MEDICAL MAPPING METHODS: DESIGNING INTERACTIONS FOR SELF-CARE

By

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ABSTRACT

This project addresses how information and interaction design can create new data collection and interpretation methods that will improve individual efficacy in the management of the chronic illness type 2 diabetes.

Medical journaling is an important method of recording and tracking the diabetes condition. Diabetics who journal to self-manage their condition can prolong their lives, gain a better understanding of their disease, and communicate more effectively with medical professionals.

To address these issues, this project aims to create a software journaling application on a hand-held personal digital assistant (PDA), where diabetics can journal their day-to-day health-related information, such as blood glucose, diet, exercise and medications. Once data is input into the application, individuals can output the data in the form of visual maps. This allows the individual to look for patterns and trends in the hope of discovering something new about what works for managing the condition. Since health literacy and numeracy are issues for some, the use of an iconic visual language to navigate the user interface makes this application simple, easy to use and interactive. The individual's effortless gathering of personal data and the ability to see that data in new visual forms offers an alternative to current self-management systems.

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PREFACE

A dear friend of mine passed away from type 1 diabetes. I often encountered him in a state of low blood sugar and would immediately give him some juice or a piece of fruit to bring his blood sugar into a normal range. He would comment on how difficult it was to manage his condition–what not to eat, when to eat and when and how much to exercise.

He was very athletic and seemed to eat very healthily, but no matter what he did, his blood sugar levels always seemed to be out of control. Sometimes he would be very depressed about managing and coping with his condition. He was so frustrated that even though he tried diligently, he still experienced no real results. His doctors wanted him to keep a detailed journal of his blood glucose levels and diet. My friend found this difficult to accomplish given his lifestyle.

The recording and tracking became a job in itself, on top of his day job and his student life. Sometimes he wouldn't check his blood glucose levels because he couldn't afford the test strips at a dollar apiece. At other times, he failed to journal because he didn't want to be reminded or bothered by his condition.

Sadly, in his case, depression and the difficulties of self-management got the best of him, and he passed away last year. As a good friend, it was difficult for me to even fathom what he was going through. I know he was disappointed that people didn't seem to understand the specifics of his condition. I wish I knew then what I know now; perhaps I could have helped him more. His story is my project.

What if, instead of a detailed, hand-written journal he could have mapped out his blood glucose levels and dietary intake in the form of a visual road map? By this I mean a road map that he could reference and use as a reflective tool to identify patterns and trends in his blood glucose levels, diet, exercise regimen and medication dosages. Though he once recorded 15 days of his blood glucose levels, insulin intake and diet, he could not "read" a pattern in the data. While his doctor wanted him to journal consistently, my friend reported getting nothing out of this activity. Therefore, my goal with this project is to employ the principles of effective information and interaction design to facilitate self-care management for people living with type 2 diabetes.¹ In proposing a software application for a PDA in which the user generates data input/output as visual road maps, the intention is to reduce the complexity exhibited in the current text/numeric systems to enable ease of use in learning about self-care and efficacy.

¹ The reason for choosing type 2 diabetes for this project instead of type 1 is because of the increase in newly diagnosed type 2 diabetics. Furthermore, the majority of people living with diabetes are those who are type 2.

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DEDICATION

In remembrance of my great friend Jacob.

Dance dance dance, Jacob, forever.

1.0 INTRODUCTION

This paper addresses the question, how can information and interaction design create a new data collection and interpretation method for improved individual efficacy in the management of the chronic illness type 2 diabetes?

The practice of self-management of chronic diseases like diabetes has become a growing issue for those with the disease, because self-management is possible, but for some is difficult. For many, studies show a decrease in success of self-management as stresses accumulate due to a lack of communication with medical professionals and health educators, navigating a complex medical system, health literacy issues and the need to learn new technologies for self-management (Albarran, Ballesteros, Morales, & Ortega, 2006). Some people actively resist help because the communication between the individual and medical professionals, family and friends can be complicated; even an overly supportive family can lead to a downward spiral as one is reminded that he/she is ill. Doctors typically ask diabetics to journal their condition as a method of recording information for reflective purposes (this methodology is also seen as a form of storytelling). Current journaling methods, which consist of handwritten diaries, Excel spread sheets, cell phones, PDAs, computer software applications and online services, can serve to highlight patterns and trends. However, these methods can fail to motivate (Polonsky, 1999). While these systems can give the medical professional something of an overview, they can fail to serve the individual doing the journaling in terms of illuminating patterns and trends occurring in the treatment and responses of type 2 diabetes.

Present journaling methods, as designed, have shortcomings. What are needed to further empower diabetics are innovative designs that give both doctors and individuals visual road maps that could potentially give insight into the individual's condition. This visual map could become a language shared between the diabetic and his/her health care consultants. In the medical field, studies show nearly half of all North American adults have difficulty understanding and using health information as the language becomes increasingly complex (Pawlak, 2005). Tools for journaling have long been put into practice and have worked to a limited extent. Currently the possibilities exist for interaction design with the use of technology to greatly improve the techniques of

journaling for type 2 diabetes. Studies in other areas of health care have shown that mapping and the use of pictographs to illustrate trends and patterns of treatment and response enhance an individual's understanding of his/her condition (Hill & Roslan, 2004). A combination of visual, written and verbal information can lead to better recall and adherence in management since the diabetic can call upon the information and see patterns in it, potentially improving health outcomes.

Currently there is much research being done in the area of self-management for type 2 diabetes. The 2008 International Consumer Electronics Show (CES), a yearly event that showcases new innovations in platforms, products and technologies, introduced a number of concept prototypes for diabetes self-management. For example, the use of touch technology provides new ways to navigate a screen space, making it more tangible for the user. New symbol systems in the form of desktop widget applications² offer simplified versions of larger applications. Advancements in mapping technologies are also enabling doctors to map the brain's functions as medical infographics. This is a project that is at the interface of medical science and design and runs parallel to the research of other institutions looking into self-management for diabetes. RED, an initiative of the UK Design Council, has a project titled ActiveMobs, which promotes a healthy lifestyle. As well, RED has a diabetes agenda that employs design innovation for self-management (Red Design Council, 2006). Roche Pharmaceuticals in Palo Alto, California, has an incubation design lab that is focusing on diabetes as a lifestyle management issue. In my discussions with them, I have learned that there is a need to move diabetes care beyond the blood glucose meter to a life-coaching design intervention.

This project aims to create a software journaling application on a hand-held PDA, whereby those with type 2 diabetes can journal their day-to-day health-related information, specifically blood glucose levels, diet, exercise and medications. While inclusion of subjective factors such as stress, sleeping patterns and even emotion and pain levels is desirable, due to the scope of this project this design application will focus

² A small, specialized graphical user interface application that provides some visual information and/or easy access to frequently used functions such as clocks, calendars, news aggregators, calculators and desktop notes (Widgets, 2008).

solely on the four trends above, because studies show that successful management of these can dramatically influence long-term outcomes (Polonsky, 1999). (The application discussed here would also be compatible with the use of a laptop or desktop computer, although this would reduce mobility.)

In using the application, the diabetic would input his/her day-to-day health data using the proposed device's visual iconographic navigation system and output the data as maps. To map is to plan, organize and methodize the representation of facts of one's condition, making the information more accessible. This transforms the data into a visual format that is represented in a simple, understandable and digestible form. Robert Horn states, "There is always something satisfying when we can see–actually visualize–what and how we are feeling and thinking through mapping" (Horn, 2000). The design intent is to offer the individual an alternative to current self-management methods and in so doing, could enable the user's ability to draw connections and see patterns and trends in his/her condition. Using visual aids in combination with text to represent, or map, what has up to now been text- and jargon-heavy should mean that diabetics can access, retain and interpret information with much greater ease. Data represented as maps creates a visual story of their condition, one that can be shared with friends, family and medical professionals.

1.1 RESEARCH METHODS

The research methods for this project began by creating a research plan that outlined primary and secondary goals which included many questions. A few of these questions were:

- · How can design contribute to the current data collection methods?
- Could the journaling method become a mapped out process offering a visual road map for the individual?
- How will making the data visual, affect and benefit people living with diabetes and their relationship with medical practitioners?

Primary goals were to create a hand-held PDA that one who is diabetic could track and record their day to day health information. In the creation of the application current self-management methods would be explored. Secondary goals included exploring an iconographic navigation interface that would address health literacy and numercy issues, and creating an interactive device that is functional and easy to use. Objectives focused on conducting concept prototyping with participants to gain feedback on manoeuvring the iconic interface. Working with diabetics I wanted to gain insight into how often diabetics journal, what they journal and what the pros and cons are of what is normally for some, a tedious task for self-managing the diabetic condition.

The three main areas of study for this project included: primary diabetes research, secondary diabetes research and primary design research. Primary diabetes research consisted of attending an educational course at the Vancouver General Hospital, Diabetes Care Centre, where I was able to gain great insight into diabetes prevention and self-management. In order to gain knowledge from the medical professionals I conducted various interviews that included doctors, nurses, counselors, diabetes researchers and educators. To explore the topics of diabetic self-management and journaling first hand, I volunteered at the Canadian Diabetes Association (CDA). In order to conduct primary research, I participated in an ethical review process, which allowed me to interview a small sample population of type 2 diabetics. I also conducted concept prototyping gaining feedback from the small sample population.

Secondary diabetes research included various articles and essays from medical journals which gave me insight into the facts and figures of the diabetic condition. I was also able to understand the economic realities of managing diabetes. Further research highlighted key issues of the diabetic condition such as the importance of self-management and journaling including the numeracy and literacy challenges associated with diabetic self-care.

Primary design research included exploring the following design topics: iconographic research, software interface design, information design, interaction design, concept mapping and pictographic mapping methods. Further, research explored current self-management methods for diabetes such as medical devices, paper logs, computer applications, cell phone and PDA applications, as well as dynamic media websites.

2.0 DIABETES

Diabetes is a chronic condition in which the pancreas does not produce enough insulin, or in which the body doesn't use insulin effectively. Hyperglycemia and other related disturbances in the body's metabolism can lead to serious damage to many of the body's systems, especially the nerves and blood vessels. There are two main types of diabetes: type 1 diabetics are people who produce little or no insulin and need daily injections of insulin to survive, whereas people with type 2 cannot use insulin effectively. Type 2 diabetics can often manage their condition with lifestyle changes alone but may also use oral drugs, and sometimes insulin, to maintain good metabolic control. A third type of diabetes, gestational diabetes mellitus (GDM), develops during some cases of pregnancy but usually disappears after pregnancy.

