

Individual Differences and Contextual Factors
Influence the Experience and Practice of Self-Care
with Type 1 Diabetes Technologies

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Declaration

I, Aisling Ann O'Kane, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Adults with Type 1 Diabetes have choices about what technologies to use to self-manage their chronic condition. They can use glucose meters, insulin pumps, continuous glucose monitors, smartphone apps, and other mobile technologies to support their everyday care. However, little is known about how user experience might influence what they choose to adopt or how they choose to use technologies when practicing self-management. A series of situated exploratory qualitative studies were conducted to examine contextual factors that influence the use of self-care technology “in the wild.” Autoethnography was used to gain empathy for the everyday use of a mobile medical device and to set up a mixed method user study, involving contextual interviews, a diary study, and the observation of a diabetes technology group meet-up. A combined bottom-up thematic analysis of the data from the user studies uncovered commonalities among the users in how context influenced the use, carrying, adoption, and misuse of these devices. However, large variability in how user experience impacted self-care for the 41 participants was also revealed. Although these self-care technologies were effective, efficient, and easy to learn for the participants from a human factors engineering perspective, context specific issues arose that impacted decisions to use them. The physical environment, the social situation, the cultural context, and individual differences influence these choices. Quality of life can be impacted by the design of Type 1 Diabetes technologies, and people sometimes prioritise quality of life over immediate or long-term health benefits. This research points to the need to study the use of these mobile medical devices in-situ to understand how their design can influence adoption and use in everyday life. However, the variety of everyday self-care contexts and the diversity of possible user preferences do not lead to straightforward or universal design implications. Future work should look at the influence of design of other self-management technologies that are being developed to deal with the move of healthcare outside of clinical settings and focus on empowering adults to make personal choices about their self-care technologies that suit the context of their, sometimes messy, everyday lives.

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C. Vincent, G. Niezen, **A.A. O’Kane**, and K. Stawarz. “Can standards and regulations keep up with health technology?” Journal of Medical Informatics Research (JMIR) mHealth and uHealth, vol. 3, no. 2, e64, June 2015.

A.A. O’Kane, Y. Rogers, and A. Blandford. “Concealing or Revealing Mobile Medical Devices? Designing for Onstage and Offstage Presentation” in Proceedings of CHI 2015, 2015, pp.1689-1698.

A.A. O’Kane. “Situated User Experience with Take-Home Technology Influences Adherence to Self-Management Plans for Adults with Type 1 Diabetes,” in the Journal of Diabetes Technology & Therapeutics, 2015, vol. 17, pp. A128-A129 (abstract only).

A.A. O’Kane, Y. Rogers, and A. Blandford. “Gaining Empathy for Non-Routine Mobile Device Use Through Autoethnography” in Proceedings of CHI 2014, 2014, pp. 987-990.

A.A. O’Kane, and A. Blandford. “Reflecting on Empathy during Mobile Medical Device Research,” in Proceedings of Workshop Enabling Empathy in Health & Care: Design Methods & Challenges in conjunction with CHI 2014, 2014.

A.A. O’Kane. “Using A Third-Wave HCI Approach for Researching Mobile Medical Devices,” in Proceedings of Workshop HCI Research in Healthcare: Using Theory from Evidence to Practice in conjunction with CHI 2014, 2014.

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E. Temir, **A.A. O’Kane**, P. Marshall, and A. Blandford. “Mobile Apps and Running: A Pragmatic Situated Study” in Extended Abstract Proceedings of CHI 2016, 2016.

M. Patel, and **A.A. O’Kane**. “Contextual Influences on the Use and Non-Use of Digital Technology While Exercising at the Gym” in Proceedings of CHI 2015, 2015, pp.2923-2932.

A. Blandford, E. Berndt, K. Catchpole, D. Furniss, A. Mayer, H. Mentis, **A.A. O’Kane**, T. Owen, A. Rajkomar, and R. Randell. “Strategies for conducting situated studies of technology use in hospitals” Journal of Cognition, Technology & Work, pp.1-14, Dec. 2014.

D. Furniss, R. Randell, **A.A. O’Kane**, S. Taneva, H. Mentis, and A. Blandford. (eds.) Fieldwork for Healthcare: Guidance for Investigating Human Factors in Computing Systems. Morgan & Claypool Publishers, 2014.

D. Furniss, **A.A. O’Kane**, R. Randell, S. Taneva, H. Mentis, and A. Blandford. (eds.) Fieldwork for Healthcare: Case Studies Investigating Human Factors in Computing Systems. Morgan & Claypool Publishers, 2014.

S. Taneva, **A.A. O’Kane**, R. Ratwani, B. Hilligoss, A. Rajkomar, A. Thieme, and K. Groth. “Establishing and Maintaining Relationships in Healthcare Fieldwork,” in Fieldwork for Healthcare: Guidance for Investigating Human Factors in Computing Systems, Morgan & Claypool Publishers, 2014.

K. Sellen, D. Furniss, Y. Chen, S. Taneva, **A.A. O’Kane**, and A. Blandford. “HCI research in healthcare: using theory from evidence to practice,” in Proceedings of CHI 2014: Extended Abstracts, 2014, pp.85-89.

D. Furniss, **A.A. O’Kane**, R. Randell, S. Taneva, H. Mentis, and A. Blandford. “HCI fieldwork in healthcare - Creating a graduate handbook,” in Proceedings of CHI 2013: Extended Abstracts, 2013, pp. 3203-3206.

A.A. O'Kane, H. Mentis, and E. Thereska. "Non-Static Nature of Patient Consent Over Time: Diabetic Patients' Changing Privacy Perspectives" in Proceedings of CSCW 2013, 2013, pp.553-562.

A.A. O'Kane and H.M. Mentis. "Sharing Medical Data vs. Health Knowledge in Chronic Illness Care," in Proceedings of CHI 2012: Extended Abstracts, pp. 2417-2422, 2012.

A.A. O'Kane and H.M. Mentis. "Sharing Health Information in the Care of Diabetes" in Proceedings of Workshop on Bridging Clinical and Non-Clinical Health Practices: Opportunities and Challenges in conjunction with CHI 2012, 2012.

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1 - Introduction

The use of technology in the everyday management of health has never before been so ubiquitous. With advances in sensors, internet and mobile technology, laypeople are using technology to track aspects of their health, compare their experiences to others, look up medical information online, and use sensors to measure values that used to only be measured in a doctor's office (Pantelopoulos & Bourbakis, 2008). This, in addition to the ubiquity of mobile technologies such as smartphones (Klasnja & Pratt, 2012) and the rising use of everyday wearable technology such as smartwatches (Swan, 2012a), has changed the lives of those who have to use and carry mobile medical technologies in order to self-manage a chronic condition.

Mobile medical technologies are used by people for the care or maintenance of a health condition outside the clinical setting. They are interactive technologies carried by patients or caregivers. Arnrich and colleagues (Arnrich, Mayora, Bardram, & Tröster, 2010) discuss the future of healthcare as being pervasive; everywhere. Although they believe there is a trade-off between the quality of sensors and patient comfort whilst wearing them, there is potential in automatic sensing and technologies for treatment as the quality of sensors continues to improve. Although there have been recent innovations in mobile medical technologies, some devices have been around for many years. For example, a nebulizer is used by a person with respiratory issues to ingest prescribed medication and an asthma inhaler can be carried by people to inhale medication in case of an asthma attack. However, the variety of mobile medical technologies now available means that the choice of devices that adults make for their personal self-care has never been as great. They are not only available through the traditional clinical routes, but are also available online on large retail sites such as Amazon, along with reviews. With technology companies increasingly adding health features to their smartwatch and smartphone technologies (Swan, 2012b) the line between medical device and consumer device is becoming less clear, although mobile medical devices are still regulated worldwide as medical devices and they require the application of medical usability engineering processes in their design and evaluation (ANSI, 2007).

Researchers and practitioners in both the Human Factors Engineering (HFE) and Human-Computer Interaction (HCI) domains have focused on healthcare in order to improve technology safety through user centred interaction research, design, and evaluation. This medical usability research has had many successes and its practitioners have adapted their methods and approaches to accommodate technological advances and changes in the practice of medicine. The result has been a worldwide acceptance of the importance of medical usability engineering, evidenced through international standards (ANSI, 2007; FDA, 2011).

A new challenge arising for medical usability engineering is dealing with chronic conditions: the move of medical care to outside the clinical context. Williams calls this a shift in the “*geographies of care*”, where care is moved from formal to informal settings (Williams, 2002). With advances in medicine, what used to cause an early death has evolved into people developing conditions that have long durations and slow progressions that they have to manage. With more people living longer and developing illnesses, there is a large financial impact, with over 70% of the healthcare costs in the UK and US being attributed to chronic conditions (Department of Health, n.d.; Wu & Green, 2000). Healthcare trends are pushing care away from hospitals towards supporting independent living and reducing the financial burden caused by large proportions of populations needing medical care. This shift includes a push towards mobile medical technologies that people can carry to self-manage their chronic conditions throughout their everyday lives (García-Lizana & Sarría-Santamera, 2007).

The approach taken in this dissertation is the exploration of the everyday use of mobile medical devices, not by analysing a chronic condition itself, but by focusing on the experience of living with medical devices used for self-management. As such, this dissertation should be read as a human-computer interaction contribution rather than a health psychology one. The aim is to bring these complex and nuanced user experiences to light in order to inform the design and manufacture of mobile medical technology by focusing on one particularly relevant chronic condition: Type 1 Diabetes (T1D). People with T1D can use a variety of mobile medical devices, such as mobile glucose meters used for testing blood sugar levels, wearable continuous glucose meters used for on-going monitoring of blood sugar levels, wearable insulin pumps used for injecting medication, diabetes applications on mobile phones for tracking variables such as diet and exercise that influence blood glucose levels, and an increasing amount of other condition specific digital technology. Essentially taking on

the role of the pancreas which does not produce the hormone insulin in sufficient quantities, adults use these technologies as part of the toolkit necessary for balancing blood glucose levels in their body and self-managing this condition in their day-to-day lives.

Leaving the context of clinical settings means that the medical usability engineering methods for design and evaluation of T1D devices should be adapted to deal with everyday mobile use (for expanded discussion, see (Vincent, Niezen, O’Kane, & Stawarz, 2015)). However, it can be difficult to capture the situated use of these devices as they can be used by adults in an ad hoc manner, they are inherently mobile, and their users are incredibly diverse. Furthermore, these users are laypeople, not trained professionals, using these devices as part of their personal self-care rather than as part of their job. As such, it is important to understand how people’s everyday experiences with these devices can influence their use and adoption of them in order to design future technologies better suited to self-care practices.

Furthermore, good user experience when using T1D devices is not just a desirable attribute for these medical devices: situated experience is intrinsically linked to health outcomes for people with Type 1 Diabetes. Stress, life events, and family environment have all been shown to impact glycaemic control (Jacobson, 1986). Arousal has been linked directly to elevated blood glucose levels, particularly extreme arousal characterised by rapid and pronounced elevation of stress hormones which are correlated with impatience or anger (Peyrot, McMurry Jr, & Kruger, 1999). These types of situated experiences need to be managed as “*glycemic levels track physiologic arousal virtually immediately*” (Peyrot et al., 1999), throwing blood glucose levels out of balance. Looking at the circumplex model of affect (Russell, 1980), this arousal can be high for both negative and positive emotions. This means that emotional experiences related to using T1D technologies might not just influence self-management best practices, but they might also be directly related to blood glucose levels. Therefore, it is important to understand how people’s everyday situated experiences related to the design of T1D devices influence their affective reactions.

This research explores the situated adoption and use of T1D technologies and how people’s experience with self-care throughout their day-to-day lives might influence if and how they are used. Insights into how users’ experiences influence the use of these devices were achieved through using methods that have not been traditionally used in

the medical usability-engineering domain. Rather, a situated “in the wild” approach was employed to explore what Bødker (2006) calls ‘third wave’ technologies that are used in everyday life, in this case, for people’s everyday health (for expanded discussion, see (O’Kane, 2014)): mobile medical devices used for the self-management of T1D by adults.

1.1 Motivation and Research Objective

Like medical devices used by trained professionals in clinical settings, these mobile medical technologies are covered by medical usability engineering standards worldwide. The international IEC 62366:2007 standard ‘Medical Devices – Application of Usability Engineering to Medical Devices’ (ANSI, 2007) is the basis for many worldwide usability standards, including those of the Federal Drug Administration (FDA, 2011) and the British Standards Institute (BSI, 2008). This worldwide standard *“specifies a process for a manufacturer to analyze, specify, design, verify and validate usability, as it relates to safety of a medical device”* (ANSI, 2007). This international standard advises designers of medical devices to apply various usability design methods in order to account for users in the design of these systems. Suggested methods include contextual inquiry, function and task analysis, and simulated use testing, all requiring some level of observation as *“formative and validation testing fulfil the requirements to test the device under realistic conditions”* (FDA, 2011). There are arguments that these methods are not sufficient even in clinical settings, including suggestions to go beyond contextual inquiry towards ethnography (Wilcox, 2012), but they do not address the issues that will arise in designing and evaluating mobile health technologies that have usage scenarios that cannot be easily observed and captured. This lack of focus on the challenges associated with the design and evaluation of mobile medical technologies motivates this research, specifically the non-static nature of the contexts that they are used in and their potentially ad-hoc use. In addition, the standard does not account for the diverse users who may use the same technology. In the case of a glucose meter, the same device could be used by children or by people very late in life, and the experiences of these different users may vary significantly. Also, the medical usability standard does not distinguish between people who might be using a medical device to care for someone else and people who might be using it on their own body and impacting their own personal health and safety.

Although there have been studies of the use of T1D devices from a HCI perspective (e.g. (Kanstrup, 2014; Mamykina, Mynatt, & Kaufman, 2006; Storni, 2013)), they have not employed situated methods able to capture the complexities of everyday life that might influence the adoption and use of these devices. Additionally, some studies of diabetes technologies were conducted when people with T1D were still early adopters of mobile digital technology before mobile consumer technologies, such as smartphones and wearables, were commonplace to carry and wear (Mol, 2008). Many of these research projects had the goal of developing a new digital technology to assist with self-management, such as mobile apps (e.g. (Mamykina, Mynatt, Davidson, & Greenblatt, 2008; Owen, Pearson, Thimbleby, & Buchanan, 2015; Owen, 2011)), rather than conducting a critical review of current self-care medical devices and how they are used and adopted in situ. Although there has been some research concentrating on the impact of experience on the self-management of T1D in children and adolescents (Toscos, Connelly, & Rogers, 2013), there has been little attention paid to how these situated experiences influence adults' choice to adopt and use T1D technologies.

In both the human factors engineering and the human-computer interaction domains, the impact that user experience has on the use of T1D devices has not been given adequate attention considering the impact that affective reactions can have on blood glucose levels (Peyrot et al., 1999). This motivated this research on the situated adoption and use of Type 1 Diabetes technologies and how people's experience with self-care throughout their everyday lives might influence if and how they are used. To gain perspective on how a mobile medical device is actually used and experienced by people with Type 1 Diabetes, this PhD dissertation set out to explore the following research question:

What aspects of a person's situated experience with Type 1 technologies influence their adoption and use of those devices?

Building on previous self-care and diabetes research, an "in the wild" approach was employed, using autoethnography to gain empathy for mobile medical device use and inform the mixed method user study, which employed three situated methods to access everyday use. The combined bottom-up thematic analysis of data gathered from 41 participants sheds light on the impact that physical environment, healthcare systems infrastructure, cultural context, social context, and personal lifestyle play on practice and experience with these devices in day-to-day life. Finally, context and individual

differences are discussed with regards to the how people can prioritise quality of life over quality of health, the implications for design of future mobile medical technologies, and future work on empowering people to design technology that fits into their own, sometimes messy, lives.

1.2 Overview of Chapters

The chapters of this dissertation are designed to lay bare the contextual and individual differences that influence the experience and practice with Type 1 Diabetes devices uncovered using a mixed method situated approach as follows:

- 2 - Background and Related Work: This chapter starts by giving more details on diabetes self-management and T1D devices, followed by a review of related work connected to medical devices, self-care devices, diabetes technologies and healthcare in everyday life. Finally, experience and context sensitive approaches are reviewed, including Technology as Experience(McCarthy & Wright, 2004), which is used throughout the dissertation to frame the findings.
- 3 - Methodology: A Situated Approach: This chapter gives a broad overview of the 'in the wild' approach taken and outlines the situated methods chosen to examine the use of T1D devices in everyday life.
- 4 - Autoethnography Study: The first study conducted is detailed in this chapter, showing how it allowed for empathy to be gained for using mobile medical devices in day-to-day life and how it influenced the user study methods employed.
- 5 - User Study Methods: The data gathering, analysis, and the participants involved in the mixed method situated user study are outlined in detail in this chapter, including some thoughts on reflexivity and limitations of this work.
- 6 - Human Factors and the Physical Environmental and Infrastructure Contexts: The first empirical chapter outlines the how the T1D devices fit into the physical environment, but also the impact these environments and infrastructure can have on the user experience of these devices when they do not conform to expectation.
- 7 - Healthcare System Context and Infrastructure: This chapter examines how healthcare systems impacted the choices that participants in London, Toronto, and LA make with regards to the adoption and use of these devices.

- 8 - Cultural Environment: This chapter outlines how the shared meanings that make up cultural contexts influence the practices of using T1D devices, dependent on the participants' familiarity or unfamiliarity with them.
- 9 - Social Context: The chapter covers how the different social situations that participants find themselves in influence if they conceal or reveal their T1D device use, despite their regular open or closed routines.
- 10 - Personal Styles, Lifestyles and Circumstance: This last empirical chapter details how participants' individual and unique traits influenced their adoption and use of T1D devices in-situ.
- 11 - Discussion: The context and the individual differences that arose in the empirical chapters are recounted in relation to the importance of conducting situated studies, the indications of the need for end-use customisation, and the implications for manufacturers, if they are to keep up with the advances in the DIY diabetes community.
- 12 - Conclusion: This final chapter gives an overview of this research as a whole and reiterates the overall contribution of this work: individual differences and context influence the experience and practice with T1D devices, and although these can be accessed through situated methods, end user customisation may be needed to deal with the context of people's messy everyday lives.

2 - Background and Related Work

Although there are many mobile devices and apps that are related to health (e.g. quantified self technologies designed to support well-being (Choe, Lee, Lee, Pratt, & Kientz, 2014), the types of devices reviewed here are limited to those that are used for a medical reason. Although some technologies are used for personal health (e.g. reducing stress or for weight loss), their use is not generally necessary to manage a health condition and, as such, will be used in a different way than a medical device needed for the self-management of a chronic condition. For example, a person may want to quit smoking and there is the possibility of using an app to help them to quit or cut down their consumption to impact overall health: this is not the same as a person with diabetes where the neglect of using mobile medical devices might lead to immediate fatal consequences. Similarly, despite some excellent work on supporting people's health, such as Thieme et al.'s (Thieme et al., 2013) design research to support women with severe mental health issues or Stawarz's et al.'s (Stawarz, Cox, & Blandford, 2014) work on supporting contraception adherence, the focus of this review of related work is on self-management of a health condition with a specific mobile medical device.

As this is a human-computer interaction dissertation, this chapter reviews research related to the use and experience of mobile medical devices in everyday life rather than the experience of chronic conditions from a health psychology perspective. Background is first presented on Type 1 Diabetes and its related self-management and technology needs. The related work that is reviewed involves medical devices used for self-care, diabetes design research, sociocultural influences on the use of personal health technologies, and user experience and safety critical systems. This is followed by a review of HCI theory and research on context aware computing and affective interaction, finally covering the perspective of Technology as Experience (McCarthy & Wright, 2004). This final perspective looking at emotion and experience as holistically – as something not able to be reduced to parts or separated from the context – is taken as inspiration to look at the experience of using mobile medical devices in everyday life to self-manage T1D.

2.1 Type 1 Diabetes

Type 1 Diabetes is a condition that requires constant monitoring, analysis, action, and reaction every day, often with the use of medical technologies carried or worn on the body. Diabetes influences the production of the hormone insulin in the pancreas, which is required for the metabolism of glucose in a person's body (Alberti & Zimmet, 1998). People with Type 1 Diabetes do not produce this hormone in sufficient quantities, while people with Type 2 Diabetes have insulin resistance, meaning that they fail to respond properly to insulin, and they may also have reduced levels of insulin production. Type 1 Diabetes is often associated with childhood onset and Type 2 is associated with late adulthood onset, but not always (Kaufman, 2002). Although they are both called diabetes, they are quite different conditions with regards to impact on health, self-management practices, and importantly for this research, technology use.

There is currently no cure for Type 1 Diabetes, so the condition must be managed with a variety of treatments and technologies. The aim is to balance blood glucose (BG) levels to attempt to minimize the consequences of the symptoms, both in the short term and in the long term. This requires personal control of variables (e.g., diet and exercise) that affect these levels and self-administering medication (NHS Choices, 2013a). Mismanagement can result in serious health consequences. Low blood sugar levels (hypoglycemia, or 'hypos') can lead to immediate health concerns: the person can feel ill or quite groggy before correcting their blood sugar, and if it is not corrected, may fall into a diabetic coma (NHS Choices, 2013b). However, hypos are complicated and complex events, which are sometimes not easily managed or solved through straightforward self-care choices (Mol & Law, 2004). On the other hand, excess levels of blood sugar (hyperglycemia, or 'hypers') can also make people feel a variety of immediate ill effects, and over time can lead to complications such as eye, foot, kidney and heart diseases. People with the same condition are quite unique, as each person requires a personal balance of treatments including diet, exercise, and medication to control their levels of blood glucose and maintain their condition, and external factors such as weather can also influence levels (Mianowska et al., 2011). Self-management practices of People With Type 1 Diabetes (PWT1D) can be complex (Mol & Law, 2004), influenced by temporal factors (for expanded discussion, see (O'Kane, Mentis, & Thereska, 2013)), and hard to coordinate with healthcare practitioners (for expanded discussion, see (O'Kane & Mentis, 2012)). Careful management practices can control the condition from significantly impacting a person's normal life, but the strategies used

vary significantly between PWT1D, as triggers, symptoms, and the details of treatments for high and low blood sugar levels are unique to each person. Even for each person, a typical day with diabetes can vary significantly, however participant DS2 attempted to describe what her typical weekday might involve with self-managing her T1D with medication and the use of her glucose meter to conduct BG tests:

“If I was, like, working, I guess I’d get up in the mornings at about seven. I’d test to see what I was and then it would be, like, I’d have to inject my base insulin and so I’d do that and then I’d have, sort of, like, a shower and get ready; go downstairs, think what I want for breakfast, because I can’t really skip meals. So I’d, sort of, think if it was, like, porridge or cereal or something; toast. Then I would, sort of, look at... think about the carbs if I don’t know them. [...] I try and stick the same sort of breakfast and lunch if I’m working because it’s just easier for my levels and stuff. So I’ll inject, sort of, my fast-acting insulin to match it to what I’m eating. And then I’ll have breakfast and then, sort of, maybe rush out the door. I’d either, sort of, get the bus, but the majority walk to the tube station, get the tube to work and then, sort of, be at work and then I’d test again at about 11am just because I know, like, it, sort of, dips sometimes then. And then if I needed to correct it then, or I needed to, sort of, eat something or drink something to bring my levels up, then I would. And then at about 1pm I’d have lunch and then I’d do a test then as well and then, sort of, carry on having lunch and then go back to work. And then, it depends as well if I don’t have time to test, then I might do it a little bit later, but I’d try and do it at, like, 3pm, see what I am and then keep going and then, sort of, leave work at 5:30pm. Sometimes I’d try do a test at 5:30pm just to make sure that I’m okay, sort of, getting home, but the majority of the time I can, kind of, tell if I’m all right and my levels are okay. And so I get home and then, sort of, begin to, like, just dump my stuff and then have some wine and then think about, a little bit later on, maybe having dinner. I tend to, sort of, have it about 7pm or 7:30pm, and then whatever I’m eating, I’ll inject for if I need to. And then, sort of, maybe hang out a bit with my housemates and then do whatever I then, sort of, think about going to bed. Then I would, sort of, have to inject my base again and then I’d test as well and then go to bed and wake up and do it again.”

