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Katherine S Blondon

The potential of improving care in diabetes through mobile devices,  
patient empowerment and financial incentives

Katherine S Blondon

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Reading Committee:

Wanda Pratt, Co-Chair

James D. Ralston, Co-Chair

Paul L. Hebert

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University of Washington

**Abstract**

The potential of improving care in diabetes through mobile devices,  
patient empowerment and financial incentives

Katherine S Blondon

Co-Chairs of the Supervisory Committee:

Professor Wanda Pratt  
Information School  
Division of Biomedical Informatics and Medical Education

Affiliate Assistant Professor James D Ralston  
Department of Health Services  
Division of Biomedical Informatics and Medical Education

**Introduction:** The rapid adoption of smartphones and the increasing prevalence of diabetes have led to the growing interest in use of mobile devices to support diabetes self-management. In my dissertation, I present three studies to explore how smartphones can be used for diabetes management. The first study focuses on the reach of smartphones in the diabetic population, and (1) compares smartphone use in individuals with diabetes to those without diabetes, and (2) explores predictors of smartphone use among those with diabetes. Although many applications have been developed for diabetes, no reports have described smartphone use among individuals with diabetes, nor explored the characteristics of the smartphone users.

Smartphone applications offer a large range of features to support diabetes. In the second study, I seek to understand how individuals with diabetes use smartphone applications to support their diabetes self-management. In particular, I focus on how needs for supportive technology evolve over time as both diabetes and diabetes self-management change with time.

Finally, I explore the use of financial incentives to drive behavior change in diabetes. Patient incentives are increasingly used to increase patient engagement in health and wellness, but have not been well studied in diabetes. In the third study, I examine the

acceptability of financial incentives to improve diabetes self-management among patients and providers.

**Results:** In the first study, I found that individuals with diabetes are less likely to use smartphones than those without diabetes, even after adjusting for age, race/ethnicity and socioeconomic factors. In my results, smartphones bear potential in reaching racial ethnic minorities who also have a higher prevalence of diabetes, as smartphone use is higher among Blacks, Asians and Hispanics. As expected, young age, high income and high education are also associated with higher smartphone use among individuals with diabetes.

In the second study, I found that diabetes self-management can be framed in three stages: an initial stage (after diagnosis), a stabilization stage and a response to change stage. Many of the tracking features guide individual learning and are particularly useful in the initial stage. After creating habits, however, these features become less useful the benefits of the tedious tracking diminish during the stabilization phase. Finally, when changes occur, transitory tracking is useful to recalibrate treatments and return to the stabilization stage.

In the third study, participants liked the idea of financial incentives and expected them to be useful in helping them take the small steps for behavior change. They also expected rewards to help acknowledge the constant efforts made for self-management. Yet participants also raised concerns for equity and privacy when using incentives.

**Conclusions:** Compared to individuals without diabetes, those with diabetes were less likely to use smartphones in our study. This gap in smartphone use has the potential to increase disparities in diabetes care, and suggests that standard diabetes care needs to be pursued while other studies are needed to confirm and explore this gap. Future applications for diabetes need to address long-term management of diabetes, as the needs in supportive technology changes over time. Although financial incentives seem acceptable, many unresolved issues including equity and privacy still need to be addressed for the design of incentive programs. In particular, careful consideration is needed to avoid undesired consequences of decreased intrinsic motivation.

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\* Include those using both smartphone and landline phone

### 1.1 Overview

My interest in smartphone use for diabetes management arose from the desire to engage patients actively in their self-management, with a resource that could provide guidance and reminders to monitor their health. As I discovered the smartphone features allowing data collection and visualization, as well as rapid email and Internet access, I realized how much smartphones—with their ubiquitous nature—could contribute to patient engagement. Diabetes is an ideal chronic condition to focus on, because it is common, requires a range of lifestyle changes and has well-established recommendations for care. Self-management of diabetes includes many daily choices and healthy behaviors, and necessitates strong motivation and engagement from the patient. Growing evidence supporting the use of smartphones for diabetes self-management has led me to seek a better understanding of *how* smartphones can drive motivation and patient engagement to improve diabetes self-management and *who* can benefit from this technology.

The rapid adoption of smartphones and the increasing prevalence of diabetes have led to the growing use of mobile devices to support diabetes self-management. Recent studies are beginning to show the benefits of smartphones for diabetes management. Yet individuals with diabetes are older than the average population, and market studies show lower adoption rates for smartphone with older age. It was therefore uncertain whether the encouraging results of these studies could be generalized to the overall population with diabetes. In Chapter 2, I will explore the current use of smartphones in a diabetic

population, based on a nation-wide survey. As healthcare moves towards a higher use of mobile devices to support patients' self-management, understanding the current reach of these devices can guide patient care and future diffusion of this technology. Furthermore, better knowledge of the users characteristics can help tailor the design of mobile applications to accommodate age-related or disease-specific needs.

Diabetes self-management includes self-monitoring of various health parameters, increasing physical activity, keeping a low carbohydrate diet and taking medications. Most diabetes-related applications focus on self-monitoring of blood glucose and dietary carbohydrates through tracking and data visualization tools, and allow sharing of data. Smartphones provide an opportunity to customize the supportive technology to each user's needs. The evolution of diabetes differs between individual, and leads to different needs for support. In Chapter 3, I will explore patient needs at different stages of disease and propose some ways to provide support for the needs of diabetes self-management.

One of the difficulties in behavior change is maintaining motivation until the behavior becomes a new habit. Successful diabetes self-management requires several behavior changes, and requires making the right choices throughout the day, every day. One of the innovative approaches to behavior change in diabetes self-management is the use of financial incentives to support these daily challenges and help drive motivation. In Chapter 4, I explore the acceptability and perceptions among patients and providers of using financial incentives to improve diabetes self-management.

Finally, I will discuss the implications of all my findings for the use of smartphones in diabetes self-management in Chapter 5. Although smartphones have the potential to reach

a population with lower access to high quality care in diabetes, determining the current reach and trends should guide future research involving smartphones for individuals with diabetes.

Smartphones offer a unique approach to many of the challenges individuals face in diabetes self-management through customized support adapted to needs at different stages of disease. In particular, the use of financial incentives to drive behavior changes in diabetes can be facilitated through smartphones, with careful considerations given to maintain privacy and equity.

## **1.1 Background**

I will provide an overview of diabetes and explain why I believe smartphones have great potential in reaching this population. I will then review behavior change theories because lifestyle changes are a large component of diabetes self-management, and review how smartphones can be supportive in diabetes self-management. I will focus on one innovative approach to behavior change—the use of financial incentives, particularly through the use of a smartphone.

### **1.1.1 Diabetes mellitus**

Diabetes mellitus is a chronic disease that affected 25.8 million people (8.3% of the population) in the U.S in 2010. Type 2 diabetes accounts for more than 90% of the individuals with diabetes, whereas type 1 accounts for 5-10 percent.(McCulloch 2012) The prevalence of diabetes has increased by 9.3% from 23.8 million in 2007.(ADA) 2012) This rising prevalence is closely associated with the epidemic of obesity: more than 85% of

individuals with type 2 diabetes are overweight, and more than half are obese.(2004) Prevalence of diabetes is higher among Blacks and Hispanics (12.6% among the non-Hispanic Blacks and 11.8% of Hispanics) and increases with age (3.7% in the 20-44 years old group, 13.7% in the 45-64 year old group and 26.9% in those over 65 years old).((ADA 2012)

Diabetes is associated with many complications and comorbidities. Diabetes increases the risk of cardiovascular events (macro-vascular complications) in all patients and is the first cause of blindness among adults age 20-74 years old. It is the leading cause of kidney failure and amputations in the U.S. (micro-vascular complications).((ADA 2012) Successful diabetes management requires a range of lifestyle changes. Regular screening and monitoring, smoking cessation and aggressive management of hypertension and hyperlipidemia can help delay the onset of these complications.(1993; Yudkin 1993; 2012; Inzucchi, Bergenstal et al. 2012) Management strategies also include improving lifestyle behaviors such as increased physical activity levels and improved diet. Studies have shown that only 7% of adults with diabetes succeed in following all the recommendations for optimal management (good glycemic control, diet, physical activity, medications adherence and disease monitoring).(Deakin, McShane et al. 2005) Self-management of type 1 diabetes and type 2 diabetes are largely the same, with the notable exception of self-monitoring of blood glucose in individuals with type 2 diabetes who are not on insulin.(Ali, Bullard et al. 2012) In these patients, the evidence for self-monitoring to improve glycemic control is limited,(1998; Mogensen 1998) and therefore, many patients with non-insulin dependent diabetes do not self-monitor their blood glucose levels.

Suboptimal diabetes self-management leads to hospitalizations and complications, and higher healthcare costs. High costs and rising prevalence make diabetes an important Public Health target for improved outcomes and prevention. Diabetes is the second most costly chronic disease in the U.S.(2008; (ADA) 2012) where chronic diseases alone account for 75% of healthcare costs,(Anderson 2010) or 99% of Medicare costs.(Medicine 2012) People with diabetes have medical expenditures that are over 2 times that of those who do not have diabetes.(Prevention 2011; (ADA) 2012; 2013) About \$1 in \$5 healthcare dollars in the United States is spent caring for someone with diagnosed diabetes, while approximately \$1 of \$10 health care dollars is attributed to diabetes.((ADA) 2012; 2013) Engaging patients to be more involved in their diabetes management can lead to better health outcomes and ultimately lower healthcare costs.(Moran, Burson et al. 2011)

### **1.1.2 Mobile devices and diabetes**

Many available smartphone applications are specifically developed for diabetes self-management,(Chomutare, Fernandez-Luque et al. 2011) some of which allow the user to export their results to their care-providers. Moreover, knowing that their providers will look at their between-visit results (e.g. blood glucose or blood pressure) can motivate patients to track their health parameters more regularly. Mobile applications can provide guidance in changing behaviors, through suggestions for small changes, for example. They can also include various reward systems, with adjustable goals and immediate feedback. A recent meta-analysis showed encouraging results of both web-based and non-web-based mobile use in diabetes management, with one study showing an additional decrease in HbA1c of 1.2% over 1 year with a mobile application compared to usual care.(Liang, Wang

et al. 2011; Quinn, Shardell et al. 2011) The uptake of smartphones has been rapid across all age groups, particularly among the 55-64 year olds,(Nielsen 2011) and among the non-white population (ex: 67.3% of Asians mobile subscribers use smartphones vs 44.7% Whites).(Nielsenwire 2012) Diabetes is more prevalent among some groups with higher smartphone users, such as racial and ethnic minorities (table 1), suggesting that smartphones could be a new approach to improve diabetes self-management and prevention in this subgroup.

Table 1.1: Diabetes prevalence, projected new diabetes cases and smartphone use by age group

Age group	Estimated percentage of people aged 20 years or older with diagnosed and undiagnosed diabetes*	Estimated number of new cases of diagnosed diabetes among people aged 20 years or older**	Penetration of smartphone use *** of (% mobile subscribers)
20-44 years	3.7%	465,000	25-34 years: 62% 35-44 years: 53%
45-64 years	13.7%	1,052,000	45-54 years: 39% 55-64 years: 30%
Over 65 years	26.9%	390,000	18%

\*United States, 2005-2008 National Health and Nutrition Examination Survey

\*\* United States, 2007-2009 National Health Interview Survey estimates project to year 2010

\*\*\*Market study data from Q3, 2011

The smartphone’s “coolness factor,” its perceived usefulness and its ease of use have contributed to its rapid uptake use in the general population, in spite of its higher cost (compared to feature phones). Rogers’ theory of diffusion of innovation seeks to explain how innovations are adopted in a population.(Rogers 1995) Rogers segments the population into five groups, based on their propensity to adopt a given innovation, with

considerable differences in their characteristics: innovators (2.5% of the population), early adopters (13.5%), the early majorities (34%), late majorities (34%) and laggards (16%). Innovators are a tiny group of people who like to spend energy and time trying out new ideas and technologies. Early adopters jump in when the benefits start to become apparent: they have time and money to invest, tend to be younger than the majority and enjoy getting an advantage over their peers. The majorities, early and late, are risk averse and sensitive to cost, and are only willing to consider an innovation when they hear about successful experiences of peers. The late majority is uncomfortable with innovation: they fear not fitting in, or being associated with the laggards. Finally, the laggards are the older minority who will resist change until the end.

Although the older adults are getting more involved in Internet and smartphones, patterns of smartphone use among older adults with diabetes still remain unclear. Diabetes is more prevalent with increasing age, ((ADA) 2012) yet older adults do not adopt technology rapidly. Moreover, older individuals face additional challenges to using mobile technologies, with physical disabilities due to impaired eyesight, hearing or dexterity, for instance, and mental disabilities with decreased cognitive function. In Chapter 2, I explore the reach of mobile technology through a nationwide survey, particularly among individuals with diabetes to gain insight into the potential reach of mobile technology for diabetes self-management.

### **1.1.3 Diabetes self-management and behavior change**

Lifestyle behaviors play an important role in the prevention and management of diabetes, yet they are hard to implement and even harder to maintain. High blood glucose levels do

not necessarily lead to perceivable symptoms, for instance, so motivation to lower glucose values through a low-carb diet might be weak. In particular, behavioral economics suggests that failures to adopt healthy behaviors could be a reflection of “present bias” or temporal discounting, which is a tendency to value small immediate rewards over large rewards in the distant future.(Logue 2000) Having an appropriate understanding of the underlying disease processes can help motivate behavior changes, and can increase self-efficacy. *Perceived self-efficacy* is the belief that a person has about their capabilities to accomplish certain levels of performance or tasks.(Bandura 1977; Benight and Bandura 2004) If, for instance, individuals use the results of blood glucose testing as feedback for their dietary efforts, they would have rapid feedback to adapt and bolster their motivation for the new diet. Higher patient involvement for self-management can lead to better health outcomes, improved care coordination and ultimately lower healthcare costs.(Moran, Burson et al. 2011)

Among the various models of behavior change, Bandura’s model of self-efficacy has been well studied for diabetes self-management.(Anderson, Funnell et al. 2000; van der Bijl and Shortridge-Baggett 2001) Bandura’s theory on self-efficacy predicts that the expectation of personal mastery (self-efficacy) and success (outcome expectation) determine how a person will behave.(Bandura 1977) Self-efficacy theory affects human behavior through four processes: cognitive, motivational, affective and selection processes.(Bandura 1977; van der Bijl and Shortridge-Baggett 2001) Cognitive processes are used to set goals according to the perceived self-appraisal of capacities. Motivational processes involve an individual’s anticipation of the outcomes of the prospective actions, and are influenced by intrinsic internal cues, and extrinsic, environmental, task-related cues. Affective processes

will affect how an individual copes with failures and successes, and selection processes guide choices of behavior and environment that will shape career and future development of capacities and skills.(Bandura 1977; Bandura 1990; Bandura, Caprara et al. 2003; Bandura 2004; Benight and Bandura 2004)

Other health behavior models integrate different concepts in diabetes self-management. The Theory of Planned Behavior (TPB) integrates self-efficacy with the notion of *self-control*, which is the perceived ease or difficulty to accomplish a task.(Schifter and Ajzen 1985) This theory also has a notion of a subjective norm, which can also influence the intention to change behaviors. Schwarzer presents the Health Action Process Approach (HAPA), which is a 2-part model, with a motivation and action component, explicitly including the issue of *maintenance over time*.(Schwarzer, Lippke et al. 2011) In this model, motivation is driven by the perception of risk and expected outcome, which will influence the intention to act or change behavior. This intention will in turn affect the planning of both action and coping, using task self-efficacy, and result in goal-setting. The action component, or goal-pursuit, uses two different types of self-efficacy: one to maintain the change, and the other to recover from errors and slips along the way. These two types of self-efficacy in turn then influence the control of action and the action itself over time. This model also describes barriers or resources—such as social support for the intent to change, the actual change and the maintenance/recovery over time.

