Managing Personal Information over the Long-term, Or Not? Experiences by Type 1 Diabetes Patients

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ABSTRACT
The management of chronic conditions is often accompanied with the long-term management of health information. By examining how patients manage their health information over time, we can develop guidelines and design technologies to support this patient work, and also contribute the patients’ perspective to the existing literature on personal information management. This study explored the long-term personal information management (LTPIM) behaviors of people living with chronic conditions. We conducted semi-structured interviews and photo-documentation with 23 experienced, type 1 diabetes patients. This mixed methods approach helped us identify five LTPIM styles, including designer, achiever, leader, curator and monitor. Those LTPIM styles differ in the information tools people used, the intensity of long-term information management behaviors, and their motivators. The nuances in those LTPIM styles are unique to the context of chronic conditions, but the categorization of those LTPIM styles can potentially be transferable to LTPIM in non-health contexts. Our results support previous literature on the major differences between LTPIM and personal information management in general. Further, we point to issues in current technologies used by patients for LTPIM, indicating a space for improvement.

Keywords
Long-term, personal information management, chronic conditions, motivators.

INTRODUCTION
What happens to information we keep over the long-term? Answering this question can help us harness everyday information to achieve our long-term goals. This paper reports the findings of an empirical study that examines whether and how type 1 diabetes patients manage their personal health information over the long-term.

Long-term personal information management (LTPIM) has gained attention because of the exploding number of information technologies that encourage the collection and keeping of information. For example, emails are used by people in the workplace to keep and organize information (Ducheneaut & Bellotti, 2001). Computers also offer us the option to create folders and bookmarks (Boardman & Sasse, 2004).

Despite this increased attention to the management of electronic information, less is known about how other tools (e.g., paper records) have been used in conjunction with information technologies and why people prefer certain ways to manage their personal information over others. This problem is especially relevant when it comes to the management of personal health information in the context of chronic conditions.

First, people living with chronic conditions can benefit from managing their health information over the long term (Pratt, Unruh, Civan, & Skeels, 2006). In addition to the short-term utility of supporting real-time decision-making and problem-solving (Lorig & Holman, 2003), keeping long-term health records can also allow patients to monitor the gradual changes in their body and the environment and adjust their treatments accordingly. For example, people living with type 1 diabetes inject insulin to enable the body to use blood sugar, but the dosage of insulin intake depends on factors such as the seasons (Hinde, Standen, Mann, & Johnston, 1989), body weight, and insulin sensitivity.

Second, living with chronic conditions is a difficult task and the information work that comes with it is highly demanding (Klasnja, Civan-Hartzler, Unruh, & Pratt, 2010). People have to juggle their work, social relations, family responsibilities, and other issues when dealing with their health condition (Unruh & Pratt, 2008). Under these circumstances, patients tend to utilize a combination of different tools to help navigate their conditions and treatments (Whetstone, 2013).

Third, the complexities of personal information management are experienced differently by each individual. For example, while some people may be overwhelmed by the number of information management technologies (van Velsen, Beauejean, & van Gemert-Pijnen, 2013), others may have difficulties retrieving information from their personal information collections (Boardman & Sasse, 2004). This is also true for people living with chronic conditions, calling for investigations on how these different complexities are addressed through different information management styles or strategies.

Through the lenses of people living with chronic conditions, this paper contributes to theories in personal information management. Specifically, the study reported in this paper aims to answer the following research questions.
(a) How do people living with chronic conditions manage their personal health information over the long term?
(b) Why do those patients manage their personal health information in the ways they reported?

Answering those questions enables us to have a glimpse into what has been working (and not working) for people’s long-term information management and point to possible improvements to guidelines for LTPIM activities and existing supporting technologies. For the general population, those improvements may mean increased productivity. For people living with chronic conditions, those improvements can potentially lead to better health outcomes and lower health care costs (Chaudhry, 2006).

RELATED STUDIES

Studies of the long-term management of personal health information are rooted in the literature of personal information management. Due to the limited space in this paper, we introduce a selective review of related studies in the rest of this section, starting from the general field of PIM to the more specific fields of LTPIM and Personal Health Information Management (PHIM).

Personal Information Management

Jones (2007) categorized PIM activities into finding/refinding activities, keeping activities, and meta-level activities. The three types of activities are connected to each other in terms of how information and needs are mapped. Finding and refinding activities involve the identification and retrieval of information based on needs generated from work tasks. Keeping activities are when people decide how to store the information acquired through the finding activities so that it can be refound when needed. Meta-level activities focus on the maintenance of the information in one’s personal information collection, addressing issues such as organization structures and privacy concerns. Many other PIM activities, such as finding and reminding (Barreau & Nardi, 1995; Malone, 1983), and organizing information by files and piles (Malone, 1983) have also been identified.