According to the World Health Organization (WHO), some common symptoms of type 1 diabetes include "excessive thirst; constant hunger; excessive urination; weight loss for no reason; rapid, hard breathing; vision changes; drowsiness or exhaustion" (World Health Organization [WHO], 2006). Type 2 diabetics have similar symptoms but usually not as noticeable. Many diabetics with type 2 have no symptoms and usually are diagnosed after many years of onset. Indeed, almost half of all people living with type 2 diabetes have no idea that they have this life-threatening condition. About 90% of diabetics are type 2; nearly all of the remaining 10% are type 1 (Canadian Diabetes Association [CDA], 2008a).

Diabetes is one of the toughest illnesses to manage. For most people living with diabetes, self-management is difficult. The diabetic's ability to self-manage may even be decreasing. As Dr. Polonsky observes, "diabetics are at war with their diabetes—and they are losing" (Polonsky, 1999). Even though there have been advancements in newer treatments and methods for diabetes care, Dr. Polonsky states that "diabetes self-care seems to be getting worse and worse." Another study concludes that "diabetes and its complications are responsible for a tremendous individual and public health burden of suffering at the present time, and the epidemic is projected to continue into the future" (Norris, Lau, Smith, Schmid, & Engelgau, 2002).

2.1 DIABETES FACTS

In the year 2000, the World Health Organization named diabetes an epidemic. The International Diabetes Federation's campaign Unite for Diabetes claims that each year, more than 3.8 million people die from diabetes-related causes. This comes to approximately one death every 10 seconds. This silent epidemic claims as many lives annually as HIV/AIDS (Unite, n.d.). The WHO also estimates that more than 180 million people worldwide suffer from diabetes, which is predicted to double by 2030 (2006).

One of the contributors to diabetes is obesity-related issues (Obesity Society, 2008a). Currently, more than 64% of US adults are obese or overweight (Beals, n.d.). Diabetes affects 7% of the North American population, or 20.8 million people (International Diabetes Federation [IDF], n.d.a).

More than 90% of all cases of type 2 diabetes involve obesity or physical inactivity (Obesity Society, 2008b). Because diabetes is so closely linked with obesity, there is a related need to improve health literacy in terms of nutrition information, diet, exercise and informed lifestyle decision making.

Many organizations are currently working on diabetes health literacy issues. These include both the Canadian and American Diabetes Associations, The World Health Organization (WHO) and the International Diabetes Federation (IDF). These organizations are running various campaigns to raise diabetes awareness and encourage prevention. Diabetes Action Now is a joint initiative by IDF and WHO. The goal of the program is to stimulate support for prevention and control of diabetes and to increase global awareness about its complications.

The growing number of people being diagnosed annually also results in an economic burden. According to the American Diabetes Association (ADA) website, in the US alone, the total estimated cost of diabetes in 2007 was \$174 billion. The ADA's research shows that 50% of the medical expenditures were hospital inpatient care. Individuals living with diabetes spend, on average, approximately \$11,744 per year. Furthermore, people living with diabetes have medical expenses that are approximately 2.3 times higher than people who don't have diabetes (American Diabetes Association

[ADA], 2008). Also, the study revealed that approximately one of every five health care dollars spent is attributed to diabetes treatment. By 2025, the estimated diabetes health care expenditures in the US will exceed \$302.5 billion (IDF, n.d.). In Canada, the estimated total diabetes health care costs are \$13.2 billion a year and are expected to increase to \$15.6 billion by 2010 and \$19.2 billion by 2020 (CDA, 2008d). North America faces a huge burden in future years dealing with diabetes. This is why new methods of diabetes care could significantly lower health care costs. The ADA notes that almost all of the dollars spent on diabetes care services are due to diabetics who are dealing with long-term complications such as heart disease, stroke, kidney disease and amputations.

2.2 CHECKUPS AND REMINDERS

Normally, diabetic individuals, after diagnosis, will go to their doctor for checkups. The doctor usually requires the individual to track and record his/her condition. Most diabetics use a handwritten journal or diary, which is reviewed by the doctor. Once reviewed, the doctor can assess and offer referrals for more specialized doctors if long-term symptoms occur. Long-term symptom detection is very important for people living with diabetes. As with HIV/AIDS, diabetics don't die of diabetes, but rather the complications. Up to 50% of individuals with type 2 diabetes have complications at diagnosis (Bailey, Del Prato, Eddy, & Zinman, 2005). Most of the complications for type 2 diabetes are attributed to a lack of glycemic control (through insufficient blood glucose testing, inappropriate diet, paucity of exercise and lack of medication compliance). The eight major complications for type 2 diabetes, as stated by the ADA (n.d.), include:

- · Heart disease,
- Stroke,
- Kidney disease,
- · Eye complications,
- Neuropathy and nerve damage,
- · Foot complications,

- Skin complications and
- · Gastroparesis.3

When any of these symptoms occur, they indicate that diabetes care is not working for the individual. This is usually due to self-management and non-compliance issues in terms of recording and tracking blood glucose levels, diet, exercise and medications on a daily basis. The journaling, if kept up consistently, becomes a tool for the doctor and the diabetic to review protocols for self-corrective behavior. The doctor can look for patterns and, if needed, refer the diabetic to specialists to deal with the complications. However, in not providing a comprehensive journal, physician checkups typically consist of either too much verbal information or too little information. This makes it difficult for the doctor to offer suggestions for the needs of the individual, including essential referrals (Polonsky, 1999).

Self-management by journaling is the key to avoiding long-term complications. If one journals and shows it to the medical professional, it helps facilitate communication between the two and helps ensure that they are both on the same page in managing the condition. Long-term complications are usually due to poor monitoring of blood glucose readings that are outside of the permitted target range for maintaining homeostasis; this may signal irreversible damage. Not maintaining glycemic control and management is the most important predictor of many of the chronic complications of diabetes (Norris et al., 2002). Homeostasis control can be achieved by monitoring blood glucose levels, diet and exercise. Indeed, evidence suggests that introducing and maintaining proper diabetic care can lead to long-term reversal of the condition for a significant number of type 2 diabetics (Polonsky, 1999).

2.3 DIABETES CARE

Self-management is a cornerstone of diabetes care, and it is believed that improving individual self-efficacy (self-confidence) is a critical pathway to improved management (Sarkar, Fisher, & Schillinger, 2006). Since the 1930s teaching individuals to manage

³ Gastroparesis, also called delayed gastric emptying, is a medical condition consisting of a partial paralysis of the stomach, resulting in food remaining in the stomach for a longer period of time than normal (Gastroparesis, 2008).

their diabetes has been considered an important part of the clinical management of diabetes (Norris et al., 2002). Studies mention four important aspects of care that must be managed correctly to maintain glycemic control: glucose levels, diet, exercise and medications (Sarkar et al., 2006). Optimally, if these four levels are self-managed effectively, the result can be healthier outcomes and fewer complications long term. The United Kingdom's National Health Service (NHS) estimates that 90% of diabetic health care takes place in the home or through self-management (NHS Choices, n.d.). Yet many with diabetes never receive any formal training in diabetes care or glycemic control. Some don't know how to use blood glucose readings to adjust their medication, their exercise plan or their diet planning (Polonsky, 1999). (Many don't even know they are predisposed to diabetes.) Education on how to manage diabetes is very important to attaining healthy outcomes. Improvements of glycemic control and effective knowledge of diabetes and continued education are integral to comprehensive diabetes care (Norris et al., 2002).

Studies suggest that once diabetics have been educated and informed about their condition, they face decisions about changing their lifestyle toward a much more controlled self-management practice. Yet some diabetics are not willing to change their present lifestyle (Polonsky, 1999). While treatment, combining medication and lifestyle adjustments can manage type 2 diabetes, success largely depends on the individual's ability to accept his/her condition and actively self-manage it (Thoolen et al., 2007). Indeed, as noted above, for some there can be permanent reversal of the condition. The Canadian Diabetes Association recommends assessment of each individual's self-management skills and knowledge of diabetes at least once a year, meaning a thorough check of what's working and/or lacking in that individual's treatment plan and education regarding diabetes (Norris et al., 2002).

However, when using present methods, other studies have been guarded in their conclusions as to benefits of individual self-management in combination with consultation with medical professionals. One study found that "interventions to improve self-management have had some success in improving individuals' lifestyles and have also led to significant reductions in cardiovascular risk factors; however, improvements have generally been small and short lived, disappearing once intensive contact with professionals is removed" (Thoolen et al., 2007). A point that should not be confused with self-management is self-efficacy, or selfconfidence. As Sarkar, Fisher and Schillinger describe it:

The concept of self-efficacy is based on social cognitive theory, which describes the interaction between behavioral, personal, and environmental factors in health and chronic disease. The theory of self-efficacy proposes that individuals' confidence in their ability to perform health behaviors influences which behaviors they will engage in (2006).

The study they conducted suggests that, because of the many barriers to effective self-management that individuals cope with, interventions must address self-efficacy within the context of the individuals' environment (Sarkar et al., 2006). Furthermore, this study concluded that self-efficacy is significantly associated with "diet, exercise, self-monitoring of blood glucose and foot care." Designing of self-management methods that specifically target self-efficacy may motivate the individual to self-manage. However, as the study suggests, improvements in care and management last only as long as checkups with medical professionals. Being in constant communication with medical professionals allows valuable feedback to the individual by suggesting small lifestyle changes that could be beneficial to maintaining glycemic control.

2.4 CURRENT SELF-MANAGEMENT METHODS

Maintenance of one's health is the key to a successful outcome for people already living with diabetes. Methods such as diet planning and being physically active help the diabetic to live a healthy lifestyle. The best way to self-manage is to keep track of specific day-to-day information such as blood glucose levels, diet, exercise and medications (CDA, 2008b). Studies have shown that goal setting and planning are also very beneficial for maintaining lifestyle changes (Thoolen et al., 2007).

Through my research and interviews with medical professionals, I have learned that it is recommended that diabetics keep a logbook, or a journal (Fig. 1, next page). Important to the maintenance of glycemic control is the tracking and recording of dayto-day diabetic information. Once recorded, the journal is often shown to medical professionals to review and to provide feedback for improving self-management. Most logbooks or journals take the form of handwritten diaries that document in numeric

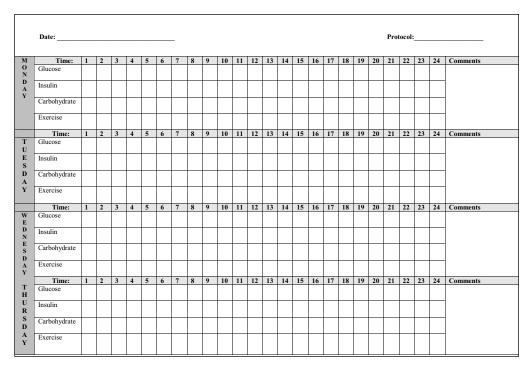


Fig. 1 Handwritten Logbook

form blood sugar levels charted by day, week, month and time of day. There is also journaling software. Some diabetics use Microsoft Excel spreadsheets, others employ proprietary applications for computers, cell phones and PDAs. Other systems use online websites that send the data input directly to medical professionals. Some of these online web services include SiDiary, Dia-log.com, Diabetes Logbook X and LogbookFX. An example of this type of system is "Life Stat," which uses a cell phone linked by Bluetooth⁴ technology to a blood glucose meter. The meter takes the blood reading, which is then transferred via Bluetooth to the cell phone and then transmitted to an online database that keeps track of the readings. Once recorded, the data can be reviewed for assessment using the internet. The key feature of this system is that it can alert medical professionals, friends and family if blood glucose levels are not being maintained.

