my email yesterday. It's that extra step you know? I guess I rather - which I guess is funny in a sense I'm kind of wasting more time Googling about trying to find it than it would take to just open my mail and scroll through yesterday's mail. It's a funny kind of, I can't explain that. I don't know why I do that.*"

6.3.4 Use

Participants use the health information they collected to manage their diabetes or help others with the condition. Table19 shows 4 information use activities, including sharing, evaluating, problem-solving, and decision-making.

Table 19
Information Use Activities

Use	Definition	Examples
Sharing	The activity of releasing the accessibility and/or ownership of a personal information collection to other people.	*"I share this with my family mainly to educate them and prepare them."*
Evaluating	The activity of using a personal information collection to make judgments on the current situation.	*"They look at the numbers and tell me how I have been doing over the past three months."*
Problem-Solving	The activity of using a personal information collection to identify the cause of a known issue.	*"When you noticed a recurring problem and you can't figure out why, that's when you go back and look at your records."*
Decision-Making	The activity of using a personal information collection to make decisions to address the cause of a known issue.	*"I noticed over time the insulin is not as effective and I have to increase the dosage."*

6.3.4.1 Sharing

Participants share their health information with their social networks to help themselves or other patients in their network to manage diabetes. Studies in interpersonal and mediated health communication examined extensively the issue of how people decide what and when to share health information. As a result, this section focuses on participants' behaviors regarding diabetes-related information, rather than their rationale as to who they choose to share information with, such as uncertainty and considerations for privacy and identity.

The social networks with which participants share their diabetes-related information include health care team, medical researchers, pharmaceutical companies, other diabetes patients, family, and friends.

Participants report sharing self-generated information with all parties except other diabetes patients and friends. (a) **Health care team**. Health care teams encouraged participants to share their self-generated information with the team so that the team can help participants adjust treatments. Participants may share with their health care team handwritten notes of blood sugar test results and diet or their medical devices (e.g., CGM, insulin pump, and blood glucose meter). In the second case, participants' health care team extracts information by downloading it from the medical devices. Participants who used patient portal systems (e.g., P8) report that they do not upload information to the portal but can share the information through secure messages with their doctors. (b) **Medical researchers**. Participants like P3 who participate in clinical trials for diabetes medication and devices share their personal health information with medical researchers at hospitals as a part of the trial. This sharing may involve handwritten notes and information downloaded from medical devices. (c) **Pharmaceutical companies**. Some participants (e.g., P16) share their health information with pharmaceutical companies such as their CGM manufacturer for the purpose of helping improve the product. To share information with pharmaceutical companies, this information is usually uploaded from participants' devices to their computer through a piece of software for the corresponding device. This information is then uploaded to the company's server through the same piece of software. (d) **Family**. Participants including P4 share their health information with family members to help the latter understand diabetes and diabetes management as well as potentially help

with diabetes management. This information sharing can occur either face-to-face through handwritten notes or shared remotely through networked technologies and services such as Google Docs used by P4 and a smartphone used by P8.

Participants also express that they share information collected from external information sources with health care team, other patients, family, and friends. (a) **Health care team**. Participants share information on new research for treatments and medical devices with their health care team to consult the team for advice on whether they can incorporate the information into their own care. (b) **Other patients**. Participants share external information with other patients when they see information that may be applicable to others' conditions. Participants like P9 keep a collection of information for the sole purpose of sharing with peer patients and this information collection may not be applicable to participants themselves. (c) **Family and friends**. Some participants mention that they share external information with family and friends for similar reasons that they share self-generated information with family – to help their family and friends gain a better understanding of diabetes and prepare them for everyday incidents (e.g., participants prick fingers for blood to test their blood sugar) and emergency situations (e.g., participants have difficulties treating themselves during hypoglycemic episodes).

6.3.4.2 Evaluating

Participants may use the health information they collected to evaluate their current situation. The evaluation process is crucial for participants to solve problems and make decisions related to their health conditions. *Evaluation* is different from *problem-solving* and *decision-making* in that *evaluation* examines the status, *problem-solving*

spots specific issues that need fixing, and *decision-making* aims to fix the issues. For example, judging how well a participant manages diabetes using blood sugar test results is *evaluation*; finding out that the cause of a high blood sugar level is because participant consumed too much fruit is *problem-solving*; deciding how much fruit to eat in the future is *decision-making*. In other words, evaluation answers the "What?" question, problem-solving answers the "Why?" question, and decision-making answers the "How?" question.

P7's experiences point to the importance of using health information for evaluation purposes. When P7 was first diagnosed, her blood glucose level was in "*the 700s* [mg/dl]". To put this number in perspective, a person with either type of diabetes may aim for blood sugar levels of between 80mg/dl and 180 mg/dl (American Diabetes Association, 2016). After she was diagnosed, her doctor gave her a meter and some strips but did not tell her what numbers she should aim for. When she tested her blood sugar, she does not understand what the numbers mean because she does not know any standard to compare them to. Later, P7 learned how to evaluate her blood sugar test results, but she may forget her only meter at home when she is outside. P7 tells the story, "*I was on the bus and I was holding on and I felt- I didn't really know what a low was at that particular- I didn't have it related, and I go to reach for the meter and I only had one meter and I said I left it home. And I'm late for an appointment and I went crazy, because I didn't know if I should go get off and go back home to get the meter or... because at the beginning, you don't know, so that was scary.*" Because of this experience, P7 keeps multiple blood glucose meter around her apartment and one in her bag that she brings on trips at all times (Figure 8), so that she can evaluate her conditions at any time.

P7 evaluates her current situation with information collected in real time. Other participants use information they collected over a period of time to evaluate their health conditions. For example, P4 does not find real-time self-generated information meaningful, so she records her blood sugar test results over the long term in order to make objective evaluations of her condition. She compares evaluations to grades for courses, "*I feel it's like if you're taking a class, and you continuously hand in all these papers, but you never know the grades on them. It's like when I test my blood sugar, it really means nothing, unless I record some in order to see the result. … it makes a difference, because I have to look at the numbers and the numbers don't lie, so it makes me evaluate the data.*"

Participants like P8 use electronic tools to help with evaluation using information collected over time. P8 uses a piece of software developed for her CGM to evaluate her situation. The software enables her to see the big picture of her blood sugar test results over time, can present weekly and monthly test results as overlapped charts, and predicts the trends of her future blood sugar levels based on her records. P8 was able to conduct evaluations such as compare her weekday blood sugar levels to her weekend levels, map the blood sugar level changes over a multi-week or multi month period, and compare tests conducted at a certain time of the day across multiple days.

Cases of evaluation mentioned by participants seem to agree that external information and self-generated information are used to set standards for evaluation, while self-generated information is used for evaluation.

6.3.4.3 Problem-Solving

Through problem-solving processes, participants establish cause-effect relationships for diabetes management. Three major problem-solving processes are adopted by participants, including observation of phenomena, statistic tests on longitudinal records, and experimentation.

Observation. Participants report they solve problems related to diabetes management by observing their behaviors and their blood sugar test results collected in certain time frames around these behaviors. For example, all participants with type 1 diabetes test their blood sugar levels before and after meals. When their test results are unexpected, they estimate or check the carbohydrate content in their meals to find out which items are responsible for causing specific test results.

Participants also solve problems by observing their long term records. For example, P2 keeps paper records of his blood sugar levels over the long term (Figure 14) and he color-codes these records according to how high the blood sugar levels are. He keeps a large board and pins his records on it so he can observe the patterns of colors in these records. When he observes a cluster of certain color, he reads the annotations in these records on the contexts of these records (e.g., food intake, insulin injection, and finger used for blood sample) to find out what may have caused these clusters of certain blood sugar levels.

Statistical analysis. Participants who maintain electronic records may conduct statistical analysis in addition to observations in order to locate potential problems. For example, P20 built annotated records of his blood sugar levels with Microsoft Excel spreadsheets (Figure 17). He describes how he uses statistical analysis to identify issues

of importance in these records, "*I noticed the clustering, I noticed the change on weekends, I noticed the changes on the seasons, because my overall requirements are a little higher in the summertime, and down a little bit in the winter time. Took me years of charts to try to work that out. ...In an effect, it speaks to me. Also in terms of time series. I go back, and then look at it month before, I look at it years before, around this time of year, and I know I'm having a seasonal change. ...This is why a data driven approach was for me. I never would have seen any of these...*"

Experimentation. Participants stress that although the overall treatments and regimens for diabetes patients are the same for each type of diabetes, everyone is different in terms of their physiological reactions to these treatment and regimen, and their behavioral preferences. P7 describes these individual differences, "*When I was newly diagnosed and I went to have support groups, I invited Sami[6] and this other woman Miranda... to spend the weekend, and I called us small, medium, large.... I was in charge of the food, so we all tested at the same time, we all had different numbers. I gave everybody the same portion of the same food, we all took a different amount of insulin, and two hours later, and we all had different numbers. So everybody was different, but it was that's when it hit me, that it's not, ok you take a pill and you are ok. Not. Because you have to learn. ...and if you put on weight, that changes. If you are stressful, that changes.*"

As a result, participants experiment on themselves to identify venues for personalized care. A strategy reported by participants is to establish a routine and test the effect of new behaviors (e.g., eating a new type of food, performing a new physical exercise, changing insulin injection schedule, mixing different types of insulin, using

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[6] All named related to participants and used in their quotes are pseudonyms.

expired insulin, and switching medical devices) on their blood sugar test results.

Participants also voice that diabetes management is a "*noisy system*" and they usually

repeat the same experiment multiple times before making a conclusion if the changes in

their blood sugar is not drastic enough.

Acquiring new external information can stimulate needs for problem-solving

processes. For example, P1 learned about a new type of CGM that is much smaller than

what she is using and she wore both CGM at the same time for a few weeks to gather

information in order to test the accuracy of the new CGM. In this sense, external

information is used by participants as a reason or context for problem-solving, but the

problem-solving process mainly relies on self-generated health information.

6.3.4.4 Decision-Making

Participants also use the health information they collected to make decisions

related to their health conditions. The decision-making process ends with participants

making actions based on what they learned from their health information and can start

with the interactions with external information, or an evaluation or problem-solving

process.

Decision-making based on external information. Participants may base their

new decisions on the acquisition of a piece of external information that contradicts or

renews their current beliefs. For example, P17 was taking large doses of Lipitor for high

cholesterol before she was diagnosed with type 1 diabetes. She later learned that the use

of Lipitor is tied to new cases of type 2 diabetes. Although the medication may not have

led to the development of both types of diabetes, P17 still decided to stop using the

medication because of her concern for a possible connection between the medication and her diagnosis of late onset type 1 diabetes.

Decision-making based on evaluating. A common behavior among all participants is monitoring. It is a behavior that involves information collection and information use. Monitoring includes two information use activities, including evaluating and decision-making activities. An example is using blood sugar test results collected before lunch to decide how many units of carbohydrates to consume during lunch and how many units of insulin to inject before lunch.

Participants also make decisions based on the evaluation of long term health records. For example, P13 has maintained stable A1c levels for a few months and she made the decision to keep her current regimen because it works fine. P18 decided to participate in an exercise group diligently because she has uncontrollable blood sugar levels and she hopes that participating in the group can help her maintain stable test results.

Decision-making based on problem-solving. Participants who identified problems when interacting with their personal health information make decisions based on how these problems can be solved. P20, who observed seasonal changes in his blood sugar levels decided to maintain his daily routine and try to stay positive when his numbers are disturbed by seasonal changes.

Participants who experimented during the problem-solving process may either accept or reject the hypotheses that they started out with and decide to either adopt the experimented behavior or abandon it. For example, participants who tested whether mixing different types of insulin may cause adverse effect did not find a change in their

blood sugar levels after mixing insulin, so they decide to mix the insulin in one injection to reduce the number of injections they have to take. Participants also reported experimenting with different diets (e.g., high protein diet, high fat diet, and high fiber diet) and adopting the diet that made their blood sugar the lowest and most stable.

The decisions participants make can be short term or long term (e.g., taking a week off to reduce work-related stress), long term (e.g., reduce lancet usage because of anticipation of increasingly reduced supplies compensated by insurance companies), or a negotiation between the two. This is because some of the short term changes may not be sustainable. For example, participants like P11 and P27decided to take breaks from her CGM once in a while because wearing the device can cause physical discomforts like bleeding and irritations at the insertion site. However, they still use the CGM most of the time in order to be able to evaluate their health condition in real time.

6.4 Affective Processes Accompanying PHIM Activities

Changes in emotions may accompany various PHIM activities. During the interviews, the participants were asked "How do you feel emotionally when you manage or organize your health information in these ways? For example, do you feel happy, relieved, frustrated, or in some other ways?" This question is asked for each information source participants used and each PHIM activity participants engaged in.

Findings on these emotions are organized according to PHIM aspects they accompany and affect – whether these emotions are positive, neutral or negative. Table20 shows the affective processes examined in this dissertation as related to different aspects of PHIM. The rest of the section offers detail on different emotions experienced by

participants and how these emotions interact with participants' diabetes management activities.

Table 20
Affective Processes

Affective Processes	Definition
Information Content Elicited Affect	Emotions caused by the content of the health information managed by patients.
Information Volume Elicited Affect	Emotions caused by the volume of information managed by patients.
PHIM Activities Elicited Affect	Emotions caused by the different PHIM activities the patients engage in.
PHIM Tools Elicited Affect	Emotions caused by the different PHIM tools that patients use to manage their personal health information.

6.4.1 Information Content Elicited Affect

The content of self-generated information and information collected from external information sources can lead to different emotions. These emotions can be positive, negative, or neutral.