Recent studies have extended our understandings of different aspects of PIM. For example, people use tags and folders in emails and on computers but folders are preferred more than tags and yield higher successes rate for information retrieval (Bergman et al., 2013). When people attempt to categorize ambiguous information items, they may change existing categories and dedicate more resources to the task of information organization (Oh & Belkin, 2014).

Research has also examined PIM activities in various contexts, such as those carried out by primary and secondary school teachers (Diekema & Olsen, 2014) and those in social contexts (Capra & Teevan, 2012). A general finding is that contextual differences matter. Diekema and Olsen found that teachers inherit information from their predecessors as a major finding activity, which is not often observed in general PIM activities. Also, when opening up the concept of PIM to social interactions, we can see a shifting landscape where the presence of and collaboration with other people can greatly influence how we perform PIM (Capra & Teevan, 2012).

Previous research in PIM points to the necessity to more closely examine different aspects of PIM and what PIM is like when considering various contexts. The next two subsections briefly go over a few related studies in the aspects of long-term PIM and the context of health care.

Long-term Personal Information Management

Jones (2007) argued that keeping activities are hard because over the long-term people may forget the information organization scheme they originally set up and create new ones based on the new information item. This can lead to ambiguities in their organization scheme and may affect future efforts in information keeping.

Much research done in LTPIM is on electronic information. For example, Marshall (2008) examined the strategies people adopt and the challenges they face when archiving personal information on digital media over time. Email is a tool frequently used by people to archive personal information. However, research has shown that refinding information in email poses great challenges because people may forget the existence of an email. (Whittaker, Bellotti, & Gwizdka, 2006). Also, it is hard to remember filing strategies and avoid creating redundant folders, and it requires great effort to keep email folder structures efficient and up-to-date (Ducheneaut & Bellotti, 2001). Other than email, people also use other tools, such as web bookmarks, to manage their information over the long term (Boardman & Sasse, 2004). Also, the tools they use and the information management strategies they employ may change over time (Boardman & Sasse, 2004).

To support the long-term management of personal information, dedicated tools have been created. For example, recent developments in lifelogging systems include applications in various contexts to facilitate the recall of earlier experiences in activities such as learning (Mutlu, 2015).

The limited amount of research in the area of LTPIM calls for more studies in this area, especially ones that extend beyond digital media. We conducted this empirical study as an attempt to address this gap through a naturalistic approach – we asked participants what information items they keep and started from there.

Personal Health Information Management

PHIM is the study of PIM in health care contexts. The field has bifurcated when defining personal information. The term PHIM is used to describe (a) “What do patients do when managing their personal health information in everyday lives?” and (b) “How do consumer-oriented technologies, such as patient portal systems and Patient Health Records (PHR) systems, facilitate the delivery of clinical health information?”

On the one hand, studies on the first topic have found that patients experience tremendous complexity when managing everyday health information. Patients’ health condition, social relations, and professional needs all influence their requirements and resources for PHIM (Pratt et al., 2006). When attempting to stay on top of their personal health information, patients use a plethora of tools to conduct PHIM (Whetstone, 2013). Also, they employ different strategies to manage information based on various criteria, such as their
anticipation of future use of their information (Moen & Brennan, 2005). Also, patients are often uncertain of what information to share and who is responsible for managing their medical information (Ancker et al., 2015). Further, the effort that patients put into managing their personal information is largely invisible to health care professionals, leading to frustration and misunderstandings (Ancker et al., 2015). Nevertheless, patients strive to make the most out of their personal health information by using it for monitoring, decision making, planning, and guiding health behaviors (Civan, Skeels, Stolyar, & Pratt, 2006).

On the other hand, research on patient-oriented information sharing technologies has examined people’s perceptions of and experiences with those technologies. For example, sharing full electronic medical records with patients can improve patient-provider communication, encourage patient learning and facilitate patient participation (Woods et al., 2013). Similar benefits have been observed among users of patient portal systems (Wade-Vuturo, Mayberry, & Osborn, 2012) and personal health records (Kim, 2012). The former are secure online websites that allow patients to access their medical records and message their doctors; the latter are online applications that enable patients to manage their own medical records. These applications aim to enhance patients’ access and control over their health information, potentially over the long term.

