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Supporting Diabetes Self-Management with Ubiquitous Computing Technologies: A User-Centered Inquiry

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Supporting Diabetes Self-Management with Ubiquitous Computing Technologies: A User-Centered Inquiry

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DECLARATION

I have personally conducted all the interviews, surveys, user-interaction studies, focus groups, and processing of data presented within this thesis, with the exception of coding by co-authors to determine intercoder reliability. That being said, the questions asked, methods, approaches, and interpretations of collected data have been influenced by the many hundreds of people I have talked to and worked with during the last several years. This includes not only my thesis supervisors, but also all the patients, participants, clinicians, industry professionals, academics, conference attendees, and others, who have impacted my research process.

In addition, my supervisors have assisted in all stages of this research. The majority of material found in Chapters 5, 6, has been previously published at CHI 2018 while at the time of writing this thesis much of Chapters 7 & 8 has been submitted for conference consideration. While I have been the first author on these and the following submissions, my supervisors provided invaluable assistance structuring, editing, and finalizing these papers. In addition, in 2016-17 I worked with Roche Diabetes Care within a patient-initiative design lab which contributed to ongoing internal projects and design concepts, as well as sponsoring a series of stakeholder design workshops which were based upon the independent academic research conducted for Chapter 5. While I have observed all IP agreements undertaken as part of that process, this collaboration contributed to my domain knowledge and idea process. I also participated in doctoral consortiums at Ubicomp 2016 and CHI 2017 which both offered the opportunity for critical feedback from peers and senior academics.

Many of the ideas and some of the figures and tables in this thesis have been published previously in the following:

Katz, D. S., Price, B. A., Holland, S. and Dalton, N. S. (2018) 'Designing for Diabetes Decision Support Systems with Fluid Contextual Reasoning', *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, Montreal QC, Canada, ACM Press, pp. 1–12. DOI: 10.1145/3173574.3174199.
Available at: https://oro.open.ac.uk/53363/

Katz, D. S., Price, B. A., Holland, S. and Dalton, N. S. (2018) 'Data, Data Everywhere, and Still Too Hard to Link: Insights from User Interactions with Diabetes Apps', *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, ACM, p. 503.
Available at: http://oro.open.ac.uk/53364/

Katz, D. S., Dalton, N., Holland, S., O'Kane, A. and Price, B. A. (2017) 'Questioning the Reflection Paradigm for Diabetes Mobile Apps', in Giokas, K., Bokor, L., and Hopfgartner, F.

(eds), *eHealth 360°: International Summit on eHealth, Budapest, Hungary, June 14-16, 2016, Revised Selected Papers*, Cham, Springer International Publishing, pp. 315–326.
Available at http://dx.doi.org/10.1007/978-3-319-49655-9_39.

Katz, D. S. (2017) 'More Than Numbers: Designing Effective Diabetes Decision Support', ACM Press, pp. 286–290 DOI: 10.1145/3027063.3027127
Available at: https://dl.acm.org/citation.cfm?id=3027063.3027127

Katz, D. S. (2016) 'Investigating the viability of automated, intuitive, and contextual insights for chronic disease self-management using ubiquitous computing technologies', *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct*, ACM, pp. 423–428.
Available at: https://dl.acm.org/citation.cfm?id=2971356

Katz, D. S., Arsand, E., Dalton, N., Holland, S., Martin, C., Olsson, C. M. and Price, B. A. (2016) 'Designing, developing, and evaluating the future internet of personal health', *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct*, ACM, pp. 1068–1073.
Available at: https://dl.acm.org/citation.cfm?doid=2968219.2972709

Katz, D. S., Dalton, N. and Price, B. (2015) 'Failing the challenge: Diabetes apps & long-term daily adoption', *International Conference on Advanced Technologies & Treatments for Diabetes (ATTD 2015), 18-21 Feb 2015, Paris*. DOI: 10.1089/dia.2015.1525.
Available at: http://oro.open.ac.uk/43222/

All figures and tables have been created by the author with the exception of Figures 8-9, 8-10, and 8-11 which show prototype interfaces supplied under the condition of anonymity by the startup in the study as well as various commercial app interfaces displaying the author's data under fair use.

Abstract

Ubiquitous computing technologies offer opportunities to improve treatments for chronic health conditions. Type 1 diabetes is a compelling use-case for such approaches, given its severity, and need for individuals to make frequent care decisions, informed by complex data. However, current apps, typically based on effortful reflection on collected data, generally show poor adoption, lack vital cognitive and emotional support, and are poorly tailored to users' actual diabetes decision making processes. This thesis investigates how diabetes apps can be improved from a user-centered perspective. An initial questionnaire-based study investigated how well existing diabetes apps meet user needs. Perceived benefits, limitations, and reasons for low adoption rates were identified. A talk-aloud study of detailed user interactions with diabetes logging apps was conducted to characterize the benefits and limitations of diverse UI elements for T1 diabetes management, and to more precisely identify wider problems with current interaction designs. This led to positing a refined version of Mamykina et al.'s model for diabetes self-management, to account for observed practices, whereby the previously accepted *habitual* and *sensemaking* cognitive states are augmented by a posited 'fluid contextual reasoning' (FCR) mode, which allows multiple contextual factors to be balanced for dynamic course correction when navigating complex situations, using previously learned knowledge. To investigate user perceptions of the levels and kinds of monitoring anticipated in next generation diabetes decision support systems, a 4-week technology probe, in which participants used multiple networked devices and external data aggregation, was used to frame requirements for user-centered development of such future systems. Integrating all of the above work, an iterative design process was undertaken to create DUETS, a card-based system to facilitate reflection by designers, users, and other stakeholders on diabetes support management systems. The resulting tool and method were then implemented and evaluated through structured sessions with stakeholder focus groups.

Acknowledgements

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Nomenclature

AADE7	American Association of Diabetes Educators 7 recommendations
AP	Artificial Pancreas
BG	Blood Glucose
CLS	Closed Loop System (also Artificial Pancreas)
CGM	Continuous Glucose Monitor
DS	Decision Support
GDPR	General Data Protection Regulations
GPS	Global Positioning System
HbA1c (A1c)	Hemoglobin A1c (a measurement of long-term blood glucose levels)
HCI	Human Computer Interaction
MDI	Multiple Daily Injections (Insulin therapy)
mHealth	Mobile Health
PWD	People with diabetes
PWT1D	People with type 1 diabetes
QOL	Quality of Life
T1D	Type 1 diabetes
T2D	Type 2 diabetes
UI	User Interface
UX	User Experience

Chapter 1: On Balance

"Unnecessarily complex tasks can be restructured, usually by using technological innovation."

— D. Norman, The Design of Everyday Things

1.1 Introduction

Type 1 diabetes is an auto-immune condition whereby the beta cells in the pancreas are unable to produce the hormone insulin. This is problematic as without insulin, the body is unable to properly transport glucose from the blood stream, causing blood glucose levels to rise to dangerous levels. This causes a cascade of metabolic disfunction which can be fatal within days. The discovery and commercial production of insulin meant that T1 diabetes was no longer a fatal diagnosis; however, insulin is just one component of a sensitive biological control loop which continuously adjusts blood glucose levels so as to stay within certain thresholds. Therefore, to preserve health it is not enough to just inject insulin, the amount of insulin in the body must be continuously in balance with needs. Too much insulin and the blood glucose level can become dangerously low (*hypoglycemia*), which can in extreme cases cause seizure, coma, brain damage, and even death. Alternately, elevated blood glucose levels (*hyperglycemia*) can over time cause serious complications such as kidney failure or blindness. Therefore, it is essential that people with diabetes maintain their blood glucose levels within certain tolerances to minimize short- and long-term risks.

The goal for diabetes treatment is straightforward: balance insulin in the body with insulin requirements to keep blood glucose levels within certain parameters. Many of the mechanisms that can influence this balance are easily explained. For example, carbohydrates are sugars, so their intake will raise blood glucose levels. Insulin helps transport glucose out of the blood stream, so injecting insulin lowers blood glucose levels. Exercise requires calories, so exercise reduces blood glucose levels. Yet, there are also many other factors which must be taken into account to maintain a near normal glycemic state. For example, carbohydrate absorption can be delayed when mixed with fiber or fat, causing a delayed increase in glycemic levels. Or strenuous exercise can lead to an unpredictable rise in blood glucose levels rather than a decrease. There are also diverse other and often individually variable factors which can all influence blood glucose levels in hard to predict ways. Examples might include emotional stress, sickness, variable insulin absorption rates, alcohol consumption, weather, and many others. A clinician can inform about these factors and recommend a daily regimen of insulin dosages, meals, and exercise. However, strict adherence to a structured plan is not only hard to maintain given the demands of everyday life, it is also often sub-optimal due to the great number of variables and contexts which can influence glycemic state. In practice, achieving relatively stable glycemic levels while maintaining a reasonable quality of life demands a

dynamic approach requiring frequent problem solving, coping with challenges, re-adjusting medication, lifestyle, and periodic correcting of out of range blood glucose levels. As many of these care decisions are best made in real-time, it is often impractical to depend on a clinician or 3rd party. Generally long-term diabetes care is most successful when the person with diabetes assumes a high level of personal engagement and responsibility in their own care. This continual and life-long process of learning, predicting, and integrating multiple factors into daily choices is commonly referred to as *diabetes self-management*. However, as noted the factors that can influence blood glucose levels are many and their effects can be both interdependent and hard to predict. For the person without diabetes this regulatory process is continuous and entirely unconscious, managed by a highly responsive metabolic control loop which can quickly release hormones to raise and lower blood glucose levels in response to subtle stimuli. In contrast, the person with diabetes must make conscious decisions and engage in deliberate actions. Given that these responses are less finely calibrated, more periodic, and take longer to take effect, even the most dedicated and experienced person with diabetes can face periods of unwanted glycemic variability. Hence diabetes management is not only cognitively and behaviorally demanding, but can be frustrating as well.

Given these many challenges, technology has long been an essential aspect of diabetes care. For example, insulin pumps can better simulate pancreatic function than periodic injections through continuous insulin infusion. And blood glucose meters provide real-time measurements to inform appropriate insulin titration. However, for all the clinical benefits of these technologies, such systems are still limited in their ability to help the individual make sense of the complex and inter-related factors which can affect management decisions. The first generation of diabetes smartphone logging apps were one attempt to address this need, offering an affordable and portable update to a paper diary, which could help to collect, visualize, and reflect on diverse personal data. Continuing advances in ubiquitous computing technologies are suggesting new opportunities to support diabetes decision making in more active ways. For example, a diabetes support system might, in addition to blood glucose, also collect data on other factors such as exercise, and location. Such data might with correct processing and delivery help users to locate correlations or outliers which could help inform more beneficial decisions. However, given the challenges of diabetes management, any intervention must be carefully considered to minimize risk to the user. From a practical as well as ethical perspective, it is essential that designers of new technologies seek in-depth understanding of the users, their opinions, their practices, and their needs so that the care practices are supported and enhanced rather than accidently impaired or undermined.

Towards the goal of improving the life of people with diabetes, this thesis seeks to contribute practical and theoretical knowledge which can be applied to improve supportive technologies, and in particular approaches that help individuals make better informed decisions in manner that respects user autonomy. The remainder of this introductory chapter will give a general overview of this thesis in order frame the approach and scope. This will include: outline of the challenges that

will be addressed, scope of the problem, my motivations and perspective, initial research question, and primary strategies. This is followed by a brief outline of the chapters within the thesis and the limitations of its scope.

1.1.1 Challenges

Despite the promise and excitement surrounding new technologies, there are significant challenges in designing systems that meet the multiple requirements posed by real-world Type 1 diabetes self-management. This thesis, while optimistic about future technologies, maintains that especially within the medical realm it is essential to retain a critical viewpoint. For example, an analysis of current diabetes apps (Chapter 4) discusses the failure of implicit design assumptions that require persistent manual logging. Chapter 5 presents evidence that continuing the trend of automating data collection is insufficient to solve diabetes app deficiencies without improving interaction design to better support user needs for situated decision-making and emotional sensitivity. In addition, current approaches often fail to support the cognitive processes used for diabetes self-management (Chapter 6). And while the aforementioned technical innovation could better meet such user needs, such systems could also introduce increased concerns about privacy, trust, and personal safety which must be carefully addressed (Chapter 7).

1.1.2 What is needed

In order to overcome such limitations, it is essential to design systems that solve actual user needs and augment user abilities, ideally forming a collaborative relationship which helps users to meet their personal goals. To accomplish this, designers must come to terms with how users interact with their data, their decision-making processes, their concerns about using such systems, and finally method of helping designers to create systems that meet those needs (Chapter 8).

1.1.3 Scope and importance of the problem

Diabetes is one of the most common major health conditions. It afflicts over 400 million people worldwide, and its prevalence is increasing (International Diabetes Federation, 2017). It is also costly both in terms of human suffering, with side effects such as kidney failure and blindness, and economically, with the International Diabetes Federation estimating that in 2017 world spending for diabetes, and related complications for adults, exceeded 850 billion USD. Effective treatment is challenging, depending not only on medications, but also continual patient engagement with factors such as emotional coping, exercise, diet, and problem solving; therefore, seeking means to support diabetes management is not constrained to clinical research, but a multi-disciplinary effort to support diverse aspects of care.

1.1.4 Personal motivation

Throughout the research presented in this thesis all attempts have been made to remain neutral in collecting data and reporting resulting conclusions from this data. However, it is important to note that I have a personal investment in diabetes beyond academic interest, and that I entered my research with pre-conceptions informed through many years of personal experience. I have lived

with T1 diabetes and depended on related technologies since the age of 13. It is possible that this has shaped my beliefs about certain aspects of diabetes management while giving a motivation to my research which would have otherwise not existed. Likewise, this research has motivated changes in own diabetes management as I have read emerging evidence, attended presentations at medical conferences, and adopted new technology. I see this first-hand experience as a valuable tool that has assisted in my reaching out and empathizing with people with diabetes, who are often saturated with requests to engage in research and at times sensitive about this auto-immune condition. Therefore, to claim complete impartiality would be dishonest. However, I would also argue that supporting diabetes self-management can be well served by addressing both objective and subjective research approaches. While blood glucose measurements and their influence on physical health are objective, there are subjective and contextual aspects which must be taken into account to determine appropriate goals, as an optimal goal blood glucose level can be dependent on shifting contexts and emotional requirements which are not always easily quantified. For example, an individual might temporarily need to maintain a higher than recommended blood glucose level in certain situations, such as to feel safe drinking alcohol, working with heavy machinery, or to reduce a family member's fear of hypoglycemia. In addition, given the importance of the affective aspects of diabetes self-management such as motivation and emotional coping, it is counter-productive to exclude the importance of subjective approaches. This thesis aligns ideologically with the growing movement asserting that it is critical that these technologies support the needs and rights of the users, rather than being exclusively means of achieving adherence to clinical metrics. It therefore follows that there is an explicit bias and assumption of the author that such tools should enhance independence and autonomy to the extent desired by the user. This calls for a balanced approach that recognizes that as well as helping to meet evidence based goals for glycemic management, users of diabetes technologies have a right to live their lives as they see fit, that diabetes management should not overly dominate lives, and that systems must be carefully considered as to their impact on user self-determination. Therefore, automation and other methods that help attain clinical targets and reduce the burden of diabetes management must be carefully balanced with the user maintaining conscious engagement and personal awareness when designing personal informatics tools.

1.1.5 Voice and research

To avoid confusion, it is important to discuss the pronouns used within this thesis. I have personally conducted all the interviews, surveys, user-interaction studies, focus groups, and processing of data presented within this thesis unless otherwise noted. That being said, the questions asked and interpretations of collected data have been influenced by the many hundreds of people I have talked to and worked with. This includes not only my thesis supervisors, but also all the patients, participants, clinicians, academics, conference attendees, and others, who have impacted my research process. Therefore, while I will use the first person singular when I am presenting a personal thought, I will at times defer to the first-person plural 'we' to refer to either

actions in which the reader is included, or to credit the collaborative processes which helped form concepts, interpretations, and ideas, though I take full responsibility for any errors or shortcomings in the findings presented.

1.1.6 The roots of the research

The initial research in this thesis was inspired by my own experiences using diabetes apps as well anecdotal observations from within the diabetes community that while many people with diabetes were excited about smartphone apps in general, diabetes apps were often failing to provide sufficient benefits to enter into daily care routines. This lack of adoption was intriguing as diabetes management is challenging and requires interaction with complex data and therefore seemed an ideal application for mobile computing technology. While in 2009 when I purchased my first iPhone there were already many diabetes apps available, by the time I started this thesis the number was in the hundreds. Some of these apps had been released by major pharmaceutical companies with significant expenditure and presumably made use of current best design practices. Yet it appeared that in contrast to social networking and other 'sticky' apps as well as devices such as continuous glucose monitors, diabetes apps consistently 'failed' to gain widespread long-term adoption by the T1 community. This discrepancy between the number of available diabetes apps, the similarity of their approach, and lack of user adoption suggested there might be something missing in the current knowledge about the interaction design of diabetes self-management apps, and that there might be important differences deserving of further investigation between designing an engaging social media or fitness apps as opposed to an engaging chronic disease management app. It was these gaps that this thesis began to explore so as to improve the design of future systems.

1.1.7 Preliminary research question

To the end of understanding if diabetes apps needed further development and if so, in which ways, this thesis set out to determine: what people with T1 diabetes thought about current products and to what extent popular interfaces supported or failed to support their needs; how such interfaces could better support decision-making process; and finally recognizing the challenges of effective clinical testing of digital health products within iterative development processes, how these findings could be brought together in a manner that could inform and support developers as they design new systems. Consequently, in the context of diabetes self-management, ubiquitous computing technologies, and in reflecting the growing movements in patient's choice, the **preliminary research question** for the thesis can be stated as follows:

> *"How can we improve the practical utility of diabetes self-management apps from a user-centered perspective?"*

The research question will be revisited and refined in Chapter 3. More generally the thesis seeks to understand the challenges and concerns people face when having to make frequent and potentially

life-threatening decisions and how tools can be designed to assist in this process. However, at the same time as addressing a research question, this thesis can be seen as having a **practical goal**:

> *This thesis is specific in its goal of helping individuals self-manage the chronic health condition, Type 1 Diabetes (T1D).*

Through a series of in-depth user studies, interviews, survey, and focus groups, this research aims to contribute to a better understanding of the requirements and mental processes of users of diabetes self-management systems and draw attention to questions that should be asked in order to help avoid future development of products that neither meet user needs nor respect user concerns. It is therefore the goal of this thesis to provide insights, observations, questions, and frameworks that can be practically applied to the design and development of future systems that will directly benefit those who must live everyday with diabetes. In addition, given that diabetes management requires attention to fundamental behaviors such as diet and exercise, I hope that aspects of this research might also be applicable for other chronic conditions and health in general.

1.1.8 Strategic approach to support of diabetes

While there is much to be agreed with in the move towards helping *clinicians* to adopt more patient-centered medicine (Berwick, 2009), given the practical and highly personalized demands of diabetes management, this thesis agrees with the principles and practical requirements of *patient empowerment* (Funnell and Anderson, 2004), e.g. helping people to be capable of making their own routine treatment decisions and thereby to take care of themselves. With this approach, clinicians still have a valuable supportive role, but the patient assumes much of the medication and lifestyle adjustment that might be otherwise be accomplished by trained medical personal. Given that a person with managed diabetes is not necessarily sick in the common sense of the term, it is perhaps more useful to think of those who rely on these tools not as *patients*, but as *users*. Therefore, it is the user-centered approach (Norman, 2016) with its methods of understanding users, their requirements, and integration into the development process (Gulliksen et al., 2003) which form the primary research approach of this thesis. In a broader sense, while T1 diabetes may have certain distinct requirements and form a relatively small part of the global population, many aspects of diabetes management, such as attention to diet, mitigating stress, and physical exercise (Educators, 2009), are generalizable to the greater population. Therefore, through careful examination of this specific use-case, I hope that insights will emerge that have relevance not only to diabetes, but other chronic health conditions, more general wellness, and even perhaps to other tasks that depend on complex data and acquired knowledge to inform frequent critical decisions.

1.2 Outline of the Thesis

In order to provide a map for reading and understanding the course of this thesis, the following section gives a brief description of the research undertaken within each chapter, and the emergent themes which have guided the following research.

1.2.1 Chapter 2: Review of the literature

In order to set the context for the approach of this thesis, the literature review begins by discussing selected papers which have been foundational for this thesis. These papers are for the most part concerned with the relationship between users, ubiquitous computing devices, and personal data, as well as how acquired knowledge can support informed decision making in a personally empowering manner. Therefore, while much of this literature is not necessarily diabetes specific, there is considerable overlap with the direction of my research. Most, though not all, of these papers emphasize the human-centered approach of computer science research, rather than more technical priorities. This is to say research which specifically seeks to understand the relationships or interactions between humans, information, and computing devices. This will be referred to within this thesis as the field of Human Computer Interaction (HCI), though there are other terms which might be equally suitable. After using this discussion to orient this thesis, it is necessary to discuss diabetes in greater detail to set a basis for further discussion. This section includes a general overview of diabetes and its treatment, which is followed by a review of commonly used diabetes technologies with an emphasis on diabetes apps. Essential aspects of more general decision support systems are then discussed, followed by a review of ethical implications of such systems, and methods of design and assessment of such systems. At the conclusion of this review is a discussion of the relation of the literature to the thesis, and conclusions drawn from this review.

1.2.2 Chapter 3: Outlines of methods and methodology

This section provides an overview of the methods which were used to gather and analyze the information gathered for this thesis. These include: questionnaires, user-interaction studies, semi-structured interviews, technology probes, and guided focus groups. For purposes of sign posting, these approaches will be briefly reviewed within this chapter and then explored in greater detail within the following chapters.

1.2.3 Chapter 4: Adoption of Diabetes Apps Pilot Study

The chapter reviews a pilot study (Katz et al., 2015) which set out to explore objectively the perhaps counterintuitive notion that many people with T1 diabetes who use smartphones and depend on technology everyday are not adopting diabetes smartphone apps. In order to investigate the user perspective, a pilot survey of 26 individuals with T1 diabetes was conducted. Through a questionnaire and in-person interviews, it was established that it was indeed common for users to abandon functioning diabetes apps, suggesting that for a majority of participants, these apps were failing to adequately meet needs. Findings related to the lack of support for affective and cognitive requirements are discussed, as well technical barriers to adoption such as the need to manually log

data, and concluding with a general discussion of these difficencies. This chapter reports on this survey, presents study data, and proposes hypotheses that served as the foundation for later research.

1.2.4 Chapter 5: Data, Data Everywhere, and Still Too Hard to Link

As the previous chapter found that manual data entry was a barrier to diabetes app adoption, this chapter investigates the utility of typical diabetes app interfaces in a possible future where all data entry could be automated. To this end, this chapter reports on a talk-aloud user interaction study (n=16) undertaken to identify and characterize the benefits and limitations of common interfaces of diabetes logging apps when used for reflecting on pre-entered diabetes relevant data (Katz et al., 2018a). By providing examples of a range of participant observations, the first part of this chapter presents evidence suggesting that, while providing certain specific benefits, these interfaces could be too cognitively demanding, potentially emotionally insensitive, and did not fully take advantage of participant's already acquired knowledge. In addition, these sessions suggested insights into participant's cognitive processes which are explored in the following chapter.

1.2.5 Chapter 6: Fluid Contextual Reasoning

In this chapter, existing dual-process cognitive models were applied to analyze participant's responses from the user-interaction study in the previous chapter. This process suggested that some participant described thought processes did not fit well within these existing models. An expanded cognitive model is introduced to better represent an apparent hybrid mode, which appears to enable decisions based on complex data in a relatively-low cognitive demanding manner. This proposed mode *Fluid Contextual Reasoning* (FCR) and its defining characteristics are outlined. The results of this analysis and the resultant expanded cognitive model motivated an online survey of people with T1 diabetes (n=192) to further investigate this hypothesis. The expanded model was used to formulate questions, which according to the model should initiate different responses when considering different diabetes scenarios (Katz et al., 2018b). These responses and their implications for the proposed extended model are discussed. The chapter concludes with a discussion of the expanded model as a framework for assessing diabetes decision support interfaces, as well as suggesting how this model could offer guidance for future design. To contribute towards the goal of real-world implementation of this approach, the following chapter investigated user concerns and potential barriers to the monitoring infrastructure that would form the data gathering structure for such an approach.

1.2.6 Chapter 7: User Concerns for Multi-Device Diabetes Monitoring

This thesis will present evidence that current diabetes logging apps have an inherent flaw in demanding significant manual data entry while delivering insufficient benefits. This chapter looks forward to a 'next generation' diabetes support system capable of providing the data needed for implementing the model in Chapter 6. This approach would make use of multiple sensors to eliminate the need for manual data entry while aggregating this data to allow for analysis and integration with other services. This chapter discusses the results of a 4-week technology probe

(n=8) in which participants were outfitted with multiple networked devices in order to learn more about user perception and willingness to adopt such multi-device monitoring. Through detailed analysis of their interview responses both before and after the study period, this chapter reports on user concerns related to sharing their medical and behavioral data with different stakeholders, changes in sentiment during the study period, software solutions that could increase user acceptance, and finally emergent questions for designers of such systems.

1.2.7 Chapter 8: DUETS: A Card-Based Tool for Stakeholder Reflection

The preceding chapters draw attention to user concerns and requirements related to app-based diabetes decision support systems. However, industrial partners might find academic research challenging to apply within actual design processes and these challenges could become even more pronounced given the increasing complexity of IoT-based systems. With the goal of bringing about real-world impact, this chapter proposes a card-based methodology for integrating and organizing such findings in a manner that can facilitate stakeholder reflection and critical discussion. This chapter suggests five criteria for assessing user requirements, which are then implemented through a described iterative development process, with a resulting card-based method for product assessment. This tool is then implemented and evaluated through three focus group sessions, the first and third with a team of developers from a diabetes analytics startup (n=3), and the second with an early adopter patient group (n=6). The strengths and weaknesses of this approach are then discussed, with suggestions for future development.

1.2.8 Chapter 9: Conclusions

This chapter reviews the research question and sub-questions, summarizes the principle findings, outputs, and contributions of the thesis, and suggests specific key questions for designers of diabetes apps. This is then followed by limitations, future work and concluding remarks.

1.3 Thesis Scope

Diabetes management is a complex topic and the knowledge from diverse fields could be applicable (and have been applied) to the development of new or improved interventions. While this thesis is situated within the computer science literature which focuses primarily on interaction design considerations between humans and computing systems, the research within this thesis has required the consideration of a variety of sources. Reviewed literature includes work conducted within the domains of clinical care, cognitive psychology, computer science, design, and others. Due to the vastness of potential sources and approaches, it has been necessary to limit or even exclude many important areas. The following section details a few of these limitations:

Not about onboarding: The focus has been almost entirely on assisting with long-term self-management, which neglects the onboarding and initial learning that takes place as the newly diagnosed learn how to manage life with diabetes (Blondon et al., 2013). While the initial phase is extremely important, this decision has been justified by the relatively short period of this first phase as opposed to the life-long aspects of living with a chronic health condition.

Not clinician-centered: This thesis emphasizes the user-perspective of the person with diabetes and has largely neglected the needs and perspectives of the clinician or many others who could also be considered users of such systems (Forlizzi, 2018). While the clinician and other diabetes professionals can play an important role in diabetes management, the majority of daily care must be carried out by those living with diabetes (Funnell and Anderson, 2004). However, this thesis in no way means to diminish the importance of these other viewpoints, which should be integrated into the development process of future systems.

Not Closed loop: And finally, this thesis has the limitation that it explores a quickly moving technology, and that over the period of the research there have been significant advances in diabetes technologies. The closed loop artificial pancreas is a prominent example, driven forward by the DIY/maker community, which has in a short time progressed far beyond commercially available options. At the start of this thesis, such systems were still being prototyped in controlled clinical settings, and the literature foresaw years of controlled studies (Peyser et al., 2014). Just a few years later, such self-built un-regulated systems are now being worn by an ever expanding early adopter community (Barnard et al., 2018). However, while closed loop systems are potentially revolutionary for insulin dependent diabetes management, such innovation need not invalidate the broader contributions of this thesis in areas such as medical/lifestyle decision support, user-interaction with complex data, UI design, user concerns regarding monitoring systems and devices, and supporting more general user-centered development practices.

1.4 Summary

While much progress has been made with diabetes related technologies, it is in the ability to fit into the complex ecology of the individual user's life and lifestyle that these technologies will truly succeed. In order to improve these technologies, we need to recognize in which ways existing products are succeeding or failing to meet user needs, understand what the unmet needs are, and then develop processes that better support the integration of these needs into the next generation of systems. In a broader sense, people with T1 diabetes form an engaging research focus, already depending on and having widely adopted sensor driven technologies. In addition, the extreme variability and responsiveness of blood glucose levels to behavioral decisions, and the ability to easily monitor these responses, forms an edge case for ubiquitous computing and self-tracking. Therefore, while this thesis is diabetes specific, it potentially provides insights into human computer interaction which will likely become increasingly relevant as the use of real-time bio-markers for personalized health-oriented decision making enters the mainstream.

Chapter 2: Related Work

This chapter contains broadly two elements – a critical review of the literature in the context of the preliminary research question, and a more practical outline of diabetes related background knowledge including a brief account of relevant technologies. These elements are interwoven to first orient the reader within the primary body of literature that this thesis builds upon, then to offer sufficient background on diabetes to support more in depth discussion, and finally the principal literature review. As noted previously, this chapter draws from several domains including research on interactions between humans and computing systems which is foundational to this thesis, as well as aspects of medicine, informatics, and psychology, which all offer valuable perspectives. The following paragraph gives a brief overview of the sub-sections of the literature review and a brief description of the reasoning behind their inclusion:

Situating thesis within the literature: Chapter 2.1 critically reflects on ways in which ubiquitous computing technologies have in the past been applied to supporting interactions with personal data in the pursuit of supporting healthier behaviors. This section will also identify and discuss examples where theory has directly informed the design of digital interventions. The work in this section has been most directly influential on my thinking and research, especially for chapter 6. There will also be a brief introduction of bio-ethical principles, as these values guide the approaches and assumptions made throughout this thesis. Ethics and computing systems will be explored in greater detail in chapter 2.5.

Diabetes general knowledge and supporting technologies: Chapter 2.2 and 2.3 presents the basics of diabetes care and the current technologies associated with diabetes management. These sections are primarily informational in nature and could be skipped by those who already have sufficient knowledge of subjects such as the normal range of blood glucose levels, details of diabetes self-management, and the characteristics of continuous glucose monitoring.

Candidate directions for next generation diabetes apps: Section 2.4 returns to the process of critical literature review to discuss potential components of next generation diabetes app-based interventions.

Ethical implications of more active approaches: Section 2.5 reviews ethical concerns for computing systems, relevant considering the potential harm caused by the more active and intelligent systems advocated by this thesis.

Methods of design and assessment: Section 2.6 reviews methods for designing and validating user-centered health systems for practical consideration of how to implement real-world future systems.

2.1 Situating this Thesis within Literature

As outlined above, this section begins by discussing selected papers from within the human computer interaction literature which have been especially relevant in informing the direction of

this thesis. While many of these papers are not diabetes specific, they are for the most part concerned with the relationship between users, ubiquitous computing devices, and their personal data as well as how such interactions can influence healthful behaviors. In addition, by setting this more general context it is hoped that the reader might be able to see the connections between diabetes care and a broader health agenda, and therefore that this thesis might provide contributions which could be applied beyond the diabetes domain.

2.1.1 Fish'n'Steps

Later chapters will discuss barriers to adoption resulting from diabetes apps which are dependent on manual logging to gather data and offer in return standard graphs and charts of this collected data. Fish'n'Steps (Lin et al., 2006) was influential for this thesis as an early example of combining automated sensor-based tracking combined with methods of visualizing data in an intuitively understandable manner. It also directly relevant for the goals of influencing user behaviors as well critical investigation of the potential affective impact of visualized personal data. In this study, the authors linked virtual fish on public and private monitors to pedometer step counts to encourage increased physical activity. Animated fish responded to the user's logged steps by growing in size, transitioning through stages of development, and changing facial expressions. The fish's environment also reflected user activity through cleanliness and added virtual features. The researchers hypothesized that a visual representation of real-world behaviors and the ability to influence an avatar through deliberate actions could help to build a sense of empowerment and thereby further support positive behaviors beyond the virtual environment. Two versions of the game were implemented, one with a solo fish, and a second with a shared tank, where fish could also be viewed in comparison to other fish, which served as a social motivator. While the positive facial expressions were noted as motivating, in some cases the 'unhappy' fish could be demotivating, leading to reduced engagement. This counter-productive aspect of negative reinforcement, and the implications for interface design will be discussed further in Chapter 5 in relation to diabetes apps, where I found that the viewing of out of range data could be discouraging for some users. Similarly, the authors reported that the social aspect could be motivating or demotivating depending on context, a finding which is potentially relevant to medical applications where 'do no harm' is especially important. The authors also noted that the game was not successful at maintaining long-term engagement, although causality was inconclusive. This study provides evidence that there are considerable challenges to integrating gamification as an intervention within the health context. At the time of this thesis, more than ten years later, there are still relatively few examples of successful implementation of game elements within diabetes apps. Therefore, it remains unknown to what extent introducing competition and virtual rewards systems is suitable for the long-term requirements of diabetes management. I will, in a limited manner, discuss findings related to gamification elements in Chapter 5.

2.1.2 Adoption of behaviour change theory into interaction design

Fish'n'Steps was also notable for adopting aspects of behavior change theory from cognitive psychology into digital interventions, which will be further explored in Chapter 6 when I propose an expanded cognitive model for analyzing and designing diabetes decision support systems. In this study, the authors attempted to apply the Transtheoretical Model (TTM) to validate the positive long-term effects of their approach. TTM proposes that individuals progress through a series of six progressive stages from not being ready or aware of a problem (pre-contemplation) to having the new habit so ingrained that there is no longer danger of relapse (termination). Interventions can therefore be tailored for the specific needs of each individual stage. The individual's confidence that they can handle a specific situation (self-efficacy) also plays an important role in this model. The authors proposed that digital interventions might allow the use of such techniques without the extensive clinical resources traditionally needed for a TTM based intervention. Additional concepts were also taken from behavior theory literature, including building a sense of control through the care of the virtual pet (internal locus of control), goal setting, and social influence through sharing the 'fish tank' with other participants. At the beginning of the Fish'n'Steps study, each participant was interviewed to assess stage along the TTM. Lin et al. reported that those in the middle stages of TTM were most likely to have the greatest change in behavior. The authors claimed that 14/19 participants either advanced stages in the TTM or increased step counts, therefore validating the approach. Those assessed in the lower stages at the beginning were most likely to progress in their willingness to change, but not their step counts. Those in the middle stages were most likely to change behavior and actions, and those with habitual exercise patterns were least likely change in either respect. Although the sample size could be too low to validate the conclusions, this study helped to support the use of theory in designing and assessing digital behavior change interventions. Such stage-based theories might be especially relevant in designing adaptive systems that personalize interactions, determining the most appropriate intervention to bring about a desired outcome. For example, interventions for those in pre-contemplation level might focus on education and awareness of state, while those in more motivated stages might be more actively encouraged by the UI to engage in specific behaviors. While not disputing the validity of such stage-based approaches and recognizing the importance of their inclusion in comprehensive interventions, this thesis and in particular Chapter 6 build upon the more cyclical approaches discussed in 2.1.6 and 2.1.7.

2.1.3 UbiFit Garden: Positive rewards and activity recognition in a mobile context

Similar to the previous study, UbiFit Garden is relevant to this thesis for its early use of mobile technologies for systems of automated data collection and situated and intuitive data presentation. UbiFit Garden (Consolvo et al., 2008) used a garden metaphor to motivate healthier behaviors. This study used a mobile phone with color display, linked to a prototype wearable for automated tracking and activity classification. There was a companion app that while automatically collecting data from the wearable, also allowed manual journaling, reviewing, and editing of

collected personal data. This app also placed a glanceable display on the home screen, with flowers that rewarded the user by growing in response to physical activities and butterflies to indicate goal attainment. The system made use exclusively of positive reinforcement, visually rewarding for behaviors such as exercise or journal entries, while avoiding the potentially discouraging negative reinforcement noted in the previous study. The flowers were also responsive to varied user actions, with different flowers being achieved for various encouraged activities, such as aerobic exercise or walking. While this study was only conducted for a relatively short period, users were positive about the interface and reported the virtual rewards as motivational. Users were also positive about automated activity sensing, although some users were irritated by the systems inability to record and reward exercise that the system could not classify. The study noted that the ability to manually correct activity logs was therefore an important feature. This study draws attention to an important challenge for health management systems in finding the right balance between automation and user engagement as well as how the display of information in non-traditional ways could encourage behavior change.

2.1.4 UbiFit Garden: Goal setting and motivation

A second UbiFit Garden study (Consolvo et al., 2009) demonstrated how theory taken from psychology literature can form the foundation for a mobile app-based intervention, an approach which offers guidance for future application of the model proposed in Chapter 6. Using the previously discussed Ubifit mobile app, the authors explored the potential for goal-setting in a persuasive technology context. Adopting Locke and Latham's Goal Setting Theory (Locke, 1968), the studied focused on two aspects of the intervention: who should set the goal (*goal sources*), and the time-period to achieve the goal (*goal timeframes*). This theory describes the ways in which different types of goal setting can affect performance, asserting: specific goals outperform overly general goals; goals should be ambitious, but not too difficult to attain; and that incentives should not be too closely linked to achievement, as this can be de-motivating when not viewed as attainable. It was reported that participants overwhelmingly chose to self-set goals, as opposed to externally set options, although customized goals from a qualified expert appealed to many. While this paper did not report how different goal-setting strategies directly affected performance, by exploring user preferences and willingness to engage in different methods of goal-setting it contributed useful guidance to implementing such strategies in future systems. While this thesis does not directly engage with this theory, these findings are relevant to the reoccurring research themes related to motivation and user autonomy.

2.1.5 Increasing awareness through data interaction: The Quantified Self

While not necessarily diabetes specific, another body of literature relevant to this thesis emerges from the Quantified Self (QS) movement, as this early adopter community has often been at the forefront of the use of emerging technologies to record, collect, integrate, and analyze diverse personal data. The Quantified Self movement's goals are often related to optimizing lifestyle behaviors such as diet, sleep, and exercise which are all directly relevant to diabetes management

(see 2.2.2.2). In addition, the early adopter and technology proficient aspects of this group generate knowledge on emerging technologies which could inform the design of more comprehensive diabetes-oriented systems. The Quantified Self movement often operates under the premise that the process of collecting and reflecting on personal data will lead to increased self-knowledge and thereby lead to the formation of more desired habits (Li et al., 2011). QS also promotes methodical recording, as it allows greater opportunities to discover important correlations than when relying on biological memory. In addition, Li et al. also emphasized the value of manually recording such data to increase awareness and engagement; however, as will be discussed later in Chapter 2.4 this aspect of QS can be problematic within certain requirements of diabetes management such as the non-elective and continuing nature of care, the non-predictability of outcomes, and the emotional impacts associated with disease complications.

2.1.6 QS and models of understanding how people make use of personal data

One of the principal paths of inquiry of this thesis is how diabetes apps can increase the utility of personal data. Relevant to this need, Li et al. (Li et al., 2011) provided frameworks that describe how people interact with their personal data and their use of supporting technologies. Li et al. proposed two modes: *discovery* and *maintenance*, noting that people transition back and forth between these states. In the former, people were actively asking questions, trying to establish cause-and-effect relationships, and goals. In contrast, in the latter they were primarily trying to maintain behaviors, or the steps needed to achieve established goals. *Discovery* phases are marked by an increased willingness to engage in effortful reflection on personal data, and thus require tools that assist in the collection and merging of data. In contrast, in *maintenance* phases the tools should primarily be for alerting the user when goals are not being met, and to assist in finding factors that could assist with goal achievement. The authors also note that in the case of long-term conditions many of the goals, such as maintaining glycemic stability, become clear over time, leading users towards more *maintenance*, and decreased *discovery* phases. This proposed dual process model is quite similar in structure to the following section, though the Mamykina et al. framework has been more explicitly tailored to the diabetes use case.

2.1.7 A theoretical framework of sensemaking in diabetes self-management

Mamykina et al. (Mamykina et al., 2015) proposed a sensemaking framework for diabetes self-management which forms the foundation of inquiry for Chapter 6. Mamykina et al. propose a framework for how individuals use and understand self-monitoring data for assisting in chronic condition management. Similar to Li et al. (Li et al., 2011), this framework emphasizes the cycling between two modes, *habitual* and *sensemaking,* (the first term being similar to what Li et al. referred to as *maintenance* and the second *discovery*). This framework also defines three *sensemaking* activities: perceiving new information related to condition, understanding this information, and actions based on this information. The authors note *problem-solving* as an essential aspect of diabetes self-management, drawing attention to how such skills allow individuals to understand and overcome barriers to better self-management practices. It is also

asserted that many of the most popular cognitive and behavioral theories used for designing digital interventions for self-management focus on motivating and controlling behaviors; Mamykina et al. in contrast, suggest how individuals can grow to understand their own condition and construct personally significant self-care mental 'models' that explain how a given behavior leads to a specific outcome. For example, such a mental model might involve that a particular breakfast cereal leads to a predictable and dramatic rise in blood glucose levels, and therefore should only be eaten before exercise. Once enough of these self-care models have been validated and learned, they can be used to guide future actions in a reflexive manner. As this knowledge is personally relevant, validated, and internalized through a learning process, this aligns well with this thesis' perspective of supporting user autonomy. This framework also addresses the dynamic nature of diabetes self-management, and in contrast to more stage-based models, there is no end stage of accomplishment. This reflects that individuals must constantly assimilate new information and must continually find new solutions to situations that do not fit within previously constructed mental models. As the *sensemaking* mode is analytic in nature, it is inherently effortful as individuals seek to create mental models that explain situations. In contrast, the *habitual* mode accesses these pre-existing models, and is therefore of low-cognitive effort. Both *sensemaking* and *habitual* mode make use of three activities: *Perception*, the acquisition of new information; *Inference*, creating or using a model; *Action*, the carrying out of a response. The following figure (Figure 2-1) visually represents these interactions:
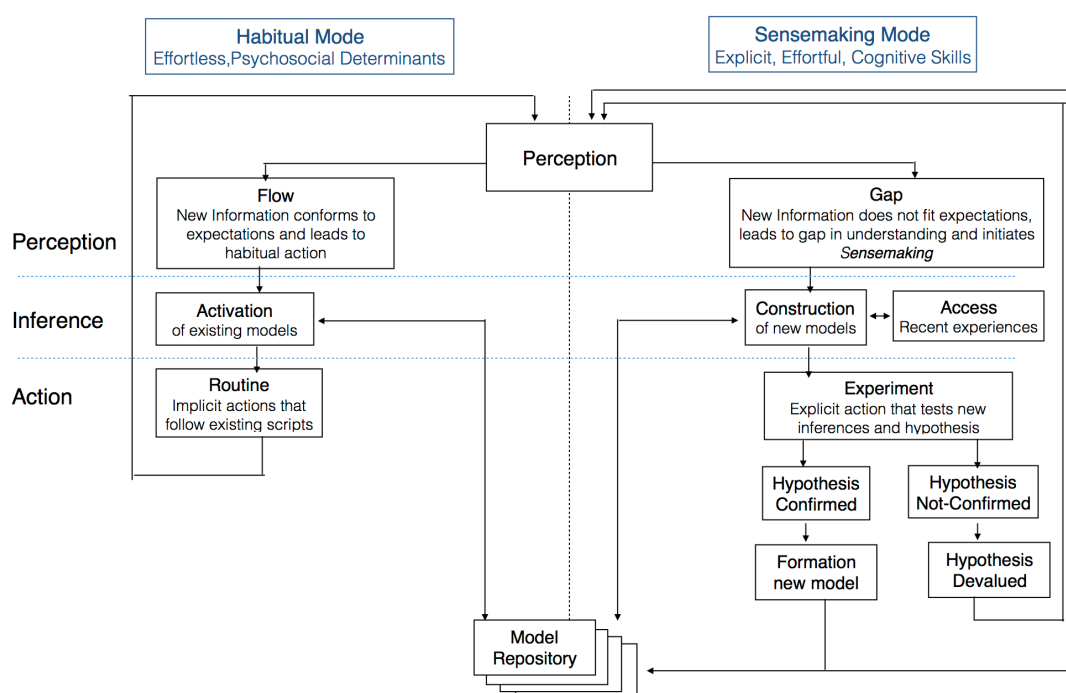
FIGURE 2-1 REPRESENTATION OF MAMYKINA ET AL'S (MAMYKINA ET AL., 2015) SENSEMAKING FRAMEWORK

The sensemaking/habitual framework in Figure 2.1 is also similar to Kahnemann's (Kahneman, 2011) proposal of System 1 and System 2 thinking, with the former being fast, instinctual, and

low effort, while the latter is effortful as it cannot draw upon an existing model or solutions, and must create new ones. Kahneman sees both systems as essential, as System 2 requires too much time and energy to be in continuous use, however System 1 is prone to common errors or biases. This is reflected in Mamykina's framework as well, as continual application of the *sensemaking* mode would be incompatible with the demands of everyday life. Similar to Li et al., Mamykina et al. also emphasize the value of recorded data to correctly formulate new mental models; as memory is prone to errors, individuals might have difficulties remembering the correct information to create accurate new mental models. However, this binary approach does not offer guidance for how an intervention might keep users engaged enough to overcome cognitive biases while still decreasing cognitive load sufficiently for frequent interaction. Chapter 6 suggests an expanded non-binary model which I term *Fluid Contextual Reasoning*. This expanded framework proposes that in certain diabetes care situations, many people make use of a reasoning process that allows them to engage with complex data and situations through application and adjustment of previously learned self-care heuristics, thereby reducing the cognitive load demanded by System 2 (*sensemaking*) processes. This chapter also suggests how this research could be applied to analyze existing approaches and suggests a path forward for the development of more user-centered approaches.

2.1.8 Moving beyond reliance on reflection with next generation approaches

While the approaches proposed by Li et al. and Mamykina et al. in the previous section have relied heavily on the user engaging in active reflection of personal data to establish internalized models, section 2.4 will discuss certain limitations to this approach for diabetes management, implying the need for systems that can provide additional cognitive support. Intille (Intille, 2004) suggested an alternate and more active approach using sensors and mobile technologies to provide 'just-in-time' reminders to promote healthier behaviors. This paper focused on how such technologies could assist in preventative medicine with text messages. Despite evolution in technology such as more graphic UI design, the essential concepts expressed are still relevant to current system design. This paper proposed that a system capable of monitoring everyday activities could offer suggestions to assist the user in key situations, thereby influencing actions. Intille offered four components for motivating behavior change:

    1. Present a simple message that is easy to understand.

    2. At just the right time.

    3. At just the right place.

    4. In a non-annoying way.

Interestingly, this work predates much of the more reflection-based research (see section 2.4) and offered over a decade ago a recipe for more active integration of computing systems into the decision-making process. However, Ohlin and Olsson (Ohlin and Olsson, 2015), recently noted that while personal data collection and visualization is easily accessible with current generations

of wearables and apps, next-generation systems with decision support are still largely lacking from the consumer space. The authors note that the model of personal informatics advanced by Li et al. depends on users acting as rational actors, which is often not the case. In order to assist users in daily life, the authors suggested a series of relationships between users and intelligent computing systems: *cooperative*, in which humans and computers work together, combining the best skills of each; *augmented*, in which computers enhance human abilities in realms such as memory, motivation, and decision making; and *ambient*, where the system senses and acts independently. The authors suggested building a sense of shared purpose between the system and the user, and then tailoring these relationships to given situations. Other key features suggested for such systems include:

- Real-time contextually aware feedback grounded in past performance.
- Exploring ways of including the user in automatic data collection to increase engagement.
- Allowing users to give feedback to the system to allow the system to adapt to user desire.
- Mutual establishment of goals.

This more active integration of ubiquitous computing capabilities into disease management, especially concerning the reduction of cognitive stresses associated with frequent decision making is a major concern of this thesis. Methods of advancing such approaches inform the approach of Chapters 6-8 which discuss the previously mentioned cognitive model, user concerns related to use of such systems, and a card-based method for working with stakeholders to reflect on ubiquitous computing systems.

2.1.9 Ethical values

Despite the limitations (discussed in 2.4) of reflection-based approaches to supporting chronic disease management, there are distinct benefits in seeking to empower the user to engage in independent learning and decision-making. A more active decision support system, as suggested by Intille and Ohlin and Olsson could require the use of automated monitoring and an overt intervention into the decision process, which can introduce a range of ethical issues. Meredith and Arnott (Meredith and Arnott, 2003) proposed that the work of Beauchamp & Childress (Beauchamp and Childress, 2001) on bio-ethical principles form a reasonable foundation for decision support systems. These include:

- *Autonomy*: respecting right of the individual to make independent decisions regarding their own welfare.
- *Non-maleficence:* avoiding within one's capabilities causing harm to others.
- *Beneficence*: maximizing benefits to others while balancing costs and risks.
- *Justice*: equitable distribution of costs, risks, and benefits.

Meredith and Arnott asserted that as a system becomes more capable of learning through experience, responsibility of action becomes more difficult to assess, and that as these systems replace human decision makers, ethical responsibility becomes difficult to assign. Maintaining

user autonomy with such technologies is also concerning, and such systems raise critical concerns respecting the right of an individual or group to self-determination. Given the user-centered perspective of this thesis, these concerns will be explored further in 2.5, as well as forming an important framework for continued investigations.

2.2 Diabetes General Knowledge

The previous section discussed literature which, while foundational to this thesis, had often focused on more general support of healthy behaviors such as increased daily exercise. While such behavior change interventions are generally beneficial to supporting diabetes care there are research issues whose relevance to T1 diabetes is difficult to appreciate without basic knowledge of the essentials of diabetes management. Therefore, to provide a foundation for understanding the context for the research, the following sections will present a general overview of: diabetes, diabetes self-management practices, and relevant diabetes technologies. Those already familiar with these topics may wish to skip to section 2.4.

2.2.1 Type 1 and Type 2 Diabetes

Type 1 diabetes (T1D), the primary focus of this thesis, is a popular and prevalent ubiquitous computing target as the estimates of people in need of assistance are in the tens of millions (Aguiree et al., 2013). It is also a compelling test case for mobile health interventions as blood glucose levels are responsive to individual decisions, allowing the effectiveness of a given intervention to be quickly measured at relatively-low cost. In addition, while the diabetes treatment regime of multiple daily insulin injections and blood glucose (BG) tests are disease specific, the essential lifestyle guidelines are highly generalizable for general health even for those not affected by diabetes.

It is important to note that there are several forms of diabetes, with Type 2 diabetes (T2D) being the most common. It is often related to lifestyle, and especially in early stages, can often be treated with changes in diet and exercise (Force, 2006). Nonetheless, many do not manage to adjust, and the majority of T2D patients will eventually require insulin to control blood glucose levels (Home et al., 2014). In contrast to T1 diabetes, generally T2 patients continue to be capable of some insulin production, though they either produce insufficient quantities, or become resistant to the insulin they produce. Therefore, T2D patients can, in some cases, be treated through lifestyle alterations such as increasing exercise, altering diet, or losing weight. In contrast, Type 1 diabetes, which afflicts 5-10% of people with diabetes is caused by the body's immune system rejecting the beta cells in the pancreas which produce the hormone insulin. While lifestyle alterations are important for management, and can reduce insulin requirements, diet and exercise cannot cause insulin to be produced, which must therefore be administered. Despite years of research and multiple approaches into biological cures for T1 diabetes, cell implantation remains costly and problematic as it still requires the use of immunosuppression medication (Pellegrini et al., 2016). Therefore, daily use of insulin is required to stabilize BG levels. Before the identification of insulin in 1921, type 1 diabetes was invariably a fatal condition, and even with

advances in treatment, side effects can still be severe. Long-term complications related to habitually elevated BG (hyperglycemia), can include blindness, kidney failure, nerve damage, and death, while short-term complications caused by severely low blood glucose levels (hypoglycemia), can include shaking, sweating, unconsciousness, seizure, coma, and in rare cases death (McGill and Ahmann, 2017). However, unlike some chronic health conditions, diabetes can be successfully managed, blood glucose levels stabilized, and complications minimized with a carefully controlled lifestyle and the correct use of medications (Aguiree et al., 2013).

While there are certain important overlaps between T1 and T2 treatment as both are concerned with stabilizing blood glucose levels, there are also important distinctions. Given the broadness of the domain and for purposes of specificity, I found it expedient to limit this thesis to T1 diabetes. Therefore, while many of the findings within this thesis might be applicable to T2 individuals, such an assertion could not be made without additional research.

2.2.2 Diabetes Management

Diabetes management is the process whereby appropriate behaviors, medications, and technologies are used together with specific strategies and problem solving to control glycemic levels (Educators, 2009). While the clinician can play an important role in supporting care, effective daily management of diabetes relies primarily on the individual's habits and management decisions (Funnell and Anderson, 2004). While monitoring in general, and blood glucose monitoring specifically is an essential part of this process, it only of benefit to the extent that it informs and brings about better treatment decisions (Klonoff, 2007). Glycemic goals are set according to diverse factors such as age, duration of diabetes, life expectancy, hypoglycemia awareness, and context. Therefore there are no definite numbers, though common goals might be a fasting capillary plasma glucose 80–130 mg/dL (4.4–7.2 mmol/L) and a peak postprandial (after eating) capillary plasma glucose <180 mg/dL (10.0 mmol/L) (American Diabetes Association, 2018). Another commonly used metric is A1c (or HbA1c), a standardized measurement of average blood glucose over the preceding months, with higher A1c associated with higher mortality and near normal A1c's associated with long-term cardiovascular outcomes similar to non-diabetic controls (McGill and Ahmann, 2017). However, the diabetes management process can be difficult to maintain, and many individuals fail to meet clinical guidelines, such as achieving a standard target A1c of < 7.0% (Miller et al., 2015). It has been estimated that 60% of patients with chronic conditions do not strictly follow medical advice, due to multiple determinants such as self-efficacy, complexity of treatment, and disruptions to normal schedules (Dunbar-Jacob and Mortimer-Stephens, 2001). In practice, achieving diabetes management guidelines depends on self-monitoring blood glucose levels and lifestyle factors multiple times per day, analyzing this information, and dynamically adjusting numerous factors accordingly (Klonoff, 2012). Therefore, as alluded to in the introduction, effective diabetes management is a continual and actively engaged process and is not just about following a set of static instructions.

2.2.2.1 Framework for patient empowerment

Given the aforementioned challenges many people with diabetes have in following medical recommendations and achieving recommended targets, it is pragmatic to question further why this is systematically occurring and how systems can be developed to function better with actual patient capabilities. Funnel and Anderson (Funnell and Anderson, 2000) (Funnell and Anderson, 2004) provide a framework for understanding these conditions and based on this analysis advocate for a patient-empowerment perspective. As their work is foundational to this thesis, some of their key points will now be reviewed:

- Much of traditional medical services are focused on acute care, where the medical professional bears responsibility for diagnosis, treatment, and outcomes. This approach assumes patients should follow medical advice, and therefore emphasizes 'compliance' or 'adherence' to a doctor-controlled treatment regime. However, this approach is often unrealistic for diabetes, and regularly fails to function within the realities, trade-offs and demands of the individual's life.

- The vast majority of diabetes care must be conducted by the patient or caregiver, so clinician centered approaches are inherently limited. Therefore, while interactions with the medical professional are important, it is the choices during daily life which determine the long-term outcomes of people with type 1 diabetes.

- A more patient-centered approach is better met with a more collaborative and empowering relationship, that emphasize the role of the professional in assisting the patient in making better informed decisions in meeting their own individual goals, with the patient taking primary responsibility for daily treatment decisions.

- While a doctor might be an expert on diabetes care in general, every individual best understands the situations of their own life, emphasizing the need for people with diabetes to take primary responsibility for their own care and lifestyle choices.

These points establish the foundation for this thesis' focus on supporting self-management practices. The next section will further discuss various aspects of this process.

2.2.2.2 AADE7 Guidelines for self-management

The American Association of Diabetes Educators recommendations or 'AADE7' provide an evidence-based and widely accepted program for effective self-management of diabetes (Educators, 2009). These include:

- **Healthy eating**: Appropriate food choices and portions are important for daily care. Diabetes management depends on being able to predict the amount of insulin required for a given serving, how quickly a given food will cause BG levels to rise, and avoidance or moderation of foods that cause glycemic instability.

- **Being active:** Regular exercise can improve glycemic control and reduce insulin requirements by lowering body mass, reducing stress, and improving insulin absorption.

It is also important for reducing the long-term cardiovascular and other risks associated with diabetes.

- **Monitoring:** Daily measurements of BG levels provide information to help those with diabetes assess and adjust treatment. Other self-monitoring, such as blood pressure and weight can also be recommended for some individuals.

- **Taking medication:** Insulin injections are essential for living with T1 diabetes, which is a fatal disease without this treatment. Insulin in the body must be kept in sufficient quantities to meet minimum requirements to reduce long-term complications, as well maintained within certain thresholds in order to avoid severe short-term complications. Effective use of insulin can significantly reduce the long-term risks associated with diabetes. Many people with T1D require additional medications to mitigate diabetes related complications, or other related conditions.

- **Problem solving:** Due to the multitude of factors which can affect BG levels, people with type 1 diabetes must quickly make decisions related to medication adjustment, treatment for hypoglycemia, dietary choices, exercise and other lifestyle factors that can affect management. Even with 'tight' management and years of experience there are continual challenges in glycemic control. These can be related to changes in health, lifestyle, environment, and other hard to control factors. Effective management is therefore dependent on continuously finding workable solutions for variable situations.

- **Healthy coping:** Psychosocial factors can play important roles in the ability for individuals to maintain health and can directly affect the motivation required for daily diabetes management. Finding effective ways of managing stress and changing unwanted behaviors or habits are important aspects of long-term care.

- **Reducing risks:** Lifestyle choices such as excessive alcohol consumption can have dramatic short-term effects on BG stability, while long-term behaviors such as cigarette smoking can increase the chances of long-term diabetes related complications. In addition, regular visits to medical services such as eye and foot exams, can help identify signs of degeneration allowing for timely treatment.

Managing these factors and behaviors can be seen as the cornerstone of diabetes management and research, and to the extent that such behaviors are supported, can serve as a useful framework with which to judge digital interventions. For example, (Breland et al., 2013) used these guidelines to assess diabetes self-management apps, noted that few apps promoted more than two of these behaviors, and that none of the apps surveyed could be considered to support all the AADE7 recommendations. Similarly (Eyler, 2013) found that while almost half of the apps surveyed supported monitoring (48%), only 5.7% supported healthy coping, although as to whether it is necessary for a diabetes apps to support all the AADE7 behaviors in order to be effective is an arguable assertion.

In order to learn the essential aspects of care, diabetes self-management education is recommended upon diagnosis and later as needed (Force, 2006). The AADE7 or other equivalent systems can be taught in an educator led weeklong course. Such diabetes self-management training and education can lead to improvement in long-term glycemic level (A1c) and improved quality of life (Reddy et al., 2016). And such programs might also be effective for reducing long-term care costs (Educators, 2009). However, while there might be some consensus within the medical community as to acceptable long and short-term blood glucose targets, and various methods of achieving such control, diabetes management remains challenging for many. A recent study (Miller et al., 2015) comprised of people in active diabetes treatment in the U.S. found that in the 18-25 year range, recommended diabetes control targets were achieved by only 14% of respondents. Furthermore, while glycemic control improved dramatically as participants approached 30 years of age, still only 30% of T1D respondents >30 years of age reported meeting clinical bio-marker recommendations. Such results argue for the need for additional research, especially in regard to sustainable and affordable methods of supporting long-term daily care. Among the many challenges for interventions is that practical diabetes management can require the individual to adjustment to shifting contexts and varying biological responses due to factors such as the effects of exercise, stresses such as illness, and delays in insulin absorption (Peyser et al., 2014). In addition, there are different phases of treatment each with its own requirements, such as an initial learning phase, stabilization, re-learning, and then eventually transition to long-term management (Blondon et al., 2013). While early stage diabetes education is essential, the primary focus of this thesis is on a later stage, where the individual has already learned the basic processes of monitoring and adjusting, and now settles into years or decades of maintenance. During this stage, the person with diabetes has considerable knowledge to draw upon but must still stay engaged to determine when and how to apply this knowledge according to shifting requirements. Therefore, this aspect of the thesis can be seen as an extension of earlier work on *sensemaking* processes (Mamykina et al., 2015), which will be explored in more detail Chapter 6.

To allow the reader a more intuitive understanding of the blood glucose deviation which might occur with T1 diabetes, the following Figure (Figure 2-2) shows a 24-hour span of blood glucose values for a person without (top) and with diabetes (bottom). The units on the left show both mg/dL and mmol/L which are used interchangeably within this thesis. In addition, common factors that can affect glycemic state are pictured at the bottom. While non-ideal, the deviation pictured is not extraordinary.
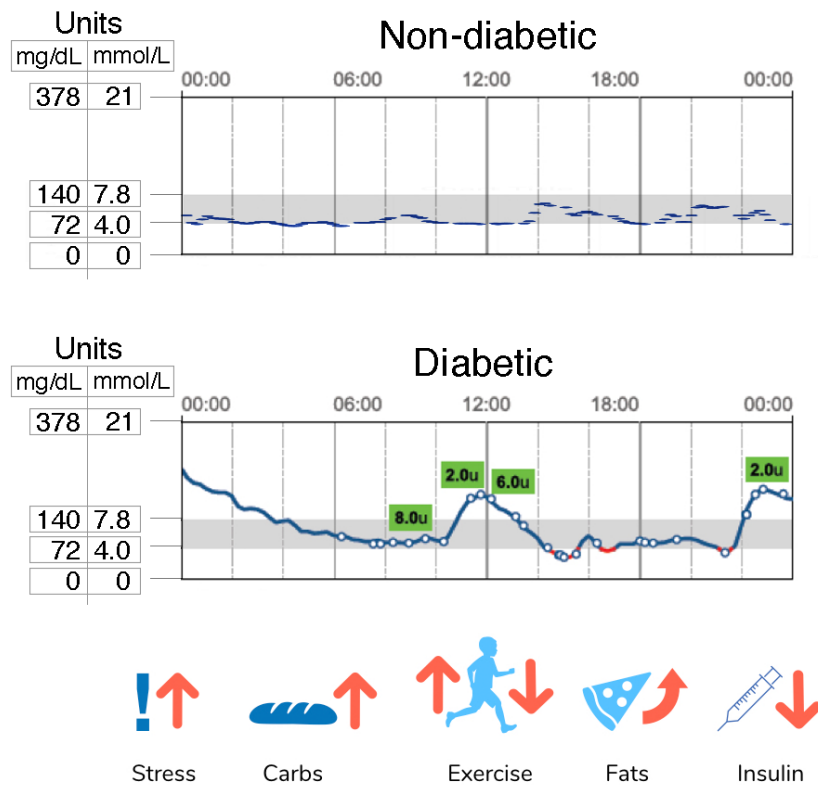
FIGURE 2-2 NON-DIABETIC VS. DIABETIC GLYCEMIC VALUES AND CONTRIBUTING FACTORS

2.3 Diabetes Technologies

While the discovery and production of insulin changed type 1 diabetes from a terminal illness to a manageable chronic health condition, regulating dosages is both critical and challenging. Diabetes technologies have been essential in improving clinical outcomes and quality of life by assisting in this process. The following sections will review established technologies associated with diabetes self-management in order to give an overview of primary devices and their role.

2.3.1 Blood glucose monitoring

The early days of diabetes self-management relied on urine tests, which were limited in only being capable of indicating when blood glucose levels had reached a threshold where glucose was excreted through the urine. In addition such tests were unreliable as they were affected by fluid intake and being retrospective were incapable of indicating current glycemic state (Clarke and Foster, 2012). While blood glucose is a superior indicator, it wasn't until the early 1980's that glucose meters targeted for personal use became commonly available, and replaced inaccurate visually read strips (Clarke and Foster, 2012). Such meters allowed people with diabetes to get an unbiased assessment of current glycemic state, facilitating real-time treatment decisions on insulin dosages, hypoglycemia treatment, dietary choices, exercise, and other lifestyle factors (Klonoff, 2012). Use and frequency of such monitoring has been correlated with decreased A1c, and improved clinical outcomes (Klonoff, 2007). These meters have continued to evolve, and are now small, low cost, and commonplace. Many of these meters now offer on-board memory for storage

of previous readings, data export functions, and basic data analysis, such as mean BG levels. However, this technology has significant limitations, as tests rely on finger sticks to obtain blood samples and such tests only reveal current value, leaving gaps in time-series data. This can be seen in Figure 2-3 where the patient has recorded time, carbohydrates (1 KHE=10 grams carbohydrate), insulin, and blood glucose level, and yet there is no knowledge as to values during the many hours between measurements. This can be contrasted with retrospective data delivered by the device in Figure 2-4.

FIGURE 2-3 DIABETES DIARY

2.3.2 Continuous monitoring of blood glucose

More recently, the continuous glucose monitor (CGM) has become adopted as a mobile T1D (and T2D) technology. It has a small sensor most often inserted into subcutaneous fat in the abdomen or upper arm and can be worn for between one and three weeks (see Figure 2-4). As these devices measure glucose in interstitial fluid and not directly in the blood stream, this can cause some delays in responsiveness to fluctuating BG levels in the 5-10 minute range (Peyser et al., 2014), though algorithms have assisted in reducing this discrepancy (Rodbard, 2016). This newer technology offers multiple benefits over early strip-based systems. CGMs offer glanceable support for diabetes management decisions by showing trends and rate of change (Pettus and Edelman, 2016), allowing a shift from the A1c as a metric of glycemic control to time in range (70–180 mg/dL or 4-10 mmol/L) (McGill and Ahmann, 2017), as well as supporting more fluid management methods (Katz et al., 2018b). The CGM can also be equipped with a transponder which can alert the user when they are exceeding or falling below pre-set threshold levels. Such

increased resolution afforded by near continuous and automated recording of data allows for a more complete record of glycemic variation, which could be useful for providing greater insights on data through analytics and predictive modelling (Donsa et al., 2015). The CGM has been shown to be clinically advantageous, with benefits such as reduction in hypoglycemia and A1c proportional to frequency of usage (Rodbard, 2016), Some CGMs, such as the Dexcom G5 offer Bluetooth data connectivity with a smartphone app, as well as incorporating cloud services to allow for real-time data sharing with other stakeholders, such as family members, friends, or medical professionals. A related device is the Flash Glucose Monitor (FGM) (seen in Figure 2-4) such as the Abbott Libre, which also has an inserted sensor, though lacking a signal transponder, the user must scan the sensor with a meter or NFC enabled smartphone to receive a reading and update of recent values. The more recent version of this devices is capable of sending a signal to warn of out of range values. Several implantable or patch-based sensors are also in development or have recently emerged onto the market, offering more convenient methods of monitoring and sharing BG data.