Self-efficacy for diabetes self-management evolves over time and allows individuals to adapt to the progression of diabetes. Some individuals with type 2 diabetes develop a need for insulin treatment at later stages of disease, for example. The need for supportive technology might therefore also evolve with both self-efficacy and disease progression over

time. In Chapter 3, I explore how the participants' needs and use of supportive technology change over time. Current applications for diabetes tend to focus on tracking features, particularly of glucose and carbohydrates. Although these tools might be useful at early stages of disease, they might become tedious and less useful later in the disease. User needs should be given high consideration for the future design of diabetes applications, and my findings of user needs in Chapter 3 will inform future designs.

#### **1.1.4 Financial incentives for patients**

One approach to implementing and maintaining behavior change is through incentive programs for diabetes self-management. Patient incentives are increasingly used to increase participation and engagement in health and wellness, with nearly 90% of employers offering reward programs for health.(Sutherland, Christianson et al. 2008; Serxner 2013) Financial incentives, defined here as an amount that the patient receives contingent to a performance (as opposed to reduced costs, or cost-sharing) have been used to influence behavior changes.(Jeffery, Wing et al. 1998; Kane, Johnson et al. 2004; Volpp, John et al. 2008; Volpp, Troxel et al. 2009; Cheng, Lee et al. 2012) Incentives can be funded externally (insurance plans or employers) or self-funded. Although more research is needed, the effectiveness of patient incentives could be due to their ability to overcome the present bias by moving the rewards of healthy behaviors forward in time, serving as a proxy for the long-term outcomes. Furthermore, financial incentives are effective for repetitive, tedious tasks. Many tasks in diabetes self-management can be perceived as tedious, particularly when people do not see an immediate benefit from their actions. Incentives are powerful tools that can improve adherence to health assessment, smoking

cessation,(Sigmon and Patrick 2012) disease management (Volpp, John et al. 2008) and weight loss,(Volpp, John et al. 2008) especially if combined with or encouraging intrinsic motivations. Intrinsic motivation is particularly important for the maintenance of behavior changes over longer periods of time.(Glanz, Rimer et al. 2008) Yet the use of financial incentives raises controversies due to the “undermining effect,”(Deci 1971; Deci, Koestner et al. 1999) as the removal of an extrinsic motivator has been shown to decrease intrinsic motivation.(Deci, Koestner et al. 1999) In most weight loss studies, people revert back to prior behaviors after discontinuing the incentive.(Volpp, John et al. 2008; John, Loewenstein et al. 2011) Although financial incentives for patients can help motivate behavior change, many questions for effective design, goal-setting and long-term effects still remain unanswered). In Chapter 5, I study the acceptability of financial incentives for diabetes self-management, and explore expectations and concerns related to the use of these incentives.

Even though patient incentives have become common for wellness and preventive health, few studies have explored the use of extrinsic rewards in diabetes self-management.(Mulvaney, Ritterband et al. 2011; Long, Jahnle et al. 2012; Lorincz, Lawson et al. 2013) Externally funded incentive programs require personal health information from patients to reward goal achievements appropriately. Although the incentive programs could incentivize process goals (tracking glucose results, regardless of the actual value), payers only benefit financially from improved outcomes (e.g., reduced hospitalizations). Whether patients would be willing to gather and share additional information for a reward program remains unclear, and is addressed in Chapter 4. Furthermore, I explore the perceived intrusiveness of reward programs into patients’ privacy, especially as these

personal data can lead to undesired consequences such as cancelled contracts due to unsatisfactory results.

## **1.2 Research questions and data sources**

In Chapter 2, I study the use of smartphones in a diabetic population compared to a non-diabetic population and to explore predictors of smartphone use among diabetics. My goal is to identify the potential reach of mobile devices as an approach to improve diabetes self-management, and reporting population characteristics to better tailor app designs to patient needs. Smartphones might be a tool to reach both young and older adults. I use a nation-wide phone survey dataset from the PEW Research Center, conducted in English and Spanish, to study mobile health in 2012. They enrolled 3014 participants (1808 on landline phones and 1206 on cell phones), which included 374 individuals with diabetes.

In Chapter 3, I explore how diabetes and its self-management change over the course of the disease and how the need for various supportive technologies and devices also evolve. My goal is to inform the design of supportive technologies, as the needs and priorities of disease management might shift when adjusting to changes over time. To address this question, I used a dataset of semi-structured individual interviews and/or focus group of twelve adults with diabetes (six with type 1 diabetes, six with type 2 diabetes).

In Chapter 4, I explore the acceptability of patient rewards for better diabetes self-management and patients' responses (or expected responses) to financial incentives. I present implications for the design and integration of an acceptable incentive system to motivate changes of behavior. For this chapter, I used the patient dataset from Chapter 3,

and included in-depth interviews with nine care-providers who are involved in diabetes care: diabetes specialists (doctors, diabetes educators (nurse and pharmacist) and a nutritionist), primary care providers (doctors, pharmacist), a psychiatrist and an ophthalmologist.

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## CHAPTER 2: An exploration of the potential reach of smartphones in diabetes

Katherine Blondon, MD, MSc Paul Hebert, PhD, James D Ralston, MD  
University of Washington, Seattle, Washington

### 2.1 Abstract

**Background:** Mobile technologies for diabetes self-management have shown potential as a new approach to improve diabetes self-management in recent studies. The reach of smartphone use among individuals with diabetes, however, has not been established.

**Objective:** to identify the reach of smartphones in a diabetic population compared to a non-diabetic population and to characterize smartphone users among individuals with diabetes.

**Design:** This is a cross-sectional, secondary analysis of phone survey data from the Pew Research Center. We used weighted logistic regression models to compare smartphone use in individuals with and without diabetes, and to determine predictors of smartphone use among those with diabetes.

**Participants:** 2989 adults (1360 smartphone and 1629 non-smartphone users) participated in the survey, including 332 individuals with diabetes (mean age 59.9y  $\pm$ 1.1, vs 45.5 y $\pm$ 0.4 in individuals without diabetes)

**Main measures:** Our main outcome is prevalence of smartphone use. Our patient characteristics potentially associated with smartphone use are age, income and education (potential confounders).

**Key results:** Smartphones were used by 20.7% individuals with diabetes and 48.6% of those without diabetes; feature phones were used by 50.6% of those with diabetes. Compared to individuals without diabetes, individuals with diabetes were less likely to be smartphone users (relative risk of 0.43, 95% CI 0.31 to 0.54) even after adjusting for age, race, ethnicity and socioeconomic status (adjusted RR of 0.78, 95%CI 0.57-0.98). Among individuals with diabetes, high income, younger age and online health information seeking were associated with higher smartphone use.

**Conclusions:** Individuals with diabetes are less likely to be smartphone users than those without diabetes, even after adjusting for potential confounders. Future studies are needed to understand and address this current gap in smartphone use, and to explore the potential of smartphones for diabetes care and prevention, particularly among racial/ethnic minorities, newly diagnosed individuals and those at high risk of diabetes.

## 2.2 Introduction

Diabetes is a chronic condition that affects nearly 26 million adults (8.3% of the U.S. population, or 11.3% among >20 years old), which requires behavior changes for its management.((ADA) 2012) The prevalence of diabetes is higher among Asian Americans (8.4% of U.S population), Hispanics (11.8%) and among the non-Hispanic Blacks (12.6%).((ADA) 2012) Diabetes prevalence is also higher with increasing age (13.7% in the

45-64 year old group, and 26.9% in those over 65 years old).((ADA) 2012) Daily diabetes management tasks (low-carb diets, blood glucose tracking if needed, exercising, and/or taking medications) are handled mainly by the individual while away from the health care providers. The “ABCs of Diabetes” goals of successful management established by the American Diabetes Association are each associated with lower morbidity and mortality: HbA1c<7%, blood pressure <130/80mmHg and LDL-C <100 mg/dl.(2012) Individual ABC goals are not often achieved, with less than a fifth of the patients achieving all three goals together.(Vouri, Shaw et al. 2011)

The rapid adoption of smartphones(Nielsenwire 2012) and the rising prevalence of diabetes(Prevention 2011) have led developers of healthcare applications to find more innovative ways for individuals to use these resources to improve their diabetes self-management. Seven out of ten American adults track a health parameter such as weight, exercise or sleep.(Fox and Duggan 2012) Smartphone applications for health and wellness have flourished, with one in five smartphone users having a health app on their device.(Fox 2012) A large array of supportive technologies (such as smartphone applications, and websites) are aimed at improving diabetes self-management in daily tasks and choices: they help learn about diabetes and its management, track health parameters with graphs and data sharing options, and allow calendaring for daily tasks or annual screening procedures.(Chomutare, Fernandez-Luque et al. 2011; El-Gayar, Timsina et al. 2013)

Although studies have examined who has diabetes and characterized smartphone users, we do not have a clear understanding of which individuals with diabetes use mobile devices. The market for smartphones has grown exponentially over the past years, and adoption

has reached people of all demographic groups.(Nielsen 2011) A recent survey on the use of mobile devices found that 50.4% of US consumers had a smartphone.(Nielsenwire 2012) The diffusion of innovation theory(Rogers 1995) claims that age predicts the adoption of technologies, with the younger population adopting new technologies before the older population. Currently, the 55-64 year old age group has the second highest adoption rate for mobile devices.(Nielsen 2011) Although higher income and higher education are strong predictors of all-age smartphone adoption, younger adults seem to be less affected by these variables. Prior research has shown that Asians and Blacks are more likely to be smartphone users than Caucasians, and that African-Americans are also more likely to have health applications on their phone than other racial/ethnic groups (15% of Blacks vs 7% of whites and 11% of Latinos). This difference is particularly relevant, as these groups also have a higher prevalence of diabetes,(Lee, Brancati et al. 2011; (ADA) 2012) with lower glycemic control in Blacks and Hispanics. Latino cell phone users are more likely to use their cell phone to seek health information than other groups.(Pew Research Center 2010)

The aim of this study is to identify the reach of use smartphones among individuals with diabetes and to examine the socio-demographic profile of smartphone users with diabetes. Although adoption trends are continuously changing, our study will also inform us about the potential reach of mobile technologies to support diabetes self-management.

We hypothesized that compared to individuals without diabetes, individuals with diabetes will be less likely to use smartphones, due to older age and lower socioeconomic status (SES).(ADA) 2012) We also hypothesized that individuals with diabetes would be more likely to use smartphones if they have high education, younger age, non-White race and

high income, as reported in market studies.(Pew Research Center 2010) Understanding who uses and does not use smartphones among patients with diabetes can inform future diffusion and design of diabetes applications.

## **2.3 Research design and methods**

### **2.3.1 Population**

This cross-sectional study uses a survey dataset of the Pew Research Center collected between August 7 and September 6, 2012. This data was collected initially to describe the use of mobile technology for health.(Pew Research Center 2012) Researchers conducted a nationwide survey using phone interviews in English and Spanish of 3,014 adults >18 years old (1,808 landline and 1,206 mobile users). Participant selection was by random digit dial of both landline and cellphone numbers. For landline sample, the interviewers asked to speak with the youngest male or female (gender based on random rotation), following a systematic respondent selection technique that closely mirrors the population in terms of age and gender when combined with cellphone sample. Both samples were oversampled for Black and Hispanic respondents. Response rates were 11.5% for landlines and 6.6% for cell phones (total of 58,848 landlines and 32,129 cell phones dialed). The survey weights supplied with the survey(Pew Research Center 2012) were used to generate population level estimates. The margin of sampling error was  $\pm 2.4$  percentage points for the complete set of weighted data. This survey was conducted by Princeton Survey Research Associates International and sponsored by the Pew Research Center's Internet & American Life Project and the California HealthCare Foundation. This current study was conducted with the permission of the Pew Research Center's Internet & American Life project.

### **2.3.2 Survey**

This phone survey was created to study how cell phones, particularly smartphones, are used to look for health information. It included questions about self-reported health conditions (overall health and common chronic diseases), tracking behaviors, use of social networks, and searching for online health information about specific diseases or treatments, health insurance, or more general food and drug safety information. Tracking behavior could be for weight, diet, exercise routine blood pressure, blood sugar, sleep patterns, headaches or any other health indicator. The complete interview (26 questions) can be found online.(Pew Research Center 2012)

### **2.3.3 Analysis**

The primary analysis (Table 2.3) compared the use of smartphones between diabetic and non-diabetic participants using unadjusted and adjusted weighted logistic regression models. Smartphone users were defined as any user of a smartphone, including those who had both a landline and a smartphone. Non-smartphone users were all other participants, and included feature phone (cell phone that is not a smartphone) users and landline-only users. The covariates in the logistic regression models were defined a priori, with an age-adjusted model and the full model (age, measures of socio-economic status, race, ethnicity). Age was hypothesized to be the main confounder of smartphone use and diabetes. The other demographic confounders are based on results from market studies of smartphone use. In these models, age, race, income and education were categorical variables, as is presented in tables 2.1 and 2.2.

The secondary analysis (Table 2.4) used a multivariate logistic regression model among

diabetics to determine predictors of smartphone use. All variables of interest were chosen a priori by the investigators and entered together in the model: age (categorical), race and ethnicity, education and income (all binary). We used a binary variable combining race and ethnicity, as well as binary variables for education and income to avoid having too few events per variable. Education was defined using a threshold of high school completion. We chose a cutoff for income level of \$50,000 per year because the annual median household income in the U.S. was \$50,502 in 2011.(Noss 2012) Our second model for this analysis also included online health information seeking as a proxy for patient engagement, and health tracking (both binary).

All analyses and characteristics of the sample were computed from the weighted sample after exclusion of missing diabetes or smartphone values (N=2989). The percentage of complete cases was 78%. Missing covariate data were infrequent ( $\leq 1.8\%$ ) other than for income (18.5%). Missing data were multiple-imputed with 25 imputed datasets using imputation by chained-equations.(White, Royston et al. 2011) The imputation model included the covariates used in all our analysis (with dependent variables), as well as three auxiliary variables: state, use of urgent care in the past 12 months and self-reported health. Categorical variables were compared using Chi-Square tests. P values from regression models were derived from Wald tests with robust standard errors. A p-value  $< 0.05$  determined statistical significance. No interaction was tested. We presented our results after conversion to relative risks using the margins function. All analyses were conducted on Stata 11 (Stata Corporation, Texas).

## 2.4 Results

We describe the diabetic and non-diabetic populations in our sample (Table 2.1), with weighted descriptive analyses. Among the 2991 respondents, 332 had diabetes (weighted proportion of 11.1%). Individuals with diabetes were significantly older than non-diabetic participants (mean age of 59.9y vs 45.5y,  $p < .001$ , Table 2.1). They also had more comorbidities (hypertension, congestive heart failure and other chronic diseases such as asthma or cancer). Gender and ethnicity were not different, but more participants with diabetes were of Black race than participants without diabetes (16.9% vs 12.7%). Socio-economic status was lower in the diabetic group, with fewer insured participants, lower educational attainment, a lower income and a higher prevalence of unemployment. Compared with non-diabetics, individuals with diabetes had a significantly higher feature phone use (50.6% vs 38.3%,  $p < .001$  Table 2.1) and a lower smartphone use (20.7% vs 48.6%,  $p < .001$ ). About half of the patients with diabetes used email and Internet, compared with over three quarters of individuals without diabetes. Moreover, five out of six participants with diabetes tracked at least one health parameter (diet, weight, carbohydrates, etc.), compared with two thirds of non-diabetics ( $p < .001$ ). Individuals with diabetes had a lower use of health applications on smartphones (3.8% vs 10.0%,  $p = .002$ ).