2.1.1 Type 1 Diabetes Self-Management

With regards to triggers, diet is a major contributor to high blood glucose levels and insulin must be injected before meals to counteract this rise. Careful attention must be paid not only to sweet food and fruit, but also to all kinds of carbohydrates (carbs), and 'carb counting' is necessary to determine the dose required. This can pose a significant problem when people are not preparing their own foods and cannot determine the quantity of carbs they are ingesting to find out how much they need to inject (Mayo Clinic, 2013). Exercise can also influence blood sugars in quite idiosyncratic ways: it depends not only on the type of exercise, the intensity, and the duration, but also on how a person's body reacts to it. Some people experience low blood sugar because of exercise, but others may experience high blood sugar levels, perhaps because of raised endorphin levels (Riddell & Perkins, 2006). Triggers, including stress, sickness, and weather conditions, are all individual, along with symptoms of low and high blood glucose that are unique to each person. Symptoms can be unique to the individual and sometimes can be hard to distinguish as attached to the condition.

Treatments are also complex, because medication works differently for each person and each person has their own routine and management practices (NHS Choices, 2013b). There are several resources that aim to educate PWT1D on the condition and how to manage their personal triggers and symptoms, including educational sources of information. These can range from the week long UK course, *Dose Adjustment For Normal Eating* (DAFNE, 2013) to peer support networks through the *Diabetes Online Community* (D.O.C.) (Hilliard, Sparling, Hitchcock, Oser, & Hood, 2015). According to Manhattan Research's Cybercitizen Health study (Manhattan Research, 2008), nine out of ten people with diabetes with access to the Internet use it to research health information, including looking for support and recommendations from other people, exploring treatment and product information, and also helping in the self-management of their condition. These numbers include over 60 million US adults who used 'Health 2.0' resources such as forums, blogs, chat rooms, and social media outlets.

2.1.2 Type 1 Diabetes Technologies

People with Type 1 Diabetes act on this information and education and use a variety of tools and technologies to manage their blood glucose levels. Different strategies use different tools, but most PWT1D use at least one type of medical technology. Different technologies exist to help in self-management, but because of the complex nature of

the condition, people's adoption and uses of diabetes technologies differ significantly. The technologies examined in this research were already in use by the participants, including glucose meters, continuous glucose meters, insulin pumps, and mobile phone applications.

2.1.2.1 Glucose Meters

Glucose meters are used to measure BG levels. These measurements are used for everyday calculations of insulin doses as well as identifying hypos and hypers (Diabetes UK, 2013a). The meter is used in conjunction with a finger-pricking device or lancet that is usually used on the tip of a finger. A small droplet of blood is put on a testing strip that is used by the meter to test blood glucose levels. Each brand of glucose meter tends to have its own proprietary strip, and some devices can use areas such as the upper arm or thigh. Some devices combine the lancet and/or a barrel of strips with the meter for a slightly larger all-in-one system. Devices require a battery, and the type depends on the device (e.g. circular watch battery, rechargeable USB battery, or AAA battery). These systems replaced the traditional urine testing strips used prior to their invention (S F Clarke & Foster, 2012). Examples of BG meters are shown in Figure 1.



Figure 1: Examples of BG Meters (from <http://bit.ly/1MvKBRB>)

2.1.2.2 Continuous Glucose Meters

Although glucose meters are used manually several times per day by people with Type 1 Diabetes, there are technologies that allow more continuous monitoring. Continuous glucose meters are used to give blood glucose readings every few minutes (JDRF,

2013). A sensor is attached most often to subcutaneous fat on a person's torso with a small needle inserted to test glucose levels, which is communicated to a receiving device. Some continuous glucose meters are wired to output devices that show the user the results and some are wirelessly connected via Bluetooth to a device that is usually carried in pockets or bags near the person. Newer versions of these devices look similar to smartphones, and different form factors are starting to be released. Examples of CGMs can be found in Figure 2.



Figure 2: Examples of CGMs (from <http://bit.ly/1REnXX3>; <http://bit.ly/1VPDYPO>; <http://bit.ly/1GFGA6A>)

2.1.2.3 Insulin Pumps

Insulin pumps can come in different form factors, including attached to the back of a user's arm or in a pager-sized device that is attached to a tube on the abdomen. They require power from batteries, liquid insulin from vials added to the device by the user, and also for the user to use it like a remote to control the injection of medication through the tube. When they are used properly, they can help control blood glucose levels better than insulin injection (Wood et al., 2006). It is estimated that approximately 6% of people with Type 1 Diabetes in the UK use pumps, whereas almost 15% of people in some places in Europe and about 40% of people in the US use a insulin pump for self managing their Type 1 Diabetes (Diabetes UK, 2013b). Some insulin pumps can be wirelessly connected to display the value from a continuous glucose monitor, but this is usually only possible between devices from the same manufacturer. Examples of insulin pumps can be seen in Figure 3.



Figure 3: Examples of insulin pumps (from <http://bit.ly/1K6liiL>)

2.1.2.4 Diabetes Applications on Smartphones

In order to maintain their condition, some PWD use personal informatics tools to track their own health data and get suggestions for insulin doses using mobile phone applications (apps) that they have downloaded. There are many apps currently on the market (over 1500 in the Android Play store at the time of writing). Although these applications require a smartphone, the popularity of smartphones has been rising every year, with 76% of adults in the UK owning or having ready access to smartphones, up from 52% in 2012 (Deloitte, 2015). There are also diabetes applications beginning to be released on smartwatches (Årsand, Muzny, Bradway, Muzik, & Hartvigsen, 2015). However, the FDA has announced that these systems are not considered medical devices that require the application of medical device usability engineering (ANSI, 2007) if they only display personal medical data (FDA, 2015).

2.2 Medical Devices and Human Factors

There is a large literature on the misuse of medical devices, with a particular focus on how device design can influence error rates. Much of this focus was spurred by the much cited book “To Err is Human: Building a Safer Health System” (Kohn, Corrigan, & Donaldson, 2000), which highlights that almost 100,000 people in the US die of medical errors that occur in hospitals every year, more than in car accidents or AIDs, which receive far much more attention. There has been a realisation that interactions between people, technology and the environment need to be considered to reduce errors, and support quality and safety in healthcare. For medical equipment, the introduction of standardised usability practice is one of many factors, encouraging

manufacturers to consider safety during the design and evaluation of medical devices (Rozich et al., 2004; Vincent, 2013).

Medical device usability engineering is accepted practice in many places worldwide, with numerous standards to support it, including: IEC 62366 “Medical devices - Application of usability engineering to medical devices” (ANSI, 2007); the ISO standard on medical device quality management (International Standards Organization, 2001); the ISO standard on risk management (International Standards Organization, n.d.); the FDA guidance on applying human factors and usability to medical device design (FDA, 2011); an AAMI/ANSI “standard” outlining design principles (ANSI, 2009); and context specific standards such as 60601-1-11 for home use medical devices (IEC, 2010).

Since the introduction of these standards, usability practice has seen mixed results when it comes to implementation, diffusion, and adoption - there are challenges regarding the availability of standards and suitability of evaluation methods (Martin, Norris, Murphy, & Crowe, 2008). The reality of usability evaluation (and its corresponding utility) falls short of its potential and this is compounded by the complexity of clinical work. Given a defined clinical workplace such as a hospital, usability evaluations are difficult with regards to ethics, access, and privacy (Furniss, O’Kane, et al., 2014; Furniss, Randell, et al., 2014). As Lowe has observed, *“you do not have to spend much time in a laboratory, clinic, ward, or operating theatre to form the opinion that the design and usability of the medical devices therein are by and large pretty poor”* (Lowe, 2006). However, it can be even harder for pervasive mobile technology. In the workplace, mismatches between the way devices are actually used, and supposed to be used, can be identified (Furniss, Blandford, & Mayer, 2011). For everyday technology, used beyond the walls of a healthcare institution, observing real use becomes significantly more complex; difficulties are only exacerbated when the use of healthcare technologies is shifted from informal to informal settings: outside the clinical setting and into everyday life (Williams, 2002).

Human Factors Engineering (HFE) approaches have been used in order to reduce incidents. Ward and Clarkson (2004) suggest that using HFE principles might be able to alleviate some issues by focusing on the design of medical devices and not focusing on blaming the users for errors that occur in hospitals. Their model of medical device related errors takes these concerns into account, but they acknowledge that there is a wider range of issues that might influence safe use.

Nolan takes a broader approach to looking at the system of patient care in order to reduce adverse events, such as error when using medical devices. He suggests a healthcare system that aims towards “*reducing complexity, optimising information processing, using automation and constraints, and mitigating unwanted effects of change*” (Nolan, 2000). These are not unlike the HFE principles suggested by others, and he even points to HFE literature on the topic of reducing errors.

2.3 Medical Devices For Self-Management

Self-care, self-management, and self-management support can be all used to describe the activities that people with chronic conditions conduct in dealing with their own health (Rijken, Jones, Heijmans, & Dixon, 2008). Although there are slightly different definitions of self-care and self-management, the definition of self-management by Glasgow et al. (Glasgow, Orleans, Wagner, Curry, & Solberg, 2001) is that adopted in this dissertation as most appropriate for the personal care that people take on: managing the symptoms of the condition, treating these symptoms and the consequences of the condition, making condition appropriate changes to lifestyle, and going further to deal with the psychosocial consequences of living with a chronic condition. In addition to a number of self-care devices developed within the HCI community (Nunes et al., 2015), several researchers that have focused on the use of technologies to assist the self-management of a chronic condition.

Rajkomar et al. (Rajkomar, Blandford, & Mayer, 2014) completed a contextual interview study with people who used home haemodialysis technology. People use this home technology to, essentially, clean their blood without having to go into a clinical setting and have a professional take care of the task. Some people use this device up to three times a week for up to four hours at a time. It is a large machine, not very mobile, and people tend to be quite ill when they use it. Users, both caregivers and the patients themselves, do a number of tasks to set the machine up, sit still for treatment, and turn off the machine. Rajkomar et al. tried to use a diary method with the participants, but because they were quite ill, their concentration was on their intensive treatment rather than the research study and this was not very successful. For a subsequent interview study, they used an interview technique from the safety critical domain, the Critical Incident Interview (Flanagan, 1954), in order to access information about near misses that were not captured with the diary study (Rajkomar, Blandford, & Mayer, 2013). Their research pointed to the trade-offs that people make between quality of health and

quality of life, showing that they adapted treatment to the context of their everyday lives and their experience of the technology could influence this (Rajkomar, Farrington, Mayer, Walker, & Blandford, 2014). Although their focus was on home studies with quite ill haemodialysis participants, the ethnographic methods chosen to examine everyday treatment and the impact that user experience can have on decisions about trade-offs between quality of health and quality of life influenced this research on diabetes technology use in everyday life.

Moore (2009) focuses on the problem of asymmetry between doctors and patients, and how a technology-supported apprenticeship for patients with chronic conditions could help with self-management and collaboration with clinicians. Focusing on diabetes, HIV, and hypertension, he created an interface that people could use with their synchronized medical devices, smartphones, tablets, and computers to collaborate with health care providers, caregivers, and other patients to create a self-management strategy and help others with theirs. He created a system called CollaboRhythm as one way to reduce costs through tele-health, but also to alleviate frustration and motivate patients in their self-management. Although his research spanned different health conditions, the user experience of devices used self-management was taken into consideration for the design of the healthcare technology, including diabetes self-care technology.

Verdezoto (2013) also examined the use of self-care technology, focusing on the 'work' that is required in the home and how everyday life influences the use of these medical devices. He argues that many of the systems are created from the perspective of the healthcare provider and do not adequately support people in choosing which care activities to perform, when to perform them, how to proceed with the activity, and understanding why these activities are important, which he frames as numerous types of home 'work'. By examining the use of a range of self-care technologies and experimenting using research through design with Grönvall (Grönvall & Verdezoto, 2013), they focused on the work that is involved in the home and how technology fits into everyday life with self-monitoring of pregnant women, people with heart conditions, and people conducting home-based rehabilitation, concluding that aspects of using these technologies that were unrelated to how they functioned, including people, resources, places, routines, knowledge, control and motivation, should be examined fully and holistically when designing self-monitoring technology in order for it to fit into everyday life.

Nunes (2015) is also critical of the provider centric design of healthcare technologies and examined the use of technologies for Parkinson's Disease. Using qualitative methods and research through design methods, he examined the role of technology in everyday life and determined collaboration is important between carers and people living with the condition in order to "*build a good life*" (Nunes and Fitzpatrick, 2015). He is critical of technologies that are built solely for individual use, and suggests that future self-care technology should be designed and evaluated with the collaborative use in mind. This is related to diabetes care, as self-management pervades all aspects of life, including social relationships, which could have a care dimension to them.

Ballegaard et al. (Ballegaard, Hansen, & Kyng, 2008) discuss healthcare technology in everyday life through studies involving building novel technologies for elderly people and pregnant women with diabetes. They argue that personal healthcare design is "*not just the matter of fixing a health condition, more importantly is the matter of sustaining everyday life as a whole.*" This paper also criticizes the presumption that people's main goals are health related, for instance that the elderly, at all cost, want to avoid disease and health related problems. This is a clinical perspective on care that has also been criticised by Nunes and Verdezoto as described above. Ballegaard et al. discuss that self-care is not just influenced by clinical knowledge being passed down from health professionals, but also by routines. Life changes alter self-care practices, as is the case with self-management of diabetes and pregnancy where changes in the body influence health needs such as required insulin. They believe that a "*citizen perspective*" on how care can be integrated into everyday life will reduce the disruptive nature of the technology, such as the mismatch between the aesthetics of the home and the technology causing non-use. Ballegaard et al. suggest using participatory approaches to personal healthcare technology design. Aarhus and Ballegaard (2010), also looked at the boundaries of using self-care technologies at home. They found that people engage in work to make self-care exist comfortably for them in their homes, specifically on two continuums: visibility-invisibility and integration-segmentation. Where people were placed on these continuums was heavily influenced by the interplay between the people involved, values and norms present, and the healthcare technology itself.

These projects give insights into the nature of self-management in general and point to the importance of taking a patient-centric approach to the design of self-care technologies. This extends not only to the quality of people's health but the quality of people's lives. This work as a corpus points to the importance of understanding how

devices are actually integrated into people's lives, and although many did not take a situated approach, they do indicate the importance of understanding how self-care devices fit into people's everyday lives and how their everyday lives influences the use of these devices.

2.4 Diabetes Technologies and Everyday Life

As described above, there are a number of commercially available Type 1 Diabetes technologies that can be used for the self-management of the condition, and there have been others developed by researchers to provide further digital assistance for self-care.

Research institutions have often developed smartphone applications with a specific research question in mind, most often about behavior change. For instance, there is research on the use of these diabetes tools for supporting maintenance activities through aiding self-reflection and tele-health (Arsand, Tatara, Østengen, & Hartvigsen, 2010; Blondon & Klasnja, 2013; Cafazzo, Casselman, Hamming, Katzman, & Palmert, 2012; Kaufman et al., 2003).

Mamykina (Mamykina et al., 2006, 2008; Mamykina, Smaldone, & Bakken, 2015; Mynatt, Abowd, Mamykina, & Kientz, 2010) has written extensively with collaborators on the use of personal informatics tools in diabetes self-care. This has particularly focused on improving sense making and reflection for people caring for Type 1 Diabetes, including designing and evaluating one of the first apps for mobile phones. More recently, Mamykina et al. have argued that apps need to help with not only reporting information, but also assisting people in pattern recognition and non-obvious correlations during self-management (Mamykina et al., 2015). Previously she developed MAHI (Mamykina et al., 2008), a system to help people reflect on their own health related data surrounding the self-care of diabetes using a mobile phone that connected with diabetes educators. This was one of the first projects that really focused on this data from a patient perspective, rather than from a clinical perspective. However, the design of MAHI occurred before the proliferation of smartphone technology, and was designed for use on an older non-smart-phone. This research is foundational in this domain, but as Owen et al. (2015) point out, situated in a time where consumer electronics were not as ubiquitous. With the rapid advancements in consumer electronics since 2008, it is of interest how this might impact the diabetes

apps designed to run on them and also standalone devices that are carried alongside them.

Owen et al. (Owen, Buchanan, & Thimbleby, 2012; Owen et al., 2015; Owen, 2011) also looked at reflection in diabetes self-management, completing a diary study and interviews with people with Type 1 Diabetes about their use of glucose meters and mobile phone applications. Through deploying apps, they investigated how the use of tags and photos could help with the problem solving involved in self-management. Their focus was on the connections between self-management and self-reflection, but their contextual interviews also indicated that there might be different influential factors on the use of diabetes technologies, including social non-routine times in peoples' lives. Although their work did not focus on these influences, it showed that these influences might be worth further investigation as they impacted the use and adoption of T1D technologies.

Specialised personal health data tools for diabetes self-care have also been developed, such as personal informatics for pregnant women with diabetes and children with diabetes. Aarhus et al (Aarhus, Ballegaard, & Hansen, 2009) built an e-diary that pregnant women with diabetes could use to reflect on their self-care data and self-management activities. This was found to aid in self-care activities and also help with the collaborations between medical professionals, similar to the findings of Mamykina and Owen described above. Again, when the study was conducted meant that smartphones were not as pervasive, so it is of interest how these findings about the successful adoption of a diabetes app might change with changes in the culture surrounding mobile devices.

Much research has looked at aiding the management of diabetes in children and adolescents through technology. In one study, a text messaging service for young people called 'Sweet Talk' was associated with improved adherence to care plans and the participants overwhelmingly thought that it had improved their diabetes self-management (Franklin, Greene, Waller, Greene, & Pagliari, 2008). Cafazzo et al. (Cafazzo et al., 2012) had some success in rewarding good behaviour through iTunes app store credit rather than punishing bad behaviour with the use of a diabetes app for adolescents. Toscos et al.'s (Toscos et al., 2013) research focused on the emotional responses that diabetes self-monitoring caused in children and how this influenced their relationships with their parents. They also looked at aiding children with diabetes

through remote monitoring that is sensitive to the diverse and different emotional needs of both parents and children (Toscos, Connelly, & Rogers, 2012). A field study of a mobile phone app technology to connect parents and children showed that there could be positive effects, if issues such as the balance between surveillance and connectivity are respected. With the focus on people's emotional reactions to data, she also explored how to decouple the strong negative emotions that are often linked to health monitoring technologies such as blood glucose monitors. They used McCarthy and Wright's (McCarthy & Wright, 2004) Technology as Experience framework to examine the felt experience of using this technology in the context of a family. Although this approach was taken with developed tele-health technology rather than existing T1D devices and with children, it is of interest how the holistic user experience might influence the choices that adults make with these technologies.

Beyond building specific digital assistants to accompany other existing diabetes technologies, there has also been some research on how existing tools could be improved for use in everyday life. Kanstrup (Kanstrup, Bertelsen, Glasemann, & Boye, 2008; Kanstrup, Bjerger, & Kristensen, 2010; Kanstrup, 2014) developed a long-term research project looking at how diabetes self-care could fit into family life. Influenced by the Scandinavian tradition of participatory design, she set up a co-design project where families could be involved in the research and also the design of new diabetes technologies. Through this, she uncovered how integrated diabetes care was within a household, particularly in caring for children with diabetes. Taking this bottom-up approach, it emerged that diabetes care within families involved complex individual and collective issues that should be viewed more holistically in the context of families' unique everyday lives.

Chen (Chen, 2010) explored how individual differences impact the use of health information in the self-management of Type 2 diabetes, defining individual differences as a "*a person's physiological, personal and social activities that impact the process of individual disease management.*" She discussed that although technologies tend to emphasize either the collection of personal information or tele-health connectivity with healthcare providers, future systems should focus on technology that enhances self-management through bringing together various information sources to inform disease management. This information is gathered and used in varied ways, beyond what is currently supposed, and is influenced by personal experience with routine, health tips coming from others, dealing with atypical events, etc. The top-down approaches to

technology development that she examined meant that people with T2D were not getting access and not using information that might have been helpful to them.

Mol (Mol & Law, 2004; Mol, 2006, 2008) has published on the care of diabetes and everyday life from a socio-technical perspective. In her book “The Logic of Care: Health and the Problem of Patient Choice” (Mol, 2008), she describes how commercial aspects of healthcare do not align with the care aspects. Looking at the management of diabetes in both the clinical and everyday life setting, she believes that the “*Cliché of the West*”, an obsession with individualism, is at odds with care, which is not an individual activity. The lens of consumerism in health is incompatible with what it actually means for the care of health, including how people to engage in self-care. Additionally, she has pushed for a shift in evaluating healthcare from proving successes through controlled trials (“*the gold standard*”) to trying to improve health practices iteratively (Mol, 2006). She uses diabetes care as an example of how the traditional view of healthcare is not compatible with what is happening in everyday life. For diabetes, symptoms such as hypos or hypers can vary significantly and feel very different between people, triggers can vary by person and by a range of external conditions, and treatments such as the type of insulin used or the amounts needed can vary by person and change over time (Mol & Law, 2004). This complexity influences self-management, and it is not supported by reductionist approaches that seek to prove successes in healthcare rather than find problems so that improvements can be made. Building on this work, Storni (Storni, 2010, 2011, 2013; Tsvyatkova & Storni, 2014) has examined the ways that diabetes technologies are evaluated, and suggests current practices do not access the complexity of everyday life. Storni adopted an ethnomethodological perspective, and attended support groups, shadowed participants, and conducted in-depth interviews to understand technology use (Storni, 2010, 2013). His work focused on the different ways technology is appropriated individually and how people’s lay expertise informs management, ultimately arguing for an approach to design that is less technologically deterministic and focused on non-compliance, as there are large individual differences between users. In order to accommodate these differences, Tsvyatkova and Storni (Tsvyatkova & Storni, 2014) developed a mobile phone based app Tag-It-Yourself to support users in generating their own meaningful contextual tags to better reflect on their own personal diabetes self-care practices.

A number of studies have focused on diabetes care in everyday life. In some projects, additional digital assistance and devices were created to aid self-management. Many have leveraged advances in smartphone technologies and focused on apps to promote reflection, as sensemaking and reflection activities are vital evidence-based components of diabetes self-care (American Association of Diabetes Educators, 2009). In other projects, there have been studies on the use of diabetes technologies in the care of children with diabetes, with evidence that experience can influence use and adoption, a research area that deserves much attention because of the physical and emotional issues with growing up (Toscos et al., 2013). Further to this, researchers have been taking ethnography inspired approaches to examine diabetes in everyday life, with Mol (Mol, 2006) suggesting changes in the way health services focus on success and Storni (Storni, 2010) building on this by suggesting new ways to evaluate diabetes technology. However, there has been little work focusing on the current use of available diabetes technologies by adults. How the choices PWT1D make with regards to adoption and use of these technologies influence their everyday lives and how their everyday lives in turn influence adoption and use has not been explored sufficiently. Based on these research projects, it is clear that a situated study of how the mobile technologies are actually used by adults in everyday life is warranted in order to understand how experience can impact use and adoption. As such, the research question remains: What aspects of a person's situated experience with Type 1 technologies influence their adoption and use of those devices?

2.5 Experiencing Healthcare Technology in Everyday Life

A person's sociocultural context has an impact on how they cope with and prioritize care when self-managing a chronic condition (Kanstrup et al., 2008; Kanstrup, 2014; Mamykina et al., 2006; Piette, 2006; Strauss et al., 1984). It has been found that chronic conditions can lead to disruptions in relationships, and that how people adapt self-care is influenced by their context, such as their social situation (Bury, 1982). Healthcare is highly personal, so privacy can be important to people with diabetes (for expanded discussion, see (O'Kane et al., 2013)). They can perceive stigma from their communities and their workplaces (McMahon, West, Mansouri, & Belongia, 2005). Perceived stigma can also cause self-consciousness around glucose meter testing and insulin pump use (Owen et al., 2012; Ritholz et al., 2007), and people often go to great lengths to hide their condition (Kanstrup, 2014). Beyond stigma, concerns about

discretion around family and friends can interfere in diabetes self-care practices (McMahon et al., 2005), and strangers can ask awkward questions (Owen et al., 2012).

On the other hand, showing off medical devices has been a trend in social media. For example, a model posted bikini pictures showing the colostomy bag that she requires for self-managing Crohn's disease. These pictures were intended to spread awareness of the condition. They went viral, with over nine million people viewing them (Writtle, 2014). Similarly, Miss Idaho 2014 showed off her insulin pump during the bikini competition (see Figure 4), causing #showmeyourpump to trend on Twitter leading to more people posting photos of their devices (Diabetes UK, 2014).