FIGURE 2-4 LIBRE GLUCOSE MONITOR AND SENSOR

The interface of the CGM (or FGM pictured in Fig. 2-4) offers not only the current BG level available on single measurement meters, but the continuous measurement and on-board recording of data also allow for a retrospective graphing of recent measurement and near term BG level prediction. This prediction is expressed as an arrow, showing direction and velocity of glycemic change. Survey research has suggested that the use of the CGM increased frequency and percentage of insulin titration and improved glycemic control (Pettus and Edelman, 2016).

Respondents in this study were asked to assess a CGM interface with equivalent BG value, but with the arrows indicating a rapid increasing as opposed rapid decrease. With the rapid increase indicator (double arrows at 90° upward on a Dexcom CGM), participants suggested an 140% increase over their usual correction dosage. The authors note that this shifts the emphasis in diabetes management from 'point-in-time' to 'anticipated' glucose levels. This focus on the use of CGM for real-time use as opposed to retrospective analysis, is particularly relevant given the challenges in meaningful interpretation of the complex data sets which are relevant to diabetes management (Franc et al., 2011), and will be further discussed in Chapter 6. However, despite potential benefits CGM use can be impaired by user who are cognitively overloaded by the quantity of information, suggesting the need for new interfaces that can decrease data complexity (Borges Jr and Kubiak, 2016), which is further addressed in Chapter 7 with the implementation of an expanded data gathering infrastructure.

2.3.3 Insulin pumps, digital pens, and other insulin delivery systems

Currently there are limited practical alternative to daily injections of insulin for those diagnosed with T1 diabetes. While there have been some successes with biological cures, such as implanting insulin producing Beta cells (Pellegrini et al., 2016), this technique is not permanent and at this time still requires the use of powerful immunosuppressant drugs. Although there is an inhalable form of insulin, the high cost restricts widespread use. So, for the time being, injected or infused insulin will continue to be the standard treatment. The insulin pen allows for more convenient handling and injection of insulin over earlier generation syringes, with a cartridge that is replaced every 1-3 weeks. More recently, these pens have become digital, allowing automated recording of dosages, and in some cases connectivity through a dedicated smartphone app (http://www.biocorpsys.com/connected-injection-devices), although actual usage remains limited. Another widely adopted technology is the insulin pump, which better simulates the body's natural production of insulin, through near continuous infusion. This externally worn device weighs approx. 100 grams and infuses a fast-acting insulin through a catheter inserted under the skin. The user must program dosage rates and notify the system for supplemental dosages (bolus) before meals or to correct for hyperglycemia. Though insulin pumps have demonstrated clinical benefits such as improved glycemic management and reduction in hypoglycemic events, they require motivated individuals who can maintain the device's operating requirements (Pickup and Keen, 2002). Insulin pumps and other diabetes devices are also becoming increasingly capable of data connectivity, allowing greater opportunities for data sharing and analysis.

2.3.4 Hybrid closed loop or Artificial Pancreas (AP)

The "artificial pancreas" or more expectation limiting "hybrid closed-loop system" aims to offer more responsive insulin delivery through the linking of a CGM, an algorithm and an insulin pump. This approach offers automated insulin dosage correction dependent on current glycemic state, thereby freeing the individual with diabetes from the burden of adjusting basal (non-mealtime) insulin rates. Early versions of such systems are in usage within patient initiative

groups that share source code through GitHub and instructions for setup through non-commercial websites (https://openaps.readthedocs.io/en/latest/index.html, n.d.). There are reportedly >1000 people using such self-built systems, with self-reported improvements in A1c and time in range (Barnard et al., 2018). Commercialized systems are now becoming available, such as the Medtronic Minimed 670G which can autonomously adjust insulin rates in response to changes in BG levels detected by an interfaced CGM sensor. However, despite the promise of this approach, there are factors which suggest that its development should not stop other research approaches, including:

- Challenges in fully automating closed-loop systems due to confounding or hard to measure factors such as: exercise, stress, illness, carbohydrates, insulin absorption, and technical challenges involved with device integration (Peyser et al., 2014).

- User dependency on fully automated systems could pose certain risks to user autonomy. Freed from the need for conscious reflection, users might not learn effective or accurate self-care models independence (Mamykina et al., 2015). This could be problematic if systems were to fail for some reason.

- The high costs and need for frequent maintenance of such systems as well as various psychosocial factors (Barnard et al., 2015) suggest that the closed loop might not be an ideal solution for all users.

- The effect of diverse lifestyle factors on blood glucose levels offers broader implications for other conditions or situations where non-professionals must make use complex multivariate data to inform critical, frequent, and contextually specific decisions.

At this time, these systems still require the user to manually enter bolus insulin dosages before meals, as the gap between rising BG levels, sensor detection, and insulin absorption can lead to consistent out of range values (Peyser et al., 2014), though it is possible that next generation faster acting insulins combined with improved algorithms for automated meal detection might lead to improved autonomous performance for such systems (Turksoy et al., 2016). In summary, while the AP is an exciting technology for assisting in daily management and could reduce the need for interaction with complex personal data, for the foreseeable future its limitations, and potential periods of malfunction or failure, suggest that it remains essential that users be capable of understanding and troubleshooting their own diabetes management process.

2.3.5 Telehealth for diabetes

The need for informed and multifaceted treatments decisions has led to significant academic and industry research focused on top-down tele-health systems. These systems depend on remote experts making treatment recommendations, either through accessing the patient's data remotely, or through solely text-based communication. Among potential constellations include transmission of data from a health care professional to a specialist for consultation, with re-transmission of results, and transmission of data from patients to health care providers (Franc et al., 2011). Franc

et al. note that in the case of situated decision support, such a system will have too great a time lag, and therefore other support remains necessary. Franc et al. also note that at that time telemedicine had failed to show significant improvements in outcomes, and that the future was in systems that empowered the patients to take increased role in their diabetes management. One recent study claimed small but statistically significant clinical benefits in telehealth coaching approaches (Lorig et al., 2016). While an earlier study asserted (Ruston et al., 2012) that the clinical benefits of telehealth for T1 diabetes remain controversial, identifying three emergent themes related to patients concerns with adoption of these technologies into their management routine. These included concerns that involving others in daily management would interfere with autonomy, that existing health IT systems (NHS) were inadequate to provide such services, and that in-person interactions were necessary for care. Moore (Moore, 2012) suggested a somewhat alternative approach, whereby such technologies could be used to provide situated training in the model of 'apprenticeship'. In this proposed model experts train the patient through a series of steps leading to independence through empowerment. These included *scaffolding* where the patient learns about their condition and the significance of their personal data, *articulation* where patients learn to discuss their condition, *modelling* where the coach demonstrates how to make decisions, *coaching* where the advisor focuses on timely nudges, and finally *reflection* and *exploration*, where the patient combines these lessons to make sense of their own data and outcomes. As such this could be seen as an adaption of more traditional self-care training program. However, with current infrastructure this approach poses economic and technical challenges related to scalability due to the prevalence of chronic diseases. Many health care systems are already overstressed and the added responsibility of continuously monitoring all their patients' data could be problematic. While remote observation technologies are valid approaches, and might be cost-effective when supported with algorithms, expert advice does not replace the need for individuals to practice self-regulation. This is in no way meant to disparage 3rd party systems, and it is entirely possible that such systems will outperform purely algorithmic solutions, for reasons such as: flexibility of insights, human empathy, contextual awareness, or perhaps because human interaction has greater motivational affects. However, scalability and cost-effectiveness of purely algorithmic systems, as well as the 24/7 nature of disease management argue for supporting the individual's ability to make independent treatment decisions. Therefore, even if remote expert assistance systems are proven cost effective and superior to autonomous systems, developing technologies to assist in data acquisition as well as methods of supporting users in effective independent real-time decision making remains essential.

2.3.6 Diabetes apps

The multivariate and data driven aspects of diabetes management, entailing constant analysis, calculation, and reaction, make T1 diabetes an excellent candidate for further digital technologies, including the development of diabetes apps. This has been taken up not only by numerous academic researchers working in the juncture of HCI and medical informatics, but also robustly

by industry. The following section reviews common features of these apps, reviews HCI contributions to type 1 diabetes apps, and clinical evidence concerning this approach.

2.3.6.1 Common features of diabetes self-management apps

As later chapters present research conducted to assess adoption and utility of popular diabetes app approaches, there will now be a brief discussion of these apps in order to establish a foundation for discussion. Diabetes apps have commonly included features such as: tracking and visualizing health information; integrating sensors to automate tracking; communication with support team; remote monitoring; social influence; peer support; accessing information; glanceable displays; and entertainment (Klasnja and Pratt, 2012). The ability to store BG data is often a defining feature of diabetes apps (Chomutare et al., 2011), and such apps are for the most part based on the traditional paper diary paradigm (see Figure 2-3 Diabetes Diary), allowing users to collect, review, ponder, and share their personal data. Such systems are increasingly integrating data streaming from medical devices such as CGMs and insulin pumps, as well as sensors embedded in consumer electronics such as accelerometers and GPSs from exercise trackers, opening up new opportunities for further development. The total number of available diabetes apps is challenging to quantify due to varied interpretations of what constitutes a diabetes app, multiple platforms, and frequent new releases; however, a recent survey cited counts as high as >1000 diabetes apps on the Google Play store (Hood et al., 2016). The authors listed journaling/monitoring as the most common feature, with apps frequently supporting the recording of glucose level, medication, diet, and physical activity. The majority of apps still require manual input of BG levels, and only a limited number automate exercise recording. Some apps contain insulin dosage calculators, although Hood et al. cautioned that there is a lack of clinical validation for the majority of these apps. Data export features are common among apps that allow recording of BG levels. Automated adaptive interfaces, and algorithmically supported individualized decision support for T1D remains an under explored area, though at the time of the writing of this thesis increased decision support is starting to enter the market.

2.3.6.2 Diabetes apps and HCI

User-centred methodologies such as participatory design have been used to investigate features to integrate into type 1 diabetes self-management apps. Many of these studies have built upon earlier work on supporting data reflection practices. Examples include:

- Mamykina et al. (Mamykina et al., 2008) investigated the use of a browser-based interface to assist T2 patients with collecting diverse personal data and disruptive experiences to assist with mediated discussion with medical personal. This approach resulted from earlier work (Mamykina and Mynatt, 2007) which had found patients often unable to make sense of collected data. Both systems made use automated transfer of blood glucose tests.

- O'Murchu (O'Murchu and Sigfridsson, 2010) and Storni (Storni, 2014) introduced an iPhone App TiY (Tag-it-Yourself) that sought to encourage reflection in diabetes management with flexible types of attachments which could support greater contextual understanding. This app attempted to empower patients in their relationships and discussions with medical support teams, by encouraging the collection of a more holistic range of experiences and events related to disease management. Although tags could be reused, and such tagging has become common in apps, this method still requires sustained effort to collect and interpret collected information.

- Smith et al. (Smith et al., 2007) investigated the use of digital photography to aid and augment memory, which could facilitate visualization, interpretation and reflection on past events. Participants in this study recorded BG levels and meals, which were combined into a timeline creating a visual reference as to how a given meal could affect glycemic stability.

- Owen et al. investigated how saved contextual information in the form of tags (Owen, 2011) and more recently photos (Owen et al., 2015) could support problem solving by supporting participants in creating richer diaries for retrospective reflection.

All of these examples can be seen as extending the paper logbook or diary approach with a shared assumption that the addition of new features for recording specific kinds of data will support diabetes management. One limitation of such research is that it typically occurs over a fixed period of time and therefore is not necessarily insightful into long-term engagement. The challenges to long-term adoption demanded by continuous data entry will be discussed further in section 2.4, and along with the cognitive and emotional demands placed by these primarily reflection-based approaches, will be a reoccurring theme of inquiry throughout this thesis.

2.3.6.3 Efficacy of diabetes self-management apps

Diabetes apps are widely and easily available, on all major platforms (Hood et al., 2016). These apps have shown some general positive results in improving daily BG averages. Bonato et al. (Bonoto et al., 2017) found significant improvements in A1c in intervention groups using digital health approaches, especially in conjunction with access to medical personal. Wu et al. (Wu et al., 2017) conducted a meta study that concluded that there were statistically significant improvements in A1c associated with app use (MD -.44), however such benefits were larger with T2 than T1 patients, and this study noted that current apps might not be adequate for meeting the complexity of T1D management. One study (Sheehy et al., 2014) looked at mobile apps for children and young adults with T1, and found only limited evidence for changes in self-efficacy and A1c. This study also noted the great difficulty in maintaining longitudinal use, and that PWD tended to stop using diary apps when they felt they had stabilized. In the juncture of medical and HCI, the Bant project (Cafazzo et al., 2012) set out to iteratively develop a diabetes smartphone app for younger users, which included design features such as wireless data transfer from a BG meter, gamification, decision support, and social network integration. This project claimed an

average increase of 50% in BG tests per day (from 2.4 to 3.6 per day, $P = .006$, n = 12) as a principal benefit, but detected no change in A1c. A Cochrane Collaboration study on the use of computer applications in conjunction with Type 2 diabetes care (Pal et al., 2013) found that mobile interventions may be more effective than desktop interventions, and that frequency of use was positively significant. This could support Intille's assertion (Intille, 2004) on the importance of the situated delivery of the intervention. Another study surveyed the functionality of existing mobile apps (Chomutare et al., 2011) and concluded that many apps at that time suffered from poor usability and lack of adherence to evidence based guidelines as expressed in the previously mentioned AADE7 behaviors for diabetes self-management. This was echoed in another study (Breland et al., 2013), which also noted that it would require additional research to define the optimal AADE7 behaviors to include in mobile interventions. And (Hood et al., 2016) recently conducted a review of studies on the effectiveness of diabetes apps for mobile health and found that much of the published research consisted of small feasibility studies rather than random controlled trials, and these studies showed small but statistically insignificant benefits. Of the control condition studies located, the authors noted that only one was significant, and suggested that more rigorous studies were required to establish clinical benefits, as there is a general lack of studies using rigorous medical research techniques.

Current diabetes apps continue to show areas of limitation not only in demonstrating clinical benefits, but also in their ability to integrate into daily management practices. For example, while diabetes requires frequent engagement and critical decision making based on complex data (Klonoff and Kerr, 2018), Arsand et al. (Arsand et al., 2007) noted in 2007 that diabetes diaries were most likely tools for periodic rather than daily use due to the challenges of maintaining such practices, and that self-recorded BG data is often incomplete and bias prone. Blondon et al. (Blondon et al., 2013) noted that the process of tracking health information can be burdensome for some, while (Mamykina et al., 2015) drew attention to the challenges in interpreting large amounts of personal data. In addition, despite the diabetes paper logbook (see Figure 2-3 Diabetes Diary) being a common clinical recommendation, it is also challenging to find clinical evidence that such continual diary practices improve glycemic control. There are also notable challenges that must be overcome to monitoring in general, with barriers such as that information confronts established beliefs, demands undesired actions, reveals unsatisfactory progress, or brings about negative emotional effects (Chang et al., 2017). So, while there has been considerable research into designing diabetes apps, the lack of clear benefits and considerable challenges argue for continued research, especially for new approaches. Now that we have reviewed diabetes, related technologies, and the existing evidence for efficacy, in the next section we will return to our review of literature directly relevant to the aims of this thesis.

2.4 Next Generation Self-Management Approaches

Despite the widespread embrace of diabetes apps for logging and reflecting on personal data, the evidence for the efficacy of this method is equivocal. Chapters 4-6 will present research that

suggest that there are inherent flaws with this approach related to cognitive effort and emotional impacts that point towards alternate approaches. In this chapter we return to more specifically computer science related literature to discuss a model for decision support systems based on a simplified feedback loop, and then use this as an organizing structure to discuss components which are relevant to the construction of a next generation approach. This will also be needed for Chapters 7 and 8, which are premised on the potential of such approaches.

2.4.1 Foundations for next generation approaches

In 1950 Norbert Wiener (Wiener, 1988) noted that in referring both to automata and living organisms one could define certain common features:

- Sensory ability of external states, including the capability to detect the effect of one's own actions.
- Means of processing this information for the purposes of decision making. Processing can either be reflexive as in an embedded system or can change based on learning from previous cycles.
- Means of performing an action

These components when linked together form a feedback loop, allowing a system to adjust its actions as it attempts to reach a goal state. In the following section, this feedback loop model is applied to consider potential aspects of diabetes management support systems, which could form a next generation approach.

2.4.1.1 A feedback-loop approach for diabetes self-management

The Wiener model is appropriate for a closed-loop approach, for example for an artificial pancreas where the system is capable of independent action, in this case regulating and administering insulin; however, for our purposed this model will be expanded (see Figure 2-5 Decision Support System Cycle) to reflect an open-loop approach where the human must engage in action after considering recommendations or visualizations provided by an interface. Therefore, we now restate the previous model with a modification in categorization to better reflect the demands of this diabetes self-management use-case.

4. User Action
diet/exercise
medication
life style

1. Data Collection
adoption/engagement
automation/wearables
privacy

Decision Support Cycle

3. Interventions
context UI/UX
cognitive models
behavioral models

2. Analysis
insights/correlations
automation/autonomy
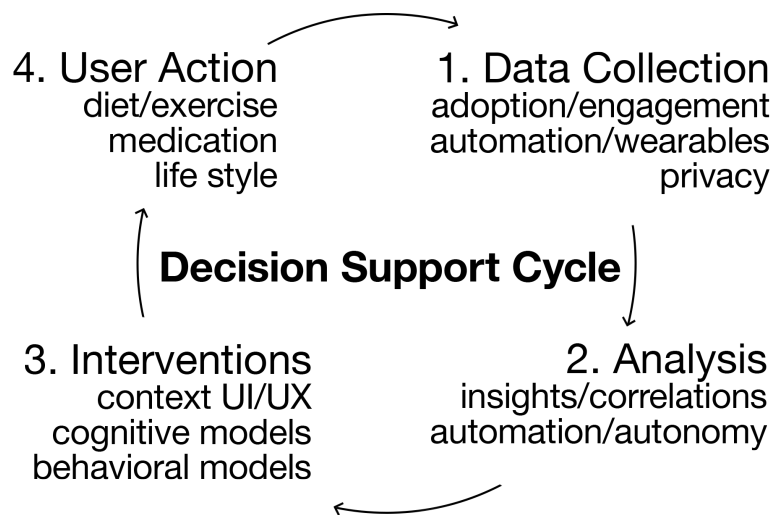
FIGURE 2-5 DECISION SUPPORT SYSTEM CYCLE

- *Data Collection:* Blood glucose levels, activity, sleep, location and other contextual factors can either be logged by the user, or in the case of a more automated system be captured with sensors embedded in wearables, smartphones, or ambient sensors within the environment.

- *Analysis:* The collected information can be processed by the user, a 3rd party, or through some combination of algorithms in order to locate correlations, predictions, or some other insights that might be useful in determining an appropriate course of action.

- *Interventions:* Information can be delivered to the user through either a human agent, or directly from the system for example as text, data visualization, auditory, or haptic output through some UI.

- *User Action:* The action that the user undertakes based on the intervention, such as a lifestyle modification, or alteration in medical treatment.

The following sections will review for each of these four aspects methods, examples, and challenges of implementation.

2.4.2 Data collection

As reviewed in 2.3.6.2, user-centered computing research on diabetes management support has often focused on the benefits of self-monitoring and collecting personal data to increase awareness and engagement with this information leading to increased self-knowledge, such as (Storni, 2014) who explored the use of tagging to assist the user's acquisition of additional contextual information, or (Owen et al., 2015) who explored the addition of rich information such as photographs for reflection. Such diary practices can have the benefit of increasing self-awareness and have been used for diverse conditions such as smoking cessation, weight loss, and mental health. Li et al. (Li et al., 2011) in discussing the tracking of personal behaviors, highlighted how automation of data acquisition potentially reduces engagement, asserting that during *discovery* phases, when users are actively involved in asking questions and trying to

understand correlations, more direct interaction with data can assist in the understanding that can be helpful for establishing beneficial behaviors. Automation can therefore inhibit such self-knowledge.

2.4.2.1 Barriers to adoption from manual data entry

However, despite these aforementioned benefits of manual data collection, such practices can form a major barrier to long-term use, and that while this engagement can be important when people are attempting to understand interactions, during *maintenance* periods users are better served by only being distracted when their attention is required (Li et al., 2011). In addition, diary approaches assumes that individuals will be motivated to engage in extensive data collection, identification of patterns, and intentional modification of behaviors (Gouveia et al., 2016).

While journaling approaches that seek to empower the user through engagement with their data are appealing, for long-term chronic care such manually recorded diaries are not only challenging to maintain, the data quality can also be questionable. Also, the multiplicity of factors, and therefore the vast amount of data that would be needed to fully understand cause and effect relationships, make this practice especially challenging. Cordeiro et al. (Cordeiro et al., 2015) examined food journaling, a small subset of diabetes relevant information, and found many barriers to continued and habitual use, such as effort, time, and monotony. The authors noted that while digital databases that allow convenient looking up of carbohydrate content and other relevant information seem like a valuable tool for assisting in easing this process, there are still challenges to adoption. Cordeiro et al. noted that a reference system that doesn't include all food options could be frustrating, and even with those participants who had managed to become habitual with their logging, skipping even a few entries could lead to terminating journaling practices. Participants also noted social stigma, as logging in front of others could be uncomfortable. Arsand et al. (Arsand et al., 2007) used PDA's and feature phones to explore the creation of diabetes diaries. They concluded that such tools would most likely be used periodically, and not on a continual basis. Mamykina (Mamykina and Mynatt, 2007) agreed, noting that meal diaries, while often recommended, are seldom maintained, and are best used for only as a limited intervention. A meta-study (Given et al., 2013) looking at eleven published papers that compared diaries with automated BG meter readings, found that manual diaries are often unreliable, with many users over-reporting non-existent tests, and under-reporting out of range values. This paper concluded that this placed significant doubt as to the use of manually recorded daily diaries for treatment decisions. These factors suggest, that even though there are some benefits to manual data entry, and that comprehensive journaling might be useful for limited periods or to clarify specific events, decision support loops must seek to avoid dependence on manual data entry for longer-term diabetes management.

2.4.2.2 Automating data collection

While current diabetes diary apps still rely significantly on manual data entry, a more automated approach is commonly advocated in the literature. Arsand et al. (Arsand et al., 2012) listed automated data transfer as a primary design consideration for diabetes mobile apps. Another study (Maniam and Dhillon, 2015) which looked at barriers to usage of diabetes self-management applications, emphasized the need for automating data entry to increase ease of use. While established diabetes technologies such as CGMs, connected blood glucose meters, and insulin pumps already offer the potential to automatically track glycemic levels and insulin dosages, there are many other life-style related sources of data that could also be tracked with existing technologies. The ubiquitous smartphone for example, has multiple sensors that could capture valuable health-related data. Trends like the Quantified-Self movement, general interest in health and wellness, and an epidemic of lifestyle related health conditions have pushed forward personal tracking into the mainstream. It is now common for people without clinical health conditions to own wearable devices that sense and record movement, sleep, pulse, and other biological markers. In addition, it is increasingly common for such devices to communicate data not only to a proprietary app, but also to Apple Health or similar aggregators, increasing the potential for more general analysis.

2.4.2.3 Wearables and Sensors

As it is recognized that the process of data collection can in general be difficult to maintain (Li et al., 2011), wearables and sensors offer the possibility to capture less biased data, as well as a greater quantity of data, which could be important for automated methods of data analysis. The primary attributes that can be measured with sensors include environment, acceleration, location, and physiological signals (Lara and Labrador, 2013). Not only can these signals be analyzed to perform activity recognition, additional activities can also be identified through their combinations. Lara and Labrador note that certain activities are distinctly more difficult to identify than others, such as whether the user is ascending or descending stairs, though certain complex activities could potentially be identified through combining multiple signals. Therefore, through networking multiple sensors, there exists the possibility of making devices more contextually aware. Milosevic et al. (Milošević et al., 2011) addressed the capabilities of Body Area Networks (BANs) to improve health through intelligent monitoring, and asserted that it was feasible to connect diverse health monitoring devices into a personal wearable system connected through a smartphone (which forms the basis for the approach taken in chapters 7 and 8). This paper also drew attention to the many challenges for context-aware sensing such as the great diversity of environments, and the range of physiological conditions that can exist among users, noting the range of technical issues such systems must address for effective implementation such as: sensor noise; node failure; multi-sensory data integration; battery life; context recognition; and filtering for relevance. Paradiso et al. (Paradiso et al., 2005) researched wearable sensors that could monitor cardiovascular conditions, using sensors that could be directly incorporated into

fabrics with standard processes, so as to minimize cost and invasiveness. While such systems are still limited, these technologies might, in the future, increase adoption by limiting social stigma and inconvenience, especially if they could harvest energy to reduce the need to charge batteries. Another study (Luštrek et al., 2015) looked at how smartphone sensors combined with an ECG monitor could detect many separate activities, such as working, sleeping, or being at home; however, detecting eating proved to be challenging, especially in the home environment, which does place certain limitations on diabetes oriented applications. The authors noted that audio could potentially be used, but that such continual monitoring created serious privacy concerns.

2.4.2.3.1 GPS correlations for T2 diabetes

Doherty et al. (Doherty et al., 2015) outfitted people with T2 diabetes with a CGM, GPS and an accelerometer. A manual journal was also used as a means of data collection for diet and other contextual factors not captured by sensors. The authors then attempted to find correlations between BG variability and collected location, movement, diet, and exercise data. While the authors successfully found correlations between BG and geographic/lifestyle data, these correlations were highly personal and could not be generalized between participants. Interestingly, diet and medication, often considered essential features for BG prediction, were less significant in explaining BG variations than locations and activities. The authors hypothesized that participants were capable of calculating medication dosages correctly for carbohydrate intake but were not as effective at calculating the effects of other variables. If this were true for T1 diabetes as well, this finding could suggest the viability of systems that could function without carbohydrate data, thereby opening the possibility of fully automated systems. The authors concluded that *'time-series analysis of data could assist in identifying risk factors personalized to the patient.'* While there were major limitations, in that study had a small sample size, was only over a 72-hour period, and was with T2 diabetes, it offers some support for the multi-device approach researched in Chapters 7-8.

While multi-source tracking systems are not yet implemented for diabetes, the abundance of research and available products in this area indicates the technical feasibility of such an approach. However, well known issues of abandonment point to the need for qualitative studies to develop such systems properly, so that they fit into people's lives in a non-intrusive and acceptable way, which will also be further explored in Chapters 7-8.

2.4.2.4 Barriers to wearables and automated data collection

Despite the potential benefits of wearable devices, there are considerable barriers to practical implementation both in regard to adoption and to practical limitations for existing technologies. For example, it is often observed that the duration of tracking device usage can be brief (Clawson et al., 2015). Harrison et al. (Harrison et al., 2015) looked at barriers to long-term use of tracking devices in the quantified-self context. The authors noted common barriers included inability to accurately track and record physical activities, poor capability for sharing data in a social context

across diverse platforms, and insufficient attention to aesthetics and comfort. While there might be greater user motivation in the medical context, there are still many considerations which can impact adoption. Pantelopoulos and Bourbakis (Pantelopoulos and Bourbakis, 2008) researched wearable bio-sensors in the medical context and that different stakeholders had different priorities. For example, decision support, comfort, aesthetics, and data security were judged to be higher priority for users than for physicians. In this study, many systems scored low on wearability and battery life, which could be important features for longitudinal acceptance. It is important to note that abandonment does not necessarily indicate that a technology has been unsuccessful. (Clawson et al., 2015) notes that abandonment can in some cases be viewed as a success of the technology, such as when users chooses to upgrade to devices with greater capabilities, for greater compatibility within a social network, or when people's needs evolve over time. Given that people with diabetes can go through cycles where they have different requirements for care (Blondon et al., 2013), it is conceivable that a specific sensor equipped device could be applied which would then be discontinued once the problem had been identified, or if when a sustainable habit had been formed. However, if one accepts that diabetes is a continual process of adjustment and re-evaluation, then some degree of monitoring must be continued. Within this context, devices can only be effective if used, and therefore establishing methods of long-term engagement with monitoring devices is needed.

2.4.2.5 Limitations of data collection automation for diabetes self-management

While there are many benefits to automating data capture and recording, there remain substantial limitations in capabilities. Manual recording allows tracking of factors such as mood (Hollis et al., 2015), which might be hard to otherwise capture. And for the diabetes, given that carbohydrate intake plays a crucial role in determining insulin dosages, such data is essential for advising on bolus injections. While there have been many attempts to mechanize calorie counting, such systems are often unwieldy. For example the GoCARB system (Anthimopoulos et al., 2015) was able to estimate grams of carbohydrate in meals within 20%. However, this required two photographic images from different angles, and a placed reference card. In addition, it would only work if foods on a plate were clearly segmented, placing limitations of such systems in real world conditions. The CalNag project (Kumar et al., 2016), used a cloud connected scale, database, and barcode reader to automate food diaries. While the authors described the system as 'effortless', it also seems limited in its application in uncontrolled environments. There are also many examples of mobile app databases to assist in calorie or carbohydrate counting, such as the Carbs & Cals app, however such systems still depend on situated selection of appropriate images. So, at this time, the logging of carbohydrates intake is an area that remains impractical to fully automate. Given these gaps, fully automated systems will need to find creative solutions to either persuade users to manually enter essential data, such as labelling for machine learning algorithms, or discover means of working with restricted data sets.

2.4.3 Data analysis

The process of understanding diverse personal data can be challenging and using this data to inform better future actions is even more difficult. Automated data processing promises to increase the utility of collected data, bridging the gap between these records and high level knowledge (Banaee et al., 2013). In an app or support system primarily geared towards reflection, the data is often ordered by time to populate a graph or chart or alternately averaged and then graphically represented. In contrast, in the case of more active systems of decision support, the data could be processed to extract domain and context relevant insights, correlations, or patterns. As noted earlier (Klonoff, 2007), acquiring data in itself has no inherent value, it is only to the extent that it can inform or motivate better decisions that it is of use. Mamykina and Mynatt (Mamykina and Mynatt, 2007) emphasized that many existing health applications make the false assumption that individuals will be able to derive correct conclusions from their collected data. They also cautioned that users interpreting collected data are susceptible to confirmation bias, and therefore this data is often used to support inaccurate beliefs. In addition, many individuals are not interested in the data for its own sake, and would rather have access to easy to understand knowledge that can be applied (Meyer et al., 2014). In the interaction study discussed in Chapter 5, I found that people with diabetes were able to understand diabetes related data within apps in a literal sense, i.e. they knew how to read through a diary and could explain entries. However, drawing actionable information from this data was often challenging, and for some users overwhelming, especially given the constraints inherent to current generation mobile devices. These arguments argue strongly for new approaches that better support users in obtaining useful knowledge from collected data.

2.4.3.1 Calls within the literature for augmenting data analysis

Given the rapid growth in new technologies for collecting and analyzing data and the great demand for improved and more efficient medical care, there are worldwide efforts to create AI systems that assist with diagnosis and treatment for health conditions. Such processing for decision support is a common theme within the literature, both for more general health and wellness and for diabetes specifically. Lazar et al. (Lazar et al., 2015) in studying abandonment of QS devices asserted that offering personalized and tailored advice could help with long-term adoption, as users quickly become uninterested in reviewing data. Supporting T2 diabetes learning, Mamykina et al. (Mamykina and Mynatt, 2007) asserted the potential benefits of tailored decision support with connected devices and algorithmic analysis, and more recently Mamykina (Mamykina et al., 2015) encouraged the development of tools that not only report but also assist in pattern recognition and non-obvious correlation discovery. And Klonoff (Klonoff, 2013) proposed that while some patients might have reservations about increasingly digital methods of diabetes treatment, such systems could help both patients and clinicians make more informed decisions. However, despite such calls, established diabetes apps are for the most part only capable of limited automated data analysis. For example, mySugr (mysugr.com) delivers

average BG levels, daily deviation, estimated A1c, and other summaries of recorded data. The primary tool for reflection is a table of recorded values and a line graph, which plots BG levels and insulin dosages over time (see Figure 5-3). Similarly, OneDrop (Onedrop.today) offers color-coded circles on a timeline, which scale to reflect entered values. In both cases, the app offers limited support for understanding the implications of collected data. Therefore, there appears to be a discrepancy between user need and existing implementation. The following section reviews research that could help close this gap.

2.4.3.2 Examples of automated analysis

While fully automated mobile diabetes decision support systems for T1 diabetes self-management are still at the early stages of development, there is already significant academic research both in general health and in diabetes management exploring and supporting the viability of such approaches. The following paragraphs discuss a few of the many relevant examples.

2.4.3.2.1 Lifestreams

Hsieh et al. (Hsieh et al., 2013) developed the 'Lifestreams' software stack which merges diverse streamed personal data, assisting in finding correlations between behaviors and markers such as stress and diet. This open-source tool using a smartphone app, included modules for feature extraction from data, feature selection, pattern identification, and data visualization tools. For example, this system identifies the user's mode of travel by combining GPS, accelerometer data, and Wi-Fi points. Other features included identifying important locations and integration of self-reported data such as mood. Relevant features were then identified through correlation analysis and highlighted. Noted examples included the relation between exercise and stress, and behaviors that caused consistent changes in glycemic state, such as returning to school. The authors reported that the system had successfully identified patterns not otherwise identified by researchers, demonstrating the technical feasibility with such approaches.

2.4.3.2.2 Insulin titration

There has been some intriguing work with machine learning, to allow the app's settings to adapt to the user's past history. A prototype app (Pesl et al., 2016) used machine learning to automatically adjust the user's carbohydrate entries to better predict insulin requirements. Therefore, as long as the user was consistent in estimating meals sizes, the system would learn to make better predictions from previous results, even if the logged data was inaccurate. While this system still relied on manual data, its ability to personalize algorithms offers an important path forward.

2.4.3.2.3 Predictive analysis

Continuing with this approach of augmenting glycemic records with data from additional sensors, Krintz et al. (Krintz et al., 2015) addressed the use of consumer wearables to predict glycemic variability. This study used exercise trackers and diverse mathematical algorithms, in the attempt

to correlate exercise with next day glycemic control, in a flexible and individualized manner. Even with devices offering only 24-hour summations of exercise, the authors claimed the addition of exercise data was helpful in predicting future glycemic variability. The authors concluded with a call for the further development of automated systems that dynamically adjust based on collected data. User-concerns related to the sorts of devices which might make up such systems form the basis of inquiry in Chapters 7-8.

2.4.3.2.4 Behavior support loop approach

While not explicitly diabetes related, Pejovic and Musolesi (Pejovic and Musolesi, 2014) suggested anticipatory mobile digital behavior change interventions (dBCIs) to make use of tracked data to support behaviors. The authors investigated the use of smartphones to deliver timely interventions based on inferred contextual information from onboard sensors. For example, they proposed a system capable of predicting onset of depression from activity and interaction sensing, which would then suggest a likely positive behavior to offset this potential state, such as meeting a peer for social activities. *Tool-effect modeling* is also discussed, or the mapping of interventions to outcomes on an individual basis. They also addressed a potential dilemma with *exploration vs. exploitation trade-off*, or whether to use a proven intervention or experiment with a different intervention that might or might not produce better results. The authors caution that unknown interventions can have serious consequences, and therefore must be introduced carefully. The authors note that this can be addressed, at least partially, by the system first going through a period of *latent learning,* where the system observes behaviors, without offering interventions or rewards. This allows the system to learn and map individualized self-motivated interventions that have already proven effective in a given situation. This approach might be well suited to diabetes, especially in its to adapt interventions to shifting needs and contexts. The research conducted in this thesis to understand user concerns for monitoring systems, potentially contributes to the future development and deployment of such an approach.

2.4.3.3 Patient resistance to automated advice

Beyond the challenges of technical implementation of diabetes decision support systems, there are diverse other factors that must be considered. From a medical perspective, Klonoff (Klonoff, 2013) cautions that systems that deliver personalized advice, rather than generic knowledge, will face greater challenges in demonstrating system safety, and therefore will be more difficult to implement. Kanstrup et al. (Kanstrup et al., 2010) created a digital teaching tool to help PWD understand how their decisions would affect BG values. Initially the authors envisioned a metaphoric GPS model for interaction, which would indicate effective 'routes' for BG daily management. However, the authors quickly abandoned this approach, as their participants indicated they did not want to turn over control of their lives to a computer system. This implies that for at least some individuals, such systems must be perceived as complementary or cooperative rather than controlling, a finding supported by the user responses in section 8.7. Mamykina et al. (Mamykina and Mynatt, 2007) cautioned that ease of use and system trust would

be essential in establishing adoption. And Skrøvseth et al. (Skrøvseth et al., 2015) developed an experimental diabetes smartphone app that attempted to deliver data-driven feedback by alerting the user to the outcomes of different medication dosages in similar past situations. This app failed to achieve clinically significant effects, and therefore was unable to demonstrate whether data-driven feedback was effective in improving glycemic control.

Such examples draw attention to the need to carefully research multiple aspects of such systems, from the paradigm of interaction, what sorts of insights might be of use, customization, and a detailed understanding of user requirements.

2.4.3.4 Summary of data analysis

While there are many examples in the literature of computing techniques to assist in data analysis, it will take effort to determine the most meaningful and potentially useful correlations to extract. Analysis of time series data is a well-explored area; however, finding correlations beneficial for lifestyle alteration might pose challenges. Due to the lack of carbohydrate data, this might necessitate shifting the system goals away from insulin titration, the primary goal of the artificial pancreas. Instead the goal might be to locate tendencies within recorded lifestyle data, which could support AADE7 behaviors and decrease glycemic variation, while improving time within goal glycemic ranges.

2.4.4 Interventions: Interfaces and Experience

Now that we have considered and discussed the use of and viability of automated data processing as an approach to reduce the barriers that stem from the reflection process, it is now important to consider how such insights are communicated from the system to the user. This next section discusses such concerns, in particular interface requirements, and theory that might be relevant to creating strategies of interaction.

2.4.4.1 Intuitive/Actionable

As discussed earlier, mobile systems offer specific benefits to delivering situated interventions when and where they are needed. When designing such mobile systems, one must consider not only the limitations on screen size relative to desktop systems, but also that users might have interaction expectations related to the device they are using. Harrison et al. (Harrison et al., 2013a) noted that due to the mobile nature of smartphones leading to varied contexts of use and restricted screen size, cognitive load is an essential factor to be considered in app usability. This is especially important as users expect the platform to reduce the stress of effortful thinking. This view implies that an app that requires excessive cognitive effort faces a major barrier to adoption. This also suggests the need for intuitive interactions, and given the challenges of visualizing multivariate data, implying a need to reduce visual complexity. Smartwatches might make such needs for simplification even more pronounced. Barr et al. (Barr et al., 2015) also support this view that intuitive interaction is an important component of mobile devices, highlighting the ways in which smartphones have become an extension of the mind. The authors drew attention to a

natural human tendency to seek to reduce cognitive load, and that the success of mobile devices is partly in the ability to in a situated manner respond to this need to reduce effortful thinking. This concern over cognitive stresses and decision making will be explored and discussed further in the research sections of this thesis.

2.4.4.2 Visual design

Visual design is important for both engaging the user and communicating content, which is reflected in heuristics for assessing mobile apps such as the Mobile App Rating Scale (MARS) (Stoyanov et al., 2015), which used *aesthetics* as a primary criteria, along with *engagement, functionality, information, and subjective quality.* Glanceability, or the ability to quickly inform the user of relevant information, could also be an essential feature for diabetes management apps. Gouveia et al. (Gouveia et al., 2015) note that as well as data being useful for recognition of patterns over time, self-monitoring can be useful for real-time feedback to control behaviors. To this end, the authors created an Android mobile app aimed at encouraging physical activity, through a tracker, goal setting, and encouragement. This app was placed on the play store for a 10-month study aimed at better understanding user interaction. The authors found that glances, which they define as 5-second interactions for checking status, were the dominant activity, and suggested these could be an effective contribution to sustaining engagement.

They extended this research with a series of prototype watch faces to investigate how to best design glanceable feedback, based on the assertion that watch faces are the most effective current means of providing frequent interaction. Through an iterative process, the authors designed a series of watch faces to explore physical activity tracking and motivation. They suggested that glanceable interfaces for behavior change should be:

- *abstract*, to allow intuitive perception of data
- *integrate with existing activities*, to promote easier and sustainable adoption (integrated with time checking by combining faces with temporal functions)
- *support comparisons to targets and norms,* to allow immediate status feedback relative to goal
- *be actionable,* to suggest helpful behaviors
- *have the capacity to lead to checking habits,* to sustain continued interest
- *act as a proxy to further engagement,* to challenge the user and encourage reflection by offering '*aha'* moments.

The authors also noted two approaches for building checking habits:

- Novelty, whereby the interface offers new information to drive engagement
- Scarcity, whereby information is only available for limited temporal periods

The authors reported that during the 28-day study period, participants checked their watches an average of 107 times per day, with over 80% of interaction involving only a glance with no

further interaction. They noted that many participants reporting having checked their watch for time and then became motivated by the feedback to be more active. The watch face with an integrated social element was motivating when users had activity counts close to others but appeared de-motivating if they were too far behind. This finding complements earlier mentioned research, and implies that in more critical health interventions, social elements must be carefully implemented to avoid the risk of negative effects. The authors suggested one solution might be benevolent falsification, altering other participants' step counts, to maximize positive effects, although once again within a more critical health context this might undermine system trust and therefore be counterproductive over the longer-term. Another approach to increasing interaction was explored with the watch face design 'Tick Tock', which explored scarcity by displaying only the previous hour's activity levels. This design was successful in encouraging more frequent glancing and frequent bouts of activity, however some participants felt that this lack of cumulative credit for activity was de-motivating. This study suggested that watch face paradigms were more or less effective depending on specific targeted behavior, for example the hourly update was more effective for encouraging more frequent movement, while a daily goal-oriented design was more effective for meeting a daily target.

This research suggesting that it might be beneficial for interfaces to trigger specific behaviors in response to different contexts and goals is an intriguing and underexplored area in app design. While I did not have time during this thesis to engage in such UI designs, the findings discussed in the research chapters offer detailed perspectives on user requirements that might help inform such approaches. Given that diabetes care must be addressed even when there are other demands on attention, this research on triggering beneficial behaviors with quick interface interactions appears especially relevant. Such research could offer guidance to both improving the app and user interface deficiencies discussed in Chapters 5 and 6, as well as for further developments of the findings of Chapter 6 which draw attention to supporting quick low-cognitive demand interactions within specific diabetes management contexts. The importance of context will be a reoccurring theme throughout this thesis and will therefore be discussed in greater detail in the following section.

2.4.4.3 Context

Previous sections have discussed not only the stage of the individual's relationship with diabetes, but also the context of care. An important aspect of context is that individuals are not necessarily constant in their needs or desires. Models like the Transtheoretical Model (see section 2.1.2) imply that as people move through different stages of personal development their needs and capabilities change, and therefore an intervention that is effective at one time might need to be different at another (Hekler et al., 2013). With a contextual approach, a system can tailor interventions algorithmically, allowing for a more dynamic and targeted approach. There are many aspects to be considered in delivering the 'right' message to the user. Dey (Dey, 2001) noted: "*A system is context-aware if it uses context to provide relevant information and/or*

services to the user, where relevancy depends on the user's task." A diabetes or other chronic condition support system could potentially integrate location, time, past patterns, medical data, and events to predict the current needs of the user, not only in terms of what information is displayed, but also in terms of how it is displayed. Sensitive situations where privacy might be a concern, such as at work, on public transit, or on a date, could affect how users interact with personal data and therefore UI design might intelligently adapt to such situations. For example, at home the user might be willing to engage in more cognitively demanding interaction, and the UI could adjust with a more reflection-based display. Or the system could record when the user typically engages in greater interaction with data and give preference to those times for triggering more reflective behaviors. In contrast, in an alternate context such as driving the user has less attention to spare and the system might deliver only critical information with highly glanceable UI.

Within the aforementioned research on diabetes apps, one approach has been to build app features that support manual contextual data collection. An example might be re-usable tags within a mobile apps (Owen, 2011), which once defined allow context to more conveniently recorded. However, this approach still requires the breaking of daily routine to record events and assumes that the user will know which events will become significant later. While at this time few diabetes or health-oriented apps are capable of contextual adaption, researchers are creating the foundation through work on situational awareness. For example, Sebillo et al. (Sebillo et al., 2015) built a mobile app which incorporated GPS data, thereby alerting the user to correlations between locations and glycemic states. The app could also provide helpful information derived from the user's coordinates, such as the location of relevant emergency medical services when traveling in unfamiliar areas. Therefore, understanding the contextual needs of users and practical methods of designing systems that are sensitive to such needs could be critical for adoption and utility, and suggest the need for the domain specific research carried out in the following chapters.

2.4.4.4 Emotionally sensitivity

Diabetes management can be emotionally stressful, as interaction with diabetes data can cause some to feel burdened by anxiety over long-term physical deterioration, which can lead to rejection of supporting technologies (Blondon et al., 2013). And Chang et al. (Chang et al., 2017) noted that emotional impacts can cause individuals to avoid interacting with their personal data, as unwanted results can cause negative feelings and cause discouragement. This finding places specific barriers in diabetes care where unwanted test results can be frequent. Owen et al. (Owen et al., 2012) proposed that for those with diabetes, stored contextual information could help to reduce the impact of measurements of unwanted BG measurement, by helping the individual to understand why a result had occurred. However, this approach was targeted primarily for mediating interactions with clinicians which play only a small part of total diabetes care. As discussed earlier, this approach also makes assumptions about user desire to continually record

information. This workload for uncertain daily benefits creates a significant barrier to longer-term adoption and practicality which will be a continuing theme throughout this thesis.

As well as emotional challenges related to interactions with data, individuals can also have complex relationships with the devices used for disease management. O'Kane et al. (O'Kane et al., 2015) investigated how T1D technologies for self-management can create feelings of stigma or situational discomfort, influencing how and if they are used in social situations, noting that some individuals are reluctant to reveal having a medical condition, and therefore would not use diabetes devices in public or in the workplace. However, O'Kane et al. also noted instances where people with diabetes intentionally used their devices visibly for specific goals, for example: to demonstrate the non-exceptional nature of the diabetes routine; get special considerations; or influence a social situation. These concerns over the affective nature of health data draw attention to the need to carefully consider such interactions when designing support systems, carefully balancing such concerns with the need to communicate essential health information. This theme which will also be addressed repeatedly in the research presented in later chapters.

2.4.4.5 Theory and HCI

Theoretical considerations have served an important function in the design of health interventions (Mamykina et al., 2015) by supporting the transference of acquired knowledge between related domains (Hekler et al., 2016). This is reflected in HCI research, where there have been numerous studies engaging with or inspired by behavior theory. Examples include Lin et al. (Lin et al., 2006) which incorporated multiple elements of behavior theory literature and the aforementioned Ubifit Garden (Consolvo et al., 2009) which investigated goal-setting theory in a persuasive technology context. The behavior change wheel (Michie et al., 2011), sought to bring together all the potential tools for developing effective behavior change interventions. Despite the attractions of such generalizable models, employing such theoretical models into specific designs can be challenging (Hekler et al., 2013) as such constructs generally lack clear steps for translation into functioning systems. In addition, Hekler et al. notes that as many app-based interventions apply only selected aspects of behavioral theories, neglecting specific elements, or combining elements from multiple theories, it is difficult to use such projects to validate a specific model. Hekler et al. notes that an alternative approach to models are design guidelines, some of which have been previously mentioned, and that these are best used as starting points to be tested in an iterative manner through user studies. Therefore, while behavioral (Michie et al., 2011) or stage-based models (Blondon et al., 2013) might potentially assist in designing interventions for supporting diabetes self-management, the vastness of this literature, and that this work does not play a prominent role in this thesis precludes a more thorough review. The following section discusses select examples, while more in-depth review of cognitive model will follow in Chapter 6 as appropriate for discussion.

2.4.4.5.1 FBM

The Fogg Behavior Model (FBM) describes behavior as a result of three primary factors: motivation, ability, and triggers (Fogg, 2009). This model also asserts that all three aspects must be present for an event to occur, and therefore an intervention must take steps to bolster any weakness in any of these aspects to ensure success. These include:

- *Motivators:* pleasure/pain, hope/fear, and social acceptance/rejection.
- *Ability:* time, money, effort, cognitive load, and routine.
- *Triggers:* an initiator, would in this case be primarily associated with some form of prompting from a mobile device

On the last of these, perhaps as suggested by Stawarz et al. (Stawarz et al., 2015) it might be possible to link to an already existing behavior as a trigger. While implementing the negative motivators poses ethical and adoption considerations within a health context, discovering means of accessing a sense of reward for diabetes management could be compelling, though it could be important to attach such rewards to behaviors rather than pre-defined glycemic outcomes (Petry et al., 2013). While this thesis does not directly build upon the Fogg model, it does draw attention to barriers which could interfere with its success. For example, Chapter 5 provides participant responses which suggest that specific UI designs can be demotivating (*motivators*), be excessively cognitively demanding (*ability*), or lack actionable feedback (*trigger*).

2.4.4.5.2 COM-B

Related to the Fogg model, the COM-B model (Michie et al., 2011) also asserts three factors for behavior change to occur:

- *Capability*: the knowledge and skills to accomplish an action, both physical and psychological
- *Opportunity*: the factors that are external to the individual, both physical and social
- *Motivation*: the desire both reflective and reflexive to accomplish an action.

The model then defines nine potential interventions that can be applied to make up for deficiencies in those areas: persuasion, incentives, coercion, training, enablement, modeling, environmental restructuring, restrictions, and education. This system is used both as a behavior model and as a basis for intervention design. One potential criticism of both Fogg and Mitchie's models is that they both define motivation as an essential aspect of a behavior, but do not necessarily address how to support positive behavior during periods of especially low motivation (Adams et al., 2015). Adams et al. addressed this concern, promoting the development of interventions that focus on the unconscious decision-making process. An analysis that draws on the work of Kahneman (Kahneman, 2011), Adams et al. asserted that the great majority of published HCI work in behavior modification address system 2 or effortful thinking, and proposed 'mindless computing,' or technologies that influence behavior without demanding user effort. Among the design considerations promoted were: reflexive rather than reflective thinking;

effective use of triggers that incorporate into existing routines; parallel rather than serial, i.e. the intervention should be minimally distracting. However, Mamykina (Mamykina et al., 2015) presents a convincing argument that greater self-knowledge will lead to more beneficial habits, and that the process of breakdowns in assumptions is vital for the process of learning. In addition, persuasive approaches must be carefully considered, as the benefits of positive behavior change must be balanced with the risks of reducing conscious decision making, and thereby impairing independent action. Persuasive design in general has also been criticized as having an inherently coercive aspect (Hekler et al., 2013). The application of persuasive technologies can therefore raise ethical and practical concerns, especially with scaled digital interventions where individuals are no longer monitored for adverse effects. This is especially true in a health context, where delivering damaging advice or disrupting established routines could be detrimental. For example, Stawarz et al. (Stawarz et al., 2015) found that systems that rely on automated reminders to trigger behaviors can impede self-sustaining habit formation, thereby creating unnecessary dependence on technology. The research in this thesis, particularly in Chapter 6 will present an integrated model that attempts to balance the need for ease of use with the need to learn effective self-care behaviors through active engagement. Considering whether it is either ethical or practical to imbed goal behaviors within a personal health system, even general wellness recommendations, brings up important issues related to user autonomy, which will be discussed further in the following section 2.5 on ethics.

2.4.4.6 Summary of next generation app approaches

This section grounded a next generation approach on historic literature suggesting the viability of the components to form a feedback-loop where sensors, automated analysis, and interfaces are joined together to inform human behaviors. Reviewed literature suggested that while each of these components has been researched, there are also substantial challenges to successful implementation, such as behaviors that are difficult to capture, user resistance, and lack of proven models to design interactions for such systems in a manner that create the right balance between user support and autonomy. A significant concern for such systems is the ethical implications of introducing such technologies into daily life. The following section will discuss this last theme in more detail.

2.5 Ethical Concerns for Computing Systems

As discussed in previous sections, the application of ubiquitous computing technologies could facilitate a next generation approach for apps, delivering contextually relevant information to assist with achieving personalized goals. However, many questions remain in how to design such systems without infringing on key ethical concerns such as self-determination or privacy. Respecting such needs requires assessment of the user's preferences as well as due diligence into potential impacts of implemented technologies. The following section will briefly review relevant ethics, benefits of an ethical approach, and relevance to thesis research on health support systems.

2.5.1.1 Ethics general

Ethics asks questions as to right and wrong and how these beliefs can be categorized and implemented in real world situations. *Normative* and *applied* ethics are particularly relevant when evaluating health technologies. The former attempts to classify what society considers to be commonly accepted standards of right and wrong behavior, while the latter is concerned with their application to specific, relevant, and often controversial concerns. For example, the assertion that technologist have an ethical obligation to consider the social and personal implications of their work is an example of a *normative* principle (Adamson, 2015). *Applied* ethics seeks to address controversial topics with a moral component and are often detailed in professional codes of conduct, such as the ACM code of ethics and professional conduct (ACM, 2018). *Applied* ethics is therefore the area of philosophy that takes theory and applies it to real world moral decisions that are directly relevant to professions, specific technologies, and public policy (Beauchamp, 2007).

2.5.1.2 Benefits of ethics

Such codes of conduct can have diverse benefits, such as providing guidance to individual members on ethical conduct, and building trust in an organization by convincing the public that the members are capable of self-regulation (Anderson et al., 1993). Ethical design reduces legal risks, increases brand loyalty, and increase general adoption, as well as to promote the willingness to share personal data (Baldini et al., 2016). When implementing such principals, it is worth noting that such codes commonly contain both *procedural* ethics related to the ways that members should act as to enable the functioning of their professional organization, and the *substantive* ethics which consider the implications of the accomplished activities (Adamson, 2015). While *computer ethics* such as in the aforementioned professional codes, relates largely to the ethical considerations of human actors creating software and devices, *machine ethics* relates to the implications of such devices and their interactions with humans and other machines (Anderson et al., 2004). Relevant to health decision support systems, Adamson (Adamson, 2015) asserted that in our desire to create autonomous devices we must not only behave in an ethical manner in the act of construction, but also assure that these devices make decisions in accordance with the same ethical rules governing human actors who they are replacing. While perhaps challenging to build, this also has certain practical advantages, as this allows us to reference diverse established codes as a basis for new systems, and thus allowing system designers to focus on integrating accepted practices, rather than having to create entirely new ethical standards (Samuel et al., 2010).

2.5.1.3 Ethics for decision support systems

As noted earlier in the section on foundational literature, (Meredith and Arnott, 2003) proposed that the work of Beauchamp & Childress (Beauchamp and Childress, 2001) on bio-ethical principles form a reasonable foundation for decision support systems. Samuel et al. (Samuel et al., 2010) used these same principles, but in regard to the specific domain of health informatics

asserted the utility of adding ethics related to data privacy and security. Wright (Wright, 2011) concurred, drawing upon the Beauchamp & Childress principles for the foundation of his framework for ethical impact assessment of IT projects, with the addition of specific privacy and security concerns. While many of these standards are legally regulated (EU General Data Protection Regulation (GDPR)), given the wide range of contexts within which a personal health system must function, it is vital that such systems not be considered solely in terms of clinical benefits, informed consent, or legal regulation; rather, such systems should also serve the needs of the individual within the ethical standards of the culture within which they operate (Gurzawska et al., 2017). To this last point, we might add the individualized desires of the user and the contexts within which they operate.

2.5.1.3.1 Learning systems

Designing and implementing ethical autonomous medical systems that are capable of independent learning pose additional challenges, as they are to some degree inherently unpredictable, therefore developers cannot be fully responsible for their decision making after training (Thekkilakattil and Dodig-Crnkovic, 2015). Therefore, some method of embedded ethics is needed to assure ethical behavior, which demands careful research on user requirements in diverse scenarios. This is in accordance with Anderson et al. (Anderson et al., 2004) who note that as machines have more responsibility, they must have increased accountability. It is important to note that it is not enough to just assume that such systems are ethically neutral, as such systems always have inherent assumptions and impose structures on the user (Chae et al., 2005). Such considerations are especially important with the amplification of effects that comes with widespread adoption of algorithms (Brey, 2012). This need for considering the implications of such systems throughout the design process is an important consideration which underlies the viewpoint of this thesis.

2.5.1.3.2 Autonomy and decision support systems

Given the intention of this thesis to support the development of user-centered systems for self-management, the ethical principle of *autonomy* is of particular relevance. Beauchamp & Childress (Beauchamp and Childress, 2001) highlighted three important criteria for an act to be considered autonomous:

- The act has to be intentional, a result of an exercise of the will, implying competence on the part of the decision maker to make decisions.
- The act has to be a result of a decision based on informed understanding.
- The act has to be free of controlling influences.

Designing computing systems that can lower the cognitive effort required for decision-making, while not infringing on these criteria will require systems that are highly responsive to the user. For example, many people have priorities in life such as family, career, or lifestyle that can at times take precedence over what clinicians might consider "ideal" disease management, such as eating on fixed schedules, avoiding alcohol or other intoxicants, or maintaining target A1c

through stressful periods. Therefore, systems (or specific aspects or components of these systems) that seek to optimize health behaviors could be detrimental or act against the user's desires, such as interfering with social obligations. This theme of understanding user needs within different contexts in order to design systems which support user autonomy is integral to this thesis.

2.6 HCI Methods for Designing and Validating User-Centered Health Systems

The following section will briefly discuss domain relevant work that informs both the user-centered research methods chosen, and the approaches pursued in later chapters which seek to support the design of more effective health management systems.

2.6.1 Design and the User

While developing new products for the medical domain poses many regulatory and technical challenges, integrating users into the design process can provide valuable design insights. As discussed earlier in section 2.4.3.3, Kanstrup et al. (Kanstrup et al., 2010) developed software and services for living with diabetes through interviews, workshops, and prototype explorations. Interestingly, the resulting prototype, was significantly different from the researcher's initial concept of a 'GPS' style guidance systems. This change in approach resulted from participants sharing that they did not want a system that would tell them what to do, but rather a way of making better informed decisions. The user involvement was therefore beneficial in preventing investment in systems users did not actually want as well as emphasizing the balance between support and autonomy. The research that will be presented in this thesis suggests that there is user interest in additional decision support, but that it must be delivered in a balanced way that allows the users to retain control over their lives. Such subtleties argue for extensive user research, and methods to allow users to participate throughout the development process.

2.6.1.1 Participatory design and apps

Arsand et al. (Arsand et al., 2012) also applied participatory design techniques to develop mobile phone apps. While the resulting app was essentially a diary app, the lessons learned included the importance of automating data entry, integration with additional sensors, and contextual sensitivity, all features which research conducted for this thesis has continued to support. McCarthy et al. (McCarthy et al., 2017) used participatory design techniques such as drawings and paper prototypes in a workshop with people with T1D, who were teamed with designers to explore how blood glucose monitoring devices could be re-designed to address stigma related to public use. Strategies such as disguising monitors to look like non-medical items, increasing brand identity, and personalization were explored to gain insights into such potential approaches. These prototypes helped locate strengths and weakness of such approaches, such as that disguising devices might be counterproductive by preventing others from recognizing a medical emergency. The authors concluded that this workshop approach was successful in idea exchange between users and designers and delivering new concepts. Such studies affirm the importance of

including stakeholders in the development process, allowing them not only to comment on existing products, but also to determine the direction and approach taken. This aspect of allowing the eventual users to play a significant role in product design is also supported by Jones et al. (Jones et al., 2017) who drew attention to the need for new technologies to not simply reinforce existing hierarchical compliance based relationships in health care, but rather to allow the user to adapt technologies to their own needs.

2.6.1.2 Frameworks for including users into design practices

In order to integrate users into the design process in a practical manner, Gulliksen et al. (Gulliksen et al., 2003) identified principles to assist in user-centered systems design (UCSD), asserting that this term was often used too generally. The promoted principles included: *User focus* should be shared by all members of a project, including understanding the detailed requirements of real users; *Active user* involvement through all stages of development; *Iterative processes* including evaluation, documented changes, and redesign in accordance; *Understandable design representations* that are suitable for stakeholders; *Prototypes* to evaluate ideas with actual stakeholders; *Evaluation* in context; *Interface and interaction* as dedicated design practice; *Multidisciplinary approach*; *Usability expert* who should have decision making in regard to system usability; *Integrated design processes* also re-examining and modifying context of use as appropriate; *Customization* for purpose. The authors note that while some have criticized usability testing as inefficient in comparison to expert led 'proper design', that the users themselves can provide needed insights that might otherwise be missed, and therefore it is essential that software and system development have usability techniques and user involvement throughout the development process. These stated principals are influential throughout this thesis, especially for the approach taken in Chapter 8 which suggests a method for lightweight prototyping of multi-component systems.

2.6.2 Usability and other methods of assessment

The user of heuristic analysis will be discussed in more detail in Chapter 8, but the next section will discuss important terms which have bearing on this later work.

2.6.2.1 Usability

The ease and pleasantness of using an interface can play an important role in the success of an application. (Nielsen, 2012) notes that there are five aspects essential for determining these qualities for user interfaces, which is frequently referred to as *Usability*:

- *Learnability*: Ease of task accomplishment on first use.
- *Efficiency*: Ease of task accomplishment after design has been learned.
- *Memorability*: Ease of task accomplishment after pausing use.
- *Errors*: Frequency, severity, and recovery from errors.
- *Satisfaction*: Pleasure related to use.

In addition, Nielsen notes that the degree to which needed features are provided is also critical, which is referred to as *Utility*, which can be seen as fitness for purpose, and therefore is separate from usability. This category is also integrated into the criteria suggested in Chapter 8.

Building on earlier work, Harrison et al. (Harrison et al., 2013b) proposed a usability model specifically for mobile applications. This model while building on earlier usability models, such as (Nielsen, 2012) or ISO 9241, notes that these commonly used usability models focus on features such as effectiveness, efficiency and satisfaction, while cognitive load is often under represented. Their usability model PACMAD (People at the Centre of Mobile Application Development), fuses multiple existing models in order to create a more complete approach. This model draws attention to three aspects which can play a role in mobile usability:

- *User*: Abilities and limitations of the user, including level of experience.
- *Task*: Objective of use.
- *Context of Use*: Environment of use

This model adds two aspects to the earlier mentioned (Nielsen, 2012) model; *Effectiveness*, or the ability to accomplish a given task in a specific context, and *Cognitive Load.* This is judged to be especially important in a mobile context, as usage can impact both the ability to accomplish other concurrent activities such as walking in traffic, while also impacting ability to accomplish the application objective. These aspects are of particular interest to mobile systems and play a prominent role in understanding user requirements for diabetes management systems and will both be reoccurring topics throughout this thesis.

2.6.2.2 Evaluations frameworks for ethical assessment

As argued previously, the advent of systems that supplement or replace human decision-making necessitate careful consideration of ethical implications. The following sections discuss general issues of ethical responsibility for such systems and how assessment and design can be informed by such concerns.

2.6.2.2.1 Ethical design

An important aspect to consider when designing health management systems is that they can have unwanted and potentially hard to predict side-affects such as rewards for step-counting leading to a reduction in activities such as swimming that cannot be sensed (Munson, 2017). Thekkilakattil and Dodig-Crnkovic (Thekkilakattil and Dodig-Crnkovic, 2015) suggested that that the relatively recent introduction of newer technologies (such as autonomous cyber-physical systems), poses special challenges in ethical design due to lack of previous experience to draw upon. The authors note that evolving technologies necessitate frequent re-assessment of ethical implications, and therefore it is imperative that people developing these technologies engage in independent ethical examination of their work, which involves identification of potential moral problems, which can be addressed during development processes.

2.6.2.2.2 Is legal compliance sufficiently ethical?

While regulation has an important role to play in protecting consumers, there are diverse reasons why it is important to consider implications of new technologies beyond established regulations. Examples include the difficulty in codifying the subtlety of complex daily interactions with assistive technology, the inherent imperfection of software (Goodman, 2016), the lag between innovation and changes in law (European Parliament et al., 2016), and the shifting in responsibility from medical personal towards technologists (Adamson, 2015). Therefore, while many user concerns such as data usage might be legally mandated, from an ethical perspective developers of complex systems should take into account these principals in order to embed protections for the user where possible within the systems, as well as take into account how developed systems could lead to potential abuses (Luger et al., 2015).

2.6.2.2.3 Methods of ethical development

An ethical approach similar to a participatory design methods, suggests integrating stakeholders throughout the development process, so that they are encouraged to express concerns and influence design (Wright, 2011). This is advantageous not only on moral grounds, but also potentially on financial grounds, as poor ethical decisions in design can hurt the success of a product or service (Wright, 2011). There are various methods of incorporating ethical approaches into product design. Lahti et al. (Lahti et al., 2012) advocated for heuristics that could be used similarly to the Nielsen Heuristics to support light-weight ethics assessment. These authors asserted the value of pre, during and post project analysis, and proposed six heuristics, *consistency, justice, respect, integrity, autonomy,* and *awareness,* as well as a set of key questions meant to assist with evaluation.

Brey (Brey, 2012) proposed the Anticipatory Technology Ethics (ATE) framework specifically for ethical assessment of not yet existing technologies, which therefore cannot be directly tested with users. He stressed the importance of early assessment, noting that once a technology has become implemented, it is far more difficult to change. Central to this framework is critical examination at three separate levels (technology, artefact, application), which are individually analyzed to uncover ethical issues. The top level, *technology* is defined as the general grouping of techniques brought together to achieve a common purpose. The *artefacts* are the devices created or derived from the technology, while the *application* level refers to a specific task or contextual use of a device for a particular purpose. The author asserts the importance of examining ethical impacts at all levels, from more general to specific, and the importance of 'forecasting' (informed prediction) for emerging technologies. Brey suggests two stages of ethical analysis, identification and evaluation, with an optional third of recommendation. The author recommends an ethical checklist to help identify areas of concerns though noting the need to supplement with domain relevant topics that might be missed.

2.6.2.3 Summary

These usability and assessment frameworks helped to inform research approaches taken in later chapters. The emphasis on cognitive load appeared especially significant and will be discussed in greater detail when exploring user challenges concerning diabetes app interfaces, as will *utility* which is found to undermine otherwise usable systems. Further discussion and examination of methods of designing and assessing user-centered systems will occur when appropriate in later chapters.

2.7 Relation of Literature to Thesis

We have reviewed Type 1 diabetes as a chronic condition and noted the importance of individuals engaging in diverse behaviors to maintain health. The review also presented evidence that despite many years of research, diabetes management remains challenging for many. We also explored some of the reasons such as complexity and emotional stresses that make this care demanding, while also demonstrating that many of the required behaviors are generalizable to broader health and wellness. We have also noted that smartphone apps with their ability to store, organize, share, and communicate diverse data appear well-suited to supporting diabetes self-management processes; however, the evidence also suggests that despite considerable efforts, the benefits of the current dominant approach remain unclear. Investigation of this discrepancy between an accepted system design and user-requirements appears well suited to user-centered research techniques. Therefore, in order to improve upon this prior work, we must understand the benefits and deficiencies of current approaches, and then look for new approaches that might better fulfill user needs. The reviewed literature has also suggested that there exist technologies and methods which could help to overcome already known barriers for supporting diabetes care, however these approaches entail potential risks and must be carefully consideration before deployment. Therefore, we set out to understand discrepancies with current approaches and seek to understand concerns and methods which could help foster next generation systems which do not repeat prior errors. The following chapter discusses the revised research questions and the methods that have been applied to them.