Handwritten journals can be tedious and hard to fill out. As can be seen in Figure 1, how does one use this form without instruction? As shown, there are 24 hour intervals

⁴ Bluetooth is a wireless personal area network (PAN) that provides a way to connect and exchange information between devices such as mobile phones, laptops, personal computers, printers and digital cameras over a secure, globally unlicensed shortrange radio frequency (Bluetooth, 2008).

illustrated. This could be confusing for those who are used to a 12-hour format. Another point that could lead to confusion is the unit of measurement; this is not explained anywhere on the sheet. Lastly, once the journal is completed, how would one decipher the numbers to gain knowledge of his/her condition from this information? In most cases the medical professional would then be the only one able to interpret this information. The drawback is that the individual does not engage in the process of journaling and therefore be more responsible in monitoring their condition. Upon interviewing a small sample population, a common theme emerged, namely the challenge of maintaining a handwritten system. Other themes reported were the cumbersome nature of carrying around a diary, and the risk of leaving it at home. This group also mentioned that if they were to use an online service they would still need to record data (though in a different way and with different problems). For example, if they went out to lunch, they would need to remember what they ate and then input the data into a computer after the fact. The majority of the participants interviewed described how they will often forget what they ate and are then discouraged to input the data online or into a spreadsheet application.

Although there are a few mobile journaling applications presently, most lack the ability to journal easily. Some are very confusing, having too many options, and too many levels of information, making it hard to "get in and get out" of the application. Most diabetics get discouraged if they have to spend too much time with self-management. Individuals will journal for a few days and then get tired and/or forget to keep up with the task. As can be seen in Figure 2 on the next page (an example of a spreadsheet application), using this method can be confusing for some with numeracy and literacy challenges. As Figure 3 illustrates, also on the next page, navigating this application may be difficult, and the information as represented may be interpreted erroneously.

Medical professionals, such as dietitians, may in most cases review journals to gain a better understanding of what foods have been consumed. They compare the diet data with blood sugar levels to see patterns or trends. They then offer advice or feedback on diet or lifestyle changes. Doctors and diabetes educators suggest that individuals themselves look for patterns and trends in their condition in the hope of identifying what works or doesn't in managing the condition.

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16	Skep B	Hrs. VActivity=> PAVelgh																	
17																			
18		Hrs.																	
19	Skep B	WActivity=> PMVelgH																	
20																			
21		Hrs.																	
22	Skep B	Hrs. Wachniyws PMVelgin																	
23																			
24																			
25	Skep B	Hrs. NActivity=> PMVelgM																	
26																			

Fig. 2 Microsoft Excel Worksheet

Due to the inability to acquire copyright permission the image shown here has been removed

The image consisted of mobile phone journaling software, allowing an individual to input blood glucose and dietary information. The interface for this software appeared complex, allowing too many options to make selections. For some this software could seem confusing and hard to navigate.

Fig. 3 SiDiary software for Windows Mobile Software

My discussions with the sample population revealed a common difficulty in identifying patterns and trends. Numeracy is an issue with diabetes. Most of the information that needs to be recorded in these journals is in the form of numbers. It is crucial to record these number ratings correctly and to interpret them effectively in order to make appropriate decisions for controlling the condition. This makes it extremely difficult for people who don't have the necessary skills to review various numbers on

a page in their journal and to interpret them to see trends in management such as diet compliance. Some individuals interviewed mentioned that they do not get anything out of doing this exercise and that they are journaling only because their doctor asked them to. Most journals look like an accounting system such as a bank statement. However, in order to know your bank balance, you need to be able to reconcile your debits and credits. So, one needs to know more than the closing balance. For the diabetic, that means being able to record and interpret the process of the condition.

The worksheets shown in Figure 4 are from a diabetes education class targeted to newly diagnosed individuals. The intent is to enable the tracking and recording

Examp	le 1				Examp	le 2			
	AM	NOON	PM	BED		AM	NOON	PM	BED
MON TUES WED THU	6.1 6.4 4.6 7.0	7.5 4.8 5.9 6.1	5.2 6.7 15.9 7.0	4.3 7.0 7.3 6.9	MON WED FRI	6.2 7.1 5.8		7.0 6.1 6.4	12.0 14.8 13.9
Examp	le 3				Examp	le 4			
Examp	le 3 AM	NOON	PM	BED	Examp	le 4 AM	NOON	PM	BED

Fig. 4 Diabetes class worksheet

of blood glucose levels and to look for patterns and trends. Example 1 shows an individual testing his/her blood four times a day, at breakfast, lunch and dinner and before bedtime, over a period of four days. Individuals are asked to keep their blood glucose levels within a target range of 4 to 7 before meals and 5 to 8 after meals (CDA, 2008c). If the number recorded for blood glucose levels is too high or too low, complications could appear, so it is important to look for any patterns that arise in order to take appropriate steps to bring the levels back within target range, such as changing one's diet or exercise regimen.

However, based on my personal observations as a class participant, the format of the worksheet seems to allow for possible confusion. Many people in the class found the worksheet, and the significance of the numerical illustrations, unclear. There is no statement in the sheet itself that indicates whether the blood reading should be done before or after each meal. And though some of the readings illustrated here or in Examples 2-4 are far out of the target range, there is no evident way to flag readings (single readings or patterns) that may be a cause for worry versus readings that may be truly dangerous. There also appears to be no way to connect the readings outside the target range with causal information.

The research conducted for this project indicates the need for new ways of dealing with numeracy issues when journaling diabetic information. Perhaps changing numbers into something more visual, such as symbols, could aid numeracy literacy. Universal visual languages using visual aids in the form of pictographs date back to early days in the medical field, such as the use of symbol systems to represent administering medications (Dowse & Ehlers, 2001).

2.5 HEALTH LITERACY

Another broader issue to be considered in connection with self-management and education for those living with diabetes is health literacy. Health literacy is defined by Parker and Ratzan as the degree to which individuals have the capacity to "obtain, process and understand" basic health information and services needed to make appropriate health decisions (as cited in American College, 2007). Limited understanding of health information leads to poor health outcomes. Low health literacy threatens people in North America despite age, race, education level or income level, although to varying degrees. The 2003 National Assessment of Adult Literacy (NAAL) survey discovered that 2 out of 5 adult Americans have problems acquiring and understanding basic health information needed to make correct health choices. NAAL has also confirmed that low health literacy affects more adult Americans than obesity, diabetes, HIV/AIDS and breast cancer combined.

Other reports mentioned by NAAL indicate that though individuals acquire health information, they do not always comply by making better health decisions. Individuals

are deemed non-compliant when they do not adhere to treatment programs, perhaps because they have not processed what they've been told. In the United States, the 2003 NAAL survey estimated that among 242 million adults, 36% had basic or below basic health literacy levels (suggesting approximately 87 million people). In Canada, with 31 million people, the International Adult Literacy and Skills Survey 2003 (IALSS) found that 18.6 million people have low health literacy. Studies have shown that there is relatively greater prevalence of low health literacy among minorities, people of low income and people of low education (Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001). Since diabetes affects all races, all incomes and people of all education levels, health literacy issues should be taken into account when thinking about new methods for diabetic care.

As it relates to diabetes, health literacy is defined as "the ability to read, understand, and act on health information" (Pfizer, 2006). Health literacy is important because the more education and understanding a diabetic has about his/her health, the greater that individual's ability to make and continue to make thoughtful health decisions in maintaining glycemic control of his/her condition.

As our society advances economically and medically and comes to rely more and more on technology, health care systems for people living with diabetes become more complex. There are more studies showing the increase of health literacy issues: with a population that is continuing to age, the complexities of the health care system and the prevalence of increasing chronic conditions, health literacy problems are worsening (Pawlak, 2005). Since studies show that health literacy issues increase as people enter the health care system, one would expect that this would also affect many people living with diabetes because of their increased involvement in the health care system due to treatment for long-term complications.

According to NAAL the average North American has a ninth grade reading level, but a survey of approximately 800 studies published between 1970 and 2006 reveals that the reading level of most written health-related materials is higher than the reading level of an average high-school graduate (Canadian Council, 2007). For people living with diabetes, as medical advances continue, the language of the medical system becomes more complex. The gap only increases as health insurance, medical forms and technology become more advanced. Pamphlets given to individuals with diabetes are often difficult to understand. In addition, there may be a need to learn new computer programs for compiling data for self-management (Figs. 2, 3, 5 and 6 all reflect such programs). Not only individuals but also medical professionals have to keep learning new technology in order to comply with treatment programs. Health literacy issues will only continue to grow as people living with diabetes are asked to learn more material and medical jargon which requires more responsibility for self-care.

Educational materials and take-away pamphlets in the average doctor's office are written for an audience with a twelfth grade reading level. For some, these materials can seem confusing and will most likely be discarded. Most forms that individuals must complete to continue care are confusing. An example is the use of medical forms that are compiled in a way that makes it difficult for people to become informed of treatment options and to know who they are giving their consent to and what they are giving their consent for (Houts et al., 2001). Though initial diagnosis of diabetes may not require the use of learning technology, becoming informed of treatment options and of the long-term complications may necessitate some form of portable device with an easy-to-learn and easy-to-use interface that supports the recording and tracking of blood glucose levels, diet, exercise and medicating regimen.

Health information today involves mainly verbal and written information. But there are studies and projects shedding light on the effects of a non-verbal/non-textual language. These include the use of pictures, icons, pictographs and the use of new visualizations of computer interfaces created to improve health literacy education and self-management. Most health care professionals assume that they are dealing with a reading population. The current health care system demands that people have a wide range of literacy skills in order to operate within the health care environment (Dowse & Ehlers, 2001). Studies, however, show that much health information is confusing and difficult to understand due to an inability to read (Dowse & Ehlers, 2001). As discussed above, most health information is written in sophisticated and complex medical jargon, which targets people of a higher level of literacy. But at the same time, and discouragingly, other literature suggests that oral medical information is not well recalled by the individual (Houts et al., 2001).

