Information Attribute Motivators of Personal Health Information Management Activities

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ABSTRACT
Understanding the motivating factors for personal health information management (PHIM) activities can inform the design of interventions to help people engage in healthful PHIM activities. This paper examines the attributes of health information that can motivate people’s PHIM activities. We explored this topic through a qualitative study using semi-structured one-on-one interviews with 47 American and Chinese patients living with type 1 or type 2 diabetes. We found 10 information attribute motivators, including the availability, abundance, credibility, accuracy, consistency, timeliness, usefulness, process level, and presentation style of, as well as the emotions elicited by, health information objects. Those motivators tell rich and complex stories of how health information is appreciated and handled on a daily basis by patients living with different health conditions or from different social contexts. Many of the motivators have not been examined in detail in the literature, pointing to the importance and necessity of involving them when designing interventions to improve health care outcomes through motivating PHIM activities.

Keywords
Personal health information management, attributes of information, motivator, social context, diabetes.

INTRODUCTION
Different attributes of an information object can have different effects on the people who come across it. Here, we present findings of a study on different attributes of health-related information that can motivate people to perform personal health information management activities, after people have found information that addresses their specific needs. Such motivators are important because they can influence whether people can find the information kept in their personal information collection and efficiently use it for desired tasks (Jones, 2007).

For people living with chronic conditions, engaging in their own health information management can facilitate patients’ self-management tasks, such as problem-solving, decision-making, and planning (Lorig & Holman, 2003). Personal health information management (PHIM) activities can empower patients in their efforts to harness personal health information and pursue better health outcomes (Civan, Skeels, Stolyar, & Pratt, 2006). However, only people who are motivated enough to perform PHIM activities can enjoy the benefit of health information to its full degree. Therefore, a better understanding of the motivating effects of different aspects of health information can help information and health care professionals guide patients toward more active self-management practices, and potentially improve their health outcomes.

This study is part of a larger research project that models the PHIM practices (including the PHIM motivators, activities, and cognitive and affective processes) of people living with chronic conditions. This paper introduces findings on the information attributes as motivators for PHIM activities reported by 47 diabetes patients in the United States and China. The purpose of this study is to identify: (a) the aspects of health information that can motivate people to engage or not engage in PHIM activities; and, (b) how the motivating effect took place. Exploration of these motivators for people from different social contexts can help us understand and tackle the global health issue of a rapidly growing population living with chronic conditions and lay the foundation for the transference of successful regional health initiatives.

In the study reported here, we examined two closely related chronic conditions, type 1 and type 2 diabetes. Both types of diabetes are related to the functionality of the pancreas and the hormones it secretes to regulate blood sugar levels in our body. A person living with type 1 diabetes has a pancreas that does not secrete enough insulin or produces none at all. For most people living with type 2 diabetes, their pancreas can preserve most of its functionality, but their body cells are less sensitive to insulin and do not make enough use of blood sugar. Although the causes of the two types of diabetes can be different, both are signified by the excessive amount of blood sugar in their circulation system. Patients who have high blood sugar (i.e., hyperglycemia) over long periods of
time face increased possibility of severe complications, such as necrosis in the limbs, kidney failure, blindness, and heart disease (Centers for Disease Control and Prevention, 2011). So far, there is no scientifically proven cure for diabetes, but the condition can be controlled by careful long-term management on a daily basis. Further, the limited resources during clinical visits make managing chronic conditions like diabetes increasingly personal, shifting the emphasis from clinical care to self-management (Funnell & Anderson, 2004). These characteristics of diabetes make PHIM activities particularly relevant and important to the health care qualities experienced by diabetes patients.

RELATED STUDIES
Research in many different fields has examined behavioral motivators from various perspectives. In this section, we briefly introduce a few selected theories and models related to behavior change and research on motivators and antecedents of information behaviors. For the purpose of this study, the review of previous research focuses on issues related to the characteristics of health information.