Chapter 3: Research Questions and Overview of Methods Chosen

After reviewing the relevant literature and discussing apparent gaps in knowledge and practice, we are now in an improved position to clarify the ambitions of this thesis as well as reframe the research question in a more comprehensive manner. After this, we will outline the chosen research methodologies and identify why they are appropriate for the research question. While this chapter will indicate the general methodological orientation of the thesis as a whole, detailed discussion of methodologies is reserved till later chapters, as different combinations and refinements of existing methodologies were necessary to address the successive stages of the research. Consequently, the methodological details are better understood in the context of the challenges uncovered and specific research objectives in chapters 4-8. As a general note, while this thesis is concerned with technology, the applied research methodologies are not primarily concerned with quantifying the performance of specific technical features. Rather, they are concerned with understanding and evaluating the intersection of technology and real-world user needs, as well as more fundamental questions about how and why popular designs fail to meet such needs, and what can be learned from these failings to improve designs and design methods for next generation products.

3.1 Expanded Research Questions

In section 1.2 we introduced the preliminary research question:

"How can we improve the practical utility of diabetes apps from a user-centered perspective?"

As we have seen in the literature review, diabetes management must occur within different contexts and people with diabetes are diverse in their needs. T1D does not discriminate, it can occur at any age, to anyone, and there is not yet any known means of prevention. Therefore, individuals might have different dietary habits, financial resources, access to or preferences for insulin delivery methods, lifestyles, responsibilities, cognitive capabilities, and so on. This great diversity of requirements for effective management support indicates the need for continued in depth user research. So, keeping in mind the wider understanding gained from the literature, we will seek to answer the following questions in the subsequent chapters:

- RQ1: *Are diabetes apps actually meeting user needs, and if not why not*? (Chapter 4)
- RQ2: *Are the standard user interface designs of diabetes self-management apps sufficient for meeting user needs, or are there inherent design flaws?* (Chapter 5)
- RQ3: *How could diabetes apps better support user decision-making processes*? (Chapter 6)
- RQ4: *What user concerns need to be addressed when developing a next generation app approach that relies on multiple networked monitoring devices*? (Chapter 7)
- RQ5: *How can we systemize these concerns to help developers address high-level requirements when developing next generation approaches*? (Chapter 8)

Within this thesis we will address each of these questions and, given the great diversity of individual requirements, seek to offer insights into processes that can assist in determining paths forward to design diabetes support systems that better meet user needs.

3.2 Overview of Methods Chosen

In order to achieve the practical goal mentioned in Chapter 1 of rethinking existing diabetes apps to better help individuals self-manage type 1 diabetes, this thesis seeks to understand the underlying requirements of primary users of these apps, the individual with diabetes. Furthermore, this thesis seeks to understand ways in which existing products succeed or fail to meet these needs, and thereby determine what sorts of questions should be asked when further developing these technologies. As such, the primary method relies on in-depth discussions with users, asking them to reflect on their experiences and needs, followed by the application of various methods to analyze these collected responses.

3.2.1 Research procedures

In the following sections, we will briefly review the research methods chosen, and why they were selected. As noted previously, there will follow more thorough descriptions of methods within the later research chapters.

3.2.1.1 Chapter 4: Longitudinal user engagement with diabetes smartphone apps

This pilot study sought to determine if diabetes apps were meeting user needs, and therefore engaged people with diabetes who had previous real-world experience and insights with these products. This study used a combination of a questionnaire which collected demographic information and a short semi-structured interview about participants' experiences and reflections on the prior usage of diabetes smartphone apps. Notes were taken during the interviews for qualitative data collection. All collected data were anonymized and input into a spreadsheet for further thematic analysis and summing of responses.

3.2.1.2 Chapter 5: Diabetes app user-interaction study

Drawing on the insights from the initial pilot study, this next study sought to determine if the user interfaces of popular diabetes apps were sufficient for helping users to make sense of diabetes relevant information. To this end diabetes data were pre-entered into representative diabetes smartphone apps so that each user could view the same data within different interfaces. Participants were then asked questions related to functional and affective aspects of apps with respect to this data and asked to "think aloud" as they used the apps. These smartphone screens and participant's hands were recorded with a webcam which captured these interactions along with an audio recording. Videos were transcribed, and then coded in NVivo according to the following categories: app, interface type, emotional response (positive, mixed, negative, neutral), and expressed usefulness (helpful, mixed, not helpful).

3.2.1.3 Chapter 6: User interaction analysis and a Questionnaire for investigating cognitive processes of T1 diabetes self-management

This study drew upon the same interviews in the previous study based on apparent discrepancies between user responses and the cognitive models discussed in 2.1. This pre-preliminary analysis was then used to propose an expanded diabetes self-management model. Then to test this theory with a larger sample size, this study made use of an online questionnaire to collect quantitative and qualitative data related to diabetes self-management thought processes and methods. All responses were input into an excel spreadsheet for quantitative and qualitative analysis, and results were analyzed for statistical significance with Jupyter Notebooks using Python 3.

3.2.1.4 Chapter 7: User Concerns for multi-device monitoring

The conclusions derived from previous chapters suggested that eco-systems of devices could provide a path forward for diabetes apps, however as discussed in 2.5 such systems could raise increased user concerns. Technology probes are used to assist in the co-design of new technologies, and draw upon an interdisciplinary approach to investigate the use of technologies in real world situations, technical feasibility, and to inspire further design (Hutchinson et al., 2003). The use of technology probes has previously been used in diabetes focused HCI research, with Mamykina et al. (Mamykina et al., 2008) employing the MAHI mobile application which automated blood glucose recording into augmented logs for assisting with the development of reflective thinking skills among newly diagnosed type 2 people with diabetes. Mamykina et al. noted that the disruption the probe causes while integrated into daily activities can provide valuable insights into new technologies. This study drew upon this methodology to investigate user concerns related to a next generation approach for automated diabetes decision support systems using multiple connected tracking device. This chapter reviews semi-structured interview with participants at the beginning and end of the 4-week study, in order to determine emerging concerns, reflections on specific devices, and to suggest technologies needed to meet these concerns. These quotes were then organized thematically to suggest emergent questions to be considered by developers of next generation diabetes decision support systems.

3.2.1.5 Chapter 8: DUETS

Attempting to meet the challenges of applying diverse qualitative findings to actual product development cycles, this chapter reviews the development and deployment of a tool for stakeholder reflection on multi-component health support systems. The iterative design process for the method is reviewed, and then the tool is assessed through a series of mediated focus groups examining a proposed diabetes decision support system. In order to establish value of this approach, it is compared to an existing heuristic-based system. The first session engaged a Berlin-based diabetes analytics startup and lead them through a series of questions and use of the card-based system to reflect on their proposed product. This was followed by a second study with people with T1 diabetes who engaged in a similar process. In the 3rd session, cumulative responses were brought

back to the startup, who engaged in a mediated discussion of product concerns. The responses for each session were then combined to identify which techniques were helpful in locating new concerns, allowing comparison of DUETS with the heuristic approach and the value of the different DUETS components.

3.2.2 Ethical considerations

In accordance with The Open University's ethics for research with human subjects, all studies were submitted to, undergone review, and granted favorable opinion (see Appendix A) by the Human Research Ethics Committee. This process involved the submission of a Proforma which included a description and rational for the project, project personal, research protocol, key ethics considerations, and general project management. While all research was considered low risk, in accordance with these standards all measures have been taken to guarantee the full anonymity of all participants in the studies which have been completed as part of this thesis. This concludes the background perspective, foundational knowledge, and outline of procedures which have guided the research direction of this thesis. The next chapter will begin the review of the research undertaken to investigate the research objectives.

Chapter 4: Adoption of Diabetes Apps Pilot Study

This pilot study was motivated by informal anecdotes suggesting that, despite the great number of available diabetes apps and the daily challenges of diabetes care, many people with T1 diabetes who had tried such apps were not integrating them into their daily self-management practices. I was, at the time of this pilot study, unable to find published longitudinal studies describing how commercially available diabetes mHealth apps were being used in the wild. It was hoped that by interviewing individuals who had sought out and used these products under natural conditions, more organic patterns could be revealed. Using a questionnaire with demographic and open-ended questions, this pilot study looked at the real-world behavior of people who had already used a diabetes smartphone app, in order to learn more about the impact of these products in their lives and to thereby seek answers to the following question:

- RQ1: *Are diabetes apps actually meeting user needs, and if not why not?*

In the process of answering this primary question, the additional sub-questions will be considered as well:

- RQ1.2: *What are real world patterns of use?*
- RQ1.3: *Which reasons cause people to stop using available apps?*
- RQ1.4: *How effective are these current app approaches for meeting user needs?*

4.1 Introduction

There has been a great deal of persuasive computing research on encouraging healthful behavior through the use of ubiquitous computing devices, but relatively little on their long-term use for supporting chronic health conditions in non-observational settings. As previously discussed in the review section, diabetes management depends on careful and ongoing attention to and active engagement with diverse data in order to inform management decisions. There was also a discussion of inconclusive evidence related to mobile phone-based apps as an effective intervention for diabetes management. This study was motivated by informal anecdotes suggesting that, despite many hundreds of available diabetes apps (Breland et al., 2013), most people with diabetes who tried them were not embracing these products. This pilot-study asked people with T1 diabetes who had used a diabetes smartphone app to reflect on their previous experiences, to try and learn to what extent these products were supporting and being integrated into self-management routines. This chapter reports on their reported experiences, preferences, and habits, and patterns of use with diabetes apps.

4.2 Methods

A survey composed of demographic, app experience, and other non-demographic semi-structured questions was undertaken for data collection and thematic analysis (see Appendix B: Chapter 4: Adoption Diabetes Smartphone Apps). Participants were recruited through diabetes related social media, diabetes related events, a diabetes related Meetups, snowball sampling, and at a diabetes

conference held in Leipzig, Germany. Participants resided in either EU countries or North America. Inclusion criteria included: adults owning a smartphone and previous or current experience with an app used in conjunction with T1 diabetes management. In order to investigate natural patterns of use, participants were not requested to download or sample additional products. A total of 26 T1 diabetics, or parents in the case of diabetic minors (the parent was involved with diabetes management) were interviewed. Age range: 11-61 years, mean age was 31.9 years (SD 11.6). Time since diagnosis: range 1-54 years, mean of 15.8 years (SD 12.5). Gender: 38% female, 62% male. All respondents were guaranteed confidentiality. Ethics approval was granted by The Open University Human Research Ethics Committee. There were no financial incentives offered. The questionnaire (see Appendix B: Chapter 4) began with questions on user characteristics, product choices, reason for these choices, previous and current patterns of diabetes and non-diabetes app usage, and opinions on diabetes apps used. This was followed by a short discussion with participants that focused on their feelings, observations and experiences with diabetes and non-diabetes related smartphone apps. While these initial questioning had focused mainly on usage patterns, such as reasons for continuing or ceasing use, the emotional dimensions quickly came to the forefront. Given the exploratory nature of this research, questions were then added to probe this issue in greater depth. The new questions included *"Please describe the feelings you get before, during and after using a diabetes (and non-diabetes) app"* and *"What is your opinion of the diabetes (and non-diabetes) apps you have used?"* Notes were taken by hand during interviews and then transcribed into an Excel worksheet for analysis and tallies. Given the exploratory nature of the analysis, an emergent coding or open coding approach was chosen (Lazar et al., 2017) in which I looked for common themes among responses. This involved repeated reading of the source material and discussions with my thesis advisors. After the two primary themes of *app functionality/utility* and *affective impacts* were agreed upon, examples were color coded within the spreadsheet. These themes as well as the more specific responses will be reviewed in the following sections.

4.3 Results

The following paragraphs discuss the results from this pilot study. First answers to the questions will be reviewed, which will be followed by a more in-depth discussion of users reported grounds for abandoning smartphone apps. (To view the collected responses, see: Appendix C: Results and other Outputs, Results from Chapter 4 diabetes app adoption)

Question: Previous experience with logging data in a paper log book?

All participant (26/26) reported having previous experience logging diabetes data, with all but one having used paper diaries and one participant reporting having only used an excel spreadsheet. This is unsurprising as daily logging is commonly recommended self-management practice.

Question: Which diabetes apps have you tried? (See Figure 4-1)
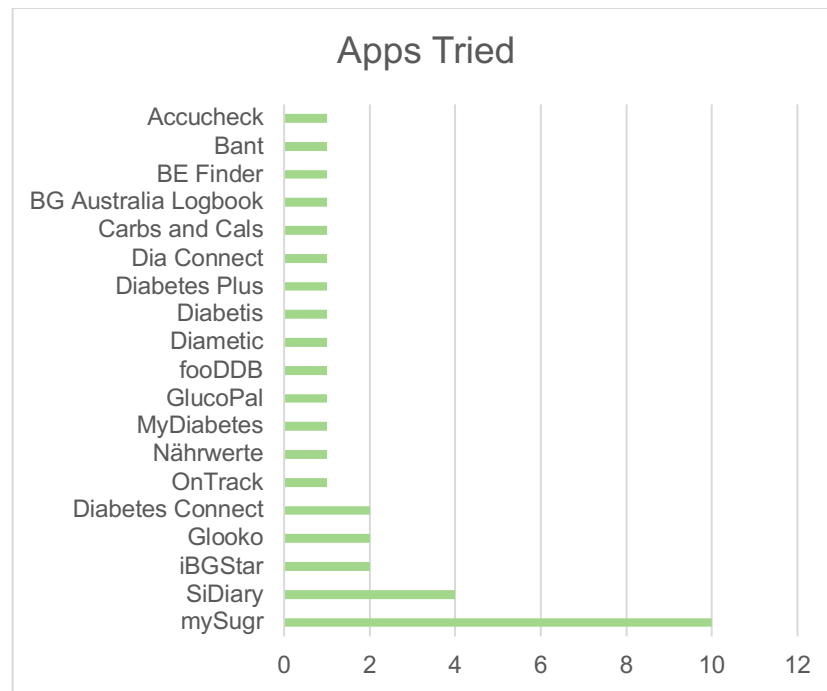
FIGURE 4-1 APPS TRIED

Participants cumulatively recalled trying 19 different apps. MySugr was the most popular with 10 participants reporting that they had tried it, followed by SiDiary with 4. There was no other app that was noted by more than 2 participants. This list is likely to be incomplete as at least 7 participants reported having tried at least 5 diabetes apps yet no participant listed by name more than 2 different apps.

Question: Do you use smartphone apps every day, if so which? (See Figure 4-2)
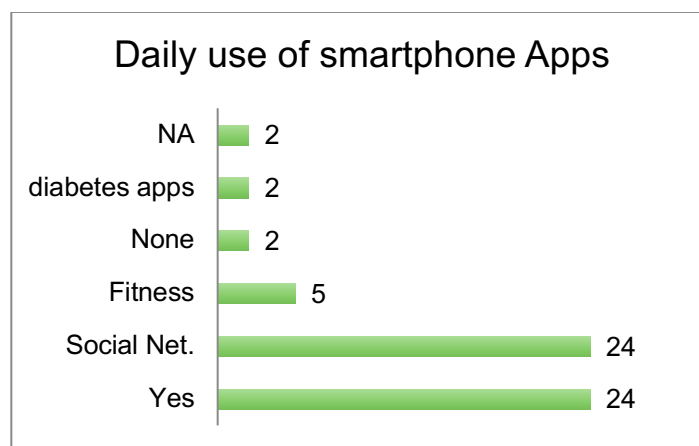
FIGURE 4-2 DAILY USE OF SMARTPHONE APPS

While not surprising given that a owning a smartphone was a study inclusion requirement, 24/26 participants reported using smartphone apps daily, with 1/26 reporting no app usage, and 1/26 reporting only using email. Of these daily app users, all reported using social media such as Facebook and/or Twitter every day, with many reporting usage multiple times per day. P4 noted

that Facebook gave *"...distractions, funny videos, entertainment, friend",* and *"...helped stay connected, take part in other's life"* and that *"Entertainment is the main thing."* P14 reported using Pinterest and WhatsApp 5-6x per day, *"Pinterest is inspiring and relaxing. WhatsApp is for social contact."* And P21 said that she looks at Facebook when she doesn't have anything else to do, reported being happy when using, and that it is out of mind when she closes it. The high adoption rates and positive responses to social networking apps indicate that these users were ready daily adopters of smartphone apps.

Question: How helpful did you find diabetes apps? (See Figure 4-3)
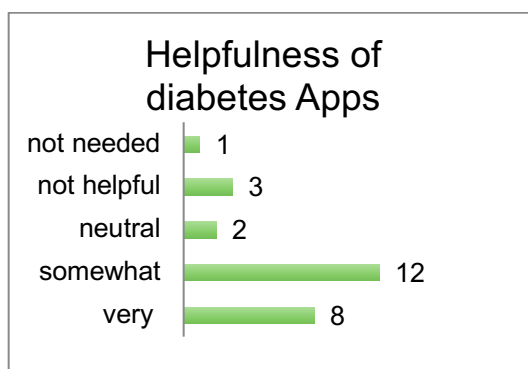
FIGURE 4-3 HELPFULNESS OF DIABETES APPS

The majority of participants (20/26) reported that they had found diabetes apps "somewhat" or "very useful", with only 4 reporting that they were "not helpful" or "not needed".

Question: In which ways were diabetes apps helpful? (See Figure 4-4)
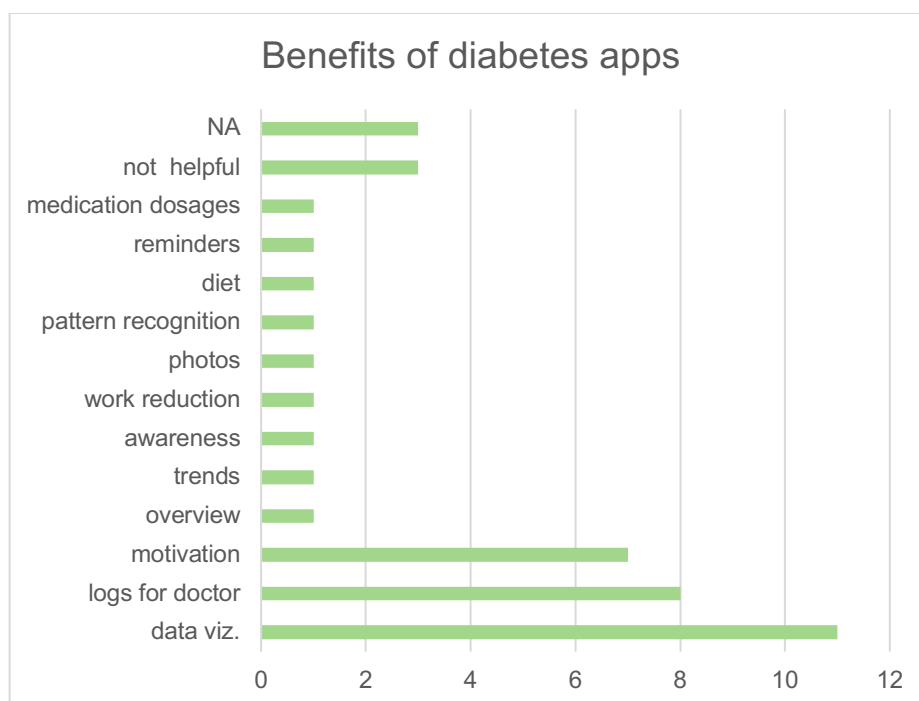
FIGURE 4-4 REPORTED BENEFITS OF DIABETES APPS

In this question participants were asked to identify from a check list all ways that they had found diabetes apps to be of benefit, or to write in additional answers if needed. As many individuals noted more than one benefit the total number is more than the number of participants. 20/26

participants found some benefit. Motivation (7), logs for doctors (8), and data visualization (11) were the most commonly cited and the only benefits noted multiple times.

Question: Are you currently using a diabetes app? (See Figure 4-5)

Current diabetes App usage

daily	2
before doctor apt.	1
0-7 x per wk.	2
BG meter data	3
non user	18
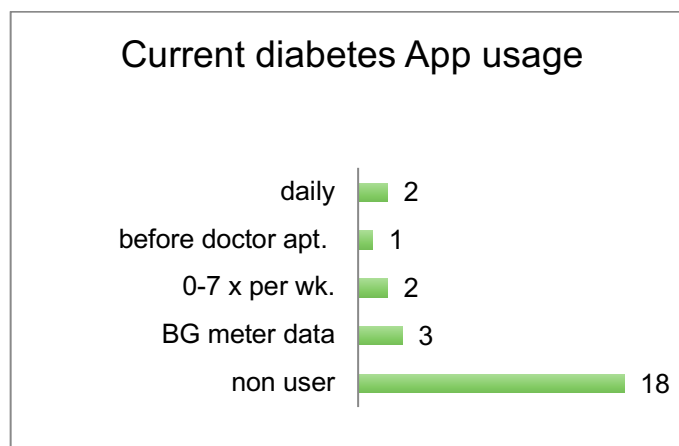
FIGURE 4-5 CURRENT DIABETES APP USAGE

Despite the positive responses and benefits noted in the previous questions, this did not translate to high levels of daily adoption, with 18/26 reporting they were no longer using diabetes related apps, and only 2/26 reporting current daily usage. 3/26 reported using the app solely for periodic storage of BG meter data, with no additional data input. The remaining 3 participants reported using apps intermittently, varying from several times a week, before medical visits, or to troubleshoot specific problems.

Question: How long did you use diabetes apps before abandoning them? (See Figure 4-6)

Diabetes app abandonment

still using	8
> 6mon.	1
3mon. - 6mon.	2
1mon.- 3mon.	0
1wk. - 1mon.	5
2days - 1wk	7
0 - 1day	3
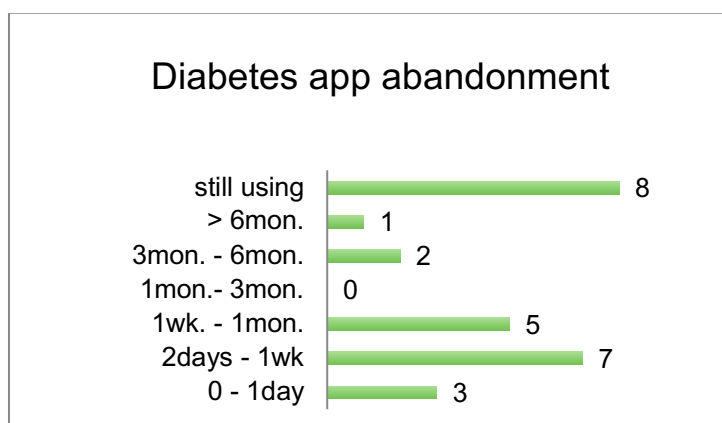
FIGURE 4-6 DIABETES APP ABANDONMENT

Of the 18 people who had completely abandoned diabetes smartphone apps, 10 reported abandonment within 1 week, and an additional 5 before reaching 1 month. Only 3/26 reported having used apps for over 3 months and then abandoning use, suggesting that perhaps some form of habitual usage is formed sometime after 1 month.

Question: Why did you stop using diabetes apps? (See Figure 4-7)
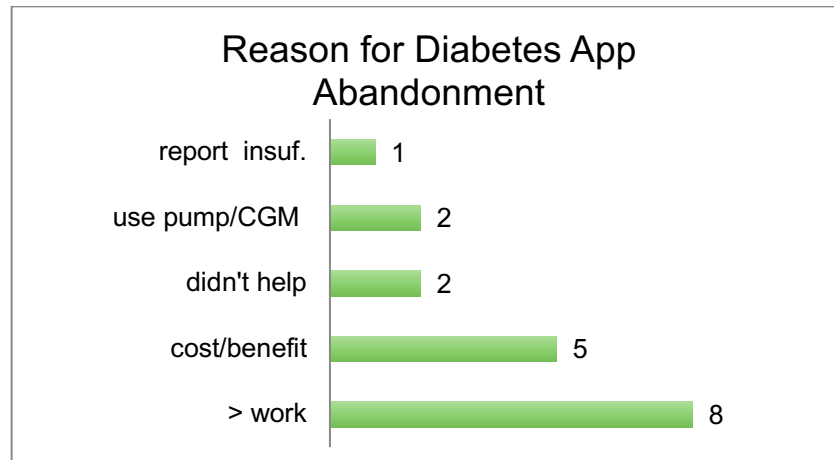
Reason for Diabetes App Abandonment

Category	Value
report insuf.	1
use pump/CGM	2
didn't help	2
cost/benefit	5
> work	8

Of the people who ceased diabetes app usage, 13/18 reported either the closely related "too much work" or poor "cost/benefit ratio" as a major contributing factor to ending use. Other reasons included: no benefit (2/18), use of continuous glucose monitor (CGM)/Pump based record keeping (2/18) and lack of app flexibility (1/18). Of the non-adopters, 9/18 listed manual data entry as a major barrier. Some participants noted that returning to paper-based logging was quicker and more flexible, or that they had moved to using PC based software, which was compatible with their BG meter. For those using a pump or CGM, the inability to exchange data between devices was a reported barrier.

4.3.1 Participant reasons for diabetes app abandonment

The following discusses in more detail participant responses related to why they had stopped using diabetes apps.

4.3.1.1.1 Functionality/Utility

Many participants reported that these apps did not provide sufficient benefits to management. P4 noted that, "*All Apps offer the same functionality, maybe some nice graphs, but I can't see the benefit.*" P26 "*If I am spending time on it, it needs to give something in return. Decision support.*" P19 noted that she "*...liked idea that she could use phone, because she always has it with her and doesn't need a pen. Was hopeful but found it annoying that she always had to record data.*". And P6 noted that "*...time is better spent on other issues than data entry.*" P25 found diabetes apps "*...too complicated to use, faster to use paper.*" Lack of integration with other devices was also noted, such as P17 who found the App good, but noted that the info is in meter/pump combo device. P7 noted that it was too much work to enter in app as well. There were also difficulties with medical team acceptance with 4 participants reported that their medical team was resistant to the viewing of digital data. P21 stated, "*My doctor doesn't understand digital.*" As P21 was expected to bring paper logs, he switched back to paper logging. P4 reported his doctor wanted a

very specific data structure, and P4 was unable to find an app that would deliver the to the doctor's specifications.

4.3.1.1.2 Negative emotional impact

In addition to these technical barriers there were also apparent emotional challenges to longer-term adoption as well. Upon further probing as to "feelings" imparted from app use, 12/26 of participants also expressed that the use of apps had negative emotional side effects, which could have reduced their desire to use these products. Some respondents felt that using a diabetes app made them feel more excluded or vulnerable. P3 said that the diabetes app "*reminds me of my weakness.*" P11 stated that diabetes Apps make him feel like an "*outsider*" as opposed to Facebook which makes him feel like "*...one of the crowd...*" And P16 noted that "*A diabetes app is a constant reminder that you have a life-threatening chronic condition.*" P13 felt her emotions tied to entering BG values and felt bad when entering perceived "*bad*" values. P14 reported having stopped using a diabetes app because she didn't like entering out of range values and felt she wasn't improving. And P20 felt having to enter out of optimal range values negatively influenced feelings. For some participants, feedback from an app can also feel judgmental. P5 reported that negative feedback from app made her feel bad. P25 didn't want to be judged on numbers, arguing the app doesn't understand context and doesn't want to be told she is "*50% out of range*". P25 explained that she might sometimes run her blood glucose levels out of ideal range for a reason, for example if she is going on long run or to a party where she is going to drink, she might choose to allow her BG value to go high and doesn't want to be judged on that. And for some daily app usage caused a constant long-term negative association, as noted by P16: "*I see my diabetes as my credit rating, I don't want to be reminded of it every day – only when there's something I need to be aware of...*"

4.4 Discussion

The following section discusses the finding of this pilot-study in light of the initial research questions.

4.4.1 RQ1: Are current diabetes apps effective in meeting user needs?

While 20/26 participants reported that there were benefits to diabetes apps, 18/26 had stopped using diabetes apps, and only a small number were using them as routine management tools. The most frequently noted benefits were for motivation, logging data for doctor's visits, and for visualizing data. Although given the discrepancy between benefits and adoption, these did not seem to sufficient to overcome usage barriers. As such, though for some users they do demonstrate benefits, this study suggests that these apps are not sufficiently effective in meeting user needs for daily management.

4.4.2 RQ1.2: What are real world patterns of use?

While the results of this pilot study would suggest diabetes app abandonment is common, these apps were successful in meeting specific needs for some users. 2/26 were using them as daily diary tools, 1/26 participants reported consistent use of an app to collect data before a doctor's

appointments, and 2/26 reporting using them routinely though not daily. There were also an additional 3/26 who continued to use apps for downloading and visualizing collected data from their blood glucose meter. These results demonstrate areas which deliver value to at least some users, and therefore might be further developed in future apps.

4.4.3 RQ1.3: Which reasons cause people to stop using available apps?

The most frequently cited ground for ceasing app use (8/26) was related to workload, with and additional 5/26 noting the closely related "benefits to workload" ratio. It is apparent that users wish for additional automation of data entry, but as to whether this would lead to long-term daily use is not clear from this data, without addressing other user concerns related to benefits. Wireless transfer of blood glucose data is already available in a few devices, but it is not clear that this in itself will lead to long-term adoption without these apps offering additional benefits. Apps with automated data input through hardware connection were used by two of the longer time users but lead only to periodic downloading to facilitate data export and for app-based data visualization. For example, P4 sought out the iBGStar meter which offers hardware integration with the iPhone, *"I thought it would help, (but) assembling all the data didn't help, still needed to interpret. Didn't offer anything more."*

4.4.4 RQ1.4: How effective are these current app approaches for meeting user needs?

We found that the mentioned apps contained many of the elements which form the basis of persuasive computing techniques. For example: Bant integrated with twitter for social sharing; mySugr offered gamification through challenges and virtual rewards; the majority offered the ability to track personal data and offered visual interpretations of collected data. Glucose Buddy and others offered programmable reminders. mySugr, the most often mentioned by our participants, features a cartoon figure, reminiscent of a Tamagotchi pet, which could be "tamed" by entering in sufficient data daily and responded to BG data. Despite mySugr's use of multiple persuasive strategies, at the time of survey it had only become adopted daily by 1/26 users and this single habitual user reported a strong personal connection with the company, including being a beta-tester.

As many respondents reported spending considerable daily time on social media, it is questionable whether engaging with a smartphone app is in itself the primary barrier. Rather, this study suggested that these apps failed to deliver sufficient rewards to justify the efforts of use, while in at least some cases causing negative emotional impacts. It was also unclear from this study to what extent users were able to make use of collected data, as presenting users with the ability to view collected data does not automatically translate to increased comprehension of the meaning of this data, and many lack the ability to translate numbers into better decision making (Mamykina et al., 2008). Some participants expressed interest in app-based decision support (5/26) for insulin dosages or diet, which deserves further research. As discussed in the literature review, diabetes management is a constant tradeoff between freedom and risk-avoidance, and even highly motivated

individuals will frequently have frustrating periods. This suggests the need for continued investigation into how data can be presented to optimally assist informed decisions without demotivating the user, and how to tailor strategies to the individual preferences of the user which form the basis of inquiry for later chapters.

4.5 Conclusions

The adoption of the smartphone throughout the world, combined with the economic scalability of apps has provoked much interest in the use of this technology for supporting health care. However, this pilot study suggested that commonly available diabetes apps were either infrequently integrated into daily diabetes care or, for a majority of users, completely abandoned. Participants drew attention to numerous technical hurdles to overcome, such as better integration with health care providers, and workload associated with data entry. However, it was not clear from this pilot-study or the available literature whether overcoming these barriers would be sufficient to meet user needs. This pilot-study also suggested that there might be essential flaws in the app interaction or interface design, such as negative emotional impacts associated with diabetes app usage or lack of sufficient cognitive support for understanding data.

The following study sought to further explore these questions through more in-depth examination of these apps. Of particular interest was trying to determine if, given a future where all data entry could be automated, current app design approaches would be adequate for supporting positive and productive interactions, whereby users could derive meaningful insights from collected data. If this were the case, then the argument could be made that the basic design of these logging apps was correct and the research emphasis should be placed on automated data collection and integration. However, if users reported unpleasant interactions, or excessive cognitive stress this might suggest that the basic design assumptions of these apps might be flawed and in need of further development. The following chapter will discuss the study undertaken to provide insights into these topics.

Chapter 5: Data, Data Everywhere, and Still Too Hard to Link

The pilot study in the last chapter found that many participants reported favorably on aspects of diabetes apps, noting benefits of data visualizations and advantages for motivation. However, for the most part these apps were rarely integrated into daily usage, and often completely abandoned. This next study set out to investigate in greater detail the benefits and deficiencies of specific diabetes app interfaces in order to better understand more specifically why these interfaces were failing to meet user needs. Therefore, this chapters asks the following question:

> *Are the standard user interface designs of diabetes self-management apps sufficient for meeting user needs, or are there inherent design flaws?*

This section presents a user-interaction study using pre-entered diabetes relevant data within 6 different commercial diabetes diary apps. From analysis of these sessions with eight user interface designs, user requirements, interface benefits, limitations, and implications are considered, revealing that while certain benefits are provided, these interfaces often fail to explicitly address the cognitive and emotional requirements of users. Resulting from thematic analysis of these interactions, and with the goal of improving these apps three challenges are posed for developers of diabetes systems: reducing cognitive demands for usage, increasing emotional sensitivity; and methods of activating the user's already acquired knowledge.

5.1 Introduction

As reviewed earlier, successful type 1 diabetes (T1D) management typically requires careful and deliberate balancing of multiple medication and lifestyle factors, which must be assisted by frequent interaction with diverse data to inform these decisions. The interfaces of mobile health apps aim to support this process by assisting in the discovery of relevant trends and patterns in collected data. However, relatively little is known about how well existing interfaces support specific T1D user requirements such as frequent decision making, extraction of relevant insights from complex data, and emotional coping. In order to investigate these issues, this chapter describes 16 mediated sessions in which people with diabetes explored relevant data using typical diabetes smartphone apps. This research focused on the logging or diary paradigm, which has become a de facto mainstay of daily diabetes management smartphone apps, a carry-over from the paper-based record book. Such apps currently have two primary mechanisms for assisting in daily self-management: the first in the increased engagement with data caused by the act of logging, and the second in the ability to reflect on and learn from this collected data in order to inform future decisions. Automated data entry is becoming increasingly viable, at least for blood glucose records, to a certain extent for exercise, and insulin dosages. And while many participants in the pilot study expressed a desire for such automation, such functionality is not yet commonly available. Given this lack of working commercial offerings and the challenges both technical and ethical in building fully functional prototypes, it is not known whether such automation alone would manage to

improve these apps to the point where they would meet user needs for diabetes decision support. These apps typically offer multiple methods of visualizing the same collected data, as well as other functionality such as data sharing, or customizable notifications. These many features can prevent studies focused on general benefits from providing useable evidence as to the effectiveness of individual components (Klasnja et al., 2017). Therefore, systematic and reproducible methods are needed to understand how specific features of differing approaches are respectively succeeding and failing to meet user needs. To investigate how specific data visualization techniques can assist users with obtaining value from collected data, I populated 8 existing commercial diabetes apps, with a single standardized data set. This enabled systematic within- and across-subject comparisons of interface designs, while at the same time mitigating confounding variables which could have resulted from using personal data. For these reasons while using personal data would be valuable for other purposes, it would have not been optimal for this study. While this research was type 1 diabetes specific, given the ubiquity of such methods of data presentation it is possible that the issues investigated here have wider implications for mobile health apps, for other chronic conditions, and potentially for health, wellness, and data driven lifestyles more generally.

5.1.1 Visualization of personal data and design issues

While there has already been a review of data visualization, there now follows a brief review of concerns especially relevant to this chapter. As noted earlier, understanding complex personal data can be challenging (Mamykina and Mynatt, 2007), and an important aspect of these apps is to help the user in this process. To this end, many of these apps make use of standard graphic visualizations such as plots, graphs, tables, and charts, which are considered to be effective methods for seeing tendencies and discovering correlations (Bollier and Firestone, 2010). However, there is a lack of specific research on the effectiveness of such techniques for assisting the lay-user in understanding complex multivariate data. Within this medical context, this interaction must be carefully designed, as presentations of data can reinforce biases rather than lead to actual insights (Mamykina and Mynatt, 2007). It is also not clear that current products are adequate for meeting user needs, as most available diabetes oriented products are primarily for the collection and visualization of data, and are often difficult for users to employ (Doryab et al., 2015). And while there are many papers that have assessed the effectiveness of an app (Gouveia et al., 2016), usability and the limitations of screen dimensions (Lapin, 2014), or describe a participatory design process (Arsand et al., 2007), there is still little available research specifically addressing how mobile UIs support self-management processes through assisting actual users in extracting actionable insights from collected diabetes relevant data.

5.1.2 Efficacy and known barriers to adoption

As discussed earlier, despite considerable effort in assisting diabetes management with mobile digital informatics tools, and some positive results (Wu et al., 2017), the last chapter discussed some of the considerable barriers to long-term adoption, while actual efficacy of apps remains controversial. In addition, the affective nature of interventions must be carefully considered, with

(Blondon et al., 2013) noting how tracking could increase feelings of disease burden while (Breland et al., 2013) questioned the clinical validity of many of these apps. Such inconclusive results suggest the need for further research to better understand the individual components that make up these apps, and how to improve them as tools for supporting better self-management practices.

5.2 Methods for the Study

In order to compare the utility of different data visualization paradigms, we initiated and analyzed mediated sessions in which people with diabetes explored pre-collected diabetes data (see "data preparation" section below), These sessions employed 8 representative methods of visualizing data taken from 6 free iOS apps. The visualizations examined were: daily logbook, scatter plot, connected scatter plot, daily logbook w/ graph, pop-up cards, statistics, data table, and pie chart (see Figures 5-(1-8)).

5.2.1 Apps included in the study

The app selection criteria were designed to address three considerations. Firstly, we prioritized coverage of what our cohort actually uses, by selecting the 3 apps most commonly mentioned in the pilot survey reviewed in Chapter 4 (mySugr, SiDiary, and iBGStar). Following that, apps were selected from the app store to ensure representation of principal UI techniques of data visualization. Finally, we made selections from within these categories, prioritizing free apps of particular research or industry interest: e.g. Bant was developed by a medical center through a participatory design process, with several academic studies on its use; Accu-chek was the centerpiece of a commercial diabetes product eco-system; Diabetik was a patient initiative, crowd funded project. While there are newer UI's, these methods of data visualization are standard and widespread.

5.2.2 Assumptions guiding study design

This study did not test usability in regards to entering data, which is a known barrier to adoption (Katz et al., 2015), as the primary focus of this study was the ability of interaction designs to support *retrospective analysis of collected data*. Pre-entered diabetes data was used within the chosen apps so that all users would be viewing identical information. While this methodology has the limitation that the data has not come from the individual participant, and therefore lacks personal contextual cues, it also offers the following advantages for our specific study goals which could have been inhibited by the use of actual personal data.

- This study sought to gain knowledge as to a specific UI's ability to communicate information, as opposed to helping people remember events, which would be a valuable (but different) study question.
- A standardized data set also limited confounding variables; for example, if one participant had easier to locate patterns or more 'ideal' measurements, this could have complicated comparison between subjects.

- A common data set also allows a uniform and testable within subject experience across multiple apps, interface elements, and users.
- Finally, reproducibility is also a benefit of such an approach, as well as providing a convenient method of comparing new UIs against older interfaces.

If users could readily extract significant value from such data, and reported favorably on such interactions, this would suggest that they could do at least as well cognitively with their own data. By contrast, if users struggled to understand or interact with data, or expressed clear concerns for cognitive, affective, or other reasons apart from conventional usability issues, then this might indicate the need to address the underlying interaction paradigms themselves. In addition, such empirical qualitative research can help to form an evidence-based foundation for future design (Hekler et al., 2013). While in early planning stages we considered using printouts, ultimately it seemed important to use an actual device to test interactions. I mounted iPhone 5s running iOS 9 mounted into a custom-built lightweight rig that allowed a fixed webcam to record audio and visual interactions. The participant held the phone in one hand naturally, while manipulating the interfaces with the other (see Figure 5-1).
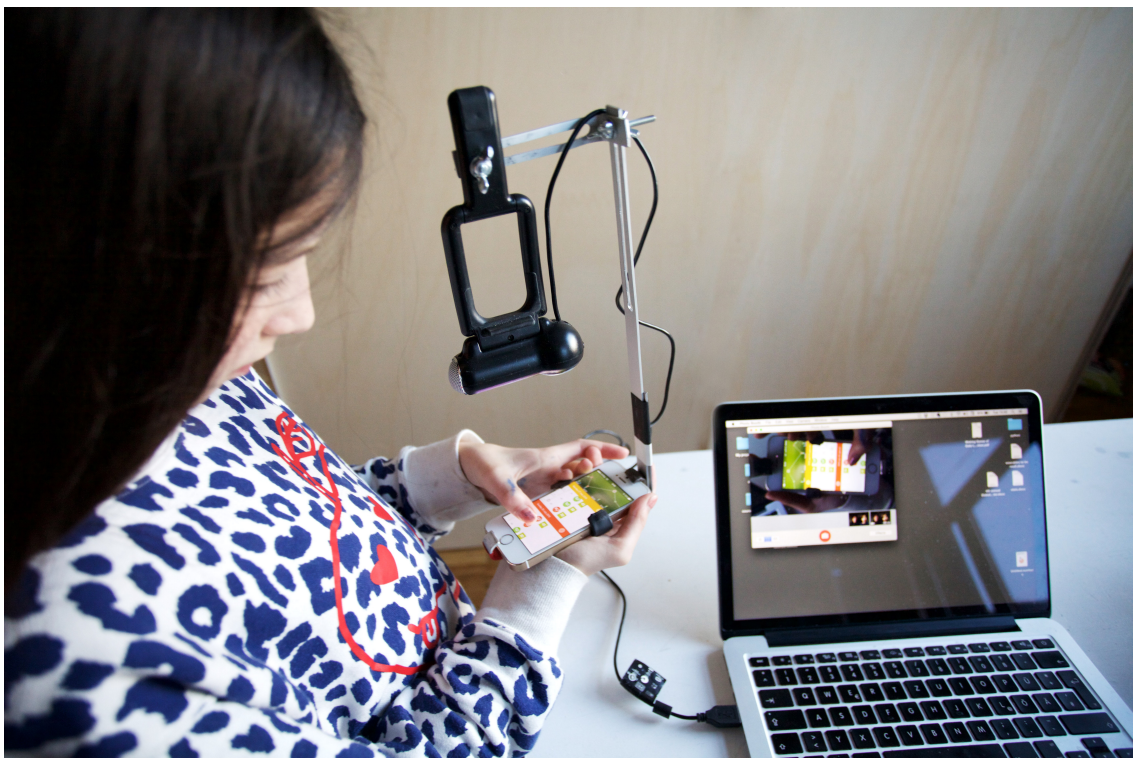
FIGURE 5-1 RIG FOR DOCUMENTING APP INTERACTIONS

5.2.3 Data preparation and procedure

It was originally hypothesized that we could measure the success of an interface, according to time and effort required to locate specific pre-determined insights. To this end, I fabricated 1 month of diabetes data in consultation with a diabetes care professional. However, it became apparent that such an approach was overly artificial as several participants (P1-P4) noted that the recorded values didn't look authentic, and the act of probing for clearly defined solutions seemed too removed from natural interactions. To correct for these discrepancies, I recorded 14 days of my actual diabetes

data comprised of blood glucose levels, carbohydrate intake, exercise, and insulin dosages (Katz and Price, 2018). There were 173 resulting entries recorded into each of the 6 selected apps. This new set was then used from the 5th participant onward. However, as these pilot observations on UIs were generally consistent with later results, relevant participant observation have been included. Participants were not notified as to origin of data, as to not bias responses. The sessions began with a briefing and a consent form. This was followed by a short profile questionnaire on personal characteristics, product choices, and patterns of diabetes app usage (see Appendix B: Chapter 5 User-Interaction study forms). Participants were then read the interaction procedure and instructed to 'think aloud' as they used the apps. To increase engagement, it was suggested that participants might role-play that they were advising a newly diagnosed person with diabetes who was showing them personal data or alternately to imagine that the data was their own. A variable length semi-structured user interaction session lasting between 20-65 min. was then conducted. Participants were asked questions which were informed by the pilot study presented in the previous chapter, particularly utility of the interface and affective nature of the interactions:

- *What do you see about the BG control in this period?*
- *Would this system help you make better decisions about your diabetes management?*
- *How do you feel about this interface?*
- *How does this interface make you feel about being diabetic?*

The order of the apps presented was random, though due to time limitations and some UIs more quickly reaching saturation of opinion, the focus remained on interfaces which were receiving richer or more varied responses. This led to not all interfaces being viewed by all participants, and therefore not all denominators are equivalent. Videos were transcribed, and then coded in NVivo, according to app, interface type, and the two themes which emerged from the pilot study, emotional impacts and app utility. The use of NVivo allowed for the videos and texts to be viewed synchronously, thereby supporting easier classification of the responses to the relevant interface. Responses coded as describing an emotional response were then further classified within the ordinal sub-categories: *positive, neutral, negative*. Responses coded as referring to the utility of the app were classified into the ordinal categories: *helpful, mixed, not helpful*. I had originally hoped that this approach might produce opportunities for statistical analysis of different design approaches. However, the relatively small sample size caused by the challenges in participant recruitment and large amount of time required for data processing curtailed the validity of this approach. Therefore, an alternate approach was selected that sought to present the diversity of participant responses. After the participant responses had been classified, they were then filtered according to app interface and ordinal classification, in order to select representative quotes. Preference was given to what I judged to be particularly emphatic or descriptive responses. The quotes classified as affirmative (*helpful, positive*) will be presented within the text under the heading *Benefits*, while negative responses are presented under *Limitations*.

The Open University Human Research Ethics Committee granted approval (see Appendix 1: Chapter 5), and there were no financial incentives offered.

5.2.4 Participants

I recruited 16 type 1 diabetic adults through a Berlin based diabetes and technology Meetup, convenience sampling, and a 1-day Berlin-based type 1 diabetes event. The inclusion criteria included being type 1 diabetic, over age 18, and speaking conversational English. Age range was from 25-49 years with a mean age of 33.7 years (SD 7.5). Time since diagnosis ranged from 2-31 years, with a mean of 13.5 (9.1). Gender was 5 females and 11 males. Overall, 13/16 participants worked or studied in a diabetes related field, information technology, graphic design or software design, and 9/16 reported post-graduate education, thereby this group was potentially biased towards diabetes knowledgeable and engagement. All participants reported they were comfortable with smartphones and 13/16 had previous experience with diabetes diary apps. At the time of the study only 1/16 of the participants was a current daily user of diabetes logging apps, and three participants stated that they still used diabetes apps on occasion. This rate of diabetes app adoption was in accordance with the pilot research discussed in the previous chapter.

5.3 Findings (Organized by 8 Visual paradigms)

The following sections report on observations in regard to participants' interactions with the selected interfaces. Reporting on known and easily fixable usability shortcomings such as slow scrolling or insufficient font size, are excluded. In some instances, more than one example of an interface paradigm was tested, and their results have been combined, though due to space limitations, only one interface of each type is pictured. The analyzed benefits and limitations for the selected apps are grouped by the 8 identified interface paradigm as follows:

- Daily Journal
- Daily Logbook with Connected Plot
- Non-Connected Scatter Plot
- Pop-up cards; Statistics
- Data table
- Pie chart.

5.3.1 Daily Journal Interface

(see Figure 5-2 Diabetes Journal/logbook)

While the daily journal is considered a principal component of diabetes self-management apps, users had mixed response as to the utility of this approach for reflecting on collected data. Participants were, for the most part, capable of retrieving stored data from these interfaces and understanding significance, but many found locating correlations across multiple days or finding deeper insights challenging. As the smartphone-based log allows the collection of extensive data, it could be useful for distinct goals, such as recording data before a medial appointment, but appears limited as a daily management tool by itself.

5.3.1.1 UI Benefits

P7 found the Accu-chek logbook serviceable, stating *"it's very easy to scroll through it forward and see."* P7 was also able to assess a day in a meaningful way*, "...if I had 16.0 one of my tests...I need to take immediate action to bring it down, even 14.0...so having 3.0 is the same, you would have some sugar to bring it back up..."* P7 also emphasized the common theme that such records would be useful for interacting with clinicians*, "very good records of everything ...I've got good amount of information to hand off to my doctor"* P9 explained that such apps support recall of specific diabetes relevant data, *"...well I understand what it's saying...on an individual point by point basis ...I can understand each one, like time, action, and then amount"*

5.3.1.2 UI Limitations

Despite benefits for browsing data, it was not clear how useful this function is for situated self-management. P7 when asked if this interface would help with daily diabetes management, stated *"it gives you a lot of information, so it has the potential to (help) but the likelihood is, if I put up this data, I wouldn't bother to look...so it probably wouldn't help.... I'm a little bit overwhelmed with information."* P12 felt a disconnect from such interfaces, *"it's just about numbers..."* P15 brought up the negative emotional aspects of tracking diabetes, *"...I have a feeling that I have to record everything, so I have actually to track my life every year every hour almost... it's not a good feeling at all...I'm not feeling free...if I track what I'm doing all the time."* And P9 firmly rejected the paradigm, *"I probably wouldn't use something like this, I would just find it frustrating and time consuming and not ...providing me what I would want...*
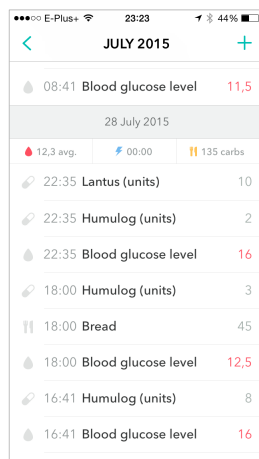
FIGURE 5-2 DIABETES JOURNAL/LOGBOOK
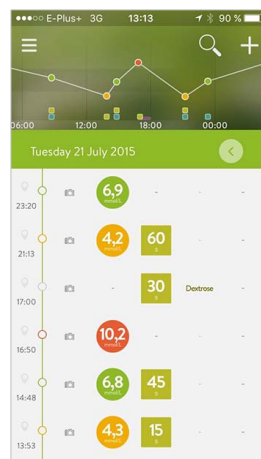
FIGURE 5-3 MYSUGR LOGBOOK/ CONNECTED PLOT
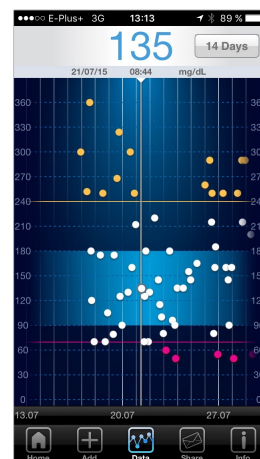
FIGURE 5-4 IBGSTAR SCATTER PLOT
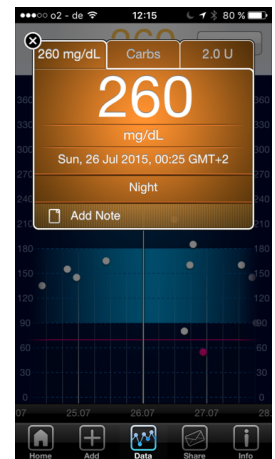
FIGURE 5-5 IBGSTAR POP-UP CARDS
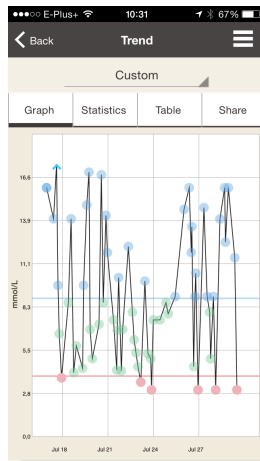
FIGURE 5-6 ACCU-CHEK CONNECTED PLOT
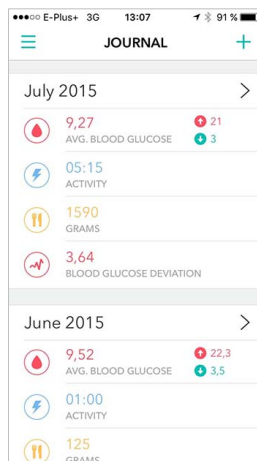
FIGURE 5-7 DIABETIK STATISTICS
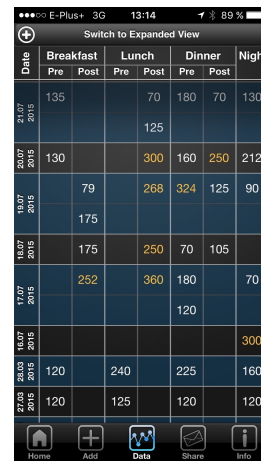
FIGURE 5-8 IBGSTAR DATA TABLE
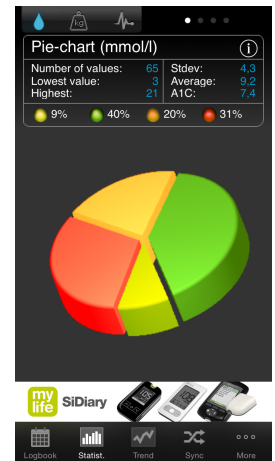
FIGURE 5-9 SIDIARY PIE CHART

5.3.2 Daily Logbook with Connected Plot

(see Figure 5-3 MySugr Logbook/ Connected Plot)

This interface combines a daily diary and a graph, which scroll together in unison. This appears to add value, and responses tended to be improved over the logbook alone. Still, underlying patterns across multiple days remained difficult to locate. This interface could be helpful for attaining a daily overview.

5.3.2.1 UI Benefits

Pairing the logbook with a graph enhanced the ability to understand the flow of data and was in general better received than the diary alone. For example, P6 stated *"...this here is actually quite nice because you can see the graph...if you have the diabetes diary you don't have the distance between the points...just from time to time when you test ...so that's actually better."* Such an overview could be useful for assessing a day, for example P5 reflected, *"If this was my day... I (would) immediately ... see why this was a bad day...I didn't do proper therapy."*

5.3.2.2 UI Limitations

However, 8/12 participants who interacted with this interface noted that the benefits of this system were still limited by lack of support for understanding underlying patterns. P16 questioned the value for data analysis, *"...I like the option to kind of wander through your glucose levels and so you can easily see if it (there) were rough times or everything went well, but...(to) get a deeper understanding, I don't think it's really helpful for me."* And P11 expressed visual overload, *"it's just too much going on, there's no focus."* P3 drew attention to the limits of this interface for understanding connections across multiple days, **"***it's not easy to compare two days, you have to always scroll up and down."* P3 also noted an inherent challenge in this paradigm, that the lack of screen space necessitates putting more contextual information in a submenu or slider, *"(it's) really annoying that you can only see more information if you click on it...so for analyzing, it's really difficult to see what's going on in your day."*

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5.3.3 Non-Connected Scatter Plot (Fig. 5.4)

(see Figure 5-4 iBGStar Scatter Plot)

Scatter plots are a common means of displaying time series data, however some participants found this UI overwhelming. This UI can give a general overview of control, but, recognizing patterns, time of day, or translating this overview into actionable information can be challenging.

5.3.3.1 UI Benefits

The primary use of this interface appears to be general retrospective assessment of frequency of in/out of range values and overview of deviation. When asked to reflect on the data, P11 observed, *"so again most of them were alright… but a lot of them were too high and some of them were too… low*." Some participants noted that this could help motivate their diabetes management, for example when asked what they would think if this was their graph, P6 said *"seeing this many high blood sugars, I'm thinking oh man you should do something, you have to change something.***"**

5.3.3.2 UI Limitations

Despite some benefits, 10/13 participants who interacted with this interface expressed reservations. P9 noted that the lack of connecting lines between dots made it difficult to understand the time series relation between data points, **"***the data … difficult to put it together…without the lines, there's so many points of data. It's hard to distinguish the trends…"* And P4 noted, *"no, these dots don't tell me anything because they don't have a relation to the other dots."* P7 noted the lack of greater insights, *"to find out what to do, I would probably have to look at each individual data point and kind of aggregate the knowledge****.****"* And P16 stated, *"(it's) not easy to extract what I think needs to be extracted..."* And understanding daily patterns was not well supported as P6 noted, *"…this system lacks the ability to easily view time of day."* In general, the lack of context seems to restrict the value for translating this collected data into actionable information. As stated by P8, *"there`s no context provided to explain why the value is that high, so I can`t draw any conclusions from it."* And P12 noted the negative affective impacts from viewing red dots indicating out of range values, observing that the viewed values would be **"...***demotivating, because maybe I tried to do my best to have more green dots… I failed."*

5.3.4 Pop Up Cards

(see Figure 5-5 iBGSTAR Pop-Up Cards)

Pop-up cards received positive feedback for allowing primary interfaces to remain uncluttered while allowing on-demand access to additional contextual information. While accessing such additional data is needed to understand the cause and effect relationships that affect BG levels, placing such information into sub-systems appeared to create excessive cognitive load.

5.3.4.1 UI Benefits

Providing additional contextual information allows for in depth information, such as insulin dosages and exercise, without cluttering up the primary interface. P16 noted, *"actually I like that… because it looks …clean and if you want more data you can get it."*

5.3.4.2 UI Limitations

In terms of understanding individual entries, this system appeared serviceable. However, in the larger context of understanding the implications of data, the sub-system creates cognitive challenges. P8 noted, *"the entries are easy to understand… it`s pretty accessible, but the analysis isn't."* This is especially problematic in pattern recognition across multiple days, an essential aspect of self-management. P3 observed, *"...there's too much information. Too many numbers…and (to)… compare the number here above …I'll have to switch through...to compare...two dates."* And P9 observed, *"…it just makes it a lot more time-consuming. It's harder to process the data because…to …get the information for everything that I need, (I have to) to go through each point individually…"* And P9 continued, *"…I feel…a little bit frustrated trying to figure out what I needed to do. Using this it seems like it would be a lot of work to get the information that I would want out of it."*

5.3.5 Connected Scatter Plot

(see Figure 5-6 Accu-Chek Connected Plot*)*

Connecting data points on a graph appeared to increase readability by better conveying the sequential nature of events and conveyed a general assessment of BG control. However, gaining more in-depth insights remained challenging, especially on a mobile device. While there are some benefits, this still appears to be a tool for general assessment rather than specific event decision support.

5.3.5.1 UI Benefits

Like the scatter plot, this visualization also gives a broad overview of glycemic stability. However relative to the non-connected plot, connecting the data points increases the ability to perceive the relationship between measurements. P8 observed, *"...because the dots are connected…it (is) possible to see some kind of trend." While* such an overview could also suggest potential treatment improvements, as noted by P4 who suggested that this deviation could indicate the need to adjust insulin therapy*, "… this going up, going down, going up… cycle. I would say the (basal) insulin is not working well."* P9 also felt that while viewing such information could be stressful, it could also be beneficial, *"… it would be frustrating to see, but also a little bit empowering knowing that I could see what I needed to do to make it better."*

5.3.5.2 UI Limitations

The small screen on the iPhone 5s appeared to limit the value of this graph, especially in terms of labeling, determining time of day, and correlations. P16 noted, *"...we are always looking for*

parallels between times and values or accidents and value, it's really hard to tell because the screen is so small…" P9 agreed, stating *"it's hard to tell where the times are, because this just listed on it on a … daily basis but I think that's probably just an issue it's dealing with it on such a small screen."* P9 concluded, *"I think it would be more useful on a computer than on the smartphone."* And P7 reported mixed impressions, stating *"this is cool stuff…you'd want to look at (it), but not on a daily basis, it would be kind of like if you want to reflect on the last week or the last month …"* P7 on observing the out of range values observed, ***"I would feel pretty negative** about fact that I had gone high and it probably a little bit confused about how to improve it…there's not really any indication about what to do to improve the situation I've definitely can see that it's bad but…"* and P5 similarly found the tool to have limited value, saying *"…just the graph doesn't really help…you just see the value. It's useless. (It) gives you that good day or a bad day feeling but…"* And P15 had a similar response, *"the only conclusion I can make is that I was six times too low and many times too high, but I don't even see the day here…(it's) complicated."*

5.3.6 Statistics

(see Figure 5-7 Diabetik Statistics*)*

Statistics allow a glanceable summary of time series data. Some participants noted this to be motivating through drawing attention to the need for greater attention to care. However, such numbers can be difficult to understand, or can hide important details.

5.3.6.1 UI Benefits

Statistics, especially when presented without visual clutter, can help alert users to important general tendencies. P11 commented on the Diabetik interface, *"…simple clean overview of your highs and lows…this gives you a first indication of if you have a problem."* P11 reflected on this interface, *"…the average seems to be a bit little bit too high and …21 times too high blood sugar. I would …look a little closer about the high blood sugar."* Having the time period clearly labelled, seems to be important for some users. P7 was positive about this feature noting, *"I like how it was broken up into month summaries…"* And P15 noted that cumulative data could help with general goals for diabetes management, *"I will try to reduce …how many times for example I'm too low."* And P9 felt that seeing personal data as numbers instead of viewing the high points on a graph was less stressful, *"…sometimes …when I look at big, overarching trends they can be discouraging. But sometimes it also gives it makes me feel more empowered to change things…the fact that it has numbers, and the way that it has it laid out, instead of it being like ups and downs, and seeing all the things from the graph, it …doesn't make me feel as bad about it."*

5.3.6.2 UI Limitations

Yet for other participants, information presented this way were perceived as limited in utility. P15 suggested it would not provide sufficient actionable data to guide action, *"I mean somehow it's not enough...I want to see the reason…for example I need to see whether it was in the night, and if it was in the night…was it too low…or too high..."* P15, who holds a PhD in mathematics, also

observed that average can be a misleading statistic, *"...so I definitely see how many times it was too high, (and) how many times it was too low and this is actually interesting information for me and of course the average blood sugar. But average is a complicated number. So, I don't know ...how to interpret this average."* P16 also brought attention to the potential misleading nature of averages based on small numbers of data points, *"...it's not the average, but just the average based on those three four five tests I had that day, and that is actually wrong information."* For some users, statistics are challenging to apply, as P6 stated, *"...my goal range, my average, ok so I can see the average of my blood sugar at breakfast lunch dinner at bed time ...it's too confusing for me."* The inclusion of standard deviation brought mixed responses. P5 was positive, *"I think that standard deviation is much more important than Hb1c (a cumulative 3-month average of BG levels) or overall ... hypers (hyperglycemia) or hypos (hypoglycemia)."* However, for others these features offer limited real-world value. P1 stated, *"I don't think these are super helpful because they just aggregate a lot, and I don't know enough about statistics, and I don't know what do with that...I know what deviation is, but I have no idea how to relate it to the number of tests."*

5.3.7 Data Table

(see Figure 5-8 iBGStar Data Table)

Data tables are an established form of interaction with diabetes information, a method of organizing data extended from the hand-written diary. Therefore, this form has the advantage of familiarity, and also provides the ability to view many days simultaneously. While some users were positive about this UI supporting quick overviews, others were either confused, or felt that such structures were not useful.

5.3.7.1 UI Benefits

Having many days of BG values in simultaneous view, especially when color-coded, allows for easy recognition of out of range values. P16 found this useful, noting *"for me it is much more structured, ...I get first attracted to compare all the post breakfast entries, and at the first glance I see that they are too high, but I actually see the low ones, 50's and 60's they were out of my sight somehow."* Noticing such details could be important for adjusting insulin dosages, as the low BG values could argue against a general increase in morning insulin. In contrast, averages could hide such insights. P9 also expressed that such formats were useful, *"...It seems like to me you can get a holistic view of each day, seeing what your blood sugars were."* P16 noted that such data structuring was **"***helpful and easier to understand right away***...***I can just compare the entries for a given time zone like what we have post-breakfast. I can easily compare (that) they are all too high for example...(to) change the dose or the meal."*

5.3.7.2 UI Limitations

Despite some benefits for trend discovery, the volume of data was cognitively challenging for some. P3 observed, *"I'm overwhelmed with numbers...if you look at (it) as a normal user and the first time you are confused and overwhelmed by information."* And P11 also found the format not

especially helpful *"…it's (like) getting through (spread) sheets…it feels technical, you don't get an overview."* And P16 was critical that the format was poorly suited to her needs, *"what I don't like is what I always hate about log books. It's this breakfast, lunch, dinner, night thing, because my day is just not structured like this. I feel like I am supposed to have that given structure and I just feel I don't want to."* P15 found this paradigm although familiar, was not delivering needed added value, explaining *"…for me that is just a piece of paper…That is what my doctor wanted… he gave me a piece of paper with such a table and said okay now you can write it down…it is not useful at all."*

5.3.8 Pie Chart

(see Figure 5-9 SIDIARY Pie Chart)

The Pie Chart gives a quick sense of values in set ranges and appeared to successfully impart a general assessment of distribution. However, it seems limited in its ability to support decisions. It might be a tool best reserved for occasional demonstration of a particular insight or observation.

5.3.8.1 UI Benefits

This interface was effective in communicating a general overview of how often the data was within certain glycemic ranges. P15 noted, *"ok, I definitely see what is the percentage of my desired range, where I want to be, and (how often I was) too low, and where I (was) too high or really too high…I see that only 37 percent is in my desired range, and I definitely sees that I'm too low too often."* And P6 could interpret this chart to suggest the need for modification in management, *"okay so … it tells me I have to improve something if every third test is high, really high blood sugar I have to do something. 20% is nearly ok, only 37% is okay, and I think it should be much more. So, I have to work to get my average value down."*

5.3.8.2 UI Limitations

Despite certain benefits, this chart lacks support for interpretation. P9 explained, *"the pie chart probably wouldn't help me make decisions, but it would probably help me just to understand how I'm doing in a general way."* And while P9 rated this interface as *"easy"* to understand, also stated that the *"utility of it is limited."* And P11, a professional designer had a strong negative response to pie charts in general, *"…I hate to look at pie charts, it makes me vomit. I really, really, hate it. So, I wouldn't open the app and look at it. I think it's too ugly."*

5.4 Discussion

Throughout analysis of participant responses, it appeared that these interfaces were for the most part capable of helping people reference data. Furthermore, participants were well aware of the meaning of these data points. In this sense, the usability of these UIs is reasonably successful. These UIs are also well suited to giving broad overviews which can be helpful for assessing performance and for some users can be motivating. However, the communication in regard to self-management is largely implicit, depending on the user to interpret data. Explicit and specific

actionable information is generally limited. Given the frequent demands of diabetes management, this study indicates the need for more actionable interfaces, that offer a cognitive load sweet point where useful knowledge is easier to acquire, while still keeping users mentally engaged with their data. One path forward might be for these apps to offer better filters to help users sift through data or specific contextual clues which could indicate where to focus attention. In addition, there are indications that excessive focus on past data is not well suited to user's actual needs for situated decision making and can place emotional strain in some circumstances.

5.5 Three Questions for Designers of Mobile Health Apps

In the previous sections, selected quotes drew attention to benefits and shortcomings of specific UI paradigms in relation to user interaction with a sample diabetes relevant data set, drawing attention specifically to two areas, cognitive and affective challenges. The following three sections identify unresolved design issues for designers of diabetes self-management apps. The first two sections relating to the cognitive and affective challenges, and a third more general question related to accessing the extensive self-care knowledge shown by our participants. For each section there is:

- An open question raised by the study
- Current approaches
- Problems or shortcomings
- Challenges
- Possible directions in which answers might lie.