Table 2.1: Weighted comparison of individuals with and without diabetes in the study population

	Diabetes	No diabetes	p-value
Total N	332 (11.1%)	2657 (88.9%)	
Mean age (SD, 95%CI)	59.9 (1.1, 57.8-62.0)	45.5 (0.4, 44.7-46.4)	<.001
18-35 yrs	8.8%	34.6%	
36-50 yrs	16.8%	28.2%	
51-64 yrs	35.4%	21.4%	
65-80 yrs	31.5%	11.4%	
>80 yrs	7.5%	4.4%	
Male	53.5%	50.9%	0.48
<b><u>Comorbidities</u></b>			
Hypertension	67.1%	20.1%	<.001
Heart disease	27.5%	4.9%	<.001
Other chronic disease	82.9%	38.0%	<.001
<b><u>Race</u></b>			0.14
White	70.2%	74.0%	
Black	16.9%	12.7%	
Asian	1.6%	3.0%	
Other race	11.3%	10.3%	
<b><u>Ethnicity</u></b>			
Hispanic	15.8%	13.2%	0.32
<b><u>Health insurance</u></b>			<.001
Uninsured	11.2%	18.5%	
Medicaid	11.2%	7.4%	
Medicare	24.3%	7.1%	
Private insurance	50.8%	64.4%	
<b><u>Education</u></b>			<.001
No high school	20.7%	10.4%	
Attained high school	62.1%	59.2%	
College or higher	17.2%	30.4%	
<b><u>Annual income</u></b>			<.001
<30,000\$	60.2%	36.4%	
30,000-99,999\$	36.0%	47.1%	
≥100,000\$	3.8%	16.5%	
<b><u>Employment</u></b>			
Employed	30.3%	58.0%	<.001
Feature phone users	50.6%	38.3%	0.001
Smartphone users	20.7%	48.6%	<.001
Use of internet	53.4%	81.6%	<.001
Use of email	47.6%	75.4%	<.001
Tracks any health parameter	84.3%	64.9%	<.001
Use of health app on smartphone	3.9%	10.0%	0.001

In Table 2.2, we report the characteristics of smartphone users in our sample (both diabetic and non-diabetic individuals included) compared with non-smartphone users. This latter group includes individuals who use feature phones and/or landlines. The sample comprised 1360 smartphone users (weighted proportion 45.5%) and 1629 non-smartphone users (1185 feature phone users and 444 individuals with only landlines, weighted proportions 39.6 % and 14.8% respectively). The landline only population was older, with more comorbidities: they had the highest prevalence of diabetes (21.4%), compared with feature phone users (14.2%) and smartphone users (5.0%). They had a higher proportion of Caucasians (81.2%) and Hispanics (16.1%) than the feature phone and smartphone users, and had lower educational attainment. They had lower use of email and Internet. Gender was not significantly different among these groups.

Compared to White participants, Asian participants had a significantly higher use of smartphones (Table 2.2). The smartphone population also had significantly higher income, employment rate and higher educational attainment than the non-smartphone population. The proportion of uninsured did not differ with smartphone use. Finally, use of emails and Internet was almost universal in the smartphone group (92% and 98% of individuals, respectively), compared to less than two thirds of the non-smartphone group. Two thirds of the participants tracked some health parameter, regardless of the type of phone technology.

Table 2.2. Weighted comparison of smartphone users\* and non-smartphone users (landline or feature phones users)

	Smartphone users	Not smartphone users	p-value
Total N	1360(45.5%)	1629 (54.5%)	
Landline only (% total population)	-	444 (14.8%)	
Diabetes (%)	5.0%	16.1%	<.001
Mean age (SD, 95%CI)	38.9 (0.5, 38.0-39.8)	54.0 (0.6, 52.8-55.2)	<.001
18-35 yrs	46.5%	19.4%	
36-50 yrs	32.9%	21.9%	
51-64 yrs	16.0%	28.7%	
65-80 yrs	3.8%	21.9%	
>80 yrs	0.7%	8.1%	
Male	50.1%	52.1%	0.41
<b><u>Comorbidities</u></b>			
Hypertension	14.7%	34.1%	<.001
Heart disease	3.1%	11.0%	<.001
Other chronic disease	30.3%	53.5%	<.001
<b><u>Race</u></b>			<.001
White	69.5%	77.0%	
Black	14.0%	12.5%	
Asian	5.1%	1.0%	
Other race	11.4%	9.5%	
<b><u>Ethnicity</u></b>			
Hispanic	14.7%	12.6%	0.2
<b><u>Health insurance</u></b>			<.001
Uninsured	17.7%	17.6%	
Medicaid	5.4%	9.9%	
Medicare	2.6%	14.3%	
Private insurance	72.2%	55.2%	
<b><u>Education</u></b>			<.001
No high school	5.5%	16.5%	
Attained high school	56.0%	62.4%	
College or higher	38.4%	21.1%	
<b><u>Annual income</u></b>			<.001
<30,000\$	27.7%	48.5%	
30,000-99,999\$	49.6%	42.8%	
≥100,000\$	22.7%	8.7%	
<b><u>Employment</u></b>			
Employed	72.3%	40.4%	<.001
Use of internet	97.7%	62.4%	<.001
Use of email	92.3%	55.7%	<.001
Tracks any health parameter	67.9%	66.3%	0.5

\*this group includes users of both smartphones and landline phones

The results of the primary analysis comparing the use of smartphone between diabetic and non-diabetic participants are presented in Table 2.3. In the unadjusted analysis, individuals with diabetes were less likely to use smartphones compared with those without diabetes (RR 0.43, 95% CI 0.31 to 0.54,  $p < .001$ ). After adjusting for age, individuals with diabetes were still less likely to be smartphone users compared with those without diabetes (RR 0.58, 95%CI 0.40 to 0.75,  $p < .001$ ). In the full model that adjusted for race, ethnicity, income and education level (potential confounders), participants with diabetes remained significantly less likely to be smartphone users compared with those without diabetes (RR 0.78, 95%CI 0.57-0.98,  $p = 0.05$ ). In this multivariate model, we also observed that Blacks, Asians and Hispanics were more likely to use a smartphone than Caucasians and non-Hispanics, respectively. We also found strong evidence that a higher income and education attainment was positively associated with smartphone use.

Table 2.3. Unadjusted and adjusted RR comparing diabetics to non-diabetics for smartphone use (N=2989)

Covariates	Unadjusted			Age-adjusted			Full model		
	RR	(95% CI)	p-value	RR	(95% CI)	p-value	RR	(95% CI)	p-value
Diabetes	0.43	(0.31-0.54)	<.001	0.58	(0.40-0.75)	<.001	0.78	(0.57-0.98)	0.05
Age						<.001			<.001
18-35 yrs				(Ref)			(Ref)		
36-50 yrs				0.81	(0.70-0.92)		0.82	(0.74 -0.90)	
51-64 yrs				0.45	(0.38-0.53)		0.48	(0.39-0.57)	
65-80 yrs				0.18	(0.13-0.23)		0.24	(0.17-0.31)	
>80 yrs				0.09	(0.04-0.15)		0.10	(0.04-0.17)	
Race									<.001
White							(Ref)		
Black							1.30	(1.04-1.56)	
Asian							2.10	(1.45-2.75)	
Other race							1.07	(0.75-1.39)	
Hispanic							1.30	(1.02-1.57)	0.02
Annual income									<.001
<30,000\$							(Ref)		
30,000-99,999\$							1.65	(1.31-1.99)	
>100,000\$							2.63	(1.98-3.28)	
Attained education									<.001
No high school							(Ref)		
High school							1.82	(1.14-2.49)	
College or higher							2.52	(1.53-3.51)	

The results of the secondary analysis of predictors of smartphone use among individuals with diabetes are shown in Table 2.4. In the multivariate model 1, younger age and higher income were strongly associated with smartphone use, whereas race/ethnicity and education were not. Model 2 further explored online health seeking behavior and health tracking behavior. Individuals who sought health information online were more likely to be smartphone users (RR 3.68, 95% CI 1.06-6.30,  $p < .001$ ). The individuals who tracked health parameters, however, were *less* likely to be smartphone users (RR of 0.62, 95%CI 0.36-0.88,  $p = 0.04$ ).

Table 2.4. Multivariate predictors of smartphone use among individuals with diabetes (N=332)

Covariates	Model 1			Model 2		
	RR	95% CI	p-value	RR	95%CI	p-value
Age 18-35yrs	(Ref)		<.001	(Ref)		<.001
Age 36-50yrs	0.37	(0.15-0.60)		0.50	(0.18-0.83)	
Age 51-64yrs	0.28	(0.12-0.44)		0.39	(0.15-0.63)	
Age >65yrs	0.13	(0.04-0.22)		0.26	(0.08-0.44)	
Non-White or Hispanic	1.42	(0.77-2.06)	0.13	1.41	(0.82-2.00)	0.10
High school education	1.22	(0.51-1.93)	0.50	0.96	(0.45-1.47)	0.88
Income >50,000\$/year	3.09	(1.35-4.84)	<.001	2.34	(1.13-3.54)	0.002
Seeks health information online				3.68	(1.06-6.30)	<.001
Tracks any health parameter				0.62	(0.36-0.88)	0.04

## 2.5 Discussion

In our nationwide sample, we found that individuals with diabetes were less likely to be smartphone users compared with individuals without diabetes, even after adjusting for potential confounding by age, SES, race and ethnicity. The pattern of lower use among the older population is consistent with market studies on smartphone adoption.(Nielsen 2012; Nielsenwire 2012) Although recent evidence supports the long-term effectiveness of mobile technologies in diabetes self-management with improved HbA1c values after 6

months(Liang, Wang et al. 2011) and 12 months,(Quinn, Shardell et al. 2011), our results suggest that these technologies might not be appropriate for all individuals, and efforts to improve standard care in diabetes self-management need to be pursued.

Understanding why individuals with diabetes have lower smartphone use is important, as healthcare delivery systems seek to move towards a higher use of smartphone applications for diabetes self-management. Diabetes, its long-term complications and related comorbidities can lead to physical and cognitive impairments, such as lower dexterity from neuropathy or visual impairments. These unmeasured factors are all barriers to smartphone use, and are all accentuated by older age. Despite the slow increase in smartphone uptake among older adults, the very rapid uptake among younger adults might therefore tend to emphasize this gap in smartphone use, unless measures are taken to address these barriers. The trend towards larger screens of newer devices (phablets, tablets) is one approach to address visibility and dexterity impairments related to diabetes and age,(Cheung, Janssen et al. 2013) but innovative designs also need to be developed to facilitate the usability of smartphone applications.(Chun and Patterson 2012) Individuals with diabetes could have a lag in the adoption curve for smartphone use, and time could allow these late adopters of technology to catch up somewhat, according to Rogers' diffusion of innovation theory.(Rogers 1995) Care-providers might also have a role to play in diffusing diabetes applications to patients who already use smartphones,(Drinkwater 2013) as they already provide guidance for websites and online communities to their patients.(Research 2013) Our findings can therefore provide new direction for future research on smartphones for diabetes self-management.

Smartphones have the potential to bridge the typical “digital divide”, or population-level gap in Internet and computer access, in racial/ethnic groups. In the unadjusted analysis for smartphone use, Asian race (vs White), high income and high education were associated with higher smartphone use. In our multivariate analyses, we found that individuals with diabetes who have higher income and younger age are more likely to use smartphones, as was expected from market studies.(Pew Research Center 2010; Nielsen 2012) We also found higher smartphone use by Blacks, Asians and Hispanics compared to Whites and non-Hispanics, reflecting the importance of race and ethnicity for smartphone use in prior studies.(Pew Research Center 2010; Nielsenwire 2012) This finding has two important implications: (1) smartphones might be a new approach to improve access to high quality care for diabetes in racial/ethnic minority groups, and (2) future diabetes applications need to take cultural differences into consideration in their design. For instance, diabetes applications in Spanish are currently very limited, although several applications have planned to add this feature in future versions. Also, most applications or websites do not include options for cultural preferences in their food plans. One possible design implication could be to integrate more culturally adapted nutrition facts in smartphone applications to facilitate the adoption and adherence to diabetes-friendly food plans in this racial/ethnic minority groups.

Although we found that smartphone use decreased with age, 16% of the individuals aged 51-64 years old used smartphones. In market studies, this age group is the second fastest growing age group for smartphone uptake.(Nielsen 2011) Over a million individuals from this age group are diagnosed with diabetes each year in the US,(Prevention 2011)

emphasizing the potential benefit of smartphones, as they are particularly well adapted to support diabetes self-management in the early stages of disease.(Blondon 2013)

As smartphone use is highest among young adults, it can offer unique opportunities for early diabetes self-management or diabetes prevention. Most diabetes applications provide tracking tools to monitor health parameters, and can guide early disease management, making these tools particularly useful at early stages of disease).(Chomutare, Fernandez-Luque et al. 2011; Blondon 2013) In addition, the reach of smartphones among racial/ethnic minorities might allow early prevention by supporting behavior change in this subpopulation with higher prevalence of early type 2 diabetes, in particular among adolescents.

Contrary to our hypothesis of smartphone use for health tracking, we found that individuals were less likely to be a smartphone user if they monitored their own health. Nearly two thirds of our participants tracked some health parameter, regardless of phone type. In a recent survey of individuals with diabetes,(Research 2013) participants generally tracked their health using pen and paper or websites, which could explain our finding.

### **2.5.1 Strengths and limitations**

One of the strengths of this paper is its secondary use of a dataset collected to study mobile health. It uses a random sample of landline and cellphone users from the national US population, without targeting any disease in particular. This helps avoid the bias related to successful diabetes self-management. It was also conducted in two languages, English and Spanish, which facilitates participation from the rapidly growing Hispanic population.

This study is to the best of our knowledge, the first report on the characteristics of smartphone users in a diabetic population. With the rapid spread in smartphone use for health, it is important to have an understanding of the reach and limitations of smartphones, especially since gaps in smartphone use have the potential to increase current disparities in diabetes care. Our findings also emphasize the potential of smartphones to prevent diabetes in younger adults, and to improve access to higher quality care for racial/ethnic minorities.

A limitation of this study is its relatively small number of individuals with diabetes, even if the prevalence of diabetes in this sample (11.1% after weighting) is comparable to the prevalence of diabetes among U.S adults. This limitation could contribute to the lack of association we had between smartphone use and race/ethnicity among individuals with diabetes. The low response rate to this survey for both the landline and cellphone samples may also limit the generalizability of our findings. Finally, this dataset only provided information about the presence of diabetes, and we await the results of future studies that also include indicators of disease duration, severity (HbA1c and comorbidities) and type of treatment (insulin use).

## **2.6 Conclusion**

Compared to individuals without diabetes, smartphone use remains significantly less likely among individuals with diabetes, even after adjusting for potential confounders. Future research is needed to better understand this gap in smartphone use, in particular to address diabetes- and age-related impairments. Despite the potential of smartphones to effectively support diabetes self-management overall, and to improve access to high quality

care in racial/ethnic minorities and younger adults, improving the current delivery of diabetes care should be pursued for individuals who are beyond the reach of these devices.