Current projects are working to create new methods in presenting this complex information in visual ways (Houts et al., 2001). Pictographs as visual aides can stimulate imagination, interest and a sense of meaningfulness in people and present an alternative method to the written word (Houts et al., 2001). In a recent study involving 21 junior college students, half of the respondents were presented with information that combined verbal and pictograph information, while the other half were only given verbal information so that half of the respondents had to rely entirely on what they heard while the other half relied on both verbal and visual information. Concluding the study, 85% of the respondents were able to recall the information when pictographs (Houts et al., 2001).

2.6 PICTOGRAPHS

Since health literacy is an issue that must be addressed when designing new self-management methods for people living with diabetes, it is important to consider the numerous studies done in the medical field using visual language to improve health literacy. Research shows that there is an overall increase in health literacy with the use of a visual language (Davies, Haines, Norris, & Wilson, 1997). One study commissioned by the UK Department of Trade and Industry showed how the use of safety pictographs affected learning and compliance among people (Davies et al., 1997). The results revealed that respondents were able to recognize and recall the use of pictures better than that of a written text. Through their research, the authors conclude that pictographs can usually be "interpreted accurately and more guickly than words," (Davies et al., 1997). Within the study, there were a series of investigations done into safety labeling on consumer products that suggested that familiarity with symbols improved people's comprehension. Symbols have more impact when they are designed in such a way that they have enough space for viewing and noticeability (Davies et al., 1997). Adding color, size and positioning together with the use of text makes the overall impact significantly greater.

However, studies show that testing pictographs without the use of text failed to educate people as to safety warnings (though there are more studies being done as to how understanding affects actual compliance among people, since understanding something and complying with it in practice are separate matters.) The use of safety pictographs that are both too complex and too abstract has also proved unsuccessful because people are required to learn them, thus affecting their ability to remember and therefore comply (Davies et al., 1997).

Another study, more directly related to the presentation of health information, examined the use of pharmaceutical pictographs in a low-literate population of South Africans (Fig. 5) (Dowse & Ehlers, 2001). The study investigated the factors of non-compliance with treatment programs in different individual populations and how local residents responded and had preference for locally designed pictographs versus

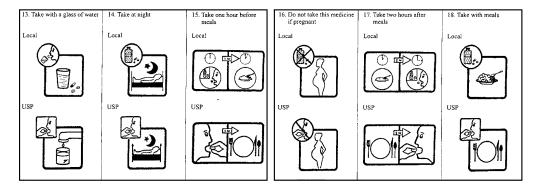


Fig. 5 Pictograph studies

pictographs designed without taking into consideration the locals' understanding.

Communicating pictographs that are successful largely depends on an intense study of design and testing to create "clear, acceptable, and appropriate" pictographs (Dowse & Ehlers, 2001). The design process can be quite complex. It entails deep insight into the target audience and also requires the involvement of the target population throughout the design process.

Visual images in most cases become successful because of the constant exposure one has to pictographs to stimulate the learning process. Interpretation demands knowledge of the representation of a three-dimensional world becoming a two-dimensional printed visual aid (Dowse & Ehlers, 2001). The authors concluded that the key to producing successful pictographs for practical implementation was requiring constant improvements and feedback for future designs. The study also indicated that people who are exposed to too many images are less able to recall the information because so many new images require more learning in order to understand and comply. But studies also show that people have a large capacity for visual information and are able to absorb and continue to retain images over time (Dowse & Ehlers, 2001). This makes it important to continue with follow-up testing to see how respondents have learned to understand and recall pictures over time. Furthermore, with the use of pictographs present over time, people with low literacy can recall large amounts of medical information, though the fact that they are able to recall this information does not mean that they will comply with it (Houts et al., 2001). But studies show that pictographs designed to act as decision aids help to facilitate decision making; these may offer quantitative information about risks and benefits of various treatment decisions (Price, Cameron, & Butow, 2007).

There are also investigations into visual mapping to communicate medical information and medical instructions. One study has found that using pictographs in a sequence can help to administer medical instructions to people who are more visually literate than prose literate (Hill & Roslan, 2004). The study, by William et al., looked at how to convey basic medical instructions such as "how to take a medication on an empty stomach," "how many pills of a prescription should be taken" and "how many times a prescription can be refilled" (as cited in Hill & Roslan, 2004, p. 1). Figure 6 on the next page offers a related example. This figure shows a sequence of pictographs used in association with text to convey taking medications with or without food over the course of the day. As pictured here, you see the low sun symbol with the word "morning" above the knife and fork symbol meaning food with the word breakfast and a picture of the prescribed medication with words of correct dosage. The sequence of symbols continues, with a high sun for noon lunch, a low sun for evening dinner and a sliver of moon for night. These sequence maps are useful to help improve the individual memory while offering directions when the medical practitioner is not present (Hill & Roslan, 2004). The study also noted that with modern computer technology and graphics, these maps can now be designed for specific individuals' protocols, including updating when needed (Hill & Roslan, 2004).

The overlapping themes in the studies referenced for this project support the need

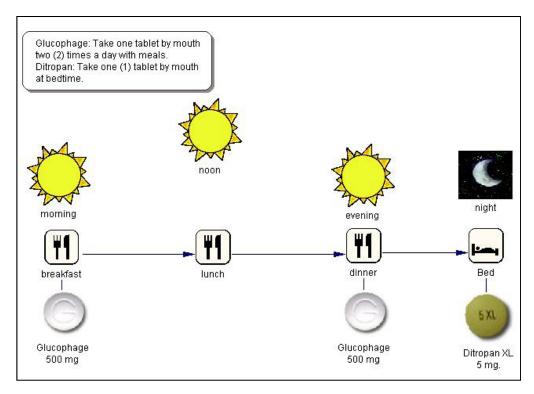


Fig. 6 Pictograph sequence mapping

for a new approach to diabetic self-management that goes beyond what is currently available. There is a real design opportunity for a software application that is crossplatform and that runs on a compact PDA or mobile—one that uses an iconic language for navigating or mapping through the graphic user interface.

Like Hill's diagram (Fig. 6) of mapping out of medical instructions using icons, my conceptual application prototype draws inspiration from this format. Using a combination of icons and text to represent diabetic information would allow individuals to access and navigate the interface with greater ease. As supported by research, individuals using this type of system would likely enable information recall more readily than text only or numbers only. This application could also provide an alternative system for diabetics who have difficulty using other journaling systems, enhancing motivation.

2.7 SELF-MANAGEMENT AND MAPPING

Currently available for diabetic self-management are software applications that output the data to graphs and charts. However, most of this software (through my research) lacks good design. As Edward Tufte (a designer and expert on information design methods) mentions, "Good design is clear thinking in action and clear thinking made visible," whereas "bad design is stupidity in action or chart junk" (Tufte, 2001). As shown in Figures 5 and 6 (preceding page), the information is still not organized in a way that allows the user to interpret the information with ease, thereby enabling him/ her to identify patterns and trends relative to needed lifestyle changes. For instance, Figure 6 appears to look like an annual report. Unless the individual is an investor or someone with prior knowledge of this type of data visualization, it may discourage the user from journaling.

What if it was possible to rethink how these charts could be represented? Figures 7 and 8 exhibit the relative information that diabetics need to monitor, but some of this software may not meet the test of good design as defined by Tufte. There are

Due to the inability to acquire copyright permission the image shown here has been removed

The image consisted of mobile phone journaling software. This specific image represented recorded data into graphs. For some these graphs could seem hard to interpret due to how the information is being represented on screen. This graphs makes use of many colours to show specific information, though the information seem unclear.

Fig. 7 DIABASS desktop software

Due to the inability to acquire copyright permission the image shown here has been removed

The image consisted of a journaling software application for diabetics to record health related information. This application for some could be seen as a calendar interface, tracking information. This specific imaged showed how the input information was then represented to the user to make use of it. Though, for some this representation could seem confusing.

Fig. 8 Diabetes Logbook X

many contemporary designers who focus on information mapping, such as Edward Tufte, Nathan Shedroff, Richard Saul Wurman, John Maeda and Jesse James Garrett. In addition, there are projects and products that make use of alternative mapping techniques to present information in simple, interactive, fun and digestible ways that people can interpret with ease. Examples include iPhone, Microsoft Surface and wefeelfine.org. Robert Horn creates "mess maps," which are "a kind of knowledge map that portray the major organizations and societal sectors involved in a mess. It generally summarizes a particular group's understanding of the problems, causes, influences, and relevant data about the mess" (Horn, 2008).

As can be seen in Figure 9, Horn has created a mess map for the Public Mental Health Department of Multnomah County in Oregon. This map visualizes and organizes

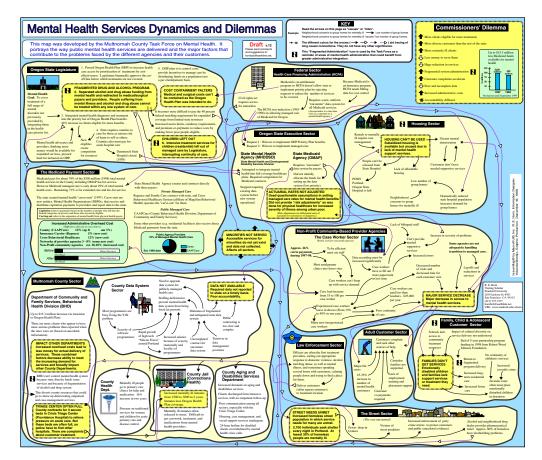
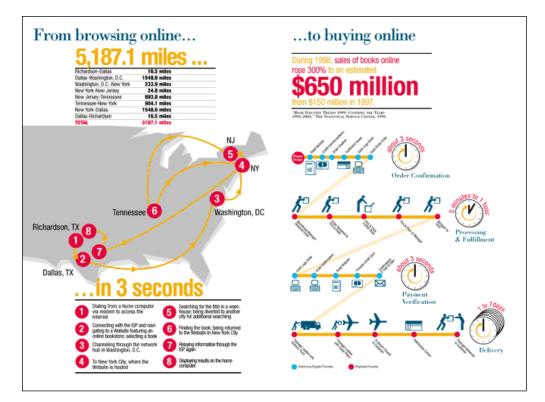


Fig. 9 Mental Health Services diagram

the department in ways that show and force visual comparisons. As designed, the user/ viewer is able to draw links or look for connections throughout the department. Keep in mind, however, that this maps a basically static "mess," while diabetes care will involve many fewer elements, but those elements will be constantly changing and interacting over time, in a dynamic fashion.