By evidencing each of these areas of concern and by identifying those that seem to have most impact on users of health apps for diabetes, attention is drawn to the potential for improvement of well-accepted UI paradigms in this area, and to emphasize the importance of finding new approaches for health app interaction design.

5.5.1 Improving interaction with data

How can we design engaging UIs that lower the cognitive demand associated with interacting and deriving value from complex data?

5.5.1.1 Shortcomings

There was a relatively low adoption of these technologies among our participants, despite a majority of individuals reporting technological skills and interest in diabetes products. It did not appear that the positive aspects of the interfaces created sufficient enthusiasm to encourage active and frequent engagement. As P11 said, such interfaces are like *"filling out an Excel spread sheet for the rest of my life."* While it might be thought that increasing automation of data collection could help overcome this problem, the study suggested that these standard data visualizations can create confusion and cognitive overload for even educated, and technology adept users. For example, information presented on multiple screens or hidden on sliders, created excess cognitive load. P3 noted how difficult it was to compare information across multiple days if it was not simultaneously visible. Such limitations suggest that increased automation will not cause these

apps to provide adequate support for utilizing collected data, without rethinking the general assumptions of these methods for visually presenting data.

5.5.1.2 Current approaches

The apps in the study used widely accepted methods for visualizing data. In many cases, participants felt that the described interfaces could assist in gaining overviews and informing management decisions. The *plotted graphs*, especially with connected dots, were successful in communicating frequency of test within certain ranges and gave an overview of variation. For example, P4 noted how such extreme variation could be indicative of the long-acting insulin needing adjustment to smooth deviation. *Statistics, and pie charts* were appreciated for giving benchmarks for performance, with P11 noting how such overviews could give a clear indication of problems that needed to be addressed. *Data tables*, especially when color-coded, allowed quick overview of multiple days, and could help to detect obvious patterns, such as sequential elevated morning glucose levels. P9 noted that such structures helped with getting a quick overview of a day.

5.5.1.3 Challenges

Parts of this first design challenge is neither new nor original, but, given continued acceptance and application of these visual techniques and the evidence presented, it is critical that new methods be explored, especially in regard to multivariate data. As noted previously (Mamykina and Mynatt, 2007), care must be taken in development to assure that such interfaces challenge rather than confirm biases. In the case of health apps in general, and diabetes apps in particular, designers need to consider the challenge of reducing the cognitive demands of interacting with complex data in the context of usage requirements, such as: high frequency; short time periods; varied contexts of use; emotional sensitivity (see next section), and lack of situated professional assistance.

5.5.1.4 Potential paths forward

One simple but often overlooked and underexplored visualization technique is to offer a tilted arrow showing trends (first derivative) over appropriate time scales. This approach fits well with regular automated data collection. For example, the home UI on the Abbott Libre supplements standard display elements such as current BG level, and graph of BG over time, with a vector arrow showing current rate and direction of BG change (see Fig. 5-10). This interface element is compelling, allowing for practical and glanceable situated advice. The user feedback in this chapter appears to suggest further exploration in departing from conventional graphs and charts as standard daily management tools, in favor of simpler and more intuitive approaches.

5.5.2 Emotional sensitivity

How can we design emotionally sensitive interfaces that draw attention to important but unwelcome information while continuing to engage the user?

5.5.2.1 Shortcomings

Collected health data can have an affective aspect that must be carefully considered when designing UIs. Alerting the user to urgent information, such as a dangerously out of range BG values, must be balanced with maintaining long-term engagement and not causing undue stress. As P16 recalls about their experience using a diabetes app *"it's nice when your blood glucose levels are under control, but once it's not… the app doesn't help you, and…I (got) more frustrated by the messages and the designs…"* When people with diabetes are having a difficult time controlling blood glucose levels, they can feel vulnerable, and being confronted with this perceived failure can be counterproductive.

5.5.2.2 Current approaches

One approach in diabetes apps is gamification, for example the use of an animated 'monster' in the popular app mySugr. However, such approaches can be self-defeating. For example, P16 felt the monster trivialized disease management, stating, *"I'm an adult, and I feel treated like a child."* Or P11 who commented on the same app's sound effects, *"I really hate the sound… it's just too playful for me."* The Akku-Chek app, chose to use blue for elevated BG levels, rather than the more conventional red, which was perceived positively by P12 who remarked that they liked having this color scheme as it reduced stress.

5.5.2.3 Design challenges

Due to variations in personality, it is not clear that there are universal solutions when it comes to affective requirements. For example, while P9 noted how seeing numbers instead of out of range points reduced stress, P15 drew attention to how having their life reduced to a continuous set of numbers created a sense of burden. Similarly, while P12 noted how viewing red dots could have a demotivating effect on diabetes management, P7 observed, *"I don't really know why the high numbers are blue because… blue seems like a good thing to me."* As out of range BG values not only demand immediate attention but are also a constant reminder of long-term risks and failure to maintain adequate control, there are diverse factors to be balanced. Examples include variation in personalities, contexts, and, levels of urgency.

5.5.2.4 Potential paths forward

It is vital that user tests be carried out not only with 'good' data, but also with 'bad' data, which is to say data that reflects undesired states. However, different users have different goal ranges, which can vary according to context. For example, P4 noted *"I need to put my blood sugar at 250 (mg/dL) when I'm working because I don't want to (have) low sugar on machines."* This highlights the importance of clarity about care targets for different individuals in different contexts, not just in interaction design but also when personalizing data for testing purposes. The importance of variation in individual preferences might suggest the need for adaptive interfaces or better options of customization. While this is a perennial topic of research (Bailoni et al., 2016), it is largely unexplored in the present context.

5.5.3 Triggering acquired knowledge

How do we design UIs that trigger the user's acquired knowledge at the appropriate time?

5.5.3.1 Shortcomings

Throughout the study, participants drew upon their already acquired and often extensive knowledge as they sought to make sense of the data. For example, P1 noted that a low BG was probably caused by exercise, before looking for confirmation. Similarly, P4 suggested that a high BG level could have been caused by an insulin dose that was supposed to last 24 hours, but, in her experience, due to shorter actual action, is best administered in split dosages so as to not leave gaps in coverage. Such examples lend support to the previously discussed Mamykina et al.'s *sensemaking* theory (see section 2.1.7) which asserts the importance of learning and then accessing a catalog of mental models that allow for practical and sustainable management. However, the findings suggest that it is far from easy to recognize which relevant knowledge could be applied to a data pattern, and this could be even more difficult when users are under common pressures such as cognitive, affective, attention, or time. The key shortcoming here is simply that none of the representative health apps appears to directly address this problem.

5.5.3.2 Current approaches

Some apps, such as mySugr, include contextual tags paired with icons for common factors that can affect BG levels, such as manual work, sickness, or travelling. However, these are entirely dependent on the user's motivation to participate in extensive logging and effortful reflection.

5.5.3.3 Design challenge

In a slight modification of Intille (Intille, 2004), we need to find ways to help *trigger the right model, at the right time, in the right way*. Due to the off-putting drudgery (for many) of maintaining continual diaries, acquisition and delivery of such information needs to occur without continual manual data input from the user.

5.5.3.4 Potential paths forward

It appears that systems able to meet such challenges will need to learn about the individual user, and what specific knowledge they must access in a given context. One possible starting point is the work of (Pejovic and Musolesi, 2014) on *'tool-effect-modeling'*, which proposes a system that correlates sensed behaviors with desired outcomes. Once these connections have been established, they can then be used to create an anticipatory positive feedback loop. Thereby encouraging the personal and specific behaviors that have been previously beneficial. While this appears a compelling approach, care must be taken to not trigger incorrect models, which could bring about harmful actions. Also careful attention must be taken as to the nature of this human machine relationship: (Ohlin and Olsson, 2015) is an insightful paper on this subject. Other relevant work includes (Doryab et al., 2015) on ranking behavior impact factors, and (Gouveia et al., 2016) for

work on glanceable displays that provoke the user to ask meaningful questions rather relying on a system supplying explicit answers.

5.6 Limitations

As noted previously, participants did not reflect on their own personal data, which through greater familiarity and attached memories could have increased insight extraction. The approach to recruitment may have led to a non-representative overly technically literate and early-adopter group. This may have biased findings towards the success of the technology; however, the many challenges encountered by this group might suggest even more problems with less technologically literate users. Many apps tested (5/6) used mmol/L as units for stored BG values, while some users were only familiar with mg/dl. While they were instructed as to the conversion factor and provided with a conversion sheet, this might have decreased performance (see Figure 2-2 Non-Diabetic vs. Diabetic glycemic values and Contributing factors).

5.7 Conclusions

Sessions with 16 users interacting with representative UI designs for diabetes self-help apps have been analyzed to see how well they meet users' needs. This study draws attention to two principal areas of failure: excessive cognitive demands on users to extract value; and the need for emotional sensitivity given the affective potential of these interactions. Cognitively, these apps require too much effort to make sense of data and locate meaningful insights, exposing users to visual confusion and cognitive overload. Emotionally, the complex relationship users have with their data appears inadequately considered. This section also proposed 3 questions for designers to advance these tools so that they can serve a more meaningful role in people's lives.

If the purpose of such apps is variously: to provide a digital tool for periodic troubleshooting of specific problems; recording diverse data for interaction with a health care provider; and to give the patient broad overviews of collected data; then one may consider these apps tolerably successful. These participants were generally comfortable browsing through and understanding the significance of individual data entries, and in most instances, given a little time for close examination, could understand data within graphs and charts. Yet, as this study has illustrated, users' day-to-day needs appear somewhat different, with many participants noting the challenges in understanding their personal data and maintaining active engagement with the diabetes care process. As discussed earlier in the literature section, the majority of diabetes care is self-care, and patients should be enabled to independently make frequent well-informed care decisions. Based on these premises, the current study gives evidence that these current diabetes apps are inadequate for such goals. Given the number of apps based on a narrow range of interaction and similar UI designs, one must ask why so many app developers continue to deliver apps that fail to adequately address users' problems, require significant daily effort to assemble representative data, show debatable improvements in outcomes, and have low adoption rates.

While the desire to avoid medical regulation is a factor, perhaps it is also because they adhere to an approach that is too closely tied to clinical requirements and conventions that focus on a mediated session with a clinician, and thereby are ill suited to actual user requirements and expectations which are primarily oriented towards self-management. It is worth considering that this might not just be a matter of adding new ways for patients to record more data, automation of data entry alone, more attractive color schemes, or even more visually appealing designs and interactions. Rather there is a need to re-consider how to help users draw value from real and often noisy diabetes data. Furthermore, there must be realistic assessment of available cognitive expenditure and emotional resilience given the contexts and frequency of usage. In summary, despite some tangible benefits from these UIs, we appear to have a widespread and repeated failure to understand user requirements combined with a lack of willingness to challenge established conventions.

The primary objective of this chapter was to provide empirical evidence for the benefits and limitations of specific methods of representing diabetes data. However, these talk-aloud sessions also produced rich data on how people with diabetes describe their sensemaking process, as well as in-depth stories of past experiences with diabetes care. As I sought methods of analysis, I turned to the Mamykina et al. (Mamykina et al., 2015) *Sensemaking* framework as a structure to categorize these statements. Through this process, I found that while many participant statements aligned well within this framework, there were other statements that were ambiguous, appearing to fall somewhere in between the reflexive responses of system 1 thinking and the effortful problem-solving which defines system 2 thinking (Kahneman, 2011). Participants often appeared to display a stream of conscious weighing of multiple factors which appeared to simultaneously share aspects of each. This discrepancy between the collected data and the *Sensemaking* framework suggested the need for further analysis. The following chapter will discuss this process and the following research that suggests possible approaches to design diabetes decision support that are more compatible with lived cognitive practices.

Chapter 6: Fluid Contextual Reasoning

While mobile technologies, such as blood glucose meters, have long been an essential part of the diabetes management process, the previous chapter provided evidence from talk-aloud interaction sessions suggesting that designing interfaces that adequately support reflection and decision-making on multivariate diabetes data remains challenging. Dual-process models (Kahneman, 2011) are a widely accepted approach to understanding such cognitive tasks. However, evidence from the user-interaction study discussed in the last section suggested that in demanding and complex situations, some individuals approached disease management in distinctive ways that do not seem to fit well within existing models. On the basis of the resulting analysis, this section posits *Fluid Contextual Reasoning* to explain how some people with diabetes respond to particular situations and discuss how an extended framework might help inform the design of user interfaces which better reflect how participants appear to interact with diabetes data. This finding motivated, and helped frame a second study, a survey (n=192) to investigate these behaviors in more detail, which will be discussed in the second part of this chapter.

6.1 Proposing Fluid Contextual Reasoning

As discussed earlier, smart devices could potentially become an automated 'doctor in the pocket' health system, intervening, guiding, and altering lifestyle and medical choices. However, designing and implementing effective behavior change interventions remain challenging (Hekler et al., 2013), while creating and promoting Decision Support Systems (DSS) raises critical ethical questions. Meredith and Arnott (Meredith and Arnott, 2003) outlined key concerns: who bears responsibility for recommendations; potential impact on the user's cognitive structures; and dangers to autonomy such as interfering with the user's right to make final choices. Stawarz et al. (Stawarz et al., 2015) concured, noting how automated reminder systems can inhibit independent habit formation, thereby causing vital behaviors such as medication adherence to become technology dependent. One potential approach to alleviate such concerns could be to support rather than replace existing self-care models and behaviors (Pejovic and Musolesi, 2014). For this and other reasons, it is essential for designers to understand the existing practices and mental processes of those who live with these chronic conditions.

6.1.1 HCI and Cognitive models

While there was earlier discussion of theory within the literature review chapter, in order to draw attention to the line of reasoning that led to the conclusion of this chapter, the following paragraphs will briefly review relevant cognitive theory.

6.1.1.1 Dual-process cognitive theories

Dual-process cognitive theories are a leading conceptual approach to understanding the reasoning process (Mamykina et al., 2015). Such cognitive theories exist in numerous permutations, with

diverse empirical and theoretical backing (Evans and Stanovich, 2013). Evans and Stanovich (Evans and Stanovich, 2013) define a generalized version of dual-process theory as:

> *"…one in which rapid autonomous processes (Type 1) are assumed to yield default responses unless intervened on by distinctive higher order reasoning processes (Type 2). What defines the difference is that Type 2 processing supports hypothetical thinking and loads heavily on working memory."*

Such dual-process approaches have been influential in HCI. Li et al. (Li et al., 2011) discussed in section 2.1.7, researched reflection on personal data to increase self-knowledge, observing two primary phases of interaction: *maintenance* and *discovery*. In the former, participants were primarily trying to sustain the behaviors or steps needed to achieve established goals. This phase, with its low cognitive demands is analogous to *Type 1*. In the latter phase, people were asking questions, trying to establish cause-and-effect relationships and goals, analogous to *Type 2*. Mamykina et al. (Mamykina et al., 2008) researched how specifically supporting reflective processes can lead to realization of cause and effect relationships, thereby enabling diabetes self-management behaviors. This research led to the *Sensemaking* theoretical framework which was discussed in the *foundational studies* section (Mamykina et al., 2015), identified the cognitive processes used in self-management behaviors, also essentially a dual-process theory. To review, this variant, especially relevant to this paper, proposes a dynamic interaction between two modes of daily management, *habitual* and *sensemaking*. Further, it presents three key stages of decision-making that occur in both modes: perceiving new information related to condition, understanding this information, and action based upon this information. Sense-making behaviors are typically triggered when the individual notes a 'gap', such as an unexplained out of range BG level. In such instances the new information does not fit into an established self-care heuristic, and the individual must experiment with new behaviors (*sensemaking*). Such hypothesis testing leads to the formation of new mental models which eventually can be used in an effortless and largely unconscious manner. This theory emphasizes that the ability to operate predominantly in the habitual mode is important for sustainable self-care, as *sensemaking* is cognitively demanding.

6.1.1.2 Tri-process theories

While there are many examples of dual-process theories in the literature (Evans and Stanovich, 2013), there are far fewer tri-process theories. Stanovich (Stanovich, 2009) suggested that it might be useful to distinguish between two aspects of *Type 2* thinking: reflective and algorithmic thinking. Alternatively, Varga and Hamburger (Varga and Hamburger, 2014) proposed a tri-axial continuous model of *control*, *effort*, and *speed*, asserting that this model allows for better classification of real world behaviors: the skilled automobile driver on an unfamiliar road offers a clear example. Such a driver has an acquired set of driving skills, which allow for fluid control over the vehicle in most circumstances. But, in a context of unfamiliar roadways, she must remain attentive and actively engaged. The same basic skills are still applied, but the driver cannot function in the largely reflexive mode used on the habitual daily commute. This example offers

intriguing parallels to the person with type 1 diabetes who applies a set of acquired self-management techniques and mental models to navigate the shifting contexts of daily life.

This chapter investigates how people with type 1 diabetes make decisions for disease self-management both in routine and abnormal circumstances. This research reviewed suggests a cognitive process, under-explored in the literature, that allows people with diabetes to engage in rapid stream-of-consciousness navigation of complex situations. We present evidence for this process, which we refer to as Fluid Contextual Reasoning (FCR) and suggest that it can serve a practical function by allowing a workaround for the respective limitations of more typical *'fast'* and *'slow'* thinking. The second part of this chapter concludes by showing how aspects of *FCR* are already being supported by more recent technologies, and suggest ways in which, based on this expanded model, user interfaces for diabetes management could more closely address users' cognitive requirements within specific contexts. This research may have implications for scalable health interventions more generally and may help embody an ethical path forward for supporting rather than supplanting functional self-care knowledge and models. Even more generally, this work, though domain specific, could have relevance to other domains that require informed but non-expert users to interact frequently with vital complex data. In order to further our understanding of these lived practices of decision-making, we conducted the following studies.

6.1.2 Methods

This section used the collected responses from the same sessions which formed the basis of the last chapter, in which 16 PwT1D talked aloud as they reflected on 14 days of pre-collected diabetes relevant data (BG, carbohydrates, exercise, insulin dosages). As an exploratory technique, I divided participant responses into short statements. I then attempted to categorize them line by line. Initially by System 1 and 2 (Kahneman, 2011), and then by the Mamykina et al. framework (see Figure 6-2).

Participant observation	Sys.	Mamykina	FCR Classification
I wasn't measuring that much	1	Perception gap: **BG**	data_retrieval: **BG**
so why it wasn't measuring	2	perception_gap: **Time**	data_retrieval: **Time**
yes, so ok this was a night	2	perception_gap: **Time**	data_retrieval: **Time**
yes so this day wasn't that good so I see	2	perception_gap:**Data**	FCR:**UI**
that I woke up	2	perception_gap:**Data**	FCR:**UI**
and it was too high	2	inference_construction:	framework_access: **UI**
and try to reduce it	2	inference_construction:	data_retrieval: **Time**
but it didn't work	2	inference_construction:	FCR:**UI**
and tried it harder	2	inference_construction:	data_retrieval: **BG**
and then I was too low	2	perception_flow: **BG**	framework_access: **Self-**
it's tells me that I was trying too hard to	2	perception_gap: **Dosage**	data_retrieval: **Time**
so probably next time should shouldn't be	2	perception_flow: **BG**	data_retrieval: **Time**

TABLE 6 -1 INVESTIGATORY CLASSIFICATION OF EACH PARTICIPANT STATEMENT

While many statements fit well into these frameworks, some statements were challenging to classify. In these statements the participant appeared to be quickly weighing multiple factors to make judgements (see Table 6 -1). Table 6-1 was preliminary and is only provided to illustrate this initial exploratory process, therefore its sub-categories were discarded and will not be further discussed.

6.1.3 Findings

The following section reports on participants' responses during the user-interaction sessions. The Mamykina et al. (Mamykina et al., 2015) *sensemaking* framework is applied as a filter through which to analyze these selected excerpts.

6.1.3.1 Support for a dual-process sensemaking perspective

During the user-interaction sessions, many participants provided detailed descriptions of the steps they undertook to successfully cope with diabetes. P11 for example said: *"I think decision-making (on) diabetes…it has a lot of steps. The first step is just recognizing you have a problem … like I have a lot of highs. The second step would be…when do I have a lot of highs? What did I do? Did I do certain things and then had a lot of highs? What…could the problem be? And then take action and then play around a little bit… but carefully."* In this quote we see evidence of the multiple stages described in (Mamykina et al., 2015), the first being the perception of a gap, (*"you have a problem")*. P11 then describes the inference stage of considering the circumstances, leading to the construction of a hypothesis, which is then followed by experimentation. P11 continues, *"And then in the last step would be ...when I recognize that I had this problem in the morning, first I was trying a little bit with the basal dosage and then it helped a little bit and then I thought okay now I can play a little more extreme. So, I changed my basal dosage from 12 to 19. OK that's kind of extreme but it worked out fine. My blood sugar is good again."* P11 has detailed the hypothesis testing, leading to the discarding of the old model (I need *x* units of slow acting insulin at night) to be replaced by the new model. Now that this new model for insulin dosages has been validated, P11 can return to the habitual behavior of a set nightly insulin dosage. To review, in the preceding example we can see the full cycle of the described framework. The 'gap' is the recognition that there are too many elevated BG levels, which initiates a series of inferences, which lead to experimentations, and finally the restoration of a habitual behavior. As long as BG values are judged to be satisfactory, a standardized treatment has been decided upon, no longer requiring cognitive effort.

A more routine use of sensemaking can be seen in P7 looking through several days data in a digital logbook: *"…they've taken the same amount of insulin with way less carbs in the morning and they still had problems keeping the blood sugar down. So…they need to …in the morning…increase the amount of insulin that it normally takes for a meal."* In this case the gap is once again elevated morning BG, the hypothesis is insufficient morning insulin, a second case is observed in the

logbook with less carbohydrate intake, which further supports this hypothesis. Presumably this would then be tested to see if it improves after breakfast BG levels, without undue hypoglycemia.

However, we also found examples that did not fit as easily in the described schema. P4 describes a process of managing diabetes during a Saturday night of partying. P4 upon reflecting on recorded data showing non-stable BG values on a Saturday night relates, "*… at night to have a blood sugar like this is always difficult because when you … drink then you have a problem to get out of there* [unwanted BG level] *depending on how much alcohol your body is having. … the most dangerous thing is drinking sweet stuff … also I know that and at 3:00 in the night 55* [mg/dL = hypoglycemia] *so I mean when you drink no sweet stuff then you'd just like Schnapps* [an unsweetened concentrated alcohol]…*then it's not a big issue when the only issue is that getting in a low sugar because then your body can't take sugar again and it's busy with alcohol when you drink sweet stuff and beer and this stuff then you need almost to inject* [insulin] *because your blood Sugar's going up but this is not allowed at all to inject for alcohol so I think it's really good to drink schnapps and dance … and drink cola because the way how to you can resolve the night because you can control your blood sugar with dancing, smoking weed, and pushing it up with Coca-Cola again*" In this quote we see P4 balancing multiple factors that can have an unpredictable effect on BG levels, using multiple mechanisms to cope with potentially risky behaviors. We see *habitual* fixed models, such as to not inject insulin while drinking alcohol so as avoid the risk of severe hypoglycemia, and to not drink sweetened alcohol, as that will overly raise BG levels. However, there are also context dependent models, such as using dancing to lower BG levels while drinking (how much? How vigorous?), or to use Coca-Cola to raise BG levels. It is not clear from the quote which effect marijuana has on BG levels, but either for medical utility or quality of life, it has been incorporated into P4's dynamic equation. With so many unpredictable factors on BG levels, as well as potential risks, it would be difficult to classify this process entirely as an 'effortless' habitual mode, but with all the cognitive impairment, distractions, and frequent in the moment adjustments, enacting such a process of diabetes management would be difficult to classify this in a strict *sensemaking* mode. This appears to have some similarities to the aforementioned expert driver, who can draw upon multiple skills in a fluid manner, adapting them to shifting contexts.

6.1.4 Discussion

As well as supporting the Mamykina et. al *Sensemaking* framework, this chapter also describes a mode of operation that appears to allow those with sufficient accumulation of self-management models, to assess and act upon complex context-dependent multivariate data. Further, they can do this in a flowing and relatively low-cognitive manner that allows them to process information that is too complex and has too many variables and unknowns to be literally 'solved'. This appears to be achieved through linking and adjusting multiple co-existing models. Further differentiating this mode from *sensemaking,* we do not see the recognition of a clearly defined '*gap*', effortful thinking, nor necessarily a process of learning leading to the creation of new models nor discarding

of old ones. We have labeled this mode of thinking *fluid contextual reasoning (FCR)*. FCR draws on behaviors at the intersection of the dual-processes (Figure 6-1); however, it combines them in new and distinctive ways – as discussed below. Table 6-2 provides a table (non-exhaustive) that suggests potential categorization.
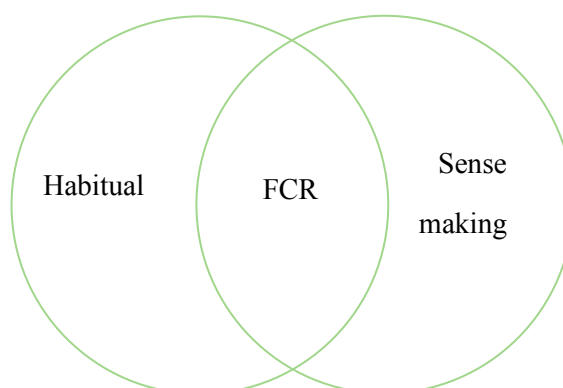
FIGURE 6-1 SELF-MANAGEMENT MODES

Habitual (Type 1)	FCR	Sensemaking (Type 2)
Implicit, Effortless	Low-demand Active Engagement	Explicit, Effortful
Applying existing static, rule-based models	Adapting/combining multiple existing models	Hypothesis testing/ Creating new models
Algorithms: Practiced / discrete	Algorithms: approximate	Algorithms: demanding or novel
$3 * 3 = 9$	$3.1 * 2.9 \approx$ $3 * 3 = 9$	$3.1 * 2.9 = 8.99$
Reflexive/ Reacting	Improvisation/ Navigating	Reflection/ Solving
Chunked memory	Connecting Chunked memory	Loading working memory
"If this, then that"	"Some combination of this and that"	"Could this cause that?"

TABLE 6-2 CHARACTERISTICS OF SELF-MANAGEMENT MODES

6.1.4.1 Habitual

This mode is defined by reflexive responses, habitual behaviors, or scripts activated in specific situations. Accessing such models allows for the low cognitive demands needed for rapid responses. These can be either a single action or a sequence of previously learned steps, models, or formulas. A multi-part habitual model might be: for elevated BG take a correction shot of 1unit insulin per 50 mg/dl, drink water, test again in 1 hour. As this response is already learned and tested, there is no need to contextually re-adjust.

6.1.4.2 Fluid Contextual Reasoning

FCR is proposed as a combination of mental models being adjusted and applied to a specific context with increased awareness of how factors relate to past, present, and future to allow 'navigation' through a time continuum. An example might be rather than just counting carbohydrate content of a meal to calculate insulin dosages, considering other factors such as exercise that might occur hours later, recent trends in insulin sensitivity, and amount of fat in meal. Indicative of this state is stream of conscious layering and combining of models, with little demand on working memory, and little concern for establishing new self-care models.

6.1.4.3 Sensemaking

A recognition of an unexplained event (gap) leading to: discovery of a new pattern; cause and effect analysis; explanation of what caused an event to occur; or a learning process, with conscious creation or revision of specific model(s). An example might be: Through experience one realizes that eating pizza typically causes hypoglycemia, followed by hyperglycemia. One hypothesizes this could be due to combination of considerable carbohydrate and fat which delays digestion. Therefore, it makes sense to try splitting insulin bolus dosages next time to see if that helps. If this is confirmed, this can transition to a habitual mode. The initial figures show a visualization of the Mamykina et al. self-management model (Fig. 6.2), while the second shows a revised model with the addition of FCR, which sits between the other modes (Fig. 6.3). The next section will investigate this proposed mode.
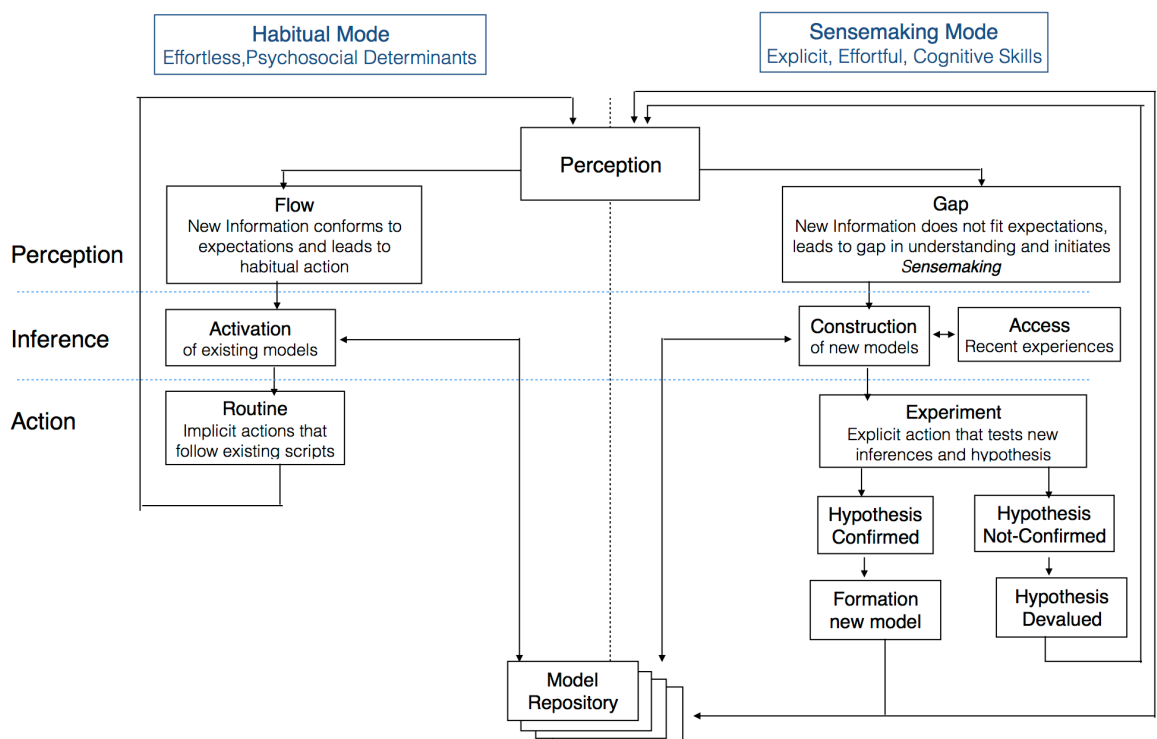
FIGURE 6-2 MAMYKINA ET AL. (MAMYKINA ET AL., 2015) SELF-MANAGEMENT SENSEMAKING FRAMEWORK

| Habitual Mode
Effortless, Psychosocial Determinants | Fluid Contextual Reasoning
Active Engagement | Sensemaking Mode
Explicit, Effortful, Cognitive Skills |

Perception

Perception

Flow
New Information conforms to expectations and leads to habitual action

Adjustment Needed
New information indicates need for course correction

Gap
New Information does not fit expectations, leads to gap in understanding and initiates *Sensemaking*

Inference

Activation
of existing models

Access
Past, current, future context

Retrieve
multiple relevant models

Construction
of new models

Access
Recent experiences

Action

Routine
Implicit actions that follow existing scripts

Dynamic Action
models are adjusted and applied according to context

Experiment
Explicit action that tests new inferences and hypothesis

Hypothesis Confirmed

Hypothesis Not-Confirmed

Monitor
frequent checking behaviour initiated

Formation new model

Hypothesis Devalued

Stored Models

Static Models

Dynamic Models

FIGURE 6-3 SELF-MANAGEMENT WITH FCR

6.2 Fluid Contextual Reasoning: An Investigatory Survey

This second section further investigated the FCR hybrid-mode hypothesis through a survey inquiring about the decision-making processes of PwT1D in relation to diabetes self-management in specific circumstances, thereby answering the question:

- RQ3: *How could apps better support user decision-making processes?*

The survey provided evidence for widespread use of FCR as defined in the previous section, across all demographics, particularly in association with of CGM adoption and increased number of insulin boluses. In the following sections we will review the methods, procedure, and findings for a follow-on study, then conclude by showing how aspects of *FCR* are already being supported by more recent technologies, and suggest ways in which, based on this expanded model, user interfaces for diabetes management could more closely address users' cognitive requirements within specific contexts.

6.2.1 Methods

During earlier research, as participant recruitment was often challenging, we decided to use an online survey to increase sample size. I developed an online survey through an iterative process with at least 5 people with T1 diabetes providing feedback, with the questions being discussed and repeatedly revised. This was followed by the resulting survey being taken by three pilot participants online, with further revisions based on answers and feedback after each session. The survey was then finalized and submitted for ethics approval. Inclusion criteria were diagnosis with T1 diabetes, in medical treatment, and a minimum of 18 years of age. The survey was distributed

online through social media including multiple T1 diabetes Facebook groups, Twitter, and, after undergoing an approval process, the online portals for the Diabetes UK and US based TU Diabetes online community. There were no incentives offered other than the appeal to help with diabetes research and the option to receive outcomes, which was done via email after the results were published (Katz et al., 2018b).

6.2.2 Survey contents

The first part of the survey was demographic in nature, establishing age, gender, duration of illness, diabetes devices used, and frequency of BG testing and insulin injection. This was then followed by a series of open-ended questions, allowing for gathering more in-depth information. Questions 8-10 were two-part, with the first part defining a scenario and requesting analysis procedure, and the second part asking for a description of how the situation was managed. These questions were split, as in our initial user testing, this two-part format appeared to generate more thorough responses. Questions Q7-14 were each designed to initiate different aspects of the proposed expanded FCR model. For example, question Q7 which asked participants to discuss a routine situation was predicted to bring about a *habitual* response, while Q8 in asking participants to recall a surprising situation, would be expected to provoke a *gap* situation that should initiate *sensemaking*. These questions are presented in condensed form below, with expected outcome tendencies. (See Appendix B, Chapter 6: FCR Survey forms for full list of questions.)

Q:	Scenario	Action	Expected outcome
#7	Normal BG	Insulin dosage calculation	Habitual mode
#8	Recall surprising out of range BG event	Description, analysis, treatment procedure	Gap situation, sensemaking
#9	Recall out of range event with obvious cause	Description, analysis, treatment procedure	Habitual mode treatment
#10	Recall out of range event caused by novel situation	Description, analysis, treatment procedure	Gap situation, sensemaking
#11	Change in diabetes management since diagnosis	Description	Tendency towards FCR management
#12	If CGM user, effect on management	Description	Tendency towards FCR management
#13	Measure current BG, report factors	Description, analysis	Dependent on prior answers
#14	Management process for meal with current BG	analysis, treatment procedure	Dependent on prior answers

TABLE 6-3 SELF-MANAGEMENT SURVEY AND PREDICTED RESPONSES

6.2.3 Procedure

Data were exported from the Google form used for collection, imported into an Excel spreadsheet, and then anonymized. Of the n=206 initially collected surveys, 14 were eliminated (3 completed under observation during the development process, 4 duplicates, 1 that was underage, and 6 that were judged too incomplete to provide meaningful data), for a total of n=192 responses. The

extended framework (see Appendix C: Results from Chapter 6 FCR) was used as a schema, which was expanded by domain specific self-care models extracted from the collected responses. Such categories included: insulin, exercise, diet, blood glucose, testing, context, devices, time, place, health cycles, interfaces, etc. After I composed the initial coding schema, it was applied to the 20 responses. A secondary coder then reviewed the responses, and the coding schema was discussed and refined. For example, the *habitual* mode category for insulin use included: fixed insulin/carb ratios, fixed BG correction factors, and fixed insulin doses. The *FCR* category for insulin use included: considering factors such as insulin on board (when not monitored by device), insulin sensitivity in relation to a specific context, intentionally waiting variable times between bolus and meal, micro-dosing insulin based on context, adjusting dosages according to trends. *Sensemaking* activities including: learning self-management models, researching how context changes insulin sensitivity, retrospective analysis of insulin effect, calculating new insulin/carb factors, and experiments to determine new fixed dosages. After frequent discussions, co-coding, and comparisons with a second and third coder, I coded the remaining data. Intercoder reliability was checked with a sample of 20 responses with a resulting Cohens Kappa = 0.698. After all responses had been classified as *habitual*, *FCR*, *sensemaking*, or *non-classifiable,* counts were summed, and analyzed.

6.2.4 Findings

The following sections review the frequency of answers classified as either *habitual, FCR, or sensemaking* from the survey. Table 6.4 reviews this information sorted by demographic, while Table 6.5 reviews the responses to the open-ended questions. The "n" in the table refers to total number of classified respondents within a specific demographic; this number can be lower than total participants due to answers that were missing, vague, or non-relevant. Totals show the count of participants who have been classified as exhibiting at least one instance of the three behaviors, emphasizing individual capability for exhibiting a mode of decision-making. For example, if P015 were to be classified with 5 instances of Habitual, 0 instances of FCR, and 6 instances of Sensemaking, this would be indicated as (1,0,1).

6.2.4.1 Cognitive mode in relation to demographics

In this section, we review the three modes in relation to demographic information. The tally of results indicate that while habitual and sensemaking were most frequent, all three states were prevalent across all demographics. FCR appeared to be significantly associated with CGM usage, might have a slight increase with the first 10 years since diagnosis, and a small but significant correlation with bolus and testing frequencies.

	Number of participants who have exhibited a given behavior						
		Habitual		**FCR**		**Sensemaking**	
	n=	**n>0**	**%>0**	**n>0**	**%>0**	**n>0**	**%>0**
Age in years							
18-24	25	23	92	19	76	25	100
25-34	51	50	98	38	75	50	98
35-44	42	39	93	27	64	40	95
45-54	30	27	90	18	60	28	93
55-64	30	25	83	26	87	29	97
65+	13	12	92	10	77	13	100
n.a.	1	1	100	1	100	1	100
Gender							
female	146	135	92	105	72	143	98
male	43	39	91	31	72	40	93
other	3	3	100	3	100	3	100
Time since diagnosis in years							
< 1	7	6	86	4	57	7	100
1-2	14	14	100	9	64	13	93
3-5	15	12	80	11	73	15	100
6-10	14	14	100	11	79	14	100
11-20	43	41	95	33	77	42	98
21-30	45	42	93	32	71	42	93
31-40	30	27	90	19	63	30	100
41-50	13	10	77	11	85	13	100
50+	10	10	100	8	80	9	90
n.a.	1	1	100	1	100	1	100
CGM/FGM use							
yes	117	104	89	96	82	112	96
no	75	73	97	43	57	74	99
Insulin pump user							
yes	121	110	91	89	74	117	97
no	71	67	94	50	70	69	97
Daily BG testing frequency							
1-2	7	7	100	3	43	7	100
3-4	25	24	96	13	52	25	100
5-7	50	49	98	33	66	50	100
8-12	48	46	96	38	79	45	94
13-17	15	11	73	13	87	15	100
18+	46	39	85	38	83	43	93
n.a.	1	1	100	1	100	1	100
Boluses/shots per day							
1-3	14	14	100	6	43	14	100
4-5	99	94	95	68	69	97	98
6-8	53	45	85	45	85	51	96
9-11	21	19	90	16	76	19	90
12 +	2	2	100	2	100	2	100
n.a.	3	3	100	2	67	3	100

TABLE 6-4 FREQUENCY OF SPECIFIC BEHAVIORS

6.2.4.2 Age in years

There were consistent and prevalent habitual and sensemaking behaviors across all age groups, with no indicators that any of the three categories are related to participant age.

6.2.4.3 Gender

No apparent significant correlations related to gender.

6.2.4.4 Time since diagnosis in years

No statistical significance in correlation, although there might be a slight upward trend in FCR within the first 10 years after diagnosis.

6.2.4.5 CGM/FGM use

Non-users of CGM/FGM might have a small tendency towards more habitual responses as opposed to users. CGM users appear to have an increase in FCR classification as opposed to non-users (82% vs. 57%), a Fisher Exact Test showed a $p < 0.01$, demonstrating significance in this category.

6.2.4.6 Insulin pump use

No apparent evidence for correlation between method of insulin delivery and reasoning modes.

6.2.4.7 Daily BG testing frequency

Frequency of daily testing appears to be associated with an increased tendency towards FCR categorization, as shown by bar graph progression in Fig. 6.5 Sensemaking appears consistent among all groups. Habitual thinking might decrease slightly with increased testing frequency, though this might be due to the small sample in the '13-17' (n=15) group. Means were determined for each demographic, which were then used to perform a Kendall's Tau test, performed with the SciPy Stats package in Jupyter Notebook. The increase in FCR behavior was found to have a small but significant correlation with daily testing frequency (Tau 0.20, $p < 0.001$).
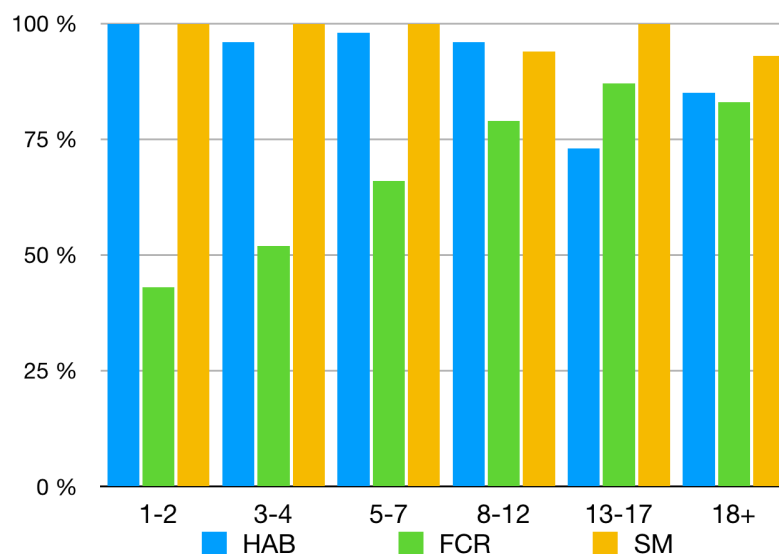
FIGURE 6-4 DAILY TESTING FREQ. VS. % W/ COGNITIVE MODE

6.2.4.8 Boluses/shots per day

While Sensemaking and Habitual modes appear unrelated to number of shots per day (Fig. 6.6), there appears to be a small correlative relationship between increased frequency of insulin injection and FCR mode. The same procedure was followed as in the previous paragraph, with indications of a small but significant correlation between injections per day and FCR classification (Tau 0.19, $p < 0.001$).
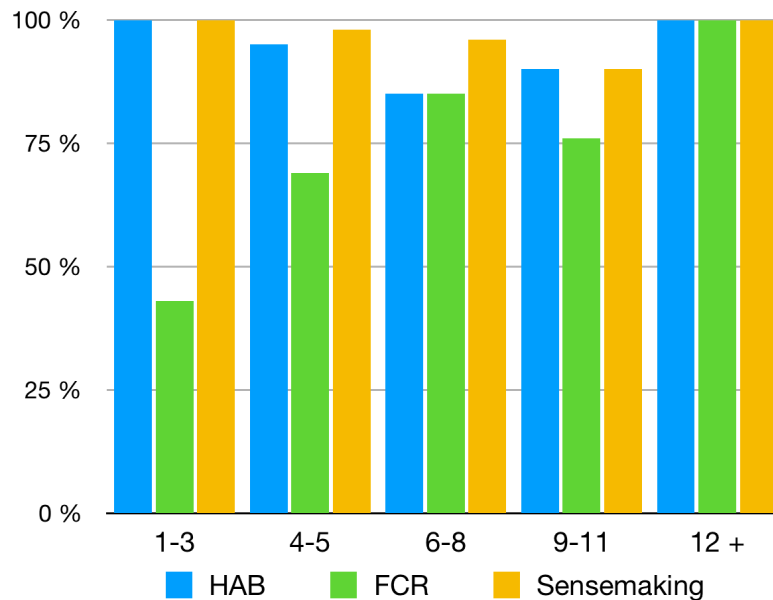
FIGURE 6-5 BOLUS/DAY AND. COGNITIVE MODE

	Habitual			FCR		Sensemaking	
	n=	n=	%	n=	%	n=	%
Q07. Normal BG/ response							
	189	73	39	116	61	0	00
Q08. Recall surprising BG event							
	166	23	14	6	04	137	83
Q08b.Treatment procedure							
	167	86	51	22	13	59	35
Q09. Out of range w. obvious cause							
	178	17	10	12	07	149	84
Q09b. Treatment procedure							
	177	132	75	21	12	24	14
Q10. Recall out of range event w/ novel situation							
	143	2	01	3	02	138	97
Q10b. Treatment procedure							
	129	67	52	24	19	38	29
Q11. Change in diabetes management since diagnosis							
	28	11	39	7	25	10	36
Q12. If CGM user, effect on management							
	39	1	03	29	74	9	23
Q13. Current BG, report factors							
	142	28	20	46	32	68	48
Q14. Management process for meal w/ current BG							
	164	85	52	79	48	0	0

TABLE 6-5 COUNTS OF RESPONSES TO OPEN ENDED SURVEY QUESTIONS

6.2.4.9 Q07. Factors for insulin dosage under normal BG conditions

Q07: Imagine that it is time for you to take an insulin dosage for a meal. You check your blood glucose level, and as you expect it is in a normal range (70-140 mg/dl or 3.9-7.8 mmol/L). Please describe the factors you might take into consideration to determine how much insulin to take for this meal.

These responses appear to lend support to the (Mamykina et al., 2015) model, as without a 'gap' to initiate effortful thinking, we do not see the effortful *sensemaking* process. This question on routine

management practices produced only habitual (39%) and FCR (61%) responses. Common examples of habitual responses were simple algorithms, such as fixed insulin to carb ratios. In contrast FCR was evidenced by answers by hard to quantify contextual situations such as P141 *"Carbs, exercise, stress, illness."* Also common were references to hypothetical events such as future exercise.

6.2.4.10 Q08. Describe situation w. serious and surprising blood glucose value

Q08: Please try and remember a situation where you had a serious and surprising high or low blood glucose value (e.g. despite being careful, you had an unexpected dangerously low blood sugar on an airplane). Please describe that specific situation, and your thought process about it. Please be as detailed as possible. 8b. In the last example please describe how you managed the situation.

In contrast to the *Q07*, this question was formulated to elicit a 'gap' situation response, which was reflected in 83% of responses being classified as sensemaking. P030 recounts, *"I learned the hard way as a teenager the effects alcohol can have on your blood sugar. I took my normal bolus the next morning with breakfast and went back to sleep. Next thing I remember is waking up very confused, with a very painful mouth and body."* In this example, we see the learning process and formation of models related to alcohol consumption. Or P060 who stated, *"I guessed wrong about carbs in a meal and over-bolused."* Thereby showing awareness of a specific cause and effect relation. However, the second part of this question on treatment procedure resulted in substantial *habitual* responses (51%). For example, P141 recounted treating unexpected hypoglycemia with *"15g fast carbs then slow carbs like biscuits or bread."* Thereby demonstrating the initiation of a script of behaviors. Sensemaking was also common in *Q08b* (35%), typically the establishment of a new habitual model, for example P154 noted, *"It made me consider potential options for keeping items by my bed to test or treat lows instead and keeping my phone close too in case I needed to call for help."*

6.2.4.11 Q09. Describe out of range event w. obvious cause

Q09: Please try and remember a time that you had done something that had caused your BG level to be out of ideal range, but you immediately understood why (e.g. eating too much cake at a birthday party). Please describe that specific situation, and your thought process about it. Please be as detailed as possible. 9b. In the last example please describe how you managed the situation.

I hypothesized that indication of an obvious cause would reduce *sensemaking*, in comparison to the 'surprising event' of *Q08*, however this was not reflected in the totals, which produced almost identical proportions to *Q08*. However, this discrepancy was reconciled in the second part of the question on treatment procedure, where we see substantially more habitual (75%) responses, and a resultant drop in sensemaking behaviors, such as new model formation.

6.2.4.12 Q10. Recall out of range event w/ novel situation

Q10: Please try and remember a situation when you were in a novel or unusual situation that dramatically affected your blood glucose level (e.g. arriving in a different time zone, becoming distracted by unusual circumstances after taking a shot, miscalculating an insulin dosage, an unusual food, etc.) Please describe this specific situation, and your thought process about it. Please be as detailed as possible. In the last example please describe how you managed the situation.

This question was designed to evoke a specific 'gap' situation, an unwanted BG value in a novel situation. This led to 97% of participants responding with a sensemaking response. The second part of the question had similar response patterns as *Q08b*, with a majority (52%) of habitual responses.

6.2.4.13 Q11. Change in diabetes management since diagnosis

Due to the small number of categorizable responses, this question will not be further discussed.

6.2.4.14 Q12. If CGM user, effect on management

If you use a CGM or Freestyle Libre, in which ways has it changed your diabetes management process as opposed to using strips? Please be as specific as possible.

While *Q12* also had only a small number of responses that could be categorized, 74% of responses were categorized as FCR, further supporting the link between CGM use and FCR in diabetes management.

6.2.4.15 Q13. Current BG, report factors

Please check your blood glucose and record the value in the space below. Describe everything that comes to your mind and what factors might have contributed to this reading.

Asking participants to analyze their current BG produced 48% in the sensemaking mode, followed by 32% in the FCR mode. Habitual responses lagged at 20%.

6.2.4.16 Q14. Management process for meal w/ current BG

Imagine that you are going to take insulin now for a meal. Given your current BG value, please describe what factors you would take into consideration, and the process you would use to decide on an appropriate insulin dosage.

This question prompted relatively even habitual and FCR responses (52% vs. 48%). Habitual responses often related the use of simple procedures. For example, P205 answers, *"I would only dose for the carbs I was about to eat. 1 unit for every 15 carbs."* While FCR responses often show fluid balancing of multiple models and emotional factors, such as P199 noting *"I would eat low carb if I have a high reading but as I'm at work I only have soup for lunch which is 18g of carb so have to eat that, I know as I'm high it's not good as I would prefer to be in range before eating, but as I am hungry I need to eat, this is where I really get frustrated with T1, I would therefore take an extra 20% dose on insulin to bring me down, as when running above 12 I also become more insulin resistant."*

6.2.5 Discussion

In the following sections, we will first consider the general findings regarding the proposed expanded cognitive framework for diabetes self-management: *habitual*, *FCR*, and *sensemaking* modes. Then, we will apply these three modes to discuss existing diabetes related UI's. And finally, we will discuss how the theoretical and practical outcomes of these study results could be applied to the design of diabetes related UI's.

6.2.5.1 Habitual

Habitual modes are a means of low-cognitive demand reaction, particularly important for treating out of range situations with obvious causes. These treatment algorithms can be relatively complex, such as multi-factor calculation of insulin dosages, given that this remains context independent. As P136 notes about calculating insulin dosages, "*I did in my head for year, so the formula is burned into my brain.*" This mode is crucial for quick responses, especially as out of range conditions were frequently cited as causing cognitive impairment. Such as P064 describing a particularly bad hypoglycemic episode, "*I was disoriented, sweaty, dizzy, couldn't see straight. I was able to test my blood sugar and it was 17* [mg/dL = severe hypoglycemic]. *At that point, my only thought that I could muster was to eat whatever I could find to try to keep conscious.*" References to this mode decreased substantially in *Q08b* and *Q10b*, where the novelty of the situation doubled the incidence of sensemaking behaviors. We concur with (Mamykina et al., 2015) that this mode is largely dependent on ready access to models incorporated through the *sensemaking* process, and that the low cognitive demands appear consistent with Type 1 thinking.

6.2.5.2 Sensemaking

In instances (*Q08, Q09, Q10*) where participants were asked to recall surprising out of normal range situations, sensemaking was a dominant mode. In support of the (Mamykina et al., 2015) model *sensemaking* appears an essential activity for building models, with extensive examples where participants recalled a specific situation that led to new habit formation or critical lesson. For example, P049 who described having a hypoglycemic episode on a plane, and not getting up to get glucose from the overhead bin because of an activated fasten seat belt sign. "*I played by the normal rules, though I shouldn't have. I should have gotten up at the moment I realized I was getting into trouble.*" The evidence appears to support that sensemaking can be seen as the foundation for both habitual and FCR modes. In its effortful ability to overcome assumptions, biases, or habitual behaviors, it is consistent with Type 2 thinking.

6.2.5.3 FCR

While FCR thinking is less prevalent than habitual and sensemaking modes, it appears common throughout all demographics, independent of gender or age. It appears associated with CGM use, frequent BG measurements, and frequent bolus injections, and possibly a slight increase within the first years after T1 diabetes diagnosis. These correlations are at least partially, by definition, due to characteristics such as 'frequent course correction' and 'watching of trends' being strongly enabled

by CGM technologies and increased insulin application. It also possible that the building of the flexible models used in FCR are enabled by the frequent checking and increased interactions supported by CGM and potentially other technologies which enable convenient data access. FCR appears most commonly in response to 'normal situations' (*Q07* 61%), relating the factors of 'current BG' (*Q13*, 32%), and for 'projected management process for a hypothetical meal (*Q14*, 48%). It is neither a retrospective tool, (*Q08*, 4%, *Q09*, 7%, *Q10*, 2%), nor a prevalent treatment mode for surprising (*Q08b*, 13%) nor for out of range events (*Q09b*, 12%, *Q10b*, 19%). FCR does not appear to be a replacement for the habitual and sensemaking modes, nor the correct method for all situations, especially such as treatment for excessive hyperglycemia, where the automatic response of habitual mode might be preferable. FCR might also not be ideal for unexplained circumstances, where the desire to avoid such situations in the future point towards *sensemaking* and formation of new preventive models. As FCR appears to share some traits of each of the two other principal modes, it might be viewed as existing somewhere in a spectrum between the two other modes. At the same time, leaving aside any claims about dual or tri-process cognitive models, FCR appears at the least to characterize distinctive user behaviors with apparent implications for UI design, as discussed below.

6.2.6 Current UI's

In the following section, we will consider two commonly used UI's and consider how their elements might relate to the discussed theories.

6.2.6.1 Diabetes Logging App Statistics UI's
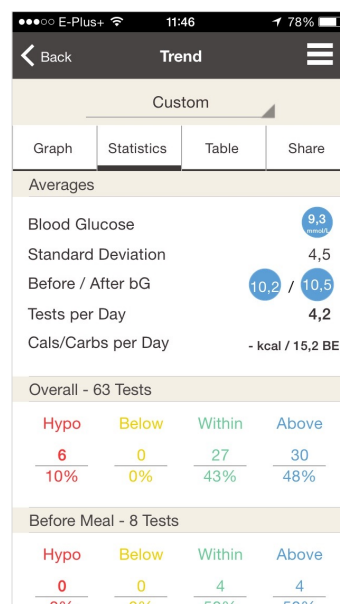
FIGURE 6-6 STATISTICS UI

The diabetes diary app, as previously discussed in the introduction/supporting technologies section, is a common approach for situated diabetes self-management. Figure 6-6 Statistics UI shows an example of such an app with the statistics tab displayed. This UI displays statistics that could help guide management through trend discovery. Using the previously noted coding scheme, I would

classify this UI as requiring 'effort' to apply to management decisions, and that its utility would be for 'Reflective or Hypothetical thinking'. Therefore, this UI could be classified primarily as a *sensemaking* tool and be used primarily for 'gap' discovery. Such gaps could be useful for drawing attention to the need to question existing habitual behaviors or undergo hypothesis testing to form new models. Such an interface would have limited benefits for supporting habitual modes, or *FCR* modes, and given the lack of sensemaking in evidence from *Q14* (management process for current meal), would not typically be of use for individual treatment decisions. As such, it could be seen primarily as a tool for intermittent use, which is in agreement with research discussed in previous chapters.

6.2.6.2 CGM/FGM UI

FIGURE 6-7 ABBOTT FGM/CGM UI

Figure 6-7 Abbott FGM/CGM UI shows the UI for the Abbott Libre Flash Glucose Meter. There are four primary design elements: current time, current BG, arrow showing direction and rate of change, and a graph showing the previous 8 hours of measurements with goal range in blue and an apple marking a meal. The time function could be a component of all three reasoning modes, dependent on context. For example, time checking can be habitual behavior. It can be useful for helping to establish context for FCR, or can be used as a sensemaking tool, for specific and determined problem solving. The BG value is largely a *habitual* tool, with reflexive interpretation of 'too high', 'too low' or 'about right', although it is also critical in FCR navigation and course correction and could be interpreted according to the requirements of a given context. It could also trigger sensemaking mode, when departing significantly from expectations. We classify the arrow as largely an FCR tool, as its implications are dependent on multiple contextual factors such as insulin on board, time of day, food already eaten, desired state, and relation to recent state. The graph as well could be used in all modes, dependent on context. Its use could be *habitual*, for

example to assure the user that they are generally in range over a given period; it could be used as an *FCR* tool for assisting in navigation through time, by helping to show general tendencies. It could also be an 'effortful' *sensemaking* tool, especially in conjunction with additional recorded data, to help understand specific cause and effect relationships. In summary, according to our coding scheme, this UI incorporates aspects of all three modes, and can be flexibly applied according to situated user requirements.

6.2.7 Implications for future adaptive UI design

The following sections discuss potential practical applications of this research for future UI development as related to the three modes. The research discussed in this chapter suggests that a binary model of cognition could be insufficient as a diabetes UI design framework, offering inadequate support for dynamic management techniques. An interface that is specifically geared towards habitual (Type 1) thinking is quick to use but might not engage the user's cognitive abilities to challenge their biases. Conversely a sensemaking (Type 2) interface, such as a robust diabetes diary app, offers a means of overcoming such biases through effortful analysis of collected data; however, the high cognitive costs associated with insight extraction could be a barrier to frequent interaction. So, the designer of a diabetes support systems using only a two-aspect model faces a challenging question: how can UI's support interactions with complex data in a manner that is of low enough cognitive demand to allow for frequent usage while still encouraging non-reflexive mindful engagement? The following section attempts to address this concern, the implications of an expanded model, and its application to design.

6.2.7.1 Habitual: design implications

The *habitual* mode appears most relevant for addressing out of range events with understandable causes. As these situations can be cognitively and affectively stressful, interfaces should support and trigger familiar and easy to understand treatment steps. Wherever possible, such interfaces should attempt to help the user to integrate and link such behaviors into already existing behaviors, and thereby establish actions that become independent of interface interactions (Stawarz et al., 2015).

6.2.7.2 FCR: design implications

As *FCR* relies on the flexible use of multiple models, a supporting interface should help to trigger appropriate models at contextually relevant times and suggest other factors that might be relevant to support active engagement with diabetes management. As *FCR* is a largely an in-the-moment technique, graphs, charts and other cognitively demanding and primarily retrospective interface elements should be de-emphasized in favor of easy to understand elements such as short text, and icons where appropriate. Short animations might also be relevant. Ways to determine the appropriate personally relevant model triggers must be further researched, as well as means of determining personally relevant context for activation.

6.2.7.3 Sensemaking: design implications

Our study suggests that *sensemaking* is a dominant behavior when encountering out-of-range or novel situations. Traditional UI elements such as graphs and charts might be appropriate in such contexts to help users find specific correlations, or to help illustrate relevant insights. The emphasis should be on helping users to hypothesis test and construct new models, which can subsequently be used for less cognitively demanding habitual and FCR modes. As sensemaking is effortful, it is not for continual application; therefore, context awareness or some means of cognitive load sensing (Rafiqi et al., 2015) might be used to determine when the user is amenable to such in depth engagement.

6.2.8 Ethical considerations

As interfaces for supporting medical practices seek to impact behaviors, their implementation has bio-ethical implications to principles such as beneficence, non-maleficence, justice, and autonomy (Beauchamp and Childress, 2001). Here we consider ethical concerns for each of the 3 cognitive models.

6.2.8.1 Habitual

As habitual behaviors can be critical for rapid responses, it is important that interfaces neither inhibit these reactions, nor interfere with successful strategies. This could argue against sustained UI engagement as a successful metric in such circumstances and point towards the importance of helping to support independent and intrinsically motivated behaviors. For example, if a user becomes dependent on their smartwatch to remind them to bring glucose when exercising, they might forget to take insulin when their watch battery is empty. Such concerns could argue that ideally such critical behaviors should be technology independent when possible. As these behaviors are largely reflexive, respecting autonomy requires that persuasive and habit-forming systems are respectful of the personal preferences of the user and have some means of assuring that the individual has made an informed decision.

6.2.8.2 FCR

As FCR depends on the access and adjustment of multiple self-care models, it is important that beneficial models are accessed, and adjusted in an appropriate manner. Ethical UI's might help this process by helping users to record personally relevant and desired self-care models, and then triggering these models in a contextually appropriate manner. Care must be taken that the user maintains the ability to choose what are appropriate suggestions without inappropriately forcing users into sensemaking mode, as this could inhibit frequent engagement.

6.2.8.3 Sensemaking

As sensemaking is essential for forming self-care models, UI's should assist with informed investigation of beneficial models, while offering some means of warning about the formation of harmful models. Given that rapid access of such models is essential for the other modes, UIs should

help to support integration of such models into practice. Care should be taken that users are educated into being able to engage in such practices independent of technology.

6.2.9 Limitations

This interaction research was conducted with a technology capable group and non-personal data which could have effects on results. The use of online recruitment could prejudice towards an engaged and knowledgeable sub-group, and therefore may not be broadly representative. Qualitative coding is always open to interpretation, especially regarding intent. As such this study is primarily exploratory, and not necessarily indicative of broader occurrences of these behaviors, nor how they may occur in 'in-the-wild' settings.

6.2.10 Conclusions

This chapter presented evidence that many people with diabetes can make decisions with their complex data in a manner that does not easily conform with established cognitive models associated with habitual (Type 1 analogous), or sensemaking (Type 2 analogous) thinking. The former is largely reflexive, and therefore limited in its ability to exhibit variously: contextual consideration of complex multivariate data; hypothetical thinking as to potential events or outcomes; and awareness of highly variable situations. By contrast, the latter requires substantial cognitive effort, hence is ill suited to continual repeated application. While FCR is not necessarily a challenge to the fundamentals of two minds thinking, the behavior that we have evidenced does not readily match either. It appears conscious and engaged with complex scenarios, but there is not necessarily identification of a '*gap*' situation, nor is there inherent discarding or formation of new models. UI designs based solely on a two minds theory have to choose between two extremes, thereby offering no clear guidelines for frequent engagement that retains critical and hypothetical thinking. The inclusion of FCR could allow for such a state. While earlier work (Varga and Hamburger, 2014) appears relevant, we are not aware of deliberate integration into current diabetes UI design. Such an extension could help to provide a useful framework to analyze increasingly adopted tools such as CGM's and help suggest new designs. FCR does not invalidate the other modes, and we observed no cases where participants displayed FCR without displaying the other modes as well. FCR could be viewed as a workaround, to conserve cognitive resources, using models built up through sensemaking and experience. FCR, while not as prevalent as *habitual* and *sensemaking*, was found to be common among all demographics within our survey population. These conclusions suggest that all three modes are important tools for diabetes self-management, and greater care should be taken that UIs for supporting self-management support these different modes within appropriate contexts.

As there is a significant body of research supporting dual-process theories, it would be premature to challenge the perceived wisdom. However, there are more modest ways of viewing FCR mode as a useful cognitive workaround or adaption that allows individuals to accomplish domain specific requirements within the limitations of dual-process thinking. This chapter has presented evidence that users appear to have found a way to integrate essential aspect of two recognized cognitive

modes in order to interact with complex and hard to calculate data streams. This appears to allow them to weigh and make predictions on likely outcomes, and use those insights to make vital decisions, all in a fluid and frequent manner. This suggests that support of such mental processes through medical UIs merits further exploration.

Continuing with this consideration on the practical application of this expanded framework, it is worth re-emphasizing that the FCR mode appears to be associated with the use of an already existing ubiquitous computing technology, the continual glucose monitor. As discussed in section 6.2.7, the user interface of the continual glucose monitor offers an intuitive and easy to apply feature, an arrow representing direction and rate of change of blood glucose. One can imagine that it might be useful for an interface to remind the user of previous exercise, relevant sleep patterns, the impact of specific locations. However, just as the data collected by the CGM extended the capability of the more traditional blood glucose monitor, likewise these other context aware functionalities are likely to also largely rely on the sort of consistent and accurate data best delivered by automation (Donsa et al., 2015). However, such an approach would be dependent on the user's willingness to adopt and maintain required sensors and devices. At the time of this thesis, such diabetes decision-support systems are not yet available. Therefore, we lack knowledge on both the viability of this approach as well as how to design such systems in a user-respecting manner. Therefore, to help lay a user-centered foundation for the development of such systems, the following chapter probes user concerns on monitoring and data aggregation by outfitting people with diabetes with a simulated diabetes lifestyle monitoring system.

Chapter 7: User Concerns for Multi-Device Diabetes Monitoring

While previous chapters have considered the design deficiencies of existing diabetes logging apps, this chapter seeks to contribute to a user-centered approach for a next generation diabetes management system that continually tracks and aggregates sensor data to offer personalized support. This chapter discusses the results of a 4-week technology probe in which participants were outfitted with multiple networked devices in order to learn more about user perceptions of such monitoring, and thereby glean insights into user-centered requirements of this approach. Through detailed analysis of interview responses both before and after the study period, this chapter reports on user concerns related to sharing of different kinds of personal medical and behavioral data with different stakeholders, potential software solutions that might help to better support these preferences, and finally emergent questions for designers of such next generation systems.

7.1 Introduction

The previous chapters have reviewed common limitations of diabetes smartphone apps and suggested that increased use of sensor technologies could reduce barriers to adoption and improve the quality of acquired data, which could open new opportunities for diabetes support such as improved glucose prediction (Donsa et al., 2015), classification of the impact of specific behaviors on health (Doryab et al., 2015), or association of GPS location with glycemic variability (Doherty et al., 2015). As discussed earlier in section 2.3.2, the continual glucose monitor (CGM) already offers an existing example of such a next generation device, replacing the workload and discomfort of finger stick blood glucose tests with a periodically inserted sensor that not only delivers at a glance past and current glycemic state, but also uses the collected data to offer an arrow to inform the user on direction and rate of glycemic change. However, current generation CGM's are primarily devices for just one aspect of diabetes management, blood glucose levels. While they do allow additional lifestyle and other data to be manually recorded, they are currently limited in their ability to integrate and correlate other relevant automated data streams such as behavioral indicators (Rodbard, 2016).

While there is substantial interest in implementing more complex sensor-based decision support systems, there are substantial barriers to implementation not only in complexity of diabetes treatment, meeting regulatory standards, and sensor accuracy, but also with user engagement (Doryab et al., 2015). Even though such sensors reduce the burden of manual data collection, the need to continuously wear or maintain these consumer devices could be perceived as burdensome (Harrison et al., 2015) or could pose risks to user privacy (Pejovic and Musolesi, 2014). Such psycho-social impacts could potentially discomfort the user or potentially lead to device rejection which would limit data quality and thereby impair system efficacy. While potential workarounds using personalized advice from a professional or aggregated data from other users might assist with

onboarding users (Pejovic and Musolesi, 2014), such systems might need a substantial training period before acquiring enough data to become capable of delivering perceived value to the user. Therefore, a willingness to maintain use of such devices for a period of time with only limited benefits could be essential for the success of such systems.