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## CHAPTER 3: Long-term engagement with health-management technology: a dynamic process in diabetes<sup>1</sup>

Katherine Blondon, MD, MSc<sup>1</sup> Predrag Klasnja, PhD,<sup>2</sup> Logan Kendall, MHA,<sup>1</sup>Wanda Pratt, PhD,<sup>1</sup>

<sup>1</sup>University of Washington, Seattle, Washington; <sup>2</sup>University of Michigan, Ann Arbor, MI

### 3.1 Abstract

Diabetes management is a complex, dynamic process that is largely incumbent on patient choices and behavior. We explore how health-management needs—and the needs for technological support—change over time for individuals with diabetes. Through interviews and a focus group, we found that after initial diagnosis, individuals face acute information needs and chiefly turn to mobile applications and Internet resources to help understand the diabetes-specific factors that affect their health. Over time their focus shifts from highly regimented routines to more flexible ones that enable them to maintain a quality of life. Our results show that long-term engagement with health technology does not necessarily require continuous, sustained use: successful disease management could lead to a decrease in use, until a new event occurs. Our findings point to a need for tools that help patients with diabetes to effectively manage their health as their bodies, treatment and circumstances change over time.

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## 3.2 Introduction

Diabetes is a common, chronic disease that affects 346 million people worldwide, and is predicted to become the seventh leading cause of death by 2030 (2011). There are two main types of diabetes: Individuals with type 1 diabetes (T1D) have a deficit in insulin, whereas those with type 2 diabetes (T2D) have an increased resistance to insulin. Type 1 diabetes accounts for 5-10% of individuals. Type 2 accounts for more than 90% of the individuals with diabetes and is associated with obesity in more than 85% of cases.(2004) Diabetes leads to increased risk of cardiovascular events, is the leading cause of kidney failure and amputations, and is a major cause of blindness. Reducing the glycated hemoglobin (HbA1c)—an indicator for the average blood glucose level over the preceding 3 months—controlling blood pressure, and treating cholesterol can delay the onset of these complications. Yet, only one in eight individuals achieves these three goals)

Such low rates of adequate self-management suggest that the standard model of care delivery consisting of short, infrequent visits with care providers conveys insufficient support for effective health management, including managing medications, improving diet, controlling weight, increasing physical activity, and smoking cessation.(Wagner, Austin et al. 1996) In recent years, mobile technology has emerged as a promising way to provide additional support for self-management that can be available to patients in the midst of their daily lives when they have to make the myriad decisions that affect their health. These types of applications offer promising ways of supporting the challenge of diabetes self-management, and the randomized controlled trials conducted on self-management

technologies clearly show that such tools can have clinically significant benefits.(Lorig, Ritter et al. 2006; Quinn, Shardell et al. 2011)

Adoption of smartphones and other mobile devices has grown exponentially in all age groups and socioeconomic classes,(Nielsen 2011) and applications for diabetes and wellness have flourished.(Chomutare, Fernandez-Luque et al. 2011) The available smartphone applications for diabetes are diverse, and allow individuals to track activities, medications, or diet, as well as to visualize the results in graphs. Applications can provide reminders for glucose testing or doctors' appointments, while offering feedback and ranges for normal results. Using smartphones, patients can access the Internet to look for further information, or send results to providers for improved discussions and care.(Chomutare, Fernandez-Luque et al. 2011)

Interventions for diabetes with mobile technologies have shown promise in clinical trials. A meta-analysis of 22 trials assessing the effect of mobile phone interventions on glycemic control showed a reduction of HbA1c of 0.5% over a median of 6 months' follow-up duration.(Liang, Wang et al. 2011) This effect was shown to be greater in individuals with T2D than in T1D.(Liang, Wang et al. 2011) Early work on mobile phones for diabetes studied the use of phone calls or text messaging.(Quinn, Shardell et al. 2011; Mulvaney, Anders et al. 2012) Newer studies focused on tracking applications (insulin, diet, blood glucose, and weight, for example), educational content, or integration with other systems, such as personal health records and social media.(Chomutare, Fernandez-Luque et al. 2011) Ralston et al found that the use of secure messaging with providers improved HbA1c results by 0.7%.(Ralston, Hirsch et al. 2009) Combining mobile device and provider

support, a randomized controlled trial with WellDoc Diabetes Manager™, a FDA-approved application that offers automated clinical coaching based on the data that patients track and supports sharing of that information with care providers, showed a 1.2% decrease in HbA1c with web- and mobile-based tools compared to usual care over a year.(Quinn, Shardell et al. 2011) This result suggests that mobile technology might be even more effective as a part of a comprehensive suite of technological tools.

Whether these preliminary efficacy results are an accurate picture of the benefits that mobile technology can have on diabetes self-management is unclear. Prior studies have employed a longitudinal design to assess the clinical impact of technological interventions for diabetes self-management.(Cho, Lee et al. 2009; Yoo, Park et al. 2009; Quinn, Shardell et al. 2011; Mulvaney, Anders et al. 2012) When patients do not use technology regularly in these evaluations, it is considered a failure. However, the lack of use could be due to a number of factors, including a mismatch between the technology evaluated and the current stage of the patient's condition. At an early stage of disease, for example, intensive tracking can help guide nutrition choices through a better understanding of glycemic variation after eating certain foods. At later stages, the perceived burden of tracking may surpass its perceived benefit, as the effect of these foods on glucose variation may already have been determined. If the application that is being evaluated relies mainly on tracking—and many diabetes self-management applications do (Chomutare, Fernandez-Luque et al. 2011)—patients in later stages of the disease might not benefit from it very much.

While research in health sciences has focused on assessing effectiveness of self-management tools for diabetes, work in human-computer interaction (HCI) is exploring

new approaches for technological support for behavior change, such as individualization and sense-making. For instance, Chen has found that in spite of a similar set of self-management needs in newly diagnosed individuals, responses to these needs vary depending on the individual's physiological, social, and personal circumstances.(Chen 2010) Mobile technology facilitates creation of highly personalized tools. Mamykina et al. have focused on the development of problem-solving skills for diabetes self-management(Mamykina 2010). Drawing on the theory of sense-making, they developed a mobile-phone application, MAHI,(Mamykina, Mynatt et al. 2008) which enables patients to collect contextual information related to their glucose measurements (e.g., what they ate, where they are, etc.). The information is uploaded to a secure website where patients can reflect on patterns in their information and discuss their data with a diabetes educator. This ability to engage in conversations about their own concrete data was rated by Mamykina et al.'s participants as the most useful feature of MAHI. Frost and colleagues took a similar approach: to facilitate reflection on patterns in glucose measures, Frost et al. used photographs to annotate glucose readings to enable patients and their providers to better understand each individual's values.(Frost 2003; Smith 2007)

The work in HCI and in health sciences has only begun to explore how patients' needs for self-management technologies change over the course of the disease and how we can design technologies to account for the evolving nature of diabetes self-management. As a result, the benefits we are seeing from self-management tools might be less than they could be, in part due to the potential mismatch between the type of technology being tested and the specific needs of the patients participating in the study. To avoid such mismatches, we

must better comprehend individuals' evolving self-management and the ways that technology can support it over time.

In this paper, we begin to close this gap in understanding by exploring how diabetes patients' health-management needs change over the course of the disease and how they use various technologies and devices to support those changing needs. Our findings can inform the design of technologies that account for the shifts in self-management priorities brought about through the progression of the disease, changes in treatment, and the patients' own evolving skills and understanding of diabetes self-care. Such technologies could provide patients with the support that is most important to them at their own stage of illness, and maximize the technology's effectiveness in helping patients improve their self-management and their health.

### **3.3 Methods**

#### **3.3.1 Data collection**

After receiving approval from the Institutional Review Board, we recruited adults with T1D or T2D through flyers in Diabetes Clinic of the University of Washington, snowball recruitment, and a diabetes support group from September 2011 to October 2012. We excluded individuals with gestational diabetes because of its limited duration, as well as those on dialysis, because they see their care-providers much more frequently than other individuals. Participants received \$25 for participation. We collected participants' socio-demographic characteristics, and information about their technology and healthcare use.

We chose not to perform purposive sampling by disease duration, as the relationship between disease duration and disease stage is not clearly established.

We led in-depth, semi-structured, individual interviews with 11 participants. All sessions were audio-recorded and transcribed for subsequent analysis. The sessions ranged from 35-100 minutes. We asked individuals to describe their current diabetes management, their trajectory since they were diagnosed, and their use of technologies, such as their use of mobile devices and the Internet (e.g., forums, blogs, other websites). We also explored their perceived role in coordinating the care they receive. Finally, we asked them about their perceptions of barriers and motivators for diabetes self-management. We also conducted a 2-hour focus group with 4 participants: three individuals with T2D (diagnosed in the past two years) and one individual with T1D (diagnosed 20 years ago). One of the participants had not been interviewed previously. During this session, participants discussed their disease, their evolving needs, barriers and motivations, and discussed their use and need for supportive technologies for diabetes.

### **3.3.2 Data analysis**

Two coders each analyzed the transcripts of the individual interviews and the focus group in Atlas.ti 7 software, using open coding to establish prominent themes encountered in the data: the evolution over time of the disease and its management; the tracked information; the comprehension, availability and usefulness of technologies such as glucose meters and their companion websites, insulin pumps, blood pressure monitors, smartphones and tablets, online forums and social networking. We also coded the disease trajectory, with modifications in symptoms, treatments, barriers and motivations for self-care. The two

coders iteratively compared their coding schemes, revising or merging them, as we found common and contrasting themes. We took into consideration duration and type of disease for this analysis.

### 3.4 Results

#### 3.4.1 Participant characteristics

We enrolled six T1D and six T2D participants, who had been diagnosed for periods ranging from 6 months to over 20 years. There were five male participants, four of whom had T2D. One patient with T2D used insulin. The patient characteristics are presented in Table 1. The age range in our sample is representative of T1D and T2D demographic characteristics in the general population.

Table 3.1: Patient demographics and disease characteristics

	Type 1	Type 2
n	6	6*
Female: male	5:1	2:4
Age range	18-34 yrs	35-64 yrs
Duration of disease by participant	1.3 yrs (P10), 8 yrs (P5), 12 yrs (P6), 19 yrs (P4), 23 yrs (P8), 27 yrs (P3),	0.5 yrs (P7), 0.5 yrs (P9), 1.2 yrs (P12), 1.5 yrs (P11), 17 yrs (P1), 21 yrs (P2),

\*Only one individual with T2D using insulin

#### 3.4.2 Evolution in health management needs

A key finding from our work is that patients' self-management needs and priorities change substantially over the course of the disease. In this section, we describe our patients' needs

and priorities in the following phases: (1) in the initial period after diagnosis, (2) in the stabilization phase, when they gained control over their illness, (3) when they need to respond to changes brought about by the disease progression and adjustments in treatment, and (4) during long-term management.

#### **3.4.2.1 Initial period after diagnosis**

Our findings indicate that the initial period after diagnosis is characterized by acute psychological distress, a need to learn about the disease, and to adopt new routines and health behaviors to control glucose levels. During this period, patients make heavy use of tracking tools and of educational websites, but find the available information insufficient.

Participants find this initial stage difficult, both at a physical and psychological level. Two participants consulted mental health professionals to help cope with their new chronic disease. Diabetes has a negative reputation, with its ban on sweets, its amputations, the painful pricks and injections and medications. Such perceptions are often buttressed by friends or family members with diabetes who have presented these complications. For example, one participant (P1, T2D) described the moment of diagnosis as *“the branding, the shock”* and her initial thought was *“I’m a failure.”* This reflects Erikson’s notion of “identity crisis” that some individuals experience when newly diagnosed.(Erikson 1970) The difficulty of finding practical information heightened the feeling of being overwhelmed by the disease in the early stages, when they spent much time trying to understand their disease and its implications: *“I wanted something early on, I just want to know if I can eat five crackers, if that’s all I have to eat, I’ll eat crackers for 90 days. [...] Give me a recipe, I can follow it and not have to think about it so much.”* – FG, P7 (T2D)

In addition, a need for intensive learning characterizes this initial period as participants search for answers about diabetes and discover how to incorporate management strategies to get better and prevent complications. Self-management at this stage focuses on understanding the basics of the disease, and changing daily activities, such as nutrition. Lifestyle changes are particularly important in type 2 diabetes, where portion control, healthy food choices, and physical activity are initial steps to decrease and stabilize glucose levels. As FG, P7 (T2D) noted, *“Going back, early on, it’s food. You know, you have to figure out what you can eat, and then it’s exercise and then it’s the combination of everything and then it’s working it all in the lifestyle stuff too.”*

To understand how to manage diabetes, individuals need to learn how to interpret many numbers, including blood glucose results and carb counts. Glucose metabolism is complex, with many intervening factors: changes in blood glucose levels vary according to the amount and content of ingested food, physical activity, and the timing of both eating and exercise. Patients might also start new medications and want to observe the effects of those drugs. As a result, individuals begin intense tracking to understand the effects of these various factors on their body. Some participants used pen and paper or Excel spreadsheets, while others turned to their smartphones for tools to assist them, with options for averages and other analyses. They particularly appreciated the ease of data retrieval and seeing associations between trends in carbohydrates and glucose levels: *“The nice thing about having it on the phone is I can just give [my providers] my last 90 days, without having to scroll back through a bunch of spreadsheets and paperwork and calculate the number. I can just quickly at a glance say where I am”* – FG, P7 (T2D)

At this early stage, patients describe changes in their lifestyle to adopt new routines for disease management. They integrate new behaviors like tracking, glucose testing, and they limit their food choices to those that were successful in the past. Restricting options is difficult, but it saves time and decreases anxiety about glucose management. Experiences like the following are typical:

*“I was tracking down to individual ingredients I was putting into my recipes and just breaking it down to what I can. You know, we were measuring every two hours after a meal, doing exactly what they were telling us to do, wake up: check, after breakfast: check, two hours before lunch: check, two hours after lunch: check. So it was a whole routine for about the first month, two months.” – FG, P7 (T2D)*

*“I’ll go to the TacoTime website and see how many carbs there are in the [...] natural beef stuffed Taco. [...] When I’m on the road and I’m trying to grab lunch or something like that, I find myself always going to Taco Time, [...] because I know exactly what that’s going to do to my blood sugar.” – Intv, P6 (T1D)*

The challenge of controlling glucose levels with food and exercise is compounded by the lack of concrete, actionable plans that new patients can adopt to get them started. Although many websites, handouts and textbooks about diabetes exist, patients expressed frustration with finding concrete information to guide daily choices. Participants found the available food plans bland, with little choice for ethnic and cultural preferences.