Figure 4: Miss Idaho 2014 Sierra Sandison shows off her pump during the competition (from <http://bit.ly/1OzfO6x>)

People's everyday lives influence the use of mobile medical technology in incredibly varied ways based on the socio-cultural and technical contexts. However, little is known about how situated user experience influences adoption and use of diabetes technologies. Therefore, how affect influences the use of interactive technology must be explored further.

2.6 Affective Experience and Its Influence on Using Technology

Much of the research on the influence of affect on the use and adoption of technology comes from the human factors domain. Phillips and Madhavan (2013) found that negative mood enhanced detection performance when participants used a simulated radar system, but negative mood also lowered self-confidence, and those in a positive mood were more swayed by the automation. Jeon and Zhang (2013) found both anger and sadness caused drivers to make significantly more errors, but also, people who were angry perceived their workload as being higher. Harrison et al. (L. Harrison, Skau,

Franconeri, Lu, & Chang, 2013) found positive affect yielding better visual judgement performance of different charts of information. In the area of serious games for health, there has been some attention on the influence of affect as well. Thin and Gotsis (2013) found that cognitive aspects (belief systems), affective aspects (motivations) aspects, and outside influences (norms) influenced the actions using serious games for health behaviour change.

Although much of this research does not involve studies of real life technology use, which is at the heart of this dissertation, it does point to the influence that affective experience can have on the use of technology, particularly negative experiences, beliefs, motivations, and norms. How these might influence the use of T1D devices in the context of use has been little discussed in the literature despite connections between anger and irritation and blood glucose levels (Peyrot et al., 1999), but the use of affective experience frameworks might be helpful in exploring these in-situ influences.

2.7 Context, Affective Experience and HCI

Against traditional views of cognitive science being applied to interactions with technology, Suchman (1987) suggested that plans do not always represent the actual performance of tasks in the situation. Through looking at the use of a photocopier machine, she was able to observe that the tasks planned were not the same as the actions that were taken by those using the technology in the situation. Plans are inherently connected to the situations in which they are used, and therefore are context-dependent. This flew in the face of traditional HCI researchers who did not take sufficient account of the 'situatedness' of actions, relying on traditional accounts of cognition as internal and independent of context in interaction design. She found that people engage with their circumstances to make sense of their situation rather than forming an abstraction of it. She used video analysis to capture actual performance rather than laboratory quantitative test to show how technologies such as expert help systems that do not allow for this kind of situated sense making by allowing for interactivity cause difficulties for users when interacting with them. Her work has been highly influential in HCI, and particularly for those looking at the influence affect can have in interaction design. This includes Dourish's notion of embodied interaction: users create and communicate meaning through their interaction with the technology, with each other, and through the technology (Dourish, 2004b). Dourish has posed the

question: “*How can sensor technologies allow computational systems to be sensitive to the settings in which they are used, so that, as we move from one physical or social setting to another, our computational devices can be attuned to these variations?*” (Dourish, 2004a). In discussing context, he argues for moving away from what he considers an inflexible view of context as something to be objectively modelled towards context as being relational, dynamic, occasioned, and arising from the activity.

Influenced by researchers such as Suchman, advances in technology, and looking towards philosophical literature, there have been different forays into examining affective experience with technology, particularly though the rise of third wave HCI.

After approaching HCI with humans as part of the work system and then seeing humans as actors with the work system, this third wave is taking the focus of HCI design from the workplace into homes and our everyday lives (Bødker, 2006).

Examining how experience and emotion has influenced design and research as HCI has moved into everyday life is important for understanding how this research may influence medical technology as it moves towards patient centric mobile devices.

Building on the findings of Toscos et al.’s (Toscos et al., 2013) work with children and families dealing with emotional experiences around T1D technologies, Technology as Experience framework can provide insight into the situated user experiences of adults choosing to use and adopt T1D technologies.

2.7.1 Technology as Experience

McCarthy and Wright’s Technology as Experience approach does not attempt to reduce emotion to separable components and focuses on the entirety of the experience with technology (McCarthy & Wright, 2004). It does not treat emotion separately, but rather as a part of a holistic ‘felt experience’ (Höök, 2012). The authors suggest a move from a deterministic view of design to acknowledging users’ agency: not designing an experience but designing for experience. The authors argue against taking the richness of experience and trying to reduce it to “*design implications, methods, or features*” (McCarthy & Wright, 2004), although this leaves designers with a fuzzy concept to work with. HCI has its roots in psychology and computer science, but there is much to be learned by looking further afield, including widening the focus on usability towards looking at user experience. HCI has progressed from seeing a user as a cog in the system to a source of error to a social actor, and now users are seen as consumers.

McCarthy and Wright examine examples of art, film, and literature that deal with the experiences of consumers. They draw on some of the findings from these fields to make connections to the design of interactive systems that are not immediately apparent through the lens of traditional HCI practice. The premise behind the book is that people do not just use technology, but they live with it. They argue for a pragmatic approach when dealing with user experience, drawing heavily on Dewey, a pragmatist art philosopher, and Bakhtin, a literary philosopher, who McCarthy and Wright argue has views that are consistent with Dewey's pragmatism. In Dewey's book "Art as Experience", he pushes for an acceptance of art in the real world, not in the confines of an art gallery or museum (Dewey, 2005). For Dewey, masterpieces that are found behind glass and protected from the outside world indicates the view that real life experience would sully these works, and he asks (Dewey, 2005):

"Why is the attempt to connect the higher and ideal things of experience with basic vital roots so often regarded as betrayal of their nature and denial of their value? Why is there repulsion when the high achievements of fine art are brought into connection with common life, the life that we share with all living creatures? Why is life thought of as an affair of low appetite, or at its best a thing of gross sensation, and ready to sink from its best to the level of lust and harsh cruelty?"

Dewey argues that the experience of everyday life and real time context should not be ignored in enjoying art, as art should be lived and experienced. The messiness of human experience and emotions are part of the experience of the art piece, and these emotions and experiences are not isolated from the social, cultural, and environmental contextual factors. McCarthy and Wright take this as inspiration about the way we should deal with interactive systems: it is not just the design of the system, but rather the entire experience of interacting with the technology in context which is of importance.

The framework McCarthy and Wright propose has four different threads, which are called upon throughout the empirical chapters of this dissertation: **sensual** is concerned with engagement and absorption into the experience; **emotional** has to do with feelings attached to the experience and connections to value judgements; **compositional** is concerned with how it unfolds and its structure; and, **spatio-**

temporal is concerned with the times and space (or place), the 'where and when' the experience takes place.

The people engaging with an experience can take action in different ways in this framework that are also used throughout empirical chapters of this dissertation to explain the felt experience of using mobile medical devices. This includes **anticipating** the experience, which has to do with expectations, both situated and based on prior experience. They then have to **connect** to this experience in order to start to creating meaning from it. **Interpretation** can then take place to make sense of what the experience means to them in the moment, but also based on past experiences. **Reflection** on that experience allows people to establish meaning and solidify value judgements about it in the moment as the experience unfolds. **Appropriation** then can occur, where the experience is set within the set of past experiences that the person has had and can be used in future experience. Finally, **recounting** an experience allows for deeper meaning to be pulled out in relation to the larger context of the experience, beyond the current situation.

Toscos et al. (Toscos et al., 2013) used this framework to look at children and parents' use of blood glucose meters in the context of their emotional reactions and how the device influenced relationships. Building on this, the Technology as Experience framework can be used to better understand how the subtleties of adults' experiences using their T1D mobile medical technologies in the context of everyday life might influence their use and adoption. Although these technologies are designed for specific purposes to be used as medical devices, they are situated in the context of people's everyday lives. Using the Technology as Experience framing, these devices can be examined in the situations that they are actually used in rather than in isolation to get closer to understanding the felt experience as a whole.

2.8 Towards A Situated Study of Adults using T1D Devices

Although there have been many studies on self-management of chronic conditions that point to the influence of everyday life experience, there is a lack of studies that have accessed the situated experience of using these devices in day-to-day life. Some studies and research projects that were conducted showed very useful insights into the use of interactive technology in self-care, but they were conducted before the proliferation of smartphones and consumer electronics into everyday life (e.g. (Mol, 2008)). Even for those studies that delved into the influence of experience (e.g.

(Toscos et al., 2013)), methods were used that relied on retrospective accounts or did not cover a wide enough range of people and often did not focus on the choices adults make for their own self-care.

Isomursu, Kuutti, and Väinäm point out that *“mobile applications are designed to be used in a mobile context, so they should also be evaluated in a mobile context”* (Isomursu, Kuutti, & Väinämö, 2004). However, this can be hard to achieve with T1D technologies, so retrospective measures of experience have typically been used. In building a mobile phone application, Owen and colleagues (Owen et al., 2012) interviewed people about their use of glucose meters. Also for the purpose of building technology to aid reflection on how lifestyle might impact self-care practices, Mamykina et al. (Mamykina et al., 2006, 2008) conducted interviews, attended support groups, and used cultural probes to investigate self-management practices, highlighting how participants generate hypotheses during self-care. User studies conducted in the healthcare technology domain have adopted a variety of methods to understand the context of use (e.g. (Furniss, Masci, Curzon, Mayer, & Blandford, 2015; Sharples et al., 2012)), but there is very little situated research on how people choose to use a range of mobile T1D technologies during their everyday self-management.

As such, a situated study of how adults use T1D devices in everyday life is warranted to explore the research question: What aspects of a person’s situated experience with Type 1 technologies influence their adoption and use of those devices?

3 - Methodology: A Pragmatic Situated Approach

Parts of this chapter have been published and presented at a CHI 2014 workshop (O’Kane, 2014) and a section of it appears published in a journal article (Vincent, Niezen, O’Kane, and Stawarz, 2015).

Based on the findings of the literature review, this chapter outlines the situated “In the Wild” methodology employed to examine mobile medical devices used by adults self-managing Type 1 Diabetes. As this dissertation takes a human-computer interaction approach rather than a health psychology approach, the methods used focused on the use of the T1D mobile medical devices. These devices were not being introduced to the participants as they were already adopting and using them in their everyday self-management practices, so an “In the Wild” approach was taken that got as close as possible to actual use whilst also being mindful of the obtrusiveness of data collection methods through the use of a flexible and pragmatic situated approach. This chapter outlines the pragmatic approach and the focus on T1D technologies taken, and then describes the autoethnography study and the mixed method situated user study undertaken using contextual interviews, diary study, and an observation of a group meet-up. The specific details about how the autoethnography was carried out is found in the following chapter, and the details about the data gathering, analysis, and participants involved in the mixed method user study is found in Chapter 5 before the empirical chapters of the combined analysis of the user data.

3.1 Towards “In the Wild”

‘In the Wild’ research has been gaining popularity in HCI research across many domains, however as presented in the last chapter, there has been little research on the use of mobile medical devices in the wild. Hutchins coined the term ‘in the wild’ from his extensive study of ship navigation (Hutchins, 1995). This study was unusual in the way anthropology was combined with psychology cognition theories. In his book “Cognition In the Wild”, he presents an extended analysis of its history, mechanics, social concerns, and the actual practice of ship navigation. His definition makes the

“distinction between the laboratory, where cognition is studied in captivity, and the natural everyday world, where human cognition adapts to its natural surroundings” (Hutchins, 1995). He believes our cognition is unique compared to animals because there is always a cultural component and believes that the history of cognitive science has tried to ignore these considerations in an attempt to “remake the person in the image of the computer” (Hutchins, 1995). He concedes that studying cognition ‘in the wild’ is inherently difficult and there is uncertainty in the outcomes.

Rogers discusses the shift in HCI towards ‘in the wild’ design (Rogers, 2011). This is pushing HCI studies and designs outside of laboratories and into the context where they will actually be used. HCI in the past has focused on solutions to issues that come about when using technologies, but this of course requires these technologies to already be designed and released for public consumption. ‘In the wild’ design attempts to think beyond what is currently used to what is possible, which has been influenced by the availability of cheap and easy to use sensor kits. This allows for quick turn around time for the design, prototyping and evaluating of interactive systems ‘in the wild’ with users in the context of use, away from controlled laboratories. This HCI shift has implications for the design of interactive devices, but there are issues associated with the evaluation of these devices ‘in the wild.’

Experimental psychology experiments are popular in HCI because they are easy to control and they use empirical methods that have been considered robust and reliable from the psychology domain. There are some within HCI that believe that this approach should be called “Interaction Science” (House et al, 2013), although there has been some controversy calling any research conducted in what is generally considered an applied field ‘science’ (Reeves et al 2015). Quantitative experimental research relies on numbers that can be more straightforward to interpret, but these experiments need to be constrained and controlled which immediately separates the results from what can be expected in the context of use. These approaches do not support real world situations, as studying these “wild” situations can be too messy and unorganized for experimental psychology methods to constrain. The results found in the lab do not necessarily translate directly to real world use of interactive technologies.

Rogers (2011) discusses a multi-touch interface that was designed for travel groups to use in tourist centres (Marshall, Morris, Rogers, Kreitmayer, & Davies, 2011). This device was designed and evaluated in a lab, but when put into the wild it was not used

in the way it was expected to be used. Instead of groups surrounding the device like they would come around a dinner table as was expected by the researchers, they separated in the tourist centre and gathered bits of information and tended to use the device individually. This kind of information could only be gleaned by trying it out in the real world, not in laboratory settings. This of course can be challenging as “the researcher has to make sense of data in the wild, where there are many factors and inter-dependencies at play that might be causing the observed effect” (Rogers, 2011, p. 59). These inter-dependencies have links to theories such as Technology as Experience, which according to Rogers promotes expanding the focus of interaction design to not just include usability or utility, but rather the felt experience as these *“interlinked facets and concerns are what most of us engage with in our everyday actions and interactions with others”* (Rogers, 2011, p. 61).

Fieldwork conducted “In the wild” has taken place in the medical domain using a variety of methods, but there is very little research on mobile medical devices used in context. Although it would be difficult to use conventional situated methods of observation and video recording in these settings, situated methods can be adapted to evaluate mobile medical devices used ‘in the wild’. This is particularly relevant for studying Type 1 Diabetes technologies that are carried on the person and used throughout the day, everyday.

3.2 Focus on Type 1 Diabetes Mobile Technologies

In the medical domain, there has been much focus on errors made with medical devices (e.g. (Lowe, 2006)) and increasingly on how some medical technologies could be used in the home (e.g. (Grönvall & Verdezoto, 2013)). There has been some research on self-care technologies, but most has focused on the development of new technologies (Nunes et al., 2015) or research through design (e.g. (Nunes, 2015)), instead of focusing on the current technologies in use and how suitable they are for people’s everyday lives. Some studies have focused on the everyday use of self-care devices (Mol, 2008), but did not use situated methods to examine the real world use of these mobile medical technologies that travel with the people that have to use them. As such, the exploratory research reported in this dissertation focuses on one such type of mobile medical technology: Type 1 Diabetes technologies.

People with Type 1 Diabetes have had to use at least one mobile technology since they were diagnosed: a glucose meter. Glucose meters have been available and

relatively inexpensive for many years (S.F. Clarke & Foster, 2012), and as such, many people with Type 1 Diabetes have been using them for many years, several times per day. The nature of the condition means that the vast majority of care is outside clinical settings so it requires adults to take responsibility for their own T1D self-management (Funnell & Anderson, 2000). What this means for their everyday lives is that they are almost required to use the device and bring it with them wherever they go. In addition to the glucose meter, people with Type 1 may have been using other technologies for some years, including insulin pumps, continuous glucose meters, and more recently, smartphone applications and other diabetes devices. These technologies can also be used several times per day, and are often worn or kept on the person. As such, the in situ use of Type 1 Diabetes technologies can be considered an exemplar use case for future mobile medical technologies and healthcare wearables that are used by people for their own self-care.

Additionally, the nature of the condition leads to more community support and peer connections between people with Type 1 Diabetes: with a condition that can be called “*relentless*” by PWT1D (for expanded discussion, see (O’Kane et al., 2013)) and lead to “*burnout*” (Polonsky, 1999), people seek out their peers and as such, there is a network of people to approach for user studies. Although there are still recruitment issues that arose (see Chapter 5), people with Type 1 Diabetes were the easiest group of long-term mobile medical device users to access at the time of this research.

3.3 Situated Studies of Type 1 Diabetes Technologies

Based on the literature reviewed, a qualitative exploratory situated approach is appropriate to investigate what aspects of a person’s affective experience with Type 1 technologies influence their adoption and use of those devices. In order to accomplish this exploratory research, a preliminary study using autoethnography was used to inform the mixed method user study that utilised three different methods to access everyday experiences of using Type 1 Diabetes technologies: contextual interviews, diary study, and observation of a T1D meet-up.

3.3.1 Autoethnography

In order to really understand the use of a technology and understand what a researcher is asking of their participants, it is good practice for the researcher to use the system for themselves. Self-studies are not a new concept in HCI; for example, in the 1990s,

Jeff Hawkins carried a block of wood in his pocket to simulate what a Palm Pilot would feel like to actually carry around (Bergman, 2000). Of course it is assumed that almost every system that is tested in the HCI domain will at least be tried by the researcher for curiosity's sake, but to understand the intricacies of the use of the system it can be used by the researcher for longer than just a one-off trial. These types of studies have been completed in the HCI domain and they fall under the heading of 'ethnography-light' or autoethnography.

In the social science domain, there has been a shift towards qualitative inquiry and Banks and Banks believe that autoethnography *"is the last goal-the full accounting for and utilization of the researcher's personal body and felt experience as research instrument-that might be most revolutionary about this emerging perspective"* (Banks & Banks, 2000). They believe that it challenges our sense of what is normal and what is an average experience. This new shift also goes beyond looking at the influences of social structures, but also cultural structures. In the examination of autoethnography in relation to television, Clough and Ellis' believe it is *"shifting the context of self-reflexivity from social structures to the cultural structures of mass mediated information/communication technologies"* (Clough & Ellis, 1997). Richardson and Pierre describe autoethnography as a narrative of the self, and further classify it with other genre bending forms of ethnography as a 'Creative Analytic Practice Ethnography', which are produced by practices that are both creative and analytic that invite people in to rethink social contexts (Richardson & Pierre, 2007).

Autoethnography in HCI arose out of the need to conduct ethnographic studies in a less time intensive way, so Cunningham and Jones suggest *"the investigator creates an ethnographic description and analysis of his/her own behavior, attempting to develop an objective understanding of the behaviors and work context under consideration by casting the investigator as both the informant 'insider and the analyst 'outsider'"* (Cunningham & Jones, 2005). They believe autoethnography addresses two grievances about using ethnography in system design. Firstly, that it takes much less time than dealing with the complexity of real users and secondly, that the presentation of the work is in the subject's words and cannot be directly translated to engineering requirements. In addition, self-studies are useful when it is just not possible to conduct ethnography: *"While active involvement of an ethnographer can yield interesting field insights, often it is not possible to be with participants when critical things occur. In part*

this is due to a lack of resources; spending twenty-four hours over several weeks with the participants is just not feasible" (Cunningham & Jones, 2005).

Autoethnography is a highly subjective method; however, it can be argued that all qualitative research is subjective and this method merely "*affirms our subjectivity*" (Banks & Banks, 2000). It challenges the way researchers write for personal engagement and to know their audience, and inculcates and models "*a critical attitude and self-disclosiveness*" (Banks & Banks, 2000). The personal aspect of the results gathered must be acknowledged and carefully considered by the researcher, as "*being able to cast oneself as a potential user, to create an understanding of the user's perspective and an empathy for the user's experiences, has obvious advantages for system design—with the caveat that the developer must not privilege the world view uncovered through autoethnography as the sole or most legitimate user perspective*" (Cunningham & Jones, 2005). Despite the highly personal nature of an autoethnography study, it has the potential to allow empathy for other users' experiences (Ljungblad, 2009; Wright & McCarthy, 2008).

Empathy is a strong resource for design and evaluation in HCI (Segal & Suri, 1997), and it is an ever-present goal in much HCI design, evaluation and research, all of which strives to 'know the user' (Wright & McCarthy, 2008). Wright and McCarthy suggest that this should be extended to involve the understanding of what it feels like to be a user, influenced by what they call a pragmatist approach: "*it involves a felt, valuational response from one's own particular, unique value position to the other (the user) who is also seen as a separate and unique centre of value*" (Wright & McCarthy, 2008). For HCI researchers and practitioners, they believe this can be achieved through dialogue, narratives, and 'the imagined other'. Much of the empathy derived from dialogues and narratives can be attained through talking with users and observing them, using methods such as ethnography, Cultural Probes (Gaver, Dunne, & Pacenti, 1999), personas, scenarios, and design workshops. Gaining empathy through 'the imagined other' involves the researchers personally in the use of the technology and includes various forms of role-play and the more "*radical*" (Wright & McCarthy, 2008) autobiographical design, where the researcher both designs and evaluates the technologies themselves (Sengers, 2006). Autoethnography is another method used to explore 'the imagined other'.

Autoethnography has been used in a wide range of HCI studies, allowing the researchers to gain empathy for the users of various types of technology. For example, for the evaluation of Affecter discussed in the last chapter (Boehner, Sengers, & Warner, 2008). Boehner, Sengers, and Warner said autobiographical design “*provided more validity in our effort to design for experiences that may be difficult to articulate or identify*” (Boehner et al., 2008). Höök conducted an autoethnography study on the aesthetic experience of horseback riding in order to transfer qualities of the embodied interaction to innovative HCI designs (Höök, 2010). Although she describes the aesthetic experiences as “*wordless*” (Höök, 2010), she used the method to show how her experience corresponded to bodily postures. Ljungblad complemented a user study of the Sensecam by conducting an autoethnography study, which gave her “*an empathic understanding about passive photography from a creative perspective*” (Ljungblad, 2009, p. 829). Efimova used autoethnography to explore the process of developing ideas through weblogs, reflecting on her own use of a blog (Efimova, 2009).

A similar technique known as Experience Prototyping has been used by IDEO to understand the context of use because “*the experience of even simple artifacts does not exist in a vacuum but, rather, in dynamic relationship with other people, places and objects*” (Buchenau & Suri, 2000). Buchenau and Suri describe this technique as a method to gain understanding of what it is like to be a user; IDEO used it for the design of an implanted defibrillator device that provides shocks to a user’s heart. Giving out pagers to the design team and having them record their experience and context when getting randomly paged/shocked throughout a weekend provided valuable understanding of what kind of situations they might be in if they were a user of an implanted defibrillator device being shocked. The context of being at home, which was generally understood by the designers already, was further fleshed out into a richer understanding of the nuances of what different situations can occur when a shock is received. For example, the design team were able to experience receiving a shock when holding a child and when using power tools, experiences that were inspirational for the design process and led to specific design requirements of a pre-shock warning system and a notification system for bystanders. These experiences gave more depth to the context of being at home, allowing the designers to empathize with the needs different users might have.

Although these HCI studies use autoethnography or similar methods in unique and innovative ways, they all aim to use the method to provide rich understanding of the

contexts of use of a device while carefully “*interpreting culture through the self-reflections and cultural refractions of identity*” (Spry, 2001) to account for the inherent subjectivity of the method. Neither autoethnography nor any other type of self-study are suggested in the medical technology usability standards to understand context, with the FDA standard going so far as to explicitly state that those involved in the design process should not participate in user studies (FDA, 2011). However, autoethnography has the potential to provide insight into the realistic situations that mobile medical technology users find themselves in which cannot be easily observed by designers and evaluators of these systems. The nuances and subtleties of these situations can provide HCI practitioners and researchers with empathy for users’ experiences.

The first study employed autoethnography to explore what it is like to have to use a medical device regularly and gain empathy for participants in the user studies that followed. This approach was chosen as the first step towards accessing the experience of having to use a medical device independent of what the current situation was, including during routine and non-routine times. Although the use of the term ‘autoethnography’ to describe this study may be controversial as I did not have a medical condition that required the use of the device and therefore could not fully engage with the holistic experience of self-managing the condition, I believe it is still the appropriate term to use. I was not pretending to use the device, but rather actually using the device, giving me experience with this interactive technology and all of the issues that arose through its use. Although ‘Experience Prototyping’ and ‘Autobiographical Design’ are similar methods, both are directly related to the design process of building and testing prototypes or designing systems for the use of the researchers themselves. In my study, I was evaluating an already available and already used consumer technology that had a medical purpose in order to access and capture the experience of carrying it and using it in my day-to-day life. This self-study of how the technology fit into my life and my experiences when using it was an autoethnography, despite my lack of the medical condition.