Despite public acceptance of wearables and wide-spread adoption of sensor-laden smartphones, due to the lack of actual implementations there remain gaps in knowledge about user concerns with such diverse monitoring within the chronic disease management context. There is also a pressing need to develop practical, ethical, and low-cost ways to test systems, as well as further knowledge needed in improving adoption of wearables in general (Clawson et al., 2015) and increasing user motivation (Lazar et al., 2015). Therefore, further research is required to determine not only how to technically develop such systems, but also the qualitative and psycho-social implications of implementation. This study sets out to meet such needs through a user-centered, low-risk, and economical approach that probe user concerns, experiences, and thoughts for future support systems.

7.2 Methods

This chapter describes the results of technology probe approach (Hutchinson et al., 2003) applied to learn more about user requirements in real-world settings. Among the primary questions addressed were:

- *What are user concerns with sharing of different sorts of personal data of multiple device monitoring systems, and how large is the impact of who it is being shared with?*
- *How might these concerns alter after awareness of being externally monitored and exposure to relevant devices?*
- *What are potential solutions to addressing emergent user concerns?*
- *What are key questions for designers of such systems to address?*

To answer these questions, this study first asked participants about their opinions on different sorts of data sharing, then equipped them with multiple tracking devices which allowed constant external monitoring. At the end of the 30 day study period they were asked again about their opinions about data sharing and their experiences with the devices, to see how such opinions change with exposure and knowledge of external monitoring, which could be relevant for an actual system's onboarding process (the study form and full list of questions are available in Appendix B: Chapter 7 Wearables Study Form). The Open University's internet-based data aggregator (Packrat) used manufacturer provided APIs to collect personal user data from a commercial smartphone tracking app, step counter, and in-bed sleep monitors (see Figure 7-1 Probe Architecture). As real-time CGM data was not available for the majority of devices used by participants, this data was gathered retrospectively. This system thereby prototyped the data gathering architecture of a diabetes decision support system, engaging participants with multiple devices and awareness of external monitoring. The study details were as follows:

- *Pre-study questions* sought to establish participant sentiment, attitudes, and experiences with diabetes management, tracking devices, and data sharing in a variety of contexts and with different stakeholders.
- *Post-study questions* repeated the pre-study questions to investigate changes in attitude, as well as questions related to study experiences and perceptions on included devices.

Data Processing: All participant interviews were fully transcribed and aggregated in an Excel spreadsheet. In addition, all responses were imported into Nvivo and then classified by device, stakeholder, data type, and sentiment (positive or open, neutral or mixed, negative or closed) to aid with integrating results and to support thematic analysis. The qualitative time-series visualizations were created in a desktop publishing program (Adobe InDesign) to aid with understanding trends. Due to the small sample size, statistical significance of responses is limited. The emphasis is therefore placed on conveying a spectrum of user concerns in order to establish a foundation for consideration and discussion when developing future systems. These procedures will be discussed in more detail in the following sections.

7.2.1 Devices and Architecture

Devices were chosen for their ability to automate the collection of potentially relevant data, ease of use, off the shelf availability, and existing public API. Table 7-1 Study Devices

 outlines the study devices chosen and their attributes, which is followed by Figure 7-1 Probe Architecture**Error! Reference source not found.** which illustrates the system architecture.

Device	Sensor	Placement	Benefits	Drawbacks	API Output
Jawbone UP	Accelerometer	-Wrist -Waist	-Low cost -Battery life	-Appearance -Limited data output	-Daily step count
Beddit in-bed sleep monitor	Pressure	-In bed	-Detailed data -Plugs in/no batteries	-Invasive of private space/habits -Recording must be initiated and terminated each session	-Hours slept -Respiration -Pulse -Time awake
Moves App	In-phone sensors	-Smartphone	-Behavior Tracking -Phone already adopted	-On private phone -Battery drain -Invasive	-Location -Activity
Abbot Libre (Flash Glucose Monitor)	Blood Glucose	Back of Arm	-Convenient tracking of BG -no calibration needed	-Sometimes inaccurate -No calibration possible	-Data downloaded from device
Dexcom Medtronic (Continual Glucose Monitor)	Blood Glucose	Abdomen	-Accuracy	-Frequent calibration required -Sometimes inaccurate	-Data downloaded from device

TABLE 7-1 STUDY DEVICES
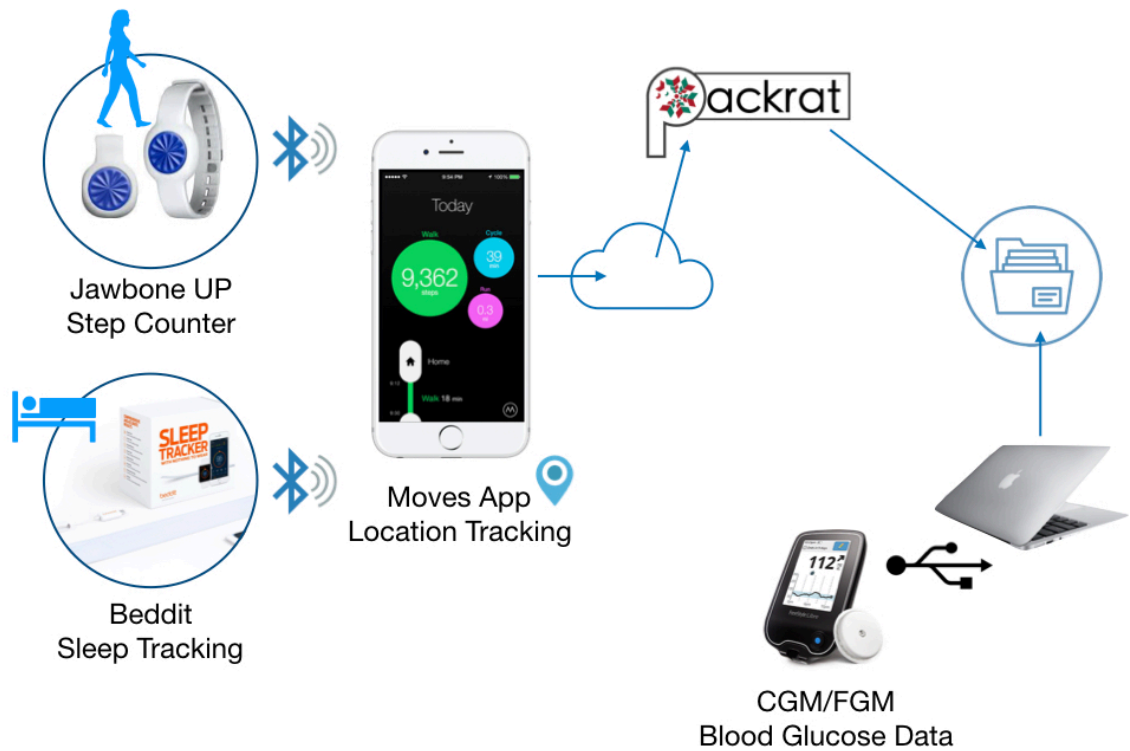
FIGURE 7-1 PROBE ARCHITECTURE

7.2.2 Pre-study procedure

The study was limited to adults currently undergoing treatment for T1 diabetes, residing in Berlin, and current users of continual glucose monitoring. Potential participants were sent an information sheet via email with an overview of the study and consent form. If participants were willing to take part in the study, an appointment was then made for the researcher to meet the participant in the location of their choosing. It was suggested by the researcher that this visit be in-home in order to set up the sleep monitor, but participants could choose any other location if they so desired. Only one participant preferred to have the appointment at their place of work, the remaining chose a home visit. All participants were familiar to the researcher, having previously taken part in studies or diabetes related co-design workshops, which led to an engaged and technically adept group. No compensation was offered, other than the option to keep the fitness tracker and access to any insights discovered in the study. Study approval was granted by The Open University Human Research Ethics Committee.

7.2.3 Study protocol

At the initial meeting, participants were asked to complete a consent form at which time they were assigned a participant ID number. This was then followed by a brief survey on basic demographics and previous use of technology. The researcher then read out loud an introduction statement to clarify the terms of the study and emphasizing that the study would offer no advice or suggestions about diabetes management, and that all participants should consult with their physician before making alterations in therapy. It was also emphasized that participation was entirely voluntary, and they were at liberty to stop using any device or app for any reason at any time. Following this

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introduction, there was a semi-structured interview on the participant's opinions regarding monitoring and sharing of various kinds of personal data with different stakeholders. After the intake interview was completed, the Beddit app, Jawbone UP app, and Moves app were downloaded from the Apple App store or Google Play store, installed on the participant's smartphone and then registered using an anonymized Gmail account. The apps were then paired with the Open University Packrat data aggregator, participants were issued the requisite devices, and finally the participant's CGM was checked to make sure that the date and time were correct. This onboarding process took approximately 1 hour per participant, including interview, app installation, and registering devices with the Packrat data aggregator, this workflow can be seen in Figure 7-2 Study Protocol.

Recruitment through social media, snowball, and previous research contacts.

↓

Potential participants are provided with study information by email.

↓

After at least 48 Hours potential participants are contacted again and asked about desire to participate.

↓

Patient given paper copy of information sheet, completes Consent form, and assigned participant ID, and completes intake survey. Researcher reads out introduction form, which if followed by the semi-structured intake interview. Beddit, Jawbone UP move, Moves app are then installed on participant's phone, and registered anonymously. Users are then signed up on Packrat and devices then registered on Packrat. Finally, the user's CGM is checked for accurate time and date.

↓

4 weeks of activity data collected → Researcher interacts with participant if technical issues arise

↓

Patient returns the Beddit, exports CGM data for study period, and completes the recorded exit interview. At this time if desired Apps can be de-installed from smartphone, and data sharing with Packrat will be disabled.

FIGURE 7-2 STUDY PROTOCOL

7.2.4 Study participants

Participant gender was 4 Female and 4 Male. Mean age was 35.6 (SD 9.4) years, with a mean time since diagnosis of 16.75 (SD 14.2) years. The following table shows demographic information for the participants:

P #	Gen.	YOB	Diag.	Occupation	Insulin	BG	A1C	Past Tracking	Knowledge/Experience
1	F	1980_	2007	Graphic Designer	MDI	Libre	7.7	Google Fit	Diabetes App Design
2	F	1991	2009	Fundraiser/Marketer	Pump	Libre	6.8	Runtastic	Diabetes Startup
3	M	1987	2006	Engineer/Founder	MDI	Libre	7.2	Google Fit Mi fitness band	Diabetes Device Startup
4	M	1985	2014	Software Engineer	MDI	Libre	6.8	Runtastic	Software Engineer
5	F	1988	2002	Marketing Analyst	Pump	Medtronic	6.6	-	Pregnancy
6	F	1965	1968	Educator	Loop	Libre	7.2	Step Counter	DIY Closed loop
7	M	1972	1995	Medical Sales	Pump	Dexcom 4	5.9	Gamin system	Ultra-Athlete/Diabetes device sales
8	M	1991	2008	Designer	Pump	Libre	7.0	Apple Watch Echo watch Mi Band	Diabetes Device Startup
MDI = multiple dose injection, Pump = insulin pump, Loop = Hybrid closed loop, A1c below 7.0% is recommended goal									

TABLE 7-2 STUDY PARTICIPANTS

During the study period, 5 participants were using insulin pumps, 3 used insulin pens, all participants were adopters of continual blood glucose monitoring, with 6 participants using the Abbot Libre, 1 using Dexcom G5, and 1 using the Medtronic sensor. The group as a whole were in good control of their diabetes with a self-reported mean A1c of 6.9 (SD=.5) with all participants near or below the recommend A1c of 7.0% (see 2.2). The majority (7/8) had previous experience with some sort of exercise tracking, using consumer apps and products such as Runtastic, step monitors, or apple fit. All participants were diabetes technology literate and had been recruited through their active participation in the diabetes activist community. The majority of participants (5/8) had previous experience in diabetes related work such as consulting for pharma or were actively involved in diabetes related startups. Of the remaining participants, one had recently built a DIY closed loop system, another was highly engaged in her first pregnancy, while the last was a PhD mathematician and full-time software engineer. As such this group could be considered an early adopter community and thus not broadly representative.

7.2.5 Data visualization

Interpreting the resulting qualitative data placed certain challenges, especially regarding the time series aspect of change in attitude over time (before and after study). The small sample size restricted the use of statistical methods. An initial attempt to color code this qualitative data with a numeric (-2 to 2) or color spectrum (green to red indicating openness to sharing data) failed to

communicate sufficient group detail or trends. Such translation also lost the subtleties of user reasoning and lost the many dimension captured by qualitative data. After much experimentation, I chose the following method, which resulted, with further modification, from an after-dinner conversation with research clinicians and computer scientists. While I am not aware of previous use of exactly this method, it is entirely possible that it exists within the HCI or other literatures. As such I can make no claims of novelty, only that it appears effective within the requirements of this use case. The process was as follows:

- Interviews were transcribed and entered into an excel spreadsheet, organized with 1 row per participants and each question in a separate column.

- Each participant response was categorized according to general sentiment. The quote was reduced to a short representative excerpt, which was done to allow placing within the graph while maintaining readability. While with a larger format the full text could have been included, this reduction has the benefit of being easier to read. As this process is interpretive and reduces information, ideally this would be repeated by additional researchers for comparison. The following two examples demonstrate my reasoning process for reducing quotes, with the bold type showing the excerpt included in the graph:

    P2 on willingness to share GPS data with doctor stated: *"I would be all right with that if I knew what they were using if for. For example, **in a quarterly session when we look at it together and analyze together, I'd be fine with it**. If the doctor is really just analyzing it with my diabetes."* While the first sentence could have been selected, I chose the second sentence as it gave a specific example of an acceptable use. The third sentence was not selected, as it primarily clarifies the previous sentence. I classified this quote as between "neutral" and "open" as P2 was willing to share but wished to maintain control over how and when such sharing occurred. The sentiment is consistent throughout the quote, so while a different excerpt could have been chosen, all would have been presented on a similar place on the graph.

P5 on willingness to share GPS data with insurer stated: *"I think I wouldn't like them to have access to my location and to my exercise pattern again. **This feels again a bit too personal for me** and doesn't make sense. Where I am, exercise, what I do and CGM, how am I doing at the moment is really a lot of information about me. All in all, it feels like somebody's got full control."* In this case I chose the excerpt where the participant notes how the data feels too personal, as this both clarifies the sentiment of the first sentence while still expressing unwillingness to share. While the following sentence adds more detail, it is longer so is ill-suited to the space limitations. The final sentence on loss of control is an important detail, though I chose not to select it as it could be harder to understand on its own. Once again as the sentiment is similar throughout, alternate selections would not have altered the graph. I classified the sentiment as private, though less so than those who flatly rejected any sharing with this their insurer, such as P2 who stated *"No way at all."*

- A graph is constructed with the time series aspect along the x-axis. As there are were only two time points within this data, there are only two segments, 'before study' and 'after study'. This system could therefore be used to visualize qualitative data over a more extended study period by adding more segments.

- The y-axis of the graph is labelled with an ordinal scale representing participant sentiment. For example, from 'Highly private' to 'Highly open'.

- Each participant quote is placed into a text box, and the text box is situated on the appropriate position on the axes. Participant number remains paired with the quote, and each participant has consistent color-coding to assist with interpretation.

- Each participant's text boxes along the x-axis are linked.

- As the excerpting loses much of the context and richness of the participant responses, after each graph there is a discussion of the responses that uses the full quotes.

At the end of this section after the analysis of the qualitative data, there will follow a reflection on the benefits of this method of data presentation.

7.3 Results

The following sections will be structured as follows:

Section	Sub-sections
User Concerns	- Views on diabetes management - CGM data and device - Exercise data and device - Sleep data and monitoring device - Summary of findings by stakeholder
Technologies for Unmet User Needs	- Real-time data flow controller - Real-time data purpose visualizer - Data blurring - Tailored reports
Questions for Developers of Future Systems	- Added workload and adoption - Emotional impacts monitoring - Unwanted or distressing information - Stigma - Differing relationships of trust with stakeholders - Trust - Personal preferences - Transparency - Privacy - Economic Security/Vulnerability

TABLE 7-3 STRUCTURE OF THE RESULTS

7.3.1 Interviews: User concerns

This section presents and then discusses the interview sessions. The included figures show the range and attitude of responses, both before and after the 4 week study period. Participants were asked questions both before and after the study period as to:

- Current satisfaction and challenges with diabetes management.

- Self-observed changes during study.

- Their attitudes towards sharing various personal data: in a general sense, with doctors, with insurers.

- Experiences with each of the devices.

Each of these topics will be discussed in turn, first with the question asked, then with a discussion of changes in attitude resulting from the study.

7.3.2 Views on diabetes management

This first set interview questions related to current satisfaction with diabetes management and existing challenges. These questions were asked to establish whether participants had unmet needs, to what extent the potential capabilities of an automated diabetes decision support system might be of use, and how the study might have influenced these attitudes.

7.3.2.1 Q: How satisfied are you with your diabetes management?

As this question sought to gain insights into general satisfaction, this graph represents these responses with increased satisfaction represented by elevation along the y-axis.
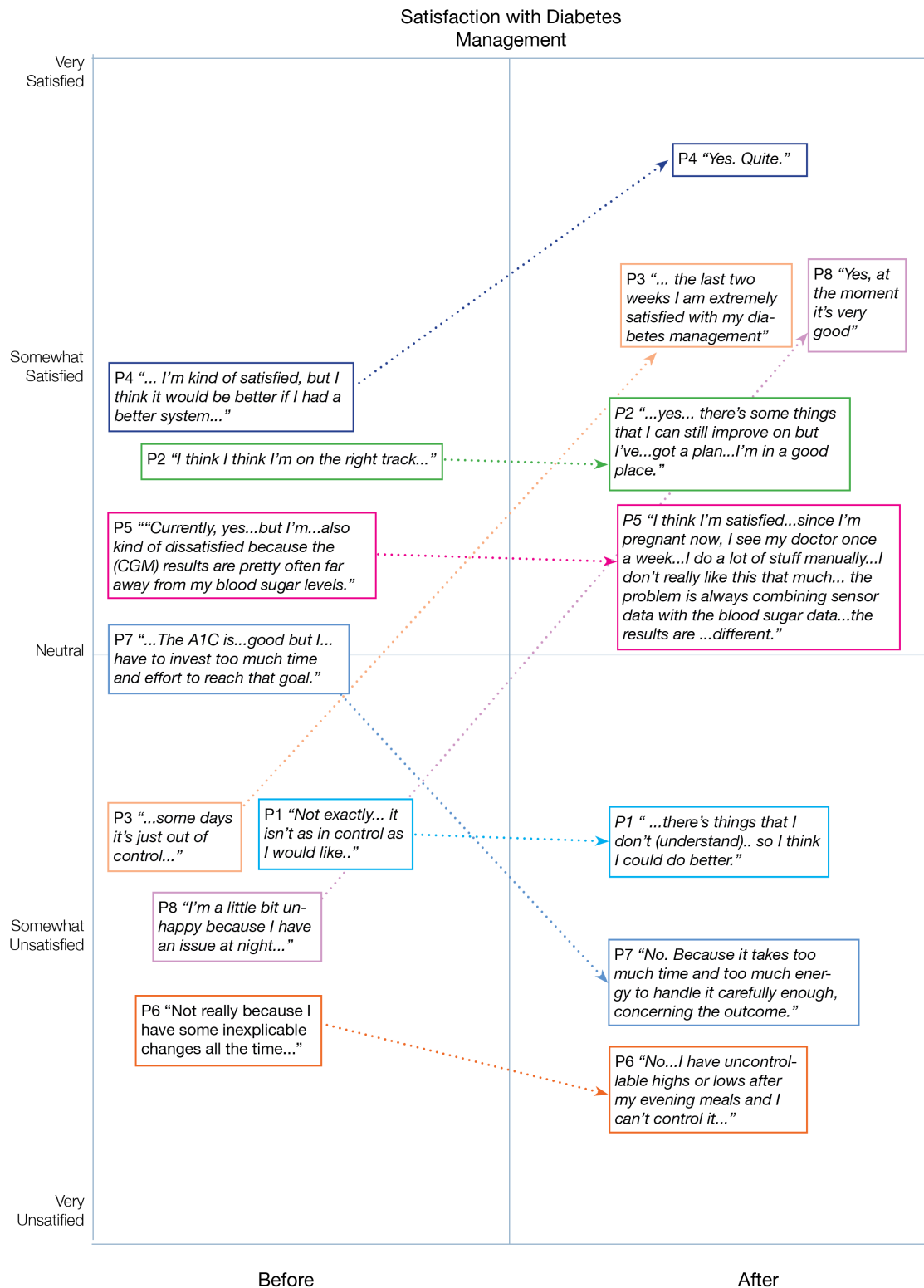
FIGURE 7-3 SATISFACTION WITH DIABETES MANAGEMENT

While the majority of participants reported blood glucose levels either below or near goal standards (see Figure 7-3 Satisfaction with Diabetes Management), all stated that they had some aspect of their diabetes management they would like to improve. The figure shows two primary groupings. The more contented group expressed being satisfied, though all conditioned this response with the desire for further improvement. P2 for example hoped that improved access to technology would increase her control, *"...I'm looking to get the full CGM covered and then I can really make use of all the features of my pump. Apart from that I am quite happy. I've got a good team and good motivation..."* P7 who reported the best A1c (5.9) of the group was somewhat dissatisfied, noting, *"The A1c is quite good but...I have to invest too much time and effort to reach that goal. I wish more automation."* The second 'somewhat unsatisfied' grouping all expressed specific challenges in their daily management. P8 said *"I'm a little bit unhappy because I have an issue at night, that I don't really...know what's going on there...sometimes I'm super stable at night, sometimes, I have a peak, so the sugar goes to 300, and I have no idea what this caused. Yes, and work, it's changing every day. So, new things appear, and new things happen."* And P3 *"...some days it just does what it wants to do that doesn't matter how much I try to get it under control...But some days it's just out of control."* Post-study, while four participant's (P:1,2,5,6) responses were consistent with the first interview, there were some changes. Figure 7-3 suggests the general distribution remains similar, with P4 a minor outlier. Of those experiencing the greatest change in a positive direction, P3 noted having changed to a different insulin, and modified his diet, noting *"the last two weeks I am extremely satisfied with my diabetes management."* P8 reported solving night time problems through the use of new technology, noting he *"...converted the Libre into a CGM to have the data on my wrist. It's...annoying to keep the battery life on and to charge the watch...but by this I automatically deal more with my disease and that helps...I'm not wearing the watch every day...I'm trying to calm down a little bit regarding this real-time data thing."* P7 reported the greatest negative trend in attitude, becoming overburdened as *"...it takes too much time and too much energy to handle it carefully enough..."* Taken as a group, the distribution remains similar though there appears to be some variation over time as participants either solved or became overwhelmed by existing challenges. Given the small sample size, it is difficult to determine an obvious trend.

7.3.2.2 Q: What are your greatest challenges in diabetes management?

P	Challenge (Pre-Study)	Category	Challenge (Post-Study)	Category
P1	*Calculating what I'm eating...*	Cognitive	*... what I eat because I'm constantly eating and sometimes I don't have the patience to wait...until my insulin reacts*	Behavioral
P2	*Keeping up my motivation...and...using the data that I gather automatically.*	Affective Cognitive	*Keeping up my motivation...even if you do the same thing every day exactly it doesn't mean that you get the same results...*	Affective Cognitive
P3	*sometimes things don't make sense...*	Cognitive	*The unexplained stuff...*	Cognitive
P4	*...low sugar in the night...headaches the next day...*	Cognitive	*...keep(ing) a steady profile. Not to have too many jumps up or jumps down...especially...in the night.*	Cognitive
P5	*I think the greatest challenge is...psychological.*	Affective	*It's managing constant changes in my insulin doses...during pregnancy.*	Cognitive
P6	*...I just want to get it a little bit better, to go from 7.2 to maybe 6 HbA1c.*	Cognitive	*...getting my values and analyzing them in the right way.*	Technical Cognitive
P7	*(after a marathon)...staying in a good range is not that easy....*	Behavioral Cognitive	*Always keeping in mind the most important facts as activity, insulin, carbohydrates and the factor x, which is the unknown thing.*	Cognitive
P8	*At the moment, it's keeping enough insulin in the fridge...*	Behavioral	*...the motivation. Like in times where you have personal issues or in your career or, yes, with your family then this is on top.*	Motivation

TABLE 7-4 CHALLENGES IN DIABETES MANAGEMENT

This question set out to gather information into each participant's challenges in diabetes management, responses are listed in Table 7-4 Challenges in Diabetes Management. These have been classified according to attitude (Krönung and Eckhardt, 2011), with the addition of a category for technical functionality (this classification structure will be discussed further in the following chapter). Cognitive challenges appear most common, with 12/16 responses noting difficulties in interpreting data in order to optimize treatment, though often in these cases this leads to other challenges. P1 notes primarily a cognitive challenge in *"Calculating what I'm eating especially because I think I'm eating all the time even though I'm not."* P5 described initial emotional challenges of management and how this impacts behaviors, *"...diabetes... a lot of stress and fear that I won't manage to do something, which might stop me from actually doing something..."* And P3 notes the difficulties in understanding relationships between factors and how this impacts physical and emotional state, *"sometimes things don't make sense...it just skyrockets and then you try to correct and then it doesn't work, and you have to inject loads of insulin to get it down again and then it starts kind of a roller coaster...it's really it's really exhausting."* And P2 also referenced all three categories, *"Keeping up my motivation...using the data that I gather automatically...gathering more data because I'm really, really bad at logging stuff."* These factors continued to be related by participants after the study. P5 who was pregnant, noted that *"It's managing constant changes in my insulin doses...I will be starting the third trimester soon, and I*

really need much more insulin than I did before being pregnant." P7 drew attention to the general cognitive challenge of diabetes "*Always keeping in mind the most important facts as activity, insulin, carbohydrates and the factor x, which is the unknown thing. Because...it's changing every day.*" P8 noted "*...motivation. Like in times where you have personal issues or in your career or, yes, with your family ...*" Overall, these quotes suggest that participant's challenges in diabetes management are ongoing, not easily solved, and often combine multiple inter-related challenges, such that a failure in glycemic control can impact the other factors. These statements emphasize the continuing cognitive, emotional, and behavioral challenges of T1 diabetes management even for those with access to available technologies, and that many seek further assistance. Many of these statements suggest that systems capable of alleviating cognitive workload are desired, though care must be taken that they do not in other ways increase burdens nor add to emotional stresses. This emphasizes the importance of understanding user concerns and preferences, so that such systems will integrate into daily life. In all these cases, understanding and making decisions informed by personal data plays an essential part of the management process.

7.3.3 CGM data and device

The following sections review participants' responses to question related to sharing of their CGM data: in a general sense, with their doctor, and then with their insurance provider. This is followed by a discussion of user's reflections on the use the continual glucose monitors during the study period.

7.3.3.1 Q: How do you feel about sharing your CGM/blood glucose data generally?

Sharing CGM Data: General

P2 *I think I feel a bit better about that because...with glucose data and diabetes I would benefit more directly from it and not only for the profit of others.*

P3 *I don't mind.*

P2 *that's fine.*

P8 *at the moment the values are good, so I'm (more) likely to share...*

P7 *I don't mind sharing data as long as I know that it's kept safe.*

P8 *I share it with close friends or family.*

P7 *It depends on who is receiving the data and for what reason*

P4 *...I would say one to one is fine if I know the person, but I wouldn't share it just with anyone.*

P5 *Not to the open audience but for the people that I trust, or I think it makes sense.*

P5 *I wouldn't like to share them on social media...*

P3 *Only with my medical team.*

P1 *(it depends) because I feel I'm not in control...*

P1 *if it's OK I have nothing to worry about. But if it is doing really bad...*

P6 *I put them in the Nightscout server, which is rather open with their data, but I don't like that...*

P6 *For a diabetic, they live through their data, so I think it's private.*

P4 *Definitely not, also not with my friends...I think it's something very private.*

Before   After

FIGURE 7-4 SHARING CGM DATA: GENERAL

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This question (see Figure 7-4 Sharing CGM Data: General) probing attitude towards non-specific sharing of BG data brought a spectrum of initial responses, ranging from open to very private. P3 for example stated, *"I don't mind"*, and P2 was willing to share such data as *"...I want to help science improve life with this condition, so I immediately see the benefits."* Others were less willing to share data such as P6 who said that while willing to share with her doctor and friends, and accepted non-secure apps, she *"...would prefer to keep them really private...I am my data. If you see my data, you know exactly how I was, what I did, if I felt well or bad. It's a very private thing. It tells a lot about me and my lifestyle and how my day was. For a diabetic, they live through their data..."* And P4 felt a need to keep such data secure, *"Definitely not, also not with my friends...I think it's something very private."* While 5/8 participant's responses remained consistent before and after the study, there could be a slight trend towards more neutral responses for those who had originally given more extreme answers (P3, P4, P7), while those who stayed consistent might have become slightly more open to sharing this data. P4 demonstrated the largest change in attitude, no longer considering this data to no longer be completely private noting,*" ...I would say one to one is fine if I know the person, but I wouldn't share it just with anyone..."* In contrast P3 went from being unconcerned with this data, to now stated, *"Only with my medical team."*

7.3.3.2 Q: How do you feel about sharing your CGM/blood glucose data with your doctor?

The next questions asked participants about their willingness to share data with their physician to explore how the confidentiality offered by the physician/patient relationship affected their sense of privacy and vulnerability.
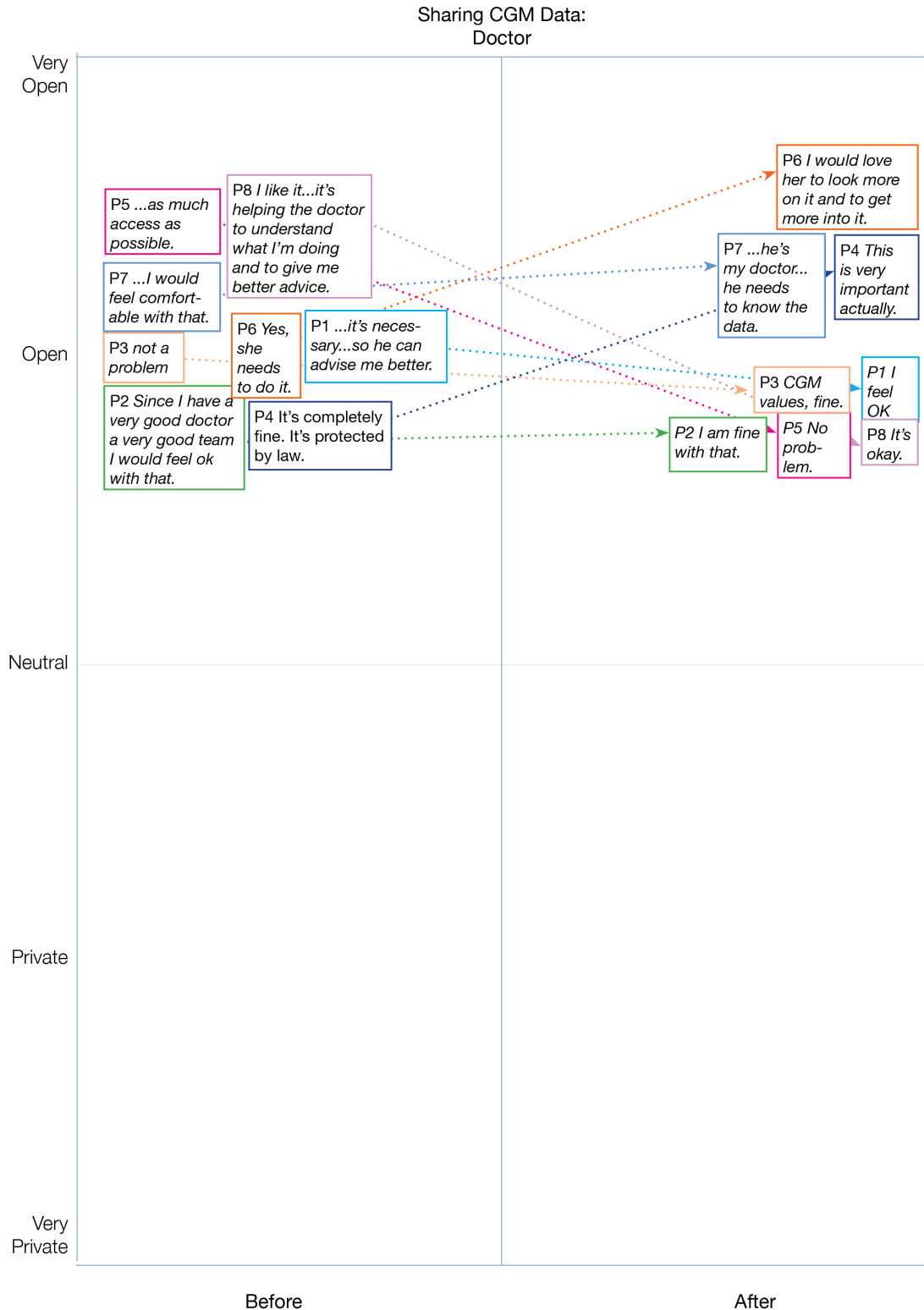
FIGURE 7-5 SHARING CGM DATA: WITH DOCTOR

In contrast to the previous graph, in Figure 7-5 Sharing CGM Data: With Doctor there appears to be a consistent clustering of responses indicating a high willingness to share and trust clinicians. All participants reported that they were comfortable with their doctor having access to their CGM data. P5 was representative stating, *"I think he has to have as much access as possible."* Or P8 who explained, *"...the doctor can help me better understand what I'm doing, because so many things belong to the disease."* However, P2 elaborated that desire to engage in such sharing was contingent on personal trust and relationships, *"Since I have a very good doctor, a very good team I would feel ok with that. I would see the benefits. I'm already in touch with my diabetes nurse through WhatsApp. So sometimes I snap a photo off of my graph to tell her how things are...although I've also seen doctors with whom I would not feel comfortable sharing all this data... I didn't feel that they had my best interests in mind."* And P4 noted that the confidentiality of this data was legally protected, and hence posed no risk to privacy. While there was some varying of placement of responses, this could be due to brevity or ambiguousness of answers.

7.3.3.3 Q: How do you feel about sharing your CGM/blood glucose data with your insurance provider?

Sharing CGM Data: Insurer

Very Open

Open
- P1 *I don't have a problem with that*
- P3 *not a problem*
- P5 *I wouldn't mind.*
- P3 *I guess that's okay.*

Neutral
- P8 *I have to send it to them, to get the cost covered.*
- P1 *Depending on how it's going to affect the coverage*

Private
- P7 *...I would think about it. But first, I would say no.*
- P8 *why does my health insurance need that...?*
- P5 *I don't trust them. I would have to understand why they can access it.*
- P6 *I don't trust them.*
- P4 *I don't want them to have this data.*
- P7 *they don't need to know that... because they don't understand diabetes.*
- P2 *Not good at all*
- P4 *No way.*
- P2 *I wouldn't want them to have access to them anytime.*
- P6 *I hate it. I like my anonymity, especially with my insurance.*

Very Private

Before   After

FIGURE 7-6 SHARING CGM DATA: WITH INSURER

Initial responses (see Figure 7-6 Sharing CGM DATA: With Insurer) were similar to the general sharing question, though distinctly less positive in comparison to sharing CGM data with clinicians. There was a cluster of 3 participants who reported being unconcerned about such

sharing at the initial session. P3 for example noted that *"This is not a problem.",* and P8 noted having to send the data for coverage. P7 was reserved, but expressed willingness with adequate transparency, *"If someone would explain and I would understand, I would think about it. But first, I would say no."* However, others such as P2 were hesitant, explaining *"...in contrast to my doctors, I am pretty sure that they don't have my best interests in mind...I think they're looking to just maximize their profits and they could use my data accordingly and they could punish me for unhealthy behavior or whatever they deem unhealthy."* And P6 feared the economic pressure stemming from health data, *"I would not like it because I don't trust them for the future... I think data will be capitalized in some way or another..."* The graph (Figure 7-6) suggests a trend towards considering CGM data more private, with those who had been more open re-considering, and those who were already hesitant becoming resolute. P1 for example became more cautious, shifting from being unconcerned to noting *"Depending on how it's going to effect the coverage."* And P5 became more suspicious, moving from *"I wouldn't mind."* to a more cautious *"...maybe they would try to sell me something and take advantage of the information that they get...Maybe they would somehow also be judgmental and limit my rights when I do something wrong...I don't trust them. I would have to understand why they can access it."* At the later stage, all but P3 express some level of hesitancy or discomfort with sharing this data with insurance providers. This would seem to suggest that increased awareness of external monitoring has increased a sense of potential vulnerability from CGM data concerning this stakeholder.

7.3.3.4 General participant reflections on CGM usage

All participants were already habitual users of CGM technologies, and as most reported no change in their relationship to this device. As P7 explained, *"... (I have) had the CGM since 2011, so this is always the same."* And P3 shared his habituation as *"...Not only do I love (Libre), I can't be without it...if a sensor fails or if I'm between sensors, that's a major source of stress."* Only P1 noted that being part of the study changed her perception of CGM use, *"...sometimes, when I did really bad...oh they are going to see it... I felt...more conscious of it..."* Though P1 did not see this necessarily as negative, noting *"I think it is a motivation for me, because I think I need to do a bit better because some people are going to see it."* However, P1questioned whether this would be beneficial over the long term, *"...at the same time I don't know if that should be the motivation. It should come from myself... you can try to please people, but for how long can you please people."* More generally, data collection and observation connected with the study did not appear to change participant's relationship with their CGM usage, although external tracking of CGM data might increase stress among some users.

7.3.4 Exercise data and monitoring device

The following sections review participants' responses to question related to sharing of their exercise data: in a general sense, with their doctor, and then with their insurance provider. This is followed by a discussion of user's reflections on the use the exercise tracker during the study period.

Sharing Exercise Data:
General

Very Open

P4 *This helps because it's ... motivation for you if your friends see when you're exercising.*

P4 *...not a problem. I even share it over this Runtastic with my friends.*

Open

P6 *I exercise...I walk the dog. No problem.*

P1 *I don't have a problem sharing.*

P3 *that is not a problem.*

P3 *That is not a problem.*

P7 *No, I don't mind...*

P8 *....not a big issue... I, personally, can't see what other people should do with it. Maybe because I don't have an overview...what's possible with this data.*

P2 *Since I don't exercise all that much it would be OK...*

P8 *I don't really care about that data...except the health insurance (company).*

P1 *...I don't care too much...maybe if I didn't do any exercise, then I would feel self-conscious.*

P7 *If I were to have a coach, I would share the data...or with friends, just to challenge each other, but I wouldn't like my insurance to know about my data.*

P5 *It depends on the purpose (ok for research) but not social media.*

Neutral

P6 *maybe for my best*

P2 *Since I don't really exercise that much it is fine...(though) it is also private. Because it (is)... for my health.*

P5 *Not to the open audience but for the people that I trust, or (if) I think it makes sense*

Private

Very Private

Before   After

FIGURE 7-7 SHARING EXERCISE DATA: GENERAL

In *Figure 7-7 Sharing Exercise data: General* at the beginning of the study participants were either open to sharing this data, or at least open with certain limitations on sharing. P1 said, "*I don't have*

a problem sharing." P4 had a similar response, *"It's also not a problem. I even share it over Runtastic with my friends."* P7 was open to sharing, but wanted to retain specific controls, *"If I were to have a coach, I would share the data, or I would share the data with friends, just to challenge each other, but I wouldn't like my insurance to know about my data."* P2 noted additional concerns as such data could contain *"...patterns that show opportunities to manipulate you as a consumer. Although I do see the opportunities for medical research."* P5 who noted being against social media in general, *"It depends on the purpose...but not social media."* Most participants had consistent post study opinions on openly sharing exercise, with slight movement towards this data being considered more private for P2, P5, and P6, who all expressed increased conditions for willingness to share data. P6 explained, *"...I just don't like sharing it at all with some unknown...Like the internet. For me, it's good to know if I exercise or not. I like it for my own purposes and maybe for my best friends... "Ah, she's doing yoga, maybe I can join her." That's a nice thing to do and to know, but not on a bigger level."*

Sharing Exercise Data:
Doctor

P6 *Yes, it's okay because she sees the consequences on my glucose and HbA, ...it's good if she knows.*

P8 *Yes, I would share it.*

P2 *Yes I would be fine with that.*

P7 *I think he needs to have that access... otherwise he cannot understand the whole diabetes thing.*

P4 *Also no problem at all.*

P1 *No I don't have a problem sharing that.*

P3 *No problem.*

P3 *That's fine.*

P8 *Also okay.*

P4 *This would be okay. Yes.*

P5 *Also, no problem.*

P5 *I guess I'm okay with this.*

P1 *right now it is also ok.*

P2 *I wouldn't like it in real time but...regular updates on a monthly basis or something like that.*

P7 *...how active I am, but I wouldn't like to let him know where and when I am active.*

P6 *No, that's private... My doctor should have access to my CGM data... but everything else should be my decision to share it or not...*

Before   After

FIGURE 7-8 SHARING EXERCISE DATA: WITH DOCTOR

In the left side of Figure 7-8, 7/8 participants reported being open to their doctors viewing their exercise data. Most expressed no concern, as P6 explained *"Yes, it's okay because she sees the consequences on my glucose and (A1c), so it's good if she knows."* Only P7 was expressed reservation *"I wouldn't mind let(ting) him know how active I am, but I wouldn't like to let him*

know where and when I am active... I would like to share data with my friends or family, but not with others outside that circle...my doctor is interested in how I handle or manage my diabetes, connected with sports, to find out things or mistakes, I would share that data for that reason.”

After the study two participants reported substantial changes in attitude. P6 became more concerned with uncontrolled sharing, altering from *“it's good if she knows”* to *“No, that’s private too. My doctor should have access to my CGM data because, that’s what she’s there for. But everything else should be my decision to share it or not share it.”* P7 changed in the opposite direction, now seeing direct value in such sharing, *“I think he needs to have that access... otherwise he cannot understand the whole diabetes thing.”* P2 underwent a less dramatic shift narrowing access from, *“I would be fine with that.”* to *“I wouldn’t like it in real time, but they could have regular updates on a monthly basis or something like that.”*

7.3.4.3 Q: How do you feel about sharing your exercise data with your insurer?

Sharing Exercise Data:
Insurer

	Before	After

Very Open

Open

P1 *I don't have a problem with that* ·········· P3 No problem. ·········· P3 That is fine. → P1 *also(ok)*

Neutral

Private

P7 Only if they ...pay me something... ·········· P7 If there's any benefit, or something like that, I could change my mind, but... so I would say no.   P8 I don't know why I should share that

P8 I always need to know why they want to see it. ··········

P5 ...exercise...is really a lot of information about me... it feels like somebody (else) has got ... full control. ·········· P5 No...I would have to understand exactly why they need it.   P6 ...If there's a trade, and if I believe them to stop after the trade is finished. Generally, not.

Very Private

P6 No. That's private...the only reason for them to know...is to... capitalise on it.   P2 It's none of their business.   P4 I would say no data at all.   P4 No... they could monetise it... I don't think it would be a good thing.   *P2 I wouldn't want them to have access... anytime.*

Before   After

FIGURE 7-9 SHARING EXERCISE DATA: INSURER

As can be seen in Figure 7-9, initially 6/8 participants expressed resistance to sharing exercise data with their health insurer. While P1 and P3 were open, considering such sharing to be "*No problem.",* other participants were far less trusting. P7 was more open given the right incentives, *"Only if they...pay me something...I'm very active, so they can see I do something to improve my*

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health." And P8 added similarly *"I think if they asked for it to cover things, I'm more willing. If they just generally collect all that data, I wouldn't. So, I always need to know why they want to see it."* However, others were dismissive of such sharing: P1 *"Also not.";* P2 *"It's none of their business.";* P4 *"I would say no data at all.";* and P6 *"No. That's private because the only reason for them to know it is to have information which to make money."* At the end of the study responses were generally consistent, though P6 noted some additional potential willingness to share data if given the right incentives.

7.3.4.4 General participant reflections on using the Jawbone up for exercise tracking(steps)

This device itself received mixed responses. While some found it non-obtrusive, other participants found fault with its aesthetics, comfort, and issues related to wearability. P1 noted, *"...I sometimes forgot that I was even wearing it. And it was interesting because some people asked me about it. Like some kind of new interaction..."* Others found it irritating as a wristband but adapted. P4 reported, *"I was wearing it next to my watch and it was a little bit disturbing. Then I started to put it into my pocket. It was fine actually."* P5 had a similar concern, with a similar resolution, *"When I wear it on my belt and not as a watch, then completely fine."* However, for P5 this was not related to physical comfort, but rather that it was "*...about aesthetics. I like my watch and it doesn't look good when I have two."* For P2 the device brought unwanted attention, *"...it's a bit annoying because my watch is here, and the band is there, and it just kind of got a little bit annoying that people asked me about it all the time. I'm very used to it, especially in the summer with any diabetes devices, but it's more natural for me to explain those are just part of me and the tracking, maybe I don't identify with it enough."* And while P3 didn't find the device intrusive, he was also disturbed that the tracker didn't give credit for certain exercise, *"It didn't bother me at all. (though) I felt that the fitness tracker was not accurate because it didn't recognize [exercise] I did in the fitness studio to do even though it was very intensive exercise."* And some, such as P7 rejected the tracker, as he experienced skin irritation from the band and found it redundant, *"No, I just stopped, I quit...I already have my own fitness wearing device, so I don't need two of them."* These responses suggest that future multi-device systems should allow users options as to which devices they use and where they are worn to meet personal preferences. Ideally the user could incorporate existing devices when possible. Systems that restrict such choices might create significant barriers to use, especially when devices replicate functionalities of already adopted and preferred devices. This points towards the importance of industry standards and open API's to allow maximum configurations or potentially minimizing number of worn required devices.

7.3.5 GPS data and device (smartphone)

The following sections review participants' responses to question related to sharing of the GPS data which was collected from the Moves App on their personal smartphone. In turn will be discussed: in a general sense, with their doctor, and then with their insurance provider. This is followed by a discussion of user's reflections on GPS monitoring during the study period.
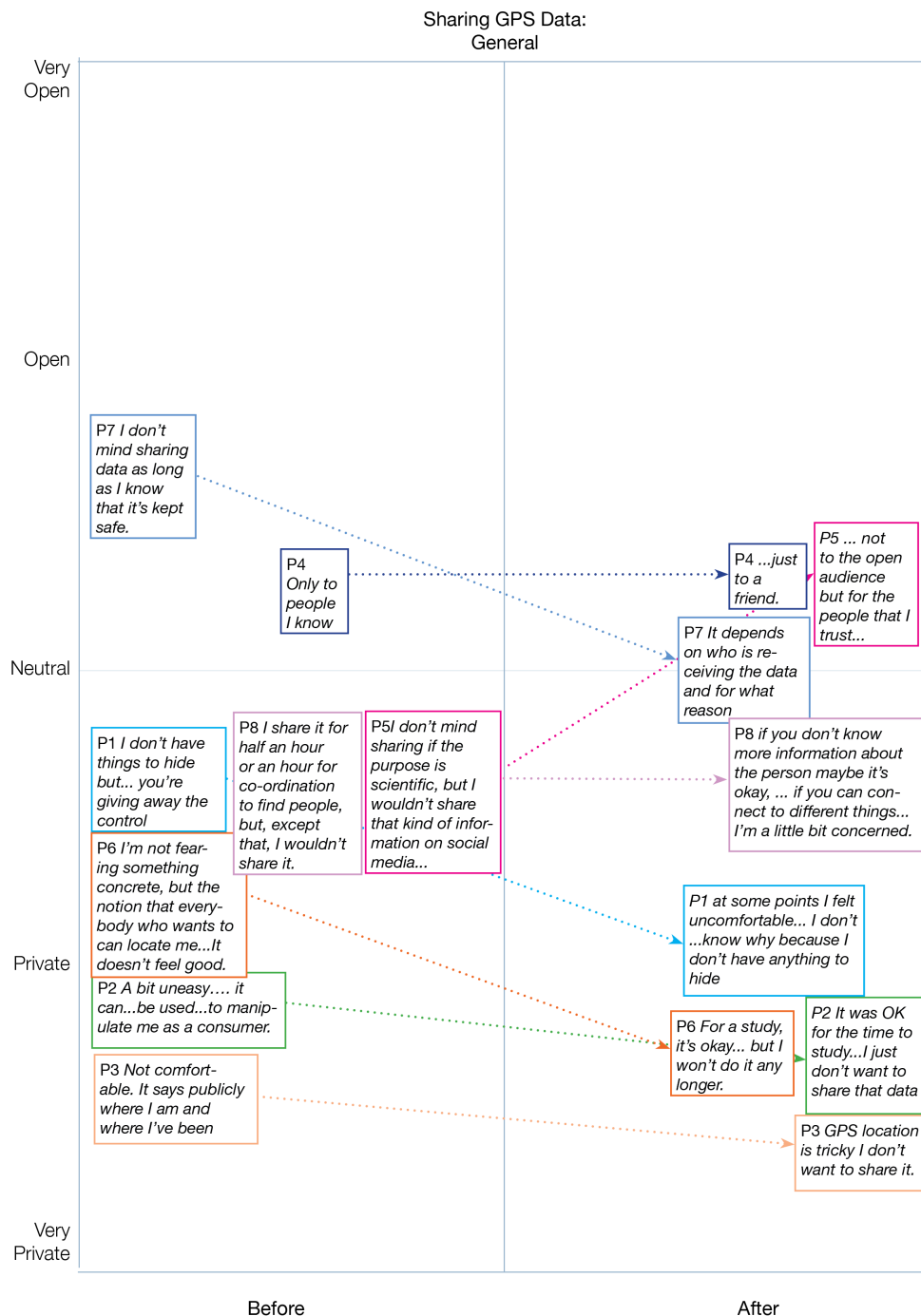
FIGURE 7-10 SHARING GPS DATA: GENERAL

Participants were then asked about their general willingness to share GPS location data. Figure 7-10 suggests that participants perceived this data as slightly more sensitive than the CGM data, with all participants expressing a desire to maintain some level of control, though the sample size limits significance. P7 was the most open, reported sharing such data for specific purposes, such as "...On a bicycle trip if you don't want to stay as a group, close together... you can see on your screen where other sports friends are riding... I don't mind sharing data as long as I know that it's

kept safe.” While P8 similarly noted also using location services, but only for short times, *“I share it for half an hour or an hour for co-ordination to find people, but, except that, I wouldn’t share it...I feel uncomfortable if someone would know where I am.”* P3 noted feeling *“Not comfortable. It says publicly where I am and where I've been so that's quite spooky.”* And P2 had specific concerns, feeling *“A bit uneasy.... I know how helpful it can be for scientists...but I think it can also be used in a way to manipulate me as a consumer.”* And P6 stated *“Well, for the study it's okay... (but I wouldn’t) make it public...the notion that everybody who wants to can locate me (can)...It doesn't feel good.”* The after-study distributions were generally consistent. P5 might have been slightly more open, with a stated willingness to share with *“people I trust”,* while others such as P6 who had previously stated some reservations about public sharing confirmed these feeling, *“I don’t like it. Because, I don’t want someone I don’t know knowing about my whereabouts. It’s just a sensation of privacy...for a study, it’s okay, it’s not a problem at all, but I won’t do it any longer.”* The interviews suggested that the majority of participants felt GPS data to be at least somewhat sensitive, and though there were some variations, this appeared constant at both interview sessions.

7.3.5.2 Q: How do you feel about sharing your GPS/location data with your doctor?

Sharing GPS Data:
Doctor

	Before	After

Very Open

Open
- P4 It's fine.
- P1 I don't have a problem with that.
- P5 I wouldn't have a prob-lem with
- P1 I think it would be ok.
- P8 If he's not sharing that data with someone else, then I think it's also okay.
- P2 ...in a quar-terly session when we look at it together and analyze together, I'd be fine with it...

Neutral
- P6 Well, why would she be in-terested?... I don't have an opinion.

- P2 I wouldn't be comfortable with live data but after the fact I could be OK with it because I see the medical benefit.
- P8 ... if there is an issue... I wouldn't generalise and say, "Okay, the doctor can always track my GPS."
- P7 I need to understand why he needs to have the access to my location.
- P4 Not really. I don't think doctors should know it. I don't see how it would help...

Private
- P5 It makes me feel a bit scared that one certain person whom I know might have such a lot of information about me.
- P7 Less com-fortable with that.

Very Private
- P3 Why would they need that? No no no.
- P3 Not fine... it's an invasion of privacy.
- P6 No. That's pri-vate.

FIGURE 7-11 SHARING GPS DATA: WITH DOCTOR

As can be seen in Figure 7-11, initially participants appeared concerned about sharing GPS data with their doctor, with only P4 and P1 being open to such sharing. Some such as P2 indicated a willingness to share if access remained controlled *"...I wouldn't be comfortable with live data, but*

after the fact I could be OK with it because I see the medical benefit...if I just give my data away freely then who knows." Others such as P5 were reflexively negative but might be open to sharing if they understood distinct value to their health *"I think if location could help...maybe in steering diabetes, then I wouldn't have a problem with this, but I think I just don't see the point. It makes me feel a bit scared that one certain person whom I know might have such a lot of information about me."* After the study the general distribution of responses is similar, though 5/8 participants appear to have changed their general perception of such sharing. P4 had increased concerns with location data, changing from *"It's fine",* to *"Not really. I don't think doctors should know it. I don't see how it would help actually."* As did P6, who shifted from *'I don't have an opinion"* to *"That's private."* For P8 in contrast this data became less sensitive, who shifted from being comfortable with in office retrospective analysis, to *"If he's not sharing that data with someone else, then I think it's also okay."* The responses suggest the importance of transparency of such sharing, especially concerning justifying potential benefits, and for patients to be able to retain control over access. At the end of the study 4/8 participants appear open to sharing, suggesting that increased use and consideration of the technology increased willingness to share for at least some participants.

7.3.5.3 Q: How do you feel about sharing your GPS/location data with your insurer?

Sharing GPS Data:
Insurer

P1 *I don't have a problem with that*

P1 *I think it would be ok.*

P7 If they have (a good reason) ... I would agree, but I cannot imagine such a reason.

P5 This feels again a bit too personal for me...

P8 if I don't understand, then the transparency is missing in that...I don't know why I should share that.

P7 No way...I don't see the reason, the outcome.

have to understand exactly why they need it.

P3 that's like too invasive.

P8 ...it's private.

P3 No.

P2 *I wouldn't want them to have access... anytim*

P4 No.

P2 No way at all.

P6 No. It's private. It's my life.

P4 No priv... data at all.

P6 Never.... it's private.

Very Open

Open

Neutral

Private

Very Private

Before   After

FIGURE 7-12 SHARING GPS DATA: INSURER

As evident in Figure 7-11 sharing location data with insurers was with the exception of P1, viewed negatively. Many such as P3 struggled to understand how this would provide benefit, "*Oh that's like too invasive. I don't see how that would bring any value.*" P5 noted similarly, "*This feels again*

a bit too personal for me and doesn't make sense." And P6 explained "*It's private. It's my life. I don't want to tell everyone where I am going, or what I'm doing.*" As did P8, "*I think this is something that shouldn't interest them...it's private.*" At the end of the study 7/8 continued to not want to share this information with P1 remaining unconcerned about this data. P7 remained skeptical, though on further questioning suggested being open given sufficient grounds "*I don't know why they should have. (If they could tell you a good reason?) I'm very curious about that reason. If they have one, then I could accept, I would agree, but I cannot imagine such a reason.*" Except for P1 participants showed consistent distrust of insures having access to their GPS data, and appear to require strong justification for altering such opinions.

7.3.5.4 Moves App on Smartphone

Many users expressed concerns about their locations being tracked, with some expressing that while it was acceptable within a research context, they were often uncomfortable with such tracking. Some participants reported dissatisfaction with this app on both practical and emotional grounds. P1 noted she stopped using the app because the constant GPS caused excessive battery depletion, "*...my phone was dying.*" P2 also expressed concerns with such monitoring, "*It was OK...for science...I'm not sure I woul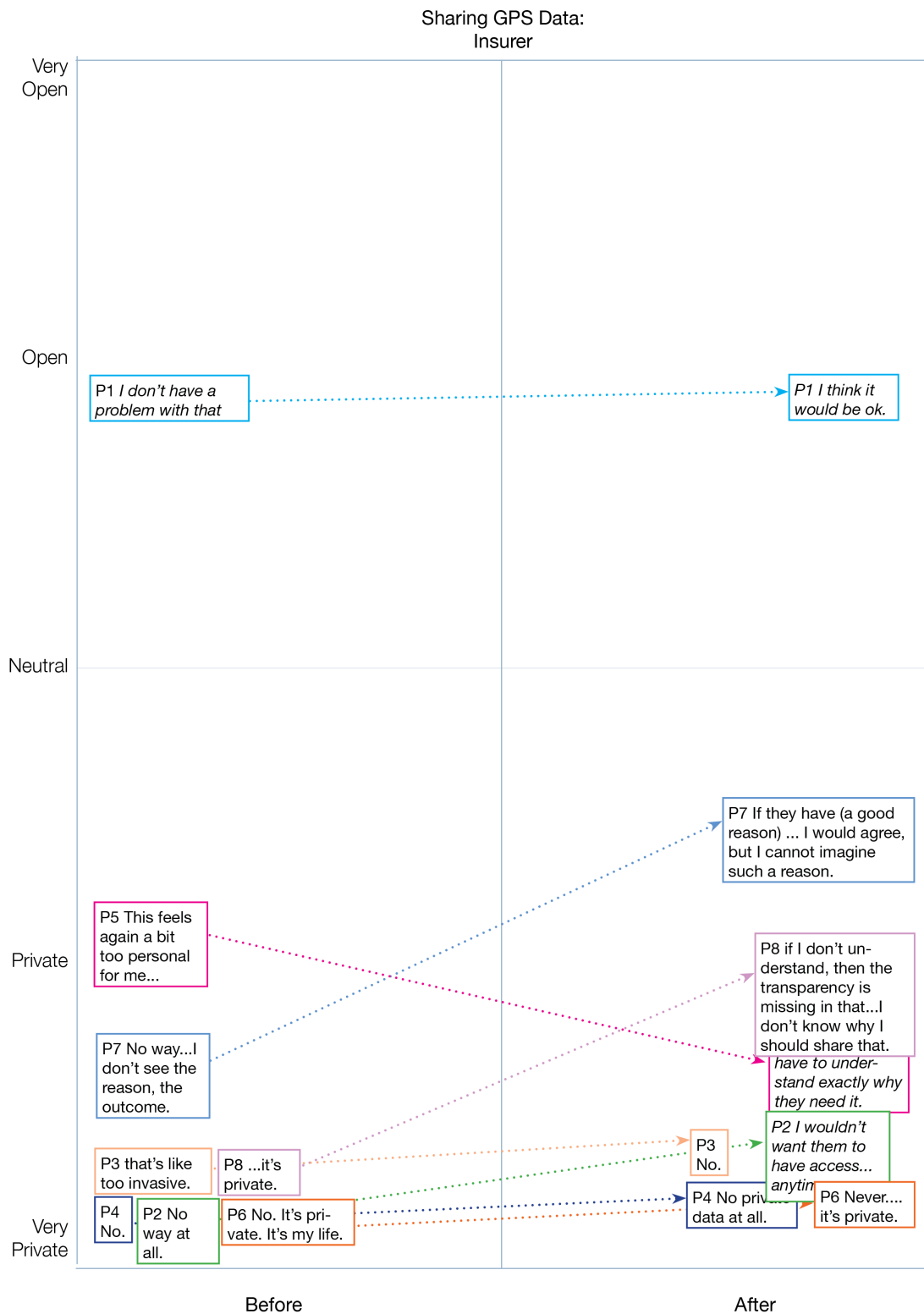d be comfortable with it all the time. Because I just don't want to share that data with anyone right now.*" P3 stated, "*GPS location is tricky. I don't want to share it.*" When P3 was asked about the apparent discrepancy between this opinion and current use of Google products, P3 explained that it was a matter of context and related to this data being associated with medical data, "*It's different...if it's a medical device...I know the dynamics of carrying the phone, and who has access to it, and what are the possible implications...That brings me value...recommendations around me for example, and I (get) paid back a lot of free services with this data. So, it's kind of fun. I gave my consent for this. And the in the case of a medical device and who am I sharing this with, is it my insurers, is it my care team...Maybe it's irrational but I still don't feel comfortable doing it.*" However, P3 later reflected on sharing such data, "*...if someone can convince me that sharing my location...brings value to me directly or to the group or to society. I guess I would reconsider that.*" And while P6 didn't find the app itself invasive, P6 also observed "*... I didn't notice it at all, but if it was without the study I would have put it off...I don't like to get tracked, that's not a nice sensation...I don't trust the big systems, it's just a, kind of, little bit of data paranoia.*" Given the current acceptance of such tracking in connection with free services such as Google Maps and Facebook, this discrepancy should be further investigated for further implications. P3 noted that this discomfort was directly related to the medical context and association with medical data. Medical systems that incorporate such data might need to educate the user as to specific benefits and consider trust building as an essential aspect of design.

7.3.6 Sleep data and monitoring device

The following section reviews participants' responses to question related to sharing of their sleep data. This is followed by a discussion of user's reflections on the use the sleep tracking device

during the study period. Due to an error in the questionnaire, participants were only asked as to general sharing and not with doctors and insurance as with the previous devices.

7.3.6.1 Q: How do you feel about sharing your sleep data generally?

Sharing Sleep Data: General

	Before	After
Very Open		
Open	P4 *...I can share this... it's less private...*	P6 I don't care. I don't think about it.
	P6 *I sleep in my home. Well, it's no problem. It's okay.*	P7 *No, I don't mind, it doesn't matter.*
		P8 *...Okay.... not a big issue.*
	P1 *I don't care too much about this.*	
Neutral	P7 *I would need to know what sense is behind that data.*	
	P5 *Not on social media... I don't share on social media.*	P4 *(OK if) my doctor or a person who wants to analyse the data and I know this person...but if it's just some company or just sharing it on a website...I wouldn't do it because I think it's too private.*
		P5 *not to the open audience but for the people that I trust or I think it makes sense*
	P8 *...I wouldn't... If it's for my health and my doctor wants to see that, I probably would show him.*	P1 *some days I felt...I was sleeping too long after many days of work...my feelings were...negative...I am going to be judged.*
Private		P2 *Although the information is ...interesting to me and ...any researcher, I don't think that I'd feel very comfortable with this in the long run... it feels ... private.*
	P2 *... super scary...if it would be out in the open I wouldn't feel comfortable...*	
Very Private	P3 Absolutely not.	P3 *That's an absolute no go.*

FIGURE 7-13 SHARING SLEEP DATA: GENERAL

As viewed in Figure 7-13, this question regarding sleep data also showed a range of responses with a slight bias towards more private. P4 who was open to sharing this data said, "*I feel I can share*

this...it's less private somehow." Others such as P8 needed to understand direct benefits before consenting to such sharing, *"I wouldn't (to) because I don't know why. If it's for my health and my doctor wants to see that, I probably would..."* However, some participants felt such data to be sensitive. P2 for example noted *"Well that would be super scary. It depends on who I'm sharing this with. But if it would be out in the open, I wouldn't feel comfortable doing that in the long run."* While the distribution is similar in the closing interview, there was some individual change in sentiment with P7 and P8 reporting less concern with sharing this data, while in contrast P4 and P1 considered this data more sensitive after the study period. P1 expressed increased concern about sharing sleep data, *"I felt like I was sleeping too long after many days of work...and then I am going to be judged about it..."* And where P4 had previously been unconcerned with sharing sleep data, it was now considered more sensitive or private *"My doctor or a person who wants to analyze the data and I know this person most likely it's fine, but if it's just some company or just sharing it on a website with someone, I wouldn't do it because I think it's too private."* In contrast some participants considered this data less important. P7 and P8 went from stating a need for justification for sharing to no longer caring, with P7 saying *"No, I don't mind, it doesn't matter."* And P8 *"I think that's not a big issue."*

7.3.6.2 Beddit sleep monitor

While some participants reported interest in the data delivered, there were noted barriers to sustained use. P4 noted the sleep data offered meaningful insights, *"... how long I sleep... was super interesting...I sleep only seven hours or less. I always thought I'm sleeping eight or more. I also have seen that sometimes I was super tired the next day. Then I just checked out the profile and have seen that I was basically not sleeping very deep. I think if it basically makes sense and it's not too invasive into lives, then it's fine."* However, while such data can be informative, some questioned its actual benefit, P6 observed *"Sleep tracking was fun to have, but since it's told me every time that I snore...I didn't like it so much, because I don't want to know about it."* And P6 noted that such information was on its own of limited utility, *"... it tells me if I slept well, but I notice myself if I have slept alright. I prefer my own sentiments about my sleeping habits."* P8 noticed a similar negative impact, *"you think you feel well, but then you see that you haven't slept well, because your device tells you. You automatically feel bad afterwards."* For some such as P3, transporting the physical device was problematic. *"The sleep tracker is really interesting...the insights and data... I don't sleep that often in my bed and sometimes I sleep in the office, or pass out on the sofa, or I forget to turn it on, but every time I used it I was very impressed with the data I got from it."* For those participants who were able to use the automatic function, non-sleeping time in bed complicated usage. P2 reflected, *"...on the weekends I spend a lot of time in bed, so that's when I have to switch off the automatic function. So that also meant that when I got to bed in the night, I had to turn it on and I kept forgetting and then sometimes the power was off, so it felt like kind of a hassle to me..."* And P1 noted *"...the first thing that I turned off (*after the study*) was the sleeping tracker, because I had to press a button and say I am going to sleep now and when I wake up I*

have to stop it again. One day I forgot it, and I was like I forgot it, I am going to ruin all the values and so finally when the time was over, I was like I don't have to do this anymore. anything that adds a task, in the long term isn't going to work out." For others, having in-bed habits monitored seemed invasive. P2 noted, "*Although the information is very interesting to me and obviously to any researcher, I don't think that I'd feel very comfortable with this in the long run...*" And P7 who folds up his futon each day, found having to set the monitor each day overly burdensome, especially when his girlfriend was spending the night. He explained, *"I used it a few days, but whenever my girlfriend was visiting me, or I was out staying at her house, I didn't bring it with me. Because I didn't want to explain what it is and what I do and so on. I had to think about it, how to use it, to place it when preparing for the night and so on.*" And P8 reported that turning on the device and the gamification aspect was disruptive to sleep routine, "*...every night I touched this button to track my sleep and somehow, I was focusing on sleeping and that made sleeping harder. Because I always said, "Okay, I have to sleep because I want to have a high score, and, while thinking about sleeping, I wasn't able to sleep.*" While participants expressed interest in their sleep pattern data, the device displayed barriers which might limit its suitability for daily data collection. These included: the need to activate and de-activate device every sleep session; transport and installation of device for alternate sleep locations; perceived invasiveness of in-bed monitoring; negative emotional effects from negative reports; and potential feelings of stigma from partners. These factors might suggest that rewards of use might have to be substantial to encourage long-term and sustained use. Further research with such devices with actual benefits beyond delivering sleep data would need to be tested to resolve such questions.