*“There’s not a website that says “eat this - you can eat this, in this proportion,” none of that. And the same thing with exercise. You know, they say “exercise” but then they don’t give you – they don’t just say “10 minutes per meal”.” – FG, P7 (T2D)*

*“[Websites] that do piece it together in the meal plans, they’re bland; [they need to be adjusted to] taste, lifestyle, you know, even down to the city, because [most] is tailored to the Caucasian diet right now.” – FG, P9 (T2D)*

Individuals found some websites useful, but described how time-consuming and impractical they were to use, particularly at early stages. This was particularly the case for a nutritional website which provides detailed breakdowns of nutrient data for an extensive selection of foods; participants described how it was difficult to utilize this data when combining several foods together. Although some information seemed difficult to find on the Internet, our subjects found comfort in its constant availability as a resource: *“It’s not just “go to this class that’s taught in two weeks” but “here’s where you could start online tonight when you’re freaking out at two o’clock in the morning” – Intv, P5 (T1D)*

Our participants wished for more guidance from their care-providers for electronic resources (websites and smartphone apps). A number of websites and apps are available for diabetes, nutrition, physical activities and weight, yet providers do not seem familiar with these resources. Patients expect their providers to suggest and advise them about these resources to ensure that patients are accessing high quality information: *“I feel like the good [providers] are also learning to go online or at least realize that there are conversations online [...] knowing good resources whether it’s diabetes.org or the*

*TuDiabetes.com network. So giving patients a starting place and not making them go to Google.” – Intv, P5 (T1D)*

Peer support from other individuals with diabetes is helpful, particularly at this early stage of disease. The experiences of peers can provide information not given or emphasized by care professionals: *“My friend actually was the one who told me to take my insulin earlier to offset like spikes and stuff. [...] She was the only person who said that to me, I guess. She’s kind of clued me in, that’s helped a lot.” – Intv, P10 (T1D)*

During this initial phase, then, patients face the challenge to understand how their bodies respond to food, medication, and exercise, and, based on that knowledge, to come up with daily routines that help stabilize their blood sugar levels. Tracking tools are a key support for this process, as are online resources such as blogs and forums where patients can get advice and tips from other patients.

#### **3.4.2.2 Stabilization phase**

As individuals make efforts to adjust to new lifestyle choices, they progressively build skills in and confidence about diabetes self-management. They realize that they can delay the onset of complications and that their actions can bear positive results, reflected in their HbA1c numbers or feedback from their care-provider. Patients also master the diabetes lingo, as P8 (T1D) described: *“Breakfast was one protein, two starches, one fat, one dairy, one fruit...”* After they gain initial control, patients also begin to slowly integrate new behaviors into their daily routines:

*“Maybe you don’t want to go out because you know what the end result is going to be. [...] It’s okay to go out, we know that now. I think that initial first three months was just getting an understanding of “can we get these numbers down,” “what is it going to take” and then now that we got them down, it seems like it’s okay to go out and have a couple of drinks with your co-workers after work or happy hour, and do stuff. [That shift occurred] after the first A1c that went down.” – FG, P7 (T2D)*

During this stabilization phase, individuals gradually lose interest in tracking their diet or other activities, because they have adopted routines that generate satisfactory results. They have discovered which foods to eat in what proportion, and have developed skills at interpreting glucose results and at estimating carbohydrates in common foods.

*“[I made] a master list of all the items that I could possibly eat and the glycemic load and the calories [...] For the first 60 days, [our glucose results] were always low because we knew exactly what we ate. So then after a while it was like it was the same thing we’re eating every day, you know what it’s going to be. So after that I just stopped [tracking]. – FG, P7 (T2D)*

*I can usually look at things and [...] probably 70 - 75 % of the time I get at least in the ballpark.” – Intv, P8 (T1D)*

Individuals gain confidence in their skills to assess carbohydrates, or predict their response to certain activities. They might even search for ways to fine-tune their glucose results through detection of complex interactions among emotions or physical activity. They recognize that mobile technologies can provide a lot of information, but do not use them as much at this point.

*“Some apps will tell you like if say, you know, three strawberries, or whatever, they will tell you how many carbs that is. But I kind of just eyeball it and you know, from experience, just sort of trial and error with different things.”* – Intv, P4 (T1D)

*“There have been a couple of times where I come out of the pool and been really low – it was at the beginning when I didn’t know exactly how it would affect me but I feel like, generally, at least now, I’m able to kind of predict what’s going to happen and I take glucose tablets with me when I run and bike and that kind of stuff.”* – Intv, P10 (T1D)

The key feature of the stabilization stage, then, is that patients have managed to internalize knowledge that previously required them to use external tools. By better understanding their bodies and the ways in which factors that affect their sugar levels interact, they are able to “eyeball” different types of foods and predict the effects that eating something will have on them. Consequently, intensive tracking technology becomes less useful at this point.

#### **3.4.2.3 Responding to changes**

Many life choices affect glucose results, but how various factors affect a person’s body can change over time. People must determine whether a meaningful change in glucose levels is a one-time event or whether there is a pattern in the change that would require an adjustment of diet or insulin regimen. Individuals adopt different strategies to answer that question: some will look at previous days, others rely on their memory, and yet others will again start tracking their food, glucose, insulin, and activities more closely: *“I don’t really track much unless I am specifically looking for a pattern.”* – Intv, P4 (T1D)

Understanding changes in glucose patterns involves many factors. Although care-providers can provide insight into some abnormal results, they might not have the contextual and lifestyle information needed to interpret all results. This lack of context can lead to misunderstandings and frustration for the patients, especially if they feel that a doctor is reprimanding them about their glucose values without understanding the full context. As P4 noted, *“The chart of all my blood sugars, it’s, like, each number has a story behind it. And it’s like, I remember, you know, that meal or I was sick or, you know, there’s so much more than just numbers that goes into it.”* – Intv, P4 (T1D)

Glucose levels can start reacting differently over time for various reasons. Changes in glucose trends can be due to progression of the disease, as insulin production decreases in T1D and insulin resistance increases in T2D over time. Providers may ask individuals to track their diet and glucose in preparation for visits. This helps assess if there is any gradual change in trends, and provides concrete points for feedback if abnormal results are found.

*“It’s [been] two years now that I’ve had diabetes; it’s changing pretty significantly now. And so I’m having to like re-learn things that I thought I kind of at least had a feel for the last couple of years, [...] But I’ve noticed that I need more insulin for any of the carbs that I do eat. I need to take them earlier, like 15 minutes before. [...] Generally speaking, I need more insulin, so any of the numbers I did learn for the foods that I typically eat, I’m kind of relearning now, how it affects me now.”* – Intv, P10 (T1D)

In addition, there are events such as new treatment regimens that can affect glucose results. A new device, such as a continuous glucose monitor or insulin pump can also

drastically alter diabetes self-management. Travels or a new job disturb routines, and can also lead to changes in lifestyle and glucose results: *“To try to eat on a regular schedule, to try to eat foods that are appropriate on a regular schedule are not simple on the road”* – Intv, P2 (T2D)

Learning to manage diabetes is not a one-time shot, but rather a continuous process. As the circumstances change, patients have to relearn how their bodies react to different factors that were once a known quantity. The need for external support often goes up in these situations. Patients will turn to their clinicians as well as technology to regain control of their glucose levels.

#### **3.4.2.4 Long-term management and quality of life**

Long-term management of diabetes is important, because effective diabetes management can reduce complications. Yet, the disease does not remain patients’ main focus. Over time, patients start prioritizing quality of life again, leading to a need to balance glucose management with the desire to explore new foods and activities.

Individuals discover over time how the metabolism of glucose can be very intricate and sensitive to a range of factors: *“I’ve had [diabetes for] almost 20 years now, it’s crazy. But, I’m still learning everyday just what I can and cannot eat and – because even if you go straight off carbs, fiber, glycemic index, like there’s other things that go into it. [...] And glycemic load is a little bit dependent on the meal. So like if you eat like grapes by themselves, they might have a certain glycemic load but if you eat them with cheese, it’ll change it.”* – FG, P4 (T1D)

Yet, keeping glucose levels under control is not patients' only priority. Quality of life is an important consideration as well. As individuals grow to live with diabetes, there is a point when they understand enough about what behaviors they should adhere to, but also realize that they are not enjoying life as much as they would like to.

*"This quality of life: like I know that I can spend so much time and be so diligent and write everything down and do what you were doing in the beginning. But is that really worth it in the long run? [...] I test on average 10 times a day. [...] But that's seven seconds out of my life, the tracking. So that's definitely a goal of mine, [...] finding that balance a little bit better and maybe doing a little less work, but still getting the good results."* – FG, P4 (T1D)

*"I mean, you're not going to live your whole life watching, counting calories, every grape that you eat. I mean I'm getting really close to that point now where [...] I'm not thinking about my meals every day. I'm content with like, if I miss a snack so, I'll make it up at dinner."* – FG, P7 (T2D)

Type 2 patients not on insulin therapy frequently taper their glucose monitoring to avoid the unpleasant finger pricks required. Although this can be patient-initiated, providers also encourage this when results are satisfactory: *"Since I've been a diabetic for over 20 years, I just do it in the morning. I don't watch it other times of the day that usually ends up being a good reflection about how things are being handled."* – Intv, P1 (T2D)

As individuals loosen their dietary restrictions, they may wonder how this affects their glucose and initiate a short period of glucose tracking to see if they are still on track: *"I check [my blood glucose] once in a while when I do try something different, when I eat*

*something different or, you know, if I'm feeling awkward or something."* – Intv, P7 (T2D).

While some individuals used electronic spreadsheets or handwritten notes, others used smartphone weight-tracking applications that provided detailed information about the breakdown of foods.

Diabetes, like many chronic conditions, can lead to a variety of different emotions. The pressure of handling food choices, calculating carbohydrates and insulin doses, and testing glucose on a daily basis can lead to anxiety in some individuals: *"I want to be able to eat food. Like I want to be able to try food and not be really scared of everything I put in my mouth"* – FG, P4 (T1D). These emotions also occur in T2D individuals, even without insulin therapy: *"There's really a mental pressure. You're talking about the constant thing. It's a constant mental pressure on me to always keep track of what I eat, how much I eat, when I eat, and on and on"* – FG, P11 (T2D)

For many, the motivation to keep up with the many daily requirements of one's regimen is to stay healthy and delay the onset of complications or need for new medications. Many individuals are influenced by a parent or relative who has experienced, or even succumbed to these complications. Fear of consequences can drive motivation for self-management: *"The negative aspect would be knowing that eventually, [diabetes] will catch up. It's a non-stopping disease and eventually it will catch up with me and I don't know why, I don't know what will happen to my bones or my eyes or skin or heart or something will eventually go. [...]* *And that knowing is sometimes hard to handle, that knowing. So my own father passed away because of complications of diabetes."* – FG, P11 (T2D)

Others described feelings of guilt when their glucose results were less satisfactory. Consideration about staying healthy for their loved ones only compounds this feeling: *“I think I just start feeling guilty because [...] I was not managing my diabetes the way that I should. [...] And it's unfair to my husband to be so nonchalant about it. So there's that guilt that kicks you into action in a positive way.”* – Intv, P6 (T1D)

The balance between highly controlled self-management and spontaneous activities is a fine line. Individuals can push themselves by setting high standards with the risk of being too demanding, or they can feel pressure from their care-providers to improve numbers. Performance in disease management can be a sensitive topic, as P8 (T1D) describes: *“While I'm willing – able and willing to talk about my diabetes, I'm not – I don't want to have any perception of being judged.”* This may be why some individuals feel a particular affinity with peers, particularly care-providers who also have diabetes. There is a shared understanding that behaviors cannot be perfect all the time and less than ideal results do not invite critical judgment.

*“This doctor, who is a type 1 diabetic that I met at diabetes camp, [...] she was the only doctor I've ever met that like I felt like really understood and really just made it okay to eat ice cream if you knew what to do and... It's okay if you have high blood sugar every once in a while, just keep on going, and keep figuring out.”* – FG, P4 (T1D)

To an outsider, diabetes appears to be a burdensome disease with many requirements for testing, medications, lifestyle changes and restrictions in diet. Yet our participants had a very positive approach and expressed an acceptance with having to live with this condition.

Individuals with T1D tended to describe the disease as the way their body was, whereas T2D participants considered it as a wake-up call because they had become so unhealthy.

*“I still have diabetes, and I still have to do this every day. [...] That's the way I am as a person.”*

– Intv, P4 (T1D)

*“I always tell the doctor that being diagnosed with diabetes was the best thing that ever happened to me, because it stopped me in my tracks. I wish I did that I'd been diagnosed twenty years ago because I would not be in the same health situation as I am now.”* – Intv, P12 (T2D).

### **3.5 Discussion and design implications**

Our finding that self-management needs change over time aligns well with the Corbin and Strauss's Chronic Illness Trajectory (Strauss 1984) and suggests that technology will play different roles at different stages of the disease. In particular, based on our studies, we identified four functions where technology could play a supportive role: understanding the new disease, responding to changes in times of stability, improving communication, and tailoring to individual motivations and needs.

#### **3.5.1 Understanding the new disease**

Supportive technologies play a particularly useful role at the onset of disease, as patients create their mental model of the disease and its management. The DAWN study found that 85% of individuals reported a high level of stress (shock, guilt, anger, anxiety, depression, and helplessness) after receiving this diagnosis. (Funnell 2006) Mobile technologies can guide initial lifestyle choices of nutrition, physical activity, glucose monitoring or

medication in three ways: (1) Tools can *facilitate tracking* by guiding patients to easily capture a full range of factors that affect glucose levels. By taking advantage of sensing and lightweight self-report, a new generation of tracking apps could enable patients to log, with little burden, not only glucose levels and food intake, but also sleep, stress, physical activity, and other potentially relevant influences on glucose variations. (2) Applications can *support learning* by enabling patients to understand the interactions among the factors they are tracking. This data interpretation could be achieved through the use of visualizations, coaching (e.g.,(Mamykina 2010)), games, and through the use of machine learning algorithms for automatic pattern detection. For instance, a tracking application could not only visualize patterns in historical data, but also use logged data to provide visualizations of likely glucose changes over the next couple of hours—visualizations that could help the user understand and make more informed choices about different foods, activities, or types of insulin. Such visualizations could help the user to get an intuitive understanding of, for example, why foods with the same amount of carbohydrates can affect their bodies so differently or on what time scales different types of insulin work. (3) Finally, mobile applications can *support skill development* through the use of video clips, for instance, to teach patients how to perform a foot exam.

### **3.5.2 Responding to changes in times of stability**

Participants indicated that intense tracking and diet restriction occurred mainly in the early stages of disease. As individuals grasp how to make healthy choices and adopt healthier behaviors, the perceived benefits of intensive tracking are surpassed by the cost in time and effort. While ongoing glucose tracking is recommended for insulin use, it might

not be necessary for those who do not need insulin.(Farmer, Wade et al. 2007) In addition, as patients learn to estimate content of different types of foods, regular carb tracking becomes less useful. At this stage, the burden of tracking could be decreased for insulin users by switching to a lower-intensity mode for routine tracking, where information is added to the patient's log automatically (via the glucose meter and sensors), while maintaining enough data to enable the system to detect significant pattern changes that need to be brought to the patient's attention.

As the disease stabilizes and the concerns about quality of life take front stage again, individuals begin to break out of strict routines and experiment with new foods and activities. One role supportive technology can play at this stage is to support such experimentation while helping individuals to maintain good glucose control. One way to do this is through the creation of a personal knowledge base that patients can use to track their glucose responses and insulin use when they try new foods or activities. Such a system could help improve future decisions through rapid retrieval of prior personal experiences and may help reduce the anxiety of decision-making under uncertainty (P4, T1D and P11, T2D). This is also an area where a large-scale, patient-reported repository could be particularly useful. If a system knew insulin sensitivity parameters for different users, it could automatically use one user's data to recommend insulin dosages for the same food or activity to other users. Practical applications of this crowdsourcing framework include insulin recommendations for areas with inadequate standardized information available such as restaurant menus, athletic activities, travel, and other activities that affect patients' glucose levels.