Although a Type 1 Diabetes technology was substituted for a mobile wrist blood pressure monitor because of health and safety concerns, the purpose was to experience what it was like to regularly use a medical device in everyday life and in different contexts, and also inform the following user studies. This included heavily influencing the planning and the structure of the three methods that made up the mixed

methods user study: contextual interviews, diary study, and an observation of a T1D technology meet-up.

3.3.2 Contextual Interviews

Contextual interviews emerged from contextual inquiry, a method used to understand the context in which a technology is used and noted as important in the design of interactive medical devices. This method includes observation and interviews and is encouraged by the worldwide standard on usability practice in the design of medical devices (ANSI, 2007) along with the FDA standard, which states: “*The method is valuable for understanding user and patient needs, capturing current user-device interactions, and identifying design input requirements for new devices.*” (FDA, 2011).

Contextual inquiry arose from the ways that traditional requirements gathering was unable to access the context into which industry software system solutions would be introduced (Holtzblatt & Jones, 1993). It has its basis in psychology, anthropology, sociology and interpretative hermeneutics, and the technique contributes to design concepts by providing an understanding of the nature of the user’s environment, tasks, and work through inquiry with intended users of the systems (Holtzblatt & Jones). This technique provides information about current work practices to inform a model that can be designed to support user’s work. This changing model can be used throughout the design process to challenge current understanding and users can be involved in this iterative process. Contextual inquiry requires a fairly static context in order to observe natural interactions, which is not easily achieved with mobile medical technologies.

The first user study method used in this PhD research involved conducting contextual interviews with people with Type 1 Diabetes who self-identified as regular users of glucose meters. Accessing the everyday context of use of the glucose meter was challenging, as it was impractical to follow users throughout their days. Although interviews could have been conducted in people’s homes where the device is used often, based on the autoethnography study, it was decided to conduct the interviews in another context of use, a café, to explore the public use of the device. Additionally, to explore the impact of international contexts on the use of the glucose meter, the interviews were conducted in three major cities, Toronto, LA, and London, all with quite different healthcare systems but all major international English speaking cities. Although this study focused on glucose meters, it also captured the variety of technologies involved in self-care, including insulin pumps and smartphone

applications. This influenced the future methods' focus on other T1D technologies as well as glucose meters.

3.3.3 *Diary Study*

Diary studies are a way to capture 'in the wild' data without the researcher actually having to be there. This method emerged from the Experience Sampling Method (ESM) (Csikszentmihalyi & Larson, 1992). The purpose of this method is to study the subjective experience of a person interacting in their natural environments in order to pursue ecological validity by accessing points in a person's real life, and for interactive technology researchers, when devices might actually be used by users 'in the wild'.

Although used in the field of HCI (e.g. (Consolvo & Walker, 2003)), it is an approach that emerged from psychology and social sciences research (Diener, Larsen, & Emmons, 1984) and its basis can be found in two methodological traditions (Csikszentmihalyi & Larson, 1992). The first is research focused on the allocation of time to everyday activities otherwise known as time budgets, where different people would invest time into activities spanning a number of categories and this would be captured. The second tradition is research measuring psychological reactions to everyday activities and experiences, where the impact of everyday life situations on psychological states could be captured.

The need for the ESM method arose from other methods that relied on retrospective accounts provided by people about their daily activities: these accounts have been shown to be inaccurate and a poor measure of how a person usually behaves as they are recorded outside the context of the situation being investigated, permitting distortions and rationalizations by the interviewee (Csikszentmihalyi & Larson, 1992). The findings therefore do not accurately reflect the internal states of the subject, and it is hard to establish clear links between behaviour and state as well as time use and experience.

ESM was a reaction to this and aims to expose regularities of experience including happiness, self-awareness, and concentration. ESM tries to relate characteristics of a person (age, gender, diagnosis), a situation (watching TV, a job), or the interaction between a person and a situation (an event or conversation). In the words of its founders (Csikszentmihalyi & Larson, 1992):

“The objective is to identify and analyze how patterns in people's subjective experience relate to wider conditions of their lives. The purpose of using this method is to be as ‘objective’ about subjective phenomena as possible without compromising the essential personal meaning of the experience”

The core of ESM is the use of a signalling device, such as a pager to alert the participant to capture their experience at different points in time. They are instructed to fill out a form immediately that should take less than two minutes to complete. The aim of this form is to seek better coverage of the respondent's external and internal situation at the time of the signal. This includes information such as location, social context, primary and secondary activity, content of thought, time at which the form is filled out, and a number of Likert scales to measure the perceived situation including affect, activation, cognitive efficiency, and motivation. They are asked to describe their life as it really is, including their joys and their problems.

Subsequent studies using this method have refined the way it can be conducted (Consolvo & Walker, 2003). In addition to the obvious ability to shift from an awkward pager system and a paper form towards an integrated mobile phone application, other adaptations of the method have been found to be useful. For instance, participants are asked to fill out a practice form in order to become familiar with the format, and a phone number is typically available to the participants that they can phone for assistance if needed. In addition, interviews or questionnaires are usually completed after about a week of using the method.

Consolvo and Walker (2003) suggest that activity codes should be used for what participants were doing at the time of the report and when coding thoughts, these should be organized based on the subject of the thought. Through *“adding up patterns within a person, it becomes possible to use ESM to evaluate the common experience of situations”* (Csikszentmihalyi & Larson, 1992). If analyzed carefully, the data can reveal whether changes in situation elicits changes in experience or in people in general. When self-reports deal with the immediate, they have been found to be a very useful source of data but of course the major limitation to this method is that it relies on the accuracy of participants' self reports.

Influenced by ESM, diary studies can be used to capture in-situ information in HCI studies. In discussing methods of the HCI field, Rieman discusses a major limitation to

performing contextual observation and close interaction with research subjects (Rieman, 1993, p. 321):

“Although it is not always the case, investigations in the workplace are generally less controlled than laboratory efforts, involving fewer subjects and relying more heavily on subjective judgments and personal interactions. These efforts are most often described as design methodologies, not research tools, and the data they yield tend to be less predictive, more anecdotal, more limited to the individual situation under investigation [...] extracting objective, general data from these reports may be difficult.”

As a response to this, he suggests a combination of this method with more traditional quantitative experimental psychology measures through the method of diary studies. A diary study includes asking participants to fill out a log form on what their activities were during a day at regular intervals in their own way (“i.e., “had dinner with Kelly,” or, “dentist - ouch!” (Rieman, 1993)). This is typically kept up for one or two weeks in order to not overburden the participants and it is followed by an interview. There can also be daily debriefings to the researcher. This provides findings from a natural setting and maintains ecological validity.

The issue of inconvenience can arise from these types of studies. Participants not only need to be persuaded to sign up for the study, but can also need to be convinced to continually fill out the entries on time and with enough detail (Rieman, 1993). This can be inconvenient as they might be able to complete the activity being tracked without much thought or preparation, but find completing a diary entry overwhelming at the time (Palen & Salzman, 2002). Also, it has been shown that participants can fill out the logs with the researcher in mind, only sharing information that they think would be of interest to the researcher. In addition, methodologically it can provide skewed representations of different days of the week, as the first couple of days are when the participant is becoming familiar with the method. Daily debriefings can be time consuming for the researcher and can be hard to fit in around a participant’s schedule (Rieman, 1993).

Of course in 1993 when this article was written, diaries were encouraged in paper form, but now there are mobile technology solutions that would allow for different types of data to be collected relatively easily. HCI studies using photos have shown it to be a powerful tool in collecting rich contextual information (O’Hara, Perry, Sellen, & Brown, 2002; O’Hara & Perry, 2001). Palen and Salzman discuss their use of voicemail to

capture audio diaries on mobile phones and rewarded participants based on their response rate, which the authors claimed increased the number of entries and did not significantly bias the data (Palen & Salzman, 2002).

Currently, it is very easy to conduct diary studies using mobile phone technology. In the UK, smartphone usage is increasing every year (Deloitte, 2015). On a suitable mobile device at the time of writing, the participant can easily complete a diary entry using text, audio, video, and photos. Of course, this can lead to an additional burden on the users as they need to use a mobile phone, which can be additional to the system that is being studied. Mobile contexts can also lead to issues with this type of recording. There are ways to reduce this inconvenience by adapting the diary study to only involve taking a snippet of text, audio, or video at the time of the occurrence on a mobile device and filling out a longer entry later on a website (Brandt, Weiss, & Klemmer, 2007). The importance of the visual aspect of the context and the interaction should not be underappreciated as it can give these diary entries “*situated meaning*” and it led to a three and a half fold increase in diary entries (Boehner et al., 2008). Visual capture or photography to catch the visual interaction in the moment is one of the strongest prompts for recall and perhaps the least time-consuming.

The diary study method is not mentioned in the medical standards on assessing medical devices, and perhaps compared with the other more conventional usability engineering methods advised, it might look out of place. This might be the result of the standards not accommodating mobile medical technologies, despite the contexts in which these devices are used being just as important as a hospital setting for their impact on safe use (Vincent et al, 2015). There is potential to use this method to extract information about a person’s experience using these mobile medical devices in their day-to-day lives.

The third of the user study data collection methods used employed a diary study conducted in London with people with Type 1 Diabetes who also used a smartphone. During the four-week study, actual cases of glucose meter use were captured by the participants who recorded diary entries after use. In addition, the participants were asked to use a diabetes smartphone application to capture their glucose meter data. As this study was run over the summer, many of the participants were involved in non-routine activities, including holidays and work trips. The combination of the diary entries, an entry interview, and an exit interview showed a variety of use and adoption

scenarios that differed quite significantly, despite the similarities in the demographics of the participants recruited. This influenced the choice to capture discussions between people with T1D in order to uncover similarities and differences.

3.3.4 Observation of a T1D Group Meet-Up

Ethnography in HCI involves in depth in situ observations of users interacting with technology. It has its roots in sociology, and numerous schools of thought exist. Ethnography's origins come from an unexpected extended fieldwork study in Melanesian New Guinea by Malinowski caused by the start of World War I (Button & Sharrock, 2009). He was able to stay and really immerse himself into the native culture, providing sociological input into what was called the first ethnography paper "Argonauts of the Western Pacific" (Malinowski, 1978) published in 1922 as a monograph containing a first hand detailed account of long-term participant-observer fieldwork. This paper was meant to show the natives as they lived their lives, and greatly influenced the Tradition of British Social Anthropology. This school of ethnography is said to influence the design of interactive systems by promoting deeper reflection on how people engage in activities, engaging the end users rather than the purchaser of these systems, and not to judge people from what they say but rather from what they do (Button & Sharrock, 2009).

The Chicago School of Sociology is based in studies of urbanization in the 1920s in and around the rapid development of Chicago. With a focus on the different immigrant populations and cultures particularly among the lower or working class, they explored how social groups function. By studying diversity, it emerged that these populations do not contain purely individual members, but rather involved on-going learning from other populations. This 'interactionist tradition' showed that ethnography could be conducted on one's own native cultures to produce interesting insights and understanding, almost as if anthropology could 'come home'. This tradition influenced design ethnography by showing that fieldwork could lead to familiarization with the diversity of social environments, get away from biases created by over use of social theory, and could garner empathy for a social group.

From this Chicago school, the idea of interactionalism in ethnography was expanded in the 1960s. This tradition was developed under the premise that people react to situations as they see them and they are influenced by their assumptions and experiences that they bring with them. As individuals can differ greatly, so can their

reactions and their conceptualizations of situations, which can be hard to generalize, although it is a group that defines a situation based on social knowledge and cultural rules. This field has greatly influenced the HCI community involved in collaborative work by promoting the importance of immersion in work cultures.

Wilcox (2012) believes that although there are strengths in fieldwork, a suggested method in the usability standards (ANSI, 2007), it does not fully address the differences between what people say and what they do as it can rely heavily on interviews and observations. He believes that these can be superficial compared to a researcher really immersing themselves into the environment. According to Wilcox, contextual inquiry should be expanded to capture more ethnographic information as longer-term observation of interaction is necessary. He described the gold standard being video recording to capture the nuances of the observation that requires careful analysis after the fact, but admits to the issues attached to this method. For examining devices such as mobile medical technologies, video observation is not possible and long-term observation would be very intrusive into the participants' day-to-day lives as these devices are constantly with them.

The final user study data collection method used was the observation of a group meet-up of T1D technology users and enthusiasts where I observed and listened without interfering or interjecting in the conversation. This allowed me to watch how people use their technologies in a public bar and also how they interacted with the technology in front of other people that also have diabetes. The conversations that occurred between groups of people were quite similar in nature to the conversations during the interviews involved in the previous two methods, but the nature of this study allowed for more open discussion. This led to some agreements from people offering stories that complemented others' experiences involving use and adoption, but also disagreements showing very different viewpoints. By observing free flowing conversation, issues involving use and adoption arose without injecting my own biases, and in part this study acted as a validation of the previous studies.

3.4 Overview of the Pragmatic Situated Methodology

This research involved the use of four situated data collection methods to understand the use of mobile medical devices as they are carried and used throughout people's day-to-day lives. First, the autoethnography informed the three methods used in the mixed method user study: contextual interviews, diary study, and observation of a

group meet-up. The data collected from the three user study methods was analysed collectively to ultimately answer the research question: What aspects of a person's situated experience with Type 1 technologies influence their adoption and use of those devices? The next chapter outlines the autoethnography study including details of how this method was carried out, followed by Chapter 5, which details the data gathering and data analysis used for the mixed method user study. The thematic empirical chapters (6-10) follow, which outline the contexts of use (physical, healthcare system, cultural, and social) and the individual differences (personal style, lifestyle, and circumstance) that influenced the adoption and use of these T1D technologies in everyday life.

4 - Autoethnography Study

The results in this chapter have been published as a Note in the Proceedings of CHI 2014 (O’Kane, Rogers, & Blandford, 2014).

4.1 Introduction

In order to understand what it is like to use an interactive technology, a researcher can try to use it themselves. As a pre-cursor to conducting user studies, I conducted an autoethnography study in order to gain insight into what it is like to use and carry a medical technology with me throughout my everyday life. This study was the first step into trying to understand the context of use of mobile medical devices as well as a pilot of future user studies. Through my personal use of a mobile medical device, my aim was to achieve the following:

1. Gain empathy for the use of a medical device in various contexts, including outside the home and in public places; and,
2. Pilot possible future user studies and diary sampling methods.

In order to explore various contexts of use for mobile medical devices and the subtleties of the different use experiences, I set up the self-study using information from preliminary interviews with mobile medical device users. An autoethnography study was planned to emulate some of the conditions the interviewees discussed and record these situations using a modified open diary keeping technique (Brandt et al., 2007). From these diary entries, thematic analysis (Braun & Clarke, 2006) of the results indicated the influence of different contexts of use on the everyday use of the mobile medical device. The method was also helpful in the planning of future user studies.

4.2 Preliminary Interviews

As my research focuses on the use of mobile medical technology and previous research I have completed involved participants with diabetes (e.g. (O’Kane et al., 2013)), I have had many informal discussions with T1D mobile medical device users about their devices. These users often share stories of where and when their use of a medical device caused an issue or embarrassment, and many demonstrated the use of these devices if they were carrying them at the time of the conversation. In addition to

these informal discussions, two interviews were conducted with medical device users specifically to inform the design of this study. One-hour face-to-face interviews were conducted with two males with T1D in their late twenties/mid thirties with academic research experience. During these interviews, the proposed study was explained along with the overall research goals. This was followed by unstructured conversation covering subjects such as their daily routines, everyday experiences with living with diabetes, past issues with using a glucose meters, and their opinions of their diabetes technologies.

Samuel (name changed) is a second year PhD student in computer science. He is in his mid-twenties, lives in London with a flatmate and has had T1 diabetes since childhood. The interview was set up through a mutual friend and he met me for a coffee on our university campus. After brief introductions, I explained why I wanted to talk to him, what my PhD research involved, and what my planned autoethnography study would be. Samuel discussed the maintenance of his condition in a dismissive way, describing it as something he does not have to think about because he has his blood sugars under control. He leaves his glucose meter at home where he is able to test his levels in the morning and evening, but he takes his insulin medication with him and injects regularly as he eats carbohydrates. At home, he tends to leave the glucose meter and medication in his room, where he tests and takes his medication. Although his flatmate knows his medical condition, he tends to close the door whilst using the device and injecting. Samuel claimed that he does not bring the device with him, but after further probing he admitted during non-routine times he is forced to. This includes when he is away for a weekend, on holiday, or going home for Christmas holidays. He admits that it can be slightly awkward, but he has not had any real issues with carrying the device and medication with him.

Gavin (name changed) is a part-time PhD student and also works full time in informatics. He is in his mid-thirties, lives in London and has had T1 diabetes since childhood. We were introduced by a mutual friend and met at a wine bar after his appointment with diabetes services at a local hospital. When I arrived, he was in a good mood after receiving respectable results about his blood glucose levels and was having a glass of white wine. Again, I introduced my PhD research, my upcoming autoethnography study, and the reason why I wanted to talk to him. Gavin was very open about his condition and mentioned that in the past he has had trouble controlling his sugars. He keeps his glucose meter and insulin medication in what he called a

“man bag” on him at all times. He was happy to show me his glucose meter and lancet, which were black and stylish and he was very interested in any new and better technology that was coming out. We discussed some of his past issues with using the devices on the go, including an anecdote about being on a night out in Camden, London with a friend who had too much to drink. Gavin needed to test his sugars and inject insulin, so had to go down an alleyway, where a couple of police officers saw him and yelled, thinking he was doing something illegal. He was able to explain the situation, but both he and the officers were embarrassed. Gavin has no issues with using the device in public and actually conducted a blood test while at the wine bar with me, hardly even looking down at the task as he had gained so much expertise in it. Gavin has become used to the routine of using and carrying the devices, but also discussed the awkwardness that can occur when routines have to be broken for a variety of reasons, including holidays.

People who care for a condition, such as Gavin and Samuel, may have a general routine during their day much like anyone else. They might wake up and go to sleep at specific times during the week or the weekend; they might eat at similar times every day; they might leave their homes during the week for work, school, or social activities; they might have weekend errands or activities such as attending church. These activities can be classified as routine times during which a person can schedule their use of a medical device, plan to bring it with them or leave it at home, and plan places to use the device. Deviations in a general routine might cause some inconvenience to these plans, but they are more easily dealt with than non-routine times.

Non-routine times can occur in these people’s lives, again like the rest of the population. They can go on weekend trips, travelling to new locales, to conferences abroad, to out of town weddings, and so on. These can be called non-routine times, but they are not uncommon. During these times, there are a different set of concerns about bringing medical equipment with them, dealing with time zone changes, and being unable to plan where to use these devices. The act of bringing this equipment can be problematic, such as when a person caring for diabetes must bring glucometers, lancets, and insulin on planes and through airport security. Time changes can disrupt routines and more importantly, body clocks. New locales mean that people might not know the social norms of the places and might be uncomfortable using their medical devices if they cannot obtain privacy. In order to explore these themes further, I took

what I learned from these discussions and previous discussions with other users and applied it in the planning of the mobile medical device autoethnography.

4.3 Method

4.4 The Mobile Medical Device

As I do not have a medical condition that requires a mobile medical device, in this study I was essentially pretending to have a medical condition. Although there are various mobile medical devices available, it was determined in consultation with my supervisors that it should be non-invasive and not have possible health effects. Based on a review of commercially available products, it was decided that a blood pressure monitor used by those with hypertension would be a suitable choice for this study.

There are numerous types of monitors, but the blood pressure monitors that are worn on the wrist are smaller and therefore more portable. Although there are simple ones available, given the scope of this research a digital programmable monitor was chosen to test in relation to newer complex mobile devices that may be available in the near future (Graham, 2010). In addition, the best seller from Boots and the second best seller from Amazon.co.uk at the time of this study was one of these more complex designs, the Omron R7 (Omron, 2012b) seen in Figure 5. This device has been validated by the British Hypertension Society (Topouchian, El Assaad, Orobinskaia, El Feghali, & Asmar, 2006).



Figure 5: Omron R7 Wrist Blood Pressure Monitor (Omron, 2012a) (left) worn on my wrist (right)

4.4.1 Context of Use

The stages of this autoethnography were determined from the interviews and informal conversations with mobile medical users. This study was conducted in three stages from April until July 2012. In the first stage to simulate a non-routine time, I was in Toronto, Canada visiting family and friends, going to a friend's wedding, flying to

Austin, Texas with a stopover in Houston, and going to a weeklong conference CHI 2012. In the second stage to simulate a routine time with occasional disruptions, I tested with the device twice a day while living in London and while I was subject to schedule changes and disruptions that are common in my life (as a PhD student in a large urban centre) including having friends visit and a brief trip to Wales. In the final stage to simulate a regimented patient routine, I tested with the device twice a day and held a strict schedule where I left the device at home and was strict with being home by a certain time, eating at the same time every day, and exercising every day. The stages of this study were not to represent the amount of time a user would be in these contexts, but rather to experience a range of situations that a user might encounter using the device over different periods of their life.

4.4.2 Medical Use Simulation

Although it is not common that this device would be used in a strict regime, for the purpose of this study it used in the way that it was prescribed. This is in line with the experiences described in the interviews conducted with Gavin and Samuel, both of whom need to use their mobile medical devices quite regularly. The instructions for testing blood pressure were gathered from the pharmacy Boots, the UK Blood Pressure Society, and the manufacturer and are presented in Appendix A.

4.4.3 Materials

For this study, I used a Sony Ericsson Xperia Pro as my mobile phone for collecting the diary entries, seen in Figure 6.



Figure 6: Sony Ericsson Xperia Pro smartphone with QWERTY keyboard used for diary entries (Sony, 2012).

Although I had limited experience with Windows, Symbian, Blackberry, and Apple smartphones, I had never used a touchscreen smartphone as my main mobile phone. I

had also never used an Android interface before, so I got used to the phone for one week before starting the study in earnest.

During that week, I was also testing various free “diary” applications on the Google Play Application Store that had functionality for the diary sampling method. This included the ability to capture user input through text and photos. I tested the ten most popular applications at that time, including Diaro, Memoires, and Moment Diary. I found Diaro easiest to use with the functionality required, and this was used for the first portion of the study.

Although simple to use at first, Diaro proved not to be the ideal application over time. The icons were not readily recognizable, there were advertisements when reviewing journal entries, and only a snippet of the original text paragraph could easily be reviewed. In addition, the data for analysis was not easy to compile and could not be uploaded automatically.

After using another application downloaded for the separate purpose of taking notes at the conference I attended, I started using this “notes” application for the diary entries. This application, *GNotes*, was also free, but had no advertising, a widget on one of the homepages for quick access, and the interface was easy to understand. The data were uploaded automatically to a Gmail account as a note.

4.5 Data Collection and Analysis

The purpose of this study was to gain empathy for medical device users, test the diary method for mobile medical device users and explore the use of autoethnography for collecting contextual information. As a result, such a subjective approach is warranted and the analysis is presented as a first hand account.

I collected diary entries every time I tested my blood pressure, ensuring my data would be journal entries containing a mixture of text and photos. As the diary application was changed from Diaro for the non-routine time to GNotes for the routines time with the device, these entries had to be collated and Excel was used to organize the data (see Figure 7).

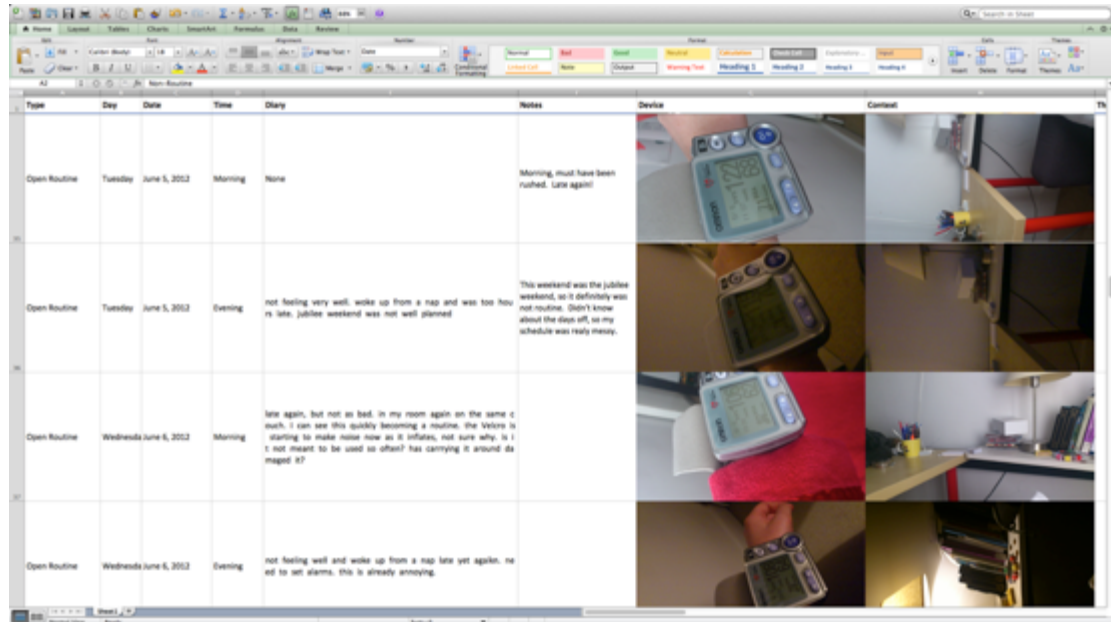


Figure 7: Collated Data Analysis for non-routine, routine, and strict routine diary entries

Thematic analysis was used as a method to systematically analyse the data whilst also exploring the emerging themes in an iterative and open way (Braun & Clarke, 2006), however a flexible and pragmatic approach to this analysis was taken, similar to the approach which is further detailed in Chapter 5. With the researcher as the participant, themes of course emerged during the use of the device. However, I did not attempt to analyse the data until the study was completed, rather allowing time to reflect on these themes in the role of a user of the device. This approach is in line with thematic analysis, which goes beyond observation towards implicit and sometimes subtle themes (Merton, 1975).