7.3.7 Summary of findings by stakeholder

The following sections discusses key emergent themes from the previous interviews organized by stakeholder.

7.3.7.1 General attitudes toward data sharing

- Participants showed awareness about the risks of sharing their data, with a tendency towards caution, with many concerned about commercial exploitation.
- Many participants were already sharing their blood glucose data with non-medical stakeholders for emotional or logistical support, though in a controlled way, such as pre-selecting data to share or with trusted stakeholders.
- While some participants were willing to use GPS services for specific purposes, many were wary as the perceived such data could lead to safety, financial, or non-specific emotional risks.
- While participants were willing to share data for research purposes, many perceived their blood glucose data as containing sensitive insights into their lives.
- Sleep data could be perceived as sensitive, requiring permission and purpose for sharing, and some were clear that they didn't want such data in the public sphere.

- Exercise data appeared less sensitive than other types, though there were some concerns stated around commercial vulnerabilities.

7.3.7.2 Doctor summary

- Participants wanted to share their blood glucose data with their doctors, though some noted this was dependent on having a good personal relationship.
- Exercise data was often perceived as directly relevant to diabetes management, and participants were unconcerned about sharing such data with their doctor.
- GPS data was perceived as being sensitive or potentially out of the scope of the patient/doctor relationship, with some participants expressing the need to understand benefits to willingly share such data.
- Though some participants had complete trust in their doctors, many wanted to maintain control over which data they would share and when.

While participants were often open to sharing with their medical professional, many expressed a desire to understand the purpose and benefits of sharing data. This could suggest that systems that collect data for use by medical staff should offer user education as to potential benefits, or alternately avoid real-time sharing and instead focus on tools for delivering retrospective insights at time of appointments, rather than linking of complete sensor data to patient records. While reported concerns were not dramatically changed, it is possible that the period of increased awareness of tracking caused some participants to become more cautious about sharing data, especially real-time with their clinician. This could imply the need for longer-term systems to integrate easy to use ways to share specific data with clinicians during appointments.

7.3.7.3 Data sharing: Insurers

Participants were often more distrustful of insurance company's motives for collecting their data than their clinicians, and many of those who were willing to share wanted a clear understanding of the specific purpose for which it was being collected and/or substantial personal benefits.

- Sharing CGM data with insurers drew mixed responses. Some participants were concerned that insurers would use such data to penalize individuals for their behaviors.
- GPS data appeared to be viewed as personally sensitive, invasive, and not relevant to the needs of the insurance industry.
- Exercise data was also often reported as private in this context.

Many participants expressed distrust of the motivations of their insurance company and were resistant to granting insurers access to their personal data, especially without transparency of purpose. If insurance companies want to promote the use of personal tracking technologies, they might need to find ways to establish better personal relationships with customers through a greater sense of shared purpose or find ways to assure users that their data is protected from insurer access.

7.4 Reflecting on the Visualization Method

After the discussion and analysis of the collected participant responses, this section will reflect on the potential benefits and limitations of the visual representation method:

- Text: Richness of responses remains available in comparison to dots.

- Transparency of coding: The placement of participant response is transparent, and open to re-interpretation. One criticism could be that the use of excerpts rather than the full quote could introduce coding biases. I justify this approach given the physical limitations of the A4 print format and the need for legible text, and that fuller responses were included in the following text. However, the use of digital media such as pdf would allow for additional text. An alternate approach might be to use excerpts, but to display the full text with when the box is selected.

- Ordinal: Allows for visualization of the ordinal aspect of responses, which would be lost in a more tabular presentation.

- Change over time: Easy interpretation of change, method could be used for any number of data points if there were additional interviews at later times. Change over time is easily viewable by angle of linking arrows, as are changes from positive to negative attitudes. This could be important for understanding product adoption or understanding how changes in a product or service influences user sentiment.

- Bias of response: Groupings or trends in sentiment are easily accessed.

- Comparison between graphs: Multiple graphs can be easily compared, for example to see if a particular participant was consistent in their attitudes across different types of data.

- Easy to access spread sheet for deeper inspection: As the question and participant remain linked, source materials can be easily accessed for further inspection of outliers.

As the following sections do not concern the above points, they will not make use of this method

7.5 Technologies for Unmet User Needs

The previous sections have discussed user concerns related to sharing data and the use of specific common monitoring devices within a connected health context. Many participants have noted that using such devices could not only decrease privacy, but also increase feelings of economic or medical vulnerability. Such feeling could potentially jeopardize acceptance of multiple-device monitoring systems. As one of the goals of this technology probe is to suggest new technologies to meet user needs, the following section proposes software-based solutions to alleviate concerns relating to contextual data sharing, transparency of data processing, anonymization, and sharing of selected information.

7.5.1 Real-time data flow controller

Many participants expressed the desire to retain control over the distribution of their data, and in some cases expressed reluctance to adopt medical systems that didn't support such control. For example, when asked about what sorts of assurances would support daily adoption of a medical

tracking system, P4 said *"That I definitely know what kind of data is shared and that I can always remove it. Basically, I have access to it and can remove it or I can export it. For example, I have disabled all the Google services on my phone. I am enabling them only when I really use them."* P4 noted concern over losing control of data once it is released, *"... it's just like a black hole. Imagine I trust someone and share the data but then I realize that somehow the people or the company are not really...responsible with my data."* This desire for control over personal data was further detailed by P7, *"I always want to know who gets which data from me concerning everything: my behavior, situation, blood glucose level, or whatever. It is my data and I would like to know who knows it."* Similarly, P2 states *"...I very much want to be in touch with who receives my data when and why."* This sense of agency appears critical, as P3 explains about sharing personal data, *"...I would happily consent to sharing it, but not if I am forced to share it."* And we can also see that this control must be easy to change or grant only specific access, as P3 notes, *"I'd like to share what's necessary with my doctor not just to make an input dump."* These quotes suggest that users desire a tool that assists with convenient permissions for personal data. However, as P6 explains *"...you always just agree to those… 50 pages long... Agreements. That means that I give it off my hand... I would like to be in control. Even if practically I'm not doing it, because I get bored and never read them to the finish and just want to go on with my app."* While new GDPR standards specify reduced text, based on these statements more visual means of both granting, editing, and suspending permissions for each aspect of personal data would better respect user preferences, allowing convenient control over when, where, and with whom they choose to share their personal data.

7.5.2 Real-time data purpose visualizer

A user-centered system for data control, could also integrate a means of helping users to in real-time see how their data is being or will be used. While such transparency of purpose is expressed in the General Data Protection Regulations, this could pose challenges for explaining complex algorithms, evolving systems, and for researchers who might not yet know exactly how they might use collected data. In the interviews, participants were unsure how correlations in personal data might hold insight for diabetes management, such as P3 who said *"...I really don't see the value in sharing more than...glucose, exercise, (and) diet...with my doctor."* And P3 noted that knowing purpose of data processing is important for consent, *"Ok so I share it and then it's anonymized but with whom, does it bring anything? Would it help find a cure for diabetes, then sure...if it is...crunched in a big machine that takes a lot of anonymized (data) that comes out with breakthroughs...but if it's sharing for the sake of sharing, then no"* Similarly P6 noted both the potential vulnerability of personal data, and the desire for understanding what is being done with the data, *"You see a lot of your personality in your data, and that is very private, I think, and I would like to choose to whom I give it. The more the person can read out of it, the more I want to know him, know what he's doing with it."* And *P8, "I don't understand why they need that, and if I don't understand, then the transparency is missing in that. If it's a black box and I give data*

somewhere and don't get feedback on that, I don't know why I should share that." These quotes suggest software that could allow real-time feedback on how data is being used would better respect user autonomy. Likewise, such systems could request access to use data for research purposes, which the user could grant for specific times or for specific data. As P1 notes, *"I think (with) my medical data (it) is important to me to know who's going to have access to it...I generally don't have a problem giving access to my information if I know it's for a study..."*

7.5.3 Data blurring

People can engage in actions which they might want to remain private. GPS and other data pose risks to their ability to maintain such anonymity. Preventative medical services are often offered non-judgmentally, for example anonymous distribution of clean needles or bleach kits for HIV-AIDS prevention. In order to protect autonomy, health guidance systems should consider how to offer analytics services while preserving anonymity. For example, if an individual had a record of an emergency room visit associated with visiting a certain location, their insurer might be tempted to leverage that insight financially, or even normal behaviors like eating at certain restaurants could be considered risky for a person with poorly controlled diabetes. P1 noted such vulnerability when asked about how she felt having her GPS position monitored during the study, *"At some points I felt uncomfortable... I don't have anything to hide. But I thought maybe this is what people will want to hide the most. For example, ...maybe if you're going to a bar and you have to work the next day...or I'm going to an ice cream place..."* And P2 said, *"I have nothing to hide. But should I ever want to rob a bank or have an affair. I think I would think about these things and try to hide my data...that's something I wouldn't want to share or want to have out there for whoever to gain access to...if I have a tracking device I would leave it at home..."* And P3 similarly noted, *"Well I know that people have a sensitive reflex to sharing...some of this stuff with either employer or the authorities because not everyone does things that are perfectly legal all the time. So. Let's say hypothetically, theoretically, speaking if I was about to do something and that is not necessarily legal or in a grey zone...I would not want to share that stuff."* Participants frequently expressed a willingness to share their data for science that they might not otherwise share but needed to feel safe in doing so. P4 noted, *"If I knew that the data was anonymized, and it's hard to track, to conclude that I was doing it, then it would be fine. I could share it, most likely, with anyone if there is some benefit from using the data."* In addition, if crowd sourcing such data could provide valuable insights to others, it is crucial that users be assured that the data will be fully anonymized. P8 noted, *"Restaurants or activities, yes, I'm more likely to share if it's anonymous."* Allowing users to disable tracking systems at specific times is not a complete solution, as missing data could reduce health benefits, or create suspicious missing data. Therefore, some means should be incorporated into such systems that supports anonymizing location and other identifying data while still allowing robust pattern recognition, machine learning algorithms, and other means of distilling value from collected data.

7.5.4 Tailored reports

Users with chronic health conditions must coordinate care with diverse stakeholders such as partners, family members, school or workplace, medical personal, payers and others. Patients might want the ability to share only specific aspects of their information dependent on these relationships. For example, P2 explained *"I wouldn't like (data sharing) in real time but(rather)...regular, updates on a monthly basis or something like that...I also don't like the idea of them accessing the CGM values in a live stream so that they could check up on me... It might be for the right reasons but it also unnecessary because I am capable of taking care of myself."* And P3 said, *"Well I'd like to share what's necessary with my doctor not just to make an input dump...the doctors have super little time to look at things anyways....maybe if there will be some kind of automated...software...that has more abilities than humans to crunch this stuff and come out with things that traditional health care professional or a team couldn't come up with."* And P6 notes of sharing CGM data her doctor, *"Yes, she needs to do it. She never reads them. I always give them to her, but they never talk about it."* Doctors might not have time to make sense of large amounts of sensor data, though this data might contain information that is important for their understanding of patient needs. This would suggest the value of a tool to assist with pre-processing and then sharing contextually relevant information. Such tool could have other templates or guides with varying levels of specificity for other stakeholders and their requirements, and if trusted could help to limit many of the stated concerns.

7.5.5 Summary

The following capabilities could be important components of designing more user-centered health management systems

- Assist users in conveniently controlling and altering 3rd party access to specific data.
- Allow users to view how and for what purposes their data is being used.
- Blurring functionalities to properly anonymize shared data according to user security preferences.
- Tailored reports to export insights without exporting data.

7.6 Questions for Developers of Future Systems

Now that we have discussed concerns related to data sharing and devices, and implication for new technologies, the following section examines representative quotes from the interviews and uses them to pose questions for designers and developers of future system. These questions could be used both in a heuristic sense for stimulating critical examination of a product, or to initiated dialog between stakeholders.

7.6.1 Added workload and adoption

Not only does data entry poses known challenges to daily adoption, any added workload creates challenges to continual use. As P1 describes it *"...so finally when the time was over, I was like I don't have to do this anymore. Anything that adds a task, in the long term isn't going to work out"*

And P2 noted *"I had some issues with the sleep tracking device sometimes it didn't work or I forgot to turn it on because on the weekends I spend a lot of time in bed so that's when I have to switch off the automatic function so that also meant that when I got to bed in the night I had to turn it on and I kept forgetting and then sometimes the power was off...it felt like kind of a hassle to me"*. And P3 notes the challenges placed by requiring work, though notes that this is manageable with sufficient rewards, *"... manual entry is a no go... the...Beddit...because of the fact that you need to pair it and connect and so on that's why I didn't do it. The freestyle Libre...there is a no problem scanning the sensor because that's something I want to know straight away."* These responses indicate that while users might be willing to engage in repetitive tasks, such workload must deliver consistent perceived value.

Q: *Does your product in any way add to daily workload? If so, what rewards does the user receive to justify this time and effort?*

7.6.2 Emotional Impacts of monitoring

Participants often discussed how their awareness of being externally monitored could increase stress, fearing that they were being judged externally for their ability to control their diabetes values. P1 was concerned about such monitoring, *"I think if (my BG values are) OK I have nothing to worry about, but if (my BG) is doing really bad...then everyone is going to see it and think (I) don't care about it..."* P2 added that having continuous data streaming to a doctor could be counterproductive as it might lead to conscious and laborious effort to alter data, *"I don't even want to have to think about whether or not I have anything to hide...if I manipulate the data I'm automatically gathering then that would make things way more complicated and also (a) more negative experience..."* P8 explained that such external observation could lack situational context, leading not only to external judgement, but also internalized pressure, *"...if you don't know what the person did, the high value, you think, "Oh my god, he didn't manage his disease." But maybe it was something really stressful or it was an accident or whatever...there's only that number and if I don't have the chance to explain myself, why this number was there, I feel guilty..."* These responses suggest that not only must monitoring systems be trustworthy in their data handling and representation to other stakeholders so as to protect users from counterproductive stress, but also that such trust might be essential to prevent system rejection.

Q: *Is the information collected by your system accessible to any stakeholder other than the primary user? If so, what is your strategy for:*

-mitigating feelings of surveillance?

-assisting the user in taking breaks from monitoring if they desire?

-allowing them to control how data is presented?

7.6.3 Unwanted or distressing information

Personal data can be interpreted by the individual as judgmental or indicative of performance, which can increase stress in counterproductive ways. P8 noted how such monitoring and scoring

could make it more difficult to sleep, *"Okay, I have to sleep because I want to have a high score, and, while thinking about sleeping, I wasn't able to sleep."* Also noting that receiving such information could negatively impact mood, *"...you think you feel well, but then you see that you haven't slept well, because your device tells you. You automatically feel bad afterwards."* Such presentation of scores or other ways of interpreting data must be considered carefully to avoid such effects.

Q: *Have you researched how the information or feedback you provide impacts your users emotionally? What strategies do you have in place for delivering data in a way that minimizes undue stress?*

7.6.4 Stigma

The use of even non-medical devices can create feelings of stigma or discomfort in specific situation. As P7 explained about not wanting to set up the Beddit device in front of his girlfriend or being questioned about a wristband. Interestingly no participants noted their blood glucose sensor as being stigmatizing, though this might be a function of time of use or perceived value.

Q: *How might your product or service create stigma in specific contexts? How might this stress be lessened? Is it possible to build for breaks in usage?*

7.6.5 Differing relationships of trust with doctors and other stakeholders

User willingness to share their data with others can be dependent on personal relationships, and it should not be assumed that users will have full trust in their medical team. P2 for example was comfortable sharing personal data with their doctor but noted *"...I've also seen doctors with whom I would not feel comfortable sharing all this data."* And users might want to edit or only share certain data, such as P6 who noted *"My doctor should have access to my CGM...but everything else should be my decision to share it or not share it."* Or P7 who felt that sharing GPS was provisional on understanding why it would be beneficial, *"I need to understand why he needs to have the access to my location."* These quotes emphasize the variability between users and their relationships with others, and that systems should be flexible enough to allow for appropriate customization.

Q: *Does your product provide personal data to medical personal or other 3ʳᵈ parties? If so:*

-what controls does the user have to manage when and which data is visible?

-could such controls be modified quickly during an appointment to allow discussion of a specific topic?

7.6.6 Trust

Participants often noted concerns about the use of their personal data, such as P1who noted, *"...I think if I really don't know what's going happen with my information... maybe it's going to be sold to third parties, and I don't have any knowledge..."* P2 was concerned that data might be used *"...to manipulate me as a consumer..."* or that insurance companies might *"...punish me for unhealthy behavior or whatever they deem unhealthy."* And others noted that there was a difference between

normal tracking, such as P3 who said, *"...It's different. Because it's a medical device."* Systems that depend on open sharing of data should must take deliberate steps to build trust for users such as P8, *"if I don't understand, then the transparency is missing...If it's a black box and I give data somewhere and don't get feedback... I don't know why I should share that."* Given the need for such systems to be continually gathering data in order to offer value, and the increased privacy concerns in a post Cambridge Analytica world, systems should carefully examine how to encourage and guarantee user trust in their products.

Q: *Why should the user trust your product? What assurances can you promise, and how can you guarantee they will be followed?*

7.6.7 Personal preferences

While some participants were comfortable with the devices in the study, others were not. P5 for example fount that the step-counter was acceptable *"When I wear it on my belt and not as a watch..."* Whereas P7 found the tracker unwelcome *"... I just stopped, I quit. Because it was, I felt uncomfortable with that because I already have my own fitness wearing device, so I don't need two of them."* This implies the need for systems to be adjustable to the device preferences of the user, rather than attempting to dictate specific devices. Ideally users will have multiple options both in terms of devices and where they are worn of installed.

Q: *Does your device or systems allow the user to adjust or alter components to meet their needs or preferences? If not, how is this justified?*

7.6.8 Transparency

The desire to retain control and consent of personal data usage was often expressed as a concern. P3 explained, that such control could be essential to sharing, *"I like to be in a position to give my consent and not be coerced into giving away my data...if I have the assurance that it is protected and it would be used in the proper way and not abused, (and) that it (is) secured...I would happily consent to sharing it, but not if I am forced to share it."* There were differing factors which appeared to impact willingness to give consent. For example, some participants noted the difference between ongoing real-time sharing and retrospective analysis for a specific purpose. P2 clarified, *"I wouldn't be comfortable with live data, but after the fact I could be OK with it (if) I see the medical benefit... If...that could improve the analysis of the data that I've gathered."* For P2 this appeared to be a precautionary step, *"...if I just give my data away freely then who knows."* P3 noted an increased willingness to share depending on purposed, *"Would it help find a cure for diabetes? Then sure...but if it's sharing for the sake of sharing, then no."* And P6 noted, *"The more the person can read out of it, the more I want to know him, know what he's doing with it."* An ethical and user-centered approach should consider how to embed transparency by design, rather than just meet minimal legal requirements.

Q: *Is your product transparent to how the data is being used? How do you keep the user informed and updated?*

7.6.9 Privacy

Comprehensive tracking can be invasive. As P6 explained, *"I am my data. If you see my data, you know exactly how I was, what I did, if I felt well or bad. It's a very private thing. It tells a lot about me and my lifestyle and how my day was. For a diabetic, they live through their data, so I think it's private."* Location was considered especially sensitive, as P8 noted, *"With location, it's difficult because if you're going home every day, you know where this person lives. So, with GPS, I wouldn't (share) because it's hard to anonymize..."* Or P1 who noted, *"... if you're going to a bar and you have to work the next day... (or) an ice cream place..."* And others were particularly concerned about being monitored during specific situation, such as P5 who shared *"...I might have a problem in intimate situations, like having sex. I think I wouldn't like to wear a tracking system."* These quotes emphasize the role that trust plays in collecting personal data, and the need to design systems that assure user privacy.

Q*: Is the information collected by your system visible to any stakeholder other than the primary user? If so, how do you:*

-Plan for monitoring pauses in sensitive contexts?

-Plan for reengagement after pauses in usage?

-Allow user to control how and which data is shared?

Q: *Does your product or service make use of GPS data?*

-In which ways do you protect the user from vulnerability, such as being identified, or having that data associated with their medical data?

Q: *Does the proposed system have a system of consent which helps the user to easily control who, when, and for what purpose each of their different data types will be used?*

- If not, how do you justify this?

-How could you implement such measures?

7.6.10 Economic Security/Vulnerability

Another common concern related to health data was that it could lead to financial risks for patients, either in the form of penalties for unhealthy behaviors or through targeted marketing. There were differences in opinion regarding incentive-based systems for behaviors. P8 reflected, *"You hear about insurances who are thinking about rewarding or punishing people for certain behavior … and as long as that takes place within a certain legal and reasonable framework...if people who behave unhealthily and behave recklessly, e.g. if someone is smoking a lot even though they know it is unhealthy, and they become very sick, the community has to bear those costs…There should be a differentiation or compensation... If people get into trouble though without their fault, they should not be asked to pay."* P4 was concerned that the sharing of exercise data with insurers could have

similar risks, *"Health insurance has interests in your health or how healthy you are. They could monetize it in a specific way, so I don't think it would be a good thing."* And P2 when asked how she felt about sharing CGM data with insurers said, *"Not good at all because in contrast to my doctors, I am pretty sure that they don't have my best interests in mind. So, I think they're looking to just maximize their profits and they could use my data accordingly and they could punish me for unhealthy behavior or whatever they deem unhealthy."* And for some it was not their current state, but potential future risks to themselves or others, such as P8 who noted that such judgement could potentially prevent data monitoring and sharing, *"At the moment, I can share because my glucose values are very good, but I guess when something happens, and my glucose values are out of control and I don't know how to change that, I feel lost, and if they charge me on top, that could change the way I use the data and share the data."* And P8 noted, *"I need to be sure that no big company is exploiting the data for their own advantages and benefits."* These concerns suggest that data monitoring systems face suspicion over how data could be used against patients' financial interests. Given that non-ideal behaviors might contain especially useful data for determining health insights, means or policies should be found to protect patients from being penalized for monitoring.

Q: *Does your business model involve using individual's personal data for targeted marketing or use by 3rd parties? If so, how do you protect the user from any harms that may result?*

These questions can be located as a list in Appendix C: Results from Chapter 7.

7.7 Study Limitations

The implemented tracking system was not capable of delivering actual real-time insights to participants, and such benefits might have changed user concerns. Recruited study participants also were previously known to the researcher and had participated in earlier studies and workshops which might have impacted trust and feeling related to privacy.

7.8 Future Work

It is not yet established if the data collected within this study contains insights which might help to form a behavior change feedback loop. Future work will include analysis of this data, as well as assessment of engagement with each of the devices.

7.9 Conclusions

While this study has limitations that could restrict the generalizability of findings, it contributes insights into user needs and preferences in an area with few actual real-world products to draw upon. While economic forces are driving the innovation needed for new approaches to reduce the costs of chronic health conditions, it is critically important both ethically and practically, that these systems are designed with the needs of the user placed at the forefront. Given how little is known about the issues investigated, and difficulties in exploring any social/technical situation that does not currently exist, this chapter contributes insights into user needs from the sorts of technologies

that are likely to make up such systems. Through the use of technology probe implemented with potential early adopters of next generation diabetes monitoring systems, this chapter has:

- Identified user concerns related to privacy and potential vulnerability from having behaviors and medical data tracked and attitudes towards specific devices.
- Defined and explored a method of representing ordinal time series qualitative data to support identification of distribution, trends, and changes.
- Explored how exposure to such systems can cause changes in perception.
- Suggested software solutions to meet allow users to maintain control over important aspects of their personal data.
- Derived important questions for developers of future health related systems.

While user concerns and requirements for diabetes decision support systems have been a major focus of the preceding chapters, they have been identified for the greater goal of contributing to the improvement of actual systems that are responsive to user needs. However, there is a potential gap between academic knowledge and translation to product design. Therefore, the next chapter will be concerned with designing and testing a methods of implementing such qualitative requirements into product design processes.

Chapter 8: DUETS: A Card-Based Tool for Stakeholder Reflection

8.1 Introduction

The preceding chapters have presented empirical evidence suggesting that the dominant approach for diabetes smartphone apps, the daily diary or logging app, can fail to adequately address user needs. This thesis has also suggested that a promising approach to overcoming these deficiencies is through networking sensors and processing the collected data to deliver targeted interventions. However, despite the potential benefits, such continuous monitoring with multiple devices could also be more invasive than existing solutions. Given that such next generation diabetes decision support systems are not yet available for user experience research, I deployed a technology probe with a simulated diabetes monitoring systems to learn more about user perceptions. The previous chapter discussed these results, bringing attention to diverse and potentially complex user concerns related to privacy, trust, and potential vulnerabilities brought about by continuous and diverse data monitoring and sharing. As T1 diabetes management depends primarily on self-care (Funnell and Anderson, 2004), it is crucial that such systems be designed in a manner agreeable to users so as to support engagement and adoption. However, designing systems based on rapidly evolving technologies challenges traditional health industry practices that have relied on slow and risk-adverse development cycles. With the move towards more active automated interventions, it is vital that such systems respect the complex eco-systems of user's lives, supporting the user's goals, emotional needs, and behaviours, while still respecting individual privacy and autonomy. Though rapid iterative design has proven itself in many industries, it remains challenging within the heavily regulated and ethically sensitive field of medicine. Consequently, there is a need for effective criteria and methods able to support design processes for health systems in ways that are safe yet can support rapid iterative design practices. Accomplishing this will require careful consideration of questions such as:

- *What are potential criteria for evaluation?*
- *What are appropriate formats for assessing new systems?*
- *How can these methods be implemented to support system designers?*
- *What sorts of outcomes would such methods produce?*
- *How can such methods be evaluated for effectiveness?*

This chapter engages with such questions through an iterative design process, which integrates the collected research conducted during this thesis to propose a card-based system called DUETS, to facilitate stakeholder reflection and critical discussion. The tool and method resulting from this procedure were then implemented and evaluated through structured sessions with stakeholder focus groups. While the proposed tool has been tailored to the requirements for diabetes decision support systems, the basic methodology and modular approach could with appropriate modification and

supplementation be adapted for a wider range of products and services that depend on complex eco-systems of devices and user interactions. The basic structure of this chapter is as follows:

- 8.2: Reviews specific concerns for diabetes decision support systems and suggest five categorical criteria for system assessment.

- 8.3: Review of relevant literature and discussion of implications for design of DUETS

- 8.4: The components and iterative process for designing the DUETS system

- 8.5: Review and discussion of the procedure and results of three stakeholder focus groups sessions using the DUETS system.

- 8.6: Discussion of the DUETS approach.

8.2 Suggesting Criteria for Assessing Health Self-Management Systems

Previous chapters have used empirical research techniques to explore barriers to adoption of diabetes apps, user interaction with these apps, the ways in which people with diabetes think about and make decisions based on their medical data, and user concerns associated with the use of monitoring systems. The findings of the previous chapters have been combined into five categories of user requirements for self-management technologies:

- *Adoption & Utility (System Functionalities):* Previous chapters in this thesis have drawn attention to the diversity of user requirements needed from diabetes decision support systems, and how deficiencies in functionalities can be associated with abandonment. Systems features should be designed to support and empower the user in achieving personally relevant goals in a way that is compatible with their lifestyle. This calls for systems and their interfaces to reflect actual user needs, while being sufficiently flexible and customizable to meet individual preferences. Ideally, self-management systems should allow the user to determine which devices and functionalities they wish to engage with and adapt to contextual needs.

- *Emotional Impacts:* Chapters 4, 5, and 7 have all discussed ways in which personal health data can bring about feelings of stigma or vulnerability in specific situations and drawn attention to the way in which specific UI design elements can reinforce counterproductive emotions, thereby reducing engagement, or causing system rejection. Therefore, it is critical that designers are diligent in minimizing negative impacts, especially given the potential for user sensitivity to undesired diabetes related data.

- *Behaviors & Actions:* Preceding chapters have drawn attention to the importance of the individual with diabetes engaging in behaviors to support both their general health as well those specific to diabetes such as treating severe hypoglycemia. Systems should therefore ideally both support and encourage a wide range of beneficial behaviors while taking steps

- to minimize overreliance on technology that might create unnecessary vulnerabilities if the technology were to fail.

- *Cognitive demands:* Chapter 5 and 6 discussed the frequent awareness and decision-making required by diabetes care and emphasized the importance of considering the cognitive demands placed on the user. System designers should work with users to assure that interfaces support convenient task completion without overloading, confusing, or misrepresenting information, while still helping users to learn from their data to build self-care models.

- *Consent & Control (Privacy & Security):* The technology probe in the previous chapter highlighted perceived privacy risks and other user concerns that can emerge from multi-device monitoring. Participants expressed the desire for control over how their data was being used, accessed, and presented. Systems should be designed to be responsive to user desires for transparency and control over their personal data.

Taken together these criteria form a preliminary framework for identifying key user concerns for systems designed to support the self-management of chronic health conditions. These categories and their criteria are expanded upon to form the basis for the *Concerns cards* described in section 8.4.2, and for purposes of convenience will be referred to as *User-centered Self-management Criteria (USC)*.

8.3 Practical Application of User-Centered Self-Management Criteria

Now that initial criteria for evaluation have been defined, the next step is to determine appropriate processes for application. In order to do this, we must first extend the literature review to consider emergent topics related to the following topic:

- *What is the role of the user in the design process?*
- *What are appropriate formats of system assessment (the use of questions and heuristics)?*
- *What are practical methods of applying USC (the card system)?*

8.3.1 The role of the user in the design process

This section reviews and discusses literature concerning design practices that asserts that integrating end-users and other key stakeholders is an important component of designing more useful products. User-centered design for example endeavors to meet the needs of the user, emphasizing simplicity, ease of use, transparency of state, and clarity of purpose (Norman, 2016). Integrating the users of a technology into the development process can help assure that products will more accurately respond to their needs, overcoming deficiencies of domain knowledge and misconceptions that might be held by system developers (Gulliksen et al., 2003). Furthermore, as new technologies can impact essential rights such as privacy and autonomy (Wright, 2011), it is critical that such issues be addressed during the development process to avoid not only harm to the user, but also risks in trust and reputation to the developer (Wright and Friedewald, 2013). Participatory design directly involves and integrates workers and other users fully into the

development process, not just for their observations, but also as contributors of design ideas and solutions (Gulliksen et al., 2003). By asking questions as to how technology can be developed to retain and support humanistic values, participatory design methods can also support humanistic beliefs such as democracy and quality of life (Muller and Kuhn, 1993). This literature affirms the importance of including stakeholders in the development process, allowing them not only to comment on existing products, but also to determine the direction and approach taken. Integrating the eventual users so as to play a significant role in product design is supported by Jones et al. (Jones et al., 2017) who drew attention to the need for new technologies to not simply reinforce existing hierarchical compliance based relationships in health care, but rather to allow the user to adapt technologies to their own needs

8.3.2 Questions as a tool for assessing health self-management systems

This following section considers appropriate methods of assessing interfaces and digital systems. Nielsen et al. asserted that there are essentially four ways to assess an interface, *formal* analysis techniques, *automated* procedures, *empirical* user experiments, and *heuristics* judgements (Nielsen and Molich, 1990). Nielsen et al. noted the practical limitations of the first two, and that empirical evaluations are time, labor, and expertise intensive, and are therefore often neglected. Therefore, Nielsen et al. advocated for heuristics. Relevant to the objectives of this thesis, Kientz et al. (Kientz et al., 2010) observed that persuasive health technologies pose significant challenges for assessment, as they can require working prototypes to assess reactions. Kientz et al. also noted that extended deployment can also be needed for assessment as long-term adoption can be a critical factor of effectiveness. Despite this last complication, heuristic evaluation offers many practical benefits, though it often relies on the knowledge or intuition of the user and can therefore lack standardization (Nielsen and Molich, 1990).

8.3.2.1 Heuristics as a means of system assessment

To assist with standardization Nielsen notably developed a list of ten heuristics including: *visibility of system status; match between system and the real world; user control and freedom; consistency and standards; error prevention; recognition rather than recall; flexibility and efficiency of use; aesthetic and minimalist design; help users recognize, diagnose, and recover from errors; help and documentation* (Nielsen, 2003). Nielsen and Molich (Nielsen and Molich, 1990) found that people were generally willing to accept that there was a usability concern once identified, and that the aggregated results of 3-5 independent evaluators were capable of discovering a substantial percentage of key errors at relatively low cost and effort. However, heuristics have their practical limitations, they are primarily for identifying problems and can be limited in their effectiveness for providing solutions to identified problems, and therefore limited for assisting in pointing towards paths of further innovation (Nielsen and Molich, 1990). Drawing upon Nielsen's methods of heuristic evaluation, Kientz et al. (Kientz et al., 2010) developed a modified set of heuristics aimed specifically at persuasive health technologies, observing that Nielsen's usability heuristics were limited in their specificity in certain critical aspects, such as predicting effectiveness in bringing

about behavior change and long-term adoption. Kientz et al. therefore created a tailored set of heuristics that included: *Appropriate Functionality; Not Irritating or Embarrassing; Protect Users' Privacy; Use of Positive Motivation Strategies; Usable and Aesthetically Appealing Design; Accuracy of Information; Appropriate Time and Place; Visibility of User's Status; Customizability; Educate Users*. Validating this approach of heuristic domain customization, Kientz et al. found their system was more successful in locating more severe concerns and problems more relevant to persuasive health technologies (Kientz et al., 2010). Especially given the cost, time, and effort of developing fully functional medical prototypes, not to mention the economic and ethical challenges of testing medical products, some form of heuristic analysis appears a promising approach for assisting developers with early identification of relevant concerns.

Questions as an alternative to heuristic statements

However, despite the popularity of a heuristic approach, there are some features of multi-component health systems that suggest alternative approaches might offer specific advantages. First, heuristics have typically been designed for use by expert evaluators, which contrast with our needs for methods that can be used by diverse stakeholders who might not have prior familiarity with usability concepts. Also, the multiple contexts of use and specific demands of diabetes management might not be adequately addressed with such guidelines. Wright et al. (Wright, 2011) asserted that when context is critical, *questions* can yield more flexible and context-sensitive assessment than *heuristics*, especially to investigate the embedded privacy and ethical values which are essential when designing and developing new technologies. Drawing on this literature, I chose to investigate this more open question-based approach given our objective to provoke discussion and reflection.

8.3.2.1.1 Wright's framework

Wright proposed a general framework for ethical impact assessment, applicable for diverse information technology systems. This system uses a set of questions within a multi-part methodology and combines with privacy and data concerns with the bio-ethics principles advocated by Beauchamp and Childress (*Autonomy*: respecting right of the individual to make independent decisions regarding their own welfare; *Non-maleficence:* avoiding within one's capabilities causing harm to others; *Beneficence*: maximizing benefits to others while balancing costs and risks; *Justice*: equitable distribution of costs, risks, and benefits) (Beauchamp and Childress, 2001). While this paper makes a convincing case for the use of tailored questions, the objectives of this approach are to define a formal assessment process for major IT infrastructure projects, and such a comprehensive and intensive approach might create too large of a barrier to function within more agile and iterative development practices. Therefore, while embracing the open question format as suggested by Wright, the needs of the use-case point towards an approach that can support designers/developers and other stakeholders in a lightweight and time efficient manner to critically examine and discuss systems.

Wright and Friedewald (Wright and Friedewald, 2013) asserted that privacy and ethics should be considered interrelated and could be assessed in an integrated process. The authors drew attention to the need for science and technology to support essential and fundamental human rights, and that privacy is an important aspect of such rights. Wright and Friedewald also drew attention to the shifting and hard to define nature of what an individual considers to be private, and the need to consider such issues within the context and effect of a given technological implementation, and that as privacy is an integral part of social interaction it should be considered when designing and developing new technologies. Wright and Friedewald also noted that greater potential risks demand more in-depth stakeholder involvement, and that such feedback is essential to help locate or identify concerns that have escaped earlier assessment. The authors also drew attention to information flows as a critical part of assessing such risks. It follows then that methods of helping stakeholders to understand these flows could be an important aspect of the development process. This places certain procedural challenges, given the diversity of user data which can be captured by commonplace sensor equipped devices, the hard to predict insights that might be extracted from such data, and the possibilities of this data being shared or sold to external 3rd parties. In addition, as systems and the way data are processed can evolve through the development and implementation process, there is a need for practical methods of iterative reassessment by relevant stakeholders.

8.3.2.2 Summary of key points for assessing health self-management systems

This section has drawn attention to a number of key points which can be integrated with the *criteria* from the previous section to help suggest a design process:

- Integrating users throughout the design process is beneficial in helping to assure that products meet user needs as well as helping to protect the developer ethically and reputationally.
- Use of questions to guide heuristic analysis and identification of key concerns to support lightweight testing procedures, especially before operational prototypes can be used for empirical testing.
- Embracing methods that can help guide iterative and incremental process.
- Multiple stakeholders to gather diverse viewpoints.
- Tailoring questions to the use-case as needed to reflect specific domain requirements.
- Embracing an ethical perspective that respects privacy and autonomy placing priority on patient needs.
- Integrating information flows and helping users understand system function as an essential aspect of the discussion process

Combined with the framework for *User-centered Self-management Criteria* the above approach forms a basis for system evaluation. The next section discusses methods of applying these questions to generate concerns.

8.3.3 Practical methods of application: Support for card-based approaches

The preceding sections discussed emergent user requirements for diabetes decision support systems and methods from the human-centered computing literature for assessing and developing user-centered systems. Given these requirements we now examine relevant literature to suggest appropriate methods of application. While Nielsen and Kientz et al. employed lists, researchers have also used other methods which might better support more creative interaction. For example, Halskov and Dalsgard (Halskov and Dalsgard, 2006) developed a card based system to inspire collaborative design. Knowledge relevant to specific projects was translated into *Domain Cards,* while specific devices or applications of technologies were recorded onto *Technology Cards*. The authors asserted that tangible objects such as cards can assist design processes through focusing and supporting constructive interactions, as well as supporting new idea synthesis. Luger et al. (Luger et al., 2015) also promoted the use of cards as a design instrument to help students and designers understand often inaccessible legal regulations in regard to data protection and privacy. Through consultation with domain experts, they produced a series of cards which addressed issues such as data breach notifications, informed consent, and privacy by design. Their study highlighted the need for data privacy concerns to be integrated throughout the design process. Lucero et al. (Lucero and Arrasvuori, 2010) developed *playful experiences* cards to facilitate brainstorming and scenario building. Thingclash (http://thingclash.com) also used cards to engage stakeholders in critical conversations about unforeseen uses, outcomes, risks, and conflicts resulting from implementation of connected technologies, within a broader goal of emphasizing the need for such devices to serve and respect the needs of users rather than primarily those who stand to profit financially from their implementation. The cards consisted of *personas, places*, and *things,* which were used to create situations, which were then analyzed for potential conflicts, risks, and other concerns. And Mora et al. (Mora et al., 2017) noted that while IoT technologies allow for augmenting or improving existing objects, there existed few tools for supporting the creation of new ideas. The authors noted that while a human-centered perspective on user experience and usability have long been integrated into software development, involvement with IoT is still relatively unexplored. The authors suggested that card-based tools are useful in aiding factors such as: engagement, communication, inspiration, collaboration, diversity of opinion, and externalization of thoughts.

While lists might be sufficient, the examples above suggest that card-based systems have proven effective for supporting collaboration, ideation, and integration. Therefore, while making no claims as to the primacy of this approach, I selected cards as an appropriate avenue of exploration and potential method of assisting developers with designing more user-centered health systems.

8.4 DUETS: Design Process and Components

Given the requirements for supporting diabetes self-management described in the initial section and influenced by the collaborative design and system assessment techniques reviewed in the second

section, this section proposes DUETS as a method for <u>D</u>esigning <u>U</u>ser-centered, <u>E</u>motionally sensitive, and <u>T</u>ransparent <u>S</u>ystems. This section will discuss:

- Iterative design process which has resulted in the current version of DUETS.
- Review of the current DUETS components.

8.4.1 Design process

This section discusses and reviews the stages of the iterative process that took place in designing the DUETS cards. While the reviewed literature guided the elements and format, multiple versions were tested and improved before a version was found adequate for study purposes.

Version 1: Taking a 'minimal viable product' approach, the first prototypes (Figure 8-1) featured hand written architecture cards. First trials session resulted in feedback that system structure was too hard to understand, and that all cards appeared too visually similar.
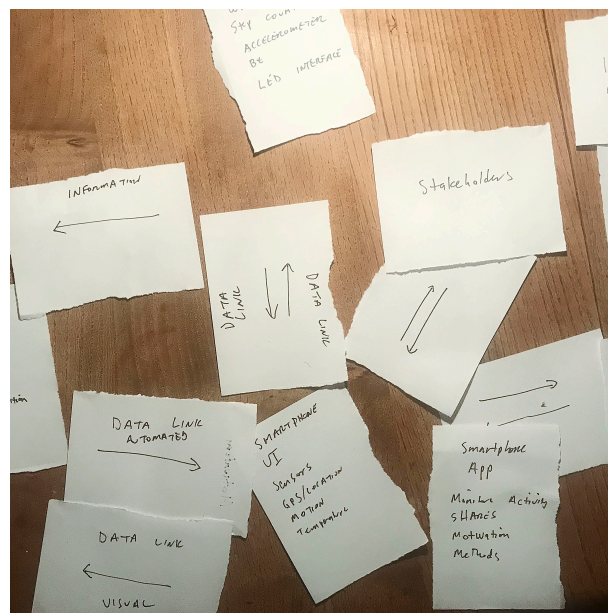
FIGURE 8-1 DUETS V.1

Version 2: The second version used hexagons to represent devices and stakeholders (Figure 8-2). These nodes were then connected with arrows to show information flows and other dependencies.
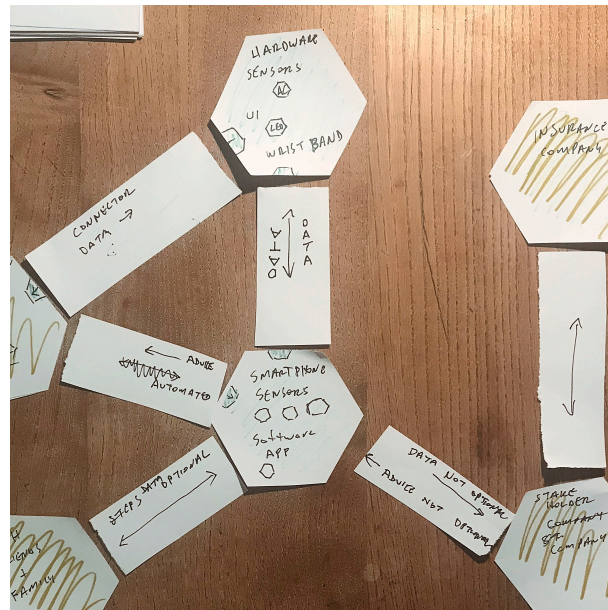
FIGURE 8-2 DUETS V.2

Version 3: In order to visually differentiate between nodes, color coding was added for three categories: people, companies, and devices (Figure 8-3). Hexagonal nodes were replaced with octagons to allow for more connections and the building of more visually appealing structures. People and companies were separated on the assumption that the commercial nature of companies could create different goals and ethical responsibilities. Arrow cards to show direction of information flows were added, with blank spaces to write in details. Nodes cards made use of tokens to prompt consideration of details that might be relevant to each node, and an open space in the middle for the placement of relevant *Concerns cards*.
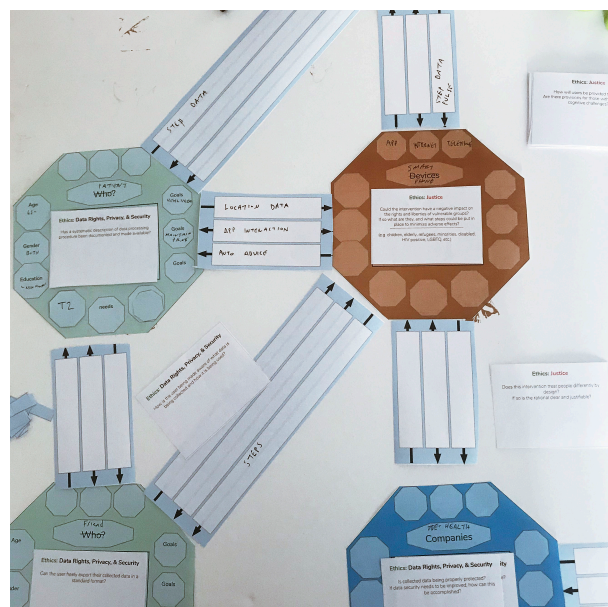
FIGURE 8-3 DUETS V.3

Version 4: The token system was adopted for the connectors as well in order to prompt reflection on what sorts of information might be flowing between nodes (Figure 8-4). This prototype was made use of a scenario for a hypothetical diabetes startup which offered insights derived from wearable devices, offering incentives and purchasing opportunities. This scenario was constructed to generate consideration of issues which might emerge from app-based commercialization of health care, incentive systems, and conflicting interests. The scenario and cards were then trialed with a small group of board game designers, who constructed the system from the description and then used the concern cards to analyze the system components. Users suggested moving away from octagonal nodes to circles in order to allow more flexibility when constructing system architecture. The test group also found the use of colored backgrounds on tokens problematic for readability.
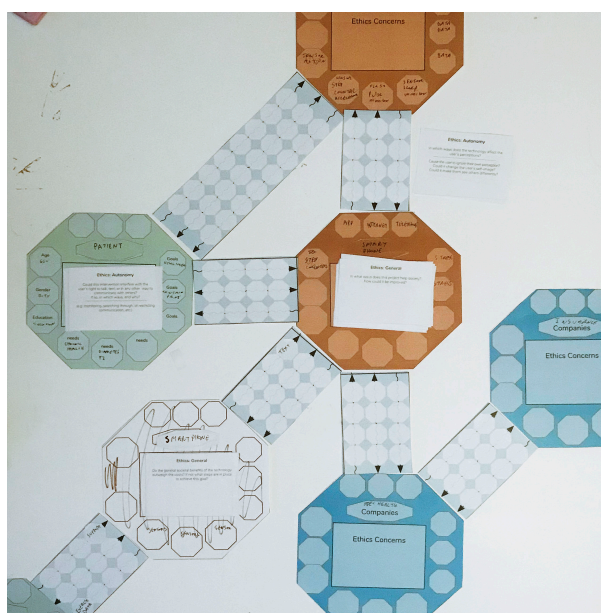
FIGURE 8-4 DUETS V.4

Version 5: In response to user feedback, this version moved to a circular design for nodes, and all white background on tokens to provide maximum contrast with black font (Figure 8-5). Colored outlines were then used on tokens, to indicate category. This version was trialed with the lead developer from a diabetes startup. This test indicated the current sizing of the nodes and connectors was too large for system construction on a standard sized table. The circular tokens were also problematic in two respects: they were slow to cut out, which might inhibit people from making their own sets and decreased the usable area for labelling.
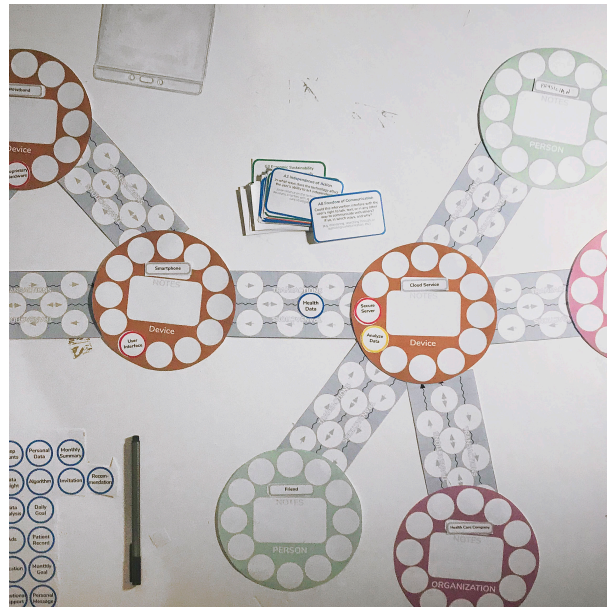
Version 6: Circles and tokens

In response to the last session, the physical size of the nodes and connector cards were reduced to decrease required table space (Figure 8-6). The colors of the nodes were re-designed, and the cards representing people were altered with a more inclusive gradient to better reflect skin-tone diversity. Tokens became squares to maximize font size to space ratio, as well as to decrease trimming time. This system was then tested with a lead designer from a Berlin-based startup. He suggested that the lack of pictures for devices and stakeholder was too visually confusing and that the basic architecture was inappropriate, noting "*It looks like a molecule.*" In addition, this participant became disengaged during the time required to locate and place pre-printed attribute tokens.

FIGURE 8-6 DUETS V.6

Version 7: Smaller Rectangular cards

In response to the criticisms in the previous session, a desire for greater usability, and on review of the literature, the next iteration was influenced by the Tiles approach (Mora et al., 2017). Therefore, icons were added to reduce cognitive demands, and tokens were discarded for checklists with tick boxes on each side of the list to indicate direction of information or influence flows (Figure 8-7). This version was then used for the studies and will be discussed in more detail in the following section.

FIGURE 8-7 DUETS V.7

8.4.2 Components of DUETS cards

The following section describes the categories and content of the *current* state of the DUETS cards: *Concerns Cards* which raise domain-specific questions for reflection and discussion*; Architecture Cards* (*also called nodes*) used to describe the high-level structure of multi-component systems; and *Attributes Cards*, which list information that might impact stakeholder concerns or impact their relationships. This system is designed to be an easily *expandable modular approach* which can be adapted to different domains, and supplemented as needed to reflect alternate hardware, stakeholders, or services (see Figure 8-8). The full cards set can be viewed in Appendix C: Results from Chapter 8 Duets: Duets Cards.

8.4.2.1 Concerns Cards

These cards are grounded on earlier research (Nielsen and Molich, 1990) that asserts that the identification of user concerns can be an important aspect of developing user-centered systems, and that further tailoring for a specific application can assist with identifying pressing and relevant areas in need of improvement (Kientz et al., 2010). The *Concerns cards* are organized by the earlier proposed *criteria for system assessment*. Each card addresses one concern, though sometimes additional short questions are added to prompt further reflection. Questions are left open, and do not suggest specific solutions.

They are also numbered to assist with record keeping. These questions on these cards are based on the research conducted during this thesis and discussed within preceding chapters and were designed to provoke reflection and discussions leading to the identification of domain relevant concerns on the following topics:

- *Adoption & Utility (19 cards):* The ratio between perceived benefits and demands, and how this can inhibit system adoption has been a frequent topic of discussion in previous chapters. These cards ask questions to help assess how different product features could impact value and workload for the user and their willingness to integrate products into daily self-management practices.

- *Emotional Impacts (5 cards):* As disease management and interaction with personal health data can be stressful, it is important that interventions are carefully considered in terms of their affective implications for the user. These questions seek to provoke consideration of how a system or UI might produce stigma, discouragement, other counter-productive emotions, or be insensitive within specific contexts.

- *Behaviors & Actions (4 cards):* User behaviors are vital for maintaining health and managing crisis situations. These cards contain question which help examine and determine how systems can best support self-care behaviors throughout a range of daily activities.

- *Cognitive demands (17 cards):* As discussed in earlier chapters, users make use of different cognitive processes within different contexts. These questions are designed to help designers reflect on manner in which systems are placing appropriate cognitive demands.

- *Consent & Control (11 cards):* Personal data can be sensitive, especially in a medical context where patients are concerned that aggregated forms could cause them to be financially or in some other form targeted. These cards ask questions as to how data is used, the transparency of the process, and the capability of users to maintain control over their information.

8.4.2.2 Architecture Cards

The Architecture cards support visualizing multi-component systems, helping users to consider which devices, services, stakeholders, and companies make up a proposed system and the relationships between them. Movable cards can also enable convenient modifications and provoke suggestions for alternative configurations. All cards contain space for note taking or the marking down of relevant attributes. The four categories are as follows.

- *Devices:* These cards picture hardware which make up systems including consumer products such as smartphones and smartwatches, medical devices, and data storage.

- *Services:* These cards help users to consider the relationships between needs and potential supporting services such as health coaching, clinical care, education, analytics, and monitoring.
- *Stakeholders:* Individuals who might be exchanging information or services within a described system. This includes patients, family, peers, co-workers and anyone to whom the patient may have a personal relationship.
- *Companies:* Care providers, corporations, startups, and others are indicated with these cards. These have been segmented apart from the *Stakeholder* due to the differences in personal and legal obligations.

8.4.2.3 Attributes Cards

The Attribute cards list specific relevant details which might help participants to understand or consider the relationships between nodes in the architecture, as well as arrows to assist in considering direction of information flows, asymmetric relationships, or implied dependencies. The cards include checkboxes to prompt consideration and notation of relevant details. The six categories are as follows.

- *Data:* Collected information that is moved during transactions.
- *Goals:* Motives or hoped for outcomes of different stakeholders.
- *Actions*: Activities that are occurring as part of normal system function.
- *Traits:* Health conditions or other qualities which might need special considerations.
- *Emotions:* Feelings that could occur with or during system use.
- *Responsibilities:* Duties or demands placed on stakeholders.

| Concerns | Device | Services | Stakeholders | Attributes |

FIGURE 8-8 DUETS CARDS

8.4.3 Summary

The preceding section has discussed the iterative development of a card-based system to support stakeholder reflection and concern identification on multi-component health self-management systems. The following sections set out to assess utility of these cards.

8.5 Assessing the DUETS system through Three Stakeholder Focus Groups

This section discusses methods and procedures used to assess the utility of the DUETS system, and how it might in practice assist with critical reflection on and support iterative design of health management systems. As I had already engaged in several rounds of feedback and iteration, at this stage I wanted to have more thorough feedback on several aspects of the design in order to determine the following:

Q1. Is the DUETS approach useful for assessing and generating new ideas for early-stage next generation apps both with developers and potential users?

Q2. Would DUETS add value over the Kientz et al. heuristics? If so, in which ways?

Q3. Would visualizing a system (Architecture and Attributes Cards used with Concerns Cards) add value over using the Concerns Cards alone?

Q4: In which ways could DUETS be improved to increase utility?

In order to address these questions efficiently, I used the following procedure initially in a session with product developers, then with potential end users. Note that the procedure was designed primarily to assess the DUETS approach, rather than the product under development. First, I asked participants to note their prior concerns. Second they applied the Kientz et al. heuristics as per (Kientz et al., 2010) to note any emerging concerns. This was followed with same procedure using the *Concerns cards*. Finally, the app system was constructed and assessed with the full DUETS deck. The final session returned to the same developer team to review the process and assess the results from the first two sessions. The structuring of the session in this way was designed to address Q's 1-4 above.

The Startup

At the time of the study, the startup had already invested over two years in data analytics research seeking to process smartphone and wearable sensor data to detect correlations and patterns, and thereby offer personally relevant insights. While their initial emphasis had been on providing analytics services to device manufactures, they had more recently decided to develop a patient focused app to showcase their technology. To this end they produced a presentation which included a brief description and three screen shots of a mocked-up smartphone app with each screen offering a combination of an informational alert, a data visualization, and short text explanation. These concept screens offered the following benefits:

- Alert the user to events or patterns detected in data, such as hypoglycemic events, and offer them the opportunity to tag such data.
- Alert the user to unusual detected behaviors such as physical activity, sleep patterns, or location, and offer suggestions as to how this might impact glucose level.

- Predict future behaviors such as physical activity or sleep from retrospective data, and offer suggestion based on these predictions.

For the purposes of convenience, the description and screen shots (see Figs. 8-9, 8-10, 8-11) will in this chapter be referred to as the 'app concept'.

8.5.1 Procedures & methods

At the beginning of the first two focus groups, each participant received an information and consent form, as well as a multi-page form with a series of questions relating to concerns and suggestions to improve the system. Each page was explained and then filled out before participants moved on to the next page. The procedure was as follows:

1. *Prior concerns*: after a briefing, participants note any concerns they have with the app concept based on their prior knowledge.
2. *Reflection with heuristics:* Participants independently read through the Kientz et al. heuristics and note any emergent concerns related to the app concept.
3. *Reflection with Concerns cards:* Participants use the DUETS *Concerns cards* consider any additional emergent issues with the product.
4. *Visualizing system with DUETS Architecture cards:* The components of the product are visualized using the *Architecture* and *Attributes* cards, and participants then sort again through the *Concerns cards*, placing them at the relevant point on the architecture and noting any emergent concerns.
5. *Feedback*: Participants reflect on the process and give feedback.

This multi-step procedure was designed to assess the added value of each stage, which could be assessed by new concerns generated. The Kientz et al. (Kientz et al., 2010) heuristics were chosen as a control as they were developed for assessing persuasive health technologies, and claimed greater domain relevance than the standard Nielsen Heuristics. As per the stated protocol of Kientz et al. each participant was given the heuristics printed on a single sheet and wrote down emergent concerns. At each stage throughout the workshop participants were asked to write down new observations, the heuristic or concern card that had initiated this observation, and rank what they felt to be the 3 top concerns, and then note any ideas or product suggestions. After the sessions had been completed the forms and any recorded discussions were transcribed and organized within the self-management criteria framework as discussed earlier. As per Nielsen protocol, participant responses were combined, and duplicates removed, as well as responses that had already been recorded unless there was new insights or details. For the developer sessions there were no incentives offered other than study results, while the user group was offered a 30 Euro Amazon gift card. The study was considered low-risk, and ethics approval was granted by the university ethics committee. The following sections details participants, and other specifics of the three focus sessions.

8.5.1.1 Details of first focus group with developer team

The first session took approximately 2 hours to complete. Participants were all members of the product development team: P1 a 29-year-old software engineer, P2 a 35-year-old backend engineer, and P3 a 41-year-old upper level manager with a computer science background. All were male. The follow up review session took approximately 1 hour.

8.5.1.2 Details of second focus group with people with diabetes

The second session took approx. 2 hours to complete with a 10-minute break after 1 hour. Participants all were people with T1 diabetes (n=6), 5 female, 1 male, Mean 32.8 years old (SD 14.1). Participants were recruited through previous studies and the Berlin Diabetes and Technology Meetup. All were familiar with diabetes self-management technology, and all had previous experience using continual glucose monitors and/or pumps. In addition, two were currently using self-built hybrid closed loop systems, and another was highly engaged with diabetes technology development.

8.5.1.3 Details of third focus group with developer team

The final session contained the same participants as the initial session. In this session, there was a modified procedure, whereby the developer team reviewed their initial sheets from the first session and were then asked to list their insights from the initial session such as features to be added or excluded, concerns, or new insights. These sheets were then discussed in a group discussion. They were then asked to read over data from the user session and mark any aspects that seemed noteworthy. This was then discussed as a group as well.

8.6 First focus group: Development Team Assesses the App Concept

The following section reviews and discusses participant responses from each stage of the assessment process. The mockups below were supplied by the developer team as potential functionalities of their proposed app.
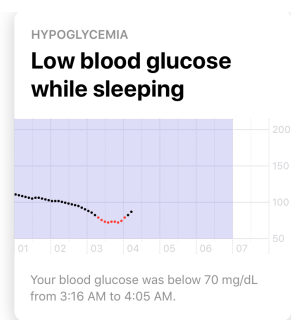
FIGURE 8-9 UI ADVERSE EVENTS
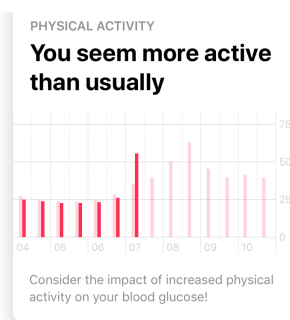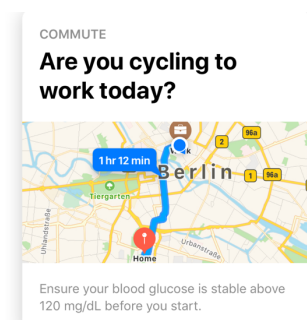
FIGURE 8-10 UI: IRREGULAR ACTIVITY

FIGURE 8-11 UI: HABIT PREDICTION

8.6.1 Prior concerns

This section reviews the observations of the developer team as they were asked to reflect upon and note any concerns related to their app concept.

Adoption & Utility: P1 noted *"Information must be relevant"*, *"Real-time information must most likely need to be processed on the devices"*, and *"Medical recommendations are dangerous"*. P2 noted that since current continuous glucose monitor manufacturers do not offer a real-time API, *"... We can't be as real time as we would like"*, that there is a *"lack of insulin data"*, it being hard to *"identify relevant pieces of information for different users"*, and that *"some cards display interesting information that might be not relevant"*. P3 noted that *"Information we can provide right now to app user is not relevant enough and does not solve a pain point"*, and that due to the lack of real-time BG and insulin data *"...a lot of the more interesting scenarios/notifications cannot be implemented right now"* There were also concerns as to optimizing as *"different diabetics may have wildly different needs and we might be optimizing for one single group"* And that *"Users do not want yet another app and (to) use multiple apps in parallel."* ***Emotional Impacts:*** The developer group noted some general concerns with the affective aspects of their app, with P1 noting that *"Information might be annoying"*, and that *"Historical data seems overwhelming."* And P2 observed that *"The apps can be annoying if it notifies too much."* ***Behaviors & Actions:*** There were limited concerns at this stage with P1 noting *"Information must be actionable."* ***Consent & Control:*** P1 wrote that *"Users have privacy concerns."*

Summary: In this first stage the developer team noted 12 concerns, demonstrating that they were aware of challenges to the viability of their concept app. They were especially concerned with the limitation placed by currently available technologies, and whether they would be able to deliver useful information, especially given diverse needs of different users. However, at this stage these concerns were often non-specific, and lacked clear paths forward for improvement.

8.6.2 Reflection with heuristics

In the second stage of this session the developer team were given a single page printout of the Kientz et al. heuristics and asked to read it over and write down any additional concerns.

Adoption & Utility: As with the first stage, the majority of noted concerns were specifically about the features offered by the app. P1 observed that *"... we have only briefly considered positive feedback/gamification."* P2 noted *"Currently our solution is totally automatic, so no user input is allowed"*, and that therefore *"Not using the phone would mean we don't have any data."* P2 also became more aware of certain general missing functionalities, such as *"User status not provided"* and *"No customizability."* There was also increased awareness of the company's current limitations, as *"Our knowledge about user interaction design is limited"*, and *"Our interface design capabilities are limited."* And the observation that *"The technology is hard to validate."* P3 was concerned that *"Our activity recognition is not 100% accurate, so it may provide wrong notification/information"*, and that *"There may be delays due to technology limitations and we will not provide the information at the right time + place."* ***Emotional impacts:*** P3 noted that *"The user may not want to be bothered about their condition at all."* ***Cognition:*** P1 wrote *"Parts of our technology might be hard to explain"*, P2 was concerned about a lack of *"...user education"*, and P3 wrote *"We stay on surface with information that truly promote learning and thereby does not*

engage the user." **Consent & Control:** P2 expressed concerns that users might have unjustified concerns which could create resistance to adoption, *"even though our App is completely anonymous, it can be perceived as a threat to privacy since it detects and logs all user actions and identifies patterns based on them."*

Summary: The heuristics helped identify 14 new concerns, drawing attention to some specific missing features such as "rewards", "status" and "customizability", and some aspects additional limitations of the notifications which could need further refinement. Also, while many of the initial concerns were domain specific, the heuristics added more general health technology concerns, especially identifying gaps in the team's skillset. User education was noted as an area needing additional work, and threats to privacy were noted, though not considered an actual risk.

8.6.3 Reflection with Concerns cards

In this stage the development team was given the DUETS *Concerns cards* and asked to note any additional emerging concerns that had not previously been noted.

Adoption & Utility: P1 observed that the app as designed had limited ability to incorporate user feedback to train the algorithm and questioned *"How do we incorporate manual feedback for automatically recognized activities/habits?",* and questioned, *"How bad is manual entry really?"* P1 also noted that the *"The product is entirely based on user data, it has a very cold start."* P2 added, *"Product is meant to be used on a daily basis. Benefits can surpass required effort, but currently there's no way of making the user aware of benefits."* And P2 wrote *"Ideally it would be accepted by doctors. We are interviewing several diabeticians to check what can be relevant to them, but we need to put more effort on this matter."* And while the lack of customization had been noted in earlier stages, P2 noted *"There is no user customization, and no justification."* P3 also more closely considered the lack of user customization, *"We may need extensive customization options."* **Emotional impacts:** The Concerns cards helped the developers become more aware of the affective aspects of their product, and the need for better product research with users. P2 wrote, *"Some cards could be stressing since they are warning about likely future adverse events."* P3 also became more aware of the limitations of their development process, as *"We have not done any user testing yet how users react to notifications/information in real-life. We only interview people."* **Behaviors & Actions:** P1 observed *"With great notifications come great responsibility (people might rely on us)."* and that *"Education might be undervalued by us"* **Cognition:** P1 reflected *"What are real problems for diabetics?"* P3 added, *"We provide little guidance on the effect of possible user actions after getting information from our system."* And that *"The product will not work on its own, i.e. the user still needs another app see his/her historical data."* **Consent & Control:** P1 noted *"Improvements to the medical outcome/diabetes management are even harder to validate."* And that *"The technology only works if people actually use phone/watch."* And that *"We should focus more on the patients."* And P3 wrote, *"People may feel uncomfortable seeing tracked and a third-party app having all their behavior and medical data."*

Summary: The use of the *Concerns cards* helps identify potential product flaws across all categories, with 20 new concerns identified. While many aspects of these concerns had been previously noted, the concern cards appeared to produce more detailed observations and deeper consideration of how their product might impact the user. The need for greater emphasis on user research and involvement was also noted. In terms of features, the developers noted several detailed interaction challenges, such integrating manual feedback, and improving the onboarding process until the algorithms became trained. In terms of emotional impact, the developers noted the need for greater user-testing, especially on interface color choices, and stress related to predictions. Concerns directly related to user behavior were also added, noting the importance of user-education, and potential adverse effects of system use. The impact of the technology on user autonomy was also noted, which is a crucial ethical concern. In terms of user data, whereas the developers had only previously noted that users might have privacy concerns, there was more specific reflection on how such user discomfort might prevent the app from functioning. While many of these issues such as privacy of data were integrated into the Kientz et al. heuristics, the cards appeared to add more detail and broader consideration of how these concerns might interact with the user.

8.6.4 Visualizing system with DUETS Architecture cards

In this stage the researcher assisted the developer team in visualizing their proposed system with the *Architecture cards* (see Fig. 8). The *Concern cards* were then divided among the team, and they were then instructed to sort through the cards, placing them onto places on the architecture that seemed most relevant to specific concerns. *Adoption & Utility:* While there were 6 cards placed at various locations on the architecture, all these concerns had been addressed in previous stages and are therefore not discussed further. *Emotional Impacts:* The developer team noted 2 new concerns, placing the card related to *stigma* and user interfaces on the smartwatch card. While the team had previously noted the potential negative emotional effects of undesired predictions, at this stage they added to the patient card the concern card related to the negative effects of undesired actual information. While a subtle difference, this card has additional design implications: one relates to *predictions* alone, as opposed to encompassing the user's own *retrospective* data. *Cognition:* The developers placed the card related to triggering the user's existing knowledge on the smartphone and noted the importance of their service delivering visualizations that would minimize misinterpretation of collected data. *Consent and Control:* While in stage 1 and 2 the developers noted privacy concerns, the more specific *Concern cards* were placed on various components of the architecture. These included the card related to the use of personal data by 3rd parties; trust; and transparency related to stakeholders within the network. P1 reflected that *"Privacy might be a bigger concern than I usually think."*

Summary: There were 10 new concerns noted and the use of the visualization appeared to help developers consider the ways in which users might have legitimate concerns about 3rd party data use. This drew attention to the need for increased transparency to promote user trust.