Finally, one challenge in the period of stability is how to detect and communicate abnormal test results. Not all abnormal results require changes in behavior. Machine learning could help detect repeated anomalous events over a short period of time and prompt the user to make an appropriate change, such as changing the basal insulin rate. In our study, we found that the way to communicate a need for change is important. Warning alerts in response to a missing or abnormal glucose measurement may aggravate an individual's feelings of guilt or may be perceived as a judgment. Future research could explore the use of more subtle cues such as changing the color of the phone's wallpaper to provide a gentle indication to examine potentially concerning changes in glucose values.

### **3.5.3 Improving communication**

When individuals have a better understanding of diabetes and its management, they can select relevant information to report for in-depth discussions and useful feedback with their providers. P4 explains how there is a “story behind each [glucose] number”, a lens through which to interpret abnormal results. Self-management technologies should allow individuals to easily capture contextual information that might be relevant for interpreting their glucose results. Smith et al.'s work on photo annotation of glucose data is a step in the right direction.(Smith 2007) Easily connecting information about location, recent sleep history, workload, stress levels, etc. with specific glucose readings would further support learning and sense-making that can occur in discussions with healthcare providers.

Our findings showed a gap between patient expectations and provider guidance for websites and apps related to diabetes. Participants' providers welcomed various formats (paper, email or apps) for patient-reported data and appreciated patients' technological

expertise, but they were not a good resource of technical information themselves. Creating a well-maintained database of diabetes-related resources and their reliability could improve patient care.

Sharing with and learning from peers is important. Individuals with a disease can become experts in that disease.(Hartzler and Pratt 2011) Our participants readily turned to peers for practical information, such as food recipes or management of insulin with a new type of sport. Peers bring in a different type of information than the providers, because they “get it”, and grasp the challenge of having to always be on top of the disease management. Future technologies could make peer exchange of actionable information and social support easier by integrating a social component with tracking tools and enabling patients to seek support (e.g., on understanding why their glucose responded in a certain way to a particular food or activity) in the context of the information that prompted the need for support. How such social functionality can be designed in a privacy-sensitive and unobtrusive way is an open research challenge.

#### **3.5.4 Tailoring to individual motivations and needs**

Motivations for diabetes self-management vary: for some people delaying the onset of complications is a motivator, whereas for others that same thought creates anxiety. Likewise, for some, the mental burden of disease is increased with tedious data entry and tracking, or bothersome alerts, whereas for others, technology simplifies data retrieval and reminders serve their purpose, allowing patients to concentrate on other activities. Such differences can lead one patient to abandon the same technology that another patient finds invaluable. For these reasons, technologies intended for long-term not only need to support

simple customizations—enabling or disabling of reminders, for example—but may need personalization at a much more fundamental level. An application that had a robust user profile that included user’s goals, motivational orientation (e.g., whether the user is promotion- or prevention-focused,(Spiegel, Grant-Pillow et al. 2004)) attitudes toward illness, and other similar factors, could adapt its behavior to the user’s need at a deep level—employing motivational strategies to which the user would be most receptive, framing glucose results in terms that would not be discouraging, and using personalized content (e.g., user’s professional goals) to support health behaviors. How to construct such rich profiles with minimal user burden is an important research question.

Just as patients’ motivations vary, so do the situations in which they have to perform health activities. Such situations—locations, people patients are with, etc.—can act both as facilitators of and barriers to effective health management. Technology can further support patients’ self-management by helping them create implementation intentions (Gollwitzer 1999)—plans when, where and how they will perform health-promoting activities or resist activities that hurt their health. Given enough data from sensors and the information that the patients themselves log, technologies could both help patients to discover situations that influence their health-related activities and incorporate those situations into effective implementation intentions that can strengthen their health practices.

By taking into account how self-care needs change over time and the individual differences that shape diabetes management, future technologies could help patients with diabetes to manage their disease effectively over the long-term, contributing both to their health and quality of life.

### **3.5.5 Limitations**

Although our participants are representative of the two types of diabetes, a limitation of our study is the small size of our sample. Due to individual differences in approaches to diabetes self-management, the full range of needs for supportive technologies may not be entirely covered in our sample. Self-selection to participate in studies can be a bias, particularly as most of our participants had outstanding diabetes management.

### **3.6 Conclusion**

With several short-term studies showing promising results for mobile technologies in chronic disease management and in particular diabetes,(Lorig, Ritter et al. 2006; Liang, Wang et al. 2011; Quinn, Shardell et al. 2011) we need to explore how to establish long-term engagement with these technologies. Where self-management evolves over time alongside disease trajectories, engagement with technology also becomes a dynamic process. Our findings suggest that the design of tools for diabetes that support long-term engagement should allow periods where the individuals can suspend use of one or more features of the application. A tool that can accommodate intermittent use raises questions of how to reengage the user at timely moments when repeatedly abnormal results or new trends are detected. If designed properly and flexibly, such tools could help patients to better control their disease and communicate with their providers more effectively, improving their overall health and quality of life.

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## CHAPTER 4: Patient attitudes toward the use of incentives to support diabetes self-management<sup>2</sup>

Katherine Blondon, MD, MSc<sup>1</sup> Predrag Klasnja, PhD,<sup>2</sup> Katie Coleman, BM, Wanda Pratt, PhD,<sup>1</sup>

<sup>1</sup>University of Washington, Seattle, Washington; <sup>2</sup>University of Michigan, Ann Arbor, MI

### 4.1 Abstract

**Objective:** To improve our understanding of the potential of incentives to enhance diabetes self-management (type 1 and type 2) and to integrate incentives into a conceptual model of diabetes self-management over time. **Methods:** Based on in-depth individual interviews with patients and providers, we conducted a qualitative analysis focused on the influence of time on patients' needs for diabetes self-management technologies and on the use of incentives to drive behavioral changes. **Results:** Ten of the 12 participants with diabetes (83%) were interested in using financial incentives to improve their diabetes self-management. We found that incentives can play two key roles in diabetes self-management: guide the learning phase during the creation of habits; and serve as an acknowledgement of efforts made in the stable phase, when providers typically only focus on the patients' failures at self-management. **Conclusion:** Incentives are acceptable to patients, and have the potential to support diabetes self-management through either small monetary amounts or tangible rewards. **Practice implications:** Incentives hold promise for

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supporting behavior changes, especially in early stages of diabetes, but they require careful planning to avoid the undesired consequence of decreased intrinsic motivation.

## 4.2 Background

Diabetes is a common, evolving chronic disease, which affects nearly 26 million Americans, or 11.3% of U.S. adults.((ADA) 2012) The main goals of diabetes self-management are to prevent immediate health complications and to delay the onset of long-term complications.(Inzucchi, Bergenstal et al. 2012) Tight glycemic control—accomplished through significant lifestyle changes and, when needed, precise insulin dosing—has clear benefits for postponing type 1 (T1D) and type 2 diabetes (T2D) complications.(Ali, Bullard et al. 2012)

As with most chronic diseases, diabetes requires self-management almost exclusively outside of the clinic setting. Unfortunately, only 7% of adults with diabetes succeed in following all recommendations for optimal self-management (e.g., good glycemic control, low-carbohydrate diet, physical activity, medication adherence and disease monitoring).(Deakin, McShane et al. 2005) The low self-management success rate stems from a number of factors, including difficulties patients have in understanding appropriate diabetes self-management goals and in making necessary lifestyle changes to meet these goals, as well as difficulties providers have in prescribing adequate treatments.(Schmittziel, Uratsu et al. 2008) In particular, behavioral economics suggests that failures to adopt healthy behaviors could be a reflection of “present bias” or temporal discounting, which is a tendency to value small immediate rewards over large rewards in the distant future.(Logue 2000)

A recent approach to facilitating health behavior change has been the use of rewards for patients. Patient incentives are increasingly used to increase participation and engagement in health and wellness, with nearly 90% of employers offering reward programs for health.(Sutherland, Christianson et al. 2008; Serxner 2013) Incentives are powerful tools that can improve adherence to health assessment, smoking cessation,(Sigmon and Patrick 2012) and disease management.(Volpp, John et al. 2008) Although more research is needed, it appears that the effectiveness of patient incentives could be due to their ability to help individuals overcome the present bias by moving the rewards of healthy behaviors forward in time, serving as a proxy for the long-term outcomes.

Although patient incentives are widely used for wellness, they have not been used in diabetes self-management, other than in one small, randomized controlled trial.(Long, Jahnle et al. 2012) Although the design only incentivized the final goal without intermediary feedback and the results were not statistically significant, a 0.5% decrease in HbA1c was reported. We explore patient reactions to the idea of using incentives to support diabetes self-management.

### **4.3 Methods**

The findings presented in this paper were part of a larger study where we investigated the potential of technology and incentives to support diabetes self-management. After receiving approval from the Institutional Review Board, we recruited adults with T1D or T2D through flyers in the Diabetes Clinic of the University of Washington, snowball recruitment, and a diabetes support group from September 2011 to October 2012. We

excluded individuals with gestational diabetes because of its limited duration, as well as patients on dialysis, because of their frequent visits with their providers. Participants received \$25. We collected participants' socio-demographic characteristics, and their technology and healthcare use. We chose not to perform purposive sampling by disease duration, because the relationship between disease duration and disease stage varies with the effectiveness of self-management.

We led in-depth, semi-structured, individual interviews with 11 patients. Interviews ranged from 35 to 100 minutes. We also conducted a 2-hour focus group with four participants: three individuals with T2D (diagnosed in the past two years) and one with T1D (diagnosed 20 years ago). Three of the participants had been interviewed previously. During all sessions, participants discussed their disease, as well as their evolving needs, barriers and motivations. All participants were also asked about their anticipated responses to financial and non-financial incentives for healthier behavior. Finally, participants described which health parameters they monitored (dietary carbohydrates and calories, weight, blood glucose, etc.) and their choices of tools for tracking (paper, websites or mobile applications).

In addition to patients, we also recruited healthcare providers who manage individuals with diabetes in the Seattle, WA metropolitan area. We used purposive sampling to recruit providers of different backgrounds, including physicians, nurse practitioners, pharmacists, and a dietician. We interviewed providers about barriers and motivations for diabetes self-management faced by their patients. Part of the interview explored whether providers used financial or non-financial incentives with their patients.

All interviews and the focus group session were audio-recorded, and then transcribed for analysis. Three investigators (KB, PK, KC) coded the transcripts. We established prominent themes about motivations, incentives (financial and non-financial), diabetes self-management tasks, use of technology, and changes in needs over time. Following a grounded theory approach, we iteratively compared our coding schemes, revising or merging them to find common and contrasting themes.

## **4.4 Results**

Overall, our patients and providers found financial incentives acceptable, and expected incentives could help them improve their behaviors. They did however raise some concerns about equitability and privacy.

### **4.4.1 Participant characteristics and overall attitudes**

We enrolled a total of six T1D and six T2D participants, who had been diagnosed for periods ranging from 6 months to over 20 years. The patient characteristics are presented in Table 1. The age range in our sample is representative of T1D and T2D demographic characteristics in the general population. We enrolled nine providers: three primary care practitioners (2 physicians, 1 pharmacist), four diabetes specialists (2 physicians, 1 pharmacist and 1 certified diabetes educator), one ophthalmologist and a psychiatrist.

Table 4.1: Patient demographics and disease characteristics

	Type 1	Type 2
n	6	6*
Female: male	5:1	2:4
Age range	18-34 yrs	35-64 yrs
Duration of disease by participant	27 yrs (P3), 12 yrs (P6), 19 yrs (P4), 23 yrs (P8), 8 years (P5) 1.3 yrs (P10)	17 yrs (P1), 0.5yrs (P9), 21 yrs (P2), 1.5 yrs (P11), 0.5 yrs (P7) 1.2 yrs (P12)

\*Only one individual with T2D using insulin

Two of the twelve patient participants (1 long-term T1D, 1 newly diagnosed T2D) had prior experience with incentives to help them reach a health goal, while the other ten had not. Ten participants liked the idea of financial incentives, and only two thought that financial incentives would not help them adopt healthier behaviors. Both of these were long-term T2D who had not used incentives before. Both individuals with prior experience with incentives had used self-set goals and incentives to help implement healthy behaviors for self-management. One also benefited from incentives offered by his insurance plan for health assessments and wellness activities. Among the providers, three providers had discussed or used financial incentive programs with their patients.

#### 4.4.2 Perceived benefits from financial incentives

Participants expected financial rewards to help them acquire new behaviors. They also liked the recognition that rewards can yield to good results, in contrast to attention typically drawn to poor results.

##### 4.4.2.1 Rewarding health-promoting behavior

Participants expected financial incentives to be useful in several ways. First of all, participants who had used incentives described how they could be used to reward

small steps taken towards a bigger goal. A T2D patient shared her experience with incentives shortly after being diagnosed:

*“I actually challenged myself when I was first on metformin and my blood sugar was up in the 150s and 145 even with good eating. I hear that a 145-150 was not a good number for blood sugar. So I challenged myself and I told myself that if I could figure out a way, however it was, to get my blood sugar down under 110, that I would reward myself with something I really, really wanted. I rewarded myself for every 5 points that I lost in my blood sugar level, I would put \$5 towards the mp3. And then I could go out and buy it.... I didn’t want my blood sugar to go up there where it would be damaging my eye sight, where it would be making my feet tingle, I don’t want that. So for me the reward was not having bad eyesight, not getting [neuropathy]” – Pat12.*

In this example, we see how a reward can serve as a proxy to prevent a long-term complication. The participant used an immediate, measurable outcome to define the rewards and change her behavior, even while knowing that the long-term preventive goal was what was important. This kind of reward is perceived differently than just going out and buying something one wants. As Pat12 explained, *“Sure you can go out and buy it go to Target, put down your \$40 or whatever but there was a goal in mind there.”* At least for some individuals, then, even a small financial reward can be enough of a boost to motivate health behaviors, even when the actual amount of the reward is not perceived as financially significant.

Providers understood the potential of incentives to reward healthy behavior as well. A diabetes specialist shared her approach to patient incentives:

*“why do you not pay yourself to do what you know you wanted to be doing, you know you should be doing, it’s a job. Therefore you should have a salary, and you should pay yourself a salary. [...] if you walk for 15 min per day, you pay yourself a quarter. [...] that’s money that goes into a jar that you call ‘personal’. That is not to be touched for 6 months. [...] At the end of the six months, you have permission to open up that jar, and you spend that money on whatever you want, on something totally frivolous.”*

In addition to providing positive reinforcement for concrete actions, incentives might also help patients make health a high priority. Patients describe how they get caught up with work, forgetting, for instance, to eat at appropriate times. Providers reported that one common barrier patients reported was a lack of time. Participants thought that incentives could help with this problem. As Pat10 (T1D) expressed it, *“Some kind of monitoring incentive or some kind of changing the way my insurance worked would [...] force myself to make my health or make my diabetes care one of my top priorities.”*

#### **4.4.2.2 Providing visibility and legitimation**

Incentives not only create motivation for patients, they can also be recognition of the many efforts made towards better health, particularly from family and providers. One participant described this situation as follows: *“Two things about diabetes: (1) nobody else gets it and (2) you only get attention if something goes wrong. Your blood sugar is*

*good, you kind of get ignored, there's nothing to do about it and you're just kind of like, oh, okay, I'm in range whatever, you move on. But this kind of helps celebrate or you get points for when you are on target" – P5 (T1D).* By providing visibility of successful-self care, incentives might be able to reframe diabetes self-management from a process that is fundamentally about avoiding failure to one that is about successes—potentially greatly affecting patients' attitudes toward their illness.