Visual maps can also be fun and interactive. As can be seen in Figures 10 and 11 (next page)-offered here as illustrations from non-diabetes applications-these

Fig. 10 E-Commerce map

maps can take complex information and present the data in a way that is inviting and interactive to the viewer, offering the combination of text, images and pictographs in multiple ways for interpretation. As Ronnie Lipton mentions, "A well designed diagram communicates more clearly and memorably than text alone. It communicates on a different level than words do because it shows, it doesn't just tell" (Lipton, 2007). This type of data representation is important for diabetics since most of the information they record is numeric. With the use of visuals and text as in Figures 8 and 9, one can see that all the words are spelled out, discreet messages help explain the information, the graphics attract the viewer and the colors are used to help illustrate the content. This same method could prove useful for diabetic representations.

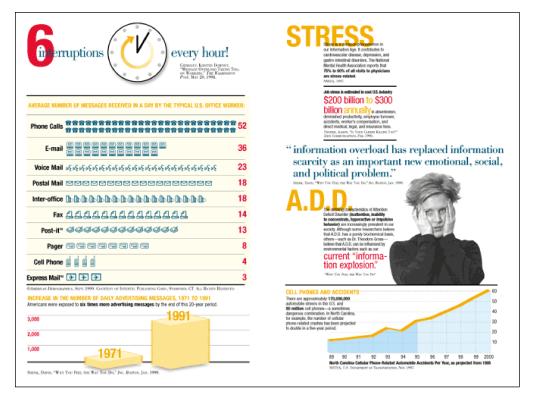


Fig. 11 Information Anxiety

3.0 INFORMATION AND INTERACTION DESIGN

Information design "analyzes, defines and structures the relationships between ideas and the way the ideas are visualized" (Hanson, 1999). Information design serves as a tool to collect data that then is organized and given structure to create meaning for an individual. With the use of information design, individuals can more readily access information they can remember, interpret and retain. This process is essentially a learning tool (Screven, 1999). Large amounts of information are simplified and can then be accessed by individuals. One's attention can only remain focused for a short amount of time (Screven, 1999); since information that is in the form of complex messages takes individuals longer to interpret, the symbolic "shorthand" for the road maps could enhance learning efficiency. However, too much information in any form can lead to information overload or information anxiety. This is a crucial issue that must be addressed in the design process of my proposed application.

Also to be considered is the notion of "mindful versus mindless" attention (Screven, 1999). By selecting some sections of information over others, the individual's mindful attention focuses on some elements and chooses not to pay attention to others. An individual's attention level may range from "highly focused and active to casual and unsystematic" (Screven, 1999). The concept of mindfulness is that greater participation levels may enable the transfer of knowledge to long-term memory. As illustrated in the "Understanding Spectrum" (Fig. 12, next page), we move from a place of perceiving to a place of learning that leads us to wisdom. In the diagram, note that the user surrounds information, knowledge and wisdom, not data. Richard Saul Wurman sees data as valueless to most people (as cited in Screven, 1999, p. 270). The data should be transformed, organized into a structure and illustrated so that it can take on value and be communicated with ease. Once the information is then transformed into knowledge, as in Screven's diagram, it further transforms into learning or wisdom. My conceptual framework proposes to catalog the diabetic's recorded data and transform it into information that is illustrated as maps and patterns that are organized, thereby offering representations that over time and usage would act as a visual road map for improved self-efficacy in health compliance.

Another example-perhaps even more relevant for the present purpose, since

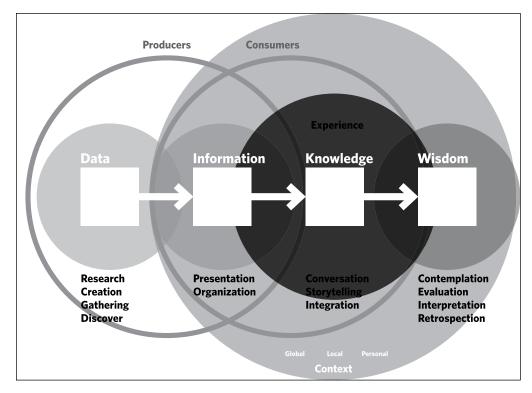


Fig. 12 Transforming data into wisdom

it carries through to action-showing the transformation of data to wisdom and into action is illustrated with Cooley's diagram (Fig. 13, next page). In the figure, the dot representing data is the starting point of the curved line. As the data transforms, it lessens in mass, forming into information, which funnels into knowledge. Once the data is transformed into knowledge, it becomes meaningful to the individual. This signals the individual can interpret the data and achieve learning that leads to wisdom. Once wisdom has been attained, the individual can take action.

The "tacit area" of Cooley's diagram is where the interaction between the data being perceived and the individual takes place. The transformation from data to wisdom and on to action can be achieved by creating experiences through interaction design (Shedroff, 1999). Interaction design studies two systems and creates a method or experience for the two systems to work with each other. For example, my proposed application would provide two levels of interaction: the first level would be the user while the second would be the human system itself (Shedroff, 1999). Interaction design creates communication by combining language, images and sound (Macy, Andersen, & Krygier, 1999). One could think of interaction design as the communication between

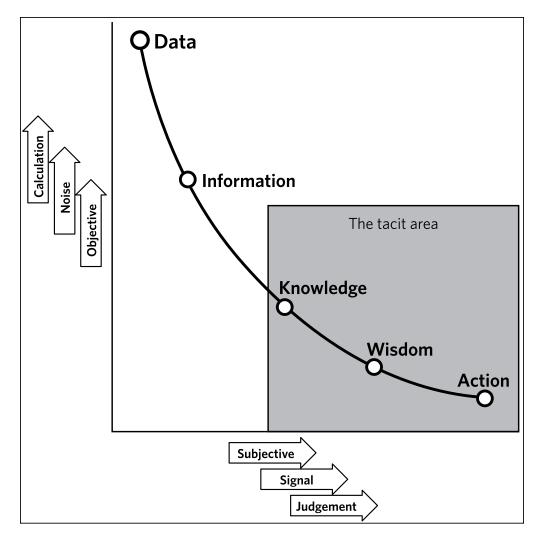


Fig. 13 Transforming data into action

a person and a handheld device. It's this back and forth communication between the person to the device that is called interaction. For example, when the device gives the user a visual message, the user can then respond to it, which then can prompt another message (Fig. 14, next page); it is a continuous cycle.

This cycle creates experiences for the participants in the form of stories or narratives that can be very meaningful. As Donald Norman puts it, "The behavior of an information processing system is not a product of the design specifications: it is a product of the interaction between the human and the system" (2004). Though the application is a complex processing system, the real design is the interaction that is created between the device and the individual. My intended application strives to create an experience for the user, from input of data to output interpretation, in the owning and

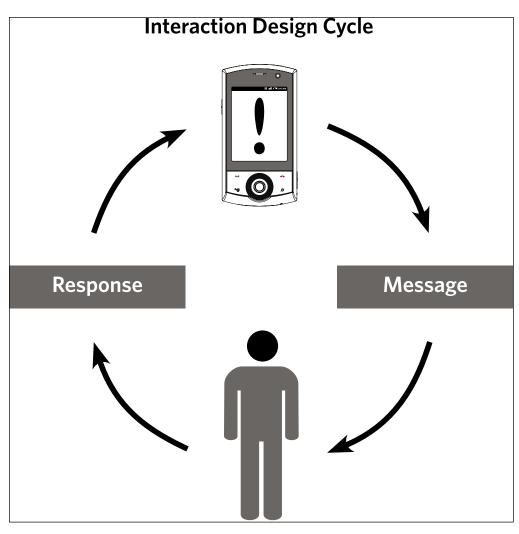


Fig. 14 Interaction Design Cycle

sharing of the visual maps produced.

The interface design will utilize different sensory methods to communicate the experience between the device and the user. Some of these features include sounds for alarms (as reminders), the use of touch technology to navigate the graphical user interface and lighted images to indicate the forward and backward steps. As Moggeridge's collection of case studies in "Designing Interactions" (2007) illustrates, interaction design is the most critical element in creating successful interactive products.

A simple design combining text and visual language such as pictographs and a number of descriptive navigational levels (like levels in a game's graphic interface) aids attentiveness to the screen culture. Too many clicks into the cyberspace may de-motivate a user to continue (as is the case with journaling by hand or digitally). As professor Mollerup of the Oslo National Academy of the Arts states, "Simplicity is a success criterion of most–if not all–serious design" (Mollerup, 2007). Driving this project has been the ever-present idea of simplicity in an interface that can be easy to learn, user friendly, accessible and smart.

3.1 APPLICATION DESIGN EXPLORATIONS

I first began my visualization design by mapping out the special features and functions illustrated in Figure 15. The four major functions for which data must be recorded are blood glucose levels, diet, exercise and medications. Keeping in mind

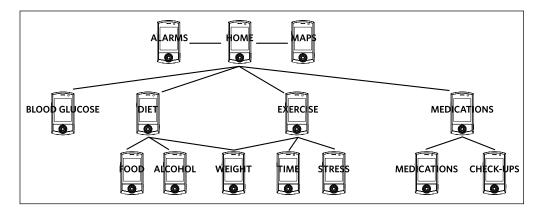


Fig. 15 Graphic user interface atlas

that literacy is an issue, the use of an icon language seems to be a good solution as a way to navigate through the levels in order to record specific data. Simply stated, my project aims to design an interface and navigation that flows intuitively with the user's needs. The iconographic language for this application is still undergoing design and testing, so some icons are more finished, while others are still sketches as research drives my design process.

Working with a small sample population proved very useful as participants provided input into the navigation design and sequence. In order to do this, prototypes, in the form of paper renditions, were printed and shown in a sequence to illustrate the navigation process. I thought it best to create software that could easily be designed for cell phones or PDAs that use touch technology. Since most individuals already carry a cell phone, with more and more of them moving to touch technology, this offers mobility to individuals to self-manage their condition. The use of touch technology offers a more tangible navigation of the interface. The user touches/selects an icon and other "road map" graphics to navigate the screen space. The user could also either use a pop-up touch screen keypad or the phone's number pad to enter data. The interface guides the user through the appropriate steps to record specific criteria. As the user navigates, the interface prompts the user with choices; once a choice is made, the device responds and guides the user to further selections.

The software/device also signals an alert when the user makes a wrong decision, thereby permitting corrections. However, the interface allows the user to be guided, rather than prompted into making decisions they don't want to make by making selections that become hard to get back to the home screen or move backwards in navigation. An important aspect of this application is its ability to be customized. Users can add new criteria that they may want to record. Another proposed feature is an artificial intelligence sensor to remind the user of his/her last location of prior usage. The application would open with a home page to orient the user to the iconography and road map metaphor. Back and home buttons would be on the top screen later as well so that the user does not become lost in the levels of information architecture.