Our study takes the first approach. Through examining what patients do with and about the health information they encounter in naturalistic settings, we aim to add to the PIM literature from a patient long-term health information management perspective.

METHODS
Sample
Participants were recruited through snowball sampling. The first author recruited the first group of participants from a patient support group based in New York City. Then, she asked the existing participants to introduce her to other potential participants. Snowball sampling is an effective way to recruit participants from vulnerable or stigmatized groups (Atkinson & Flint, 2001). Indeed, we tried other recruiting methods, such as reaching out to diabetes online communities, sending out advertisements through university listservs, and posting paper advertisements at local teaching and research facilities as well as community centers. We received no response during the 10 months that we were actively recruiting. Although snowball sampling can result in a biased population, which is a serious limitation of this study, it is a sacrifice we had to make in exchange for a larger sample size and more data.

All our participants were recruited in the United States between December 2014 and September 2015. Our participants have lived with type 1 diabetes for between 5 and 60 years and have extensive experiences with long-term health information management. We recruited type 1 diabetes patients for this study because type 1 diabetes is a chronic condition that relies heavily on the long-term management of personal information (e.g., blood sugar levels, insulin injection dosages, and diet and exercise information) for better health outcomes.

We recruited 23 participants for this study, including 6 male and 17 female participants. They reported a wide range of occupations, including student, designer, performance artist, painter, engineer, and doctor. All 23 participants were over 18 years old, with 1 between 19 and 24 years old, 3 between 25 and 34 years old, 3 between 35 and 44 years old, 4 between 45 and 54 years old, 6 between 55 and 64 years old, and 5 65 years old and above. Regarding our participants’ years of experience with diabetes, 2 patients had between 5 and 9 years of experience, 6 had between 10 and 19 years, 7 had between 20 and 29 years, 1 between 30 and 39 years, 4 between 40 and 49 years, and 2 had 50 or more years.

Data Collection
In this study, a mixed methods approach was adopted. We conducted one-on-one semi-structured interviews and photo-documentation (i.e., the researchers collaborate with participants and use photographs to document participants’ personal health information management activities) with all participants. Interviews can yield high-quality data suited for thick description (Geertz, 1973) and photo-documentation provides visual support for what is hard to describe in words.

The study reported in this paper was carried out in three stages. The first round of interviews was carried out to explore how patients manage their personal health information over the long-term. The interview started with questions regarding the participants’ sources of health information, to ease participants into the concept for LTPIM. Then, participants described their experiences with everyday health information management with prompts from the researcher. After that, participants were asked to describe how their information management activities may have changed over the long-term (e.g., “Did you manage the information collected from the Internet in the same way when you were first diagnosed?” and “You mentioned you used to keep a collection of diabetes-related articles. What happened to the collection?”).

After the first interview, a list of personal health information management activities and the items used to assist these activities was made for each participant (e.g., P2’s paper forms used to record daily health activities and outcomes and P9’s log book). Then the researcher collaborated with the participants to collect pictures of items on the list. Six of these interviews were conducted at the participants’ homes, where the researcher took the pictures with the participants’ consent. When the interview was conducted at other locations or by phone or over Skype, participants took photographs of items on the list and other relevant items and activities at their own convenience, and then sent them to the researcher through emails or multi-media text messages. All photographs were collected within a week after the first interview. Five participants were invited to take part in the second round of interviews to provide more information on the pictures. For example, a participant sent the researcher pictures of her folders in a file cabinet. During the second interview, the researcher confirmed with the participant the reasons for arranging the folders in the way depicted in the pictures.
The results section is organized according to different LTPIM styles. We categorized our participants into different types of information organizers. Each individual can fall into more than one category because they may manage information with different content and format in different ways. For each type, we introduce whether patients manage their personal health information over the long-term and how information management was carried out by the long-term information managers (versus short-term ones). Further, we explore why patients pursue different LTPIM styles, in relation to their health condition and psychosocial status. The LTPIM styles we identified in this paper are not all mutually exclusive. Aside from the monitors, who do not perform LTPIM activities, almost any other styles can appear in the same person.

### 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. Five participants in our samples are classified as designers. P2, for example, developed an intricate system over the course of more than 10 years. He uses this system to daily track information generated from diabetes management. His day starts with keeping a small scrap of paper in his wallet and using it to record transitory information (e.g., time, location and results of blood sugar tests as well as the date and diet) throughout the day. At the end of each day, he transcribes information from the scrap of paper onto a paper spreadsheet he designed (Figure 1). This spreadsheet records a week’s worth of information and the results of a few calculations, such as the total number of blood sugar tests in one day and over the course of a week, and also daily and weekly average blood sugar levels. Further, P2 color codes his blood sugar levels to mark them as in range (green), slightly high (orange), and very high (purple), according to his standards.