Motivators of Behavior Change
Several widely used theories and models in psychology and health communication have examined the factors that may motivate or discourage behavior change. Social cognitive theory (Bandura, 1977), for example, suggests that self-efficacy (i.e., an individual’s belief that he/she can successfully perform the task in question) can influence whether a person can successfully perform a task. This influence is achieved partially through self-efficacy’s effect on motivations of behavior change, and can be positively boosted by exposing a person to successful stories and examples from others. In this sense, social cognitive theory attempts to identify the sources of and the emotions associated with information which can motivate behavior change.

The theory of reasoned action (Fishbein, 1967) also points to the motivating effect of some attributes of information. This theory holds that people’s intentions to perform certain behaviors determine if they would actually engage in these behaviors. Such intentions are influenced by people’s attitude toward the behaviors in question and their subjective norms, with the latter influenced by other people’s thoughts. Although this theory does not focus on how the influences of people’s social network take place, it does consider a process of communication, where information is delivered through interpersonal or mass communication channels.

Developed in health care settings, the self-regulatory model, also known as the parallel process model and the common sense model of illness also examines how aspects of the information received by patients can affect their behaviors (Leventhal, Diefenbach, & Leventhal, 1992). This model suggests that patients engage in two simultaneous processes, including an objective process and an emotional process. Both processes involve the assessment of the coherence of behavioral outcomes, such as the coherence between symptoms and treatments, treatments and outcomes, and personal values and other people’s values. To conduct these appraisals, patients would need to gather information about their health conditions and other people’s thoughts. Whether information about these different topics would match to tell a coherent story can motivate patients to perform or not perform certain health activities.

These theories and models all address, at least in part, the role that information attributes play as motivators in directing behavior change, but none examines this role systematically or in great detail.

Motivators of Information Behaviors
Research on what may motivate people to seek or avoid information has also examined information attributes as potential motivators.

Studies in health communication regarding uncertainty and its impact on information seeking behaviors mainly examine the effects of the emotions elicited by certain information. Uncertainty in illness theory (Mishel, 1988) posits that for patients with acute conditions, seeking information may increase their anxiety levels. In this situation, patients may intentionally increase their levels of uncertainty by avoiding information pertaining to their conditions. Uncertainty management theory (Babrow, Kasch, & Ford, 1998), on the other hand, suggests that all health information is not equal and patients living with chronic conditions may pick and choose between information in an attempt to elicit positive emotions such as hope.

Theories and models in library and information science include motivators beyond information-elicited emotion. Wilson’s revised general model of information behavior (Wilson, 1997) suggests that the characteristics of information sources, including access, credibility and channel of communication, can be potential barriers to information seeking. This model also incorporates the concept of self-efficacy to address the emotional aspect of motivation.

Another model examining the motivators of information seeking behaviors is Johnson and Meischke’s (1993) comprehensive model of information seeking. This model distinguishes antecedents from aspects of information carriers. The antecedents affect the utilities of information carriers and include demographics, experience, salience, and beliefs. In addition to utility, information carrier factors also include message content attributes such as editorial tone and communication potential. Many of these factors are related to the attributes of information. Specifically, salience refers to whether a piece of information is applicable to the situation at hand; editorial tone can be connected to information credibility; communication potential refers to people’s perception of information presentation style.

Other than models that investigated the interaction between multiple motivators and antecedents of information behaviors, research has also explored specific information attributes. For example, Fidel and Green (2004) explored the meaning of
information accessibility. They found that the format, detail level, concentration level, and familiarity with the information source can affect the sources engineers choose when seeking for information in depth. Another example is Chatman's (1991) study on the information seeking behaviors of a lower socio-economic class population. She found this particular population to have information needs but little motivation to seek information because they felt information from outside sources would not be applicable to their situation. Studies have also found that factors such as the volume of information available (Bawden & Robinson, 2008) and how useful the information is for certain tasks (Freund, 2014) can motivate information seeking.

It is evident that we have some understanding of information attributes as motivators for information seeking. However, we know less about motivators for managing information after the information seeking process. This paper attempts to address some of this gap by examining aspects of health information that can motivate PHIM activities of people living with chronic conditions.