Providers' experiences validate this point. As a diabetes specialist explained about the effect of incentives on her patients, *"[Incentives] can be a motivator because of that constant design of paying myself to legitimize my efforts, which means I legitimize my time, I legitimize my effort, I legitimize the fact that, yeah, I can do something myself. For many of us, that's really tough, you know, I should be doing something for the family, should be doing this for the school, should be doing this... But to say no, I'm doing this, I'm paying myself as a recognition of the energy and effort that goes into it."* Another participant emphasized the importance of this acknowledgement of constant effort from his health insurance as well: *"[Insurance-plan incentives] are good from a health perspective. It's also good from a morale perspective. [...] Just the fact that [my efforts] are, you know, acknowledged and tracked and quantified in some way would be meaningful."* – Pat3 (T1D).

#### **4.4.2.3 Financial help**

A few patients and providers spoke about the financial challenge of diabetes care, even when insured. The high out-of-pocket expenditures and insurance premium make any financial aid beneficial. Other tangible incentives mentioned were diabetes-related or

health-related in general, such as glucose strips, glucose tabs or vouchers for fruits and vegetables. One patient related incentives to saved costs for diabetes: *"[Having an insurance sponsor the incentives] would be my incentive because they would be acknowledging that what you're doing is saving you money upfront and long term and us money upfront and long term."* – Pat5 (T1D).

#### **4.4.3 Forms of incentives**

Gamification and reward programs have spread rapidly for health and wellness, taking form of rewards, lotteries and competitions. Choosing the right form for an incentive program might be key for its effectiveness. Some individuals might respond more to rewards, while others might prefer being in a competition. Age seems to be a key variable that influences the form of incentives to which individuals respond. Our providers told us about their successful experiences using stickers and financial incentives with young adults and adolescents. However, our participants did not think such incentives would work for adults. As one long-term T1D participant expressed: *"Gamification, rewards — I really don't get anything out of it. But I think, had it gotten out when I was younger or had the same kind of technology, it would have been really valuable"* – Pat5 (T1D). Similarly, most participants were not interested in competing against other people, because diabetes was considered a very personal issue. Instead, they felt they were competing against their own previous results: *"I'm not competing against him but I'm competing, you know, with myself a lot."* – Pat9 (T2D). In general, patients did not feel that having their name on a scoreboard would help motivate them to improve their diabetes management. *"If I were to be judged against everyone else, I*

*think [scoreboards wouldn't be helpful]"* – Pat8 (T1D). For diabetes, there is no personal benefit in being healthier than another diabetic. It is the absolute and not relative personal performance that will lead to better health outcomes.

Our results suggest, then, that the forms of incentives prevalent in other domains—gamification, competitions, etc.—might not work as a unique strategy for diabetes self-management. They might work for younger patients, but adult patients do not expect to be receptive to such incentive strategies.

Although participants favored financial over non-financial rewards, interestingly, participants did not think large amounts were needed to motivate them. Among participants willing to consider financial incentives for healthier behaviors, several spontaneously mentioned the amount of \$25 a month. One participant with insurance-sponsored incentives said: *"I don't think there's really a threshold or difference between like a hundred dollars or a thousand dollars, or a dollar that really exists, at least in my case."* – Pat3 (T1D). Rather than being primarily about money, financial incentives seem to be valuable for their psychological effects, which might be achievable even with relatively low amounts.

#### **4.4.3.1 Concerns about incentives**

Although improved health outcomes are the final desired goal, choosing which goals to reward can be difficult. Incentives can reward a process (tracking of results, for example), an outcome (HbA1c) or a change in outcome. Participants found incentivizing the tracking process less invasive and more acceptable than outcome-

tracking, although they understood the importance of improving the outcome for future health. Better tracking does not necessarily lead to a better outcome, but can be the initial step to behavior change.

One argument against the use of incentives was about the implied value of rewarded behaviors. This inferred judgment could be very discouraging when learning a new behavior. *"[Family camps] were really all about telling the parents to not judge. There is no good and no bad. It's just is what it is. [...] I think the reward system kind of goes against that because that's saying, "Oh, this is good." [...] It just seems sort of, like, patronizing."*- Pat4 (T1D). In addition, participants expressed concern about privacy when rewards require (1) having some form of health tracking, and (2) accepting that the funding source gets to see data about tracking (process) or glucose results (outcome).

Another concern had to do with the source of financial incentives. Patients were reluctant to have insurance companies see all their results, since they were concerned that they might lose their coverage based on that data. As Pat8 (T1D) said: *"The health insurances using [tracked process or outcomes] to motivate and/or kick people off of their insurance really actually bothers me."* Self-funded rewards were an interesting alternative that some of our participants had used.

## 4.5 Discussion

Diabetes self-management and its needs for support evolve over time. Prior research has found three stages to characterize this evolution.(Corbin and Strauss 1991;

Blondon 2013) The first stage occurs after receiving the diagnosis, when individuals are overwhelmed by the amount of diabetes knowledge, skills and behaviors that they need to rapidly acquire, and are driven by the fear of complications. The second stage is the stabilization, where individuals have developed effective routines for diabetes self-management, and have learned about the appropriate amount and choices of foods. At this stage, individuals have acquired self-confidence and self-efficacy about managing their diabetes in usual conditions, and the fear of complications has subsided somewhat. The third stage includes both acute and chronic changes. Acute changes occur often, and variations in glucose results can be due to unexpected changes in routine (forgotten meal, new restaurant for example) or an acute illness. Chronic changes are related to the progression of disease, increasing insulin needs, onset of diabetes-related complications, or improvements due to weight loss.

Overall, we found that most participants—both patients and providers—agreed that financial incentives could play a role in improving diabetes self-management. Incentives were acceptable to guide and motivate the implementation and short-term maintenance of better diabetes self-management behaviors. In addition, incentives acknowledged the efforts made, helped patients prioritize health, and made barriers seem easier to overcome. We can frame our results about motivations and incentives within the framework of diabetes self-management stages. Incentives can play an important role in facilitating the transition from the initial stage to the stage of stabilization. Early in the illness, incentives can encourage new health behaviors until the patient starts seeing changes in the outcome. Using incentives in this way could help maintain new behaviors, leading to improved knowledge and better self-efficacy.

During this time, incentives might also help by making self-management a priority. Incentives can help with patients whose initial motivation (fear) might not be strong enough to drive chronic behavior change or who sharply discount negative health outcomes.

The need to incentivize behaviors is likely to change over time, though. Improving test results, or no longer requiring medication or glucose testing in T2D, are positive feedback that could become intrinsic motivators to maintain healthy behaviors, and could replace the need for financial incentives in the long-term. For some patients, however, incentives might play an important role even in the later stages. During these stages, rewards could help reinforce successful self-management, which is sometimes lacking from the care-providers.

How incentives should be implemented is an important and complex issue. Wide availability of smartphones, for instance, creates opportunities for low-effort tracking and immediate gratification through in-app reward systems. Using a smartphone app could also allow for better individualization of the rewards, by adapting to baseline knowledge and stage of disease management, and by identifying areas that are more challenging for each person.

The amounts of financial incentives are important to consider. Our participants suggested relatively small amounts compared to out-of-pocket costs (\$350-500/month),(2009; Novak 2013) such as \$25 per month for tracking and reporting glucose results. Employers typically employ similar amounts for action-based incentives, or rewards for taking action (joining a weight loss program, for example)

after going through a risk assessment.(Wieczner 2013) Prior research has found that very large amounts can lead to lower performances, because the individual feels pressure to perform well. Likewise, amounts that are too small lead to lower performances, even lower than those who do not have any incentive.(Kamenica 2012) These considerations suggest that our participants' intuitions about the reward amounts are in the right ballpark, although this needs to be evaluated empirically.

A number of questions about incentives remain unsolved. Although many larger companies and health insurance companies already have incentivized reward programs for wellness or health, participants raised concerns about payers' access to data that would give them more power to choose to keep or cancel insurance contracts. Potential ethical questions arise from rewarding individuals with diabetes—particularly in the case of T2D, which is partly due to unhealthy behavior patterns—and not the healthy individuals. Equitability and privacy will depend on the precise structure of each given incentive program.

Finally, using financial incentives to motivate behavioral change raises controversies due to the “undermining effect,”(Deci 1971; Deci, Koestner et al. 1999) as the removal of an extrinsic motivator has been shown to decrease intrinsic motivation.(Deci, Koestner et al. 1999) In most weight loss studies, people revert back to prior behaviors after discontinuing the incentive.(Volpp, John et al. 2008; John, Loewenstein et al. 2011) One study showed, however, that lower financial motivation has less undermining effect than higher financial motivation: the lower incentive group did not revert back and regain weight after discontinuation of the incentive, whereas the

higher incentive group did.(Moller, McFadden et al. 2012) In addition, a meta-analysis on the effect of rewards on motivation found that financial rewards could be used to enhance time and performance on tasks that initially held little enjoyment without any evidence of the undermining effect.(Deci, Koestner et al. 1999; Cameron, Banko et al. 2001) Many tasks in diabetes self-management can be perceived as tedious, particularly when people do not see an immediate benefit from their actions. Choosing to incentivize tedious tasks like glucose tracking could be a part of the initial step towards understanding the relationships between the type and quantity of food, exercise and glucose results. Nonetheless, the mixed results from prior studies clearly indicate that financial reward programs need careful consideration and that more research is needed on how incentives can be used while providing support for the transition from extrinsic to intrinsic motivation.

#### **4.5.1 Limitations and strengths**

We provide an in-depth analysis of the attitudes toward the use of incentives for better diabetes self-management. Although the interest in financial incentives for health and wellness is growing rapidly, they have only been studied for diabetes in one small clinical trial. Another strength of our study is the integration of both patient and provider data, as providers have an overview of how their panel of diabetic patients manages their disease. This combined data source allows for better generalizability of our findings.

The limitations to our study lie mainly in the study design. We enquired about attitudes toward incentives, which are *expected* responses for all participants who had

no prior experience with incentives for health. Although our study found that incentives are a promising avenue for supporting diabetes self-management, the accuracy of participants' expectations can only be established through a study of an actual incentives program. Finally, although in-depth interviews allow for a better understanding of the relationships between the various factors involved in diabetes self-management, the number of participants was relatively small. Future studies are needed to further explore the acceptability and feasibility of incentives for diabetes self-management in a larger population.

#### **4.6 Conclusion**

Our participants found financial incentives acceptable to improve diabetes self-management, as they have the potential to guide learning of new behaviors, decrease present bias, and give recognition for successful self-care. Competitive reward designs were expected to be more effective among younger people. Incentives were proposed to be small financial amounts or diabetes-related tangible gifts to reduce out-of-pocket costs. Although concerns for privacy and equity exist, incentive programs have already been implemented for weight loss or smoking cessation.

#### **4.7 Practice implications**

Patient incentives have the potential to improve diabetes by guiding self-management in early stages of disease and recognizing the efforts that are constantly required. Reward programs need to both respect patient privacy and avoid the undesired consequence of decreased intrinsic motivation through careful planning. Future

studies are needed to determine the design of the incentives and to assess the actual effect of incentives in a large diabetic population.

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## CHAPTER 5: Discussion and conclusions

### 5.1 Discussion

In my dissertation, I explore the potential of smartphones among individuals with diabetes as supportive tool for diabetes self-management. The rapidly growing adoption of these devices in the general population, particularly for health and wellness, have led to innovative ways to use applications to guide and support behavioral changes for diabetes care. In this conclusion, I start by discussing the implications of the reach of smartphone use in the diabetic population compared to that of the general population, particularly in relation to age, as well as demographic and socioeconomic factors, which affect smartphone adoption and the prevalence of diabetes. A better understanding of smartphone users and non-users can guide future design and dissemination of this tool and identify its limitations for diabetes self-management.

Drawing from Chapter 3, I then review the needs for supportive technology in diabetes self-management, particularly in smartphone applications, and discuss how these needs evolve over time, driven by changes of the disease itself and of the effectiveness of diabetes self-management. Our findings suggest new ways to engage individuals for long-term use of smartphone applications for diabetes.

Finally, I discuss possibilities and challenges in the use of financial incentives to improve diabetes self-management. Behavior changes required in diabetes self-management are complex and challenging to motivate and maintain. In chapter 4, I

studied patient and provider acceptability and perceptions of the use of financial incentives for behavior change in diabetes, because smartphones are a unique tool for incentive programs. Keeping smartphones within easy reach, as most users do, facilitates tracking and allows rapid provision of feedback and rewards, all of which can optimize the effectiveness of incentives. Challenges and controversies about financial incentives for diabetes self-management remain, however, particularly for privacy and equity.

Through these three studies, I underline the growing role that smartphones have in diabetes self-management in improving access to quality care for certain underserved populations, in learning, in organizing and visualizing data, in reporting and communicating data with providers, and in providing feedback and incentives to promote behavior changes. Yet despite its rapid growth, smartphone use currently does not reach all individuals, and careful consideration is needed to avoid increasing disparities in diabetes care.

### **5.1.1 Reach of smartphones for diabetes self-management**

The aim of the study in Chapter 2 was to identify the reach of smartphones in a population with diabetes, compared to those without diabetes. In our nation-wide sample, the likelihood of smartphone use among individuals with diabetes was lower than among individuals without diabetes, even after adjusting for age, race, ethnicity and SES (RR 0.78, 95% 0.57-0.98). Although smartphone uptake continues to rise in all age groups, including in older adults—late adopters in Rogers’ theory of diffusion (Rogers 1995)—this gap is concerning, particularly as unmeasured diabetes- and age-

related factors could disproportionately contribute to this gap among the older adults. Furthermore, the main barrier for technology use among the older adults might be the lack of perceived relevance or benefit, as reported in a study on Internet use: half of these individuals feel they can get the desired information elsewhere, 20% evoke price-related issues and 20% cite usability issues.(Zickuhr and Smith 2012) Understanding this gap in smartphone use is therefore needed to avoid increasing disparities in diabetes care, as the healthcare delivery system seeks to move towards using supportive mobile technologies for diabetes. Our findings should guide future research on smartphone use and design to discover how to address the barriers for smartphone use. Our findings also imply that this solution does not currently fit all individuals with diabetes, however, and efforts to improve diabetes self-management using standard care need to be pursued.

The higher smartphone use among younger adults has two main implications. The first implication is that smartphones could play a bigger role for newly diagnosed individuals. Although the individuals with diabetes are older than the general population, over 1.5 million US adults between the ages of 20 and 64 years are newly diagnosed with diabetes each year. Diabetes applications are particularly helpful to learn about and guide diabetes self-monitoring early in disease, as we saw in Chapter 3.

The second implication is that smartphones can be used to improve preventive care. Many wellness and health applications seek to modify lifestyle behaviors and choices. Although studies have shown the effectiveness of preventive programs for diabetes

and in preventing cardiovascular events, we await studies with interventions using smartphone applications.

Smartphones have the potential to help bridge the “digital divide”—or population-level gap in Internet and computer access— through its higher reach in racial ethnic minority groups, and high use in the younger adults in spite of lower SES. The digital divide has been a concern for equity of access to care, by isolating those who are older, who have lower SES and from racial ethnic minority groups. (Neter and Brainin 2012) These demographic characteristics also characterize a population with higher prevalence of diabetes. ((ADA) 2012) We found that Blacks, Asians and Hispanics are more likely to be smartphone users than Whites and non-Hispanics after adjusting for diabetes, age and socioeconomic status, as was suggested in prior studies.(Pew Research Center 2010) Furthermore, the use of technology varies with race and ethnicity, as Blacks and Hispanics tend to access Internet from their mobile browsers rather than from computer browsers, and tend to use more social media than Whites and non-Hispanics.) The mobile browsers and increasing use of Internet among the older adults are closing the gap for Internet.(Zickuhr and Smith 2012) Future studies of the still rapidly growing smartphone adoption are needed to determine which proportion of the underserved population can be reached by smartphones.