Starting from this weekly spreadsheet, P2 developed two different tools to assist his long-term information management. The first one was a table (Figure 2) that compiled the numbers from the lower right corner of the spreadsheet featured in Figure 1. This table recorded a year’s worth of weekly average blood sugar test results and the total number of tests. The purpose of this table was to calculate the yearly average blood sugar levels and compare it with the HbA1c levels from previous years (numbers at the top of the table). The second

<table>
<thead>
<tr>
<th>LTPIM Styles</th>
<th>Definition</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Designer</td>
<td>Behaviors of developing new information management tools or altering the structures of tools to manage information over the long term.</td>
<td>“[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 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.”</td>
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<tr>
<td>Achiever</td>
<td>Behaviors of using existing tools to manage information over the long term for certain personal goals. The tools’ structures must not be altered.</td>
<td>“…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.”</td>
</tr>
<tr>
<td>Leader</td>
<td>Behaviors of using existing tools to manage information over the long term for certain social goals. The tools’ structures must not be altered.</td>
<td>“…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.”</td>
</tr>
<tr>
<td>Curator</td>
<td>Behaviors of managing information using existing tools over the long-term without a clear objective in mind. The tools’ structures must not be altered.</td>
<td>“‘Yknow 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.”</td>
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<tr>
<td>Monitor</td>
<td>Behaviors of managing information for short-term use. Information is not kept over the long-term after use.</td>
<td>“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.”</td>
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Table 1. Long-term Personal Information Management Styles (LTPIM).

Note: Because of the limited space in this paper, the examples in the table are excerpts from the semantic units coded.

### Data Analysis Methods
The interview recordings were transcribed and the pictures were matched with corresponding portions of the transcription. Then, latent content analysis (Graneheim & Lundman, 2004) was conducted on each semantic unit (i.e., an exchange or multiple exchanges between a participant and the researcher that is on a coherent topic). This data analysis method facilitates the identification of hidden themes and is particularly suitable for our exploratory study. Codes were developed and assigned based on participants’ long-term and short-term PIM behaviors. Although the study focused on LTPIM, exploring why people perform PIM activities but not LTPIM activities can help us gain a more comprehensive understanding of the latter. When a semantic unit does not include PIM behaviors, it is not assigned a code. Coding was done by the first author and the coding scheme was discussed by both authors iteratively throughout the coding process for continuous revisions. Table 1 shows the coding scheme we used to identify different LTPIM styles.

### RESULTS
The results section is organized according to different LTPIM styles. We categorized our participants into different types of information organizers. Each individual can fall into more than one category because they may manage information with different content and format in different ways. For each type, we introduce whether patients manage their personal health information over the long-term and how information management was carried out by the long-term information managers (versus short-term ones). Further, we explore why patients pursue different LTPIM styles, in relation to their health condition and psychosocial status. The LTPIM styles we identified in this paper are not all mutually exclusive. Aside from the monitors, who do not perform LTPIM activities, almost any other styles can appear in the same person.

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tool developed by P2 from the weekly spreadsheet was a chart that resembled a decision tree (Figure 3). This chart shows, when starting from a certain blood sugar level (i.e., numbers on the left side), that injecting a certain amount of insulin (i.e., numbers on the arrows) would bring the blood sugar to a certain level (i.e., numbers on the right). P2 uses this chart as a heuristic guide toward blood sugar adjustments. P2 also used the accumulated records over the years to detect trends in his diabetes management approaches and results. He pinned his color-coded weekly spreadsheets on a large board and observed the change of colors, which was an indication of blood sugar levels. When he saw a cluster of orange and purple colors, he would look into the detailed contextual information on diet and insulin injection recorded on the weekly spreadsheet to pursue the cause of those changes.

Similarly, P15 tracked his blood sugar levels and insulin intake on a daily basis. Instead of paper tools, P15 used a Microsoft Office Excel spreadsheet that he designed to follow the structure of his patient portal system. Every day, he measured his blood sugar levels on his blood glucose meter and entered his insulin intake. Once or twice a week, he transcribed the information from the meter to the spreadsheet. He did this by creating a new row for each day and input his test results and insulin dosages according to the time of the day starting from the left side. He tested and injected around the same time every day and he aligned each column according to the time of day, marked by meals (e.g., from left to right, the headings for each column are: dosage, lunch, dosage, dinner, dosage, late PM, dosage). He also used the comment function in the spreadsheet to insert contextual information, such as diet and stress levels.