**METHODS**

**Participant Recruiting**

Participants were all recruited through snowball sampling. The first author recruited several participants from her personal network, including family, friends, colleagues, and patient support groups. After interviewing these participants, they were asked to refer other patients who might be interested in contributing to the study. This "snowball" sampling method is economical, effective, and efficient for reaching potential participants from vulnerable or stigmatized population (Atkinson & Flint, 2001).

Between December 2014 and April 2015, a total of 47 type 1 and type 2 diabetes patients were recruited, including 16 patients living with type 1 and 31 with type 2 diabetes. Among the participants, 27 are female (two of which identified as members of the LGBTQ community) and 20 are male. Participants reported a wide range of occupations (e.g., professor, student, doctor, military veteran, designer, actor/actress, engineer, business administrator, and accountant) and industries (e.g., education, business, entertainment, medicine, construction, food and hospitality, and finance). All participants are over 18 years old, with 1 aged between 18 and 24 years old, 11 between 25 and 44 years old, 23 between 45 and 64 years old, and 12 over 70 years old. Four of the participants have had diabetes for less than 2 years, 32 have lived with it for between 3 and 19 years, 10 had it for between 20 and 40 years, and 1 participant had more than 50 years of experience with diabetes. It is worth noting that the participants living with type 1 diabetes tended to have more years of experience with the condition, perhaps because type 1 diabetes generally has an earlier onset than type 2.

Participants were recruited from the United States and mainland China. For participants in the US, the first author started the recruitment at a patient support group for type 1 diabetes based in a diabetes health center in New York City. These participants introduced others based in not only New York City but a few other large cities in the US (e.g., Chicago). In comparison, all participants recruited in China are affiliated with a research university and its large teaching hospital in southern China. Among the 47 participants, 30 live in China (including 1 person with type 1 diabetes and 29 people with type 2 diabetes) and 17 are from the US (including 15 people with type 1 diabetes and 2 people with type 2 diabetes). The differences in the two samples collected from the US and China reflect the different composition of the first author’s personal network in the two research sites. While the two samples may be biased, they offer a glimpse into the different PHIM motivators for people living with different health conditions and from different social contexts.

**Data Collection**

Semi-structured one-on-one interviews were conducted to explore information attribute motivators for PHIM activities. The interviews with participants in the US were all conducted in English and those with participants in China used Mandarin, a local Mandarin dialect, or both. Interviewing was chosen for its ability to elicit in-depth data from each participant (Bingham & Moore, 1959). Despite the high cost associated with this method, the rich data it delivers is necessary for understanding issues like behavioral motivators that are difficult to observe by outsiders.

This study is part of a larger project that examines not only the information attribute motivators of PHIM activities, but also other PHIM motivators, activities, and the cognitive and affective processes accompanying the PHIM activities. The interviews explored all these aspects and lasted for about an hour on average. Those with participants in the US (averaging about 103 minutes) are generally longer than those with participants in China (averaging about 36 minutes). The difference between the length of the interviews for the two groups of participants may be due to differences in the pronunciation speed between English and Mandarin (Hoosain & Salili, 1987). This gap may be also related to the differences between participants’ PHIM styles. For example, many participants from China reported that they did not perform PHIM activities compared to many of their US counterparts who carry out PHIM activities multiple times every day. However, these participants all described reasons that motivated or discouraged them from PHIM activities. In this regard, the data collected from the two research sites is comparable.

**Data Analysis**

The notes and audio recordings from the interviews performed in the US were transcribed in English and those from China in Chinese and then translated to English. All transcripts were analyzed with latent content analysis, which emphasizes the underlying meaning of texts (Graneheim & Lundman, 2004). This method is particularly useful when exploring less visible and not readily classified PHIM motivators. First, the conversations were divided into
semantic units that have coherent meaning (Burla et al., 2008). These units usually include one question from the researcher and the corresponding answer from a participant. Then, each semantic unit was assigned one or more codes that reflected aspect(s) of PHIM practices. During the coding process, the first and second author discussed and modified the codes. After that, the previously assigned codes were updated. The data did not reach a saturation point with 47 participants and the codes were constantly modified throughout the coding process.