I began with some early sketches and then moved to digital renditions (Fig. 16). An early idea for this application was based on loading onto the iPhone platform and using the same touch icon system. Though the icons in the figure are not designed,



Fig. 16 Early interface exploration

this illustrates the navigation of the user interface. I then decided to do further research into mobile device platforms and discovered that the iPhone is so heavily copyrighted that the thought of this project moving into a prototype stage on the iPhone could be years away. Further research led me to Google's new software platform called Android, which is open source.⁵ Google is the first to start an open-source platform for PDAs. As long as this application lived on Android, it would allow my application to live on multiple PDAs or phones that were Android friendly.

In leaving the iPhone behind, I found another phone with touch technology called the HTC touch. HTC has agreed to be part of Google's Android platform, though at the moment HTC currently uses Microsoft Mobile 6 software. Exploring other interface navigation, Figure 17 illustrates this. The home page allows the user to move the features in a clockwise or counter clockwise rotation. However, in testing this concept



Fig. 17 Further interface exploration

for feedback, participants expressed that the type and icons were too small and that it seemed too difficult to navigate. It was not clear where to start to navigate the space or how the user would move to the next level. At this point, my application design process began to move from the stage of explorations to that of possible solution.

⁵ Open source is a set of principles and practices on how to write software, the most important of which is that the source code is openly available. The Open Source Definition, which was created by Bruce Perens and Eric Raymond and is currently maintained by the Open Source Initiative, adds additional meaning to the term: one should not only get the source code but also have the right to use it. If the latter is denied, the license is categorized as a shared source license (Open source, 2008).

3.2 APPLICATION DESIGN SOLUTION (ONGOING)

Explorations and working with the small sample population have led me to understand the need for an interface design that is easy to follow, clear in its communication intent and with a visual language that is easily learned and interpreted. Note that this is not a finished design solution. I am still performing further testing and design explorations with my sample population before finalizing the icon designs and the interface navigation. The current concept prototype does not take into consideration the issues involved with those who have gastric diabetes.

The first action for the user would be the recording of his/her blood glucose level. As can be seen in Figure 18, this illustrates the sequencing of the interface navigation. To record the blood glucose reading, the user would first use a blood glucose meter



Fig. 18 Navigating the interface: blood glucose

to check his/her blood glucose level. Next, the user would navigate the application home screen and select the blood glucose icon which is represented as a small and simplified version of a conventional shape for a blood glucose meter. Once selected, the user would be taken to another screen with a list of options. The first option is at what time of day the reading was taken; the user would enter morning, noon, evening or nighttime. If the user is taking a reading with a meal, he/she can specify whether the reading was taken before or after the meal. Once entered by pressing the return key, the user is taken to another screen with a number pad. Next, the user can enter the blood reading taken from their blood glucose monitor by using the number pad. If the user entered the number incorrectly, he/she could press the clear key on the number pad. Once entered, the user would press the enter key on the number pad. The application would then show a screen that is it processing the information followed by a new screen that would confirm the information had been entered.

The second action for the diabetic would be the recording of diet. As seen in Figure 19, this feature is the most complicated for the user. Discussions with dietitians indicated that they require a journal of recorded diet information that is very detailed



Fig. 19 Navigating the interface: diet

and specific. In contrast, conversations with my small sample population indicated that this degree of recording is so tedious that it discourages journaling. This contradictory feedback was a design challenge in that it required simplifying the complex. The illustrated solution (Fig. 19) seems to work as a temporary placeholder, though with further testing, it could be modified or changed. In this scenario visualization, the user would select the diet icon and be taken to the recording screen. First, the user would select the meal: breakfast, lunch, dinner or snack. This next screen is the most complex of all the features. The user would select the type of food from a drop-down menu and input the number of portions using the plus and minus icons. Next, the user would use a drop-down menu to select the portion size: small, medium, large or extra large. To simplify the input of food types or the kinds of food consumed, I have thought it best to only give the user the ability to select foods from the major food groups. Otherwise, the design of this feature would be too complex for the user to enter all the required information. Men's Health Magazine mentions that even though individuals who are trying to lose weight ideally need to record everything they eat, even if they record a portion as simply small, medium, large and extra large, it is better than not recording at all (Men's Health, 2007). The design and complexity of this feature may change with more work following sample population testing and discussions with dietitians. However, there is also what might amount to an ultimate simplifier–a cross-check against diet–which is the daily recording of weight. This data also relates to exercise, and is discussed below. Also within this feature is the ability to record liquids such as juices and alcohol, which are important to self-management. These are still under development and are not illustrated here.

The third action feature is the recording of exercise. This feature takes into account the activities that would have larger affects on the individual's Basal Metabolic Rate (BMR) such as running, cycling, weight lifting, swimming etc. At this time this application will not have the features that would record low energy activities such sleeping, knitting, household activities etc. Since this application is being designed to be individually customized, these low energy activities could be added features in the future. As can be seen in Figure 20, this feature is much like that of blood glucose.



Fig. 20 Navigating the interface: exercise

Keeping the interface consistent is important to the user navigating the system. The more familiar one becomes with the software, the less additional learning is needed to navigate. The user would simply choose the minutes-of-exercise category and input

the number of minutes performed for each type of exercise. Different types of exercise icons include aerobics, running, walking, swimming, cycling and yoga, with a few more still in the drafting stage.

However, limiting the types is important so the user is not overwhelmed with too many options requiring more time to input the information. The type of exercise currently illustrated in the figure is running. To select a different type of exercise, the user would simply use the drop-down menu. The next data set is the recording of stress levels. This is still under development but is important to self-management. Studies show that mental stress can increase blood glucose levels (Diabetes Control for Life, 2008). This makes it important to track and record stress as it will have an affect on maintaining metabolic control. The third data entry is weight management, which also relates to maintaining a healthy diet as noted above. This would involve once-a-day weighing and entry of the weight number. This feature of interface navigation, like that of recording minutes of exercise, would be like that for blood glucose. Again, time entries for each of these (e.g., time of day of exercise) would be recorded.

The fourth data set is the recording of medications. As illustrated in Figure 21



Fig. 21 Navigating the interface: medication

on the next page, this follows the same interface navigation as the recording of blood glucose, etc. The user would select which medications they use by using the dropdown menu and input the number of milligrams they administer. Time of medication would, again, be recorded.

Another feature of this application is to alert and remind the user when, for example, he/she needs to take a blood glucose reading. The user can set visual and audible reminders for specific times to take a blood glucose recording. This is not illustrated but could prove a very important function in reminding the individual of certain situations for self-management.

This application is not only limited to the illustrated features above. There could be many additional features built in, such as recording subjective information: sleeping patterns, rating one's feeling, pain levels or moments of extreme thirst or dizziness. However, it is necessary to strike a balance so that there are not too many options making the software complicated and the activity of journaling cumbersome.

A final comment as to this application's functions is that the device records all of the mentioned features, saving and storing all the information so that it can be called upon by the individual and medical professionals. A future idea for this application would allow for all data recorded to serve as a digital record of the diabetic's condition. Future designs could allow the input of additional medical information such as eye exam results, blood test results performed by a doctor and time of the exams. This information would all be recorded in one place (the PDA application) to be called upon by both the individual and doctor, not only for the diabetic's family doctor but also making the recorded medical information digitally and easily transferable to specialists when there is a referral.

Future potentials for this application would be to create a widget application for desktop computers. This would allow journaling at home or in the office as an option for those who may not have or want to use the mobile application device. However, future designs could offer that all three devices—work computer, home computer and the mobile device—could be in sync with one another. With the use of current technology, this could easily be possible. The three always in sync could allow the ready sharing of information with medical professionals, friends and family. There could be endless possibilities of this application because it's created as open-source software, allowing users' medical advisors to manipulate and add features according to their needs. This

application could take advantage of new and upcoming technologies and continue to evolve. With advancing technologies in diabetes care, perhaps this software, adapted for use to type 1 diabetes, could communicate wirelessly with an insulin pump.⁶ This would allow a wireless auto-recording of blood glucose levels and of the administration of insulin, requiring no manual journaling.

3.3 OUTPUT MAPS

The output feature is a distinctly different feature of the software/PDA device. This feature would organize, simplify, make visual and establish context for the recorded diabetic information in the form of a visual map or whole view of the process of the user's condition. For example, the user and his/her caregivers could review these maps and look for patterns and trends. This would be achieved by comparing and contrasting the recorded data of blood glucose readings and minutes of exercise over a period of time such as a week–or through other forms of connection and representation, showing various relationships. The creation of maps could offer diabetics readily accessible information instead of complex information graphics.

Since the prototyping has remained at the conceptual/paper level, I am not able– at this stage of what is potentially a large software creation challenge–to present actual renditions of what the output maps would look like based on my sample population inputting data into a digital prototype. However, I have designed mock-ups with typical diabetes information to demonstrate the potential of mapping. The information needs to be represented in a way so that the user could look for patterns and trends and draw connections to, for example, eating less for breakfast due to persistently higher blood glucose levels just prior to lunch. Or due to higher blood glucose levels before lunch, one could add exercise, such as a short walk in between breakfast and lunch to burn up the caloric intake accumulated at breakfast. Most diabetics need to try different patterns in diet, exercise and administering medications in light of variations in blood

⁶ An insulin pump is a medical device used for the administration of insulin in the treatment of diabetes mellitus. The insulin pump is an alternative to multiple daily injections of insulin by insulin syringe or an insulin pen and allows for intensive insulin therapy when used in conjunction with blood glucose monitoring and carb counting (Insulin pump, 2008).

glucose readings. It is this back-and-forth system of checks and balances that makes self-management vital to the health of type 2 diabetics. For those who do not journal, information as to what they ate, what they weighed, how long they exercised, or how many milligrams of medication they took would often-perhaps nearly always-be forgotten and lost.

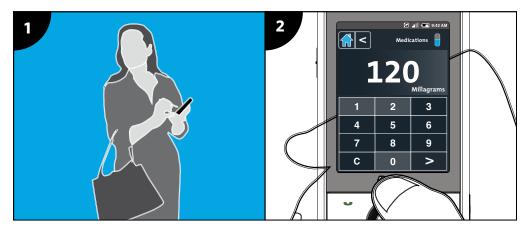
Following are two fictitious scenarios that I have designed that illustrate, one very simply and one in a somewhat more complex form, how output maps might translate the application into action for someone with diabetes. These scenarios also take into account feedback received from my sample population that helped me assess their goals and behaviors but do not describe any individual.