Emotions elicited by self-generated information. Participants reported that the content of health information can be perceived as "good", "neutral" or "bad". "Good" information is information connected to better health, vice versa. In terms of self-generated information, it is perhaps intuitive that blood sugar test results that are within the range of normal blood sugar levels would make patient feel positive, while higher or lower numbers can bring negative emotion. For example, P10 describes changes in her emotional reactions to her blood sugar test results, "*It depends on the number. So if the*

number is within its goal, within a normal range, then I'm just fine, there's no emotion, it's just what I'm supposed to be. If it's low or high, then it's frustration."

Managing emotions elicited by self-generated information. Participants also noted that although emotions that arise from self-generated information are sometimes inevitable, the negative emotions arising from "bad" information do not help them achieve better health outcomes.P5, for example, explains that she "*feel(s) empowered, because basically I am receiving data that can help me. As long as I see it as a positive, rather than like a shameful reminder that is over 300[7]yesterday at 2pm, but like let's think about what was happening at that time, what did I do? How could I have prevented that? So it's empowering is a good word I think.*" P5 switched her attention from using her blood sugar test results as indications of her short term health outcomes to using these outcomes to direct problem-solving activities and behavior changes that can boost long term health outcomes.

Over the long term, participants can become experts at harnessing their self-generated information and experience fewer emotional episodes when interacting with this information. For example, P2 has lived with type 1 diabetes for over 50 years. Like many other diabetes patients, P2 experiences acute diabetes episodes, but the ensuing emotion is dampened. He says, "*You can have good readings for weeks, and then all of a sudden the readings can go haywire. … If there's suddenly a change, … then I'd probably be upset, but my guess is that anything like that can be fixed. It's just a matter of sitting down, thinking about it, and thinking about what the problem might be, and I'm*

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[7] The Unit of the blood glucose level used by P5 is mg/dL. Diabetes patients are recommended to keep their blood sugar levels below 180 mg/dL (American Diabetes Association, 2016).

not sure that an endocrinologist would be able to guide me in another direction. ... I'm confident with the fact that I see where I am and I see I'm stable. That keeps me secure." P2 mentions that he used to experience emotional episodes during the first few years after the diagnosis, but he attempted to decode his health through extensive recording of factors that can lead to changes in his blood sugar levels, such as diet, insulin intake, and location of testing. This effort paid off in the long term, when he anticipated the day-to-day fluctuations in his numbers and learned how to fix the abnormalities. However, P2 stresses that his confidence in his own case does not necessarily allow him to solve other patients' cases with similar levels of confidence, because people's physiological characteristics and lifestyles are different.

Interestingly, participants have found ways to make the content of their self-generated information less emotion-inducing. P1, for example, prefers to not call blood sugar test numbers "good" or "bad". Rather, she refers to normal blood sugar levels as "in range" and those that indicate health issues as "out of range". P1 suggests, *"this is not as any kind of judgment, but information. So you see that your numbers are higher than they should be, it's information to do something. It's lower than it should be, it's information to do something. So they are really not using the idea of calling the numbers good and bad."* In some sense, P1 reframes the messages delivered by her blood sugar levels, making it easier to make use of the information without the interference of unnecessary emotion.

Emotions elicited by external information. Other than self-generated information, patients also interact with information collected from external information sources. Some examples of these external sources include the mass media (e.g., the

Internet, television, newspaper, radio, etc.) and patients' health care team (e.g., doctors, nurses, pharmacists, certified diabetes educators, dieticians, physical therapists, etc.) and their personal network (e.g., family, friends, colleagues, other diabetes patients, etc.). This information may also elicit emotion in patients and referred to by patients as "good" or "bad. For instance, P1 mentions that some books and health care providers would stress the possible negative health outcomes of living with diabetes, instead of *"offer(ing) hope and possibilities"*. She explains, "*Threatening, making people scared doesn't work. It works for some time. It's not sustaining. I might do something for a week or two because I'm scared. ... But it's not going to let me do it for much longer.*"

Some participants divided the health information they collect from external sources according to how it may be applicable to their specific circumstances. This applicability may be a combination various information attributes, such as usefulness, timeliness, and credibility. Managing health information that is applicable to participants' situations can result in positive emotions. For example, P10 mentions that she felt "*motivated*" when she received comments from other patients she talked to. This emotion encouraged her to keep taking good care of herself and communicating what she learned with other patients. Also, the management of "good" external health information can trigger the acquisition of more information, leading to an upward spiral in spirit and learning behavior. P13, for example, felt "*interested and intrigued*" when her doctor directed her to the scientific literature concerning diabetes.

On the other hand, encountering health information that is not applicable to participants' conditions can breed negative emotions. As P7 puts it, "*If it's information that can benefit me, I feel good. If it's the same old crap, I feel like it's never gonna*

end…". Aside from the lack of new information, participants also mentioned the issue that much information from mass media is irrelevant. For example, P15 notes that it is hard to locate information relevant to type 1 diabetes when the mass media tend to focus more on type 2 diabetes. P15 expresses her frustration with this phenomenon, "*TV, radio, everything is about type 2, I mean everything. That is also kind of frustrating. Everyone in the world knows what type 2 is, and they assume it's the same thing, and that's super annoying.*" People living with type 2 diabetes can be treated with pills and in many cases do not need to use injected insulin. This difference means that messages targeting patients with type 2 diabetes typically do not address the major concerns of those with type 1 diabetes, such as insulin dosage, insulin injection time and location, insulin injection devices, hypoglycemia episodes, and the calculation of carbohydrate amount in food. Participants like P15 tend to experience the gradual accumulation of negative emotion to a point when they reduce their use of mass media as an information source and turn to personal networks instead.

Emotions elicited by the presentation of external information. When patients acquire health information from their personal networks, different people in patients' networks may provide information with varied content. In particular, family and friends are reported by participants to provide the larger portion of the "bad" information they acquire. P5 complained about information from her family and friends, "*They know just a very little bit about diabetes and it's probably from 2008. Y'know, I don't expect them to follow it closely but it's just that 'Oh, you shouldn't eat sugar'. 'Oh, you're acting funny, your blood sugar must be low.' I don't know, it's a little frustrating sometimes to talk to every person on the street about it if they don't have some knowledge already. So I tend to*

talk to my friends who are diabetic." The frustration experienced by P5 is shared by many other participants. The reasons for such frustration are (a) the information provided was wrong, partial, out-of-date, or repetitive, and (b) the person provided the information in ways way that were perceived by patients as threatening, patronizing, or commanding.

Participants note that the health information provided by health care providers can be hard to digest because of the intense negative emotions provoked by the expression of the information. For example, P7 left her previous endocrinologist because every time the doctor looks at her numbers, the doctor would shake their head and say, "*I just don't know what you did wrong.*" Similar issues with health care providers are experienced by other participants as well. To avoid such experiences, patients like P7 and P15 tend to go through great trouble to locate endocrinologists who also live with diabetes, with the hope that their communication would be more pleasant because of a shared background.

The timing at which health information is acquired can also affect patients' emotional reactions to it. P25 stresses the importance of timing, "*If I think about going to an article on the Internet that said never use anything sharp to pare your feet, right? And then I go back to it after I had the tip of my toe amputated, then how would I feel? I feel like a stupid idiot, you know? Again, you made certain mistakes you can't go back to change it. You know you have to just deal with where you are, take the information, and use it to your benefit now. So sometimes it could be remorse, sometimes it could be regret, sometimes it could be empowering.*" P25 had his toe removed due to necrosis. He wishes he had access to a piece of information on the possible causes of inflammation before he unknowingly pared his foot. However, after the fact, he would rather not encounter that information because its utility was lost with only negative emotion left.

Managing emotions elicited by external information. Participants also developed ways to frame information from external information sources in order to elicit positive emotion. For example, P14 made two lists of food that are either good or bad for blood sugar management. In order to feel that she has many good options and relatively fewer things she needs to avoid, she transcribed the lists with the following modifications: (a) she expanded the list of beneficial foods and kept the other list concise, and (b) she transcribed the desirable list in pink, her favorite color, and the other list in an alarming red. P14 keeps this new list on her pantry door, using it as a tool for diet management and as a reminder of the many good food options she has (Figure 16).

To sum up, the content of health information patients collect from themselves and other sources can influence their emotion. Different people may experience this emotion differently and the emotion may evolve over time or change due to different ways of framing. Furthermore, these emotional experiences may prompt patients to perform different actions toward the information they acquired and their health condition in general.

6.4.2 Information Volume Elicited Affect

The volume of the health information encountered by participants can elicit different emotions depending on participants' purpose of interacting with the information and how they interact with it.

Emotions elicited by the volume of information for personal use. Some information was collected by participants for their personal use, such as for evaluating, problem solving, and decision making. Our participants report that they usually welcome

high volume of health information, whether it is self-generated or acquired from other sources. For example, P20 records his blood sugar test results in a spreadsheet and accumulated a large collection of time-mapped test results over the years (Figure 17). He runs time series analysis on these test results to identify patterns that emerge in the changing blood sugar levels. When comparing his blood sugar levels over the years, P20 noticed a seasonal pattern, where his blood sugar levels were uncontrollably high during a few weeks in the winter. He shared his findings with his health care providers, who adjusted his treatment plan accordingly. P20 reported that having access to a large amount of self-generated health information and being able to reformat it in ways that facilitate understanding makes him feel positive and in control.

When patients collect health information from external sources, not all information can be applicable to their situations and high volume is not always desired. For instance, P11 voices that there are too many information sources on the Internet. The amount of information from these sources is "*overwhelming*", while the content is "*not as deep as you want them to be*". P17 also mentions that people around her provide "*too much information. I have no place to put it, ...and I don't trust computer, it can break.*" In these cases, the overwhelming high volume of external information seems to be accompanied by other issues such as limited usefulness due to lack of depth or relevance, the lack of space, and the limited use of modern technologies.

Emotions elicited by the volume of information for sharing. When patients collect information for the purpose of sharing, they seem to experience more positive emotions with higher information volumes. For example, P2 scans printed magazines, newspapers, and brochures regularly for information on diabetes-related regimen and

treatments. He brings collections of health information he found to a patient support group on a monthly basis to share with fellow patients. He also prints multiple copies of the same printed media so that other patients can take them home. P2 said he was "*happy to share, since some people will find it useful.*" The altruism was shared by other participants who contributed artifacts such as printed articles, books and brochures to help their peers.

Similarly, participants report positive emotions when sharing high volumes of self-generated information with their health care providers. For example, P25 was instructed by his doctors to make written records of his blood sugar levels and share these records at their appointment. P25 explains the reason that he kept detailed records, "*the doctor seems to be much happier and give you a lot more praise and say that you're doing much better if you have notes. If you have no notes, they're like, what do you want from me? I can't do anything for you, I can't help you. ... I feel relieved that it's* (i.e., recording blood sugar levels) *getting done, because in that way when I go to the doctor, the doctor's not gonna make me feel pessimistic and depressed.*" In this case, the doctor's expectations for the patient to share his self-generated information seem to mediate the connection between the volume of information shared and the patient's emotional experiences.

On the other hand, participants who share information about themselves with family members experience mixed emotions and feel the need to find a balance in the volume of information shared. This balance point should minimize the anxiety levels of the person on the receiving end. The tricky part is that high volumes of information can lead to unnecessary guess work and high levels of anxiety, while low volumes of

information do not allow the family member to get a clear picture of the participant's health status. Both cases put increased stress on participants. As P11 notes, "*I think my mother would prefer that I had something in place like that* (i.e., the patient share real time blood sugar readings with her mother through a smart phone)*, as a way for her to keep an eye on me, ... but it's a lot of information for someone other than me to process. ... It's creating anxiety for the sake of anxiety. For instance, if my sensor came out accidentally, I might get a fake alarm, but I know that the sensor came out. Other people may not know… So analyzing the data without the contextual information is very difficult.*"

6.4.3 PHIM Activities Elicited Affect

Various PHIM activities are accompanied by different emotional responses from participants.

Emotions elicited by PHIM activities. Collecting and organizing self-generated information require dedication. Participants report that PHIM activities such as testing blood sugar, injecting insulin, and writing down the test results and insulin dosages take less than 5 minutes each time once the participants are familiar with the procedures. However, the high frequencies of such activities (e.g., participants who use blood glucose meters test their blood sugar between 4 and 11 times a day) and the need to remember to perform such activities can lead to negative emotions. P15 describes how her daily routines can be disrupted by having to record her diet and blood sugar levels, "…*I was doing MyFitnessPal to lose weight. And I used to put in all the foods, and I'm like okay, I can't do this anymore. ... I want to just sit down and eat, ... but I test myself and I'm*

putting it in my pump, and I just get so annoyed." As a result, the participants in this

dissertation express that technologies that can automatically collect their health indicators,

communicate with their insulin pumps to guide insulin dosing, and present the patient-

generated information in meaningful ways are highly desirable. However, they also

voiced concerns for the safety of relevant projects that are not FDA approved (e.g., the

Nightscout Project[8]) and the loss of contextual information (e.g., food, exercise, emotions,

etc.) in an effort to automate the information collection process.