Over time, P15 accumulated a large amount of structured information on the spreadsheet and he used it to build different types of time series plots. He calculated daily, monthly and yearly averages and created scattered plots using these averages. By observing those plots, he discovered trends that he was not able to detect when performing the daily measuring and recording activities. For example, P15 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. Then, he looked at the big picture using scattered plots constructed from data from multiple years and noticed a spike in blood sugar levels around the same period of time every year. He speculated that it was an uncontrollable seasonal effect, which was later confirmed by his endocrinologist. Interestingly, P15 also used the same spreadsheet to manage his diabetes supplies inventory. Given the different ways the information on the same spreadsheet can be used, P15 described the spreadsheet as the “foundation” and “ingredients”, and the diverse utilities as “the cake”.

The purposes for which P2 and P15 created these tools are the same — to gain a better understanding of how their condition was progressing and evaluate the outcomes of their diabetes management.
management efforts. However, they each chose different tools for the same objective. When asked the reason, P2 explained that the paper tools give him tremendous flexibility, allowing him to color code the numbers so he had visual cues to support his evaluations. Also, being able to view structured information (e.g., blood sugar levels and insulin dosages) and free text (e.g., diet and testing location) at one glance enabled him to make rapid connections between potential causes and effects. Unfortunately, the accumulation of paper files eventually hit the hard cap of physical space. P2 has the bottom layer of his closet filled with 10 years’ worth of the spreadsheets, tables and charts he designed and he had to discard the earlier records to make room for new ones.

P15, on the other hand, did not experience this issue, as space in an Excel spreadsheet is limitless for his purpose. Another advantage of the limitless space is that a large amount of information recorded can paint a more accurate picture of longitudinal trends and patterns. However, P2 reported that a reason he did not use electronic tools was that those tools did not offer the same level of flexibility as paper. Specifically, a piece of paper can be easily carried around when the patient is on the go. Also, presenting structured information and free text on the same piece of paper is simpler and more intuitive than doing so in spreadsheets on the computer.

Aside from different ways to synthesize and retrieve information, other participants also reported various filing systems. For example, P5 kept her diabetes information, such as doctor’s notes, health records, receipts, and brochures in a file cabinet. She used a flat filing strategy without having different levels of folders. Each folder was for information items on the same topic and items in each folder were arranged according to the date of the item. P8, on the other hand, had two levels in her paper folders. Aside from the same structure P5 used, P8 added another level by placing information she intended to share with other patients (e.g., basic information on diabetes management for newly diagnosed patients) and personal information (e.g., doctor’s notes and health records) in two different stacks on her shelf.

To maintain their folders, both P5 and P8 updated the folders’ names and number from time to time according to their goal at the moment. Because of the limited space, they had to clean up the file cabinet or file stacks once in a while and discard the older and less applicable files. Because previous studies have researched extensively into the matter of filing strategies, this paper will not go into more details on this issue.

Interestingly, P18 was the only participant observed in this sample who designed his long-term information management in conjunction with his job. P18 was a painter and he kept a bookshelf full of sketchbooks. He used those sketchbooks to practice sketching multiple times a day and he also used them as folders to keep his diabetes-related information. Specifically, P18 kept paper items, such as the notes he took during doctor’s visits, doctor’s notes, and medical bills between pages in his sketchbook. As those sketchbooks were gradually filled up with drawings, he marked the year on their binders and put them on the bookshelves in his office.

However, P18 did 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, P18 once had an intern put his sketchbooks in time order, but the shelf soon reverted back to randomness due to his professional needs. P18 reported that he kept diabetes-related information with his sketchbooks used for work because of two reasons. First, the lack of organization was not a serious issue because he seldom needed to find anything related to diabetes from his old sketchbooks. When he did, he remembered the year when the information was kept and flipped through all sketchbooks put away in that year. The time spent with this rare task was much less than the time he would have spent keeping the books in order. Second, keeping diabetes-related information with his sketchbooks motivated him to keep the information – if he had kept his health information somewhere else, it would soon be lost.

Overall, designers are a motivated group who develop their own tools for LTPIM. 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 (e.g., P2 and P15), personalization (e.g., P5 and P8), and motivation (e.g., P18).

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. Among our participants in this study, 9 were categorized as achievers.