When the three stages of qualitative data collection were finished for non-routine, routine, and regimented routine times, an iterative three-part coding scheme was completed starting with initial themes generated from my perspective as a user. These arose from problems experienced during the study: issues with carrying the device and issues with using the device itself.

These themes influenced me when going through the data and taking notes on each of the instances. This led to coding the data with the general themes of physical environment issues, social context issues, and issues dealing with the aesthetics of the device. The final stage of coding allowed for a deeper analysis of subtleties that arose out of the data, which were not captured in the prior dialogues with mobile medical device users.

4.6 Results

In total, 27 tests were completed between April 26th and May 12th 2012 during non-routine times, 14 tests were completed between June 5th and June 25th during regular routine times, and 12 tests were completed every day between July 5th and July 10th during strict routine times. The disruption the testing caused during the non-routine times influenced me to delay the second two sets of testing.

The results are presented under general themes, but this is not to imply that there is not significant intertwining of these themes of environmental context, social context, and aesthetic considerations. In many cases, it is quite hard to differentiate because the social aspects influence the environmental aspects, which are impacted by the aesthetics of the device, and so on, but they are separated to organise the findings.

4.6.1 *Physical Environment Context*

In the dialogues and interviews conducted with mobile medical device users, it was mentioned that using these devices in public was not always ideal. In some cases, users choose to use the devices away from others in the privacy of a washroom stall or in a hidden area. The awkwardness that this might cause was described, with noise and time concerns being paramount.

During my use of the wrist blood pressure monitor through non-routine, open-routine and strict routine times, I often found myself using a washroom stall or a more private area to conduct the testing alone. The earlier interviews prepared me for these situations, but the subtleties of these experiences were not fully understood until I experienced them myself.

The device made noise during the testing procedure. Although the buttons did not make noises, when I was adjusting my arm towards the proper angle for testing, there were beeping noises as feedback that I was getting closer. In addition, the device had to inflate around my wrist in order to test my blood pressure, which caused a flowing air sound. Although these sounds were not particularly loud, they were quite distinct. This of course was an issue in public toilets, where the noises could be a great source of embarrassment, but could cause issues of embarrassment in other places, including at work and in my own home (see Figure 8).

Tuesday, June 19, Morning, Open routine:

"A friend of my flatmate is staying with us, she doesn't know my research and im a little worried she heard it. I didn't shut my door though."

Monday, June 25, Morning, Open routine:

"currently at work, and it is really slient so the test was very loud."

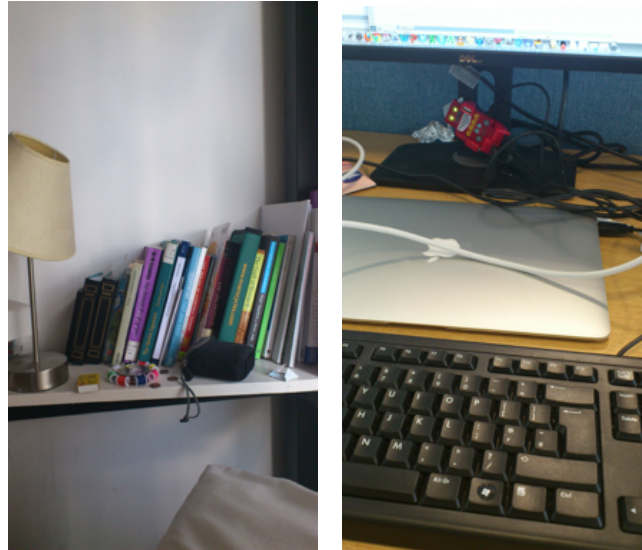


Figure 8: Hiding in my room testing (left) and testing at a silent workplace (right)

The features of the device seemed to be conducive to a certain physical setting and did not support variations in the testing environment. This was very clear when I was stuck in a restaurant's washroom with dark lighting and could barely see the numbers on the device after testing (see Figure 9). This also occurred when I came home late one night after meeting a friend for an unplanned trip to the pub (see Figure 9).

Tuesday, June 19, Evening, Open Routine:

"this is the first time I've done the test in the dark, but it is annoying to turn on a light and I don't really want to wake up any more than I am [...] not immediately clear which way it goes. seen this on other people trying it out. again not backlit don't know what's going on. need to light it with the phone."

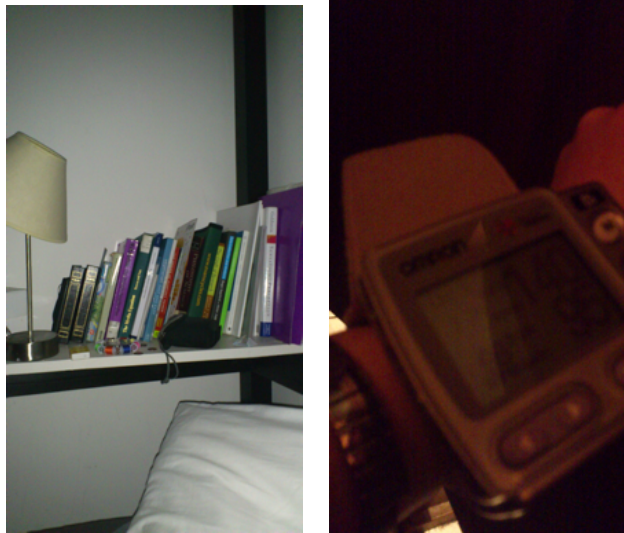


Figure 9: Using the device in the dark in my room (left) and in a dark washroom stall (right)

The testing process requires a person to sit down and rest for about 5 minutes before taking the test. This can be inconvenient as it can cause disruptions in normal activities in order to relax, but the need to sit down also could cause issues, depending on the environment that the testing was taking place in. This issue only came up once during the weeks of testing: the conference venue washrooms did not have seats on their toilets (see Figure 10). As I did not think there was another easy or convenient location option to conduct the test, I tried to perch on the toilet paper dispenser and conduct the test, which of course caused tension in my legs producing an error message on the device (see Figure 11). Although this only caused inconvenience once, because I knew that the conference centre washrooms could not be used, I had to more carefully plan where to conduct the testing for that entire week.



Figure 10: Toilet without a seat during testing (left) and the toilet paper dispenser I perched on (right)



Figure 11: Error message received on the device after the proper posture was not taken

As the device was mobile and I was not using it in consistent environmental conditions, my experience with using the device in different physical settings varied. I often found myself in conditions that the device design was not suited to, which generally affected my use of the device at the time.

4.6.2 Social Environment Context

Although I used the device to test myself, there was no escape from outsiders getting involved in the process, whether it was friends, family, or strangers. Based on the interviews and the dialogues I had with medical device users, I had expectations of what it would be like to have to plan a day around conducting these tests. I was told by medical device users that it became quite routine and one more step in your day, which has some impact on social situations but is as minor as brushing your teeth.

I was interested in how daily routines would be changed and how this might impact day-to-day life. It was only through experiencing the testing that I was made aware of the significant impact social situations had on testing. On the other hand, when I was alone, the test had the effect of being almost intrusive.

In public places, such as in coffee shops, restaurants and in the conference centres, I chose to go to the washroom to conduct the testing (see Figure 12). By doing this, I was able to avoid the eyes of strangers completely and going into a stall as a female was not an unusual act. Despite some noises from the device and spending a longer time in the stall than would be average, this act did not bring any attention to me and quite effectively removed social stigmas.



Figure 12: Pictures of testing in restaurant (left) and conference centre (right) washroom stalls

Depending on the context though, the impact of this stigma could be completely forgotten in some instances where my mood at the time or the circumstances of the testing environment almost made me immune to what others would think of the device or me. For instance, I was on a stopover in Denver with a large suitcase, a small suitcase, a carry on bag and my coat. Although I could manage to get these all into a washroom stall, I did not feel like fighting with the suitcases at the time. I sat down in a seat that was not private, but easy to manoeuvre my suitcases to (see Figure 13). When I conducted my test, I was not inclined to cover up the device or hide what I was doing as I was just too tired and did not care what others thought of me in this airport. Because there were other travellers around me at the time who could be assumed to be slightly bored waiting for flights, the device did get some attention that onlookers tried to be coy about. Despite this attention, my circumstances influenced my self-consciousness and I did not care what others thought of me.

Friday May 4th, Morning, Non-routine:

“Currently I am on a 3 hour stopover in Denver airport, which I haven't been to before but it looks massive. I could go to the washroom to do the test but I have an awkward amount of luggage.”

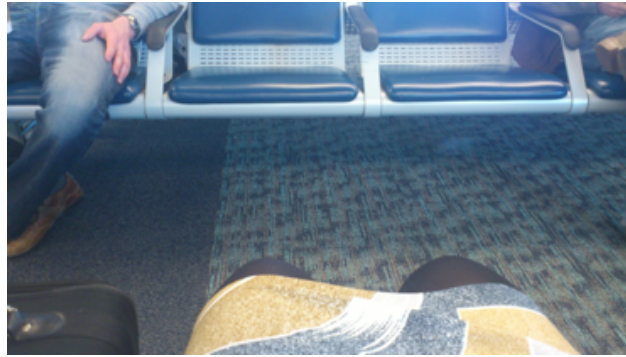


Figure 13: Picture of testing in the Denver airport passenger lounge

In another instance, I also did not hide the device but it received no attention at all. Near an intersection in Toronto where it is not strange to see homeless people, prostitutes, residents from a nearby YMCA, and patients from a nearby rehabilitation centre, it is not common to make eye contact on the street or pay too much attention to people. Although I was with a friend for lunch in a \$5 sushi lunch restaurant, when I conducted the test across from her, no one else in the restaurant paid any attention to me (see Figure 14). I knew in this area people would not look at me regardless of what I did, so I felt completely comfortable completing the test without any stigma. Knowing the culture of this neighbourhood assured me that no one would look at me as I did the test, and therefore I did not care to take the device to the washroom or hide it as I conducted the test.

Wednesday, May 2, Morning, Non-routine:

“At a restaurant for lunch with friend. No one looked at me. [...] The particular restaurant we were at was at [a busy Toronto intersection] which is known for being frequented by those with drug addiction and prostitutes. Although it was the middle of the day and in a restaurant, the people that worked there and the other customers either did not see me or pretended to not see me.”



Figure 14: Picture of testing in a cheap restaurant in a busy area of Toronto

When I was among friends and family, the test should not have been an issue because they knew my research, much like someone else's friends and family might know their condition and understand the demands of taking care of the condition. This was not always the case, and I had varied experiences that influenced my use and adoption of the device. I was visiting my family and friends in Toronto when I started the autoethnography study and continued the testing during the CHI 2012 conference with colleagues where I was able to explain the research and the nature of the study. Although they were supportive of my efforts, there were instances where the actual testing would cause them mild annoyance. Like anyone visiting home or attending a conference, I had many social engagements and was often carrying the device with me. Frequently this would put me in a situation where I was rushing to complete the test as I felt social pressure to not keep people waiting (see Figure 15). This also occurred when I was in London and was routinely meeting friends (see Figure 15). This rushing impacted my level of compliance of testing and also how the testing was conducted. Rushing through the test impacted the test results, as my blood pressure would be raised and I would hurry through the steps of the procedure.

Thursday, June 21, Evening, Open routine:

"late, out the door with 2 people waiting."

Friday May 4, Evening, Non-routine:

"Just arrived at the hotel and people are waiting for me. Pressured."



Figure 15: Pictures of my kitchen table (left) and of people waiting for me at a hotel (right)

The testing time not only came up before social engagements, but during them. If the alarm went off during a conversation or social interaction, I would have to interrupt that act to take the test. Sometime this was not very disruptive and could even provide a topic of conversation, and additionally an informal first time user test. Friends and colleagues were particularly interested in trying the device, perhaps out of curiosity (see Figure 16). Some were shy in asking to use it, somewhat similar to how someone might approach a medical device user curious of their technology. When trying the device for the first time, most were not able to figure out how to use it even with the instructions on the device. There were also quite a few instances of stark changes in the experience from positive to negative when the device was in the middle of testing. They would start the test light-hearted and interested and watch the numbers count up on the device, but the device would count up and over what was the final number giving the impression of very high blood pressure during the test.



Figure 16: A friend using the device in a restaurant (left) and a friend having trouble with the instructions at a party (right)

Disruptions could also cause me great annoyance when they occurred during social interactions where they would interrupt the interaction. For my very first test, I awoke at a friend's house and we were discussing our research (see Figure 17). As she was a PhD student in bioethical sciences, we were having a conversation that was bordering on a debate. As the alarm went off, I knew I had to stop the conversation in order to lower my blood pressure. After taking the test, we did not pick up the conversation where we left off, as it was too much of a disruption and the debate seemed out of place then.

Thursday, April 26, Morning:

"First test waking up after sleeping on her couch. Had to stop a conversation that was getting me worked up, almost like a debate."



Figure 17: Picture of testing in a friend's house and disrupting conversation

Disruptions like the one previously described were annoying, but could be explained to the friends, family, and colleagues that I was with. In other circumstances, these disruptions in social interactions were not explained to companions. Although I was quite open with my research, in some circumstances I felt more comfortable excusing myself and not explaining my absence as I took the test. This occurred with instances of interacting with acquaintances, but also in circumstances where I did not want to bring attention to myself, even with family (see Figure 18). One instance of this was at a friend's wedding where I only knew a handful of other guests (see Figure 19). After being delayed in the testing because of speeches, I excused myself during polite conversation with someone at my table to conduct the test in the washroom.

Saturday, April 28, Evening, Non-routine:

"At the wedding. Had to wait until dinner was served and then also a speech so I'm late. No one knows my research here and I feel silly explaining this study."

So I'm in the washroom trying to be silent but also quick so that my table doesn't notice."

Thursday, April 26, Evening, Non-routine:

"At family dinner, forgot about the test for 30 min. Awkward to break conversation and explain, so I excused myself."



Figure 18: Picture of washroom stall I tested in at a wedding (left) and during family dinner (right)

Often when the alarm went off for a test, I would be by myself and in the middle of something. This alarm and the testing that followed acted as an obtrusive interruption to my activity, whatever it was. The device started to have a social presence of someone you do not want to see, but have to see for other reasons. In some cases, the test did not bother me. If I was not busy or a bit bored, I would not mind doing the test and was interested in the results of the test (Figure 19). At these times, I did not feel like the test was a chore, but rather an activity that I was interested in.

Tuesday, May 1, Evening, Non-Routine:

"Not bad this time. I am at home with my parents and I don't mind doing the test. I have been having late dinners so 7ish is not getting in the way. [...] Really low score. Going to try again. Low again. Now I'm googling the result. [...] Found a chart online, so I feel better about it. I even looked up heart rate as well."



Figure 19: Picture of testing in my parent's living room

Interruptions were not just a social experience. During the non-routine and open routine times, I often found that the test would interrupt an activity such as working on my laptop or watching a movie. It would also add to the tasks I would have to do before I left my home, causing me to rush (see Figure 20). The act of testing could induce a negative emotional reaction.

Monday, April 30, Evening, Non-routine:

"I am in a rush to get out the door to greet friends for dinner. This probably will impact my test. I am looking at it as one more thing to do, like brushing my teeth or packing my purse. Annoying but doable."

Sunday, July 9, Morning, Strict routine:

"In a rush, was going to skip breakfast but then I realized this is the strict week."



Figure 20: Picture of test taking in parent's living room near the door (left and in my kitchen with the breakfast I was going to skip (right)

The impacts on that the social environment had on my testing was surprising to me even with the knowledge gained from the interviews with mobile medical device users. I did not suspect the impacts of who could potentially see or hear the device, and even being alone influenced my use and adoption of the device.

4.6.3 Aesthetics

The mobile medical device users that I interviewed formally and informally prior to starting this study used a variety of devices, ranging from the traditional blue asthma inhaler to a sleek black glucometer. All seemed interested in more updated and modern looking devices, often using their smartphones as a comparison. I was aware that the medical aesthetic of the device might be a source of embarrassment when using it during testing, or even just carrying it around with me every day.

The design of this blood pressure monitor clearly included a medical aesthetic in its form. At the time of the study, there were heart pressure monitors that looked more like consumer devices than medical devices. For the sake of this research, a prototypical wrist blood pressure monitor was used and experienced. As I normally carry a handbag around, I was not expecting to be inconvenienced by the size of the device and as I was not actually ill, I thought that the medical aesthetics would not influence my use. Through conducting the tests myself, I realized that these assumptions were wrong.

Throughout the study, I was very aware that I would have to plan my day around testing and plan whether I would bring the device with me or not. Although the device was relatively small, it was an issue in some circumstances. I normally brings a handbag around with me to carry a wallet, phone, umbrella, sweater, etc., and on my way to the university, I usually bring a sizable bag to fit a laptop and charger in addition to these items. This larger laptop bag was easily able to accommodate the device and it was not a noticeable addition, but smaller handbags proved to be an issue. Although most of my bags could fit the device, often other items had to be sacrificed, such as an umbrella. I also found that I started carrying one larger handbag almost all the time to the point where it was getting worn out by the end of the study (see Figure 21).

Although my bag was a fairly minor concern most of the time, in some cases it was truly inconvenient. When I was going to my friend's wedding, I had to find an evening purse that would fit the device. In the end, I only had one bag that fitted the device. This bag was a striking orange colour, meaning I had to change my entire outfit to match the only purse that could carry the device. I also found I could not fit the device

along with my laptop in the handbag that I brought to CHI 2012 to use, so I ended up having to use the conference bag the entire week which was not ideal for evening activities (see Figure 22). This brought up feelings of annoyance and frustration throughout the study.

Saturday, April 28, Evening, Non-routine:

“The device hardly fit in the only purse that matched my dress and it is quite chunky looking [at the wedding].”



Figure 21: The handbag that fit the device well so I used often (left) and the conference bag that fit my belongings and the device (right)

The hardware was cased in grey and beige plastic, much like many other medical devices found in clinical settings. This look gave the wrist blood pressure monitor the feel of a trusted sterile medical device, but it also reminded me and possibly other about being in a hospital and being sick. This led to issues with its use and adoption. In public, I was open to the eyes of strangers. Being exposed to people who do not actually matter in my life should not have mattered that much, but self-consciousness with using the device in public affected my use of the device as well as my adoption of testing. Although I did not have a condition that warranted the use of the device, using a medical looking device in public made me aware that I could be seen as a sick person. I felt stigma using it in public without a companion, so I tried to hide my use. This was accomplished in various ways, including using a washroom stall. Other times, it was not possible to go to a washroom. These were generally times when I had belongings on me that I was not able to take with me to a washroom stall easily or that could not be left as I went to a washroom stall. When at a coffee shop working on my

laptop, I did not want to close my computer, unplug my laptop, pack up my bag, give up my seat, and take my coat to the washroom, just to unpack everything once I completed the test (see Figure 22). In another case, I had to excuse myself from an evening seminar at my university so I could do the test. Already making a small commotion leaving the room with my bag, coat, and bicycle helmet, I did not feel like finding a washroom and decided to conduct the test in a hallway in the university. In the case of the coffee shop, I turned away from the rest of the customers and hid the device with my hair as I conducted the test. In the case of the university hallway, I waited until the hallway was almost clear and hid the device behind my hair again (see Figure 22). In both these instances, I decided that the inconvenience outweighed the stigma but I still tried to minimize my exposure to the public.

Wednesday, May 2, Non-Routine:

"I did hide the device slightly behind my hair whilst doing the actual test and didn't look up to make eye contact. When taking a pic of the device someone saw me and gave me a strange look before quickly looking away. No one else seemed to notice. I am in a coffee shop frequented by university students working and friends meeting. Not that embarrassed, but maybe because I felt if anyone did pay too much attention to me they would be in the wrong judging someone with a health issue. I also couldn't go to the washroom as I would have to pack up all my stuff including a laptop."

Thursday, June 7, Open Routine:

"Had to leave an evening lecture as my alarm went off in the middle of it. Very disruptive. Sat in the hallway of a [university] building, only one person passed and I found myself covering the device with my hair."

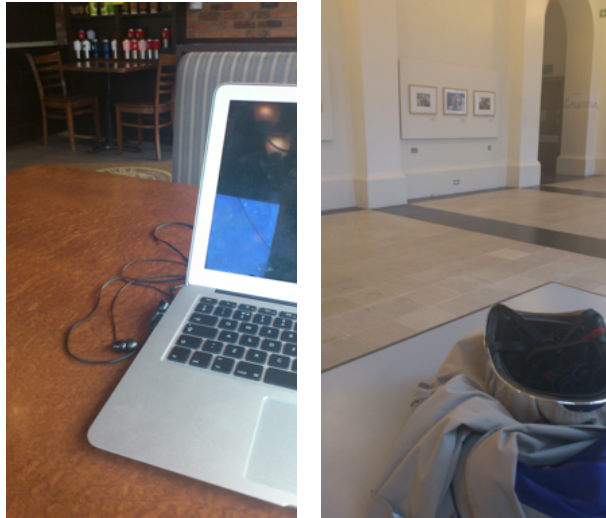


Figure 22: Pictures of testing in a cafe (left) and university hallway (right)

The design of the device influenced its use, as it looks like a medical device and I felt moments of embarrassment in using it. Although this could be solved using a work-around such as going to the washroom and hiding the device while testing, it was a source of frustration, along with issues with carrying the chunky device.

4.7 Discussion

4.7.1 *Autoethnography and Empathy*

The informal and more formal interviews with mobile medical device users were very helpful in gaining empathy for the contexts in which they use their devices. As discussed by Wright and McCarthy (2008), this empathy was achieved through dialogue and this method is an easy way to gain empathy quickly for HCI designers, evaluators and researchers. However, the main advantage of these specific dialogues was that they informed the autoethnography study so that I could share some of these experiences. The dialogues were not able to give a rich understanding of the contexts in which these devices were used, as witnessed through the subtleties and nuances that I experienced through the autoethnography study. I experienced what it is to not only plan your day around the device, but even sometimes plan your outfit because of the shape of the device. I felt what it is like to have strangers look at me and experienced how my strategies to minimize this were influenced by the design of the device. Through exploring the device with friends, I was able to informally test first time users and compare this with my experiences of understanding how to use the device

and its affordances. Knowing that there were sounds that the device made was completely different to feeling the embarrassment of causing noise in a silent office.

Some of these insights might be gained through an ethnographic study or a contextual inquiry where HCI practitioners can observe users with their devices in context. Of course, they may not be captured as being an observer puts the researcher on the outside, whereas using autoethnography puts the researcher inherently on the inside. This method does not focus on analysing tasks or functions, but goes further to allow the researcher to comprehend the experience of using the device. As this is the case, autoethnography should be considered as an additional method that designers, evaluators and researchers in the medical usability domain could call on to acquire empathy for user experiences.

However, autoethnography is highly subjective: it is a very personal method that will give insights about some circumstances, but these results are dependent on the researcher, and situations can be inherently artificial. It should not be expected that the results are common across the very large and diverse group of mobile medical device users or that the results could be replicated. What it does allow is the designer, evaluator or researcher to experience *how it feels* to be a user, and it challenges assumptions that can sometimes be unavoidable when judging new technologies. Understanding and empathizing with the user is an important part of fully comprehending what it is like to be a mobile medical device user. Although it can be artificial and only analogous situations can be conceived, the method is an excellent surrogate for accessing part of the experience of using a mobile medical device in context.