<table>
<thead>
<tr>
<th>Motivators</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Availability</td>
<td>“The doctor gave me a book, so I read it.”</td>
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<tr>
<td>Abundance</td>
<td>“There is just too much information for me to manage.”</td>
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<tr>
<td>Credibility</td>
<td>“They all claim to cure diabetes. I don’t believe it.”</td>
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<tr>
<td>Accuracy</td>
<td>“I doubt if the blood glucose meter’s readings are accurate.”</td>
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<tr>
<td>Consistency</td>
<td>“I just hope there is one consistent guide about how to manage diabetes.”</td>
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<tr>
<td>Timeliness</td>
<td>“When you think of going back to the files, they are already obsolete.”</td>
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<tr>
<td>Usefulness</td>
<td>“In case I’m in critical condition, my family can have the records to show doctors.”</td>
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<tr>
<td>Process Level</td>
<td>“The integrated information is some extra motivation because you see all the efforts put together.”</td>
</tr>
<tr>
<td>Presentation Style</td>
<td>“Books generally take too long to get to the point.”</td>
</tr>
<tr>
<td>Emotions Elicited</td>
<td>“I don’t write notes, as the pictures on complications in the book scare me.”</td>
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| Table 1. Information attribute motivators of personal health information management (PHIM) activities. |

RESULTS
The result of the coding was a set of information attribute motivators, described in brief in Table 1. In the rest of this section, each type of information attribute motivator is introduced and illustrated by a few typical examples. Each of the 47 participants was assigned a code ranging from P1 to P47; P1-P30 refer to participants recruited in China and P31-P47 refer to those recruited in the US.

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, P19 had type 2 diabetes for a long time. When she was first diagnosed over 30 years ago, there was little diabetes-related information in China because of the limited medical development and communication channels. Nowadays, and even in the US, some patients still experience difficulties accessing the information they need. For example, P47 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”.

Similarly, some participants experienced difficulties when trying to obtain their own health information. For example, P22 was discouraged from getting a copy of his blood glucose readings during hospitalization. The information was on a nurse’s paper work notes, but was mixed with other patients’ data and hard to locate. Also, this hospital did not provide copy services, so the patient would have had to write down all the numbers by hand. In contrast, other hospitals allow patients to copy their own data with a flash drive. As a result, P22 gave up collecting information during this hospitalization but kept a record of all his other hospital visits. The lack of desired health information can create a situation where patients have to make bricks without straw, causing some patients to eventually give up the attempt at performing PHIM activities.

On the other hand, when information is available, patients can be motivated to manage it. For example, P17 said that the reason for him to keep a record of his health conditions is just because it is available, “I did not think too much. The numbers are there so I just wrote it down.” Also, P13 mentioned her experiences of collecting information from a local hospital “I went to the hospital because they hand out free materials on World Diabetes Day. This came in a bag and I read it”.

Some patients experienced serendipitous encounters when managing their health information. For example, P11 described how he accessed information that helped with diabetes management through his social network: “I didn’t ask anybody. The few of us staying in the same hospital just engaged in a random chat, but what they said really helped.” Social networks involving other peers with the same type of diabetes was often identified by participants in the US as environments that they intentionally engage in to boost serendipity encounters for potentially useful information although less often for participants in China.

Serendipity encounters not involving social networks are also reported. P4 mentioned that he kept a large collection of information about different health conditions on his computer, and when he looks for information on another health condition, he may review the information on diabetes simply because he sees a folder named “diabetes”.

In addition, patients can lose interest in PHIM activities although they have access to health information, because
new information is not available. For example, P24 stopped writing down health information she received through conversations with others because it coincides with what she already knew. Other patients have also stopped searching for information from other sources, such as health care providers, the Internet, and TV, for similar reasons.

**Information Abundance**

When health information is available, its volume can also motivate or discourage patients from performing PHIM. For example, P4 argued that he does not read any health-related books because there are too many books and it is almost impossible to gain an all-around view from reading them. Instead, he searches the Internet and only looks at the first few pages for the information he needs. Many other patients have indicated their lack of a personal collection of health information is because of the abundance of such information available through mass media and personal networks. Too much information may have led to information overload in these patients.