For instance, P7 used a Continuous Glucose Monitor (CGM), a medical device that tests her blood sugar levels once every few minutes, providing nearly real-time guidance. Different types of CGMs have different capacities for data storage, ranging from a few hours to a few months. When the storage reaches its maximum capacity, the device automatically deletes the oldest tests and stores the new ones. To avoid losing the old data, P7 uploaded test results in her cell phone to a piece of software on her computer that was downloaded from the CGM’s website. This software not only enabled the storage of a large amount of information on the CGM readings but also offered a range of functions that process the CGM readings. For example, the software can generate different charts for test results at different times in the day and can compare the patterns of the condition between two periods of time. P7 found this data storage and processing function helpful, not only for herself but also for sharing with her doctor. Together, they make short-term adjustments based on the patterns they identified in the long-term records. To make sure that she had continuous access to this privilege, P7 uploaded information from her CGM to her computer about once a week to keep the information current and avoid missing data points.

We also identified cases where participants used social media to manage the web pages they visited. For example, when P17 found news articles, blogs or research related to diabetes management, she would share it on her Facebook page. She also kept articles shared by others in Facebook groups for
diabetes patients by sharing the article on her own account. When she recalled that certain events she experienced (e.g., hypoglycemia) were related to articles she kept, she used Facebook’s search function to retrieve relevant articles shared by her account. In this case, P17 used existing tools that are not designed for health information management. However, P17 was satisfied with those functions because (a) using Facebook was a habit, not an added responsibility; (b) she joined diabetes patient support groups on Facebook and at a click of a button, information shared in her group can be added to her own collection; (c) news articles that were not on Facebook usually have buttons that allow the sharing of the article to various social media and Facebook was usually one of the options; and (d) it was easy to search articles she shared on Facebook. Our participants also used other social media, such as Pinterest, to manage their health information over the long-term.

In addition, participants reported using mobile apps (e.g., S Health and MyFitnessPal) to assist their personal information management. However, none of these apps were used for more than 5 years in terms of managing diabetes-related information. Participants explained that it is because of two reasons. Firstly, the various types of health apps were still fairly new. Some participants did not learn about them (e.g., P13) and some did not own a smart phone (e.g., P16) five years ago. Secondly, those technologies did not provide enough support for diabetes specifically. For example, S Health and MyFitnessPal are both general logging apps that track diet and exercise. They do not have space for logging blood sugar levels or insulin intake. They also do not allow the viewing of long-term trends and contrasting between multiple time periods.

Other than the electronic tools, participants also reported using paper logs over the long-term. Like many other participants, P9 received a log book from her doctor. She also received copies from pharmacies and those that came with blood glucose meters, but they were all very similar. Those log books guided P9 to record her blood sugar test results when using a blood glucose meter and had space to write down diet, exercise and other related information. Over the years, P9 accumulated stacks of those log books, arranged according to time. She would flip through some of them occasionally to see how her numbers were a few months back or a few year ago, compared to where she was when entering the new information. Similar to the experiences of designer P2, participants like P9 considered space restrictions as an indication of the necessity to throw out old information. P9 mentioned that spring cleaning was a great opportunity to dump the old records occupying the boxes in her closet and move the newly completed ones in.

It is worth noting that 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. For example, P14 used to record his blood sugar levels diligently on a log book from his doctor, but after he became familiar with the pattern of his condition, he switched to active monitoring instead.

The Leaders
The leaders keep information for the purpose of sharing with other patients and helping them. 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. There are 8 leaders in our sample.

P12 was an A1C Champion, a peer leader at a diabetes education program by Sanofi-Aventis U.S. LLC. A part of P12’s responsibility in this program was to give talks at patient support groups and medical centers to educate and motivate other diabetes patients. Over the years, P12 accumulated a selective and relatively stable collection of information on the basics of diabetes management that he would distribute at those talks.

For patients who are regular members of a network, the leader may push information periodically. For example, P15 was interested in diabetes-related technologies and medical research. He subscribed to various newspapers, newsletters and magazines stay on top of the latest developments related to diabetes. He also frequented a face-to-face patient support group for type 1 diabetes patients that meet monthly. When he identified new information, he shared it with the group and initiated discussions on related issues. Leaders like P15 do not directly perform LTPIM by distributing information, but they contribute to at least part of the information that initiates the long-term information management processes for all LTPIM 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 information curators accumulate information, but without necessarily having a clear objective in mind. Out of the 7 curators identified in our study, some do it because they have space (when keeping paper information items) and time, or the tools they use made it convenient to keep information. P4, for example, used Google Docs to share diabetes-related information with her mother. This information was intended for short-term use. That is, P4’s mother was a nurse and she provided feedback on the information shared by P4 to help with P4’s diabetes management. After they both reviewed the information, it stayed in P4’s Google Docs, along with other files created for communication purposes. There was no urgent need to use or delete those files and they were kept over the long-term out of convenience.