      Emotions elicited by disruptions to PHIM activities. Disruptions to participants'

routine PHIM activities can also lead to various emotions. Participants report that major

life events and being an inpatient are associated with high levels of uncertainty and stress

due to major shifts in responsibilities for PHIM activities. For example, P19 recalls how

he withheld health information from his health care providers when he was young,

because he did not consider recording and sharing diabetes-related information his

responsibility. "*Having to deal with something very responsibly at too young of an age,*

and slowly opening up versus immediately snapping into attention, and just debouching

and being completely transparent. It (i.e., withholding health information) *was a way to*

kind of protect myself. Because it wasn't someone who, they were being judgmental and

critical, as much as I took anything they said as judgmental and critical, so it was work

that I need to do to understand, I'm not alone, but I didn't know that it's time." P19

reports that the loneliness, dullness, awkwardness and shame in struggling to take on the

responsibilities of dealing with the disease and related health information stretched

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[8]The Nightscout Project is a patient-initiated effort to use smart phones as a medium to enable the communication between continuous glucose monitors and insulin pumps. The system creates a closed-loop system that allows the automatic administering of insulin according to the automatically collected information on blood sugar levels.

through his teenage years. As he grew older, the realization of a partnership between him and his health care team sink in, and the strong emotions slowly subsides. P11, who also experienced such transitions, reports mixed emotions she experienced when she took the responsibilities of diabetes information management into her own hands: "*It was a little overwhelming at first but it's nice to have this intimate understanding of how my body works … If something goes wrong, it's frustrating because I have nobody else to blame, but it's just what it is and I'm trying to have the positive outlook of the situation.*"

In contrast, some participants may experience more positive emotions when the disruption of PHIM activities is accompanied with increased support from others. For instance, P1 used to have blood sugar levels that were frequently out of range, and she did not collect diabetes-related information to help with her health. However, her marriage brought tremendous changes to her perspectives and actions. She feels "*loved*", "*secure*", and "*confident*", because her husband shared her diabetes management responsibilities in monitoring her status, giving her reminders, and carrying around her devices and tools. P8 refers to the support "*[p]eople who themselves* don't have diabetes but they're so involved in living with somebody who does" as "*type 3*" diabetes patients. Participants who are living with type 3 "patients" express that their type 3s make them experience PHIM activities more positively due to the support and the bonds that the support facilitates.

Furthermore, the transition between the home and the clinical environment as an in-patient can cause short term disruptions to participants' routines of PHIM activities and can invoke emotions. Participants voice their concerns about the low literacy levels about diabetes among their in-patient care teams. Doctors and nurses alike are not sure

what to do with the pumps and continuous glucose monitors attached to the patients

through surgery and the hospital serves food with high levels of carbohydrates, which is

against diabetes patients' recommended diet. P7 mentions that she had to convince her

clinicians to allow her to test her own blood sugar and administer insulin accordingly

because the clinicians were concerned about possible responsibilities associated with the

interaction between the insulin and the surgery.

6.4.4 PHIM Tools Elicited Affect

Participants use a wide variety of PHIM tools to manage their personal health

information and report different emotions related to the use of these tools.

Emotions elicited by PHIM tools. Participants express that they are grateful for

the PHIM tools available to them because their lives and quality of life depend on these

tools. For example, P5 mentions her Continuous Glucose Monitor (CGM), a wearable

medical device that offers blood glucose readings roughly every 5 to 15 minutes,

depending on the product. In addition to nearly real-time blood glucose level display, a

CGM also offers information on whether the numbers go up or down and how fast these

changes occur at the latest data point. Participants use this device as an information

display and storage tool. P5 finds the CGM particularly helpful because it allows her to

see future trends and proactively adjust her medication and everyday activities, such as

diet and exercise. In fact, she wanted this information to be "*right there in my face*" to

show "*how my blood sugar was rising and falling, right on the background as like my

desktop background*". P18 described this necessity to constantly check her device as

some kind of "*addiction*": "*I look at it all the time. It's fascinating to see the graph

extends and the changes in the arrows[9]. I can't imagine what my life would be like without it." Interestingly, P1 developed a strong attachment to her CGM and named it as one would a pet. P1 calls her CGM Pinky because it is pink, and the name made it sound "*cute*". Pinky helps P1 as a travel companion and an assistant to get back on track during uncontrollable diabetes episodes.

Participants also report that some PHIM tools they use lead to negative emotions. For example, P29 mentions that she takes breaks from her CGM from time to time because "*I get tired wearing it. It's just another thing attached to your body, and one day people will be wrapped up in wires.*" Other participants report issues with PHIM tools that make them less appealing, such as size, looks, the location where it is attached, and the ease of inserting the sensors. For example, P4 notes that the device she has is large and hard to hide. Also, the design of the device does not match with her favorite outfits. As a result, she struggles with the idea of having to bring the device to special occasions. Although compared to the other bulkier devices that P4's friends wore she would rather deal with what she has, but the lack of a better device leaves her frustrated and unsatisfied.

Paper tools can also elicit emotions. For example, P19 comments on the log books he received from his doctors, "*They are very dry, very routine, and another add to it would be just juvenile. ... They* [i.e., health care providers] *would be like, here is the best thing we come up with and we have like a frog on it and it was just, it was silly. It was just very childish. ...Animal, little animals in the woods, or like an Amazon being like frogs and lizards, or dinosaurs. ... You can understand why even a 13 year-old would*

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[9] P5's CGM displays an arrow at the last data point to indicate the direction and pace of blood sugar changes

reject that, let alone adults." For P19, the frustration with the workload added by diabetes information management seemed to be intensified by the unsatisfactory design of the PHIM tools he used.

Further, participants report issues related to the logistics of acquiring PHIM tools. Although the existence of tools that allow participants to monitor their blood sugar levels at home is appreciated, participants report frustration in their effort to gain access to such tools because of the financial strains created by these tools. For example, modern blood glucose meters consume testing strips with each test. The diabetes patients recruited for this dissertation test between 4 and 11 times a day. Over time, the large consumption of strips and the limited supplies that patients' insurance covers adds stress to patients' ability to maintain their preferred levels of information work. Participants report that their insurance companies used to provide around 300 strips a month, but that number was cut down to around 100 lately, which is barely enough to sustain the least volume of consumption reported by participants. Similar situations exist for CGMs. These devices have sensors that are attached patients' body to collect information on blood sugar levels. Participants note that while the device itself can last a year or two, the sensors last a week and can cost around $70 each out of pocket. Participants' insurance covers some types of CGM and the coverage can change over time, making it frustrating and stressful to deal with either the insurance or cost of the device.

Managing emotions elicited by PHIM tools. Participants developed creative ways to turn the daily chore of recording self-generated information into a positive experience. For example, P14 records her stories of living with diabetes through pictures

and free text. As an artist, P14 does not find joy in structured recording, but was attracted to colorful drawings. Since she started the picture diary, she was looking forward to her daily recording and found herself laughing as she immersed in the lively narratives. Figure 18 (a) and (b) show an example of P14's picture diaries. This diary includes all the information required by the table format records recommended by health care providers (Figure 20), but presents it very differently. In P14's case, she spends more time and energy to compile the picture diaries compared to just writing down the numbers in a structured format, but the positive emotions associated with creating the photo diaries enables her to carry on with the recording over the long term.

Figure 20. P21's blood sugar and insulin records
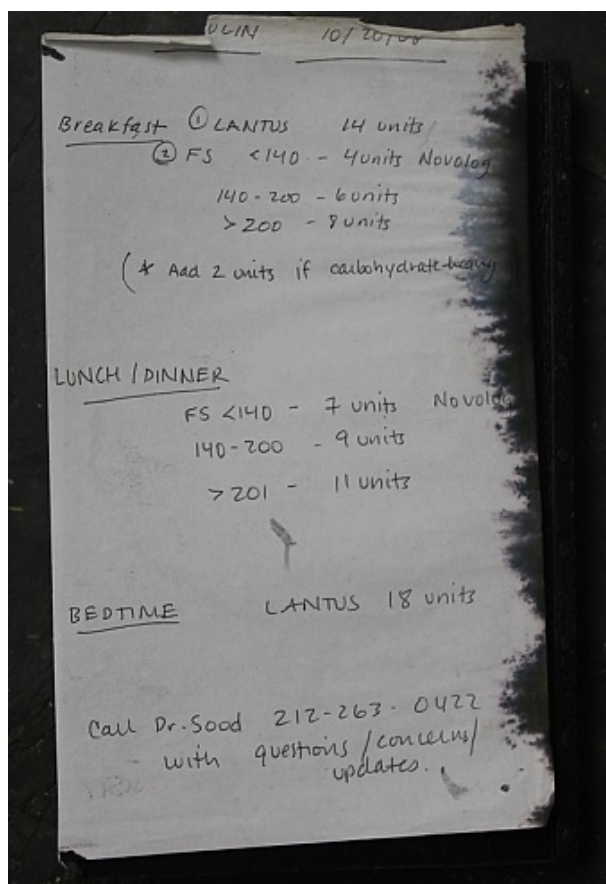
Figure 21. P25's note from health care providers kept between leaves of his sketchbook

Participants also personalize the ways in which they interact with the information collected from external sources. For instance, P25 brought home handwritten notes from his health care providers, which includes important information on insulin dosage adjustment methods according to insulin types, time of the day, and blood sugar levels. P25 understands the importance of such information but he may not have access to it when he needs it. However, as a painter, P25 brings a sketchbook with him at all times and he keeps the doctor's notes between pages of his sketchbook (Figure 21). P25 reports that he is "*always happy*" when he makes good sketches and this makes recording and reviewing health information collected in these sketchbooks more pleasant. Aside from

doctor's notes, P25 also keeps printed diabetes-related articles and rough notes of his health in the sketchbook. Essentially, P25's sketchbook was used as a multi-functional tool: (a) a drawing pad, (b) a folder, and (c) a motivating tool for collecting and reviewing diabetes-related information. P25 performs diabetes-related PHIM activities with his sketchbooks as central information items because of the positive emotions associated with these sketchbooks and his career that these sketchbooks stand for.

CHAPTER 7 DISCUSSION

In this dissertation, the researcher examines the personal health information management (PHIM) processes of people living with type 1 or type 2 diabetes and aims to present a comprehensive model of PHIM in chronic illnesses. In this chapter, a comprehensive model of PHIM, updated from the research framework (Figure 2), is presented.

7.1 A Comprehensive Model of PHIM Processes in Chronic Illnesses

A comprehensive model of PHIM processes in chronic illnesses (Figure 22) is developed based on the rich data collected for this dissertation. The chapter on research results paints a complex picture that depicts the relationships between 39 motivators, 23 PHIM activities, and emotions of 3 different affects caused by 4 aspects of PHIM processes.
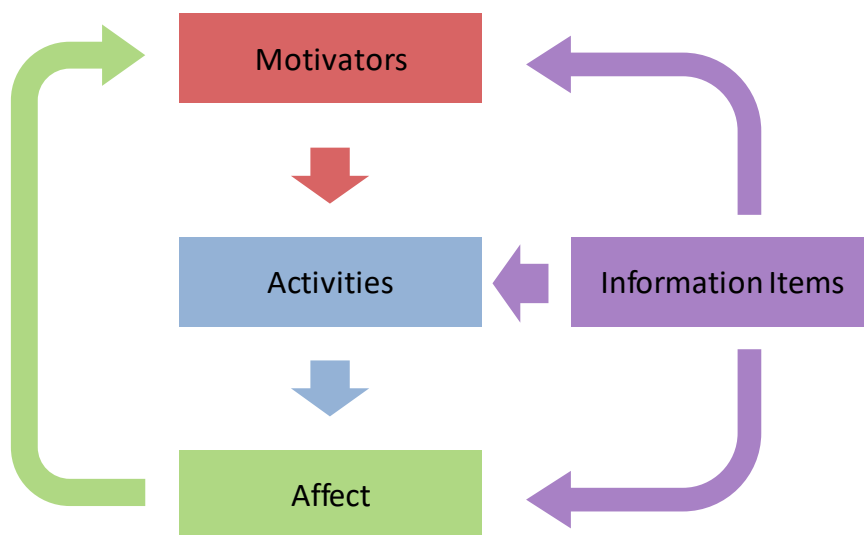
Figure 22. A Comprehensive Model of PHIM Processes in Diabetes (CMPHIM)

Major relationships depicted in the model include, (a) the varying effects of different motivators on different PHIM activities; (b) the affects caused by different PHIM activities; (c) the motivating power of emotions on PHIM activities; and (d) information items' motivating power, usage, and impact on affects. This section presents details on these relationships.

7.1.1 Motivators Impact Activities

By definition, PHIM motivators can influence patients' performance of PHIM activities. Findings reported in Chapter 6 point to a large number of motivators (i.e., 39 motivators) that interact to influence the performance of PHIM activities. The influences are dynamic and patients constantly negotiate between different positive and negative motivators in order to made decisions on what PHIM activities to perform and to what extent these activities are performed. This finding adds to the complexity of how motivators function for patients and points to the necessity of addressing the dynamics of multiple motivators when examining patients' information work.

The Comprehensive Model of PHIM Processes in Chronic Illnesses (CMPHIM) identified motivators that are also mentioned in the classic theories and models of information seeking behavior and information search behavior. First, information behaviors can be motivated by needs to address real-life issues (Belkin et al., 1982). Participants in this study express that their need to address noticeable symptoms and severe health conditions and their anticipation to improve health outcomes are some of the reasons that they look for external health information and collect self-generated health information.

Second, information behaviors are performed to bridge gaps in people's knowledge (Dervin, 1983). Participants mention that an important attribute of the health information they actively collect is that it is new to them. Participants report they usually do not collect information provided by family members, friends, and some mass media information sources because this information is usually repetitive. Participants also note that when their blood sugar test results become stable and predictable, they may stop collecting this information because it is not new.

Third, information behaviors can be accompanied by emotions and this emotion may change as people progress through their information behavior processes (Kuhlthau, 1991). Although Kuhlthau's model of information search process is developed for information search behaviors, findings in the dissertation support that the prevalence of emotion holds true for other PHIM activities. These emotions can have motivating powers on patients' PHIM activities, making the inclusion of emotions when examining information behaviors ever more relevant.