4.7.2 Autoethnography as One of Several Methodologies

Some of my experiences were specific to someone who was using the device for the first time, not someone who has used it for many years. Experiences such as not being able to fit the device into an evening bag for the wedding would not occur for a long-term user who would generally buy handbags that would fit the device. However, this type of situation might occur for someone who was newly diagnosed with a condition or someone who had recently started using a new device. This insight into these situations could be a great source of inspiration for further user studies. By knowing these details and experiencing them, the researcher can dive deeper into issues that long-term users may not consciously think of as they have developed coping

mechanisms and routines around these devices. This can help researchers in designing future interview studies and observations, and can also act as a pilot for a diary study with users.

Autoethnography cannot replace other more established methodologies for understanding the context in which medical devices are used such as interviews or diary studies with participants. Rather, autoethnography is a means of understanding context when observation is very difficult and a good process for further empathizing with users of these devices. If used in combination with what Wright and McCarthy (2008) call dialogues and narratives, the HCI researcher can use this 'imagined other' as another technique for gaining empathy for users' experiences. Empathy is important in the design of mobile medical devices: a person's experience with this type of technology can impact their use of it, and medical usability practitioners need to be aware of the subtleties that can have this type of impact.

4.7.3 Using the Diary Method with Mobile Medical Devices

The act of completing a medical task requires a level of juggling and discretion in a washroom that diabetes patients might have grown accustomed to, but with the addition of the requirement to make a diary entry, the entire task is changed. Although this might not be routine for them, diabetes patients would have some expertise in how to carry out this task in a safe way. There is additional burden on the patient participant when they have to use one technology and then switch to another type of technology to capture the diary entry. Although handling two devices at once can be awkward, the diary method used in conjunction with a user's smart mobile phone was found to be easy to maintain and did not gain too much attention, and it allowed details of the context to be quickly captured through photos and further fleshed out with text.

I was using a blood pressure monitor during a non-routine time where I crossed an ocean to visit home, go to a wedding, took a flight to another time zone, and went to a weeklong conference. This non-routine time caused specific issues that I had to overcome, but it also made clear the importance of testing the device in both settings. Simply getting a patient to complete a diary study for one week will not give an idea about the breadth of uses of the device. Some of the most challenging situations can occur during these non-routine times, but these are the hardest to capture for experience during diary studies as they are less common and can be more invasive into a participant's life than getting them to integrate a diary study into a routine.

The application that was used to gather these diary entries was more than sufficient for its purpose. The ability to take a picture of the context was important, but the text really gave the picture meaning and included details that I might have forgotten. When I got too busy, I would not make a text entry, which of course hampered the results but seemed like a good alternative to not taking a diary entry at all. The ability for me to use my personal mobile phone was also important, as this was not an unusual occurrence and I was able to add text entries while probably looking as though I was using my phone to text or to email.

4.7.4 Inspiration for Future Interviews

This autoethnography study was used as inspiration for the planned user studies. Based on this study, interview questions were developed for the user studies, particularly routines and changes in routine. Throughout this study, I went through various routines, which influenced my use of the device and the way that I carried it around, influencing the interest in how routines influence mobile medical device use and if mobile medical device use influences routines. There were also specific questions about using the device in unpredictable environments such as when on holiday. Questions were also asked about how participants' use of their current device compares to experiences with other devices. This is particularly important if they were first time users of mobile medical devices or if they were long time users of mobile medical devices. This is of interest as a first time user might have different insights to someone who has experience with a variety of devices, especially if some interviewees have experience with updated versions of the same technology. If they had used various devices for different conditions, this was also probed further to see how their experiences with different devices have varied.

Questions were also asked about past experiences that stuck out in their minds with the devices. Examples from the autoethnography study were used as prompts, especially issues of embarrassment and awkwardness. Positive experiences were also given as examples to try to solicit the pros and cons of the device.

Based on this autoethnography study, questions were asked based on the themes that emerged. These included social context questions where the interviewee was given examples of social situations and asked to comment on how their use of their devices might be influenced. For the environmental context questions, examples were also

given of physical environments they might be in and also asked how this might influence their device use.

The autoethnography study also inspired more creative questions to probe mobile medical device users' emotional experiences with these devices, based on some of the stronger negative emotional reactions to the aesthetics of the device and the social situations I had to test in. Questions were asked about their current device, including what gender they think it would be and if they had to name the device, what name would they give it. Pushing the interviewees to personify the device provided insight into the subtleties of experience with the devices that influence safe use or adoption.

4.7.5 Limitations and Considerations

The autoethnography method should be adopted with some caution, especially for medical devices. This method is not appropriate for devices that are invasive or could cause health concerns for the researcher. Much like using a wooden block instead of a Palm Pilot or a pager instead of an implanted heart defibrillator, a non-invasive device can be used in order to get a general idea of what it is like to use a mobile medical device. Autoethnography can be very disruptive in the researcher's life if the study is taken seriously, and the sympathy one might expect from friends and family over a medical condition does not apply for a research project. I caused friends and family disruption, so I could see their frustration. Also, as integrated as the study can be in one's life, the researcher should not expect that they will understand what it truly means to be a user of this device for the care or maintenance of a medical condition. Although there were times that I felt stigma, I do not think I could fully understand many social interactions where a person *has* to use the device as part of treatment or maintenance of a condition. Missed tests were common for me, which shows that I was not able to fully commit to the role I was trying to play. If I had an actual condition that required this level of maintenance, I would not have the luxury of skipping so many tests.

4.8 Conclusions

Researchers need to be aware of their research participants' needs and limitations, and an autoethnography study is a way to gain some empathy. While not a traditional HCI method, autoethnography can help practitioners to gain empathy for the users of mobile devices, including medical technologies. When observation is not possible, this

method can be used to gain a richer understanding of contexts where these devices are used. It allows practitioners to capture some of the subtleties and nuances of those contexts that can influence the adoption and use of the device, which may not be achieved without experiencing them. Despite the disruptiveness of the method and how subjective and personal its results can be, if a HCI practitioner keeps these concerns in mind, their reflections on the results can produce interesting insights on the use of mobile medical technologies. Although this method should not replace established and standardized usability methods, it is a powerful tool for challenging assumptions, gaining empathy with user experiences, and planning future user studies as an additional method in a HCI practitioner's toolbox. It was particularly helpful in providing insight into future users studies. As with IDEO's Experience Prototyping , the Chinese philosopher Lao Tse sums up autoethnography's strength: "What I hear I forget. What I see, I remember. What I do, I understand!" (Buchenau et al., 2000, p. 424).

5 - User Study Methods

Parts of this chapter have been published and presented at two CHI workshops (O’Kane & Blandford, 2013, 2014).

This chapter outlines the data gathering and the data analysis activities that formed the basis of the mixed methods user study. Contextual interviews were carried out in London, Los Angeles and Toronto, a diary study in London was conducted in between the Los Angeles and Toronto interviews, and finally an observation of a T1D tech meet-up in London was completed.

Initially, these methods were planned to stand alone as separate studies, but the timing of the studies was intertwined because of recruitment issues. Furthermore, initial analysis of the data collected from the contextual interviews showed that similar themes were emerging from the diary study. When initially writing up the analysis, it was found that incorporating data from across the three studies enriched the presentation and through combining the data sets, the latent themes that emerged were stronger because of the comparisons between the data collected with mixed methods that could take place. As such, the results are presented as thematic chapters covering in detail the overarching themes that emerged across the three methods of data collection.

The details of these three data gathering methods and how they had to be adjusted, the participants involved in the mixed methods user study, and the collective data analysis conducted are detailed below.

5.1 Contextual Interviews

5.1.1 Introduction

For the users of mobile medical technology, the context of use can be anywhere they find themselves. This makes conducting contextual interviews difficult to plan. Of course the interviews could be conducted in the users’ homes, but this is just one environment and very different to conducting the interviews in public places. To explore how mobile medical devices are used in public, interviews could be conducted in places outside the home that the user might find themselves in. Of course this would

be very different for different people, and not all public places are conducive to interviewing. Therefore, contextual interviews were carried out in coffee shops, cafes, or restaurants of the participant's choosing.

These interviews were conducted across three major cities, each with different healthcare cultures. The medical usability standard (ANSI, 2007) is an international one and although it suggests exploring the context of use of medical devices, it does not suggest that the user's healthcare system might influence their use of the device. This study sets out to understand if users in different healthcare systems might use their technology in different ways to complement the research question of what aspects of situated experience influence use and adoption of T1D devices. Because English is the only language I can conduct interviews in and I had the opportunity to conduct interviews in London, LA, and Toronto, interviews were conducted in each of these cities. They are all major international cities and all three have different healthcare systems. Although all are Western cities, they are very diverse and multicultural. In London, the National Health Service (NHS) covers all aspects of healthcare including medication and technology, although they do not provide continuous glucose meters, and insulin pumps must be applied for. In LA, there are services such as Medicare to care for the very young and old, but the consumer pays for healthcare and insurance plans cover medication and technology. In Toronto, most healthcare costs are covered by the Ontario Health Insurance Plan (OHIP), with the exception of medication and technology, but these can be partly or fully covered by private insurance or through province wide programs that must be applied for. These systems mean that healthcare is experienced in very different ways for inhabitants of London, LA, and Toronto.

5.1.2 Purpose

This study was conducted over seven months and overlapped briefly with the diary study described below. The purpose of this data gathering method was twofold:

1. To explore the influence that context can have on the adoption and use of Type 1 Diabetes technologies
2. To explore the influence that healthcare systems have on the everyday use of Type 1 Diabetes technologies

5.1.3 Recruitment

Numerous recruitment strategies were employed to attempt to get a range of people with Type 1 Diabetes to interview. The first was based on a previous study conducted in eastern England where a diverse set of participants with Type 1 and Type 2 diabetes were recruited through a range of advertisements, both physical and online (O'Kane, 2013). Toronto was meant to be the first location of the interviews as they were going to coincide with a Christmas holiday at home. The aim was to attract 10 participants in each of the three cities, starting with Toronto. It was decided to get ethical clearance through University College London for fieldwork completed abroad. This limited the recruitment to what could be replicated in each city and would not involve institutions that had their own ethical procedures. Therefore, unlike the UK study, the Toronto study did not attempt to recruit from support groups or a university, but rather focused on recruitment from grocery stores using posters (see Appendix B) and online on Craigslist.org. Some of the Toronto grocery stores that were approached did not have community boards and had a policy against the general public posting notices, but one larger discount chain, No Frills, had a community notice board in all its large grocery stores. Ten grocery stores, mostly from this one chain, were approached and the recruitment poster was posted. After no success in attracting participants from Craigslist or the grocery stores, the advertisement was posted to nine additional online sources, which was still within the boundaries set by the UCL ethics approval. The recruitment and the interviews were intended to be conducted from December 8th 2012 until January 10th 2013. Based on the quick response rate for the recruitment in the English study, it was assumed that a number of Type 1 Diabetes patients would be able to be recruited in a short time period in the Toronto study starting December 12, 2012. As of January 7, 2013, there were no phone calls to the research study's contact number, no emails to the research study's contact email address, and no visits to the research study's website (for expanded discussion, see (O'Kane and Blandford, 2013)).

Based on this failure, an amendment was made to the ethics approval for the study to enable recruitment in pharmacies. Posters and recruitment flyers were given to 10 pharmacies and posters were put up in 5 grocery stores in London. This, in addition to online advertisements on Gumtree recruited 6 participants for the interview study. This method was then replicated in LA with 10 pharmacies in and around the area of Long Beach and online recruitment on Craigslist, Backpages.com, and Reddit.com. In LA, no

grocery stores were found to have community boards to post advertisements. After having good success in London recruiting through diabetes charities sharing recruitment notices through their social media presence, during the second trip to Toronto, Canadian diabetes charities in Toronto were contacted and one sent out notices to their social networks, in addition to recruiting through 10 pharmacies downtown, and online on Craigslist, Kijiji, Backpages, and Reddit. An example poster and flyer can be seen in Appendix B.

5.1.4 Technologies

The recruitment notice required the participant to use a glucose meter, but the participants ranged in their technology use. Although questions centred on glucose meter use, participants also talked about their use of insulin pumps and diabetes applications online and on their smartphone.

5.1.5 Research Setting

After the participants contacted me and provided verbal informed consent that they would participate in the interview, they were asked to suggest a location for the interview to occur. It was suggested that the location should be a café or coffee shop, and participants in all three locations overwhelmingly chose to meet in large chain coffee shops such as Starbucks. One LA participant suggested that they do not drink coffee and wanted to meet in a fast food restaurant. These settings were chosen so that a contextual interview could be conducted in a public place where they might choose to use their diabetes technologies, but also a public place that would be safe to meet a stranger. After meeting the participant, I introduced the study and gave them an information sheet describing the study and what would be expected of them to read while I bought a drink for them. They signed the information sheet and received a copy of it, and all agreed to be audio recorded. After the interview, they were compensated with an Amazon voucher of £15, \$20 USD, or \$20 CAD depending on their currency.

5.1.6 Interview Questions

It was left to the participants to decide when and where to meet me for the interview after questions were asked over the phone or by email to determine if the participants met the inclusion criteria. Although they would usually be able to choose a café or coffee shop based on what was convenient, some had to be prompted to choose one that would be close to them and they had been to before. I also asked them to bring

their glucose meter with them if they felt comfortable doing so, and met them at the agreed time and place. After they had signed the informed consent form and asked if they had any questions about the interview or my research, I then started the audio recorder and asked demographic questions followed by three sets of questions that were asked of all the participants.

Ethnography inspired questions were asked first. These questions used the environment that the contextual interview was being held in as a prompt to talk about issues that had been identified during the autoethnographic study, specifically about routine and non-routine times, as well as the influence of different contexts, including being in public. As each set of participants had their own cultural references based on location, questions had to be tailored and explained further in some instances (for example, explaining Thanksgiving as an overindulgent holiday to London participants).

Following the ethnography inspired questions, I asked questions that focused on negative experiences from the past. This interview technique is called the Critical Incident Interview Technique (Flanagan, 1954) and has been used in research involving medical devices used in the home, such as haemodialysis machines (Rajkomar et al., 2013). The questions had to be tailored away from their original intended purpose in the safety critical domain, towards issues that might occur with glucose meters. These were identified in the autoethnography study and the questions tried to bring up the circumstances around when, where, why, and how these might happen.

After focusing on the negative, I asked questions that would bring out some creative thinking with regards to Type 1 Diabetes technologies. By using a technique from marketing, I tried to get them to think of the devices as a consumer product rather than a medical product. Specifically, I used the projective interview technique (Haire, 1950), where a sentence is started and the participant needs to finish it, and ended with questions that were supposed to make the participant think of the device as humanized.

Finally, based on how comfortable I perceived them to be from our interview together, I asked them if they would test their blood sugars. During this time, I took photos using the camera on my smartphone with their permission.

The pre-interview, demographic, ethnographic, critical incident, and projective technique questions can be found in Appendix A.

5.1.7 Data Collection

After the audio recorder was started, I sat next to them or across from them reading the questions off of my laptop computer. I did not take notes during the interview as I wanted them to feel as though they were having a conversation with me and I did not want to look as though my attention was elsewhere. All participants were asked the same questions, but the interview was conducted in a semi-structured manner, so that any points of interest were probed further. All the interviews were planned to last one hour, but depending on the conversation, they lasted from 45 minutes to 2 hours.

All of the interviews were transcribed verbatim (dependent on quality of audio) and the data was organized in Atlas.ti.

5.2 Diary Study

5.2.1 Introduction

This diary study aimed to explore the everyday use of diabetes technologies in the self-management practices of people with T1D who lived in London for one month. In addition to the technologies that the participants were already using as part of their everyday personal health management practices, they were asked to use a mobile phone application during the diary study to see how this would be integrated into their current self-management practices. Although this could be considered an artificial condition of the study, it was felt to be important given the interest in the HFE and HCI communities in personal informatics to aid self-management of Type 1 Diabetes (e.g. (Owen et al., 2015)). Although many of the participants mentioned that they had used mobile phone applications in many of the studies, no participants were using them on a regular basis and found it hard to discuss them with regards to usage scenarios. As such, this was introduced as an additional technology to try.

5.2.2 Purpose

This study was conducted between June 2013 and August 2013, so the Toronto contextual interviews had not yet been completed. Despite this, the diary study built on the findings from the autoethnography and the contextual interviews and served the following purposes in this research:

1. To explore the influence that context, public or otherwise, can have on the adoption and use of T1D technologies

2. To explore the use of a mobile medical smartphone application

5.2.3 Recruitment

Through the experience of recruiting in London for the contextual interviews, a range of recruitment methods were used focusing mainly on online recruitment. Online message boards had notices posted to them, including Gumtree, Backpages, and Reddit. In addition, through a personal contact, a diabetes charity was contacted. This charity posted the study on their social media, and others reposted. This snowball sampling meant that a few of the participants knew each other and knew that they were participating in the same study. In addition, one participant was recruited from an old recruitment poster used for the contextual interviews left at a grocery store. The inclusion criteria were the same for the contextual interviews with regards to age (over 18 years of age), location (in or near London), and condition (Type 1 Diabetes), but the inclusion criterion for how long ago they were diagnosed was relaxed to 6 months when the number of interested participants dwindled. They also had to have an iPhone to use with the mobile phone application. Ten participants were sought for this study, but only nine were recruited and all participated until the end of the study.

5.2.4 Technologies

The technologies that the participants used were their own, which meant they used a variety of different models of glucose meters, insulin pumps, and continuous glucose meters. One participant changed their glucose meter during the study, and many used numerous glucose meters, for instance one left at work, one left at home, one left in the car, etc.

During the study, the participants were asked to use a mobile phone application to track their glucose meter readings. Mobile phone applications for use by people with diabetes are readily available on all application stores, some of which are free and some of which are paid for. Although they are not physical mobile medical devices, smartphones may be considered a medical technology in some cases as they can connect to mobile devices such as insulin pumps and continuous glucose meters. As such, it was appropriate to see how these devices would be used during a month long study of T1D technologies, even if they were not a part of the current self-management practices of the participants.

The mobile application used was created by a research team to explore the influence self reflection on glucose levels could have with adolescents if it was paired with a rewards system (Cafazzo et al., 2012). The research team was looking to expand the use of this application, and had already released it on the iPhone application market in a few different languages and not aimed specifically at one user group, such as adolescents. It used a drag and drop interface to allow people to easily input their levels and also attach a context to that particular data point that they could decide on (pre-breakfast, hypo check, etc). It was also possible to look back at previous data and use graphs to see trends in their levels.

5.2.5 Research Setting

The nine participants collected data for four weeks over the summer of 2013 between June and August. All the participants were based in and around London, and they were asked to take diary entries of their everyday experience, including at work, at home, and also when they were out and about. They were asked to use their technologies as they normally would and to make diary entries every time they used their glucose meter. In addition, they were asked to track their glucose levels using the mobile phone application. They were compensated for their time spent on this study at £7 per hour and also given a wide-angle camera lens for their iPhone camera.

As the study was conducted over summer months, many participants went away on holiday, travelled for work, left town for the weekend, etc. Some were unemployed and looking for work, and two of them experienced relatively serious sicknesses. One of the participants had a young child and one broke her iPhone in the first week of the study and continued using the app and the diary keeping with an iPad. All participants were female and aged 24 to 39.

5.2.6 Interview Questions

For the 1.5-hour entry interview, the same questions were asked of the participants that were asked in the contextual interviews, also in a semi-structured manner (see Appendix C). They were also asked to conduct a blood glucose level test and input this into the diabetes iPhone application. For the 2-hour exit interview, each of the diary entries was reviewed by the participant and they were asked to explain them further. If any issues arose, the participants were probed further about the incident. After the

diary entries were reviewed, the participant had an unstructured conversation with me for as long as they felt like, which ranged from 5 minutes to an additional hour.

5.2.7 Data Collection

For the entry interview, the participant was videotaped. After the semi-structured interview, the mobile phone application and the diary keeping application were downloaded and installed on their iPhone. They were then asked to use their glucose meter, add this result to the app, and then add a diary entry to capture the context of the test, which were all also videotaped as the first time use of the app and also to check whether there were any issues with these tasks. No notes were taken during these tasks as I wanted the conversation to flow naturally and to build rapport with the participants.

The participants were phoned every week to ensure that they did not have any problems with diary keeping and also to ask how they were doing with the mobile phone application. These calls were typically under 15 minutes and were voice recorded.

During the 4-week study, the participants were asked to keep a diary of their use of the device. During this time, each week they were asked to take a week worth of photos with a text entry, wide angle lens photos with a text entry, text entries, or whatever diary keeping method they wanted to during the week. This was initially to explore the usefulness of each data collection method, but this research question was later dropped. The following schedule can be found below:

Participant	Week One	Week Two	Week Three	Week Four
DS1	<i>wide</i>	<i>text</i>	<i>anything</i>	<i>camera</i>
DS2	<i>wide</i>	<i>camera</i>	<i>text</i>	<i>anything</i>
DS3	<i>anything</i>	<i>wide</i>	<i>text</i>	<i>camera</i>
DS4	<i>anything</i>	<i>text</i>	<i>camera</i>	<i>wide</i>
DS5	<i>camera</i>	<i>anything</i>	<i>wide</i>	<i>text</i>
DS6	<i>text</i>	<i>camera</i>	<i>anything</i>	<i>wide</i>
DS7	<i>camera</i>	<i>wide</i>	<i>text</i>	<i>anything</i>
DS8	<i>text</i>	<i>camera</i>	<i>anything</i>	<i>wide</i>
DS9	<i>wide</i>	<i>anything</i>	<i>text</i>	<i>camera</i>

The diary application was a free application that hosted the data on a website for free (but has since shut down). This site made it possible to download this data and during the exit interview, each of the participants were able to scroll through the data on the application's website on a large monitor screen.

During the exit interview, the participants were audio recorded and the monitor that they were scrolling through with their diary data was filmed. Again, no notes were taken in order to allow conversation to flow more naturally.

All recordings were transcribed verbatim and the data were organised using Atlas.ti.

5.3 Group T1D Tech Meet-Up Observation

5.3.1 Introduction

Support groups for people with diabetes are common in larger urban centres, but there are also meet-ups that are organised by charities or by groups of people with common interests. An opportunity arose where I was invited to a meet-up of diabetes insulin pump users and I used the meet-up as a study. Although I had been attending support groups in and around London for diabetes, these had been mostly attended by older people with Type 2 diabetes and the structure of these meetings had been around a guest speaker giving a lecture on a certain aspect of diabetes care rather than an open discussion. This diabetes technology meet-up was significantly different, as it was not structured, but rather a social meet-up of people with the same interests. The people with T1D who attended are technically savvy and interested in research about diabetes and advances in technology, and were quite happy to help with research around these topics. Although I was invited, I did not want to interfere with the meet-up so I endeavoured to act as 'a fly on the wall' by listening and observing instead of shaping the conversation. As such, I was far less disruptive and able to hear conversations ebb and flow naturally between the attendees. Additionally, because of the location of the meet-up at a hotel bar with a restaurant attached, I was able to see people use their technology before drinking and eating, as well as how they took out their technology to talk about it.

This study was the last of the series of four studies, which meant that I knew many of the topics and issues that they were bringing up. In many ways, this user study acted as a validation of previous findings because users with different opinions could argue over certain aspects of the experience of using the technology.

5.3.2 Purpose

The purpose of using this method was twofold:

1. To explore the influence that context and personal experience can have on the adoption and use of Type 1 Diabetes technologies
2. To compare earlier findings with the discussions of Type 1 Diabetes technology users.

5.3.3 Research Setting and Recruitment

This T1D technology meet-up consisted of a group of people who had organized online through an email list, a specific forum, and also through a Facebook group. They meet every three to four months at a hotel bar in London to discuss their use of diabetes technologies, discuss their diabetes in general, and also move online friendships to face-to-face encounters. It is a very relaxed environment where people gather to have drinks and some have dinner together during the discussion. Many of the participants were involved in diabetes charities and were quite tech savvy, with the majority currently using insulin pumps and some with continuous glucose meters. They are a very well informed group, with many having an interest in diabetes research and particularly in advances in diabetes technologies. I was invited to attend by a member who has an organizing role in these meet-ups. They sent out an email to the group list saying that a diabetes technology researcher from UCL would be attending, listening in on the conversations, and also buying a round of drinks for the participants, with the information sheet of the study attached. This email was considered informed consent for participation in this study.