The development team wrote the following feedback for the DUETS system. P2 stated, *"I think this has been a really useful process in order to identify the system's concerns. Having to think about the problems and let me find my actual concerns and put into perspective the ones I was focused on."* There was also critical feedback, P1 noted *"Marking which data exactly flows from A to B seems useless for our case."* P3 suggested that noting which data was aggregated and/or anonymized should be better indicated. There was also the suggestion that participants be encouraged to create *Concerns cards* during the reflection process, and that the process should include more time for group discussion.

	Adoption & Utility	Emotional Impacts	Behaviors & Actions	Cognition	Consent & Control	Totals
Developer focus group n=3, novel concerns located						
Prior	7	3	1	0	1	12
Heuristics	9	1	0	2	2	14
Concerns cards only	**6**	**3**	**2**	**3**	**4**	**18**
DUETS (all cards)	**1**	**2**	**0**	**2**	**3**	**8**
totals	23	9	3	7	10	52
Users focus group n=6, novel concerns located						
Prior	13	5	0	2	1	21
Heuristics	5	4	0	1	2	12
Concerns cards only	**16**	**7**	**1**	**6**	**4**	**34**
DUETS (all cards)	**17**	**6**	**2**	**4**	**4**	**33**
Totals	51	22	3	13	11	100

TABLE 8-1 CONCERNS LOCATED DURING FOCUS GROUPS

8.6.6 Summary of developer session

Given these examples of the developer's reflections, it is useful to now reflect on this process. Each stage of the session produced additional concerns (Table 8-1), with the observations becoming more detailed and specific to the use-case. The Kientz et al. heuristics were successful in drawing attention to many concerns, especially in *Adoption & Utility* category. The *Concerns cards* delivered more detailed user-centered concerns, such as the need to engage stakeholders more directly in the development process, as opposed to the heuristics which tended to be interpreted by the developers as pointing towards the need for more staff. While the *Architecture cards* did assist with the identification of some concerns, the process was somewhat unengaging, and benefits were not clear cut, though this might have been due to the cumulative fatigue from the multi-stage study design which would be avoided in a non-research study context. Though there were important concerns identified with the visualized system, especially with privacy vulnerabilities, these

sessions suggested that the DUETS system is still in need of further improvement to increase usability. Now that we have reviewed the observations of the development team, the next section will review a follow-on session with a focus group of patients.

8.7 Second focus group: People with Diabetes Evaluate App Concept

This second session was with people with T1 diabetes, the general target group of the app. This session was carried out to allow a between group comparison of the methods and identified concerns. The basic protocol was similar to the initial sessions, with some minor variations which have been previously discussed in the methods and procedures section.

8.7.1 Prior concerns

This section reviews the concerns recorded by the session participants after receiving the briefing provided by the AI startup. Each category will be discussed in turn as before, with repetitive in-group observations removed. At this stage, the PWD user group identified 21 concerns. Of these, 14 had been identified by the developers in the prior-knowledge stage; 3 in the heuristics' session, and 1 using the *Concerns* cards. Thus, this preliminary session chiefly duplicated concerns identified by the developer group, though at times in richer detail.

Adoption & Utility: P5 was concerned that the app would provide *"Too many notifications from the system,"*, too much *"non-relevant information",* and *"No turn off mode for meetings or when I just want to get nothing."* P7 cautioned, *"Another additional system? Should be really good and give info that is not available otherwise."* And that it would be *"...great only if it really can predict problems."* P8 expressed concerns that the system omitted usual diabetes parameters such as *"Insulin dosage, nutritional, intake, stress"*, and that as configured, *"Parameters seem secondary to what we know/seem to know."* Which echoed developer concerns about the need to explain the reasoning of the system. There were also comments related to system transparency or a desire to better understand functionality. P6 wanted to know *"Is the system able to detect or learn new behaviors?"* And P9 had a series of such questions which might provide a useful starting point for the startups marketing department, asking *"How does it do all these things? What data is it based on? How reliable is the data? How does the algorithm behind it work? Is it certified, FDA approved, etc.? Are the actual suggestions for my therapy really based on algorithms or does a medical professional check them? Will the system be integrated with other medical devices?"*
Emotional impacts: Participants expressed a number of concerns about the emotional impact of such systems, from general pre-existing system fatigue such as P6, *"User is already tired of apps and devices."* Annoyance with suggestion was another concern, with P9 questioning *"Will it be annoying?",* and *"Will I grow tired of it?"* P5 was concerned that she would *"... just click on the 'ok' button, because I'm already annoyed."* While P6 was concerned that about having *"No trust in the suggestions' safety".* ***Cognition***: P5 was concerned that there would be *"Too much text to read",* and that if one didn't understand why suggestion were being given, this could cause unwelcome cognitive stress *"Why is it asking me that right now for god's sake?"* ***Consent &***

Control: P6 expressed the sole concern related to data privacy, noting a *"General lack of trust in the data's safety."*

Summary: The user group identified 21 concerns, with 14 of them having been identified by the developers in their prior-knowledge, 3 being identified in heuristics session, and 1 using the *Concerns* cards. There were 2 concerns not explicitly mentioned by the developers in any of their sessions. While the developers had expressed concerns about delivering value, the users noted that some added value shouldn't cause too much added effort. There was also 1 feature suggestion for a quiet mode. In summary this session was quite similar to concerns expressed by the developer group, though at times offering more details.

8.7.2 Reflection with heuristics

Following the protocol of the first session, participants were provided with the Kientz et al. heuristics and asked to note any additional concerns. As the principal outcome was the location of new or richer concerns, duplicates have been removed. 12 new concerns were located, though once again all but 2 had been identified by the developers at some stage. Of these, the developers identified 6 with the use of the heuristics, and 2 with the use of the full DUETS system. The users found 2 new concerns: 3rd parties becoming annoyed by increased interaction; and risks of accidental sharing of data on social media - which was not an offered feature. User identified concerns continued to be more detailed and descriptive than developer concerns.

Adoption & Utility: P9 was concerned about *"Functionality, so that I will actually use the system"*, *"Design"*, and *"Visibility of progress."* P8 noted *"How will the system know that I have been sleeping? Phone could have been forgotten or left somewhere for charging, while PwD was active"*, adding *"Night time isn't always sleep time (parties or night shifts)."* And P7 wrote *"design should be simple and not decorative, with additional info available only as an option."*

Emotional impacts*: P5 expressed concern that over-engagement with such systems could be socially stigmatizing, *"Too many people around me are getting interested what I'm doing all the time with my phone-questions about my diabetes + judging."* Adding, *"People (could get) annoyed because they think I'm playing with my mobile phone the whole time."* And noted the importance of *"positive communication and (to be) motivating."* **Cognition:** P5 was concerned that the *"UI has too many information graphics, animations, text, overwhelming not on the point."* **Consent & Control:** There were some details added to user concerns about privacy. P9 wondered, *"is my data safe? Can I trust the company with it? What is it used for?"* And P5 had concerns about *"Accidently sharing my diabetes data on twitter or Facebook, with the family WhatsApp group."*

Summary: The reflection with heuristics helped locate 12 new concerns, though once again all but 2 had been identified by the developers as well. Of these, 6 had also been identified with the use of the heuristics, and 2 with the use of the full DUETS system. There were 2 new concerns: 3rd parties becoming annoyed by increased interaction, and risks of accidental sharing of data on social media, which was not an offered feature. User concerns continued to be more detailed and descriptive than developer concerns.

With the same protocol as the first developer session, the *Concerns cards* were distributed to participants who were asked to independently write down any concerns with the described system they had not previously noted. The comments have been classified according to the card that was noted as having generated the concern, even though in some cases their content may have been relevant to another criteria category. At this stage, the users identified 36 new concerns, although 19 had been previously identified as concerns by the developer group. Many of the novel concerns were in the form of suggestions for new features, such as integration with clinical software. There were some newly stated concerns around the need to minimize workload for the user - which the developers might have missed, given the manual data entry already eliminated by the app. There were also concerns expressed about business models and developer motives, and the ability to operate system remotely without sharing data.

***Adoption & Utility*:** P6 noted the need for customization as *"If alteration would be limited, number of possible users is lowered"*, adding that user should be able to *"Choose or opt the kind of assistance"*, *"If a certain kind of field of support is not wanted, inhibit the display of all related inputs"* and that *"All info/alerts provide by the system can be deactivated."* There was also a request for a feature that would *"Show the remaining time/actions until the system is able to work properly/ best if there is investment needed. Tell why and for how long."* P6 also was concerned about correctability or some means of the system detecting and omitting faulty data such as, *"...wrong sensor readings, data that derives from that should not be interpreted."* And that existing interface designs appeared to have *"No way to retrospectively collect or delete sensor data on a pre-existing CGM."* P6, also suggested that *"The product could be used solely by the PwD, but it could be greatly beneficial if it could be implemented into a software that the diabetes team uses to interpret patient data."* P8 questioned *"Are the rewards actual glycemic control improvements or ...abstract? this is unclear."* P7 drew attention to the need for alarms to not be disruptive, *"(Noise/alarms) important point (had an alarm going off in a theater)."* P5 noted that the apps messaging was not explicit enough, *"You seem more active than usual doesn't help me... what does this mean? Positive? Negative? Missing the main point, not relevant info visible for me in that moment",* and also observed that on the screen that displays, *"Are you cycling to work today?" where is the 'yes' 'no' button? Just want to answer fast and put the mobile phone back in my pocket."* P5 suggested this app could be counter-productive for users who want a decrease in diabetes workload, *"More thinking and working on diabetes because I'm getting lot of notifications",* and *"Users need immediate benefits gift for what they're doing-like information, positive feedback...their therapy has to get better and less thinking... otherwise they won't see the reason to use it."* And P5 warned system developers of the need to offer transparency of function, predicting *"Users won't trust product because they don't understand how it's working."*

Emotional impacts: While the emotional impacts of UIs had been previously noted in earlier stages, P9 added some details that might be of use to developers, noting *"Design choices should be*

positive & non-judgmental...You might want to (re) think using the color red esp. for high blood glucose." And also suggested that to alleviate stigma, *"Privacy option like on the Apple watch could be an option. Like the choice between showing the content of a notification right away and just showing you have a notification by (startup)"* P5 was critical of the mockup UI design, as it *"Looks clinical, old graphic design, it's not motivating me to use it, old and new UI design elements are mixing."* **Cognition:** Participants reflected on how the product fit in with their decision-making thought processes. For example, P5 asked *"What is the goal of the product? To think less about diabetes or to teach people?"* and noted that assessment *"Depends on the main goal. The examples are asking but aren't supporting in that moment."* P5 also noted a desire for *"Retrospection just later, I'm not interested in that in all moments"* and added, *"I want to use the product as little as possible."* This comment draws attention to how successful health app engagement might differ from other products such as social media. P9 wondered *"How does it help me to improve my daily therapy decisions? Will it keep me focused on what actually counts or will it confuse me, cause too much work, distract me in specific situations in the long run (focus energy wisely + effectively)."* P9 also suggested that the system could help with the sensemaking process if the algorithms could help *"Consider adverse events like clogged infusion sets."* And P6 hoped that the system could detect outliers and problematic data to assist with better quality data set collection, *"Show which input / data lead to the confusion-possibility to reset parts of the collected data."* **Consent & Control:** Some participants raised more detailed questions related to the use and transparency of collected data. P9 wanted to be better informed as to question such as, *"Who is behind this product? Why should I trust them? Is the patient the primary stakeholder? How is money being earned from this? Is my data being used for anything other than my own therapy improvement? How will I be able to access the product? How much will it cost?"* And P8 noted that how much information is being collected from *user "should be made very clear since its all individual data, you probably don't need a bigger group for functioning = no need to give data away."*

Summary: The user group identified 36 new concerns, although 19 had been identified as concerns by the developer group. The majority of novel information was either in the form of suggestion for new features, such as integration with clinical software. There were some newly stated concerns around the need to minimize workload for the user, which might have been missed by the developers as they might have assumed the lack of manual data might cause little added workload. There were also newly stated concerns, not just around transparency of how system function, but also around business models and developer motives, as well as the ability to operated system remotely without sharing data.

8.7.4 Visualizing system with DUETS Architecture cards

In this last stage, in a departure from the originally planned protocol, the participants engaged in a 45-minute free flowing conversation prompted by questions read out loud by the moderator from the *Concerns cards*. The discussion was recorded with permission and transcribed. The comments

have been sorted according to the category of the card which provoked the discussion, and where the conversation has evolved further according to the category judged most appropriate. This user discussion session produced 35 new concerns, with 23 of them not having been mentioned by the developer group. Of these, 11 were suggestions for new features. This session appeared especially useful for eliciting detailed observations and thoughts about new functionalities or interaction approaches.

Adoption & Utility: Participants discussed in detail their needs from diabetes product. While P7 had previously noted that she was already using many products, and a new product be in competition with existing apps and responsibilities, she added *"I'm really full, with the system I'm using now. It consumes a lot of my time. And for anything to be getting extra time, which is not my dog, my kids or Netflix, it has to be really good."* Participants also suggested that such a system would have constrained time to prove itself. P9 would give it *"Less than a month"*, P5 *"A few weeks"*, P7 *"A few days maybe, usually they are very quick"* P8 added, *"I would prefer right away if it's going to access my retrospective data. If not, then a few days."* After this discussion, P9 reassessed to, *"Not more than a week....and that's only passive. If I actually have to do something..."* Such comments could indicate that the proposed system must find ways of delivering perceived values quickly in order to retain users. Participants also desired a high degree of customization, emphasizing impact on adoption, *"Everything should be opt-in....notifications that you don't want...will kill any app and you will stop using it."* P6 agreed noting *"Yes, this should be an opt-in option...you have to say, 'I want to have them' not that you get them always."* Participants also desired that such a system be highly flexible in terms of which devices it allowed as well as which devices are required to deliver insights. P9 explained, *"...if I only want to use my CGM and my smartphone, let's say, but I don't want to use the fitness tracker, then it should still be able to work. And if I disable the GPS function it should still be able to work. I might be aware that it won't have all the functions. It won't be as useful as it potentially could be...It has to accommodate my personal preferences."* P8 suggested that being able to customize the format of notifications might be important, *"...if it's going to show them the insight right away, they would be more likely to use...if it's just a secret notification and you would have to interact with it, to see...the message."* P8 thought the development team *"...should rather focus on designing watch interfaces..."* as this might be more practical as *"you cannot go and check every phone notification all the time."* Though P5 cautioned, *"...not everybody wants to wear a watch, so I think it's...interesting how they are creating the notifications on the lock screen..."* P8 suggested using questions to assist with the customization process, *"If you do in a quiz in the beginning where you ask the person, 'Do you prefer this or that?' If it's just five questions and it will show you an example where you get a question and like a phrase, like a recommendation, not a question, then you would just pick whatever you like."* Noting this approach would be *"...easier for the end user than to have a million of options that you can toggle on and toggle off."* P8 also noted the importance of having diabetes related adjustable settings such as *"threshold values, where a low*

begins and a high...It's completely different to a toddler or ...to a pregnant woman. So, if you would have hard coded when it's a low or a high, that's just not going to work." Participants also suggested new features that could improve the final product. P7 suggested *"You could (integrate) weather...so you see you're going to your workplace and you're using a bicycle, but the wind is very strong today, so probably your blood sugar will go down...That would be...information I did not have before."* P9 also found this connecting of data to be a compelling feature, especially if it helped to connect *"...objective information with my subjective analysis...that could be really helpful."* P9 added another example, *"I have a lot of days where I just sit in the office and I don't move a lot. And, for me, it would be helpful...to get the information ...on Mondays you're super busy and that just wreaks havoc on your blood sugars."* P9 also thought some sort of intelligent reminder might be a compelling feature, *"...it could be really helpful when it learns that I go to this place (yoga class) every Tuesday. I'm active and I always go low. It could be really helpful to have this reminder a few hours earlier to actually make the decisions more seamless..."* P9 also suggested that the app could ask questions when detecting outliers, which could help form a valuable record for retrospective analysis, *"... the typical endo appointment (they look at your graph and ask) "Okay, on Tuesday 22 March, what happened there? You went low." That makes absolutely no sense, but the app can do that in a really seamless way, if I feel like answering that question, "Hey S., you went low, half an hour, glad you're feeling better now, but what was that about?"* P9 continued, *"And then I can say, "This was my own fault." Like I mis-calculated or I worked out and I didn't realize that I had to eat something or maybe it was the weather. And, then, based on that, if I actually feel like it's worth giving the data, putting in all that extra effort, then maybe I can in the end, enjoy the benefits of this additional knowledge...if we, actually, gather data in a useful way, this could be something I would use in the long run."* P8 noted that while live-streaming to the clinician is *"...useless, but if ...you have the appointment, those insights are really gold..."* Towards the end of the session after considerable discussion on customization P9 suggested that the product might need to clearly define a subset of the population, *"...it's worth deciding on a target group and making harsh decisions and accepting that either this won't be used by me, because it's too simple and it doesn't give enough information, or it won't be used by them, because it's too complicated." **Emotional impacts:*** Participants discussed the ways in which apps could be annoying or stressful. P9 noted *"even if I find one tool within this really useful, if the others annoy me... I will never use it again."* And was concerned that having so many devices could lead to such problems, *"...if I go low...I already have my CGM giving me an alarm. If there are like five apps at the same time telling me to do something and then if I don't react quickly enough it will give an even worse alarm and call my boyfriend...it won't be useful."* And P4 was also concerned about too many messages and the importance of careful selection criteria, *"I think it will be important to highlight some messages... I would be really annoyed if I got like 10 messages every few hours and I think I would delete it, because I hate apps that do that."* Participants also stressed how the wording of such messages could create unwanted affective interactions, and how sensitive they can be to such interaction. P9 *noted "I think language is really important...if it's*

worded in a negative way that puts blame on me in any way, I would immediately stop using it. I would not like to use it if it calls me a diabetic, for example, instead of person with diabetes." And, *"I would not like...anything that sounds like I don't have a choice, like, 'Do this, do that.' I think the actual structure and the wording of the suggestions is really important, because if I feel like I'm being governed by this app and it tells me to do this immediately, that's the kind of language that would need to be reserved for very specific situations..."* But P9 also felt that such interactions *"should give me an option but shouldn't be any kind of authority."* P6 suggested that to avoid such tones *"Maybe it could ask questions, if this would be better than to say, "Do this, do that."* Although P9 was resistant to the approach, sharing *"That's also a really, really individual thing, like I hate that kind of thing, if it's a chat-bot, I know that so many people really like it, they feel that it's more personal and more attainable. I hate it. If the machine acts like a person..."* Participants had some concerns about use of color. P8 felt that Red should be used sparingly as *"...it's like you did something wrong, error. It's an emergency color."* P9 suggested that red should be reserved for *"when I'm below 60."* And that perhaps shouldn't be used at all *"...for high blood sugars. Like, I know I'm high, I know that pizza is still somewhere there and I'm dealing with it. And the color red should only be used as an exception really."* Besides general concerns with data privacy, there were also concerns on trusting medical products. P9 said, *"...I'm not sure if it needs FDA approval...but some kind of certification, because that was my first question or my first idea. Like, how does it actually analyze these things? Like, what's the algorithm? Who designed it? Why? With what goal in mind? And how can I be sure that it's, actually, scientifically sound? So, why should I trust, not only the company with my data, but why should I trust the information that it's giving me."* **Behaviors & Actions:** Elaborating on the developers' initial concerns about actionability, P9 suggested *"...instead of lunchbreak in the kitchen, which involves 20 steps maybe, go for a walk and get lunch outside, something like that...take it a step further and analyze and come up with a specific action that could help me."* **Cognition:** Simplicity and ease of use was desired. P7 said *"If I have to sit there and read everything and give numbers and push, 'Okay' etc., if it gets too complicated, I won't use it."* P7 likewise noted, *"It consumes less time if I see everything with one look and I don't have to scroll over to the other things."* P8 stressed the importance of making interfaces usable by lower education users, *"...not everybody is able to read graphs. So, I guess, the majority of us who are designing these products have a high school education, but the users most likely don't...So, is there a way to visualize it in a way that they would still understand?"* And P8 was especially interested in system that helped the individual learn more about what factors affects diabetes management, *"So, I think there's a big potential in finding out what, actually, has an impact on you as a person. And, again, this is different for everybody."* **Consent & Control:** Participants had mixed opinions on the use of GPS tracking. P7 stated, *"I don't want people I don't know knowing my whereabouts."* But in contrast P9 felt it to be a question of benefits *"...If it's...used in a way that's beneficial for my diabetes therapy, I ...would, potentially... go for that trade-off..."* P8 was also unconcerned about GPS tracking *"...because a number of my apps do that already."* However, P8 elaborated *"... I would be concerned about the*

way (GPS) is used... it suggested (to) me to go to a mozzarella place. So, this is not really diabetes related. So, I feel like the suggestions the system would give you based on your location and your CGM, should not be something that pushes you to spend money." And P8 continued, *"...it feels like advertising and I don't want to be used for that, just because I have diabetes."* In terms of data sharing, P8 suggested that *"It should be modular, just like everything in the system. Like, for example, if I would like to let my doctor have access to my CGM readings and the insights, but not let them see my GPS all the time. Also, for partners or parents, it should be completely optional when you would like to track which."* Noting *"...I like my partner having the option to live track my glucose levels, but not my doctor. I don't want my doctor calling me because I'm low or I'm high."*

8.7.5 Summary of user session

In general, the users appeared able to draw upon their experiences to give more detailed examples than the developers. For instance, while the developers questioned *"How do we incorporate manual feedback for automatically recognized activities/ habits ...?",* a user suggests *"Are you cycling to work today" where is the 'yes' 'no' button. Just want to answer fast and put the mobile phone back in my pocket."* Or while a developer noted *"The user may not want to be bothered about their condition at",* a user explained *"...therapy has to get better and less thinking... otherwise (we) won't see the reason to use it."* Or while a developer might be concerned that *"Parts of our technology might be hard to explain",* a user provided insights towards desired answers *"...how does it actually analyze these things? Like, what's the algorithm? Who designed it? Why? With what goal in mind?"*

8.8 Third focus group: Developers Review and Discuss Previous Sessions

In the final session the developer team reviewed their original responses as well as the results of the PWD user session. Upon the start of the session, the developer team stated that in the intervening 7 weeks since the initial session, their company had undergone a large pivot. P2 noted, *"We changed the concept to focus on diabetes Type 2 and focus on habit formation. This happened as we felt the previous concept was not compelling enough and did not address a true need."* And P1 added *"...Type 1 diabetes ...we don't know enough about it."* P3 listed that they had concerns that *"Availability of data was not very good, Unclear what problems we were solving, T1 people have very heterogenous needs."* P3 noted that their first session *"... helped catalyze our decision to shift our product concept."* Upon reading over the user responses, P3 observed that their initial session had successfully identified the majority of high-level issues, while the user session had offered deeper insights into features. P3 added, *"I think getting this kind of user feedback can be very beneficial, but our old concept was in a very early stage. Maybe too early stage for this kind of feedback. I don't think it was really clear what we wanted to achieve with our concept."* One of the developers noted that they thought the DUETS process would offer more benefits with frequent brief sessions.

Summary: The developer group was positive about the first session for helping them to realize the flaws and shortcoming of their app concept. They concluded that due to technical limitations beyond their control, the abundance of T1 requirements, and their insufficient domain knowledge, they should undergo a significant product pivot.

8.9 Discussion Duets Tool and Process

This chapter has proposed a method for organizing insights gathered through diverse research methods into *Concerns* cards, which are then used with other cards that assist with creating a light-weight visual prototype of complex health system architectures. The aim of this approach is to engage diverse stakeholders with focused critical reflection and ideation on complex health eco-systems. The following sections is structured through discussion of this section's research questions.

Q1. Is the DUETS approach useful for assessing and generating new ideas for early-stage next generation apps both with developers and potential users?

The initial session helped the developers to understand design challenges inherent in diabetes decision support systems and they credited the process with helping them to confront critical gaps between their concept and a desirable product. DUETS components drew attention to the need for increased understanding of their user, as well as serious product design flaws. These issues were clarified to such an extent that it became apparent to the developer team that they had neither the knowledge nor technical capacity to meet actual needs effectively. Such critical product assessment could benefit developers, since the competition posed by the great number of diabetes apps already on the market heightens the value of 'failing fast' before significant investment. The patient sessions appeared useful for in-depth analysis of concerns and generating ideas for new features. Within the limitations of this preliminary evaluation (noted in *Limitations*), the DUETS system appears to provide a usable framework for assessing the featured prototype.

As the developer focus group identified the majority of higher-level patient user group concerns, it appeared useful for helping to anticipate more general user concerns. It might be suitable for initial assessment, which could be followed by user focus groups *after* initial concerns have been located and solved in house, and when developers are looking for *more in-depth insights*, or are searching for new features. It is worth emphasizing the continuing challenge with health product development in the distance between system designers and users. The intention is that DUETS can provide a suitable tool for bridging this gap, and therefore it is critical that additional testing is done with additional stakeholder groups to assure communication between the full spectrum of system participants.

Q2. Did DUETS add value over the Kientz et al. heuristics? If so, in what ways?

DUETS appeared beneficial for suggesting concerns not previously known nor located by the Kientz et al. heuristics, with both the developers and patient group discovering many additional

concerns. In addition, it helped the developers to confront that products of this kind might be greeted with suspicion by users, and the consequent need to actively build trust with users, and the need for clear statements of purpose.

Another issue that needs further research relates to why the Kientz et al. heuristics did not necessarily lead to concern identification even when referenced. For example, the concern related to "*incorporating manual feedback*" might be seen as implicit in Kientz et al. *Heuristic 6*, that states that the technology should allow manual editing or updating of data. And concerns that the app could interfere with autonomy might be inferred from *Heuristic 10*, which refers to the need to educate users. Explanations for missing these concerns at the heuristic analysis stage might be that these heuristics were developed for expert evaluators, and the developers and patients lacked the knowledge to fully exploit the heuristics, or alternately that the density of the heuristics inhibited their effective use. If the latter were true, breaking the heuristics down into shorter sentences on cards might help to alleviate this problem. This suggests that further research is needed to clarify the extent to which the Kientz et al. heuristics are well-suited to a non-UX professional stakeholders, especially if they are adapted into the DUETS cards.

Q3. Would visualizing a system (Architecture and Attributes Cards used with Concerns Cards) add value over using the Concerns Cards alone?

Despite apparent benefits, specifically for helping to draw attention to data privacy and transparency concerns, there was some uncertainty on the effectiveness of the *Architecture cards*, which should be addressed by further studies. This could be done with a between-group study, with one group only using *Concerns cards* compared to the other using *Concerns cards* and *Architecture cards*. The patient session with the *Architecture* cards did produce many concerns, though this could have been due to the engaged conversational nature of this session. Further research is needed, especially as to process optimization.

Q4: In which ways could DUETS be improved to increase utility?

As DUETS is intended as an *expandable modular approach*, the work presented in this paper should be seen as a starting point requiring further development, especially in regard to other use-cases. In addition, care must be taken that it doesn't frame discussion so as to restrict outcomes. Therefore, these cards should not be seen as comprehensive nor a substitute for all other research methods, but rather as a way of operationalizing acquired knowledge on user requirements. For example, the *Concerns* cards might need additional cards when used with other health conditions to better reflect domain specific needs. This could be accomplished through adding concerns identified through other research methods, as well as concerns that emerge through DUETS sessions. It is therefore important to not restrict exploration to the current *Concern* cards. The *Architecture* cards might also require supplementing, to reflect additional devices or services. Likewise, the process for integrating DUETS into actual product development workflows requires further development. A worksheet or set of instructions might be added to increase utility. It is also important to draw attention to what DUETS is and what it is not. For example, there are user

requirements that might emerge only with actual long-term product use which emphasizes the importance of investigating contexts of use or appropriation within real life. Perhaps the current system might integrate a more open or less literal architecture to allow for better addressing such issues or suggesting supplementary research methods.

8.10 Future Work

DUETS is an *expandable modular system*. The use of cards could be customized, for example by the inclusion of additional cards to reflect identified needs. Concerns identified by developers could be added to the *Concerns* deck either for in-house discussion after iteration, or to elicit feedback from other stakeholders. Likewise, *Architecture* cards could be easily added to, reflecting new devices or services. While DUETS supported concerns identification, further development is needed. The Kientz et al. heuristics elicited many concerns, especially with the developer team, and could be directly incorporated into the *Concerns cards*. The *Behaviors & Actions* category elicited the fewest *Concerns* and might benefit from additional cards or clarification. Despite apparent benefits, specifically for helping to draw attention to data privacy and transparency concerns, there was some inconclusiveness on the effectiveness of the *Architecture cards*, which might be addressed by further studies. This could be done with a between-group study, with one group only using *Concerns cards* compared to the other using *Concerns cards* and *Architecture cards*. Given the bio-ethical implications of decision support systems (Meredith and Arnott, 2003), the framework proposed by Beauchamp & Childress (Beauchamp and Childress, 2001) might be an alternative to the current criteria, with augmentation for privacy and security (Wright, 2011) and technical features. System usability might be improved by reducing the number of *Concerns cards*.

8.11 Limitations

This study is an exploratory case study. No claim is made regarding a rigorous comparison between methods. The small sample size limits the generalizability of conclusions. The sessions did not randomize procedure order, which could influence the quality, quantity and ratios of identified concerns. The user group was an engaged and technology aware group, and their insights might not be broadly representative. The researcher brought prior knowledge which could have influenced outcomes; the utility and usability of the DUETS system without such support might be different. DUETS was developed for a diabetes use-case and therefore might require additional or different cards for other health conditions. Some apparent benefits of DUETS might be due simply to use of a question-based rather than a statement-based format. The added benefits of the *Architecture cards* as opposed to using the *Concerns cards* alone requires further investigation given the small sample size and variables. The proper assessment of the value of the DUETS system for helping to support more user-centered, emotionally sensitive, and transparent systems requires further development both for the cards and their method of integration into design processes. In general, the system

needs further refinement to lower cognitive effort. Further testing and iteration are called for throughout.

8.12 Conclusions

Through three sessions, the first and third with the developer team of a funded startup, and the second with a motivated user group, the DUETS tool was assessed for its ability to assist in the location of concerns which could impact the effectiveness of multi-component user-centered health systems. In the initial developer session, DUETS contributed to the team identifying, in under 2 hours, critical failings in their app concept, technical limitations, and domain knowledge which, by their own account, led to the decision to make a substantial pivot. Supporting such early strategic decision-making can be valuable, given the high costs associated with developing functional medical systems. The session with potential users validated the developer's concerns, added in-depth experiences that supported the reasoning behind these concerns, and identified many suggestions for potential features. Within the limitations previously outlined, these sessions evidence how the DUETS tool can be used as a method both for developers to critically examine their assumptions and concerns for early stage products, and for potential users to offer critical and constructive critiques.

DUETS appeared successful in drawing attention to the high-level concerns related to functionalities, emotional impacts, and cognitive demands, as well as drawing attention to user privacy and security concerns, in particular emphasizing the need for product transparency. The DUETS process drew attention to aspects of requirements for user-centered design, such as greater integration with stakeholders and their needs, and clear identification of true user problems. Given that the DUETS tool helped the developers to locate many of the high-level concerns held by the user group, it may have a useful role in helping developers to locate user concerns during early stage development. Following subsequent prototype iteration, DUETS may provide utility in the design process to elicit and marshal in-depth critical stakeholder feedback.

In summary, DUETS offers a modular card-based method, readily expandable and tailorable, that can be used to visualize and assess multi-component health systems that involve a complex ecology of devices, services, and stakeholders. By facilitating an overview of the information flows between components, stakeholders, and services, as well as considering resultant implications, this approach could support developers and other stakeholders in assessing relationships, identifying concerns, and suggesting new features for next generation health support systems.

Chapter 9: Conclusions

Chronic health conditions are burdensome both to those afflicted as well as stressing health systems worldwide. Ubiquitous computing technologies offer diverse opportunities to improve treatments for chronic health conditions. This thesis has focused on improving the process whereby these technologies are used to gather and process data to supply targeted information to inform better decisions. Type 1 diabetes is a compelling use case to apply such capabilities due to both its severity and need for each individual to make frequent self-care decisions informed by complex data. Yet, the dominant app-based approaches based on effortful reflection on collected data have shown poor adoption (Chapter 4), lack needed cognitive and emotional support (Chapter 5) and are not well tailored to users' actual diabetes decision making processes (Chapter 6). A next generation approach that leverages wearable sensors and automated data processing could offer more explicit support for daily care; however, these more comprehensive systems bring with them a range of user concerns such as privacy, emotional impacts, trust, autonomy, security and others, which could inhibit adoption (Chapter 7). Therefore, the development of next generation systems requires practical methods to make sure that such concerns are properly addressed. Such methods could potentially support developers in anticipating user needs, while helping diverse and potentially non-technically knowledgeable stakeholders to understand complex technologies so they can participate throughout the design process (Chapter 8).

To summarize: this thesis began with anecdotal observations that existing T1 diabetes smartphone apps were not meeting user needs. Through a series of user studies, diverse reasons behind this shortcoming were uncovered. Finally, these findings were integrated through an iterative design process, suggesting a method for alleviating or avoiding these pitfalls in next generation systems. In this concluding chapter we discuss:

- Answers to each of the research sub-questions (Chapter 3.1) and review the principal findings and outputs of Chapters 4-8
- Primary contributions of this thesis to diabetes care as well as wider implications
- Overall research limitations
- Future work
- Concluding remarks

9.1 Research Questions:

The beginning of this thesis asked the research question:

"How can we improve the practical utility of diabetes apps from a user-centered perspective?"

This question was then explored and addressed through the following five sub-questions which will be attended to in turn:

9.1.1 RQ1: Are diabetes apps actually meeting user needs, and if not why not? (Chapter 4)

This question was addressed through a questionnaire, with demographic questions to establish user characteristics, and open-ended questions that asked participants to reflect on their previous experience with diabetes apps. While most participants reported that there were benefits to diabetes apps, the majority had stopped using them. And of those who continued with use, only a small number were using them as part of daily management routines. Despite this, these apps were successful in meeting specific needs for some users, such as tools for recording data before meetings with clinicians or visualizing collected blood glucose measurement data to provide overviews. This suggested workable areas of utility which might be built upon in future apps.

Workload in using the apps, especially in relation to benefits, was the most reported area in need of addressing, with many users expressing the desire for additional automation. However, in the case of apps which already delivered such functionality, automation of blood glucose value input alone did not appear to be sufficient to promote frequent use. While not expressed as the primary reason for abandonment, and without having been prompted, 50% of users reported negative emotional impacts of using these apps. Given the evidence resulting from this study, despite some positive user assessment, this generation of diabetes apps appears insufficient for supporting user needs, especially as tools for daily care. This prompted the subsequent study to gather more in-depth knowledge as to how users interacted with these products.

Principal findings and outcomes of RQ1

The principal findings and outcomes which resulted from addressing this question included:

- Knowledge of specific barriers to the adoption of diabetes apps.
- An n=26 data set of people with T1 diabetes user characteristics; and their experiences with a specific generation of diabetes-specific and other apps.
- Insights into areas in need of further investigation and improvement for diabetes self-management apps.

9.1.2 RQ2: Are the standard user interface designs of diabetes self-management apps sufficient for decision support or are there inherent design flaws ? (Chapter 5)

The previous chapter suggested that there were specific flaws with the approach of diabetes logging apps. However, there were unanswered questions as to whether the primary flaw was in the workload associated with data entry which could be solved through automation of data entry. Therefore, I used a talk-aloud study to investigate the capabilities of diabetes logging app UIs to support user interactions with already entered diabetes relevant data to isolate the sensemaking process. This approach led to a detailed characterization of the benefits and limitations of diverse

UI elements in this context, as well as identifying specific areas in need of further consideration for next generation systems.

This study revealed, through analysis of participant responses, several positives in current app interface designs. Namely, these interfaces were capable of helping people to reference data, to attach high-level meaning to specific data points, and were in most cases usable. They were also found well suited to giving broad overviews of condition management. However, despite these benefits, the examined logging app interfaces appeared to have two principal areas of failure. Firstly, these apps require too much cognitive effort to make sense of data and to locate meaningful insights applicable to treatment decisions. This exposes users to visual confusion and cognitive overload. Secondly, the complex emotional relationship users have with their data appears to have been inadequately considered by designers. Neglect of this aspect of app design can lead to demotivation and interaction avoidance. Analysis of these interactions suggests three principal design challenges for next generation apps: more active support for users to gain utility from their data, methods of building and triggering the user's self-care models, and increased emotional sensitivity related to interaction with undesired data.

Principal findings and outcomes of RQ2

The principal findings and outcomes which resulted from addressing this question included:

- Empirical evidence for the benefits and limitations of specific and frequently used data visualization UI designs.
- Specific design challenges for next generation health management apps.

9.1.3 RQ3: How could apps better support user decision-making processes? (Chapter 6)

Evidence collected from the user-interaction study discussed in Chapter 6 led to positing a refined version of the Mamykina et al. (2.1.7) model for diabetes self-management to better account for observed practices. After this refined model was characterized based on available evidence, an online survey of demographic and open-ended questions on diabetes management practices in varying contexts was conducted to further investigate its validity. The expanded model defines three cognitive states: the previously accepted *habitual* and *sensemaking* modes, augmented by the newly proposed mode '*Fluid Contextual Reasoning*' (FCR) which describes a process of balancing multiple contextual factors using previously learned knowledge, thus allowing for dynamic course correction when navigating complex situations. This expanded cognitive model provides both an answer to the question posed for this chapter, as well as a UI design framework for next generation diabetes management systems that will offer more active decision support.

Principal findings and outcomes of RQ3

The principal findings and outcomes which resulted from addressing this question included:

- An expanded self-management model that builds upon previous academic work to define an under-represented cognitive process.
- A proposed framework to apply this model to assess existing self-management UI's as well as to support the design of next-generation diabetes self-management UI's.
- An n=192 rich qualitative data set of patient responses detailing methods and practices of diabetes self-management. This data set could be further mined to provide guidance to apps that seek to support self-care learning and activation of appropriate behaviors.

9.1.4 RQ4: What user concerns need to be addressed when developing a next generation app approach that relies on multiple networked monitoring devices? (Chapter 7)

Previous chapters suggested the need to minimize workload while still delivering information that could support complex decision making in an emotionally sensitive manner. Multiple networked sensors appear a likely component of an approach for meeting these needs. However, the lack of currently functional systems of this kind restricts current empirical knowledge of user concerns resulting from such comprehensive health and behavior monitoring. In order to help fill this gap, a 4-week technology probe in which participants were outfitted with multiple networked devices with external data aggregation established a setting and altered context to user routine. This enabled investigation of user perceptions of such monitoring, and thereby insights into user-centered requirements for development of this intensively networked approach.

The results of the probe showed that study participants showed awareness of the risks of sharing their data, with many concerned about commercial exploitation. While some participants were willing to use GPS services for specific purposes, many were wary as they perceived emotional, safety, or financial risks. Many participants perceived their blood glucose data as containing sensitive insights into their lives. Sleep data could be perceived as sensitive, requiring permission and purpose for sharing. Exercise data appeared less sensitive than other types, though there were some concerns mentioned around commercial vulnerabilities.

While participants were generally open to sharing much of their data with medical professionals, many expressed a desire to understand the purpose and benefits of specific cases of sharing data while expressing that personal relationships were an important aspect of this sharing. This could suggest that systems that collect data for use by medical staff should offer user education and transparency as to potential benefits, or alternately avoid real-time sharing and instead focus on tools for delivering aggregated retrospective insights at the time of appointments. Many participants expressed distrust of the motivations of their insurance company and were resistant to granting insurers access to their personal data, especially without transparency of purpose. If insurance companies want to promote the use of personal tracking technologies, they might need to find ways to establish better personal relationships with customers through a greater sense of

shared purpose, or to find ways to assure users that their data is protected from access for insurance evaluation. Analysis of the study responses drew attention to specific concerns related to the following: added workload and adoption, emotional impacts of monitoring, unwanted or distressing information, stigma, differing relationships of trust with doctors and other stakeholders, trust, personal preferences, transparency, privacy, and economic security/vulnerability. This study suggested that users have considerable concerns about such comprehensive monitoring, and while they might accept certain risks to gain benefits, failure to address these concerns properly could create additional psycho-social stresses upon users or lead to devices abandonment. The diversity of user needs and complexity of such systems suggested the need for tools to help support the design process.

Principal findings and outcomes of RQ4

The principal findings and outcomes which resulted from addressing this question included:

- Evidenced information about attitudes towards sharing specific kinds of personal data with different stakeholders.
- Evidenced information about user attitudes toward the use of specific kinds of monitoring devices.
- Evidence of how participant attitudes towards sharing of personal data are influenced by external monitoring.
- A list of user concerns that could be applied to heuristic analysis of next-generation health monitoring systems.
- Four suggested software solutions to help mitigate user concerns related to the use of health monitoring systems.
- A potentially novel method for visual analysis of change in individual and group attitudes over time. This method is readily applicable to other qualitative research containing participant attitudes and could be used for ordinal data.

9.1.5 RQ5: How can we systemize these concerns to help developers address high-level requirements to avoid the production of non-user-centered apps? (Chapter 8)

The previous chapters explored diverse user concerns and requirements for diabetes support systems and drew attention to specific ways in which current diabetes app approaches have not properly reflected these needs. The preceding chapters also asserted that a likely path forward depends on systems capable of delivering more active decision support in a manner which compliments user's existing cognitive processes. Given the complexity and diverse potential negative consequences of such an approach, this chapter sought to develop a practical method to apply the findings of this thesis to the design of such future systems. This resulted in DUETS, a

card-based system to facilitate stakeholder reflection and critical discussion on complex diabetes management systems. The following paragraphs briefly review the components and design process.

- The findings of the thesis were organized into five categories of user requirements for self-management technologies: *Adoption & Utility*, *Emotional Impacts*, *Behaviors & Actions*, *Cognitive demands,* and *Consent & Control.*

- These concerns were then implemented through an iterative design process to develop a card-based system to visualize, assess, and modify multi-component health systems.

- This system was then applied to two focus groups, the first with a team of developers and the second with a group of people with T1 diabetes. These sessions evidenced the suitability of the DUETS tool for two different but related purposes: firstly, as a method for developers to critically examine their assumptions and concerns for early stage products, and secondly for potential users to offer critical and constructive feedback on multi-component systems.

- DUETS showed evidence of drawing attention to at least two kinds of relevant concerns: firstly, high-level concerns related to functionalities, emotional impacts, and cognitive demands, and secondly user privacy and security concerns. In particular, DUETS highlighted to designers the need for product transparency. More generally, the DUETS process drew attention to diverse results of the research conducted for this thesis, in this way supporting the developers in understanding the importance of integration with stakeholders and their needs and helping the developers to identify user concerns.

In the first focus group session, the DUETS tool helped the developers to locate a majority of the high-level concerns held by the user group, thereby demonstrating that it could be effective in helping developers to locate user concerns quickly during early stage development. This second session demonstrated that DUETS provided a tool and method for explaining complex systems to patient stakeholder groups and assisting in structured constructive discussion. In these various respects, the DUETS method contributes to an answer to the research question.

Principal findings and outcomes of RQ5

The principal findings and outcomes which resulted from addressing this question included:

- Five categorical criteria for assessment of user-centered health systems.
- A set of questions which have been applied both as developer heuristics and to focus stakeholder discussion.
- A flexible and extendable card-based system for visualizing, assessing, and modifying multi-component IoT systems, usable both by system designers and other stakeholders.
- A tested process for applying the DUETS system to help locate user-centered concerns.

9.2 Primary contributions of this thesis

While the previous section summarized the findings and outputs of this thesis, this section will summarize the principal contributions of the thesis. These are organized first by contributions specific to diabetes in relation to human-centered computing literature, followed by contributions with broader implications.

9.2.1 Contributions specific to diabetes

The thesis provides the following primary contributions to knowledge to support the further development of apps and other tools for decision support for diabetes self-management.

- This thesis provides the first systematic empirical evidence that apps that rely exclusively on tools for collecting and reflecting on personal data fail to adequately support the diabetes self-management decision making process, and the first thoroughly evidenced characterization of the principal reasons for that failure. Stemming from this contribution to knowledge, the thesis also provides a practical contribution to improving future apps by drawing attention to the faulty but widespread design assumption that users primarily desire new tools to record and view additional data. Indeed, the predominant approach in the existing literature to improving such apps focuses almost exclusively on new tools for supporting the *sensemaking* process (Smith et al., 2007), (Owen, 2011), (Storni, 2014), (Owen et al., 2015) but crucially does not into account that people with diabetes are already overburdened by their data.

- A systematic account of the specific benefits and limitations of widely used methods of visualizing diabetes data. This contribution to knowledge also serves as a contribution to practice by providing reference for designers for appropriate use in designing decision support tools for diabetes self-management and was previously absent from the literature.

- An expansion of Mamykina et al.'s Sensemaking framework to better represent participant's apparent cognitive processes. The expanded framework suggests a means of interpreting existing products and explaining specific ways in which they fail to support reasoning processes. The framework also acts as a tool for designers to extend current products to better support user needs.

9.2.2 Contributions with implications beyond diabetes

Beyond diabetes, this thesis has contributed a conceptual framework for the design of decision support systems applicable to a wide range of domains where individuals must make real-time decisions informed by complex data in a manner that augments rather than replaces user reasoning. In contrast with previous work based on a dual process cognitive approach for supporting cognitive processes, this thesis characterizes a previously little explored third option. Technology designs based on the dual process model limit themselves to targeting either conscious and effortful learning or triggering unconscious and reflexive action. By contrast, this thesis has identified recurring user behaviors not well characterized by the dual model, that balance and combine

elements of both poles. The thesis has explored ways in which designers might support such user behaviors, thus providing new benefits while reducing cognitive costs, thereby supporting continued tool use. The new approach does not seek to replace previous approaches, but rather to complement and expand the options for designers and users. This approach has relevance to the self-care of demanding chronic conditions generally, as well as to other situations involving the need for rapid real-time decisions informed by complex data.

It is instructive to consider this wider contribution in the context of the wider literature. In the foundational period of ubiquitous computing Weiser (Weiser, 1991) advocated for "calm computing" where small computers embedded throughout the environment could anticipate and satisfy user needs. Rogers (Rogers, 2006) questioned this approach advocating instead for the importance of engaging and empowering users. Both Li (Li et al., 2011) and Mamykina et al. (Mamykina et al., 2015) integrated aspects of both these approaches, noting the benefits of reflexive action for maintaining routine and in-depth reflection to support learning. This thesis recognizes both of these aspects as important but advocates an extended and more balanced approach by the inclusion of tools that support a middle ground. This involves working with the user to lower the effort required to determine responses to complex situations while retaining active engagement.

9.2.3 Key questions for diabetes app designers

This section lists key questions for diabetes apps and decision support systems derived from the research conducted for this thesis.

Functionality

- *Have you considered the full range of stakeholders who will in some manner interact with this product? How can all their needs be balanced while still addressing the needs of the primary user?*

- *Does the product in any way add to user daily workload? If so, how can you assure that the benefits exceed time invested, especially in the early stages of use?*

- *If this product is intended for situated decision making, could the user be better served by more pre-processed data or more glanceable information?*

Emotional Impacts

- *How can we design emotionally sensitive interfaces that draw attention to important but unwelcome information while continuing to engage the user?*

- *Are the design choices such as color, sounds, and interface elements motivating or demotivating? Are they sensitive to the feelings of the user within different contexts such as date, job interview, public space, etc.? How has this been tested in a way appropriate to intended usage?*

Cognition

- *How do we design UI's and interactions that can help users learn and retain a personal library of beneficial behaviors for managing specific situations?*
- *How do we design UIs that trigger the user's acquired knowledge at the appropriate time?*
- *How can we make it cognitively easier for users to consider their context when making decisions?*

Privacy and Security

- *Does your business model involve using individual's personal data for targeted marketing or use by 3rd parties? If so, is it possible for you to consider an alternate business model?*
- *Do you consider the patient the primary stakeholder? If not, how is this justified and is the reasoning fully transparent to the user?*
- *Is the information collected by your system visible to or accessible by any stakeholder other than the primary user? If so, how do you:*
  -Enable user to pause monitoring in sensitive contexts?
  -Allow user to control which and how data is shared?

Behaviors & Action

- *How could your system support the user's self-care actions becoming more independent from the system over time?*
- *How can a system help to reinforce already existing positive behaviors?*
- *Could this product interfere with the user engaging in necessary actions? If so, how can this be minimized?*

9.3 Research Limitations

Due to the diversity of research carried out in this thesis, research limitations have appeared at the end of each of the research chapters. While to repeat the full list of these limitations would be impractical, there are some limitations which have acted as reoccurring themes throughout this thesis and are therefore worthy of reiteration.

While diabetes rates might soon be approaching nine percent of world population, people with Type 1 diabetes are estimated to constitute only five to ten percent of this group; therefore, since they constitute less than one percent of the general population, finding people with T1 diabetes willing to participate in technology-oriented user studies poses recruitment challenges. The recruitment methods often drew on those already active with, or interested in, diabetes technologies. This may have caused biases which restrict broader application. In addition, these recruitment challenges led to some participants appearing in more than one study, which may have also introduced biases related to familiarity with the subject matter. Thematic sorting and selection of interview quotes to discuss may have introduced confirmation or selection biases, however as these quotes have primarily been used to draw attention to the existence of user concerns, the primary limitation would be in omission rather than commission – by contrast, in the chapter 6 FCR study, where statistical claims were asserted, a second coder was used to validate the coding

methodology and establish inter-coder reliability. While this provides a level of validation, the FCR model has not been validated as a cognitive model by measuring cognitive load, for example by measuring pupillary response (Iqbal et al., 2004). Finally, since all research was conducted exclusively with people with Type 1 diabetes, generalizability of findings to those with T2 or other forms of diabetes, as well as to more general health and wellness requires further investigation.

9.4 Future Work

This thesis stemmed from an observation about the non-adoption of a class of apps. It addressed many questions as to why this was occurring and considered how future systems might be better designed. Many questions remain. The following section discusses future work arising from the research.

9.4.1 Empirical validation of the FCR model to move towards a theory

This thesis has hypothesized that *FCR* exists somewhere between *habitual* and *sensemaking* in terms of cognitive load. A natural next step would be to further investigate FCR as a cognitive model, and further develop a design framework that could be applied to develop new UI's based on this work. Such UI's might have adaptive elements which support each of the three modes in turn, dependent on contextual requirements. Potential research questions might include:

- Is there a measurable and reproducible spectrum of cognitive load demand related to interacting with specific smartphone interfaces and paradigms?
- What are effective techniques of measuring such cognitive load within situated contexts?
- Is ideal cognitive demand context dependent, and if so, how can this be determined and applied in a practical way?
- Given sufficient delivered value, would optimizing cognitive load demands to context increase adoption?
- Is it possible to design UIs for the different cognitive demands suggested by the FCR model?
- Might Shannon's information theory have a role to play in optimizing such interactions?

9.4.2 Refining the DUETS system

The DUETS cards introduced in Chapter 8 would benefit from further development. New specialty *Concerns cards* might be added, such to draw attention to specific domains such as ethics. The work of Wright et al. (Wright, 2011) could provide a useful framework. Another approach might be to move from a paper-based system to software, which could enable additional functionalities, such as:

- *Tool box of objects:* DUETS could offer a large selection of sensors, devices, and services which could use a drag and drop method to visually build systems.
- *Data streams:* The above components could have their potential data streams already built-in, thereby prompting options to assist system visualization.

- *Intelligent concerns:* Visualized systems could suggest concerns for stakeholders to reflect upon, for example warning about potential risks to privacy or security from specific sensors being connected to specific stakeholders.
- *Implementation of services:* The user services suggested in Chapter 7 (Real time Data Flows, Data purpose resolver, Data Blurring, Tailored reports) could all be integrated into the DUETS systems, either for purposes of discussion, or eventually as a tool kit to help users visually control and construct their personal health network. Potentially this could move DUETS from a research tool into personal software. Great care would have to be taken to allow this system to offer the usability required for non-expert configuration and use.

Research questions include:

- Might some form of gamification make the system more enjoyable to use?
- How could the card system be improved to make it easier to use?
- Could the concerns question set be expanded and categorized so that a given system configuration would suggest certain specific questions?
- How could DUETS be expanded to analyze feedback loops?

9.4.3 Ethical assessment of diabetes systems

As discussed earlier, the DUETS system was originally conceived to assist with ethical assessment of diabetes management systems. There are diverse questions that emerge with active algorithmic decision support in a health care context. Some examples might include:

- Is it ethical for a company to only allow their service to be accessed if the user gives consent to have their data collected? This could be considered extortive in certain medical situations and therefore non-ethical.
- In the case of personal health systems that monitor and aggregate personal data, is adherence to the EU General Data Protection Regulation (GDPR) sufficient for protecting the user?
- Are financial penalties for risky behaviors, such as visiting a high-risk location, ethical? Is it permissible for health systems to restrict certain user behaviors in exchange for coverage?
- What is the balance between encouraging healthier behaviors and infringing on autonomy? Does the use of interventions in cognitive biases constitute unethical manipulation? How can such system reflect user preferences, given that many users might not understand or have little desire to engage in complex system configurations?

9.4.4 User-centered AI

The next-generation approach suggested in this thesis will require AI algorithms that can process collected data and offer personally relevant suggestion. Despite the promise of automating human

cognitive processes, there are significant barriers to successful implementation — and the potential for adverse effects on users and society. Challenges for designers include insufficient or inaccurate data for training or analysis, problems in identifying and communicating contextually relevant and personalized usable insights, developing interpretable ML algorithms, and avoiding algorithms that can spread destructive biases. Overcoming these limitations will require careful understanding and integration of diverse processes behind interactions with human users, so that systems can appropriately support human cognitive processes, psycho-social requirements, and complement the needs and goals of individual users. Relevant research questions might include:

- Which ML techniques will produce the best results for extracting meaningful and actionable insights from personal data to support a given chronic health condition or optimize a desired beneficial behavior?
- How is the relationship between the system and the user designed to optimize transitions between system automation and required user intervention?
- How can systems prompt users for needed training data in a manageable and sustainable manner?
- What assurances are required for the user to trust the system?
- How can systems be developed to support and augment cognitive processes while developing user autonomy?
- What are the requirements for the user-centered design of AI-augmented networked pervasive health systems?
- What are effective methods of evaluating AI-augmented networked pervasive health systems?

The above issues illustrate the need to develop comprehensive user-centered approaches for the integration of AI methods into pervasive digital health systems, considering the multiple sensitivities of human users, diverse stakeholders, and wider society.

9.5 Concluding Remarks

Throughout this thesis I have had the opportunity to participate in forums, workshops, interviews, and conversation in four different countries (Germany, US, UK, France), seven different cities (Berlin, London, Paris, San Francisco, Oakland, Mannheim/Heidelberg, Leipzig), and with many hundreds of people with T1 diabetes who come from and live all over the world. This thesis is foremost about those who depend on diabetes technologies every day, their needs within the complex and diverse ecosystems that form their daily lives, and finally how we can design systems to help support them. It is critical to realize that while clinical metrics are important, life quality is the central goal, not an afterthought.

One of challenges in researching and designing effective diabetes interventions is the need to balance that which can be measured and that which can only be felt. On the one hand, there is

strong evidence that maintaining in range glycemic values reduces medical complication. On the other hand, the individual's perceptions and feelings about their care and their life play vital roles in determining ability to maintain motivation and self-care practices. Furthermore, both aspects are intertwined: stress makes diabetes clinically harder to manage, and presentation of undesired health data values can increase stress and frustration. Each individual must find a personal balance between risk avoidance and their life as they choose to (or must) live it. Therefore, practical interventions must find ways to integrate both objective and subjective aspects of the diabetes experience. Another aspect of diabetes to consider is that the human body is a noisy system. Diabetes is seldom completely mastered. There will always be some measurements that are higher and others that are lower. Approaches that seek to reward results therefore risk frustrating the individual who does everything right and yet has an unpredictable outcome. Diabetes management is about each individual finding a balance that works for them within their life and re-balancing this approach as context changes. The approaches and findings in this thesis such as *FCR* embrace this dynamic approach, and a principal conclusion of this thesis is that an intervention must be developed that takes into account complex ecologies of care and the uncertainty which they imply.

On a final and personal note, it is my hope that the insights gained from the challenges I have faced living many years with diabetes have in some way benefited this research, offering a perspective both as an academic and as a user. I would like to encourage those who have a condition or viewpoint that places them at certain disadvantages to see this also as a strength for the experiences so gained.

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Chapter 10: Appendixes

10.1 Appendix A: Ethics Approval

The Open University

From	Dr Duncan Banks
	Chair, The Open University Human Research Ethics Committee
Email	duncan.banks@open.ac.uk
Extension	59198
To	Dmitri Katz, Computing and Communications
Subject	*"Longitudinal User Engagement with Diabetes smartphone Apps."*
Ref	HREC/2015/1953/Katz/1
AMS (Red)	
Submitted	11 May 2015
Date	18 May 2015

Memorandum

This memorandum is to confirm that the research protocol for the above-named research project, as submitted for ethics review, **has been given a favourable opinion** by the Open University Human Research Ethics Committee by **Chair's action** as it is thought to be low risk.

Please make sure that any question(s) relating to your application and approval are sent to Research-REC-Review@open.ac.uk quoting the HREC reference number above. We will endeavour to respond as quickly as possible so that your research is not delayed in any way.

At the conclusion of your project, by the date that you stated in your application, the Committee would like to receive a summary report on the progress of this project, any ethical issues that have arisen and how they have been dealt with.

Regards,

Dr Duncan Banks
Chair OU HREC

HREC_2015_1953-Katz-1-favourable-opinion-chairs-action

The Open University

From	Dr Duncan Banks
	Chair, The Open University Human Research Ethics Committee
Email	duncan.banks@open.ac.uk
Extension	59198

| To | Dmitri Katz, Computing and Communications |

Subject	*"Longitudinal User Engagement with Diabetes smartphone Apps."*
Ref	HREC/2015/1953/Katz/2
AMS (Red)	
Submitted	10 September 2015
Date	21 September 2015

Memorandum

This memorandum is to confirm that **the modifications to** the research protocol for the above-named research project, as submitted for ethics review, **has been given a favourable opinion** by the Open University Human Research Ethics Committee by **Chair's action** as it is thought to be low risk.

Please make sure that any question(s) relating to your application and approval are sent to Research-REC-Review@open.ac.uk quoting the HREC reference number above. We will endeavour to respond as quickly as possible so that your research is not delayed in any way.

At the conclusion of your project, by the date that you stated in your application, the Committee would like to receive a summary report on the progress of this project, any ethical issues that have arisen and how they have been dealt with.

Regards,

Dr Duncan Banks
Deputy Chair OU HREC

Human Research Ethics Committee (HREC)

From	Dr Duncan Banks, Deputy Chair
	The Open University Human Research Ethics Committee
Email	duncan.banks@open.ac.uk
Extension	(6) 59198
To	Dmitri Katz, STEM
Project title	Wearable devices for diabetes lifestyle support.
HREC ref	HREC/2016/2434/Katz/1
AMS ref	N/A

Memorandum

Date application submitted: 19/01/17
Date of HREC response: 19/01/17

This memorandum is to confirm that the research protocol for the above-named research project, as submitted to the OU HREC for ethics review, has been given a favourable opinion by the HREC review panel.

Please note the following:

1. You are responsible for notifying the HREC immediately of any information received by you, or of which you become aware which would cast doubt on, or alter, any information contained in the original application, or a later amendment which would raise questions about the safety and/or continued conduct of the research.

2. It is essential that any proposed amendments to the research are sent to the HREC for review, so they can be recorded and a favourable opinion given prior to any changes being implemented (except only in cases of emergency when the welfare of the participant or researcher is or may be effected).

3. Please include your HREC reference number in any documents or correspondence, also any publicity seeking participants or advertising your research, so it is clear that it has been reviewed by HREC and adheres to OU ethics review processes.

4. You are authorised to present this memorandum to outside bodies such as NHS Research Ethics Committees in support of any application for future research clearance. Also, where there is an external ethics review, a copy of the application and outcome should be sent to the HREC.

5. OU research ethics review procedures are fully compliant with the majority of grant awarding bodies and where they exist, their frameworks for research ethics.

6. At the conclusion of your project, by the date you have stated in your application, you are required to provide the Committee with a final report to reflect how the project has progressed, and importantly whether any ethics issues arose and how they were dealt with. A copy of the final report template can be found on the research ethics website - http://www.open.ac.uk/research/ethics/human-research/human-research-ethics-full-review-process-and-proforma#final_report

Best regards,

Dr Duncan Banks, Deputy Chair
The Open University Human Research Ethics Committee   http://www.open.ac.uk/research/ethics/

Human Research Ethics Committee (HREC)

From	Dr Duncan Banks, Deputy Chair
	The Open University Human Research Ethics Committee
Email	duncan.banks@open.ac.uk
Extension	(6) 59198
To	Dmitri Katz, C&C/STEM
Project title	Questionnaire for investigating cognitive processes of T1 Diabetes Self-Management.
HREC ref	HREC/2017/2524/Katz/1
AMS ref	n/a

Memorandum

Date application submitted: 04/04/17
Date of HREC response: 04/04/17

This memorandum is to confirm that the research protocol for the above-named research project, as submitted to the OU HREC for ethics review, has been given a favourable opinion by the HREC review panel.

Please note the following:

1. You are responsible for notifying the HREC immediately of any information received by you, or of which you become aware which would cast doubt on, or alter, any information contained in the original application, or a later amendment which would raise questions about the safety and/or continued conduct of the research.

2. It is essential that any proposed amendments to the research are sent to the HREC for review, so they can be recorded and a favourable opinion given prior to any changes being implemented (except only in cases of emergency when the welfare of the participant or researcher is or may be effected).

3. Please include your HREC reference number in any documents or correspondence, also any publicity seeking participants or advertising your research, so it is clear that it has been reviewed by HREC and adheres to OU ethics review processes.

4. You are authorised to present this memorandum to outside bodies such as NHS Research Ethics Committees in support of any application for future research clearance. Also, where there is an external ethics review, a copy of the application and outcome should be sent to the HREC.

5. OU research ethics review procedures are fully compliant with the majority of grant awarding bodies and where they exist, their frameworks for research ethics.

6. At the conclusion of your project, by the date you have stated in your application, you are required to provide the Committee with a final report to reflect how the project has progressed, and importantly whether any ethics issues arose and how they were dealt with. A copy of the final report template can be found on the research ethics website - http://www.open.ac.uk/research/ethics/human-research/human-research-ethics-full-review-process-and-proforma#final_report

Best regards,

Dr Duncan Banks, Deputy Chair
The Open University Human Research Ethics Committee   http://www.open.ac.uk/research/ethics/

● **Wendy.King**   📎   15. June 2018 at 12:45

HREC/2911/Katz: HREC Favourable opinion   Details

To: Dmitri.Katz,   Research-REC-Review,   Cc: B.A.Price

Project title: **DUETS (Designing for Under-centred, Emotionally sensitive, and Transparent Systems): A Card-Based system for reflecting on multi-component, multi-stakeholder IoT systems**

Date application submitted: 24/05/2018   **HREC response date:**   15/06/2018

This message confirms that the research protocol for the above-named research project, as submitted for ethics review, has been given a favourable opinion, by Chair's action, on behalf of The Open University Human Research Ethics Committee.

As part of your favourable opinion, it is essential that you are aware of and comply with the following:

1. You are responsible for notifying the HREC immediately of any information received by you, or of which you become aware which would cast doubt on, or alter, information in your original application, in order to ensure your continued safety and the good conduct of the research.

2. It is essential that you contact the HREC with any proposed amendments to your research, for example: a change in location or participants. HREC agreement needs to be in place before any changes are implemented, except only in cases of emergency when the welfare of the participant or researcher is or may be affected.

3. Your HREC reference number has to be included in any publicity or correspondence related to your research, e.g. when seeking participants or advertising your research, so it is clear that it has been agreed by the HREC and adheres to OU ethics review processes.

4. Researchers should have discussed any project-related risks with their Line Manager and/or Supervisor, to ensure that all the relevant checks have been made and permissions are in place, prior to a project commencing, for example compliance with IT security and Data protection regulations.

5. Researchers need to have read and adhere to relevant OU policies and guidance, in particular the Ethics Principles for Research involving Human Participants and the Code of Practice for Research - http://www.open.ac.uk/research/ethics/.

6. The Open University's research ethics review procedures are fully compliant with the majority of research council, professional organisations and grant awarding bodies research ethics guidelines. Where required, this message is evidence of OU HREC support and can be included in an external research ethics review application. The HREC should be sent a copy of any external applications, and their outcome, so we have a full ethics review record.

7. At the end of your project you are required to assess your research for ethics related issues and/or any major changes. Where these have occurred you will need to provide the Committee with a HREC final report to reflect how these were dealt with using the template on the research ethics website - http://www.open.ac.uk/research/ethics/human-research/full-review-process (HREC Final Report form)

Sent on behalf of the Human Research Ethics Committee

Professor Louise Westmarland   **Dr Duncan Banks**   **Dr Claire Hewson**
Chair   Deputy Chair   Deputy Chair

The Open University

Human Research Ethics Committee
The Open University
Walton Hall, Milton Keynes, MK7 6AA   Tel: +44 (0) 1908 654858

http://www.open.ac.uk/research/ethics

10.2 Appendix B: Study Forms (Information, Consent, Questionnaires)

Date: /   /   Participant No.

This interview took _____ minutes

Diabetes smartphone Apps questionnaire

This questionnaire and semi-structured interview is being conducted by Dmitri Katz (+49(0)177 494 4496, dmitri.katz@my.open.ac.uk), a PhD student at The Open University, UK. Dmitri is interested in improving diabetes care by investigating how mobile apps on smart phones can be designed to improve the lives of people with diabetes. We will be asking about your previous or current use of apps and do not advocate the use or non-use of any app, and will not give any advice on diabetes treatment. The questionnaire should take about 5 minutes to complete. The semi-structured interview should also take about 5 minutes but may take longer depending on your answers. There are no known risks to taking part in this research. You do not need to identify yourself, but if you choose to provide any personally identifying information it will be stored separately from your answers and identified only by a code number. If you do choose to provide contact details or personally identifying information it will be stored securely in accordance with the UK Data Protection Act 1988 and relevant European Data Protection legislation. If you have any questions about this research, please contact Dmitri directly. If you have any concerns about the research you can contact Dmitri's supervisor, Dr Dalton (+44 (0)7908 64 9005, sheep.dalton @ open.ac.uk). Thank you for your time.