The CMPHIM also points to the need to distinguish between motivators and information behaviors and examine the nuances of connections between motivators and information behaviors. This issue is not studied enough in the field of PHIM. In fact, the literature points to the complexity that patients experience when navigating their health and their health information (e.g., Ancker et al., 2015; Pratt et al., 2006; Whetstone, 2013), but there is not enough research that examine the motivators in detail while distinguishing between motivators and activities. For example, Civan, Skeels, Stolyar, and Pratt(2006) found that patients may record their self-generated health information to address their own needs or the needs of people in their social networks. However, Civan

and colleagues did not address the details of these needs and how patients record information and use this recorded information differently for different members of their social network. Understanding these nuances is crucial for motivating different patients to perform PHIM activities that can potentially help with their health, because the complex joined effect of multiple motivations on each PHIM activity means that the big picture has the potential to create outcomes that are more effective than its parts.

Furthermore, the CMPHIM adds to the literature of behavior change, supporting that there are many factors identified for the general population's health behavior change can also apply to patients' health information behavior change. For example, the Health Belief Model (Janz & Becker, 1984) examines people's perceived susceptibility to a health condition, perceived severity of that health condition, perceived benefits of carrying out healthful behaviors, and perceived barriers toward behavior change. These factors loosely correspond to these factors identified in CMPHIM: symptom notability, condition severity, anticipated health outcomes, discomfort prohibiting information management, and discomfort caused by information management. Also, the Comprehensive Model of Information Seeking (Johnson et al., 1995) points to people's direct experiences with behavior change, salience or the applicability of behavior change, and personal beliefs as precursors of information seeking. These factors are also found in CMPHIM, including continuity of existing behaviors, information usefulness, and outlook on life. These similarities point to the potential transferability of motivators identified in CMPHIM to those for the information behaviors by the general population.

7.1.1.1 The Impact of Multiple Motivators

Results show that each participant's PHIM activities are influenced by 10 to 20 different motivators. Most of these motivators influence information collection activities. This means that patients may experience a tug-of-war between myriad motivators before they make decisions as to whether to collect health information, what health information to collect, and how to collect it. For example, when making decisions about whether and how to record blood sugar levels collected using blood glucose meters, P25 debates between how useful are the results to him and his health care team, whether he can reliably remember the test results, whether recording the results can influence his future health outcomes, how severe his conditions are, what are his health care team's expectations for and reactions to him regarding such records, what the stories from exemplars can inform him, who is responsible for making such records, and his outlook on life.

Given that so many different motivators can impact a PHIM activity, only examining certain categories of PHIM motivators, such as characteristics of information sources and medical motivators, may not paint a complete picture of how patients are motivated. First, the same motivator can result in different directions of the same information management activity, which means that the single motivator alone may not explain the patient's behavior. For example, patients manage their health information differently when motivated by information consistency. Some participants report they collect and use information more frequently when information is inconsistent so that they can potentially balance out the inconsistency with the volume of information. Others

suggest that they perform such activities less frequently when the information they collect is inconsistent, because they perceive inconsistent information as less useful.

Second, the same behavior can be prompted by different motivators. For example, marking information items may be prompted by motivators such as information usefulness, anticipated health outcomes, continuity of existing behaviors, interest in the activities, and ease of information management process. A person may be motivated to mark information items because of all these motivators or some of them. Also, some motivators may have different strength of motivation for different people. For example, P13 reports that one of the major reasons that she marks her health information items and many other non-health related items at home is because of her strong interest in marking items. In contract, a major motivator for P23 to mark the pages in her books because of the potential usefulness of the information on the page, although she is not interested in the PHIM activity *per se*. Understanding how the same PHIM activities are prompted by different motivators can help us identify ways to stimulate the same behaviors through different venues and potentially reduce the barriers for some populations when they attempt these behaviors.

Third, the same goal of pursuing better health may be achieved by different PHIM activities that are prompted by different motivators. For example, P20 uses an Excel spreadsheet to manage his self-generated health information because he already uses the tool for work, it is easy to filter information, and the spreadsheet supports the construction of time series models. In contrast, P1 does not record her self-generated health information. She uses electronic devices to monitor her blood glucose levels in real time and adjusts her activities and treatments accordingly. Sometimes, she wears multiple

devices that serve the same function to assure the accuracy of the test results she receives. Both P1 and P20 have lived with type 1 diabetes for over 40 years and neither has developed diabetes-related complications. In this case, the information management activities may differ, and their corresponding motivators vary, but their purposes are similar, and so are their effects. The importance of investigating the different motivators for different behaviors that aim for the same goals lies in its value of potentially making certain goals achievable for different groups of people through means that work the best for them.

7.1.1.2 The Dynamic Motivators

The motivators for certain PHIM activities during a certain period of time may not have the same effect on the same person as time passes. The types of motivators for the same activity may change over time. For example, P19 recalled that he used to record his blood glucose test results as a child, albeit reluctantly, because it is expected by his health care team. P19 now records his test results because he sees the usefulness of such records to guide his self-management activities and he perceives the responsibility of creating such records to be on himself.

The changes in the motivators may even cause reversed effects on patients' PHIM activities. For example, P13 used to record her blood glucose test results when she was newly diagnosed because the test results are inconsistent and they are useful to help her evaluate her situation. After a few months, she developed better understanding of her health condition and she stopped recording her blood glucose test results, because her symptoms are more consistent and the recording takes up time.

The dynamic nature of motivators and the interactions between different motivators point to the necessity to re-evaluate motivational items and services as time passes, so that interventions for motivating certain activities stay relevant.

7.1.1.3 The Rational and Emotional Motivators

Emotions play an important part in motivating patients' PHIM activities. Motivators such as information elicited emotions, social identity, expectations from others, reactions from others, social significance of information items, stigma, social relations, interest in the activities, and interest in the information can be motivating patients through emotions. Findings in this dissertation suggest that emotions are inevitable in many cases when patients interact with health information and it may have positive or negative effects on certain PHIM activities. Also, patients may suppress emotions because they are irrelevant or they may attempt to stimulate positive emotions and associate such emotions with certain PHIM activities and information items to motivate these activities. These findings suggest that patients may be constantly balancing the rational self and the emotional self when aiming for health outcome goals. In other words, it is not only important to understand the role that emotions play in motivating PHIM activities, it is also useful to examine the interactions between emotions and reasons and how patients negotiate the two aspects to achieve their goals. Figure 23 maps how all the motivators identified in this study are distributed, in terms of whether they tend to be more rational or emotional motivators.

Figure 23. Rational Versus Emotional Motivators (Rational – Blue, e.g., Availability; Emotional – Yellow, e.g., Social Identity; Mixed – Green, e.g., Abundance)

Recently, there is increased research in the area of emotions in chronic illnesses and their effect on people's health-related behaviors. For example, Gonzalez, Tanenbaum, and Commissariat (2016) found that emotional distress can be a hurdle for diabetes patients to take medications as recommended by their health care team. Similar results are observed among cirrhosis patients (Polis et al., 2016). In contrast, managing emotions can motivate diabetes patients' effort for self-management (Sabourin & Pursley, 2013). Also, negative emotions, such as worry, can lead cancer patients to seek health information (Lee & Hawkins, 2016).

However, there is not enough research on understanding the interactions between emotions and motivators for PHIM. The results in this dissertation address some of this gap in the literature.

7.1.1.4 Attrition of PHIM Activities

The negative motivators that prevent patients from performing certain PHIM activities can indirectly influence the PHIM activities that are based on previous activities. For example, participants in this study who do not record health information for later use may still collect health information in other ways, such as consulting, updating, searching, browsing, and through serendipity encounters. They may use this information immediately after they encounter it. However, without the recorded information, it is impossible to delete such information, organize it, and retrieve it.

Figure 24 is an illustration of how motivators may influence activities. In this illustration, the size of the boxes of the four PHIM activities symbolizes the frequency and intensity these activities are performed. All participants collect health information. Some of this information is used by participants, some is discarded, and some is recorded without using it. Among the recorded information, some may be organized and some not. Either way, patients can retrieve recorded information from their personal health information collection and use it after the retrieval process.

The above process suggests that information organization is the least performed activities as reported by participants in this study, since the information that participants collect can skip the information organization activities and proceed to retrieval activities, or skip both information organization and retrieval activities and go straight to
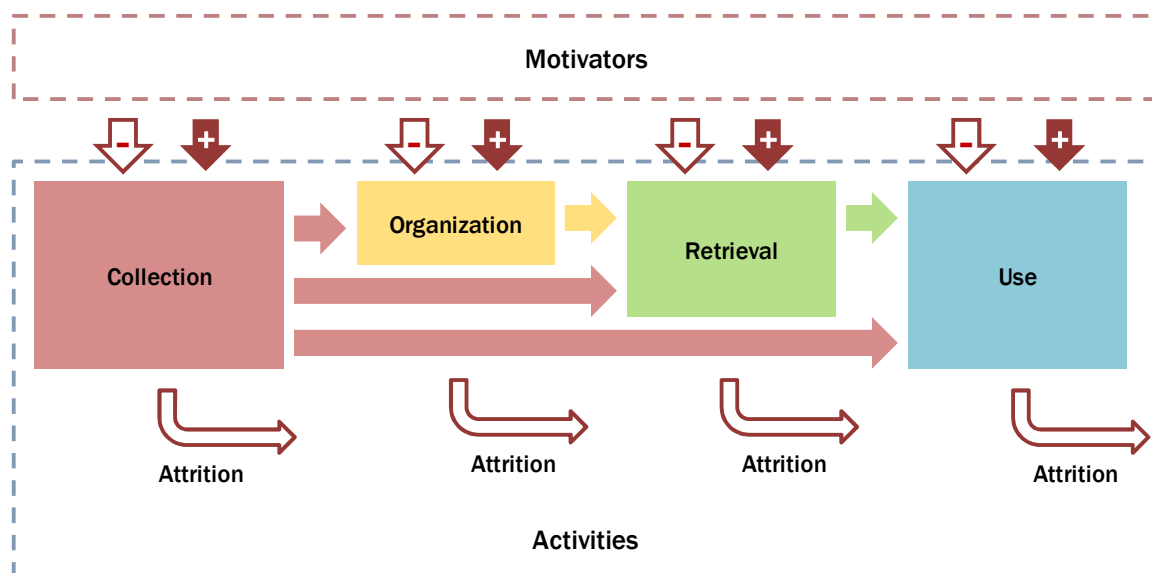
Figure 24. An illustration of the attrition of PHIM activities

information use.

The attrition of PHIM activities does not mean that information organization is the least useful or meaningful step. On the contrary, participants who do not organize their health information report that information organization can be helpful because it can facilitate future information retrieval activities. However, the negative motivations related to information organization, such as the difficulty of these activities and the lack of time, pushed participants away from these activities.

These observations related to the attrition of PHIM activities suggest that there is an urgent need to support information organization and retrieval activities for patients with chronic conditions, in order for them to take the full advantage of PHIM.

7.1.2 Activities Generate Affect

PHIM activities can cause neutral, positive, or negative affect. Neutral affect is observed when participants focus on performing the PHIM activities. Participants report that they feel neutral because the PHIM activities are "*just business*". Positive affect is reported when participants focus on the prospect of the utility of the health information for guiding future behaviors. Some participants also feel positive because they are interested in performing the PHIM activities. Negative affect arises when participants who report to not enjoy PHIM activities focus on the process of performing PHIM activities.

These results suggest that patients' preferences, perspectives, and perceptions pay an important part in determining their affect caused by PHIM activities. However, these findings do not mean that patients are to be blamed for the affect that arise from PHIM activities. Rather, the reports of participants turning negative experiences into positive ones argue for the potential of making PHIM activities a more positive experience with the support of tools that address the source of negative affect and enhance the effects of positive affect.

Also, participants mention different emotions that fall into neutral, positive, or negative affect. These specific emotions differ from person to person. For example, P2 feels in control when recording self-generated information, while P25 feels relieved when performing the same activity. In both cases, the emotions show positive affect. Measuring the affect is useful, because affect streamlines the connections between emotions and people's motivations for PHIM activities. Understanding the nuances of emotions is also useful, because such investigation allows us to take a deeper look into what aspects of

PHIM cause these emotions and how we can make PHIM activities a more positive experience.

These findings contribute to the literature in information science and health information behavior. Studies argues that searching for information can cause emotions (Kuhlthau, 1993; Lopatovska & Arapakis, 2011) and these emotions may differ for different steps in an information search process (Kuhlthau, 1993). Also, seeking for health information can lead to positive emotions, such as empowerment, locus of control, and satisfaction (Longo et al., 2010). Despite the importance of examining emotions in information behaviors in the health care context, studies on health information behaviors have not paid enough attention to this topic (Julien & Fourie, 2015). This study attempts to address some of the gap in the literature.

On the one hand, findings in this dissertation point to the possibility that the results from the literature on emotions and information seeking and search processes may also be applicable to other information behaviors, such as information organization.

On the other hand, this dissertation adds to the research on the relationships between emotions and information behaviors by taking an in-depth look at these relationships experienced by patients living with chronic conditions. While there are some similarities between the general population and patients with regard to emotions elicited by information management activities, major differences also exist in areas such as the importance and frequency of information management activities, the social dynamics of such activities and their relationships with emotions, and the tools used to support these activities. These differences call for the necessity to use caution when

transferring interventions on information behavior for the general population to patient populations.