5.3.4 Technologies

As this was a meeting of people with diabetes technologies, most of the participants were using an insulin pump along with their glucose meters. Most had tried smartphone applications in the past and some continued to use them. There were also quite a few people with continuous glucose monitors. Most of the insulin pumps were the same brand, offered by the NHS, but the rest of the medical devices differed among participants.

5.3.5 Data Collection

I wore my university nametag, introduced myself to all attendees as they arrived, and visibly took notes in a notepad so that they were sure who I was and what I was doing. Although I took two audio recorders, at the time of the meeting it did not feel appropriate to use them considering people were arriving and leaving at different times and the meet up was at a long table rather than a circular one, which meant the placement of the audio recorder would be an issue. People came and left when it suited them and the long nature of the table meant that the maximum size of the conversation was 6 people and most of the conversations that took place happened between 2-3 people. I moved my location 4 times during the 5-hour meet-up in order to hear different conversations, but it was not possible to gain access to all conversations being held.

5.3.6 Participants

Overall, 12 people attended the meet-up. As I did not want to disrupt the flow of conversation and wanted to act more 'as a fly on the wall,' I did not collect detailed demographic information, but rather gleaned what I could from the conversations I was listening to. I did not get much information about some participants or their technology use because of the nature of the physical set-up of the meet-up. It can be assumed that all participants are technically savvy as they had heard about the meeting by being part of an online community and the topic of the meetings was about diabetes technology use.

5.4 Participants

The 41 participants involved in these three studies ranged in age from 23 to 65 and 10 males were recruited. Although all participants used a glucose meter at the time the study was conducted, only 17 used an insulin pump, 4 used a continuous glucose monitor, and only two identified as regularly using a mobile phone app. The breakdown of participants is found below and they are coded according to the type of data collection method that was used: CI for contextual interview, DS for diary study, and MU for observation of the technology meet-up.

Participant	Location	Gender	Age	Technology
CI1	LA	Female	25	Glucose Meter, Insulin Pump
CI2	LA	Female	33	Glucose Meter, Insulin Pump
CI3	LA	Male	24	Glucose Meter, Insulin Pump
CI4	LA	Female	23	Glucose Meter, Insulin Pump
CI5	LA	Female	53	Glucose Meter
CI6	LA	Male	26	Glucose Meter
CI7	LA	Female	23	Glucose Meter
CI8	Toronto	Female	23	Glucose Meter, Insulin Pump
CI9	Toronto	Male	31	Glucose Meter
CI10	Toronto	Female	28	Glucose Meter
CI11	Toronto	Female	26	Glucose Meter
CI12	Toronto	Female	28	Glucose Meter
CI13	Toronto	Female	29	Glucose Meter
CI14	Toronto	Male	23	Glucose Meter
CI15	London	Male	65	Glucose Meter
CI16	London	Male	35	Glucose Meter
CI17	London	Male	26	Glucose Meter
CI18	London	Female	46	Glucose Meter
CI19	London	Female	54	Glucose Meter
CI20	London	Male	27	Glucose Meter
DS1	London	Female	24	Glucose Meter
DS2	London	Female	32	Glucose Meter, Insulin Pump
DS3	London	Female	39	Glucose Meter
DS4	London	Female	29	Glucose Meter, Insulin Pump
DS5	London	Female	37	Glucose Meter, Insulin Pump
DS6	London	Female	24	Glucose Meter
DS7	London	Female	31	Glucose Meter, Insulin Pump, CGM
DS8	London	Female	26	Glucose Meter, Mobile Phone App
DS9	London	Female	34	Glucose Meter
MU1	London	Female	50s	Glucose Meter, CGM
MU2	London	Female	40s	Glucose Meter, Insulin Pump, Mobile Phone App
MU3	London	Female	20s	Glucose Meter, Insulin Pump
MU4	London	Female	40s	Glucose Meter, Insulin Pump
MU5	London	Female	40s	Glucose Meter, Insulin Pump, CGM
MU6	London	Male	40s	Glucose Meter, Insulin Pump
MU7	London	Female	20s	Glucose Meter
MU8	London	Male	20s	Glucose Meter
MU9	London	Female	30s	Glucose Meter, Insulin Pump
MU10	London	Female	20s	Glucose Meter
MU11	London	Female	30s	Glucose Meter, Insulin Pump
MU12	London	Female	30s	Glucose Meter, Insulin Pump, CGM

5.5 Data Analysis of the User Studies

Thematic analysis was chosen as a data analysis method as it reaches across data sets to find repetition in the patterns of meaning.

Although a literature review showed a few related research projects (e.g. (Owen et al., 2012; Storni, 2013)), it was decided that a bottom up approach to analysis would be more appropriate given the exploratory nature of the situated studies used. Latent thematic analysis was conducted in an inductive, bottom-up way:

“a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher’s analytic preconceptions. However, it is important to note [...], that researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum” (Braun & Clarke, 2006).

As such, the situated approach to the data collection swayed the analysis, along with the interest in what influences the use of T1D devices in everyday life. The specific research question evolved through this bottom-up approach to focus on detailed accounts of how situated experience and practice influences the use of T1D devices. Despite taking an inductive approach, latent themes emerged that required interpretation through relation to theory: *“the development of the themes themselves involves interpretative work, and the analysis that is produced is not just description, but is already theorised”* (Braun & Clarke, 2006). As such, this approach can be seen as being based in the constructionist paradigm (with regards to the impact of culture on meaning and interaction), which is not at odds with the phenomenological tradition (with regards to going beyond cultural consciousness to access people’s immediate experience) championed by Dourish to understanding the dynamic impact of context in embodied interaction (Dourish, 2004b).

The following are the stages of data analysis, organized by the six phases of analysis suggested by Braun and Clarke with some flexibility to allow the final themes to emerge:

Phase 1 - Familiarisation with the data:

1. Transcription was completed of the contextual interview and meet-up data, and the professionally transcriptions from the diary study were reviewed.
2. The transcribed collective data set was read and reviewed.

3. A summary for each participant was created to give an overview of personal experience (see Appendix D for an example).

Phase 2 - Generating Initial Codes

4. Initial open coding was completed for 10 sets of data with the initial analytic question: 'what influences use?'
5. The codes generated from the initial coding were compared to the findings of the autoethnography, specifically with regards to social, physical, and aesthetic influences along with situational influences on the use of the devices, leading to opening up the coding to examine 'what influences adoption?'

Phase 3 - Searching for Themes:

6. Further coding was completed by breaking down 'use' and 'adoption' into specific scenario codes: carrying/not carrying, adopting/not adopting, using/not using, and unintended use. This coding was used throughout the 10 participant data sets.

Phase 4 - Reviewing Themes:

7. Based on these initial themes, each of the participant summaries were compared to the codes, and contradictions within a participant data set were searched for along with comparable situations across the participants.
8. Using these initial codes to shape the strategy for reviewing the collective data set, a review was conducted to examine related themes that were emerging from these scenario codes across the entire data set.

Phase 5 - Defining and Naming Themes

9. Based on the review, further coding was conducted using the scenario codes to tap into latent influencing factors, however this process was not linear and involved numerous iterations involving Steps 10 to 12 in order to solidify the following themes: physical environment, healthcare system infrastructure, cultural environment, social situation, and personal styles, lifestyles, and circumstance.
10. With input from my supervisors and from looking again within and across the data for contradictions or comparable situations with regards to these influencing factors, the themes were further separated and commonalities between themes were better defined in order to shape the thematic chapters

that were to emerge. For instance, this process lead to defining a social situation as a face-to-face encounter, rather than an encounter with the general public, which was then coded as cultural environment based on shared meanings influencing use and adoption in these public situations.

11. Further interpretation of the themes was then conducted in relation to literature in the healthcare domain, and other framings that helped to organise the themes further. For instance, in the social thematic chapter, Goffman's (Goffman, 1959) Presentation of Self was used to break down the theme into concealing and revealing behaviours with medical devices based on routine social situations and non-routine social situations.

Phase 6 - Producing the Report

12. The qualitative descriptive summary of the findings was written up under the major themes of physical environment, healthcare system infrastructure, cultural environment, social situation, and personal styles, lifestyles, and circumstance individually. After writing up each thematic chapter, the specific themes were reviewed again and amended as per Step 9 through 11 above, as the act of writing the chapter provided further insight into the overall meaning of each of the themes and they related to the other major themes. For instance, the personal aesthetics that emerged in the personal styles, lifestyles, and circumstances chapter was separated from the general cultural aesthetics of mobile technologies that were considered shared meanings and therefore belonged in the thematic chapter on cultural influences. Through iterating through Steps 9 through 12 in a flexible manner, but also using the guidance on conducting thematic analysis, the final thematic chapters were produced.

5.6 Limitations on Generalisations

The nature of small qualitative studies means that the results and the discussion cannot provide overarching generalisations. This study had 41 participants, but overall it was small and ethnographic in nature and ultimately influenced by who I am in relation to these participants and who these participants were.

5.6.1 *My Personal Impact*

Rode (2011) argues that the ethnographic methods that have been taken up by HCI have not developed with the advances in anthropology, particularly discussions of

insiders vs. outsiders and first vs. third person. She talks about the need to realize that ethnographers do not research the subject of study, but rather they research within the subject of study. She points to anthropologists who take into account the personal in conducting anthropology, including Geertz (1975), who talks about “*the myth of the chameleon field-worker perfectly self-tuned to his exotic surroundings – a walking miracle of empathy*”.

When introducing myself, I tended to immediately downplay my knowledge of diabetes and always told the participant that I did not have a medical background and did not have diabetes myself. I always made a point of describing myself as a student of engineering and computer science. Not only did this steer the conversation towards their use of technology; it also made the atmosphere more comfortable as participants did not associate me with the medical profession. As they assumed I did not know much about their daily lives, they went into details of the condition to ‘set the scene’, and gave personal accounts for me to better understand their experiences. Being a computer science student rather than a seasoned healthcare researcher seemed to make it easier for participants to talk openly in a way that allowed empathy to develop. The fact that I was a Canadian living in London, and unfamiliar with the healthcare systems where the interviews took place, made it possible and legitimate to ask naïve questions. When conducting interviews in LA, I asked about insurance coverage, a subject which can be both sensitive (with regards to past experiences of financially challenging times) and also political. In London, I could explore people’s experience with the NHS, also a sensitive subject with regards to whether a particular device will be provided by the health service or can be obtained privately. Even in Toronto, I had been out of the country for four years and did not have up-to-date knowledge of the ‘system’. This led to dialogues that were explanatory in nature, but also contained much emotion, particularly with regards to past experiences. Although many experiences might have been shared with a researcher who was familiar with the system, I do not believe that they would have been framed in relation to the healthcare system: this came about because of my lack of experience, and this opened the dialogue to facilitate empathy.

Beyond the way I introduced myself, participants could infer information about me based on my appearance. This impacted rapport with participants for many reasons, including my gender and age. Most participants were female, although I cannot be sure whether my gender influenced the recruitment calls as some were without my name

attached and my first name is not particularly common or easily gendered by those who have not encountered it before. I found it much easier to build rapport with female than male participants. Regardless of age or background, I found that females were much more open about topics such as managing the embarrassment of using ugly medical devices. This included wearing a device that could be seen under clothing, bringing a device out in front of acquaintances, and carrying a device in public places. Interviews felt far more relaxed with women than with men. Even if men did open up about incidents that might have been embarrassing, they tended to do this later in the interview when they trusted me a bit more. Empathy through rapport with the interviewee was influenced by my gender, and this influenced how the interview was conducted, including what I felt comfortable asking for clarification or elaboration on.

My age also influenced the interviews, beyond the act of introducing myself as a student. At the time of the studies, I was in my late twenties, which meant I was not completely naïve with regards to life experience, but I am of a generation that is fairly open about sensitive topics. This emerged through discussions of romantic and sexual relationships and how diabetes technologies influenced them. I found that younger people were more likely to discuss issues of dating and sex related to the display of their diabetes technologies than people who were older, regardless of their apparent relationship status. Such experiences still might have been shared with an older or younger researcher, but I believe that the younger participants felt that I would be able to empathise with these situations, perhaps because of my age.

Beyond gender and age, how I dressed and looked influenced my ability to empathise with participants. Although I dressed and had my hair in different styles on different occasions, I always wore (and wear) dresses and makeup, often with my long hair down and a large amount of eyeliner. In previous work in male dominated industries, I believe this diminished my credibility as a 'serious engineer', presumably based on traditional stereotypes of what engineers and computer scientists are supposed to look like. However, in the user studies reported here, it both aided and discouraged dialogues, depending on the degree of empathy achieved. In one contextual interview with an older retired gentleman in London, when discussing how he carried his glucose meter, he became visibly uncomfortable when talking about the plastic shopping bag he used. I tried to probe why he did not use something more substantial for carrying a medical device, but he was not forthcoming on the reasons behind his choice. Although I can speculate that perhaps, as an older man, it is less socially appropriate to carry a

bag in case it was made fun of as a 'man purse,' this was not offered as an explanation by the participant. He did not seem to trust that I would understand, perhaps because of the way I presented myself. I had a very different experience with a female participant around the same age as me: the participant was more than happy to show off her modified diabetes kit bag in a Louis Vuitton purse and encouraged me to take a photo.

Who the researcher is, how they introduce themselves, and how they present themselves influences how the user study will proceed. In the mixed method study reported here, there are aspects of who I am that I believe highly influenced my ability to build empathy with Type 1 Diabetes technology users and ultimately influenced the results. Being a student, a foreigner, and not a medical professional made me appear naïve and encouraged explanations of the contexts around situations and decisions of the participants. My gender, age, and physical presentation also influenced my ability to gain empathy with my participants' experiences, both positively and negatively (when I was too different from them). These are concerns for all user studies that involve face-to-face contact: this is perhaps most noticeable during data gathering, but is likely to also influence recruitment and data analysis. There is a growing recognition of the importance of reflexivity in HCI research (Blandford, 2013): the degree and nature of empathy attained with participants affects both the quality of data gathered and the kinds of insights that can be achieved from that data.

5.6.2 *The Impact of Recruitment*

Additionally, there is another limitation to the generalizability of the results and the discussion: the range of participants recruited. Type 1 Diabetes is a condition that affects both genders across a range of ages, socio-economic statuses, races, etc. It affects people everywhere, and as such generalisations are hard to make about technology usage.

For these user studies, recruitment issues did arise as discussed earlier in this chapter. Efforts were made to get as wide a range of participants as possible, but time and location influenced the success of different recruitment methods. In the end, the majority of the participants were female, relatively technically savvy, and in their twenties. This of course means that the results and the discussion is influenced by these demographics.

Additionally, recruitment was centred around three major western cities, which excludes those living in rural areas and also a large part of the world. They were all English speaking as well, which meant they had access to resources and information that may not be as readily available and heavily discussed in other languages.

The nature of the recruitment in general also meant that most participants were somewhat engaged in their own self-management. Although I did not collect information on their HBA1C, a clinical test of blood glucose management, most participants did not bring up ill health effects of their condition. Despite the importance of understanding why certain people do not engage with self-management using T1D technologies, I believe that these people are not usually the type to sign up for research studies or even come across recruitment notifications on diabetes forums or at pharmacies.

5.6.3 Usefulness of the Results

Overall, I believe that I was unable to get a wide range of participants because of practical limitations, so I believe this influences the generalizability of the results. However, I do not believe that this influences the usefulness of these results found. This qualitative study of mobile T1D technologies used in situ provide insights into what designers and evaluators should be cognizant of when releasing these devices into the consumer market. Overall, it was found that context and individual differences impact use and that the current devices being used are not adequately designed for the variety of situations they are used in and the variety of users they are used by. The chapters outline the situated aspects that arose from the data that influence practice and experience for these devices, with the following structure:

- Human Factors and the Physical, Environmental, and Infrastructure Context,
- Healthcare System Context,
- Cultural Context,
- Social Context, and
- Personal Styles, Lifestyles, and Circumstance.

Each of these chapters represents aspects that influence the experience and practice with these T1D devices, leading to choices about use and adoption. Moreover, this research points to overall implications for the design of future mobile medical devices including the importance of using situated methods and the need for personalisation of medical devices, that are discussed in the Discussion chapter.

6 - Human Factors and the Physical, Environmental and Infrastructure Context

The T1D devices examined were brought into a variety of environments, as the participants used them throughout their days in diverse places. The different times and the different locations they were used meant that the physical environment in which they were using the devices could be quite variable. This influenced how the devices were used and the experience of the participants.

The physical and environmental context where interactive technology is used is a well-established consideration in the HCI and human factors domains. With the first pushes towards mobile devices, the differing physical contexts that devices might be used in started to gain attention (Rodden, Cheverst, Davies, & Dix, 1998) along with infrastructure concerns (Dix et al., 2000). By examining what influenced experience and practice, effects from the physical, environmental, and infrastructure context emerged across the data set, the spatio-temporal thread of the felt experience (McCarthy & Wright, 2004). Although there were some commonalities between similar situations, there was wide variation in the physical, environmental, and infrastructural situations in which Type 1 Diabetes technology was used or was supposed to be used, and these environments influenced use. In many cases, this was not an issue and the design of the devices allowed for the variation in the physical environment not to influence use or adoption. For the most part, the device did not disrupt the experience or the self-management practice, pointing to the strength of the human factors evaluations that these devices go through during their development and design. However, because participants appropriated these experiences, when specific issues from the physical environment, the environmental influences, and the infrastructure arose unanticipated, this caused sometimes quite negative experiences when engaging with the technology, the sensual thread of felt experience (McCarthy & Wright, 2004), and influenced the participants' situated experiences and practices.

6.1 Human Factors Engineering “Usability” Accounted For

Generally, the devices worked well enough in most environments. Glucose meters, continuous glucose meters, and insulin pumps have been designed to a certain standard and have been evaluated by randomised control trial in order to ensure that the risk of human error is low and these devices can be easily used by the intended users. Overall, the participants found that the devices worked for their purposes, they performed efficiently enough, and they were easy to learn how to use.

Most devices had sufficient lighting for regular use based on what was observed in the diary study, the meet-up and at the contextual interviews. Figure 23 shows three glucose meters in different lighting situations in cafes, and they all have interfaces and buttons that can be easily read and understood.

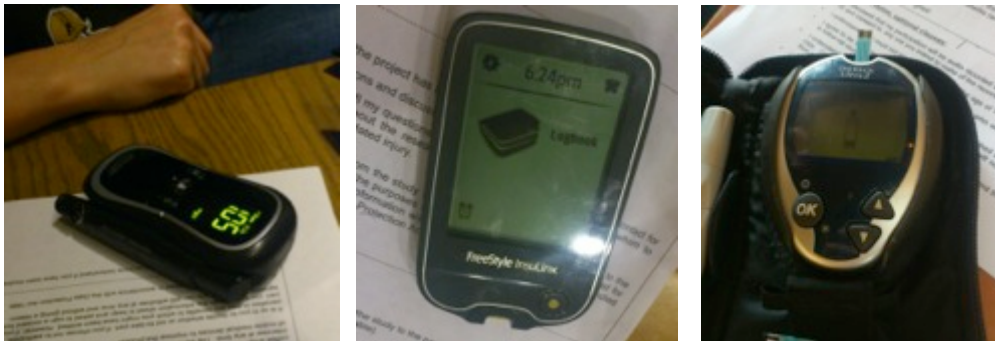


Figure 23: Glucose meters with visible screens and buttons

Although there were some issues brought up about the devices, most of the participants appreciated that they were generally fit for purpose. Their expectations (or anticipation (McCarthy & Wright, 2004)) for the use of the devices were mostly met, and many were satisfied with the function of the devices. Throughout the dataset, traditional effective use issues did not arise, but rather the participants' views on their devices indicated appropriate human factors design:

“There’s probably small grievances with this, but it works, and it’s small”. – D9

“This one kinda just works” – CI2

“Easy to use it. I can easily use it. It is not very difficult.” – CI10

Participants were actually pretty accepting of their glucose meters, and felt that the accuracy of the results they got from the devices was sufficient for their purposes. One participant was able to describe how they separated the emotional response of the

reading from the device itself, and ultimately made a value judgement prioritising their satisfaction with its accuracy:

“Even if I don’t like what it is telling me, I assume it will run correctly. The meter is pretty good at doing what it does. [...] it is so accurate these days, I am not worried about it.” – C13

Even when they had to deal with issues with the device, participants were pretty satisfied with solving the issues in the traditional ways they dealt with issues with other electronics. For instance, the tried and tested way of resolving many issues – turning it off and then turning it on:

“I usually just turn it off and try it again. It usually works itself out” – C12

Some had adopted these devices into their lives in a similar way to how their mobile phones have been adopted into their lives. Much like leaving the house with keys and a wallet, C13 also described packing up his mobile phone and insulin pump:

“I taught myself that I have four things in my pocket: I have my cell phone and my wallet over here, my keys and insulin pump over here [...] so I can always check I have my four things. If I don’t have one, I am definitely doing something wrong. A good way to remember [...] it’s like playing Tetris with your pockets, this has this spot, this has this spot. Goes together well enough.” – C13

When asked if they remember who taught them how to use their devices, many participants were unable to remember and had to guess: *“I think my mom. I can’t say for sure. It could be the doctor but....I think its my mom.” – C17*. Not many complained about the usability of the devices and overall found them easy to learn: *“big screen, easy to navigate” – C18*. Even though C16 had some issues with some of the more advanced functions, he was still able to use the device to check his blood glucose levels: *“You know, I am not sure how to even connect this to this my computer and get data off. I don’t know how to set the date and times, all that stuff is totally wrong.”* Many participants found that they can just figure out how to use new glucose meters because they do not differ significantly from others they have used in the past, showing that ease of learning is pretty acceptable for most BG meters:

“The very first time I got one, it was my mom in combination with the doctor’s office [teaching me]. And none of the ones here, nobody’s really explained the details of it. It is more like “here you go, here is a free glucose meter” – C14

“Probably, my first one was probably a diabetic nurse. I don’t remember being taught to use any of the other ones.” – DS9

“When I got diagnosed I got taught, like, how to use it, but, like, every meter is the same. You put the strip in and it's, like, put your blood on the strip, and, yes, I've never had a problem learning how to use one.” – DS1

Beyond the more ubiquitous glucose meter, even insulin pumps were generally easy to learn how to use by the participants. Compared to using syringes or pens, some participants found adopting an insulin pump quite straightforward, easy to learn and easy to adopt into their lives:

“It has been three years. Almost exactly three years. I like it. My control is a lot better with it. And it is comparably easier then syringes or pens or like...you put it in, and you are good to go” – CI4

People were also impressed by how long the devices lasted, probably compared to the poor performance of some other consumer electronics. Some of the batteries and devices had staying power, almost giving the impression that they never run out:

“I have never had to retire one. They seem to last forever.” – CI5

Overall, even if participants felt there could be some small improvements, they were overall satisfied with the human factors of the devices. When asked how they would describe their devices if they were personified, although there were some negative responses, overall participants chose fairly positive attributes for their devices:

“I mean I am thinking of like, the best doctor I ever had would probably be this meter. Very helpful, very nice. Low voice. Female, same attitude. Just really helpful, you know” – CI6

6.1.1 Summary of Human Factors and Usability

Participants generally did not encounter major usability issues with the devices that they used or had experience with that influenced their use: the devices worked suitably well at telling them their blood glucose levels and enabling them to inject insulin. These devices were generally easy to use, effective and perceived to be accurate. Many participants were not able remember who taught them how to use them and some were able to pick up new models and begin using them right away. There were very few instances of human error with these devices, and overall the human factors design of

the devices was appropriate for the users. However, there were cases where the physical or infrastructure contexts did influence use, which could influence user experience.

6.2 Physical Environmental Influence Caused Frustration

Although rare, when the devices did not act in the way they were expected or anticipated to, this tended to cause quite strong negative emotional responses among participants. This included when the physical environment influenced the use of the devices or even the consequence of the user experience of having to perform self-care in a specific physical environment. Although these instances seemed to be rare, they did cause frustration that was noteworthy among the participants, having a larger impact because of the sensual responses attached to the felt experience caused by expectation (McCarthy & Wright, 2004). This included contextual issues with light, temperature, weather, contaminants and the physical space.