On the other hand, having a small amount of information can also discourage carrying out PHIM activities. P4 described how he decides how much energy to allocate to information management, “I may be able to find my diabetes information more efficiently if I make a table of contents, but it is very easy to just browse through the document because I have little such information. At the start, I had all my health information in one document. Later, I accumulated lots of information on other health topics, and I found it increasingly inconvenient to browse through everything, so I took the time to divide the document into several files on different topics.” P4 is living with multiple health conditions and his management of diabetes-related information is in parallel with that for other conditions. When P4 had little health information, he stored everything in one document, but the increase of health information he kept caused him to divide the one document for all diseases into separate ones for every condition. Now he has one document for diabetes-related information. Although he can think of ways to organize it in a better way, he does not bother to make the effort because the low volume of this information makes it not worthwhile. It seems that there is a balance point in the volume of information where patients may be encouraged to perform PHIM, but this point may be influenced by the interaction between a number of factors, such as how the information is presented (e.g., all at once or page by page), sources of information (e.g., books or the Internet), information management tools used (e.g., whether a tool allows navigating to locations in a document through a table of content), etc.

The dearth of information from certain information sources can even lead to their abandonment. A few participants with type 1 diabetes mentioned that the abundance of information for type 2 diabetes and the lack for type 1 has caused them to cease using certain mass media (e.g., television, radio and newspapers) as information sources.

**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. P26 said that information from other diabetes patients is sometimes more trustworthy than that from doctors. “That person has diabetes, so I believe in her and want to follow her advice to take Chinese medicine. My daughter studies medicine and she is against it, but the other patient is taking this medicine and says it works well.” Also, P33 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.”

Other patients noted that looking at the source alone does not warrant the credibility of information. For example, P4 mentioned that he saw some advertisements for cures for diabetes on a Chinese party newspaper, where only serious news on the country’s developments is published. The medications advertised also had permission numbers from the China Food and Drug Administration. P4 was sure that there is currently no cure for diabetes and he was greatly discouraged from collecting information from newspapers because a credible information source does not guarantee credible information. Similarly, P28 voiced her doubts on information authorities “Many doctors have positions at a large hospital and a small clinic. They earned their credentials at the large hospitals and earn money at the small clinics by selling fake information and treatments. I ran into a doctor from our hospital who works as a specialist at a small clinic. This clinic claims to have cured diabetes, so I asked him how come he can promise better health outcomes at small clinics rather than at larger hospitals. He said that the small clinic has better equipment. Then why don’t the large hospitals get this equipment to serve a larger population?”

Questionable marketing behaviors also push patients further away from PHIM activities. For example, P6 used to go to free classes on diabetes management only to find that they intended to sell health supplements such as propolis (i.e., a building material for bee hives collected by honey bees from plants). When the patient tried to leave, she was stopped at the door and forced to stay until she spent a few thousand RMB, which is about the monthly income of a mid-class person living in China. The experience of P6 is no news to many participants. Some have stopped collecting health information from some official sources.
(e.g., The Dr. Oz Show) because they find the content of the information questionable. A few participants noted that older patients are particularly vulnerable to this kind of scam because they do not know how to effectively judge the credibility of health information, especially without the help of modern information technologies.

However, some judgments on the credibility of health information are not shared among patients. 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. P47 found it very effective, but P37 found 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.”

Some opinions on credibility can be misinformed. For example, P1 mentioned that a large local teaching hospital offers “pancreas transplant but requires the patients to increase their weight to 80kg [or about 176 lbs] to qualify for the surgery”. The patient also mentioned that this surgery will involve “opening a hole in the stomach and redirecting some food through a tube”. The patient found this surgery problematic because increasing one’s body weight seems to be imprudent for diabetes patients. The patient’s description of the surgery, however, bears more similarity with gastric bypass surgery, which involves rearranging the connections between the small intestine and the stomach to reduce the effective size of the stomach. It is a weight loss surgery for people weighing 176 lb and above, and has led to positive outcomes in people living with type 2 diabetes (Buchwald et al., 2004). In such cases, the information provided by the hospital may be interpreted by patients in different ways, potentially leading to unnecessary suspicions in its credibility.