7.1.3 Affect Alters Motivators

Distinguishing between affects generated by PHIM activities and affects that are results of other aspects of PHIM is important. This is because results in this study suggest that the former has streamlined motivating effects on PHIM activities, while the effect of the latter is more complex. Positive affects caused by PHIM activities tend to motivate patients to enhance such behaviors, vice versa. In contrast, affects from other sources, such as the content of health information collected by patients, may have different influences on different people. For example, negative health information may induce fear in patients and cause them to avoid the information. Negative information may also be desired by patients, because the information can alert patients of possible dangers despite the negative emotions it causes (e.g., the high blood sugar levels recorded by P2).

With these differences in mind, Figure 25 presents some examples of the relationships between PHIM activity-induced affect and the motivators related to the affect. These results show that there is a feedback loop between the three processes of PHIM, including activities, affect, and motivators.

This finding contributes to the literature on emotions and health care. The literature suggests that emotions are related to cognitive functions such as decision-making activities (Damasio, 2006), such as by hastening or disrupting the decision-making processes (Lopatovska & Arapakis, 2011). On the other hand, emotions can be caused by managing chronic conditions (Eccleston, Crombez, Scotford, Clinch, &

Connell, 2004), and emotion is an integral part of a patient's health outcomes (Delahanty et al., 2007). The results of this dissertation support that the findings of previous studies also hold true when examining the relationship between emotions and an important aspect of disease management – PHIM activities.
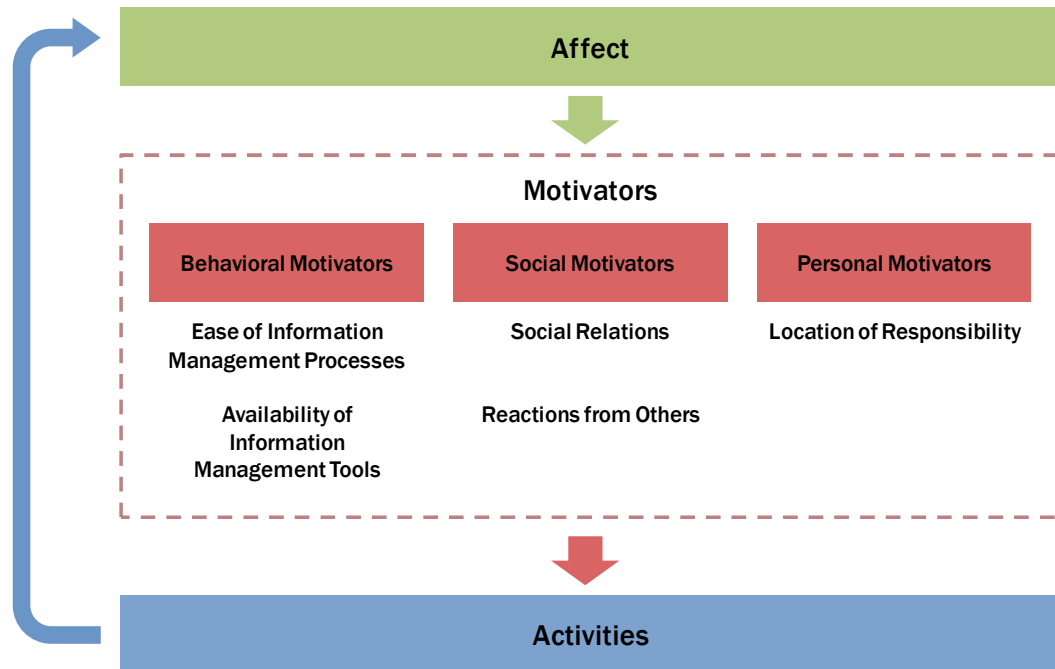
Figure 25. Affect's influences on motivations close a feedback loop of PHIM processes

7.1.4 Information Items' Role in PHIM

Information items are deeply embedded in all three aspects of PHIM that are examined in this study. Information items can have motivating effects for PHIM activities. Motivators including discomfort caused by information management, availability of information management tools, ease-of-use of information management tools, social significance of information items, abundance of space, secure information, and financial motivators, are essentially related to information items. Also, all PHIM

activities have to use information items as media to carry health information. Furthermore, information items can elicit emotions and even attachments from patients.

The ubiquity of information item in all three PHIM processes suggest that understanding the success and failure of existing tools and develop better tools can be a key to creating a positive feedback loop between motivators, activities, and emotions, in addition to the behavioral interventions and medical interventions, when attempting to achieve improved health outcomes.

7.2 Complexity of PHIM Processes

PHIM in chronic illnesses show some unique complexities compared to PIM by the general population. The uniqueness identified in this study spur from differences between health conditions, differences between individuals, and development of PHIM processes in the long term.

7.2.1 Type 1 and Type 2 Diabetes Patients' Perception of PHIM

The purpose of including two different but related health conditions (i.e., type 1 diabetes and type 2 diabetes) when recruiting participants for this study is to see if there are differences between the perceptions of PHIM between the two groups. The results suggest similarities as well as differences.

7.2.1.1 Similarities between Type 1 and Type 2 Diabetes Patients' Perception of PHIM

Both groups of participants report similar PHIM motivators, activities, and affects. The 4 participants living with type 2 diabetes mention that their PHIM activities are

motivated by all categories of PHIM motivators except for environmental motivators. They also report all 4 categories of PHIM activities and emotions elicited by information content and PHIM activities. The lack of report in some categories may be related to the small sample size of patients with type 2 diabetes. These similarities in reported PHIM processes may relate to the medical similarities, similarities in PHIM tools, and the social connections between the two groups.

Medical similarities. Both groups of participants mention similar diabetes management routines and similar potential health outcomes. All participants are concerned about elevated blood glucose levels and test their blood glucose to measure their short term health outcomes. Both groups voice the importance of healthy food choices, such as the moderate consumption of sugar, the benefits of high fiber foods and protein, and the difficulties of maintaining their regimen when dining out.

Also, both groups see their endocrinologists regularly and tend to consult a medical team that include professionals such as ophthalmologists, podiatrists, neurologists, certified diabetes educators, nutritionists, and personal trainers. During their hospital visits, both groups test their A1c levels and receive advice on how to achieve or maintain certain A1c levels.

Furthermore, treatments for both conditions can be the same in some cases. For example, P27 lives with type 1 diabetes, but takes Metformin, which is a medication typically prescribed for type 2 diabetes patients. She explains that the use of Metformin helps lower her insulin consumption. Also, P6 lives with type 2 diabetes, but takes insulin, which is usually prescribed for type 1 diabetes patients.

These medical similarities determine the similarities in the information sought by the two groups and the diabetes management activities they perform.

Tool similarities. Participants living with either type of diabetes use similar tools to manage their health information. For example, both groups use CGM, insulin pump, blood glucose meter, food diary, and blood glucose diary to manage their self-generated health information. They also use similar information items to manage their health information collected from external sources, such as emails, brochures, magazines, and medical notes from clinical visits.

The similarities in the tools used by the two groups of participants point to the similarities in the premises of PHIM activities and indicate potential similarities between the types of information they manage and their PHIM activities.

Social connections between the two groups. Some participants believe there are more similarities than differences between the two groups. P7, for example, organizes a patient support group that is open to both type 1 and type 2 diabetes patients. Aside from the medical and tool similarities between the two groups, P7 also proposes that communication between them can increase their understandings toward each other and allow both groups to gain new and useful information and perspectives that are usually more accessible to the other group.

Participants also report connections between the two conditions on professional levels. A participant[10] with type 2 diabetes works with an endocrinologist, who has type 1 diabetes, in an international initiative to educate and treat patients with type 1 diabetes in developing countries. In addition, among the 30 participants, 4 are A1c Champions, and 1

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[10] The participant's ID is not mentioned because the detail may jeopardize the participant's identity.

of them lives with type 2 diabetes. These connections in professional terms potentially point to the similarities in some aspects of the two conditions,

The similarities between the two groups point to the potential transferability of some of the findings in this study to other health conditions, especially other chronic conditions that rely heavily on self-management such as heart failure and lung diseases.

7.2.1.2 Differences between Type 1 and Type 2 Diabetes Patients' Perception of PHIM

Differences also exist regarding the two groups of participants living with type 1 and type 2 diabetes respectively. These differences mainly reside within the nuances of PHIM processes, such as the specific health information participants collect based on their particular health conditions and their perceptions of the other condition.

Information differences. Unsurprisingly, participants living with type 1 tend to collect information related to type 1 diabetes and those with type 2 seek out information on type 2 diabetes. The majority of the patients recruited in this study does not use treatments and follow self-management guidelines for the other type of diabetes. They find information for the other condition distracting and it dilutes the possibility of finding relevant information for their condition. People with type 1 diabetes, in particular, report they have difficulties locating information for type 1 diabetes because the information they find through search engines and advertisements are mainly targeting those with type 2 diabetes. The difficulties in finding the desired information cause some patients with type 1 to experience negative emotions, such as frustration, as they tease out irrelevant information.

Participants with type 2 diabetes voice similar concerns about their access to relevant information. A participant mentions, "*It's interesting because when you speak to people with type 1, they always tell you that 'Oh there's not enough support groups for people with type 1, it's all for type 2'. But when I went online and went on Dlife and whatever, all of the talks were either all based on people who were type 1 or insulin dependent, you know, type 2s on insulin. So I was just like, okay you know? So, not really applicable.*"

In both cases, the repeated occurrence of these difficulties can lead to adverse emotions toward the other health condition.

Perception of the other health condition. The results in this study reveal the perceptions of some participants of the other health condition. A few participants with type 1 diabetes perceive type 2 diabetes as a condition that can be treated relatively easily by taking pills. These participants also perceive type 2 diabetes as a condition that does not require intensive PHIM activities due to the easier treatments. Some believe that most cases of type 2 diabetes are caused by consuming excessive sugar, while type 1 diabetes is not caused by patients. In addition, some participant with type 1 diabetes believe type 2 diabetes can be cured through dieting, at least during the early stage, but type 2 diabetes is not treatable.

In contrast, participants with type 2 diabetes, especially these who are insulin dependent, report that their condition is not necessarily easy. P12, for example, lives with type 2 and is also insulin dependent. He expresses that patients with type 1 diabetes can have a more consistent feeling because they can control the volume of insulin in their body by controlling their insulin injection. P12, however, do not have such control

because his body inconsistently produces some insulin and it is hard to know when and how much insulin is produced when he attempts to administer additional insulin through injections.

These perceptions of the other condition lead to participants' considerations of information sources from social networks, especially that from people living with the other health condition.

The different perceptions of participants from the two difference health conditions suggest that when attempting to transfer the results of this study to other health conditions, although the major PHIM processes can be similar, the nuances may be different and require scrutiny.

7.2.2 Individual Differences in PHIM Preferences

Some motivators identified in this study have inconsistent results on different participants. For example, some participants report they prefer personalized information items, such as P2's diabetes information worksheets (Figure 19) and P14's picture diaries (Figure 18). Others prefer generic information items for the simplicity. Also, participants report different reactions toward different reward mechanisms from doctors. For example, P20 enjoys a "*handwritten note from doctor saying 'Excellent progress!' with a star to the left and a smiley face to the right*" of his blood glucose records. In contrast, P19 finds a similar approach childish.

When the same motivators have different effects on different people, other factors (e.g., personality, social background, and cultural context) may be in play. This study excludes the examination of these factors when defining the research questions.

Nevertheless, professional background was brought up multiple times by participants as they explain their preferences. For example, P14 and P25 are artists and they prefer to connect their PHIM activities with their art work; P20 uses Excel for work and continues to use it for diabetes information management; P13 extends the bookmarking tools she use for her work to diabetes information management; and P21 keeps diabetes-related information for work and for her own use.

Previous studies suggest that personality can also influence people's experiences with health information (Heinström, 2003). Sex and age may also have an impact (Ybarra & Suman, 2008). It is possible that these factors and other related factors can explain the personal preferences of PHIM processes identified in this study.

7.2.3 Long Term PHIM Progression

Among the 30 participants recruited in this study, 27 have lived with either type of diabetes for over 5 years, including 23 type 1 diabetes patients and all 4 type 2 diabetes patients. Findings in this dissertation suggest 5 styles of long term PHIM. Table 21 includes the definition of the 5 long term PHIM styles and their corresponding examples. Each patient may fall into more than one of these styles.

Table 21
Long Term PHIM Styles (Sun & Belkin, 2016)

Styles	Definition	Examples
Designer	Behaviors of developing new information management tools or altering the structures of tools to manage	"[Author's note: Participant describes color coding scheme] *So that 260 I do in purple, that tells me bad. For me purple is bad, orange is ok, green is good. That's all craziness, but when I look into this sheet, I see immediately what the*

	information over the long term.	*patterns are. I can see how many greens I have, that tells me I had a very good reading. And I can see where the purples are. That means there were problems.*"
Achiever	Behaviors of using existing tools to manage information over the long term for certain personal goals. The tools' structures must not be altered.	"*…when I do yoga in the morning I try to use something called Swr Kit. That actually links to MyFitnessPal, so it'll translate how much exercise I've done into calorie burning, so that integration is also kind of some extra motivation, because you can see all the effects together opposed to separately.*"
Leader	Behaviors of using existing tools to manage information over the long term for certain social goals. The tools' structures must not be altered.	"*...because I'm a peer mentor, so when I got out and I give this peer mentor presentation, I share a lot of this stuff with other patients.*"
Curator	Behaviors of managing information using existing tools over the long-term without a clear objective in mind. The tools' structures must not be altered.	"*Y'know a lot of the things that comes in like via email weekly or couple times a week. I often won't delete it especially if I've skimmed it or if I haven't looked at it at all. I usually keep it, but that's why I have over 10 thousand unread emails in my inbox.*"
Monitor	Behaviors of managing information for short-term use. Information is not kept over the long-term after use.	"*I don't want it to become all of my life, you know, it's just do what I have to do and I don't want to think about it.*"

The designers. The designers are very motivated in managing their health

information. They not only develop unique ways to keep and organize information but

they also continuously perfect these methods over time. For example, P2 developed an

intricate system over the course of more than 10 years (Figure 19). In contrast to the

paper system designed by P2, P20 uses a Microsoft Office Excel spreadsheet (Figure 17)

to record his blood glucose levels and relevant contextual information, and then build time series models using information in these spreadsheets. Other participants developed different filing and information categorization schemes to accommodate to their individualized purposes and contexts of health information management. A major reason that designers developed their own tools seems to be that existing tools that they have access to do not satisfy their needs for information organization, such as flexibility, personalization, and motivation.