General questions:

Q1.1 How often do you keep a paper diabetes diary or log of information such as medication dosages, blood sugars, diet, etc:

Never   ☐
1-5 days per month   ☐
6-15 days per month   ☐
16-27 days per month   ☐
everyday   ☐

Q1.2 Have you ever used a diabetes smart phone App: Yes ☐   No ☐

Q1.3 If Yes, which App(s) and on which device(s)?

App name   Device/OS

_____   _____

_____   _____

_____   _____

_____   _____

Q1.4 Approximately how many diabetes apps have you tried in total? _____

Q 1.5 How many times per day do you measure your blood sugar?

0   ☐
1-2   ☐
2-4   ☐
4-6   ☐
more than 6   ☐
Continual Glucose Monitor (CGM) ☐

Q 1.6 Are you currently using a diabetes smartphone App?

yes   ☐   proceed to section 2
no   ☐   proceed to section 3

1

225

Section 2
If you <u>are</u> currently and regularly using a diabetes App:

Q2.1 What is name of the main App you are currently using? _____

Q2.2 Why did you start using the App? Please select all that Apply
doctor's/primary caregiver's recommendation ☐
pharmacist's recommendation ☐
friend's recommendation ☐
internet/blog recommendation ☐
health insurance suggestion ☐
clinical/academic evidence ☐
unplanned (e.g App Store) ☐
something else?_____ ☐

Q2.3 How many days do use this diabetes App in an average week? (choose one)
one day ☐
2 to 5 days ☐
everyday ☐
more than once per day ☐
other_____ ☐

Q2.4 How long have you been using this App? (choose one)
1 day ☐
2 days -1 week ☐
1 week -1 month ☐
1 month- 3 months ☐
3 months- 6 months ☐
longer than 6 months ☐

Q2.5 In which ways has this App helped you? (Please check all that Apply)
logs/records for caregiver(e.g. doctor) ☐
motivation ☐
diet/recipe support ☐
reminders/alarms ☐
medical advice/education ☐
data visualization/insight ☐
doesn't help ☐
other_____ ☐

Q2.6 Do you find this App helpful? (choose one)
Very helpful ☐
somewhat helpful ☐
neutral ☐
not helpful ☐
other_____ ☐

2

Section 3
If you are <u>not</u> currently regularly using a diabetes App, BUT HAVE USED ONE IN THE PAST:

Q3.1 What was the name of the primary App you were using? _____

Q3.2 Why did you start using the App?

doctor's/primary caregiver's recommendation ☐
pharmacist's recommendation ☐
friend's recommendation ☐
Internet/blog recommendation ☐
health insurance suggestion ☐
clinical/academic evidence ☐
unplanned (e.g App Store) ☐
other?_____ ☐

Q3.3 How long had you been using the App before stopping? (choose one)

One time to 1 day ☐
2 days -1 week ☐
1 week -1 month ☐
1 month- 3 months ☐
3 months- 6 months ☐
longer than 6 months ☐

Q3.3b How many times were you using this diabetes App in an average week?

1-2 ☐
2-4 ☐
4-6 ☐
1x per day ☐
More than 1x per day ☐

Q3.4 While you were using this App did you find it helpful? (choose one)

Very helpful ☐
somewhat helpful ☐
neutral ☐
not helpful at all ☐

Q3.5 If you did find the App helpful, in which ways? (Please check all that Apply)

logs/records for caregiver(e.g doctor) ☐
motivation ☐
diet/recipe support ☐
reminders/alarms ☐
medical advice/education ☐
data visualization/insight ☐
didn't help ☐
other_____ ☐

Q3.6. Why did you stop using the App.? (choose one)

Fulfilled goal ☐
Didn't help ☐
I couldn't make it work ☐
App stopped working ☐
Too much work ☐
other_____ ☐

3

Section 4
Diabetes Apps:

Q4.1 What is your opinion of the diabetes apps you have used?

Q4.2 Please describe what kind of feelings you get before, during and after using a diabetes App?

before:

during:

after:

4

Section 5
Non-Diabetes smartphone Apps :

Q5.1 Do you use any of these Apps every day?(choose as many as Apply)

Games	☐
Facebook	☐
Twitter	☐
Other Social networking	☐
What'sApp/Texting	☐
Health/Fitness	☐
Other_____	☐

Q5.2 What are your favorite non-diabetes Apps and how often do you use them in an average week?

Q5.3 What do you get from using these Apps?

Q5.4 Please describe what kind of feelings you get before, during and after using your favorite non-diabetes Apps?

before:

during:

after:

5

Section 6
About you:

Year of Birth: _____
Gender: Male ☐   Female ☐
Type of Diabetes T1 ☐T2 ☐ Gestational ☐ Other_____
Year of Diagnosis_____

Q4.2 Would you like to receive the anonymized results of the survey?
☐ Yes, my email address is _____
☐ No

Q4.3 If there are any follow up questions, may I contact you by email or telephone?
☐ Yes please do
☐ Name(optional): _____
☐ Email address(optional): _____
☐ Telephone /Mobile (optional): _____
☐ No, do not

That's it ! Thanks for your help.

 I consent that the anonymous information gathered with this survey can be used for research on diabetes app usage.

_____
Date/Signature

Additional comments:

6

Diabetes App Study

The following survey and user test aims to understand the use of mobile phone apps primarily designed and developed for diabetes self-management

Participant Consent form

The diabetes app study is being conducted by Dmitri Katz (+49(0)177 494 4496, dmitri.katz@my.open.ac.uk), who is a PhD student at The Open University, UK. Dmitri is interested in improving diabetes care by investigating how mobile phone apps developed for use on smart phones can be designed to improve the lives of people with diabetes.

There are no known risks to taking part in this research. As a participant in this study, you do not need to identify yourself and all information will be anonymized. If you choose to provide any identifying information this data will be stored separately from your answers and identified only by a unique code number.

There will be video recording of the mobile phone interface, your voice and hands. Your face will at no time be visible and you will only be identified by a unique number, i.e. participant #1.

If you do choose to provide contact details or personal information this data will be stored securely in accordance with the UK Data Protection Act 1988 and the relevant European Data Protection legislation.

If you have any questions about this research, please contact Dmitri directly. If you have any concerns about the research or to resign yourself and data from the study please contact, Dr. N. Dalton (+44 (0)7908 64 9005, sheep.dalton @ open.ac.uk) who is supervising Dmitri through his graduate studies. Thank you for your time.

I consent that the anonymous information gathered in this study can be used for presentations, journal and conference presentations/papers and for use in the final PhD thesis.

Name:_____   Participant I.D._____

_____
 Date/Signature

1

Survey/Scenario of the diabetes app

In order to understand more about how people use diabetes mobile phone apps you will be asked a series of questions relating to the features, preferences, motivations and descriptions of popular diabetes apps. This study aims to understand how best to display diabetes app data to users, and it is not the requirement of the study for you to know and understand how to use the app ahead of time. You will be asked a series of questions before, during and after the use of these products.

We are trying to understand more about how people relate to their collected health data, so we would like you to imagine a scenario that all the recorded data is your personal data, and you are explaining this period to your doctor.

Please do your best to help, and talk out loud about what you think. In order to understand the process better, the conversation, the smartphone screen, and your hands will be recorded. Your face will at no time be visible, as we are measuring the performance of the software, not the user.

2

Mobile app use and experience general:

I am comfortable using a smartphone.

Strongly agree	agree	neutral	disagree	Strongly disagree

I engage readily with reading graphs e.g in newspapers, presentations.

Strongly agree	agree	neutral	disagree	Strongly disagree

I enjoy solving puzzles.

Strongly agree	agree	neutral	disagree	Strongly disagree

I am confident that I can troubleshoot my diabetes logs to understand problems.

Strongly agree	agree	neutral	disagree	Strongly disagree

I feel comfortable using diabetes apps

Strongly agree	agree	neutral	disagree	Strongly disagree

I am in general satisfied with the level of my diabetes control.

Strongly agree	agree	neutral	disagree	Strongly disagree

I am comfortable using smartphone apps in general.

Strongly agree	agree	neutral	disagree	Strongly disagree

I have used self-tracking/logging apps (logging weight, exercise or diet with jawbone, fitbit, garmin, strava, my fitness pal, etc.) for purposes other than diabetes management.

Strongly agree	agree	neutral	disagree	Strongly disagree

3

If you have used a diabetes app, it was difficult to understand what it was telling you about your diabetes.

Strongly agree	agree	neutral	disagree	Strongly disagree

I don't like using maps to find a route, and would rather be directed with a navigator.

Strongly agree	agree	neutral	disagree	Strongly disagree

4

App Test:

There will be a series of questions about the data entered into the app. As you are answering these questions, please talk about what you are thinking or feeling. Please share any observations about the app, what you would like to know, what works or doesn't.
Look at data on each app from July 16th to July 30th. (go through each app)
Functionality
1. What do you see about this period?
2. What would you do differently based on this data?
3. How useful is this app for helping you understand this diabetes data?

Emotional
1. Talk about how each interface makes you feel about being diabetic
2. Please look at July 28th, what happened to your control on that day? How do you feel about that day?
3. Please look at July 21st, how do you feel reviewing this day?

App ratings (cumulative)
desirable and undesirable characteristics (5 point Likert)

1. Diabetes apps are motivating

Strongly agree	agree	neutral	disagree	Strongly disagree

2. Diabetes apps are fun

Strongly agree	agree	neutral	disagree	Strongly disagree

3. Diabetes apps are boring

Strongly agree	agree	neutral	disagree	Strongly disagree

4. Diabetes apps are useful.

Strongly agree	agree	neutral	disagree	Strongly disagree

5. Using diabetes apps is frustrating.

Strongly agree	agree	neutral	disagree	Strongly disagree

6. Diabetes apps are gimicky

Strongly agree	agree	neutral	disagree	Strongly disagree

5

7. Using a diabetes app makes me feel guilty about my diabetes control.				
Strongly agree	agree	neutral	disagree	Strongly disagree

Personal Preferences:

What form are you best able to understand information, i.e. charts, sentences, audio, read, etc.

Please describe your feelings and motivations of using the diabetes app. Consider and explain your previous experiences of using diabetes apps, what difficulties you had, what aspects you found informative.

If you use diabetes apps, are there particular times you use them more than other times?

Do you share your diabetes data with other people, e.g friends, family, partner, doctor?

Why do you share this information? In what ways does it help?

Have you ever felt any stigma or negative effects from sharing your data, such as BG, diet, exercise, or other information?
You have been shown several apps, please explain which apps you find the best and which the worst.

Did you feel one app in particular was more encouraging. Was any app more discouraging than the others?

Demographic data

1. Year of Birth: _____
Gender: Male   Female

2. I am a T1 diabetic_____
Year of Diagnosis_____
Profession:_____

I am a health care professional or caregiver to a T1 diabetic_____
What is your profession or relationship to diabetes?_____

6

3. Which diabetes apps have you tried previously?
Do you use graphical charts or diagrams in your work life?
What is the highest level of education you have completed?

4. Do you use now or have you ever used a smart phone app to track your diabetes?
If so which:

5. Length/frequency of using an app for tracking diabetes?
Current usage: regular/irregular/stopped
Describe:

6. What type of phone do you use?
Is it a smart phone?

7. Do you use a web or desktop interface to track your diabetes?
If so which:

8. Why do you use the particular device, i.e. home computer, laptop, smartphone, smartwatch, insulin pump, meter, etc.?

Would you like to receive the anonymized results of the survey?
     Yes, my email address is _____
     No_____

If there are any follow up questions, may I contact you by email or telephone?
     Yes please do
     Name(optional): _____
     Email address(optional): _____
     Telephone /Mobile (optional): _____
     No, please do not contact me:_____

7

Online survey on T1 diabetes self-management

This online survey is being conducted by Dmitri Katz, a PhD student at The Open University, UK. Dmitri is interested in improving diabetes care by investigating how people living with Type 1 Diabetes make decisions about their diabetes management. We hope that the information collected will help guide designers in creating easier to understand ways of displaying personal health data. We will be asking about your opinions, thoughts and experiences, and will not give any advice on your current diabetes treatment. You must be at least 18 years old, and under medical treatment for T1 diabetes. The questionnaire should take about 5-10 minutes to complete, and there are no known risks to taking part in this research. You do not need to identify yourself, but if you choose to provide an email address to receive the results of this research or to be contacted if there are any further questions, it will be stored separately from your answers that will be identified only by a code number. Only the principal university researchers will have access to this data. If you do choose to provide contact details or personally identifying information it will be stored securely in accordance with the UK Data Protection Act 1988 and relevant European Data Protection legislation. This research is in part being supported by a research grant from the European Research Council, the UK Engineering and Physical Sciences Research Council, and researchers from the Open University. You may choose to withdraw your data from the survey through email notification until the end of the collection period in July 2017. Once we have begun to analyze the data we will no longer be able to remove your answers. However, if you choose to submit an email address, this can be removed at any time upon your request. Please note that completion and submission of this questionnaire implies consent to your data being used for the academic research purposed, and your answers (in anonymized form) may be used or quoted in published academic literature. If you have any questions about this research, please contact Dmitri directly (+49 (0) 177 494 4496, dmitri.katz@open.ac.uk). If you have any concerns about the research you can contact Dmitri's supervisor, Blaine Price (+44 (0)1908 653 701, b.a.price@open.ac.uk). Ethics approval for this survey was granted by The Open University Human Research Ethics Committee (HREC/2017/2524/Katz/1). Thank you for your time.

1. What is your age in years?
2. What is your identified gender
3. How long has it been since you were diagnosed with T1 diabetes?
4. Which specific devices do you currently use in your daily or near daily diabetes management? (i.e insulin pumps, Blood Glucose meters, insulin pens, fitness trackers, smartphone apps, etc.) Please include model names and numbers if you know them such as Dexcom G5, Abbott Libre, Contour Next, or Medtronic 530G.
5. How many times do you check your BG values on a normal day? (If you use a CGM or FGM note how many times you look at the display on an average day.)
6. How many shots (boluses or manual dosage rate adjustments, if you are a pump user) do you normally make per day?
7. Imagine that it is time for you to take an insulin dosage for a meal. You check your blood glucose level, and as you expect it is in a normal range (70-140 mg/dl or 3.9-7.8 mmol/L). Please describe the factors you might take into consideration to determine how much insulin to take for this meal.
8. Please try and remember a situation where you had a serious and surprising high or low blood glucose value (e.g. despite being careful, you had an unexpected dangerously low blood sugar on an airplane). Please describe that specific situation, and your thought process about it. Please be as detailed as possible.
8b. In the last example please describe how you managed the situation.
9. Please try and remember a time that you had done something that had caused your BG level to be out of ideal range, but you immediately understood why (e.g. eating too much cake at a birthday party). Please describe that specific situation, and your thought process about it. Please be as detailed as possible.
9b. In the last example please describe how you managed the situation.
10. Please try and remember a situation when you were in a novel or unusual situation that dramatically affected your blood glucose level (e.g. arriving in a different time zone, becoming distracted by unusual circumstances after taking a shot, miscalculating an insulin dosage, an unusual food, etc.) Please describe this specific situation, and your thought process about it. Please be as detailed as possible.
10b.In the last example please describe how you managed the situation.
11. Is your diabetes management process different now in comparison to when you first became diabetic? If so, please explain in which ways.
12. If you use a CGM or Freestyle Libre, in which ways has it changed your diabetes management process as opposed to using strips? Please be as specific as possible.
13. Please check your blood glucose, and record the value in the space below. Describe everything that comes to your mind and what factors might have contributed to this reading.
14. Imagine that you are going to take insulin now for a meal. Given your current BG value, please describe what factors you would take into consideration, and the process you would use to decide on an appropriate insulin dosage.
15. If you wish to receive the results of this survey please enter your email address. You will not be contacted for any commercial offers and your identity will be kept strictly confidential. (This is entirely optional)

Application for assistance with research recruitment

DiABETES UK
CARE. CONNECT. CAMPAIGN.

1. Classification of organisation Please indicate the type of organisation you are applying on behalf of:	
Not for profit organisation (i.e. University) NHS Commercial company Other	x ☐ ☐ ☐ ☐ please specify: _____
Name of organisation	The Open University, Milton Keynes

2. Research and lead investigator details (PhD students must provide the details of a PhD supervisor)			
Title of research project/activity	Questionnaire for investigating cognitive processes of T1 Diabetes Self-Management		
Name and title of lead investigator	Mr. Blaine Price	Position held	Senior Lecturer
Telephone number	01908 653701	Email	Blaine.price@open.ac.uk
Address	School of Computing and Comms, The Open University, Milton Keynes, MK7 6AA		

3. Main point of contact for research participants (if different to above)			
Name and title	Dmitri katz	Position held	PhD student
Telephone number	++49 177 494 4496	Email	Dmitri.katz@open.ac.uk
Address	Rigaerstr. 16, 10247 Berlin Germany		

4. Research funding	
Name(s) of funders/partners	European Research Council, the UK Engineering and Physical Sciences Research Council
Has this research been through a process of peer-review?	Yes ☒ No ☐
If yes, please provide brief details	3 PhD supervisors reviewed protocol

Diabetes Monitoring – Patient Information Sheet v2.0 18 Dec 2016   1

Milton Keynes University Hospital **NHS**
NHS Foundation Trust

A feasibility study to monitor lifestyle activities of people living with Type 1 Diabetes

Patient Information Sheet

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. We suggest that it may take about 10 minutes to read thoroughly. If, after reading this information sheet, you think you may be interested in taking part one of our team will go through the sheet with you via telephone and answer any questions you have.

You have been selected because you are a patient living with Type 1 diabetes. At this stage approximately 16-20 patients are expected to take part.

Milton Keynes University Hospital **NHS**
NHS Foundation Trust

The Open University

Patient Identification Number for this trial:_____

CONSENT FORM

Title of Project: A feasibility study to monitor lifestyle activities of people living with Type 1 Diabetes

Name of Researcher: Dmitri Katz

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated **xxx** for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. I understand that if I withdraw during the study I may be asked for my consent to use the data collected to that point. I understand that if I withdraw after the study period it may not be possible to delete my anonymized data if it has already been analysed for publication.

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from **The Open University** from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I give permission for the research team to send me study related text messages or emails, or for a relative or carer to receive study related texts or emails on my behalf.

5. I agree to my GP being informed of my participation in the study.

6. I agree to return the continuous glucose monitor (delete if patient has own) and the sleep monitor to the researchers once my participation in the study is completed

7.   I agree to allow the researchers to use audio recordings for the purpose of note-taking.

3 copies to be signed. 1 to be retained by patient,
1 to go into patient notes and 1 to go into the investigator study file.   Page 1 of 2

8. (Optional) I agree to being contacted for an additional interview at a later time.

9. I agree to take part in the above study.

Name of Participant	Date	Signature

Name of Person taking consent.	Date	Signature

3 copies to be signed. 1 to be retained by patient,
1 to go into patient notes and 1 to go into the investigator study file.   Page 2 of 2

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Milton Keynes University Hospital **NHS**

NHS Foundation Trust

Intake Survey for pilot study on Diabetes Monitoring**:**

Participant ID number_____

1. Gender:_____

2. Year of birth: _____

3. Year of diabetes diagnosis: _____

4. Occupation: _____

5. Circle the insulin therapy you are using: Pump   Multiple Dosage Insulin (MDI)

6. Average number insulin injections per day: _____

7. Types of insulin taken daily: _____

8. Latest A1C, if known: _____

9. Do you use a continuous glucose monitor, if so, which? YES / NO

   _____

10. Do you currently use any tracking devices or apps, if so which?

    _____

Page 1 of 1

Milton Keynes University Hospital NHS
NHS Foundation Trust

The Open University

Hello _____,

Before we get started I want to tell you a little about this study. We are investigating how the lifestyle choices you make, like where you eat or when you exercise, affects your diabetes management. We are also interested in how you feel about using devices like smartphones together with health devices, which will be important in developing personal health systems that are sensitive to your needs.

In order to do this, we will ask you to install an app on your phone, wear a fitness band, and use a CGM (Continuous Glucose Monitor). If you do not have a CGM, we will supply you one for the duration of the study, though we may need you to return the CGM meter at the end of the study. There is no need for you to in any way change your daily routine, and in fact please do not make any changes relating to your diabetes treatment without first consulting with your doctor. We are not trying to change your behaviour, we just want to learn more about your blood glucose patterns in relation to your activities.

During the 4-week study period your devices will be recording your location, exercise, sleep, and blood glucose level. This information will be stored anonymously, and your identity will be protected. We request that you do your best to keep your phone, your fitness band, and your CGM with you and batteries charged. If at any time you want to stop using one or more of the devices, that is your right, and there will be no penalties.

At the end of the study period, you will be free to de-install the app from your phone. Please return the CGM if you have been loaned one. You may keep the fitness band if you so desire.

We would now like to ask you a few questions about diabetes and your opinions on your personal data. For convenience sake, if it is ok with you, we would like to record audio of this interview. If you do not wish to, we can just record the information by hand.

Milton Keynes University Hospital NHS
NHS Foundation Trust

Semi-structured interviews for study on diabetes lifestyle correlations

Before Study period:

1. Can you tell me something about yourself?
2. Have you used any exercise tracking devices, if so which?
3. Are you currently satisfied with your diabetes management, why or why not?
4. What are your greatest challenges in diabetes management?
5. Do you think people are too cautious or overly easy about sharing their data?
6. Do you share your diabetes data, if so who with, and how often?
7. How do you feel about sharing your personal data such as:
   a. GPS location?
   b. BG values?
   c. How often and where you sleep?
   d. When and how you exercise?
   e. Where you shop?
   f. Which restaurants you go to?
   g. Recreational locations and activities?
8. Would your opinions in the previous question be altered if you were assured your data was properly anonymized?
9. How do you feel about your doctor having access to your personal data such as:
   a. CGM values?
   b. Location?
   c. Exercise?
   d. Is there any other type of information that you would prefer not to share with your doctor? If so, without giving sensitive details, can you explain?
10. How do you feel your health insurance provider having access to your personal data such:
    a. CGM values?
    b. Location?
    c. Exercise?
11. Can you share any circumstances where you might not want to be wearing a system that tracks your health and other personal information? If so what might you do in such times?
12. Do you have any questions or concerns about this study?

Following study period:

1. How did you feel about wearing tracking devices?
2. Are you currently satisfied with your diabetes management? Please explain.
3. If you stopped using any of the devices, which ones and why?
4. What are your greatest challenges in diabetes management?
5. Having worn these devices for 30 days has this in anyway affected how you feel about tracking and sharing your personal data?
6. Did the wearing of data tracking devices in any way change your behaviors or awareness?
7. How was wearing the fitness band during the study period?
8. How did your feel about wearing the CGM during the study period?
9. How did you feel about sharing your personal data such as:
    a. GPS location?
    b. BG values?
    c. How often and where you sleep?
    d. When and how you exercise?
    e. Where you shop?
    f. Which restaurants you go to?
    g. Where you are at night?
10. Do you think the sharing of your personal data would prevent you from wearing a medical or tracking device everyday?
11. If so, what assurances would make a difference?
12. Do you feel a difference between your data being accessed by a person or an automated system? If so, in which ways?
13. How do you feel about your doctor having access to your personal data such as:
    a. CGM values?
    b. Location?
    c. Exercise?
14. How do you feel about How do you feel your health insurance provider having access to your personal data such having access to your personal data such as:
    a. CGM values?
    b. Location?
    c. Exercise?
15. Is it important to you that you control access to your personal data? If so, which data and to whom?
16. What circumstances might change your attitudes to sharing personal data?
17. What assurances/risks might change your opinions as to sharing personal data?
18. Can you think of any particular times or circumstances where you might want to hide your data or location? If so, can you share any of them?
19. Do you have any questions or concerns about this study?

DUETS System Analysis Tool

The following session aims to better understand how a card-based tool can be used to visualize and reflect on health systems in order to assist developers in better understanding and integrating user needs.

Participant Information and Consent form

This study is being conducted by Dmitri Katz (+49(0)177 494 4496, dmitri.katz@open.ac.uk), who is a PhD student at The Open University, UK. Dmitri is interested in improving health care by investigating how stakeholder opinions and needs can be better identified and integrated into product development processes. It will involve about 2 hours of your time but you can choose to leave at any time. The tasks will involve considering a design for a diabetes support system using usability heuristics and paper-based tools to reflect on the potential utility of the product, shortcomings, and ways that you think the product could be improved. You will not be asked to share any of your personal health records, medical details, experiences, or behaviors.

We would like to offer you an Amazon voucher in recognition of you donating your valuable time.

There are no known risks to taking part in this research. As a participant in this study, you do not need to identify yourself and all information will be anonymized. If you choose to provide any identifying information this data will be stored separately from your answers and identified only by a unique code number. If you do choose to provide contact details or personal information this data will be stored securely in accordance with the EU General Data Protection Regulation (GDPR) and will be deleted within 6 months of study completion. Your participation in the study is entirely voluntary, and you may discontinue at any time, without prejudice, and you may ask to have your data deleted, though after analysis it may not be possible to delete your aggregated and anonymized data.

If you have any questions about this research, please contact Dmitri directly. If you have any concerns about the research or you wish to delete your data from the study please contact, Prof. Blaine Price (b.a.price @ open.ac.uk) who is supervising Dmitri through his graduate studies. Thank you for your time.

I consent to participating in this study and agree that the anonymous information gathered in this study which cannot be used to identify me may be used for academic purposes.

Name:_____   Participant I.D._____

_____
Date/Signature

1

Participant #   Age   Gender   Date   Profession

Phase 1: Description of system	
Systems Concern (mark top 3)	
Ideas, modification, and new directions	
Phase 2: Reflection with heuristics	
Systems Concern (mark top 3)	Heuristic #
Ideas, modification, and new directions	
Phase 3: Reflection with Concerns cards	
Systems Concern (mark top 3)	Card #
Ideas, modification, and new directions	
Phase 4: Reflection with Concerns cards and System Cards	
Systems Concern (mark top 3)	Card #
Ideas, modification, and new directions	
Phase 5: Modify system with DUETS cards	
Systems Concern (mark top 3)	
Ideas, modification, and new directions	

Thoughts, comments, suggestion on workshop:

Thoughts, comments, suggestions on DUETS tool:

Concerns cards in particular:

Architecture cards in particular:

DUETS cards are:	I agree	Somewhat agree	neutral	I somewhat disagree	I disagree
Fun to use					
Easy to understand					
Process provided guidance					
Information on cards useful					
Visual design is appealing					
Was easy to represent systems					
Had ideas I would not have had without cards					
Architecture cards were useful for understanding systems					
Concerns cards were useful for thinking about system					

10.3 Appendix C: Results and other Outputs

10.3.1 Results from Chapter 4 diabetes app adoption

(available for download at: https://figshare.com/articles/Supporting_Diabetes_Self-Management_with_Ubiquitous_Computing_Technologies_A_User-Centered_Inquiry/7269398)

Participant #	survey #	Date of Survey	length of survey in min.	paper log experience(b)	Primary App	SecondaryApp	approx number of d Apps tried	Primary OS	Average BG measurements per day.
1	1			yes	Närwerte	iBGStar	NA	iOS	
2	1			yes	mySugr	Bayer Contour software	NA	iOS	
3	1			yes	unknown	unkown	5	iOS	
4	1			yes	mySugr	no	1	iOS	6 to 10 pr day
5	1		25 min.	yes	Diamedic	no	1	iOS	
6	1			yes	GlucoPal	BG Australia Logbook	several	iOS/Android	
7	1			yes	unknown		NA	iOS	
8	1			excel spreadsheet	MyDiabetes	no	10	Android	
9	1			yes	mySugr	no	10	iOS	
10	1			yes	MySugr	SiDiary	2	iOS	
11	1			yes	Bant	Glooko	3	iOS	
12	1			yes	Carbs and Cals	no	1	iOS	
13	1			yes	mySugr	SiDiary	2	iOS	
14	1	11.05.14		yes	mySugr	no	10	iOS	2-4 per day
15	1	11.15.14	20	yes			6	iOS	2-4 per day
16	1	11.17.14 approx.	20	yes	Glooko	no	NA	iOS	>6
17	1	11.23.14	15	yes	SiDiary	no	NA	Android	>6
20	1	11.23.14		yes	SiDiary	MySugr	NA	Android	4-6 per day
21	1	11.23.14		yes	On Track		NA	Android	2-4 per day
22	1	11.23.14	10	yes	Diabetis?	fooDDB	several	iOS	4-6 per day
23	1	11.23.14		yes	Diabetes Plus	Diabetes Connect	2	Android	>6
24	1	11.23.14	15	yes	SiDiary	MySugr	several	Android	was 4-6 per day
25	1	11.23.14	10	yes	mySugr	Diabetes Connect	NA	iOS	1-2x per day
26	1	11.23.14		yes	mySugr		>6	iOS/Android	before cgm 4-6x per day
27	1	11.23.14	15	yes	BE Finder	no	NA	iOS	>6
28	1	1.7.14		yes	DiaConnect	Sanovi(iBGStar)	30	iOS	5

CGM	Current diabetes smartphone	Primary App referrer	Secondary App referrer	current frequency of smartphone D app usage per week	Length of App use	how many times per week were you using app	How has/did app helped	How has/did app helped
	yes	App store	Doctor	downloads meter readings	>6 months		Logs for doctor	motivation
	no	App Store	no	0	1 week-1 month		Overview	
	no	App Store	no	0	2 days - 1 week		NA	
	no	Internet/blog	no	0	2 days - 1 week	10x	NA	
	occasional	doctor's recomm.	no	before doctor's visits	>6 months	mixed	Logs for doctor	data viz.
	no	Internet/blog	no	0	2 days - 1 week		NA	
	no	App Store	no	0	2 days - 1 week		no	no
	no	App store	no	0	3 months-6 months		data visualization	trends
	developing own app	App Store	no	0	1 week-1 month		Motivation	data viz.
	yes	App Store	Internet/blog	0-7	>6 months		Motivation	data viz.
	no	Internet/blog	no	0	2 days - 1 week		Awareness	
	no	Friend's rec.	no	0	1 day		not needed	no
	yes	Internet/blog	no	2x per week records values from BG meter	>6 months		Motivation	data viz.
	no	Internet/blog	no	0	2 weeks	10	Motivation	
libre	no	App store	no	0	1 day	2 x	not helpful at all	no
no	yes	Internet/blog	no	2 x per month transfers BG info	>6 months	·	data visualization	reduces work no manual logging
no	no	Internet/blog	no	0	2 days - 1 week	4-6x per day	Photo of food helped with insulin dosages	
no	no	Internet/blog	no	0	>6 months	> 1x per day	data viz.	
no	no	Husband suggested	no	0	1 week-1 month	> 1x per day	logs/records for doctor	

How helpful is/was app	Reason for stopping	manual entry barrier	Year of birth	age in years in 2014	Gender	type of diabetes	year of diagnosis	years diabetic	apps used daily	approx. times used daily	apps used daily	approx. times used daily	apps used daily
somewhat helpful	NA	1	2003	11	m	Type 1	2011	3	instagram	3x	whats app	10x	
very helpful	too much work	1	1987	27	m	Type 1	2006	8	Twiter				
slightly helpful	Cost/Benefit	1	1977	37	m	Type 1	1994	20	social networking		health fitness		
slightly helpful	too much work	1	1981	33	m	Type 1	2008	6	facebook	10x day	twitter	2x	news
somewhat helpful	usually too much work	1	1978	36	f	Type 1	1992	22	no		no		
not helpful	Cost/Benefit	1	1999	15	f	Type 1	2001	13	What's App				
not helpful	Cost/Benefit	0	2001	13	m	Type 1	2004	10	Games		What's App		no
very helpful	CGM has built in app	0	2011	37	f	Type 1	2013	1	parent uses facebook		news		no
Neutral	too much work	0	1991	23	m	Type 1	2007	7	facebook		What's App		no
very helpful	NA	0	1990	24	f	Type 1	2013	1	facebook		twitter		other social
somewhat helpful	too much work	0	1983	31	m	Type 1	1986	28	facebook		Instagram		no
not needed	Cost/Benefit	0	1953	61	m	Type 1	1960	54	facebook		no		no
somewhat helpful	NA	1	1988	26	m	Type 1	2006	8	facebook		What's App		health/fitness
somewhat	too much work		1986	28	f	Type 1	1999	15	What's App		Pinterest		
not	didn't help		1974	40	m	Type 1	1998	16	Facebook		Twitter		My fitness pal
somewhat helpful	NA		1975	39	m	Type 1	2003	11	LinkedIn		Bloomberg		
very helpful	too much work		1987	27	f	Type 1	2000	14	Facebook	10x day	What's App		
very helpful	uses pump app		1977	37	m	Type 1	1993	21	Facebook	10x per day	What's App		Music player
somewhat helpful	report was not flexible enough	1	1986	28	f	Type 1	1996	18	Facebook	10x day	What's App	3-4 x per day	Runtastic
somewhat helpful	NA		1963	51	m	Type 1	1999	15	email				
very helpful	too much work		1959	55	f	Type 1	1971	43	What's App	2-10x per day	weather	1x per day	no
somewhat helpful	too much work		1990	24	f	Type 1	1998	16	facebook	10x per day	What's App		Newsfeed
very helpful	NA		1980	34	m	Type 1	2009	5	facebook	>10x per day	What's App	20x per day	Instagram
very helpful	NA		1983	31	m	Type 1	1990	24	facebook	10x per day	twitter		What's App
neutral	didn't help		1984	30	f	Type 1	2011	3	Wikipedia app	2-5x per day	what's app		
somewhat helpful	wasn't helpful enough		1982	32	m	Type 1	1986	28	Facebook	3x	what's app	1x per day	nikerun

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approx. times used daily	apps used daily	approx. Times used daily	apps used daily	apps used daily	
10x					Father of diabetic 11 year old son, uses Närwete sometimes, learned most of it. Just uses app to download values bet... uses totrack blood sugar. Uses logging when he needs it. Has found records useful for pattern recognition. Dis...
					uploads measurements directly
					diabetes app usage remir...
2x	news		weather		dislikes interface, cluttered.benefit of virtual badge not meaningful. Dario doesn't have hardware, no interest in mar... videos, entertainment, friends. Stay connected take part in others life. Enterainment is main thing. Twitter is comple... it would help, assembling all the data didn't help, still needed to interpret. Didn't offer anything more. Didn't like man... ok because it looked nicer. IBGstar was kitschy. If the benefit was there it doesn't have to be pretty, but has to have be... look amateur, not trust worthy. All Apps offer same functionality, maybe some nice graphs, but can't see benefit. Doct... provide.W...
					privacy issues with cloud feels invasive. Emails logs to doctor sometimes. When she uses App measures 6x per day... many times per day, or doesn't. when she uses App doesn't forget. Numbers on display doesn't mean anything, needs... good feeling. I don't love it. A bit like war with my app. when I use it is good. time issues get in way... daughter is diabetic. Father feels time...
	no	no	no		Diabetic son. Found pen and paper faster. Troubles ...
	no	no	no		Participent is father of 2 year old with diabetes. Found app helpful, but now using app incorporated into CGM syste... meter.Found lack of error correction in app frustra...
	no		no		Participant found App useful. liked app at first , but then found not more helpful than paper. Is now developing own Ap...
	other social		What's App	Health/Fitness	likes design and ideas of ...
	no	no	no		Diabetes App feels like "outsider", as opposed to facebook which feels one of the crowd. Doesn't want to be define... Keeps paper blog before doc...
	no	no	no		Biggest challenge is in daily life is continuous demands. Would like app that reduces work with predictive model... thinking about...
	health/fitness		evernote		Enters data into app from meter 2x per week. Feels good when values are good, feels bad when values are unstable. Ir... connectivity with pump. Has problem maitaining constant level of diabetes discipli...
					Pinterest and WhatsApp 5-6x per day.Pinterest is inspiring and relaxing. WhatsApp used for social contact. mySug... didn't like having her diabetes metaphor "is like a monster". Found positive aspects good. mySugr increased engage... enter in "bad" values. She rejected app because she felt she wasn't improving. At first liked reward system, but th...
	My fitness pal				Uses Facebook to find out what friends and family are doing. Felt frustration with diabetes apps, because none d... export data into a particular format. He then stopped looking, fee...
					Uses Bloomberg app often to check value of stocks. This brings," excitement, apprehension, all kinds of human emotio... not emotional but habitual in order to build business network. He is looking for "convenience and simplicity...avoid... heavy, unstructured and confusing" He uses the app to download his values onto his smartphone twice a month from... using a diabetes App everyday to be very unappealing. Found diabetes apps to be functional but not exciting." tra... related content is never going to offer the same level of 'entertainment' – a diabetes app is a constant reminder that y... hardly exciting stuff! I think I said this before but I see my diabetes as my credit rating, I don't want to be reminded of ... need to be aware of or action (e.g. "you've had 4 hypos this week in...
					Found App good, but info is in meter/pump combo device. Found it too much work to enter in App.as well.She gets go... family pics. Contributor to Facebook diabetes group. Learns from others, fee...
	Music player				Describes himself as kind of person who "needs new things" likes facebook to read about what's new, and for curiosity... good when he had good BG readings, and bad when he entered bad values. Was satisfied with App, but using sm...
3-4 x per day	Runtastic		Instagram		likes using Facebook to connect to others. Looks at Facebook when she doens't have anything else to do, reports being... she closes it. Found Diabetes App too rigid, didn't record all her data in reports, for example between meals would... could use phone, because she always has it with her and doens't need a pen.. Was hopeful but found it annoying... want...
					uses email daily business comm...
1x per day	no	no	no	no	Found app good, but often doesn't carry smartphone with her. Liked App but didn't v...
	Newsfeed				Uses Apps to kill time when bored. Mostly reading, says when she is really busy she doesn't check facebook. Consid... might use an app if itegrated with meter and pump, but currently too much work.She liked that SiDiary connected to ... data was ok, once she got used t...
20x per day	Instagram				Uses social networking 'to see what is new' 'there is always something new' was using diabetes App everyday until... and make sense, though finds there is 'much still to do' in terms of development. Has good feeling while us... accom...
	What's App				Mostly uses non-Diabetes Apps for communication. Likes mySugr monster, is "responsive and funny" sees diabetes ... App sees himself as being a bit under pressure. Sees challe...
					uses non diabetes apps for information and language learning. Feels efficient. Found diabetes app too complicate... emotionally different from paper, describes high values as feeling like "negative bank balance". but app didin't ... numbers, thinks app doesn't understand context. She says she just wants data, not to be told she is "50% out of ra... where she is going to drink she might choose to be h...
1x per day	nikerun	excel			apps not useful enough, sometimes incorrect. Data entry was slow.if I am spending time on it, it needs to... Communication with others.2 or 3 months since using. Curiosity wou...

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10.3.2 Results from Chapter 6 FCR

Coding Scheme

(available for download at: https://figshare.com/articles/Supporting_Diabetes_Self-Management_with_Ubiquitous_Computing_Technologies_A_User-Centered_Inquiry/7269398)

Table 1

type of model	Habitual	FCR	Sensemaking
	low cognitive demand	medium cognitive demand	high cognitive demand
	Implicit, Effortless	Active Engagement	Explicit, Effortful
	frequent/continuous	frequent	occasional
	Applying existing static, rule-based models	Adapting/ combining multiple existing models	Problem solving /Hypothesis/Learning
	Fixed discrete algorithms	Fuzzy algorithms	demanding or new algorithms
	3 * 3 = 9	3.1* 2.9 ≈ 3 * 3 = 9	3.1 * 2.9 = 8.99
	Reflexive/Reactive	Improvisation/proactive	Reflective or Hypothetical thinking
	Memorization	Connecting Chunked memory	Loading working memory
	response to event	navigation of event	unexpected/hard to explain event
	"If this, then that"	"Some combination of this and that"	"Could this cause that?"
	A reflexive responses, habitual behaviors, or a script activated that allow for low cognitive demand execution of either a single or sequence of previously learned steps, models, or forumulas? (e.g. for elevated BG take a correction shot of 1 unit insulin per 50 mg/dl, drink water, test again in 1 hour.)	A combination of models being adjusted and applied to a specific context with increased awareness of how factors affect past, present, and future to allow 'steering through' an extended time continuum.	A recognition of an unexplained event, discovery of a new pattern, cause and effect analysis, explanation of what caused an event to occur, a learning process, with conscious creation or revision of specific model(s). (e.g.
insulin	fixed Insulin to carb ratio	insulin on board (if not monitored by device)	building models
	bg correction factor	insulin sensitivity in relation to a context	researching how context changes insulin sensitivity
	fixed insulin dosages	waiting variable times before eating	retrospective analysis of insulin effect
		changing individual insulin dosage in relation to multiple factors	calculating new insulin/carb factors
		micro-dosing for small changes	experimenting to determine new fixed dosages
		reducing insulin on board for specific contexts	
		series of small shots to deal with unusual situation	
		adjusting dosages according to trend anticipation	
		adjusting according anticipated length of meal	
exercise	set schedule	engaging in variable exercise to for glycemic control	determining what effect exercise had on outcome
	x exercise has x effect	factoring in variable exercise effects	
	past known exercise with set model	anticipated future exercise to alter insulin dosages	
dietary	carb counting	considering contextual effect of carbs	trying specific meals and learning effect
	same meals at same time	Glycemic index of combined foods	discovering glycemic index of different foods through experimentation
	Glycemic index if quantified	Fat content delaying glucose response.	
	specific meals	estimating cumulative effect of absorption carbs vs fat vs. protein	
		predicting duration of meal	
		predicted time before meal	
		over correction for specfic context	
Blood glucose	fixed treatment for correction	variable corrections dependent on context	discovering how much a given amount of carbs raises BG
	over eating for hypos/bouncing	micro-dosing for small changes	
	15/15 rule (15 grams carb, wait 15 minutes)	increasing testing frequency to observe results and adjust	

1

type of model	Habitual	FCR	Sensemaking
	drink water for hypers	correcting as needed per context	
	reactive correction	changing target BG according to context	
	setting fixed target BG	seeking to stabilize rather than meet certain targets	
Testing	test before meals	test as needed	test before and after an action to learn its effect
		frequent watching of CGM for course corrections	
	habitual checking	frequent checking/ frequentcy dependent on contect	checking to trouble shoot a specific problem
Context	limiting contextual variables	changing treatment according to context	analysis of how much a given termperature changes insulin requirement to form new dosages
		temperature	
		weather	
		how much effort is predicted to be put into diabetes management in given time period	
	accept device recommendation	use device recomendation as one aspect of decision	program device
Devices/ Interfaces	bolus advisor	trends(graphs and arrow on CGM/ rate of change)	reflecting on charts and graphs to change treatment regime
	BG value on meter	judging BG or average with context of situation	
		watching for change in direction of curve to trigger events	using average on meter to change habitual insulin therapy
	change infusion set on schedule	change infusion if it seems like a likely risk	trouble shoot that infusion set is to blame for problem through process of elimination
	responsing to event with fixed plan	using CGM to correct for predicted event	graphs if used for retrospective analysis
		graph if used to assess general tendency over time	program bolus advisor
		frequent looking for trends and patterns in CGM curves and adjusting accordingly	detailed examination of curves to modify habitual treatment
		using arrow angle to adjust treatment	
time	set responses for given times	time of day as factor to be considered with others	figuring out how time affects diabetes management
		BG level over recent past	
		projection to future possibilities	
		time of year	
health		changing insulin dosage for sickness	
		menstration cycle	
		factoring in effect of other health conditions on control	
		general sense of wellness	

2

Participant	01. Age	02. Gender	03. Time since Diagnosis	04. devices	05. testing frequency	06. boluses per day	07. Normal BG/ response	HAB..=1, FCR =2, SM = 3, ? = 4, NA = 5	08. Recall surprising BG event	HAB= 1, FCR =2, SM = 3, ? = 4, NA = 5	08b. Treatment procedure	HT, FCR =2, SM =3, ? =	09. out of range w. obvious cause	HAB=1, FCR =2, SM = 3, ?= 4, NA = 5	09b. Treatment procedure	HAB=1, FCR =2, SM = 3, ? = 4, NA = 5	10. Recall out of range event w/ novel situation
P004	18-24 years old	Male	11-20 years	Blood glucose meter/accuche ck NAnci) insulin pens(humalog lispro), phone apps(onedrop) insulin syringes (bd ultrafine) regular basal insulin (lantus)	5-7	4-5	Insulin to carb ratio, and bg correction factor	1	Soon after starting a new exercise routine my sugar dropped to 46. It has happened before so i simply corrected the situation with sime juice.	1	Orange juice was used	1	Pizza always makes my bg go berserk	3	I have to correct almost double insulin to carb ratio and double bg correction	1	Travelling from Costa Rica to Spain, due to the change in schedule I miscalculated a dose kf my basal insulin so I was stih higher level bg for the next day
P005	18-24 years old	Female	11-20 years	Blood glucose meter as accu chek performa and element plus infopia, smartphone app diabetes connect, insulin pens humalog	5-7	4-5	The type of meal i'll eat, if there's many carbs, and the activity i'll make later like excercise, or play	2	I was on my way to the university and I felt low, but I forgot to bring my matter with me so I waited till I arrived and immediately went to emergency at the U, and they check my blood sugar and I was 42mg/dL.	3	As I said, I went to emergency at the University, they know me because I told them that I have DM T1, and they made me a test and I was 42mg/dL, and then put me an inyection with glucose or something like that... and then I ate a cookie and juice	5	One day, I was at a birthday party, and I really like sNAcks, so I ate sNAcks as if there's no tomorrow and I didn't put more insulin to cover all the carbs I ate and was like 500mg/dL.	3	I decide to stop eating that, and start to drink water and put more insulin to low my blood sugar and feel better	1	The other day I was about to go out for dinner with friends and I though that we were going to dinner on one restaurant but at least they changed the place and because of that I arrived late and because the hurry I miscalculated the insulin dosage, then I got a low BG around 2am
P007	25-34 years old	Female	21-30 years	Blood Glucose meters, insulin pens, smartphone apps (one drops and socialdiabetes)	8-12	NA	Use the indicated insulin dose	1	If my glucose value if low I need eat sugar, but is high I need drink water or use insulin	1	When my glucose is low, I use glucose tablets and meters my glucose again, eat a carb and meter my glucose again. If my glucose is low repeat the progress. When my glucose is high I applied insulin and meter my glucose 2 hours later.	1	When you apply the wrong dosage of insulin	1	I apply insulin	1	Forget to apply insulin dosage when eating and the level is high then.
P008	18-24 years old	Male	1-2 years	Glucose meter (Accu-check Performa) insulin pumps (lantus and cristalina) smartphone apps (Runtastic, Diabetes	1-2	4-5	I consider if I will do exercise later, if I am hungry or not, I always think on the body part where I will apply my injection and what I will eat in that meal	2	I was in a pretty regular day on my school doing a classwork, and I didn't noticed about I injected 3 units more than normally, and I was losting my ideas but I	3	I applied the 15/15 rule (eat 15 fast CHO and wait 15 minutes) and I had to repeat it 2 times	1	I was tasting a new ice cream flavour because my friends wanted to go out and the day	3	As soon as I reach at home I applied my correction doiss and I normalized it, it took 1 hour	1	This one is a little funny xD I was dating and the girl asked me for go to my home together, so I really got nervous and my sugar just raised up fast (from 130 to 356) but

10.3.3 Results from Chapter 7 Wearables study

(data set available for download at: https://figshare.com/articles/Supporting_Diabetes_Self-Management_with_Ubiquitous_Computing_Technologies_A_User-Centered_Inquiry/7269398)

participant #	Average number of injection per day/bolus for pump users	A1c	CGM	notes	2_in. Have you used any exercise tracking devices, if so which?	3_in. satisfied diabetes management?	4_in. challe
1	6.50	7.7	Libre	interview done 1 week after device install	google fit on phone	Not exactly. I thing I started trying to take care of it like a year ago again because I spend some time the thing I wasn't paying too much attention. And then I decided I need to get back on track its getting better but I still feel like it isn't as in control as I would like to.	Calculating eating all th I wasn't pay is too high n attention to v
2	5.50	6.8	Libre		I tried it. Well I don't exercise all that much. But I have tried it but I had a really bad phone. So the app always crashed was runtastic. So yeah I really exercise since I got my new phone so I should probably give it a try again.	I think I think I'm on the right track because I've made a lot of improvements and I've good I've got good technology that really helps me a lot. I'd like to upgrade it a little bit since I'm using the free style libra right now and I just got the mini med pump. So I'm looking to get the full CGM covered and then I can really make use of all the features of my pump. apart from that I am quite happy I've got a good team and good motivation right now.	Keeping up that I gather I'm really re
3	6.00	7.2	Libre		in the past. Yes I used the xiome Me fitness band and the Google fit app two years ago. (They were) Quite interesting I found the Google app on the phone much more accurate and precise than the fitness tracking device especially in recognizing the difference between biking and walking or running. So that was interesting like to see the effort I do when I bike or just walk. And I used the fitness tracker mainly to see my sleep cycles because of a super interesting to see. Sometimes I would wake up and I think I had I said that it's long enough but I still don't feel well and I'm sometimes I sleep a much shorter night, but still I feel much better than other nights when I sleep longer and I realize that it has a lot to do with the sleep cycle and the deep sleep stuff and so on. So yeah it was quite interesting to see that.	Not entirely. I mean some days it just does what it wants to do that doesn't matter how much I try to get it under control. I have a freestyle Libre and it helps a lot. And I do multiple injections a day and pay attention to what I eat. But some days it's just out of control. And what really pisses me off is that I was using Treciba insulin last year and it is no longer available in Germany without a big hassle and I'm back to Lantus and I think that it's not as good as the treciba to get things under control. So yeah I like the short answer is I'm not that satisfied could be better.	sometimes witchcraft. Y and then it ju it doesn't wo down again really it's re
4	5.9	6.0	Libre		Runtastic (stopped) I'm not running anymore	Yes. I'm kind of satisfied, but I think it would be better if I had	Under ever

Questions from Wearables study

Q: *Does your product in any way add to daily workload? If so, what rewards does the user receive to justify this time and effort?*

Q: *Is the information collected by your system accessible to any stakeholder other than the primary user? If so what is your strategy for:*
-mitigating feelings of surveillance?
-assisting the user in taking breaks from monitoring if they desire?
-allowing them to control how data is presented?

Q: *How might your product or service create stigma in specific contexts? How might this stress be lessened? Is it possible to build for breaks in usage?*

Q: *Does your product provide personal data to medical personal or other 3rd parties? If so:*
-what controls does the user have to manage when and which data is visible?
-could such controls be modified quickly during an appointment to allow discussion of a specific topic?

Q: *Why should the user trust your product? What assurances can you promise, and how can you guarantee they will be followed?*

Q: *Does your device or systems allow the user to adjust or alter components to meet their needs or preferences? If not, how is this justified?*

Q: *Is your product transparent to how the data is being used? How do you keep the user informed and updated?*

Q: *Is the information collected by your system visible to any stakeholder other than the primary user? If so, how do you:*
-Plan for monitoring pauses in sensitive contexts?
-Plan for reengagement after pauses?
-Allow user to control how and which data is shared?

Q: *Does your product or service make use of GPS data?*
-In which ways do you protect the user from vulnerability, such as being identified, or having that data associated with their medical data?

Q: *Does the proposed system have a system of consent which helps the user to easily control who, when, and for what purpose each of their different data types will be used?*
- If not, how do you justify this?
-How could you implement such measures?

Q: *Does your business model involve using individual's personal data for targeted marketing or use by 3rd parties? If so, how do you protect the user from any harms that may result?*

10.3.4 Results from Chapter 8 DUETS

Following tables show simplified results from the study organized by stage and categorization. Color coding show which stage the concern was located by the other focus group.

DUETS study First focus group: Concerns identified by Developers					
Stage	Adoption & Utility	Emotional Impacts	Behaviors & Actions	Cognition	Consent & Control
Stage 1 Prior	1a. Relevancy of information -Real-time BG availability -Recommendation risks -On device processing for real-time information -Insulin data -Personalization -User resistance to more apps	-Information annoying -Historical data overwhelming -Excess notification	-Actionable information		-Privacy concerns
Stage 2 heuristics	-Rewards systems -No user-input -Phone dependent -No user status -User interaction design -Technology validation -UI Design -Inaccurate notifications -Notification context	-Resistance to increased diabetes engagement		-Explaining technology -User education	-User privacy concerns due to misunderstanding product
Stage 3 Concerns cards	-Incorporate manual feedback 6 -How bad is manual entry? 6 -Cold start -Informing as to potential benefits -Doctor involvement -No justification for no customization 9	-Further research on UI color -Stress related to potential adverse future events -No user-testing	-Incorporating user algorithm training -System over-reliance	-Interference with autonomy -Guidance on recommendation effects -App not free-standing	-Validating outcomes -Technology dependent on device adoption -Increased attention to user -Discomfort with tracking
Stage 4 All cards	"Providing accurate information given the lack of data, no user input, no user feedback"	-Watch interface could cause stigma -Effects of non-favorable information		-Triggering user's existing knowledge -Misleading data presentation	-Personal data usage by other parties -User trust -Concealed stakeholders

	Adoption & Utility	Emotional Impacts	Behaviors & Actions	Cognition	Consent & Control	totals
Developer focus group n=3, novel concerns located						
Prior	7	3	1	0	1	12
heuristics	9	1		2	2	14
Concerns	6	3	2	3	4	18
DUETS	1	2		2	3	8
totals	23	9	3	7	10	52
Users focus group n=6, novel concerns located						
Prior	13	5	0	2	1	21
heuristics	5	4	0	1	2	12
Concerns	16	7	1	6	4	34
DUETS	17	6	2	4	4	33
totals	51	22	3	13	11	100

DUETS study					
Second focus group: Concerns identified by Users					
Stage	Adoption & Utility	Emotional Impacts	Behaviors & Actions	Cognition	Consent & Control
Stage 1 Prior	-Notification frequency -Excess non-relevant information -Customization -Relevancy -Reliability -Quiet mode -Benefit/Effort ratio -Prediction -Additional parameters -System transparency -Detecting or learning behaviors -Medical certification -Integration with medical devices	-Pre-existing App and device fatigue -Lack of trust in safety -Notifications annoying -Notification frequency annoying -System fatigue		-Too much text to read -Suggestions too hard to understand	-Data security
Stage 2 heuristics	-Functionality that promote usage -Design -Progress visibility (feature) -Accuracy of information -Usability	-Stigma from usage -Others annoyed by phone usage -UI emotionally overwhelming -positive & motivating		-UI cognitively overwhelming -	-Unclear what data is being used for -accidentally sharing data on social media
Stage 3 concerns cards	-Actionable information -Customizable type of assistance -Adaptively displayed data -Optional gamification only -Optional info /alerts -Display and explain status until sufficient data for prediction. -Rewards clinical or virtual? -False sensor readings excludable -Pre-existing CGM data integration -Integration with HCP software -Display uncertainty of detected activities -Minimize workload -Contextual sensing for alarms -Ambiguity of messages -Convenient manual feedback -Not increasing diabetes management time	-Design should be non-judgmental -Reconsider use of red -Privacy UI options -Non-visually coherent UI design -Current UI doesn't support, just information -Data looks fake -Blackbox inhibits trust	-Clinical relevancy	-Highlight flawed collected data -Focus or distraction? -Device malfunction could cause bad advice -Intuitive alerts -Goal of product unclear -Contextual display of retrospective data -Minimize usage of systems by design	-Motives of developer -Transparency of profit and data --Independent usage -Access -Affordability
Stage 4 Con. Cards+ Archit.	-Already using many apps-> high barriers to entry -Too complicated ->abandonment -A few days to a month to prove value -Must work right away if it uses retrospective data -Should function without GPS -Quiz at beginning for customization (short) -Adjustable thresholds for hypo/hyper -Connecting with API's like weather for novel insights -Customized by previous answers -Prompt data entry/outliers to assist medical appointments -Glanceable highlights -Insights for medical personal -Questions rather than statements -Stress detector function -Target specific group rather than broad appeal -Glanceable/hidden insight option -focus on watch interfaces rather than phone	-Single annoying feature->abandonment -Stress from too many devices going off simultaneously -Machine simulating human annoying -Language must be carefully phrased -red only for actual emergency situations -Full transparency for trust	-Specific behavior suggestions -low distractions in emergency situations	-Separate reduced screens -graphs too complicated -Help users understand behavioral impacts -Training on how to use system	-Hide locations option -Don't nudge purchasing -Sharing of data to customizable for individual stakeholders -Allow sharing of insights without actual data

DUETS Cards

Functionality

To what extent does the system adjust or allow adjustment for individual preferences?

How easy are such adjustments to locate and manipulate?

Concerns   01

Functionality

Will this product be capable of delivering perceived value if the user fails to consistently manually enter data?

If not, what rewards does the user receive for data entry?

Concerns   02

Functionality

Does this product depend on non-primary users such as doctors to accept this product?

If so, how have you verified that they will be willing to do so?

Concerns   03

Functionality

Does the product in any way add to user daily workload?

If so, what indications are there that the benefits are sufficient for time invested?

Concerns   04

Functionality

Can the user gain benefits when they use product without having to have invested effort on previous occasions?

If not, how much effort will they need to invest, and why will the user do so?

Concerns   05

Functionality

How much effort per day will users have to invest in order to attain benefits?

How is this request for user time justified?

Concerns   06

Functionality

Is this product meant for frequent usage?

If so, can it support user needs without requiring significant cognitive effort?

Concerns   07

Functionality

If this product requires continual use to deliver benefits, how much effort does each use require?

How can this be decreased?

Concerns   08

Functionality

Is this product meant as a daily usage tool?

If so, to what extent do benefits surpass required effort?

Concerns   09

Functionality

How useful for your user is the information presented?

What actual user problem does this information solve?

Concerns   10

Functionality

Does the system offer explicit actionable information? If not, why not?

Could the user be better served by more processed data?

Concerns   11

Functionality

If the system displays significant retrospective data, in what ways does this assist actual user needs?

If less data were visible by default, would the user still be able to complete their task?

Concerns   12

Functionality

Are any extra elements such as sound effects?

Can they be customized or turned off if they are intrusive?

If they add essential information, are there alternate ways for the user to receive this information?

Concerns   13

Functionality

Does the product assist with an actual user need?

What is this need?

How could it better meet this need?

Concerns   14

Functionality

Can the system offer benefits with a glance from the user?

If not, why not?

Could it?

Concerns   15

Functionality

If there are elements such as gamification, are they appropriate to the context of use?

How can this be verified?

Concerns   17

Functionality

Does your device or systems allow the user to alter, adjust, or exchange components to meet their needs or preferences?

If not, how is this justified?

Concerns 19

Functionality

Concerns

Emotional Impacts

Could this system or interface create feelings of stigma or vulnerability in specific situations? e.g. date, job interview, public space, etc.

How could it be made more sensitive?

Concerns 20

Emotional Impacts

How does the interface display sensitive or undesired data?

Can it alert user to important situations, without creating undue stress?

Could this be improved?

Concerns 21

Emotional Impacts

Are design element colors sensitive to the feelings of the user?

Has the use of alert colors like red been properly tested for emotional reaction from users?

Concerns 22

Emotional Impacts

Are the design choices such as color, sounds, and interface motivating or demotivating?

How has this been tested in a way appropriate to intended usage?

Concerns 23

Emotional Impacts

Have you adequately researched how the information or feedback you provide impacts your users emotionally?

What strategies do you have in place for delivering data in a way that minimizes undue stress?

Concerns 23

Emotional Impacts

Concerns

Cognition

Does the interface help to activate or jog the users' existing knowledge?

If not, how could this be improved?

Concerns 24

Cognition

If the system offers retrospective information, to what extent does such retrospection serve user needs?

Is this data always needed or just in specific cases?

Concerns 25

Cognition

Could information presented give a false impression of actual data? (For example, graphs that draw lines between data points, or averages that conceal deviation.)

Concerns 26

Cognition

If the user becomes confused by the system, what means are in place to help them understand it?

Concerns 27

Cognition

Does the interface present all information needed for task simultaneously, e.g. a single screen?

Why not?

Could it be changed to allow this to happen?

Concerns 28

Cognition

How much effort is required for the user to interpret the interface?

Could the complexity be reduced without impairing essential functions?

Concerns 29

Cognition

In what ways does this interface help the user to question the habitual behaviors they do that might not be helpful?

Concerns 30

Cognition

Could this product add to confusion or delays in critical situations, such as with complicated interfaces, distracting, or overly engaging interfaces?

If so, how is this risk justified?

Concerns 31

Cognition

Could users become unnecessarily dependent on this product for decisions?

Would it be possible for this product to help the user to learn to not depend on it for decision making?

Concerns   32

Cognition

Does this product support in-the-moment decisions without undue effort?

Concerns   33

Cognition

Does this product help users to correct and adjust their decisions according to specific contextual need?

Concerns   34

Cognition

Does this product help users to access knowledge they already possess in a fluid and flexible manner?

How could it do so?

Concerns   35

Cognition

Do interface elements assist users in predicting the result of following the advice?

If not, could such functionality be integrated?

Concerns   36

Cognition

Does this product assist users in recognizing problems or unusual events?

How does it assist them in understanding what is the problem?

How could it do this?

Concerns   38

Cognition

How does this product help users to question, explore, and test their assumptions?

Could this process be better supported?

Concerns   39

Cognition

In what ways does this product help users to identify and make sense of patterns?

How could such functionality be included?

Concerns   40

Cognition

In what ways does this product help users to form new ideas about how best to manage challenging situations?

Concerns   41

Cognition

Concerns

Privacy & Security

Which aspects of the system are you most concerned about?

What would you change if you could?

Concerns   42

Privacy & Security

Does the proposed system have a system of consent which helps the user to easily control who, when, and for what purpose each of their different data will be used?

If not, how do you justify this?

How could such measures be implemented?

Concerns   43

Privacy & Security

Concerns

Privacy & Security

Does your business model involve using individual's personal data for targeted marketing or use by 3rd parties?

If so, how do you protect the user from any harms that may result?

Concerns   44

Privacy & Security

Is the information collected by your system visible to any stakeholder other than the primary user? If so, how do you:

Enable user to pause monitoring in sensitive contexts?

Allow user to control which and how data is shared?

Concerns   45

Privacy & Security

Does your product provide user data to medical personal? If so:

-what controls does the user have to manage when and which data is visible?

-could such controls be modified quickly during an appointment to allow review of specific data?

Concerns   46

Privacy & Security

Does your product or service make use of GPS data?

If so, in which ways do you protect the user from:
-identification
-linking with medical data
-vulnerability

How could the user be better protected?

Concerns   47

Privacy & Security

How transparent is the ways in which the user's data is:
-being used?
-who has access?

How could you better inform the user?

Concerns   48

Privacy & Security

Why should the user trust your product?

What assurances can you promise?

How can you guarantee they will be followed?

Concerns   49

Privacy & Security

How how much personal information is collected form the user?

Is there an imbalance in data collected and data received?

Is this data only being used to serve the user, or are there other purposes?

Concerns   50

Privacy & Security

Are there any stakeholders that the user is unaware of?

Are they receiving any data, anonymized or otherwise?

Do you think the user would be less likely to use this product if they were aware of this?

Concerns   51

Privacy & Security

Do you consider the patient the primary stakeholder?

If not, how is this justified?

Concerns   52

Privacy & Security

Concerns   53

Behavior & Action

Can the interface help users to react quickly in crucial situations?

If so, in what ways could the system assist in the user becoming more independent ?

Concerns   54

Behavior & Action

Does the system try to enforce a structure on the user, such as a set daily time schedule?

If so, how is this justified?

Can it be easily customized?

Concerns   55

Behavior & Action

Does this product help users to act quickly in critical situations?

How could it better assist in such instances?

Concerns   56

Behavior & Action

Could this product interfere with the user engaging in necessary actions?

If so, how is this justified?

Concerns   57

Behavior & Action

Concerns   C-38

Smartphone

Notes

Devices   Dev-01

Smartwatch

Notes

Devices   Dev-02

Pad

Notes

Devices   Dev-03

Laptop

Notes

Devices   Dev-04

Cloud Computing

Notes

Devices   Dev-05

Cloud Service

Notes

Devices   Dev-06

Cloud Documents

Notes

Devices   Dev-07

Cloud

Notes

Devices   Dev-08

IoT Health Device

Notes

Devices   Dev-09

Health Device

Notes

Devices   Dev-10

IoT Health Device

Notes

Devices   Dev-11

Network Data Base

Notes

Devices   Dev-12

Desktop Computer

Notes

Devices   Dev-13

Fitness Band

Notes

Devices   Dev-14

LAN Network

Notes

Devices   Dev-15

Networked Drive

Notes

Devices   Dev-16

Local Drive

Notes

Devices   Dev-17

Server Farm

Notes

Devices   Dev-18

IoT medical device

Notes

Devices   Dev-19

Notes

Devices   Dev-20

Medical Service

Notes

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Services · Ser-01

Health Coaching

Notes

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Services · Ser-02

Clinical Support

Notes

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Services · Ser-03

Education

Notes

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Services · Ser-04

Remote Monitoring

Notes

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Services · Ser-05

Diagnosis

Notes

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Services · Ser-06

Medical Evaluation

Notes

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Services · Ser-07

Analytics

Notes

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Services · Ser-08

Big Data Analytics

Notes

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Services · Ser-09

Peer Support

Notes

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Services · Ser-10

Notes

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Services · Ser-__

Patient

Notes

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Stakeholder · SH-01

Family

Notes

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Stakeholder · SH-02

Friend

Notes

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Stakeholder · SH-03

Parent

Notes

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Stakeholder · SH-04

Co-Worker

Notes

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Stakeholder · SH-05

Medical Worker

Notes
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Stakeholder   SH-06

Startup

Notes
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Company   Com-01

Health Insurer

Notes
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Company   Com-02

Tech Company

Notes
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Company   Com-03

Care Provider

Notes
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Company   Com-04

Corporation

Notes
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Company   Com-05

Notes
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Company   Com-__

Data

Exercise
Step counts
Blood glucose
Behaviors
Locations
GPS
Insights
Records
Advice
Sleep
Goals
Peer support
Financial
Alerts
Encryption
Ads

Goals

Habit Change
Social Interaction
Stress Reduction
More Exercise
Save Times
Coping
Emotional Support
Sell Product
Maximize Profit
Collect Data
Sell Service
Improve Health
Improve Diet
Improve Biomarker
Reduce Risk
Earn Money

Actions

Analyze Data
Change Goal
Exercise
Eat/Drink
Sleep
Pressure
Encourage
Comment
Collect Data
Invitate
Adapt Algorithm
Reflect
Exercise
Sense
Read
Control

Traits

Health Condition
Proprietary
Secure
Vulnerable
Gender
Cognitive Disability
illness
Learning disability
Physical disability

Emotions

Fear
Anger
Sadness
Joy
Disgust
Surprise
Trust
Anticpation
Suspicion
Shame
Envy
Love
Worry
Concern
Vulnerability
Stress

Responsibilities

Financial
Emotional
Familial
Professional
Social
Monitoring
Household
Maintenance
Management
Recording
Coordination

Sensors

GPS
Fingerprint
Barometer
Three-axis gyro
Accelerometer
Proximity
Ambient light
Camera
Compass
Altimeter
Heart rate
Gyroscope
Ambient light
WiFi/ LTE

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