Other participants curated diabetes-related information to prepare for future use. For example, P5 subscribed to various health-related newsletters and received updates two to three times a week. She opened all of them and read selectively, and then she closed them all but she would like to go back to some of the newsletters and read them closely. For those newsletters that she wanted to read again, she marked them as unread. Later, she had a chance to reread
some of the marked emails but many were forgotten. Over time, she accumulated a tremendous amount of unread emails, more than 10 thousand at the time of the interview, and she believed that those emails made her smartphone function slower. P5 also reported that she used the accumulated emails from time to time. When she recalled reading a newsletter that had information pertaining to her or others’ current needs, she went back to search her emails. However, she did not attempt to reread every old newsletter that was marked as unread in her inbox. In a sense, P5 curated diabetes related information that she did not necessarily remember existed and email searching made this specific type of curated information useful in the long-term.

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. Because of the limited space in this paper, we will not go into details on this issue.

For most curators who consciously build up their information collection, they may also actively clean up the information if it does not prove to be useful.Those cleaning methods include (a) mastery desertion, (b) new item rejection, and (c) disruption dumping.

Mastery desertion was the behavior of stopping curating a specific type of information because of high levels of familiarity with that information. As mentioned in the previous section, 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.

When individuals find a certain type of information useful but not updated often enough, they may keep the information they have and reject new copies of the same information. For example, P18 kept a tattered book on carbohydrate counting in his pocket. He used that book for years and he enjoyed using it because it has everything he ever needed on carbohydrate counting. When he tried to find a new book for replacement, he even attempted to get the same edition of the same book, so that he did not have to become familiar with a new format.

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.

Most participants in this sample who performed LTPIM used at least one way to clean up the information they accumulated over the long-term, depending on the content and media of the information they collected. Because of the limited space in this paper, we will not elaborate on the details.

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. This definition of the monitors is different from what is usually referred to in the research on general PIM. All participants recruited in this study perform short-term monitoring. In many cases, monitoring is where the information for LTPIM comes from. The monitoring behavior reported in this paper refers exclusively to participants who do not perform LTPIM, in order to differentiate between short-term and long-term information management styles. Given this strict definition, we identified a total of 6 monitors among our participants.

P6, for example, used multiple devices to closely monitor her condition. She kept multiple copies of blood glucose meters around her apartment so that those tools were always in sight (as reminders) and in reach (for convenience). She also used a CGM to closely monitor her blood sugar levels in real time and made necessary adjustments accordingly. P6 explained the two reasons that she did not perform LTPIM. First, because she addressed the short-term issues, problems will not accumulate until they lead to long-term consequences. Therefore, keeping health information over the long-term does not help with her condition. Second, managing diabetes is a stressful full-time job. Managing health information over the long-term will add to this unwanted burden. This added stress can affect the hormone levels in one’s body, which can cause uncontrolled diabetes episodes. Because the stress added by LTPIM can lead to negative health consequences, the effort can backfire.

Other participants reported that they would like to manage their information over the long-term but they do not have the time or energy to do so. For example, P13 experienced chronic fatigue so severe that she felt her fingers were pinned to the bed when she attempted to get up in the morning. In an effort to improve her health, she acquired a CGM and forced herself to manually test her blood sugar levels for calibration purposes. However, the low energy levels made the thought of attempting LTPIM excruciating. Also, P19 was juggling multiple health conditions aside from diabetes. Each of those conditions required very different and even conflicting regimen. For example, the treatments for lupus include steroids that can shoot up blood sugar levels. When navigating her way through multiple chronic illnesses, P19 found it hard to keep up with the daily monitoring tasks, not to mention long-term information management.

Monitors do not perform LTPIM, so they cannot simultaneously be designers, achievers or curators. However, monitors can be the second type of leaders, who share information with fellow patients. For example, P6 was the leader of two diabetes support groups. Although she did not keep health information for a long period of time, she communicated news about new developments in diabetes research and stories experienced by others at the support groups.

DISCUSSION
PIM May Be Experienced Differently in the Long-term
All PIM activities outlined by Jones (2007) were observed in this study on LTPIM. Those activities include
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). The difficulty and intensity of LTPIM, however, may be experienced differently from those of PIM.