The achievers. Similar to the designers, the achievers also regularly manage their personal health information. What is different is that rather than designing new tools, achievers rely on available ones, such as the paper log books offered by their health care team, their CGM, patient portal systems, and various smart phone apps. Although all of our participants reported using some sort of existing tools to manage their diabetes-related information, not all of them carried on with the behavior over the long-term. Once participants are familiar with the condition or the health information, they may switch to other long term PHIM styles.

The leaders. The leaders keep health information for the purpose of sharing with other patients and helping these patients. For those who are new to the social network for diabetes patients, the leaders may dig up information from their long-term information collection, such as the basics of diabetes management. Leaders do not directly perform long term PHIM by distributing information, but they contribute to at least part of the information that initiates the long-term information management processes for all long term PHIM types. The leaders in our sample reported that they were motivated to keep

information that they may not need over a long period of time because of a sense of responsibility in helping other diabetes patients.

The curators. The curators accumulate health information, but without necessarily having a clear objective in mind. Some curators do it because they have space (when keeping paper information items) and time, or the tools they use made it convenient to keep information. Sometimes, curators may not be fully aware that they are accumulating information over the long-term because their information collections are built up by their social networks or information technologies.

The monitors. The monitors may actively collect information but they do not keep this information over the long-term. Instead, they consume the information immediately or keep it for a short period of time until consumption. As a result, monitors may skip some information collection activities (e.g., recording) and the information organization and retrieval activities. All participants recruited in this study perform some form of short-term monitoring. In many cases, monitoring is where the information for long term PHIM comes from.

Compared to the classic work the PIM, such as the finding/refinding activities (i.e., acquire information based on need), keeping activities (i.e., satisfy need based on available information), and meta-level activities (i.e., the maintenance of information) identified by Jones (2007), the findings in this study that are related to long term PHIM identified all these PIM activities, but the nuances experienced by a person carrying out PIM activities and a patient performing PHIM over the long term may be different.

First, meta-level activities seem to be significantly harder in LTPIM.

New content calls for updated information storage structure (Whittaker, Bellotti, & Gwizdka, 2006). For example, designers P5 and P9 updated their folders' tags from time to time to reflect the changing content in them. Neither P5 nor P9 manage over 50 documents with the help of paper folders. If they keep hundreds or even more than 10 thousand documents, like the emails collected by P5, keeping the folders' content consistent and up-to-date can be much harder.

Storage issue. The growing volume of information over time will take up more space, but the restrictions in physical space and digital memory dictates that people have to eventually delete information. This can be an issue for designers and achievers because they rely on big data to locate patterns and events that can guide their health behavior change.

Engaging in meta-level activities over the long-term adds stress. The monitors identified in this study report that they do not perform PHIM activities, such as recording information and the information organization and retrieval that occur afterwards, over the long term because it is not necessary. By focusing on the immediate use of information collected, monitors can still use their health information to help themselves and others.

Second, refinding or retrieving information can also be harder if keeping and meta-level activities are insufficient (Jones, 2007). P25's unorganized sketchbooks and P5's email collection are two examples. However, the difficulties in refinding information seem to be balanced by low frequency of having to refind information.

Third, the need for different long term PHIM styles may change over time (Boardman & Sasse, 2004). For example, participants reported that when first diagnosed, they tried to follow doctor's orders and use the tools recommended and provided by

doctors (e.g., blood glucose meters and log books). Over time, they gradually became familiar with how their body reacts to different regimens and treatments as well as with the tools available for managing diabetes. From there, they may divert to become designers (current tools do not satisfy their needs for long term PHIM), curators (do not find immediate use for information but have formed the habit of or are using tools that facilitate information storage), leaders (shifting part of the focus from oneself to other patients), and/or monitors (do not find any use for the stored information).

CHAPTER 8 IMPLICATIONS

The findings of this study point to the important dynamic between motivation and action as well as the crucial role that emotion plays in this process. PHIM activities can be prompted or hindered by a complex combination of motivators that can be rational, emotional, or a mixture of both. Also, some of the emotions rising from various PHIM activities and tools are motivators for actions, closing the feedback loop between motivation, action, and emotions. Therefore, when designing interventions and technologies to promote desired PHIM activities, taking emotion into consideration in addition to designing for utility may enhance the results.

In this chapter, design ideas are presented to address the issue that some PHIM activities are not performed at the desired frequency or intensity, although some participants considered these activities meaningful. These design ideas are generated through two means, (a) directly addressing participants' concerns, as identified in this research, and (b) learning from experienced participants to address participants' concerns. In the first case, other participants did not report potential solutions to some participants' problems; in the second case, the participants in this study have identified solutions or workarounds that address other participants' problems but these solutions are not incorporated into existing tools publicly available to diabetes patients.

Two types of design ideas for technologies and interventions for diabetes patients are presented to address some of the rational and emotional motivators respectively, i.e., designing for utility and designing for emotion.

8.1 Design for Utility

The more rational motivators that are not directly related to emotions are mainly concerned with the functionality of PHIM tools. Two major themes emerged from the findings in this study on the utilities that patients seek in PHIM tools, including their capacity to offer useful and high quality health information and their ability to do so with minimal involvement from patients.

8.1.1 Design for Information-Related Utility

Participants report different nuances in PHIM activities with external health information compared to self-generated health information. It would be cautious to approach the design of tools that support these two types of information respectively.

Patients collect external health information from various sources and a major barrier for them to proceed with PHIM activities with the information they encounter is lack of consistent categorization of the information. On the other hand, the biggest challenge faced by patients collecting self-generated health information is the lack of meaningful information. Participants also reported barriers such as the lack of new and high quality information from external information sources, however, these issues caused participants to switch information sources and the problems no longer persist when they use their preferred information sources. As a result, the focus of this section is on the two major challenges that are reported by participants as on-going issues without acceptable solutions.

Design to support information categorization structure. Results in this study agree with previous research that maintaining information categorization structures are difficult (Oh, 2013), especially when such activities are performed over the long term (Boardman & Sasse, 2004; Jones, 2008).

The PHIM tools reported by participant to support the categorization of external information allow the flexibility of constructing individualized information categorization structures. For example, the bookmarks on P13's browser enable her to place links to web pages in folders and test folders within each other. However, flexibility makes it easy to forget the existing information management structure when a new piece of information requires categorization, especially when there is ambiguity in the existing categories (Jones, 2007). Tagging, another information organization structure, still does not solve the issue of forgetting existing tags (Fastrez & Jacques, 2015). Also, the results in this study suggest that forgetting is possible even for participants who reported that they are confident with their memory.

A possible solution for these problems is to use reminders to assist the recall of information categorization structures. Natural language processing tools that retrieve parts of the existing categories using n-grams and matching word forms and their synonyms can be a part of the solution. N-grams allow the proposed tool to retrieve snippets from the information categorization structures of a continuous collection of N words. Matching words by their forms and their synonyms can assist with the issue of people modifying the categorization structure by adding a folder that uses different word forms and their synonyms of the existing categories.

Enter your new category here.

Retrieved relevant categories
(Click to use existing category.)

| Artificial pancreas | **+** | **×** |

Diabetes

Pancreatic cancer

Diabetes technologies

Bionic pancreas

Diabetes treatments

Islet transplant

Figure 26. A design to support information categorization structure

Figure 26 is an example of the proposed tool. As patients enter new categories, existing categories that are matched by the tool appear and patients have the choice of either creating a new category or keeping the new information in an existing category. In the example shown in Figure 26, because artificial pancreas and bionic pancreas are different expressions of the same concept, the participant is likely to keep the new information in the existing folder "Bionic pancreas", which is nested under the folder "Diabetes technologies", instead of creating a new folder called "Artificial pancreas". A similar approach was proposed in the literature to guide patients to relevant topics by presenting labels that summarize a cluster of topics (Chen, 2012).

Design to support meaningful information. Participants report that the health information they manage using existing tools do not allow the recording or the processing of their self-generated information to tell a coherent story. As a result, the information they keep does not provide enough guidance for self-management activities. For example, P11 finds MyFitnessPal, a smart phone app, does not allow the connections between

blood glucose levels, carbohydrate counts, and exercises. In fact, the app's website suggests that such functions are available but P11 does not perceive possible access to these functions. Other participants report that CGMs do not allow the entry of rich contextual information, making it hard to connect an out of range blood glucose reading with potential causes.

Because of these problems, participants like P2 and P14 designed their own tools that incorporate contextual information and allow the connections between different self-generated information. A major challenge with these patient-developed tools, however, is the retrieval of relevant information in the long term, when free text and pictures accumulate to a point where browsing is no longer a realistic method of information retrieval.

There are at least two ways to address this challenge. First, for patients who use pictures of food and free text on restricted topics, technologies exist that can potentially automatically recognize the items mentioned and store them in structured ways, such as food image recognition (Martinel, Piciarelli, Foresti, & Micheloni, 2016) and keyword searching in the free text using relevant thesaurus. Second, use structured information (e.g., blood sugar levels) as anchor and information in other format (e.g., pictures, voice recording and videos) as contextual information. In this way, patients have more control over the input of contextual information and they can still retrieve it as long as it is attached to certain events that are reflected in the structured information (e.g., lower than expected blood sugar level, patterns of high blood sugar 2 hours after lunch, and rapid climbing of blood sugar levels before sleep).

8.1.2 Design for Utility with Minimal Patient Involvement

Participants complain that performing PHIM activities and remembering to perform PHIM activities takes up time, consumes energy, and adds stress. Because of this, some participants report that they do not record, organize or retrieve their health information. Instead, they use health information as soon as they acquire it and discard it after use. However, participants note cases where they need the information they encountered but cannot retrieve it because of reasons such as forgetting the keywords used to find a piece of external information and discarded a piece of self-generated information without backups.

To address the issue that too much work is required to perform PHIM activities, a type of technology referred to as zero-effort technologies (Mihailidis, Boger, Hoey, & Jiancaro, 2011) can offer potential solutions. These technologies use a combination of technologies, such as sensors, speech and picture recognition technologies, and decision-support systems, to automatically collect, record, analyze, and display information, enabling the possibility of zero effort from patients.

The recently FDA approved Medtronic hybrid closed loop system allows the communication between a CGM and an insulin pump, allowing diabetes patients to treat their condition hands-free to some extent (Sheng, 2016). This is a step toward zero-effort technologies for diabetes patients and people living with other chronic conditions, but the space for development is tremendous, especially with the advancement of sensor technologies and wearable devices and the burgeoning efforts in deep learning.

8.2 Design for Emotion

Motivators that are directly related to emotions are less concerned about the functionality of PHIM tools than their presentation. Three major themes are identified from the findings in this study regarding how PHIM tools can be designed to harness positive emotions to motivate PHIM activities. These three themes include positive affect, positive framing, and milestone planning.

8.2.1 Design for Emotion to Support Positive Affect

Participants in this study report that although information work can be a stressful chore, they try to associate it with their established positive thoughts, actions and items to steer their emotions and create motivations. For example, P25 associates recording self-generated diabetes-related information and reviewing doctors' notes and diabetes-related articles with making sketches (Figure 21), which makes the record making and reviewing activities feel more positive. Also, P14 records her diabetes-related information in the format of picture diaries (Figure 18)and she looks forward to the record-making activities because she enjoys making colorful pictures, writings, and flipping through them.

These behaviors are similar to what the field of behavioral economics refers to as *reward substitution* (Pearlin & Schooler, 1978) or *temptation bundling* (Milkman, Minson, & Volpp, 2014). Both concepts involve motivating helpful but unpleasant or unexciting activities by binding them with pleasant or exciting activities. However, a major difference in what is observed in this study is that the originally undesired but helpful activities (i.e., interacting with diabetes-related information) seem to become positive experiences when participants modify the ways in which these activities are

carried out to suit their personal preferences. In comparison, the undesired activities remain undesirable when reward substitution and temptation bundling are used. Participants seem to perceive the helpful activities that they used to avoid in a more positive light because their attitudes toward the activities are transformed, not because they are rewarded with something else while performing these helpful activities.