Angela

Angela is a 32-year-old type 2 diabetic who works as a secretary for a small business firm. Angela's concerns are:

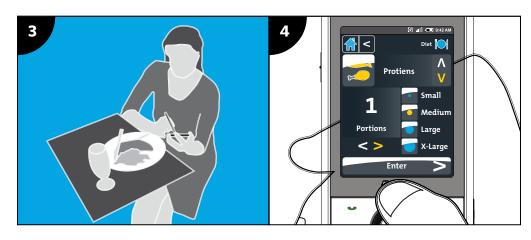
- Mobility: she is always on the go, no time to manage her diabetes
- Too busy: she should take more time to track and record her condition, but journaling in the form of a handwritten journal is too hard
- Forgetful: she needs to journal her condition, otherwise she forgets, which causes miscommunications with her doctor

The following sequence of illustrations demonstrates the application in action against the background of these concerns



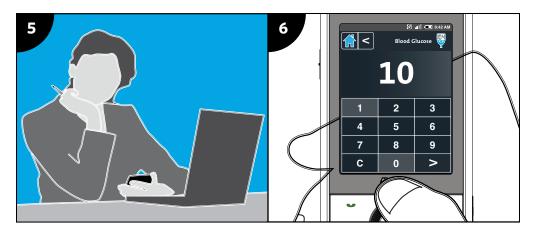
As Angela is rushing for work, she is unable to have any breakfast. She quickly grabs her medications and takes them.

Once she has taken the medications, she grabs her diabetes PDA guide and quickly records the medications she just took by selecting the type of medications and then inputting the time of day and milligram amount. Once the data is finished recording, she then puts her diabetes guide into her purse.



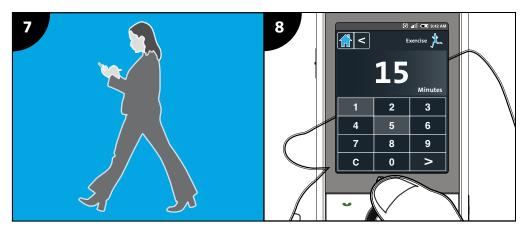
At 12:00 p.m., Angela decides to get some lunch. Before she eats, she checks her blood glucose level. It appears to be fine, and she records the blood glucose entry into her diabetes PDA guide along with the time of day.

She also records what she is about to eat in case she needs to recall the information later.



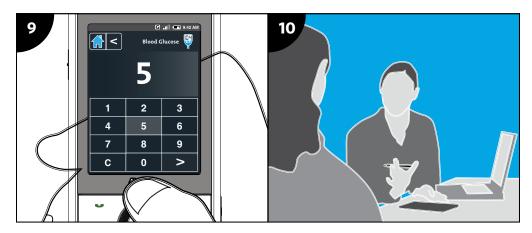
As the clock strikes 3:00 p.m., Angela realizes that it has been two hours since she ate and decides to check her blood glucose level again.

The meter gives a reading of 10. This is too high and not within her target range of 4–7. She enters the reading and time into her diabetes PDA guide and ponders as to how to bring her blood glucose level back to her target.



Since 3:30 p.m. is her afternoon break, Angela decides to get a little exercise to help bring her blood glucose level back down. She decides to take a 15-minute stroll outside.

As she walks, she quickly records the minutes of exercise and the type of exercise so she can see if this makes a difference in bringing her blood glucose level back down.



Angela checks her blood glucose before having dinner at home, and the metered reading is a 5. Angela is back in her target. She then enters it into her diabetes PDA guide.

The next week, Angela meets with her doctor and explains that she noticed a high reading and thought she would try something new (a stroll during her break) to bring the level back within target. Angela then showed the steps by outputting a map created by her diabetes PDA guide. The doctor was delighted that Angela was able to try something new and was thankful to see her progress. Upon reviewing other data that Angela had journaled throughout the week, her doctor then understood what she had been going through and offered some other suggestions.

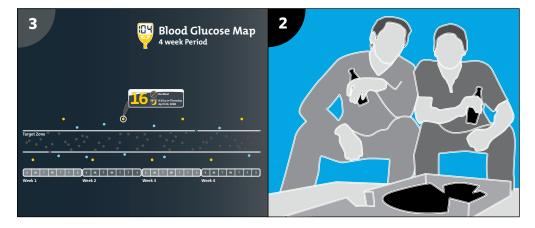
The behaviors and connections illustrated from panels 1-9 for Angela can easily be set out in a map (not provided here at this stage). In this case, the linkages are so straightforward that Angela may be aware of the connections before actually creating a map, and the latter would be helpful mainly to make a record and inform her doctor.

Daniel

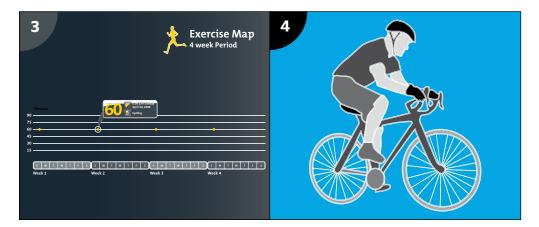
Daniel is a 53-year-old salesman and type 2 diabetic. Daniel's concerns are:

- Confused: he is always confused as to how to manage his diabetes
- Loves junk food: eating junk food too often makes his blood glucose levels off target
- Likes to exercise: too much exercise can lower his blood glucose levels

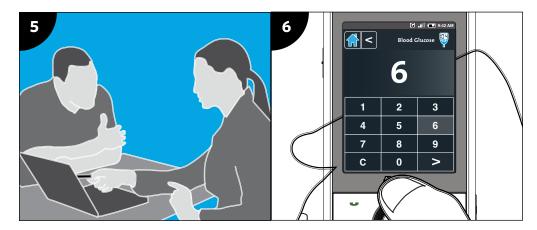
Again, the following sequence of illustrations demonstrates the application in action against the background of these concerns.



Daniel has been journaling his condition for one month now, using his diabetes PDA guide. He creates a map to see his progression of his recordings of blood glucose. He notices that over the course of the month, there is a pattern of high blood glucose readings every Thursday evening before bed. He also sees a pattern of low blood glucose readings every Monday morning. He then wonders what could have caused this. Daniel thinks back and realizes that every Thursday evening, he gets together with his friends and watches the ball game. While they watch the game, they usually order in pizza and cola, which would make this the likely reason for the high blood glucose readings.



Daniel wonders what could have caused the Monday morning pattern of low blood glucose. He knows that he is eating a healthy meal at dinner Sunday evening, so that should not affect his blood glucose level. He decides to output a map of exercise and his blood glucose readings to see if there are any comparisons. He notices on the new map that the low blood glucose reading Monday morning is a few hours after he performs his weekly exercise Sunday evening. Every Sunday evening after dinner, Daniel goes cycling for about 60 minutes, but he is confused whether this would affect his blood glucose level. Daniel doesn't know what to do to get his blood glucose back within target. Not knowing what to do, Daniel decides to make an appointment with his doctor.



Meeting with his doctor, Daniel asks how he can keep doing the activities he loves and get his blood glucose back within target range. Reviewing the output maps and hearing Daniel's interpretation of the possible reasons for his repeating pattern of high and low blood glucose levels, his doctor offers a few suggestions. His doctor determines that Daniel's levels are high on Thursday nights due to eating unhealthy foods and that his levels are low Monday morning due to too much exercise. Daniel's doctor makes a suggestion that instead of exercising for a full hour Sunday, he might cut it back to 30 minutes, which might bring his Monday morning blood glucose level within target range. Then he mentions that to make up the lost 30 minutes of exercise on Sunday, Daniel might transfer 30 minutes of cycling or the equivalent to Thursday evening after the ball game, which might help in bringing Thursday night's blood glucose reading back into range. Daniel's doctor urges trying these suggestions out and seeing what happens. If there is no change in the pattern, the doctor suggests he should come see her again to reevaluate and offer other adjustments to his situation. His doctor tells him to keep up the good work, and he is happy Daniel is continuing to journal to see patterns. The illustrated scenarios offer insight into self-management for diabetics. The easy-to-use journaling application with output mapping software as the example seen in Figure 22, allows individuals to look for related patterns and trends and see

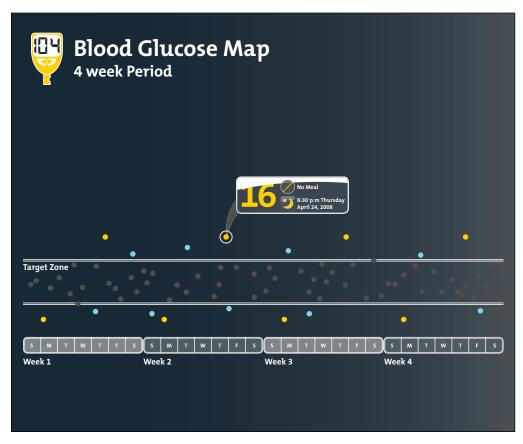


Fig. 22 Blood Glucose Map

connections, and offers a method to problem solve, trying new lifestyle changes and learning something new in order to meet the needs in self-management. Output mapping also allows individuals to share their information in a form that is readily and quickly accessible with their doctor. This puts both on the same page, allowing them to brainstorm and problem solve, trying out alternatives that might work in maintaining glycemic control. By producing these maps, individuals have greater ownership over their condition, which might allow for increased self-efficacy.

3.4 CONCLUSION

While focused on type 2 diabetes, the alternative approach to self-management systems that is discussed in this paper is one that has potential for many other conditions that require self-management over long periods of time, such as high blood pressure, morbid obesity, gout or HIV/AIDS–and, of course, with some modifications (such as the need to keep track of insulin injections), for people living with type 1 diabetes.

Ultimately, the present paper may be thought of as an effort to respond to some of the researched inadequacies of doctor-patient communication by attempting to bring design knowledge-in the context of rapidly developing information and communication technology-to bear on the perception that for some, many doctors and patients are not on the same page in terms of understanding and applying treatment protocols. The proposed application tries to mediate the patient/doctor communication dynamic in the form of a visual intervention. This is important for self-efficacy as the communication gap dissonance can play special havoc when there is a medical condition that is both long term and potentially life threatening if self-management fails.

A single master's thesis, of course, cannot do more than set the problem and give, hopefully, a sense of how design approaches, and the latest information technology, might have a major role in contributing a solution. To carry significantly beyond this point probably requires the labors not of a single individual, but of large organizations, private or public, that become aware of this fundamental problem and of the likelihood that solutions exist. The next steps seem to involve the engagement of such organizations in supporting an effort that should involve collaborations of various discipline: medical science, information technology, design, software development and perhaps others.