First, meta-level activities seem to be significantly harder in LTPIM.

(a) New content calls for updated information storage structure (Whittaker et al., 2006). For example, designers P5 and P8 updated their folders’ tags from time to time to reflect the changing content in them. Neither P5 nor P8 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.

(b) 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 we have to eventually dump 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.

(c) Engaging in meta-level activities over the long-term adds stress. The monitors identified in our study reported that they do not perform LTPIM 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). P18’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 LTPIM 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 LTPIM), 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).

LTPIM May Manifest Differently in Chronic Conditions

The long-term personal health information management behaviors reported by participants in this study have many similarities with LTPIM by the general population. The five LTPIM styles can potentially be applicable to other settings, such as business, education, and everyday lives. For example, people in whatever context may consume information without keeping it for long-term use (Whittaker, 2011). This can correspond to the monitors in our paper. Also, people may design filing structures for their emails using tested folders (Ducheneaut & Bellotti, 2001). This generally resembles what is done by designers.

However, considerable differences are also involved when we look at the specific behaviors and motivators. First, the LTPIM styles reported in this paper may be transferable to other settings, but they also exhibit characteristics that are unique to chronic conditions and to diabetes as a specific chronic condition. For example, some participants in this study who were categorized as designers compiled daily and weekly numbers on blood sugar levels and generated charts that display long-term trends for their blood sugar. In contrast, calculations and chart display may not be meaningful when managing emails, as studied in previous research. Also, the necessity to connect blood sugar levels with insulin injection, diet, exercise, and a number of other factors is unique to diseases like diabetes that affect the whole body. For other chronic conditions, such as Lyme disease and autism, keeping information on those specific aspects would make little sense.

Second, the motivations that drive patients to certain LTPIM styles can be different for the general population. For instance, P7 is an achiever who uploaded information from her CGM to a piece of software on her computer. She did this because the CGM had limited data storage capacity and she was concerned that missed data points in her records would cause the software to generate less meaningful charts. This is a motivator that is not only specific to chronic conditions (i.e., long-term collection of health information), but also to diabetes patients (i.e., blood sugar testing) and CGM users. Also, the monitors brought up the issue that the stress caused by LTPIM and that resulted from living with a chronic condition can become a downward spiral toward worse health condition. This would not be applicable if we examine LTPIM in the workplace.

Understanding these nuances is important because it enables us to provide better support to a specific population who experience drastically different complexities. In the next section, we briefly discuss the ways in which existing tools reported in our study have not provided enough support for patients like our participants.

Current Tools Do Not Offer Enough Support

Existing information management tools, such as smartphone apps and log books, can be lacking for some patients. The designers, specifically, developed their own tools because existing tools do not support the level of flexibility they value (e.g., P2 hoped to synthesize his long-term health records to support his everyday decision making). Although the achievers use the existing tools, many of them are not satisfied with their functionalities (e.g., P7 hoped for wirelessly synchronize her CGM with her computer). Further, the monitors gave up on LTPIM because it added unnecessary work and stress. They wanted...
tools that can automatically collect and keep their health information without much human intervention.

Interestingly, our participants expressed diverse attitudes and knowledge toward two patient-oriented clinical information systems, including PHRs and patient portal systems. Three participants reported using patient portal systems through activities such as messaging their doctors and viewing test results. They learned about the patient portal systems from their doctors. Other patients still use emails and texting to contact their doctors as well as access their paper records at the doctor’s office. In contrast, none of our participants reported using PHRs to manage their health information, potentially because doctors were not solicited to advertise them to patients.

CONCLUSION
This paper contributes to the literature in long-term personal information management behaviors by exploring how they were performed in the context of chronic conditions. We identified five LT-PIM styles by type 1 diabetes patients that offer nuances on health information management, but can also be applicable when describing those behaviors concerning non-health-related information. Further, our findings point to what is lacking in existing technologies and how people with different LT-PIM styles may experience those imperfections.

Our study suffers from two serious limitations and our results need to be taken with caution. First, snowball sampling may cause sampling bias and biases in the results reported in this paper. In the future, we will attempt to acquire more balanced samples to verify our findings. Second, a single coder coded the data. Although the two authors discussed the coding scheme and the assignment of some codes, it is not a good practice for high-quality coding. A single coder is involved because the results reported in this paper are part of an ongoing study. In the future, we will recruit a second coder to confirm our coding.

REFERENCES