Furthermore, in terms of effect and long-term sustainability, studies involving reward substitution and temptation bundling observe minimal impact on health indicators such as stress levels (e.g., Needle, Griffin, & Svendsen, 1981) and reduced effect over time (e.g., Milkman et al., 2014). In contrast, participants in this study report helpful behaviors maintained over a year (P14) and over 4 years (P25) without a sign of declination. The natural occurrence of these strategies in the data collected for this study means that it might be helpful to other patients as well.
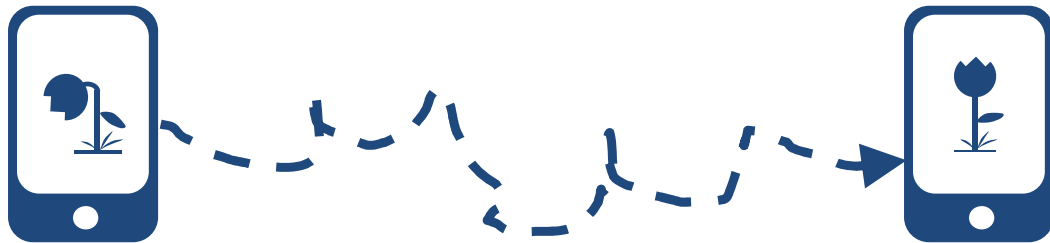
Figure 27. A design to support positive affect (left – out of range blood glucose levels; right – in range blood glucose levels)

Behavior change support systems can be enhanced by incorporating elements of positive affect. For example, patients like P14 and P25 may appreciate utilizing certain visual functions on their smart phones (e.g., photo, drawing board, emoticon, picture search and insertion, etc.) for information entry and revisiting. Figure 27 shows an

illustration on how artistic forms can be connected to health outcomes. These data entries

in artistic forms can be used in conjunction with (e.g., P25) or in the place of (e.g., P14)

structured data entry (e.g., entering blood sugar levels in a smart phone app). In the first

case, the artwork produced by type 1 diabetes patients can be used as contextual

information and attached to the structured data entered in devices. For example, patients

may find it helpful to attach to their smart phone entries of blood sugar levels pictures of

their daily activities, the drawings and picture diaries they produce, and emoticons or

preloaded pictures that visually describe their emotions. This artwork would become part

of the patient record, allowing for potential long-term reuse. Research argues that

metaphor-based visualization (e.g., using art work of a well grown garden to symbolize

an active lifestyle and the lack of flowers in this garden to symbolize a sedentary lifestyle)

can enhance healthy activities (Mamykina & Mynatt, 2009). This study adds that patient-

produced art work can also boost diabetes-related information work.

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8.2.2 Design for Emotion through Positive Framing

Framing methods have been studied extensively in the field of health

communication. These are methods of behavior change through expressing messages to

people in ways that may promote healthy behaviors. Our results agree with the health

communication literature (e.g., Soames Job, 1988) that messages framed to induce fear

(e.g., stressing that type 1 diabetes, if unattended, can lead to blindness, kidney failure,

amputations, and other serious health consequences) are usually not as effective as those

framed positively (e.g., emphasizing that people living with well managed type 1 diabetes

can lead a normal life and even prosper because they tend to be more cognizant toward

following healthy lifestyles). People's preference for positive versus negative messages is also reported in the fields of psychology (e.g., Levin, 1987) and behavioral economics (e.g., Kahneman, 2013).

Framing in technology design refers to focusing on certain features to guide people toward more relevant tasks or issues (Ylirisku, Halttunen, Nuojua, & Juustila, 2009). In fact, framing is argued to be an important component of the third paradigm in human computer interaction (Ylirisku et al., 2009). However, not enough is reported on how framing can be combined with technology design in the domain of chronic condition management. Results in this study point to some directions: (a) information should be presented in positive ways, and (b) positive information should be emphasized. An example for the former is that instead of informing patients who exercise on how much more time or amount of exercise they need to complete in order to achieve their daily goals, stressing how much they have already completed may offer better motivating effects. Similarly, an example for the latter is that when showing patients their blood sugar level records, emphasize the numbers that are in range, rather than highlighting those beyond range, can potentially motivate patients to pay more attention to their numbers and use their health records to guide their actions.

8.2.3 Design for Emotion through Milestone Planning

Participants in this study report that significant moments in their lives may lead to tremendous changes in their emotional experiences with information work. Leaving care partnerships can lead to negative emotions while entering them can bring positive emotions.

While it is not necessarily restricted to age groups, children and adolescents tend to experience the former more frequently because as they grow up, conditions that used to apply to them would no longer be valid (e.g., out growing the pediatric ward, starting school, and switching between schools for higher level education). Also, children have less control of resources that can help mitigate the impact of changes. Participants recall that these changes when they were younger were inevitable yet highly stressful. When transitioning to a situation with less support, social robots with diabetes education components may make up for some social support missing in these children and teenagers. Research supports that such robots can promote information work (van der Drift, Beun, Looije, Blanson Henkemans, & Neerincx, 2014).

On the other hand, when patients enter into care partnerships, it is an excellent opportunity to instigate immediate behavior change that can potentially be sustainable. The health communication literature has found support for short term behavior change in smoke cessation, where people receive a series of messages leading up to a pre-set quit date (Lenert, Muñoz, Perez, & Bansod, 2004). In the context of diabetes management, where patients often need to perform a great deal of information work in order to effectively manage their illness, applications can be designed for patients' devices (e.g., smart phone, computer, and continuous glucose monitors) to enable them to identify dates of significance. Similar to the smoke cessation campaign, the application can send patients messages leading up to their date of significance as a way to remind them of the imminent partnership and prepare them to pick up and share responsibilities of diabetes management.

CHAPTER 9 CONCLUSION

9.1 Answering the Research Questions

RQ1: Why do patients with chronic conditions engage or not engage in PHIM activities?

A total of 7 categories of PHIM motivators and their 39 corresponding subcategories are identified in this study (Table 22). These motivators can impact patients' PHIM activities either positively or negatively depending on whether the conditions of these motivators are met (e.g., information availability can motivate PHIM activities positively when the desired information is available and can have a negative effect on PHIM activities when such information is unavailable) and how patients perceive these conditions (e.g., information accuracy can motivate PHIM activities positively when patients consider the accurate information of high quality; inaccuracy of information can also motivate PHIM activities if patients attempt to verify the information at hand with new information).

Table 22.
PHIM Motivator Categories and Sub-Categories.

PHIM Motivators	PHIM Motivator Sub-Categories
Information Attributes Motivators	Information Availability
	Information Abundance
	Information Credibility
	Information Accuracy
	Information Consistency
	Information Timeliness
	Information Usefulness
	Information Process Level
	Information Presentation Style
	Information-Elicited Emotions

Medical Motivators	Symptom Notability
	Symptom Consistency
	Condition severity
	Discomfort Prohibiting Information Management
	Discomfort Caused by Information Management
	Anticipated Health Outcomes
Behavioral Motivators	Continuity of Existing Behaviors
	Ease of Information Management Processes
	Availability of Information Management Tools
	Ease-of-Use of Information Management Tools
Social Motivators	Social Identity
	Exclusiveness of Benefits
	Expectations from Others
	Reactions from Others
	Exemplars
	Social significance of information items
	Stigma
	Social Norms
	Social Relations
Personal Motivators	Outlook On Life
	Interest in the Activities
	Interest in the Information
	Location of Responsibility
	Abundance of Time
	Abundance of Space
	Confidence in Memory
	Secure Information
Financial Motivators	
Environmental Motivators	

RQ2: How do the PHIM activities patients engage in interact to assist self-management?

Built on the 4 categories of PHIM activities identified from the literature, 23 sub-categories of PHIM activities are found in this study (Table 23). All activities are reported by participants as integral components of their diabetes self-management work, based on information items that are used to assist diabetes management.

The PHIM activities are dependent upon one another, because the results of some activities are the necessary components for others activities. For example, to categorize health information in patients' personal information collection, patients have to have recorded the information in the first place.

Because of this dependent relationship, PHIM activities show patterns of attrition with the activities that require more work performed less frequently (e.g., more frequent collection activities compared to fewer organization activities). The attrition effect points to the potential issue that patients may not be harnessing health information to its full potential due to barriers associated with certain PHIM activities.

Table 23
PHIM Activity Categories and Sub-Categories

PHIM Activities	PHIM Activity Sub-Categories
Collection	Consulting Updating Serendipity Encounter in external information collection Searching external information sources Browsing external information sources Recording Deleting
Organization	Remembering Categorizing Marking Reproducing Formatting Connecting
Retrieval	Search in personal information collection Browse in personal information collection Spontaneous Recall Reminded Recall Serendipity encounter in personal information collection
Use	Sharing Evaluating Problem solving Decision making

RQ3: What are the affective processes that accompany patients' PHIM activities?

Patients can experience affect elicited by the content and volume of the health information they interact with, the PHIM activities they engage in, and the PHIM tools they use (Table 24). For both positive and negative affect, patients may experience a spectrum of emotions. These emotions can transform into motivators that impact PHIM activities.

Table 24
PHIM Affective Processes and Affective Process Sub-Categories

PHIM Affective Processes	PHIM Affective Process Sub-Categories
Information Content Elicited Affect	Information Content Elicited Positive Affect
	Information Content Elicited Negative Affect
	Information Content Elicited Neutral Affect
Information Volume Elicited Affect	Information Volume Elicited Positive Affect
	Information Volume Elicited Negative Affect
	Information Volume Elicited Neutral Affect
PHIM Activities Elicited Affect	PHIM Activities Elicited Positive Affect
	PHIM Activities Elicited Negative Affect
	PHIM Activities Elicited Neutral Affect
PHIM Tools Elicited Affect	PHIM Tools Elicited Positive Affect
	PHIM Tools Elicited Negative Affect
	PHIM Tools Elicited Neutral Affect

9.2 Key Findings

The major contribution of this dissertation is the development of an original model – a comprehensive model of PHIM in diabetes. This model points to four key findings, including (a) the relationships between motivation and action are convoluted; (b) affect plays an important part in completing a feedback loop between motivation and action; (c) PHIM activities are not performed at the same frequency by participants, with

information organization as a least performed activity; and (d) information items have the potential to impact motivation, action and emotion. The rest of this section explains these key findings and their broader impact in details.

First, the manifold motivators and the complex relationships between motivation and action point to the potential to discover new possibilities for medical interventions and technology designs. These interventions and technology designs aiming for PHIM behavior change may help diabetes patients achieve self-management goals through performing PHIM activities that they desire but are not self-motivated enough to perform. For example, testing and recording blood glucose is considered important to some participants but the process can be tedious and repetitive, causing some participants to report that they perform the activities less frequently than they prefer or as advised by their doctors.

Interventions and technology design can benefit from the findings on motivators in this dissertation in three ways, including (a) addressing multiple motivators when attempting to promote a potentially helpful PHIM activity to utilize the combined effect of multiple motivators; (b) designing interventions and technologies for different groups of people who are motivated by different combinations of motivators; and (c) learning from participants who motivated themselves to perform PHIM activities and applying their successful experiences of self-motivation as interventions on other diabetes patients.

Second, emotions of different affect play a surprisingly important role in PHIM, as PHIM motivators and results of PHIM activities. Twenty-two out of the 39 motivators have affective components (Figure 23), suggesting that affect can impact action and some of this impact may be challenging to tease apart from rational motivators. Also, multiple

aspects of PHIM (i.e., information content and volume as well as PHIM activities and tools) have the potential to invoke affect and some of the affects have motivating effects for PHIM activities. This finding suggests that interventions and technologies designed to support PHIM may have enhanced effects if considering affect or emotions in addition to designing for utility.

Third, information organization activities seem to be performed at lower frequency and intensity than the other PHIM activities, including information collection, retrieval and use. This phenomenon appears to be caused by the large amount of work required for information organization activities and the invisibility of such work(Ancker et al., 2015). Participants reported that this process is important because it facilitates information retrieval and use, but the tools available to them do not offer enough support. As a result, some participants attempt to retrieve their personal health information without information organization or they use this information immediately after information collection. Other participants developed workarounds or their own tools to address their individualized needs. This finding points to the urgent need to design technologies that can support health information organization activities, which seems to be a weak link in participants' PHIM efforts.

Fourth, this dissertation found that information items influence PHIM motivations, actions and emotions. This finding points to the possibility that designing and redesigning information items (in the PHIM context this refers also to the PHIM tools that carry health information) may be able to impact all three aspects of the CMPHIM feedback loop and offer enhanced support to PHIM processes.

9.3 Limitations

This study has two major limitations related to research methods and sampling, including (a) self-report through interviews can lead to self-report bias, and (b) snowball sampling can cause sampling bias.

Self-report through interviews can lead to self-report bias. Methods that collect self-reported data such as interviews and surveys can have the issue of self-report bias (Adams, Soumerai, Lomas, & Ross-Degnan, 1999). This bias is also observed and reported in this study. Self-report bias can lead to biases in research results and undermine the internal validity of the study.

The possibility of self-report bias is partially addressed in this study through photo-documentation, where the researcher and participants collaborate to produce data. This approach successfully avoided some cases of self-report bias (e.g., some participants forget the existence of an information item or do not report certain PHIM activities during the interviews because of their different understandings of related PHIM concepts). However, biases can potentially still exist, especially in cases where the interviews are not conducted face to face.

Another potential solution to address some self-report biases is to collect research data through field observation, because researchers can collect data without necessarily altering the behaviors of interest (F. Gardner, 2000).

Snowball sampling can cause sampling bias. The sample in this study is not a good representation of the populating living with type 1 or type 2 diabetes, as elaborated in Section "6.1.2 Sampling Bias".

To address this issue, the researcher will strive to collect data from bigger samples through surveys and work with hospitals and clinics to enhance the reach of these surveys.

9.4 Future Research

This study raises five major areas of interest for future research. First, quantitative research methods (e.g., surveys) can potentially be applied to extend the findings in this exploratory study. Quantitative methods involving a larger sample size may be able to identify new findings and nuances to the current findings that are not observed in this study. Furthermore, this study found many motivators that impact PHIM activities jointly, but there is not enough evidence to support which motivators and combinations of these motivators have dominant effects. Quantitative methods may lead to new developments in behavior change regarding PHIM activities.

Second, this study does not focus on demographics (e.g., age, sex, and income) and personal traits (e.g., personality) as possible predictors of PHIM activities and the findings suggest that those factors may indeed play a part in influencing PHIM activities. Future studies can incorporate these factors with the PHIM motivators identified in this study to explore the dynamics between demographics, personal traits, cognition, and emotions. It would be meaningful to examine whether some of these factors may produce a more dominant effect than others and point to directions for more effective interventions.