**Information Accuracy**
Participants have questions about the accuracy of self-generated data. For example, P9 was concerned about the accuracy of his blood glucose meter “The doctor mentioned that our electronic sphygmomanometer for measuring blood pressure levels may not be as accurate as the ones using mercury, so I am wondering if my electronic blood glucose meter is accurate at all.” Because of his doubt, P9 did not rely on the numbers from his electronic meter, but only kept the numbers he received during hospital visits.

**Information Consistency**
The consistency of information also affects whether patients will manage it. For example, P27 wondered why two consecutive blood sugar testing results can be different “Sometimes when I test myself, I get 20.03 for the first time and 17 for the second time only one minute after.” This inconsistency in test results made P27 not take the numbers seriously. She also tested herself less often and did not keep a record of these numbers. In contrast, many 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, P21 was discouraged by the different versions of diabetes management regimen he came across “There is no standard for diabetes management in China or in the US. Everybody says differently. There are so many different types of plants and meats, I have no idea what is edible and what is not.”

While some patients may avoid problematic information, others may bring it to the attention of others. For example, P43 reported that she talks to her doctor if she has doubts about something. In order to do this, she performs PHIM activities, such as entering the information in a to-do list on her smart phone. In short, the consistency or inconsistency of health information can both lead patients to either conduct or not conduct PHIM activities.

**Information Timeliness**
Newly generated information is sometimes valued. P37 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. P37 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, P37 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. P41 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.”

**Information Usefulness**
A major motivator for patients to perform PHIM is whether they consider the health information useful to themselves and others. Many patients said that recorded health information can help them make self-management decisions
and solve problems. For example, P16 measures her blood glucose levels to determine how much she will have for the next few meals. Some patients also use information to make long term adjustments. P32 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 P32 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 patients benefit indirectly through managing their personal health records, mainly by sharing these records with their health care team. For instance, P20 keeps a book of her blood glucose levels, diet, exercises, stress levels and other diabetes-related information. She said, “I write in this journal every day so I can share it with my doctor during my yearly hospitalization. He gave me very specific suggestions on how to improve after reading it briefly.”

Not only would the benefits for oneself motivate patients to perform PHIM activities, but the anticipated utility of information for others would also have similar effects. Several participants in the US are A1C Champions and they keep information from sources other than themselves to “help others and help themselves”. For example, P42 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, P4 participated in a research project at a local hospital. A reason that he kept detailed records of his health conditions was “the doctors are all very interested in my diary. I feel happy to be helpful to their research”. Similarly, P46 mentioned that he kept and sent his daily blood sugar logs through the online portal systems of a drug company to help with their research and development.

Keeping family members and caregivers informed may also be a motivating factor for some patients. For example, P38 set 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.

In contrast, many participants tried recording their health information but stopped after they found it not as useful as they thought. P8, for example, used to test his blood glucose levels once every 3-4 days, but stopped because he did not see connections between these numbers. However, P8 felt that the health records given to him when he was discharged from the hospital were much more useful than the numbers recorded by himself, because data on his health indicators and doctor’s comments “makes it very clear what needs to be done”.

**Information Process Level**

Much of the information patients gather on a daily basis is raw data with low levels of processing. For example, many 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 patients also keep articles they found online which can be about individual topics that do not reflect much about health care strategies for individual patients. A few participants were encouraged to organize their information because of how much this information is processed (e.g., integrated) to show meaningful patterns that can be readily used in their own care. For example, P41 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. P41 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.”

**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 (i.e., a device that shows real-time blood sugar levels and the direction at which they are heading). 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 P48 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.

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1 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 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.
On the other hand, some ways of presenting health information may not be well accepted by patients with specific needs. For example, P47 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. Many books try to engage readers by using examples and analogies in their introductions, but for P47, succinctly presented information is more desirable.