Diabetes- and age-related impairments can be addressed in part through innovations in the design of mobile devices and their applications. Diabetes leads to complications and comorbidities that impair physical and cognitive disabilities—most of which also occur commonly with older age—which hinder the use of technology.(Chun and

Patterson 2012) For example, eye disease makes small smartphone screens with small fonts difficult to read, and lower dexterity due to peripheral neuropathy can make the small touch screens hard to manipulate. Senior adults >65 years accounted for 4.4 million smartphone users in 2011, up 127% from 2010.(Owens 2011) Some companies are targeting senior adults with devices with larger screens (e.g, phablets), as well as new applications to slow down speech rate or to optimize comprehension when calling through age-specific audio frequencies.(Fried 2013; Miller 2013) For diabetes applications, older individuals have higher use of medication-related features (reminders, trackers, etc.) and future design should also consider larger fonts, and innovations such as voice recognition to address visual impairments and decreased dexterity, for example. For cognitive decline, small or focal deficits could be assisted by technologies with sensors and reminders, whereas more global or severe cognitive decline might have more limited benefits from smartphones.

### **5.1.2 Needs for adapted supportive technology in diabetes self-management**

In Chapter 3, I found that diabetes self-management can be conceptualized in a 3-stage framework, based on my data: the initial stage after diagnosis, the stabilization stage and a “response to changes” stage involving both acute or chronic changes. Using this framework, I found that the features of current diabetes applications such as tracking tools and reminders are useful particularly at the initial stage of diabetes, by guiding the disease monitoring, helping create habits and building knowledge to reach the stabilization stage. With time, however, these tools lose their benefits. For instance, intense tracking becomes tedious and the information provided becomes less useful as

individuals become more familiar with diabetes self-management. The results suggested a need for new designs in diabetes applications for individuals with longer duration of disease: the new design should be able to detect abnormal patterns and use them to trigger temporary tracking.

Although the perceived effort intensive tracking increases over time with a decrease in perceived benefit, innovations in sensing could perhaps change patient perspectives. New methods for “effortless” tracking are being developed, such as ingestible tracers to track medication adherence, transcutaneous glucose measurements, or sensors in clothes. Yet not every parameter has such promising solutions: food data entry is one task that patients find particularly tedious and time-consuming task. Some developers are studying the use of barcodes or photo analyses, but these solutions are still far from being available as an application.

Long-term engagement with technology in diabetes might take on a new meaning in diabetes. Although engagement is usually defined by continued use of an application, our study findings suggest that long-term engagement in diabetes could mean an intermittent use of the application, perhaps with intermittent reminders, or alerts triggered by a pattern of abnormal results. For example, if glucose results are abnormal in several measurements, an alert could be sent from the application, requesting whether the user wishes to resume tracking of the given parameter. Future studies are needed to establish whether continuously tracked data during long periods still retains a benefit for diabetes self-management, and whether the type of data

tracked (steps walked vs blood pressure, for example) affects the usefulness of the tracked data over time.

An interesting finding from this study was the vulnerability patients feel when they report their glucose results. Participants were very sensitive to negative comments on their results, and described feeling easily judged by their providers or family. This stems from the strong link between choices patients make for food and lifestyle behaviors and their blood glucose results. Although a similar link exists between taking medications and other outcomes such as anticoagulation or blood pressure, patients are more likely to report these outcomes rather than blood glucose. This barrier to reporting glucose results can be partially addressed by facilitating data entry for glucose results (through Bluetooth or devices that connect to the phone directly, such as the iBGStar®), but this still requires performing the actual testing.

The participants in my study shared their often-unmet expectation of receiving guidance about electronic resources (websites or applications) for diabetes from their care-providers. These resources evolve rapidly, and might not necessarily be well publicized. Providers do not have the time to keep up with these rapidly changing resources, and until recently, did not have a medically certified source that can provide this information. Furthermore, applications are often not developed with or overviewed by a medical professional. Until mid 2011, the Food and Drug Administration was largely silent on the regulation of smartphone applications, and does not propose to regulate applications that are used to track general health and wellness, according to the current draft guidance (final guidance planned for Oct.1,

2013). Despite some medical liability when prescribing any electronic resource to their patients under the “learned intermediary doctrine,”<sup>3</sup> some providers are setting a new trend in clinical care, by starting to prescribe applications for health.(Bowman 2013) An m-Health solutions company, Happtique,(Happtique 2013) has recently launched a new certification process for applications in collaboration with the Association of American Medical Colleges (AAMC) to support providers for prescribing applications for health.

### **5.1.3 Patient incentives for diabetes self-management**

In Chapter 4, I found that overall, patients and providers found financial incentives to be acceptable for improving diabetes self-management. The participants expected incentives to help them overcome present bias, with small rewards to encourage the steps leading to the final goal. They also expected incentives to help prioritize health in their daily choices: for example, incentives could help them keep to a regular meal schedule at work during hectic days. The incentives were also perceived as positive reinforcement of good diabetes self-management. As seen above, individuals with diabetes are very sensitive to feedback about glucose results, and participants felt that comments—particularly from their care-providers—often focused on the bad results. Incentives were expected to help validate the good health results on behalf of providers, employers and/or insurance plans.

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<sup>3</sup>*Ellis v. C.R. Bard, Inc.*, 311 F.3d 1272, 1280 (11th Cir.2002)

Smartphones offer a unique opportunity for supporting behavioral change as they are usually “glued” to the owner during the day. This facilitates data tracking, and makes it more accurate than having to get back to one’s computer later in the day. Smartphones can also provide feedback and rewards with very little delay, therefore improving behavior changes. Smartphones could allow users to have a customized reward program, by providing a choice of goal topics that users could prioritize (e.g., smoking cessation before weight loss), for example. Yet the degree to which programs should be customizable is not clear: a meta-analysis of financial incentives for weight loss programs found that incentives were more effective in programs with imposed weight loss goals compared to programs with self-set goals. Further studies are needed, particularly in a diabetic population where there is a range of lifestyle habits to change, to inform the design of reward programs for diabetes self-management.

Financial incentives, although supported by the 2010 healthcare reform, still have many unresolved issues, particularly for equity and respect of individual privacy. The participants shared their concerns about sharing additional personal information with insurance plans, which could then use that information to cancel their contracts. One way to work around this could be to create applications that can document results and provide rewards, but without divulging the detailed information to the payer. The two major concerns for equity are (1) rewarding individuals with diabetes who have unhealthy behaviors while not offering the similar opportunities for rewards among those without diabetes, and (2) disproportionately rewarding sicker or healthier individuals, depending on the chosen goals in the reward program. Goals can be process- or participation-based, outcomes-based or progress-based, each of which will

have trade-offs. For instance, rewarding outcomes favors the healthier, whereas rewarding progress will favor the sicker. Although rewarding participant is the most equitable, participation does not necessarily lead to improved outcomes, and would therefore returns on investment might not be beneficial for the payer.

Another major unresolved issue is the source of funding for the rewards. Possible sources of rewards include insurance plans, employers, or even self-funded rewards. Although higher patient engagement can lead to reduced costs, the delay until the costs are avoided could be several years. Patients might need to commit to a reward program over several years to avoid switching insurance plans before the payer can benefit from the improved health. Future cost-effectiveness studies comparing various models for rewards will be needed to determine the best design for reward programs.

The duration of reward programs, or its sequential design after reaching one goal, also need careful consideration. Controversies about the negative effect of financial incentives for intrinsic motivation are source of concern, because it is intrinsic motivation that needs to be supported for successful long-term behavior change. Finally, goals and rewards need to be carefully framed for participants, as perceptions are the driving force behind feelings of injustice and inequity, and will influence their willingness to participate. For instance, a monthly rebate for responding to a health assessment can be perceived as a monthly surcharge for those who do not want to share their health information. As shown in research in positive psychology, the mental framework can influence the outcomes,(Fredrickson 2009) so participants' perceptions of the reward program should be kept as positive as possible.

## 5.2 Implications

Although smartphones have many potentially useful features for diabetes self-management, they might not be able to help all individuals equally. First, the reach of smartphones is lower among individuals with diabetes, compared to those without diabetes. This gap in smartphone use persists after adjusting for age, socioeconomic factors and race and ethnicity. Second, the devices and applications (small fonts on small screens) are not well adapted for diabetes and age-related impairments. (Chun and Patterson 2012; Cheung, Janssen et al. 2013) Third, as we saw in Chapter 3, most diabetes applications are more useful for recently diagnosed diabetes, and lack features to support long-term use. Furthermore, older individuals might not use a new technology because they already have a way to get that information or accomplish that task. Nearly 85% of the patients with diabetes currently tracked health information in Chapter 2, but <4% use smartphone applications for this purpose: many patients use pen and paper, or spreadsheets to record their data. Finally, as the majority of older individuals have non-insulin dependent type 2 diabetes, self-monitoring of blood glucose—a quasi-universal feature in diabetes applications—might not be needed, particularly in the long-term. These individuals might have greater use of medication-related features, or features for smoking cessation, which to my knowledge is never integrated in diabetes apps. Therefore, although healthcare delivery systems hope to rely more on smartphones applications for diabetes self-management, other options need to be maintained for older adults. In-person visits, phone calls, telemedicine (Shea, Weinstock et al. 2009) and shared medical records with secure

messaging(Weppner, Ralston et al. 2010) can effectively engage older patients, and should not be replaced by smartphones.

The reach of smartphones among the newly diagnosed individuals with diabetes provides a unique approach to improve diabetes care. Although diabetes is more frequent among older adults, over 1.5 million new diagnoses occur in individuals between the age of 20 and 64 years each year in the U.S. (Prevention 2011) This younger age group is more likely to be smartphone users than individuals with diabetes. They will also include more racial and ethnic minorities, who have a higher prevalence of diabetes. Smartphones and diabetes applications can therefore be a particularly useful tool for diabetes self-management, particularly shortly after diagnosis, in this population. Furthermore, as seen in Chapter 4, this younger population could be more receptive to gamification and financial incentives to motivate diabetes self-management. Although incentives still need further clarification, having a device to deploy an incentive program, which optimizes tracking and administration of rewards is a step forward.

Smartphone use among younger adults emphasizes its potential to improve preventive care overall, and particularly for diabetes. Prediabetes is defined by abnormal glucose levels that remain below the threshold for diabetes and predisposes to type 2 diabetes.(Prevention 2011) The prevalence of prediabetes in 2008 was 79 million or 35% of the U.S population aged 20 years and older.(Prevention 2011) Diabetes prevention programs can effectively decrease the incidence of diabetes through lifestyle changes, with a decrease in the incidence of diabetes ranging from 24% to

43% high-risk adults.(Albright and Gregg 2013) Although many applications support a variety of healthy lifestyle changes, weight loss seems to be the most effective in preventing diabetes. Moreover, the use of financial incentives for weight loss can improve the effectiveness of weight loss interventions. (Volpp, John et al. 2008; John, Loewenstein et al. 2011; Kullgren, Troxel et al. 2013) Future studies are needed to assess the effectiveness of smartphones in preventing diabetes through financial incentives for weight loss.

The lower use of smartphones among individuals with diabetes compared to individuals without diabetes is only a proxy to estimate smartphone use for diabetes. Using a smartphone does not necessarily imply that it is being use for diabetes self-management. From the patients in Chapter 3, we learned that many individuals do not use smartphone applications for diabetes because they do not know about them. An approach to increase smartphone use for diabetes might therefore be to improve awareness about diabetes applications. Although this awareness will not change the gap in overall smartphone use, it will reduce the difference between smartphone use overall and smartphone use for diabetes. Care-providers guide their patients, providing information about available resources for diabetes, and thereby increase awareness about applications. I am not expecting individuals to acquire a smartphone to manage their diabetes, I am simply suggesting that providing patients with better information about available resources for diabetes, including websites, online communities and diabetes applications can contribute to better self-management.

### 5.3 Conclusions and future directions

Understanding the reach of smartphones is a key step in seeking to use smartphones to improve diabetes self-management, because smartphones do not reach all individuals equally. In my first study about the reach of smartphone in a diabetic population, compared to a non-diabetic population, I found that there currently is a gap in smartphone use in these two populations, with lower smartphone use among individuals with diabetes. Although the older age of these individuals and their lower SES cannot be influenced, new designs of smartphones and diabetes applications could address some of the diabetes-related impairments (lower dexterity, lower eyesight and higher cognitive decline) that contribute to this gap. Although the uptake of smartphones in the older adults continues to increase slowly, this gap in smartphone use among older patients with diabetes will persist. My findings also revealed, however, that smartphones have the potential to help close the gap among racial ethnic groups with diabetes, through a higher use among Blacks, Asians and Hispanics, who have a higher prevalence of diabetes. Future research in diabetes self-management must take these findings in consideration both to avoid increasing disparities in diabetes care and to define the optimal target population for smartphones. Although healthcare delivery systems are hoping to rely more on smartphone applications for diabetes self-management, older adults are more likely to benefit from in-person or phone support for diabetes care, at least for the time being.

Many applications have already been developed for diabetes self-management. Most of the features in these applications are particularly useful in the early stages of diabetes.

Studies on smartphones have started to show their benefit in diabetes self-management. Furthermore, the majority of new cases of diabetes are diagnosed each year in the 20 to 64-year-old age group. As this demographic group is also rapidly adopting smartphones, diabetes applications could be particularly useful to this population. Yet research needs to continue to improve the design of diabetes applications, particularly taking into consideration the changing needs for supportive technologies as patients acquire knowledge and new habits in diabetes self-management. For instance, detecting abnormal patterns in various health parameters, and designs for intermittent use could be useful at later stages. Furthermore, with the growing interest in incentives, new diabetes applications could integrate financial incentives to reward either tracking or outcomes. Although the 2010 healthcare reform made provisions for incentives, careful considerations need to be made when implementing an incentive program. Future research is needed to study many yet unresolved issues in incentive programs.

Smartphones also have an important role to play in preventing diabetes. About 35% of the US adults (79 million individuals) have pre-diabetes.(Prevention 2011) Progression to diabetes can be delayed by lifestyle changes, such as losing weight or increasing physical activity.(Albright and Gregg 2013) The higher use of smartphones among racial and ethnic minority groups and among younger adults, particularly those with low SES, makes this device a particularly useful tool in diabetes prevention. Young age and low SES could also increase the interest in financial incentives for behavior change. By engaging patients to be more active for their health, smartphones could

lead to more effective lifestyle changes, with or without incentive programs, and contribute to controlling healthcare costs through prevention.

In spite of the disparity in smartphone use, with higher uptake in the younger adults and in those with higher SES, I believe that smartphones are an important approach to healthcare. They can improve the health of a subset of the population, and therefore allow the saved costs from this healthier population to be spent on those who are beyond the reach of smartphones. As long as healthcare promoters realize that there is a subset of the population that will not benefit from smartphone technologies, they can plan and provide more adapted care for that subset.

Future directions for my research on smartphones and diabetes will include analyzing the survey I conducted on smartphones, diabetes and financial incentives. I also plan to complement the study in Chapter 3 with a paper with a conceptual model on the changes of needed technological support during the course of diabetes. Finally, I plan to finish the initial project intended for Chapter 2, using a dataset on the use of Group Health's patient portal, and studying the access by smartphone in a population with diabetes.

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