Third, it is unclear how the PHIM processes impact health outcomes. Future studies addressing this issue need to be cautious about the issue of co-morbidity, which is prevalent in the sample recruited for this study. Examining this issue can lead to

important findings on how to direct information management behaviors in patients to enhance positive health outcomes.

Fourth, the complexities of PHIM processes supported by this study point to the urgent need to design interventions for PHIM activities both on the clinical side and in the home. For example, this study found that personal health records are not only unused by participants, but are also unknown to them. On the other hand, patient portal systems are reported by participants, but only a few have heard that the technology is called patient portal systems. Also, participants do not find smart phone apps useful and most participants prefer paper tools and tools designed for purposes other than diabetes management or wellness when managing their diabetes-related information. The findings of this study can potentially guide the design and re-design of these technologies.

Fifth, future studies can potentially expand the findings of this study to examine the PHIM or PIM processes by the general population and the PHIM processes by patients living with other conditions, to investigate how much of the findings concerning diabetes patients can be applicable to other populations under certain circumstances and guide the design of technologies for other populations.

APPENDICES

Appendix 1

Recruitment Letter

**An Invitation to Participate in Research on
Personal Health Information Management (PHIM) in Chronic Illnesses**

> **Participate to help our fellow patients and
> advance evolution in health information technologies!**

<u>Who are we?</u>
I am Si Sun, a Ph.D. Candidate at the School of Communication and Information at Rutgers University. This study is my dissertation and the foundation for my future work.

<u>Who are we looking for?</u>
We are looking for 30 participants with either **<u>type 1 or type 2 diabetes</u>**.

<u>What is our study about?</u>
Our study examines how diabetes patients manage their daily health information, which is the process after patients collect the information and before they use it.

<u>Why you should participate?</u>
You will be entered to win **<u>one of our three $100 Amazon.com electronic gift cards</u>** at the end of the data collection process (projected time is October, 2015).

Your contributions will push the evolution of health information technologies and can help many others who are living with diabetes.

With a better understanding of PHIM, we can design more effective interventions, such as education programs and health care technologies to solve PHIM issues and support PHIM activities for the ultimate purpose of improving patients' health care outcomes.

<u>What activities will you participate in?</u>
Our participants will take part in a face-to-face **<u>interview</u>** lasting about an hour.

We would greatly appreciate it if you can also demonstrate your daily health information activities by capturing them through **<u>photos</u>** of various health information management strategies and interactions with information management tools.

Participating in this study is unlikely to result in more harm or discomfort then experienced in daily life. You can withdraw from the study at any time, with no adverse consequences for you.

> **To be part of our endeavor to support diabetes patients,**
> please contact the principle investigator:
>
> **Si Sun**
> **sisun@rutgers.edu**
>
> School of Communication and Information
> Rutgers, the State University of New Jersey
> 4 Huntington St., New Brunswick, NJ 08901

Thank you for considering this invitation!

Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu	Diabetes Info Study sisun@rutgers.edu

Appendix 2

Interview Informed Consent Form

Thank you for your participation! You are among our 30 generous participants. Your contribution advances the evolution of health information technologies and can help many others who are going through the same process as you are.

Purpose:

I am Si Sun, a Ph.D. Candidate at the School of Communication and Information at Rutgers University. My study examines how patients with chronic conditions manage their daily personal health information, which is the process after patients collect the information and before they use it.

With a better understanding of PHIM, we can design more effective interventions, such as education programs and health care technologies to solve PHIM issues, support PHIM activities, motivate more frequent and higher levels of engagement in PHIM for the ultimate purpose of improving patients' health care outcomes.

Procedures and incentives:

You are among the 30 participating patients we are interviewing. During the interview, the researcher will ask you some questions about your experiences with managing your health information. These questions will concentrate on information management behaviors rather than the health information itself. An example question is "Could you please describe how you deal with and use health-related information that you collected on a typical day?" Please feel free to expand on the topic or talk about related ideas.

You will be entered to win one of our three $100 Amazon.com electronic gift cards at the end of the data collection process (projected time is October, 2015).

You will also be among the first to receive a summary of all our participants' experiences with personal health information management, which may offer you new insights toward better self-management. Your generous contribution will also help many others who are going through the same process.

Age Requirement

You must be at least 18 years old to participate in this study.

Risks and Discomforts

No significant psychological or physical harm or negative side effects are expected for the participants during the study. Your participation is entirely voluntary. If there are any questions you would rather not answer or that you do not feel comfortable answering, please say so and we will stop the interview or move on to the next question, whichever you prefer. **You may also decide to withdraw from the study at any time for any reason, even after you have signed this consent form, with no adverse consequences for you**.

Confidentiality and Anonymity

This research is confidential. Confidential means that the research records will include some information about you and this information will be stored in such a manner that some linkage between your identity and the response in the research exists. Some of the information collected about you includes age, gender, and health status,. Please note that we will keep this information confidential by limiting access to the research data to the researcher and her supervisor, and keeping it in a secure location. The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. Upon completion of this project, all data will be kept for three years in a secure location, and then destroyed. If a report of this

study is published, or the results are presented at a professional conference, only group results will be stated.

Audio Recording Addendum
The interview will be **audio recorded**. You understand if you say anything that you believe at a later point may be hurtful to you or damage your reputation, then you can ask the interviewer to record over such information or ask that certain text be removed from the transcripts. The interviewer will then ask you if you would like to continue the interview.

The recording(s) will be used for analysis by Si Sun. The recording(s) will include identifiers such as age, gender, and health conditions. The recording(s) will be stored in a locked file cabinet and linked with a code to your identity– a fake name that we make up at the beginning of the interview and observation –and will be destroyed upon publication of study results.

Contact
If you have any general questions concerning this research project, please contact the principal investigator:

Si Sun
Rutgers University
4 Huntington St.,
New Brunswick, NJ 08901
Phone: 848-xxx-xxxx [researcher's personal phone number is not obscured in the original document]
Email: sisun@rutgers.edu

Consent
If you have any questions about your rights as a research participant, you can contact the Institutional Review Board at Rutgers (which is a committee that reviews research studies in order to protect research participants). The IRB Administrator at Rutgers can be reached at:

Institutional Review Board
Rutgers University, the State University of New Jersey
Liberty Plaza / Suite 3200
335 George Street, 3rd Floor
New Brunswick, NJ 08901
Phone: 732-235-9806
Email: humansubjects@orsp.rutgers.edu

You will be offered a copy of this consent form that you may keep for your own reference.

Once you have read the above form and, with the understanding that you can withdraw at any time and for whatever reason, you need to let me know your decision to participate in today's interview.

Your signature on this form grants the investigator named above permission to record you as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written permission.

Subject (Print Name) _____

Subject Signature _____   Date _____

Principal Investigator Signature _____   Date _____

Appendix 3

Photo-Documentation Informed Consent Form

Thank you for your participation! You are among our 20 generous participants. Your contribution the evolution of health information technologies and can help many others who are going through the same process as you are.

Purpose:

I am Si Sun, a Ph.D. Candidate at the School of Communication and Information at Rutgers University. My study examines how patients with chronic conditions manage their daily personal health information, which is the process after patients collect the information and before they use it.

With a better understanding of PHIM, we can design more effective interventions, such as education programs and health care technologies to solve PHIM issues, support PHIM activities, motivate more frequent and higher levels of engagement in PHIM for the ultimate purpose of improving patients' health care outcomes.

Procedures and incentives:

You are among the 20 people participating in photo-documentation in this research. You will receive two disposable cameras (you can also use other tools you prefer, such as screen shots and the camera on your phone). You will be instructed to use these tools to document your daily health information management activities at your comfort and convenience. We will assure the safety and confidentiality of the data you collect and protect your privacy by double checking with you before we use any of your data in our reports. After photo-documentation, you will be invited to participate in a short interview. In this interview, we will ask you to guide us through the photos you took, in connection to what we learned during the first interview.

You will be entered to win one of our three $100 Amazon.com electronic gift cards at the end of the data collection process (projected time is October, 2015).

You will also be among the first to receive a summary of all our participants' experiences with personal health information management, which may offer you new insights toward better self-management. Your generous contribution will also help many others who are going through the same process.

Age Requirement

You must be at least 18 years old to participate in this study.

Risks and Discomforts

No significant psychological or physical harm or negative side effects are expected for the participants during the study. Your participation is entirely voluntary. If there are any questions you would rather not answer or that you do not feel comfortable answering, please say so and we will stop the interview or move on to the next question, whichever you prefer. **You may also decide to withdraw from the study at any time for any reason, even after you have signed this consent form, without any adverse consequences for you**.

Confidentiality and Anonymity

This research is confidential. Confidential means that the research records will include some information about you and this information will be stored in such a manner that some linkage between your identity and the response in the research exists. Some of the information collected about you includes age, gender, and health status. Please note that we will keep this information confidential by limiting access to the research data to the researcher and her supervisor, and keeping it in a secure location. The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. Upon

completion of this project, all data will be kept for three years in a secure location, and then destroyed. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated.

Photographing Addendum

This study involves **photographing** your activities. You understand if we have photographed anything that you believe at a later point may be hurtful to you or damage your reputation, then you can ask the researcher to obscure parts of the photos or have the photos deleted.

The photographs will be used for analysis by Si Sun. The photographs may include identifiers such as gender and health conditions. The photographs will be stored in a locked file cabinet and linked with a code to your identity– a fake name that we make up at the beginning of the interview and observation –and will be destroyed upon publication of study results.

Contact

If you have any general questions concerning this research project, please contact the principal investigator:

Si Sun
Rutgers University
4 Huntington St.,
New Brunswick, NJ 08901
Phone: 848-xxx-xxxx [researcher's personal phone number is not obscured in the original document]
Email: sisun@rutgers.edu

Consent

If you have any questions about your rights as a research participant, you can contact the Institutional Review Board at Rutgers (which is a committee that reviews research studies in order to protect research participants). The IRB Administrator at Rutgers can be reached at:

Institutional Review Board
Rutgers University, the State University of New Jersey
Liberty Plaza / Suite 3200
335 George Street, 3rd Floor
New Brunswick, NJ 08901
Phone: 732-235-9806
Email: humansubjects@orsp.rutgers.edu

You will be offered a copy of this consent form that you may keep for your own reference.

Once you have read the above form and, with the understanding that you can withdraw at any time and for whatever reason, you need to let me know your decision to participate in today's interview.

Your signature on this form grants the investigator named above permission to record you as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written permission.

Subject (Print Name) _____

Subject Signature _____   Date _____

Principal Investigator Signature _____   Date _____

Appendix 4

Initial Interview Questions

[This is an interview guide. All questions should be covered, but not necessarily in the listed order or using the exact same words. The interview should proceed as a conversation, and participants should be encouraged to talk about relevant issues they consider important.]

Could you please describe how you deal with and use health-related information that you collected on a typical day?

What kind of information related to your condition did you keep over the past month? Did you ever collect information related to your condition that is different from what you just described?

Please think about the health information you kept, did you manage or organize it in some way? For example, did you keep it in a folder, sort it by time, or try to remember it? Could you give me three most typical examples of how you manage your health information? Did you manage it in some other ways? [PHIM activities and information items will be examined when participants answer these questions.]
Did you use any tools to help you manage your health information?
Why did you manage or organize your health information in these ways?
How do you feel emotionally when you manage or organize your health information in these ways? For example, do you feel happy, relieved, frustrated, or in some other ways?

What was the reason that you started managing (do not manage) your health information? What made you continue doing it?

What are the difficulties you had when managing your health information? What kind of tools, services, knowledge, or other types of support do you think can help you overcome these difficulties?

Appendix 5

Revised Interview Questions

[This is an interview guide. All questions should be covered, but not necessarily in the listed order or using exactly the same words. The interview should proceed as a conversation, and participants should be encouraged to talk about relevant issues they consider important.]

- Are you living with type 1 or type 2 diabetes?
- How many years have you had diabetes?
- What are your basic strategies for managing diabetes?

- From what sources did you receive diabetes-related health information?
  You may have received diabetes-related health information from mass media (e.g., TV, newspapers, radio, and the Internet), printed media (e.g., books, magazines, brochures, and fliers) personal connections (e.g., family, friends, and other patients), health care providers (e.g., doctors, nurses, dieticians, personal trainers, and diabetes educators), and yourself by collecting information on your health status.

- Do you collect/gather the information you received from these sources?
- How do you collect it?
- Why did you collect it?

- Do you organize/arrange/manage the information you collected?
- How do you organize it?
- Why did you organize it in this way?
- What made you to continue organizing this information over time?
  [Make sure all sources the participant mentioned are covered.]

- Did you ever use any tools to help organize your diabetes-related health information?
- How do you use these tools?

- How do you feel emotionally when you manage or organize your health information in these ways? For example, do you feel happy, relieved, frustrated, or in some other ways?

- What are the difficulties you had when managing your health information? What kind of tools, services, knowledge, or other types of support do you think can help you overcome these difficulties?

Appendix 6

Second Interview Questions

[This is an interview guide. All questions should be covered, but not necessarily in the listed order or using exactly the same words. The interview should proceed as a conversation, and participants should be encouraged to talk about relevant issues they consider important.]

Could you please describe what this photo is about?

[If the photo includes tools] Could you please describe how this tool helps you deal with and use health-related information that you collect on a typical day?

[Connect to the first interview] In our first interview, you mentioned _____ (an information management activity), is this photo a demonstration of that activity?

[Connect to other photos] Is this photo related to some other photos you took? / Are these photos related in some way?

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