**Information-Elicited Emotions**
When patients are exposed to diabetes-related information, they may avoid it if it brings unpleasant emotions. For example, P2 reported that she never takes notes on what she reads in books on diabetes management because the pictures on possible complications frightened her. This negative emotion also made her stop reading diabetes-related books altogether. P41 agreed that she does not feel it appropriate to share her real-time health data with others because the lack of contextual information may cause unnecessary concerns, “It’s creating anxiety for the sake of anxiety and for instance, if my sensor came out accidentally, I might get a false 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, P32 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 P32 to carry on the work of keeping extensive records about himself.

**DISCUSSION AND IMPLICATIONS**
Our results show a variety of information attribute motivators reported by diabetes patients. While some of these attributes are not entirely new compared to what was found in previous studies, the detailed classification of the motivators and the contexts in which they were identified are novel. The findings demonstrate that not only does health information itself have a plethora of aspects that have different motivating effects on patients PHIM activities, but these aspects can also have different effects on people with different health conditions and living in different social contexts.

**Information Attributes Have Different Motivating Effects**
The information attributes we identified can be roughly categorized into three types: the content of information (i.e., availability, credibility, accuracy, and consistency), the delivery of information (i.e., abundance, timeliness, process level, and presentation style), and the result of information (i.e., usefulness and emotions elicited). While these attributes are used to describe information, they are perceptions reported by participants and may not reflect the actual status of the information. However, because our focus is to explore motivators of PHIM activities, participants’ perceptions and understandings should be more relevant for this study.

Information content is mainly determined by information sources. Among the four information content attributes, information availability and credibility have been investigated in many existing studies. Here, availability is a different concept compared to accessibility as defined by Fidel and Green (2004). While availability refers to whether the information is provided by a source and accessed by the patient, accessibility can also include issues such as whether the information is well presented and the information seeker’s familiarity with the topic.

The credibility of information and its sources are also examined in previous studies (e.g., Flanagin and Metzger, 2000). However, it is surprising that the more experienced patients in our study reported information from traditional mass media is less credible than information from the Internet because of their negative experiences with the former. Although studies have warned that people may have difficulties judging the credibility of online health information (e.g., Eysenbach & Köhler, 2002), people living with chronic conditions may develop more ways of judging credibility through trial and error.

Although the accuracy and consistency of health information are observed multiple times among our participants, they are studied less in the existing literature, perhaps because the judgment of these two information attributes either requires pre-existing knowledge of the topic at hand or engagement in longitudinal data.

We also identified multiple PHIM motivators that describe how health information is delivered, including abundance, timeliness, process level and presentation style. Too much information is commonly mentioned in the literature as a source of cognitive overload, deterring people from gathering more information. Our data suggests that for PHIM activities, not only too much information can be discouraging, too little information can also reduce the need to organize it. This difference in how the same factors affect information seeking behaviors and information management behaviors differently points to the necessity of examining PHIM motivators separately from their information seeking counterparts.

What we found about information timeliness is also intriguing in that both when the information is updated and when the patient comes across the information count as motivating factors. For chronic conditions like diabetes, the disease itself develops rather slowly. Many participants have lived with the condition for over 30 years without complications. However, information related to the condition from external sources is updated rapidly. For example, insulin is developed with a series of improvements that build up little by little over time. Also, information technologies for diabetes patients are developing alongside those for smartphones. These rapid changes make many patients...
update their knowledge periodically to keep up with the new findings on the disease and new treatments available. Nevertheless, different types of information may be desired at different times. While patients keep themselves updated, they may not consider certain information relevant when their situation does not suggest the case. In this sense, timeliness may be similar to part of what salience means in the comprehensive model of information seeking. That is, some information about a situation may be relevant during the period when the situation is present or imminent but not so much in other times.

Information process levels and information presentation styles are similar to the message content attributes mentioned in the comprehensive model of information seeking. These two attributes are considered information delivery factors because our participants reported the same information may be valued differently when delivered in different ways, which calls for a distinction between content and content delivery. Information process levels examine the amount of work put into connecting different sets of data by comparing, contrasting, and calculating. Much of this work is related to the PHIM activities, so for some participants, the motivation to perform PHIM activities is the smaller amount of work remaining. Information presentation style, on the other hand, is more about the esthetics of rather than the logical work involved in the information. Better presentation styles of the same information not only can improve its readability but also can lead to elevated moods for PHIM tasks.