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Living with Diabetes Study				
LETTER OF INVITATION				

[Date here]

Dear [Prospective Participant],

I would like to invite you to be part of a research project that I am conducting. This project is part of the requirement for a Masters of Applied Arts degree in design, at Emily Carr Institute of Art and Design. My name is Nathan Winkel and my credentials with Emily Carr Institute of Art and Design can be established by calling Dr. Monique Fouquet Vice-President of Academic at 604-844-3865.

The objective of my research project is to attain specific information pertaining to living with diabetes. In addition to submitting my final essay to Emily Carr Institute of Art and Design in partial fulfillment for a Masters of Applied Arts in design degree, I will also be sharing my research findings with possible medical practitioners and publications.

My research project will consist of an in person interview consisting of open-ended questions and is foreseen to last approximately 30 minutes. For foreseen questions that will be asked ,please refer to the attached sample questions sheet.

Your name was chosen because of your experience of diabetes.

Information will be recorded in hand-written and audio-recorded format and, where appropriate summarized, in an anonymous format (number and letter codes for example: Subject 2B), in the body of the final report. At no time will any specific comments be attributed to any individual unless your specific agreement has been obtained beforehand. All documentation will be kept strictly confidential.

A copy of the final essay will be published and housed at the library of Emily Carr Institute of Art and Design, available online through databases and the Theses Canada portal and will be publicly accessible. Access and distribution will be unrestricted.

Please feel free to contact me at any time should you have questions regarding the project and its outcomes. Attached with this invitation is an Abstract of the project which summarizes the projects intent.

You are not compelled to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

If you would like to participate in my research project, please contact me at:

Nathan Winkel nathanwinkel@mac.com 604 357 3724 (Work) 778 840 5053 (Cell)

Sincerely,

Letter.of.invitation.revNov01.2007



1. RESEARCHER'S NAME AND CONTACT INFORMATION

Nathan Winkel 203 - 1 East Cordova, Vancouver, BC V6A-4H3 Work: 604-357-3724 nathanwinkel@mac.com

2. SUPERVISOR'S NAME

Deborah Shackleton

3. PROGRAM:

Masters of Applied Arts in Design

4. TITLE OF PROJECT

Medical Mapping Methods: Design interactions for self-care

5. TYPE OF PROJECT

___ Class Project X Thesis.

6. PURPOSE OF RESEARCH

To gain a better understanding of self-care methods employed by those living with diabetes. To understand literacy issues associated with diabetic self-care compliance. To explore new methods for improving self-care of diabetes. To explore how interaction design can improve self-management and patient efficacy.

7. POTENTIAL BENEFITS AND RISKS:

Minimal risk — See Tri-Council for more information

8. HOW WAS RESPONDENT CHOSEN

Respondent was chosen because of their knowledge of Diabetes.

9. WHAT WILL RESPONDENT BE ASKED TO DO

Respondent will be asked questions pertaining to their illness, more specifically how they self-manage their illness.

Respondent will beta-test a paper prototype of the new proposed journaling application.

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10. WHO WILL HAVE ACCESS TO RESPONDENTS' RESPONSES

Only the Principal Investigator - Nathan Winkel.

11. VOLUNTARY NATURE OF THEIR PARTICIPATION (INCLUDING PARTICIPANT'S RIGHT TO WITHDRAW AT ANY TIME):

No one knows whether or not you will benefit from this study. There may or may not be direct benefits to you from taking part in this study.

12. WHETHER THERE IS REMUNERATION FOR PARTICIPATION (REMUNERATION SHOULD NOT BE REDUCED IF PARTICIPANT WITHDRAWS):

Participation in this research is entirely voluntary. Participant may withdraw from this study at any time. If participant decides to enter the study and to withdraw at any time in the future, there will be no penalty or loss of benefits to which the participant are otherwise entitled, and their care will not be affected.

13. HOW ANONYMITY AND CONFIDENTIALITY ADDRESSED

Participant confidentiality will be respected. No information that discloses participants identity will be released or published without their specific consent to the disclosure. Participants name will not be used in this study. The participant will be identified by code numbers and letters only.

15. HOW INFORMATION IS STORED AND FOR HOW LONG

Information will be stored on principal investigators computer with encrypted access. All paper documents will stored in a safe and secure filing system. The date that the study is completed all data will be destroyed in one years time (deleting of all computer files including back-ups and shredding of all paper documents), unless consent by you is given.

16. NAME AND PHONE NUMBER OF PERSON TO CONTACT IN CASE QUESTIONS ARISE

If you have any questions or desire further information about this study before or during participation, you can contact principal investigator: Nathan Winkel at 604-357-3721 (Work), 778-840-5053 (Cell) nathanwinkel@mac. com or Emily Carr representative: Dr. Monique Fouquet Vice-President of Academic at 604-844-3865.

17. HOW TO GET COPY OF RESEARCH RESULTS?

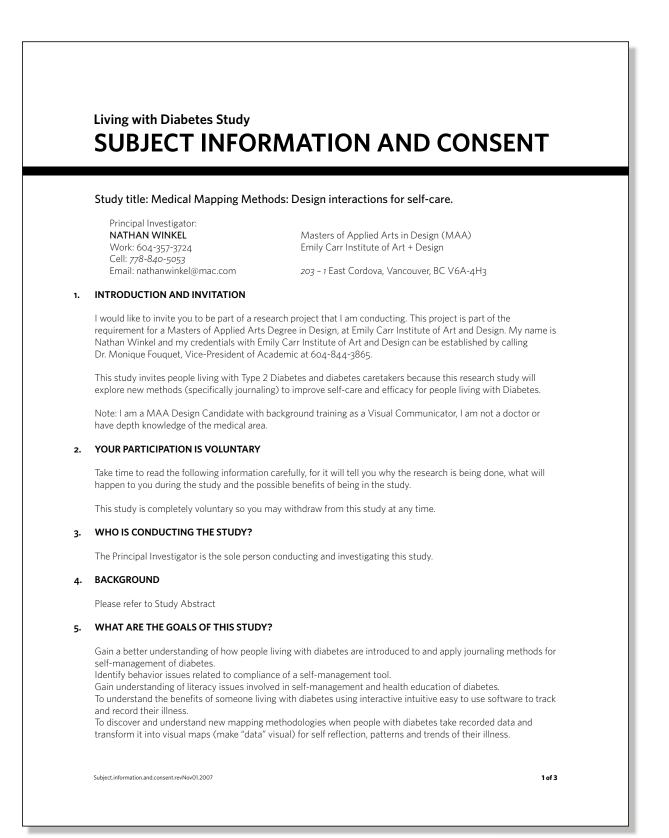
A copy of the final essay will be published. A copy will be housed at Emily Carr Institute of Art and Design, available through the library and online through the Emily Carr Institute of Art and Design databases and the Theses Canada portal and will be publicly accessible. Access and distribution will be unrestricted.

18. NAME AND PHONE NUMBER OF PERSON TO CALL FOR MORE INFORMATION:

Principal Investigator - Nathan Winkel 778 840 5053

ANY COMPLAINTS ABOUT THE PROJECT SHOULD BE DIRECTED TO THE OFFICE OF THE VICE-PRESIDENT, ACADEMIC, 604.8344.3865 OR BY EMAIL: MISBERG@ECIAD.CA

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6. WHAT DOES THE STUDY INVOLVE?

The first study would be to meet and chat about your diabetes lifestyle. The format would be free form with some questions framed depending on each persons needs.

The second study entails the testing of a paper prototype of the proposed application. We will be looking for usability, suggestions, and improvements that can be made to the application to meet user specific needs. This would consist of a workshop allowing you to test and try out the application.

The input criteria for the journaling application could include

 Quantitative information:
 Quantitative information:
 Quantitative information:

 Glucose levels
 Still

 Insulin doses
 De

 Diet
 Stell

 Exercise
 Fe

 Medications
 Portion sizes

 Alcohol consumption
 Stell

Qualitative information: Stress Depression Sleep Patterns Feeling Rating

• You can choose to take part in one or more of the studies.

7. WHAT ARE THE BENEFITS AND COSTS OF PARTICIPATING IN THIS STUDY?

No one knows whether or not you will benefit from this study. We hope that the information learned from this study can be used in the future to benefit other people with a similar disease.

You will not be paid for participating.

8. AFTER THE STUDY IS FINISHED

A copy of the final essay will be published. A copy will be housed at Emily Carr Institute of Art and Design, available through the library and online through the Emily Carr Institute of Art and Design databases and the Theses Canada portal and will be publicly accessible. Access and distribution will be unrestricted.

9. WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

No information that discloses your identity will be released or published without your specific consent. Your name will not be used in this study. You will be identified by code numbers and letters only. Information will be stored on one single computer with encrypted access. All paper documents will stored in a safe and secure filing system. The date that the study is completed all data will be destroyed in one years time (deleting of all computer files including back-ups and shredding of all paper documents), unless consent by you is given.

10. WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?

If you have any questions or desire further information about this study before or during participation, you can contact Principal Investigator: Nathan Winkel at 604-357-3721 (Work), 778-840-5053 (Cell) nathanwinkel@mac. com or Emily Carr representative: Dr. Monique Fouquet, Vice-President of Academic at 604-844-3865.

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11.	SUBJECT	CONSENT TO	D PARTICIPATE
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I have read and understood the subject information and consent form.

I have had sufficient time to consider the information provided and to ask for advice if necessary. I have had the opportunity to ask questions and have had satisfactory responses to my questions. I understand that all of the information collected will be kept confidential and that the result will only be used for scientific objectives.

I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time.

I understand that I am not waiving any of my legal rights as a result of signing this consent form.

I understand that there is no guarantee that this study will provide any benefits to me.

I have read this form and I freely consent to participate in this study.

I have been told that I will receive a dated and signed copy of this form.

SIGNATURES

Printed name of participant	_		
Signature	_ Date		
Printed name of witness	_		
Signature	_ Date		
Printed name of principal investigator			
Signature	Date		

In case you have concerns with this study you can contact Dr. Monique Fouquet of Academic at 604-844-3865.

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Living with Diabetes Study SAMPLE QUESTIONS	
What are some of the ways in which you self-manage diabetes?	
Is journaling a method in which you have considered?	
If so, how do you go about recording your day to day information? Do you record information using hand written paper sheets or do you journal using a computer applications or both?	
What are some of the criteria that you journal? Blood glucose and diet or other information?	
How often do you journal? I understand that journaling can be quite tedious. Per day, week, or month?	
Do you share journaled information with your doctor? Or, do you journal just for yourself.	
Does your doctor review your journal with you?	
Do you gain any benefit from journaling, please explain.	
Do you notice any patterns and trends as you view your journal that could help in your management of diabetes?	
Do you try new things in your diet as you review and keep track of your journal to see what works best for you?	
Sample questions.revNov01.2007	
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