Furthermore, the results or anticipated results of managing certain health information can also be motivating. Similar to the parallel process model, these results can be objective (i.e., the usefulness of the information as perceived by patients) or emotional (i.e., emotions elicited by information). Usefulness is one of the most commonly reported motivators for PHIM activities. Our results suggest that most participants put logic before emotion when they make PHIM decisions. However, emotions can sometimes determine whether patients decide to give up managing information even if it may be helpful. These findings are in line with the uncertainty theories of information seeking. The results reported in this study provides a rich description of the multitude and complexity involved in the participants’ thinking and reasoning process. This rich data can be particularly helpful when designing corresponding interventions for some PHIM motivation issues.

**Social Contexts Can Affect Motivations**

Participants of this study were recruited from two very different social contexts, the US and mainland China. This difference can affect not only the types of motivating factors, but also how these factors are experienced and appraised. Generally, participants in China seemed to be less motivated to keep diabetes-related information because of credibility issues and their US counterparts tended to be more motivated by how much their information is processed and how it is presented.

First, how health systems function can affect patients’ PHIM motivations through different payment dynamics. Lately, China has been undergoing a health system reform characterized by a drastic increase in privatization of hospitals (Yip & Hsiao, 2015). This is one of the reasons that caused what P28 described as doctors degeneration in credibility. With hospitals increasingly becoming private properties, doctors may feel more incentivized to work at smaller private clinics for higher income. However, the US health system is highly privatized, why did we not observe problems similar to what P28 reported? This leads to the next point.

Second, regulations have not followed up fast enough as China goes through health system reform (Yan, Wang, Ortiz, & Huo, 2014). Lack of regulations and its reinforcement on advertising led to the prevalence of deceptive advertising. Although participants from both social contexts reported receiving problematic health information, those in China seemed to experience a more rampant flood of deceptive advertising and much worse personal experiences.

Third, the parallel system of Chinese and western medications practiced in China further complicated Chinese patients’ judgments on whether a piece of health information is credible. Many people in China use Chinese medicine as a complement to western medicine (Chung et al., 2014) but have no knowledge that many types of Chinese medicine have not been scientifically proven to work on diabetes.

Fourth, the participants recruited in the US seem to have a higher health literacy level than those recruited in China. We observed some cases where patients in China reported motivators for not performing PHIM (e.g., P1’s story about pancreas transplant and P8’s perception that recording self-generated data is of little use) were due to misunderstandings that could be avoided by being better informed. With higher levels of health literacy, patients in the US may better understand how their information is processed and presented.

We can see that the differences in the two social contexts examined may have led to considerable differences between the types of motivators for PHIM activities and how the motivators take effect. The shifting landscape of Chinese health system, the difference in regulations, the use of both Chinese herbal medicine and western medication, and the need for improvements in Chinese patients’ health literacy levels, combine to create these complicated differences. Therefore, when designing or transplanting interventions to motivate PHIM activities, it would be useful to take all of these intertwining dynamics into consideration.

**CONCLUSION**

This study explored the information attribute motivators for personal health information management activities. Our findings and discussions demonstrate a large variety of information attributes that extend the existing theories of motivators for information behaviors. We discussed how
these information attributes may differentially influence PHIM behaviors of people from different social contexts.

When considering these results, a few limitations need to be taken into account. First, snowball sampling can lead to sampling bias. This bias can result in missing important issues that could have been raised by non-participants. Second, one person coded all of the transcripts, which can lead to coder bias. The authors corrected this to some extent by jointly discussing and modifying the coding scheme, but results from two coders would still be preferred, and will be obtained in future work with this data set. Third, we do not have as many participants in the US (17) as those China (30). It is possible that the smaller sample size of the participants in the US may raise the issue of not reaching a saturation point for qualitative analysis. Nevertheless, the richness, depth, and volume of data contributed by our participants are valuable for understanding and potentially intervening in what makes an information object a motivator for PHIM activities.

REFERENCES