6.2.1 Variable Light Levels and Glare Required Workarounds

In order to interact with many interactive technologies, the user should be able to see the interface. Although some diabetes technologies are designed for people who have issues with eyesight (T1D is linked with vision issues), participants in the user studies did not mention these devices. However, issues with being able to see the device in order to use it were mentioned. As devices are mobile and should be carried throughout a person's day, many different lighting levels were encountered by participants when conducting self-care activities. Three main factors that arose around light were: backlighting of the interface of a glucose meter, light needed to accurately use the strip for a glucose meter, and glare from the screen.

With regards to backlighting, there were few devices that were not designed to be backlit. One of DS9's glucose meters does not have this kind of lighting, but she has managed to deal with the lack of a feature that normally would be considered essential. She described her work-around strategy in the movie theatre:

"I think in that particular place, we were quite close to the door and I could see it, kind of. You know, if you tilt, you know, in the cinema usually, if you just wait a minute, it'll get bright, even though you have, like, a dark movie scene and then a brighter one and you can see when it's bright." – DS9

The movie theatre was a context in which participants identified a few lighting issues, as it is a place which is generally darker than most environments and the participants did not have control the lighting. One participant complained about the backlighting in this context, as even the workaround of using their mobile phone to light up the screen might not work, while another discussed the frustration of waiting for a daylight scene:

“Some of the times when it is like darker, it gets, and I guess my phone battery is low and it can’t light it up, [...] I do wish this one had a light” – C12

“Where it is too dark and I can’t see what my blood sugar is, and I just had a box of Mike and Ikes [candy] or something stupid, and I should get a shot, but like, I’m waiting for like a daylight scene or something where I can actually read the screen, because you can’t read the screen at all” – C16

The opposite could occur in some very lighted environments. The light would bounce off the interface screen and cause glare, making the devices hard to read from some angles (see Figure 24), but this was easily solved by participants by tilting the device away from the light.

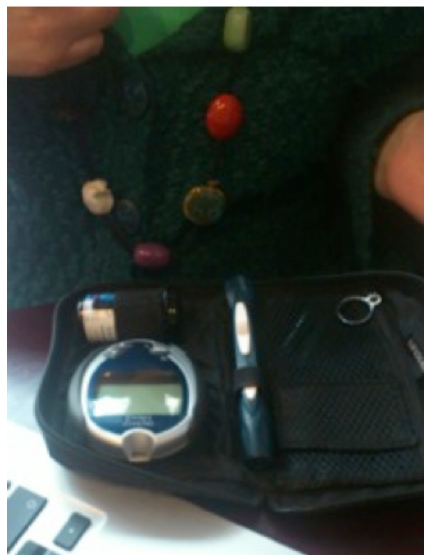


Figure 24: Glucose meter showing glare from sunlight

Some participants mentioned having a light on the area where the strip needed to be placed in the glucose meter as a vital feature of the device. This feature was particularly important at night when there was little light and BG levels needed to be tested. This was a concern if the participant slept with a partner in the same bed, as the light could also disrupt their sleep. When waking up in the middle of the night, the

participants were used to the dark so turning on a bedside light just to do a BG level test was hard on their eyes:

“I think sometimes if you test at night you can almost get away with just going straight back to sleep, but because I don't have the test strip light on the other end, you have to put the light on and, yes.” – DS1 (see Figure 25)

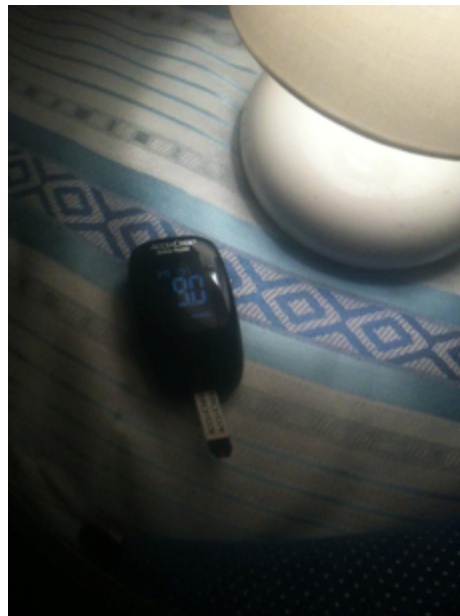


Figure 25: DS1 turning on a bedside lamp so that she could see where to put the strip into the glucose meter

6.2.2 Weather Conditions Influence the Ability to Use the Devices

Not only did the weather influence the use of the diabetes technologies in sunny weather with glare, but also in a range of different climate conditions. These technologies are meant to be used when they are needed by the user, and this can be outdoors in different seasons and during different activities (see Figure 26). Numerous times the weather arose as an influencing factor on if and how the diabetes technology was used by the participants in the user studies, specifically related to temperature, wind, and precipitation.



Figure 26: The outdoor stadium DS4 was testing in on a chilly evening

Although temperature could be a major issue for the insulin (as discussed in the following section), it was also a problem for the interactive medical devices. According to instructions often found in accompanying booklets, glucose meters need to be within a range of temperatures in order to function properly, and because the devices are mobile, they can be taken into different temperature environments. This could mean that the participants would try to solve out of range temperature conditions themselves, for instance by putting it in the freezer:

“If it gets too hot, you put in in a freezer, or if it gets too cold you warm it up in your hand before.” – C13

This was a particular issue for people that had to deal with colder climates regularly, such as the participants in Toronto where temperatures in winter are often involve below freezing, although this was not dissimilar to circumstances they had to deal with in order to use their mobile phones:

“Sometimes if it gets cold, relevant to the Canadian contingent, yeah, if it gets cold it will slow down or like, get errors occasionally. [...] Like if you left your cell phone outside. It will power up slowly, like the LCD will be messed up, and like once it returns to normal temperature, it will resume normal functionality.” – C19

Although some of the frustration can be attributed to the emotional aspects of having a chronic condition (further explored in the individual differences chapter), these temperature issues could also cause strong negative emotions. DS9 often has to deal with temperature issues because of cold weather in London on her bicycle:

“In the morning, like when I... if I cycle in to work on my bike on a winter’s day here on my bike, it won’t work when you... when I get into work [...] You just have to take the case off the back and warm it up... warm the battery up. [...] So, it just takes an extra couple of seconds, so if you’re in a hurry and you’re in the cold, it’s like, “oh, for God’s sake, work!”” – DS9

Wind could also be a concern with the devices, as strips were very light and could be blown away while trying to use a glucose meter. DS1 was outside when she felt the need to test in one diary entry. Although usually she would be able to test standing up, it was a particularly windy day, so she had to find a bench to test on. She also said that rain would have meant the same change in self-care practice:

“It was so windy that day and I’d just got out of the station. It was insane, so I sat down to, like, get everything out because it was like a hurricane. [...] the strips and then just, like, if your bag’s flying around everywhere, and you needed to hold on to everything, and if you’re, like, unzipping this, you don’t want everything else to fall out as well. [...] Yes, I’d just do it while I’m walking down the street, but, I don’t know, if it’s raining or something then I’d, kind of, have to sit down and get everything out.” – DS1

6.2.3 Environmental Contaminants Disrupted Use and Caused Worry

The glucose meter relies on a blood sample from a person, and from the time that this blood leaves the participants finger to the time it reaches the strip, there is the chance that it comes in contact with substances that can contaminate it. The results of this could be a high or low reading, depending on what the substance was.

Some participants were very wary of this, and went out of their way to make sure that this contamination did not occur, in some cases basing their self-management routine around it. When asked about her social use of the device, CI2 said it wasn’t an issue as she would constantly test in washroom so that she could wash her hands before testing: *“You have to stop to wash your hands.”*

When participants did not wash their hands before testing, the test results could be influenced by contaminants on their hands. At the least, this could give misleading results, but at the worst, could cause them to take self-care actions that were inappropriate:

"I tested before and it said I was like 300, and I was like "That's impossible". So I washed my hands, came back, retested, retested ha! And um, and I was fine. So, I have been there before though where I've tested and then tested a second time there will be like a 90 point difference and so I'll test a third time just to be sure, you know. Because sometimes there's something on your hand or you've got lotion on or something because I've had it before where lotion has severely affected what the result was on my meter, so." – CI1

"If you haven't washed your hands properly then you test, you can get a reading of, like, 25, panic, inject heaps, test, like, 20 seconds later, and it's a normal reading. And you're like, "I've just injected, like, five units and my blood sugar's normal." Yes, that's the only other thing that you have to, like, sanitise. If you've touched any sugar or anything if you're cooking then you're going to get a false reading." – DS1

Although CI1 said that this happens *"almost never. I've had it happen maybe 4 or 5 times over the entire time I have had diabetes. So it is very rare."* – CI1, DS1 said that she often gets these *"false readings"* when cooking.

These external contaminants have also influenced participants not to test as well, as some were concerned that the possibility that exposing a small open wound on their finger may be dangerous:

"I don't think I would do it at work, because I work in a lab, so there is a lot of bacteria and stuff around, so if I did bring it to work, I would probably do it in the bathroom or in my car" – CI7

6.2.4 Physical Space Could Constrain Carrying the Devices

Physical attributes of the environment also influenced the use of the devices, and how they were carried and adopted. For instance, some CGMS needed to connect to the receiver, so MU1 *"can't be 2 yards away from it"* and has to keep the receiver in her back pocket.

The nature of CGMs and insulin pumps meant that a part of them had to be worn on the body. The insulin pump itself had to be attached to a supply of insulin, and for most participants, their models included a tube from the device to the infusion set on their body. This tube, of course, could sometimes get in the way, with *"kitchen cabinet knobs [...] at waist level"* – MU3. MU4 thinks pulling it out is inevitable: *"you'll do it one day"*.

MU3 said “*reflexes*” become “*so fast with the pump*”, and some other participants found ways to avoid this issue:

“I just clip it to my pocket and the cord kind of hangs out, but if it is hanging really low, I will tuck the cord in my pocket, because I get it caught on doorknobs and stuff, yeah.” – CI1

The physical space that these devices take up and the nature of their physicality were mentioned by participants. Although not a digital tool, “Carbs and Cals” is a book with visual representations of carbohydrates in a meal compared to a plate and has been brought up at numerous support group meetings I have attended. MU2 bought the mobile phone application version because the book form of the information was “*too heavy*” to bring around.

Although many of the devices were not that large, they could be frustrating to have to carry around, particularly if they did not easily fit where the participant needed them to fit to carry them around: “*It’s really ok, depending on the bag I am carrying. It can be a pain though if it doesn’t really fit. It is one more thing to carry. That is the biggest annoyance I guess.*” – CI2. CI2 also suggested she might take it out of the case and carry the kit “*separately*” in order for it to fit. CI6 had to carry around a backpack, a satchel or put the kit in “*my coat if I am wearing a coat*” because it wouldn’t fit into his pockets:

“Between two cell phones, keys, wallet, and everything like that. No.” – CI9

CI5 and CI10 who were very private about their self-care practices found issues in some of the washrooms where they preferred to test. As found in the autoethnography study, not all toilets allowed for easy self-care practices:

“I would go in the bathroom and I test my glucose. You can’t always sit in the stall.” – CI5

“I do it on the toilet paper dispenser on the top of it, because that’s the only place I can do it. Yeah, it’s not very user friendly because there are different parts to it, you have to kind of assemble.” – CI10

Similarly, some physical environments could be useful for placing the devices and some could not, with DS4 able to use machines at the gym because she could place her glucose meter in front of her (see Figure 27).



Figure 27: DS4 was able to use machines at the gym where she could place her glucose meter

6.2.5 Summary of Physical Environment

Although the participants were able to use the devices in most physical and environmental conditions, there were issues that arose with the physical environment that caused frustration. Issues with light influenced how these devices could be seen in different environments, which was particularly frustrating in dark environments. Weather could also influence the use of the devices and participants had to make extra effort to accommodate for temperature, wind and rain. Contaminants could impact self-care practice, even so far as to influence routine practice. The physical space itself also influenced how the devices were worn and carried. Overall, there were not many instances where the physical environment influenced the use of the devices, but in the instances where it impacted self-care the participants' user experiences with these devices were quite negative, with annoyance and frustration mentioned.

6.3 Infrastructure For Using the Devices Influenced Use

Like all electronic devices, digital medical devices used for self-care of Type 1 Diabetes require energy to operate properly, which means the use of batteries, as these are mobile devices. In addition, medical components are needed, including the use of insulin for pumps and strips for glucose meters. These are what I have classified as infrastructure issues and they can influence the use and experience of T1D devices.

6.3.1 Batteries Needed For Devices Could Cause Frustration

Batteries are part of the infrastructure of most mobile devices, and diabetes technologies are not exempt from this. Like with any devices, these batteries must be recharged and/or replaced in order to keep these technologies in working order. As the participants carry around different devices, they encountered different issues with batteries.

Many of the glucose meters would last quite a long time as the screen and the technology consumed very little energy. This was an appreciated quality by many of the participants, as they did not have to worry about replacing the battery often or worry about recharging it.

“I don’t have a backup battery, but the batteries in the meter last a long long long long time, so it is not really a problem.” – CI3

“Batteries, are usually pretty good, because it is such a low tech, like black and white screen.” – CI6

On the other hand, because it lasted so long, some participants would not be prepared when the battery ran out. This led to some preparing in advance with backups or sometimes just having to deal with the situation:

“Right now actually, is one of the first times I am having issues with the battery. So its low, I haven’t changed it. Like, I don’t remember ever changing it. So I think that’s kind of amazing, that it lasts that long. It is one of those like weird circular silver batteries, so now I got to go find them somewhere.” – CI6

“Circular battery. And from now on, there’s a little pouch in it, I keep a battery in there. I think actually, I need to replace it again. [...] Whenever I am able to get that battery, I always buy it” – CI7

Participants also discussed pushing the limits of these batteries to try to get the most out of them, not dissimilar to the way to people push the limits of the batteries in other mobile technologies (or even remote controls):

“It’s been a long time since it’s kind of just screwed up. I mean I know before, one time low battery sign came on. This was a couple months ago. And usually I can test it another 7 or 8 times before it won’t turn on again, but it just didn’t turn on and so I mean I just changed batteries and it was fine. I was just

surprised, like I only got one little notice about the batteries being low and it....but, it's not really that big.” – CI1

“I just pull the batteries out and put them back in again and hope for the best or put new ones in, yes.” – DS1

“Sometimes the battery gives me grief, and then I have to like shake it or turn it off and on and it will work again.” – CI9

Issues also arose for the types of batteries used for the devices. Although some batteries lasted quite a long time, they were not types of batteries that were available everywhere: what CI6 above describes as “weird”. For CI3’s insulin pump, she is appreciative of the use of widely available triple A’s because of her experience with replacing less available batteries for her glucose meter:

“It is great to have the triple A instead of the circular battery, that’s very important. Because if you get a low battery and you are in the middle of nowhere, the triple A’s are more common.” – CI3

Even if the batteries were easy to find, the expense of replacing them could be annoying for the participants:

“I think it is the little circle watch battery. [...] Not sure which ones they are [...] I would go to CVS. They are expensive though, the batteries.” – CI4

Other people’s devices had rechargeable batteries with the USB plug-in, particularly for devices that had larger screens or colour screens that used more energy. Although the ability to recharge easily was appreciated for some (CI4 was an exception: “My mom told me about, where you have to charge the meter. That’s a pain in the ass, I wouldn’t do that at all.”), the amount of time it could take for these plug in models could be a source of annoyance:

“That was kind of annoying because it doesn’t charge all the way, and it takes a while to charge. But it is kind of cool I can plug it in.” – CI2

6.3.2 Consumables Needed for the Devices Cause Frustration with the Device

One of the largest annoyances caused to the participants was when there was an issue with the strip. “Error 5” was mentioned by many of the participants. This occurred if there was not enough blood on the strip sensor by the time the glucose meter read it. Many participants described this error as “frustrating” – DS1, “pretty annoying” – CI2

and “a pain” – CI4, particularly because it is something they believed could easily be fixed:

“There is one thing that annoys me, and I have had to think about it, [...] not enough blood on the strip. I think that something they could engineer out, a little key that would tell you that blood has gotten far enough up there to actually measure. [...] It cannot be that complicated to engineer out” – CI3

What it requires is another strip, as that one is wasted, and also for the person to prick their finger again:

“I guess the biggest annoyance I have with it is the Error 5, not enough blood on the strip. And that is like, and that is mostly my laziness, I don’t want to prick my finger again and get it on that” – CI4

Sarcastically: *““Oh great, I have to poke myself again. Oh great there goes a test strip.”” – CI10*

Although participants said “Error 5” (caused by too little blood on a strip) did not happen that often, it caused waste of expensive strips and more effort on their part, which could cause great annoyance to participants wary of the costs of strips, particularly if it was paid out of pocket:

“You know anytime it gives me an Error number 5, yeah, and even though it’s like full of blood, and in my mind, I am losing strips, wasting strips. It happens, not that often but it does happen every like three weeks or something. It will just be full of blood, and I will still get the error number 5. “Dammit. I have wasted another strip” – CI6

“It drives me nuts when like a strip gets burnt because of an error, because it’s just, it’s so expensive, like that, that is bothersome.” – CI9

Additionally, the physical set-up of the device could also sometimes cause frustrations among the participants with regards to the consumables needed. The strip had to be put in the meter, and often participants did not want to pull the meter out of the carrying case, as this would be one more step when they quickly wanted to test their blood glucose levels. The designers of CI7’s case designed it so that *“It’s actually upside down, but it has to be this way, because when you put in the strip, it can’t be this way because the strip bottle here. [...] you can’t really put it in because there is something*

blocking its way.” If the case for the glucose meter did not suit using strips, it could also cause annoyance:

“The edge of the test strip basically lines up with the zipper, which is like...it is one of those engineering things that they really should have been like, this is dumb” – C13 (see Figure 28 below)

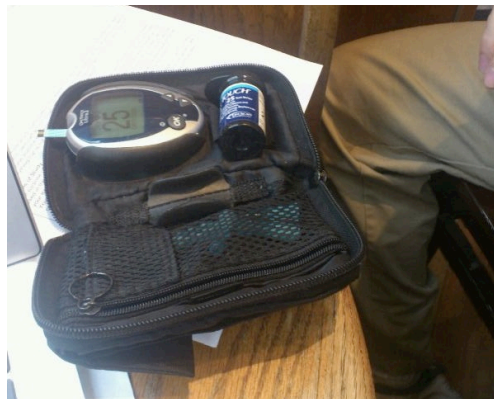


Figure 28: Strip lining up with BG Meter bag's zipper for C13

Adding more time to the act of testing blood glucose levels with the meter was not appreciated by some of the participants, and the packaging of the consumables could influence this user experience. Individually wrapped strips could take more time to unwrap and test with, causing more waste: *“someone probably thought that was a good idea. They probably weren't diabetic”* – C13. However, some participants really appreciated them:

“The one I carry around is like my travel one and I keep one at home because it is one of those ones where all the strips are like a bottle, but I find the bottle cumbersome to carry around. The one I carry, it is all, they are all individually wrapped [...] It uses individually wrapped strips, which I like [...] It doesn't take up a lot of space” – C19 (see Figure 29 below)



Figure 29: C19's glucose meter and an unwrapped strip

The insulin needed for the pump and for injections could also cause some issues for the participants' self-care practices. The temperature could influence how insulin could work, particularly in heat where it starts to degrade or cold where it doesn't seem to work: *"It works differently when you're hot, in the heat [...] like if you're in the cold, insulin doesn't seem to work so well."* – DS9. The insulin is usually stored in participants' fridges to keep it from degrading, but MU4 discussed forgetting the insulin pens outside the fridge and MU10 said that they dropped it out of the fridge once, shattering the container that the insulin was held in.

6.3.3 Summary of Infrastructure Issues

Although the focus of this research is on the devices themselves, they cannot function without consumables and infrastructure. These devices need batteries, and the type of batteries could cause some annoyance for participants. The strips needed could have their own issues, including inducing 'Error 5' on a glucose meter which caused a lot of frustration among participants. The insulin itself could also cause issues for participants, as it was very temperature sensitive. Overall, the issues with the consumables could be so annoying that the experience would trickle down to the devices themselves, and participants sometimes attributed these negative experiences to their diabetes technology, and the designers that designed them that way.

6.4 Discussion of the Physical and Infrastructure Contextual Influences

For the participants, overall it was found that the devices were capable of producing results for their primary purpose: allowing them to conduct self-care practices. Blood

glucose meters were able to take their blood, measure it, and produce a result for participants most of the time. This shows that they are effective devices. They were also able to produce a result that was sufficiently efficient, and the participants' discussions on this shows a lack of data on this point, which tells a larger story of how the device generally suited their needs. Many participants were unable to tell me who taught them to use their devices, particularly if they were not recently diagnosed. This shows that they were sufficiently easy to use. The human factors evaluations carried out by the manufacturers with regards to ease of use was impressive: if you knew how to use one glucose meter, you could basically use any glucose meter. Less data was collected on the use of other technologies such as continuous glucose monitors and insulin pumps, as most participants were not using these devices. However, none of these reasons indicated that human factors engineering was to blame for this lack of use. Usability and human factors was not often mentioned by participants, and there were no instances uncovered where devices were abandoned because of the lack of attention to usability. Essentially across the board, the quality of the usability engineering of these devices was appreciated, whether consciously or not. This speaks for itself to the attention manufacturers have paid the medical usability standards and the methods associated with them for the design and evaluation of diabetes devices. These devices were overall fit for purpose and through experience, participants developed familiarity with these experiences for their "anticipated future" use, what Wright and McCarthy call appropriation (McCarthy & Wright, 2004).

However, this appropriation meant that when expectations were not met for these technologies based on physical context, there could be negative engagement with the technologies, the sensual thread of felt experience. For instance, this occurred when low temperatures impacted the use of the devices. This could cause minor inconvenience for a rare outdoor concert, but also could cause major annoyance for someone who consistently commuted to work by bicycle and had to deal with a slow device throughout the winter when she wanted to test. Consumables also caused some of the most major instances of negative user experience. Most participants discussed 'Error 5,' which brought with it a lot of baggage. By wasting a strip on this error caused by not enough blood, participants were reminded that they had to prick their finger in the first place, prick their finger again, and use another very expensive strip.

The spatio-temporal thread of the experience of using these devices was not consistent, as they are mobile medical devices that have to be used in a variety of

physical and environmental contexts. In most cases, these devices were able to function appropriately in ways that participants valued over negative emotional responses to the device or the condition at large, such as being reminded of poor blood glucose levels. However, when the device failed to function as the participants became accustomed to, it could lead to negative emotional experiences with the device. Negative emotional experiences with other consumer electronics might lead to disengagement with the device, but as these technologies serve a medical purpose, participants sometimes had to work around these circumstances. For instance with the impact of contaminants, developing self-care habits around having to wash their hands before glucose meter testing, and therefore always testing in washrooms. Some people were often exposed to contaminants, and ended up not using the device in some contexts, for instance at work in a science lab in case of bacteria contamination. In the case of missing functionality of having a light on a glucose meter to light up a strip when in low lighting, the participants knew that low blood glucose levels at night are a reality. Instead of a workaround, they prioritised waking themselves or their partners up to do these tests, despite the on-going annoyance this caused.

Some of the functional issues surrounding the physical, environmental, and infrastructure contexts in which these devices are used can and have been addressed by traditional human factors usability methods. Other issues have been uncovered using situated methods to access the variety of contexts, and they could be solved through changing the design of the devices. For instance, having backlighting on screens and having a light where the strip goes on the glucose meter can be implemented. However, there are functional issues that cannot be easily addressed through design changes, such as dealing with contamination of the blood before it goes on the strip or dealing with too little blood on a strip without massive changes in the way blood glucose levels are tested. Getting rid of strips is not likely to be a design change that manufacturers will be happy with, as proprietary strips that are sold with specific glucose meters is where much of the profit comes from.

Although the devices were generally easy to use, effective, efficient and easy to learn, the physical context in which they were used influenced how people used these devices and their user experience with these devices. Although they were appropriate and fit for purpose from a human factors engineering standpoint, they caused much frustration and annoyance among participants in the variety of physical, environmental

and infrastructure contexts, which were uncovered through the use of situated methods.

7 - Healthcare System Context and Infrastructure

Beyond the infrastructure issues caused by the consumables needed for the devices, there is an overarching infrastructure that influences the use and adoption of these devices: the healthcare system. One data gathering method involved contextual interviews with participants in three different major cities with three different healthcare systems: London UK, Toronto Canada, and Los Angeles USA. There were similarities between these majority English speaking 'western world' major cities, such as large diverse and multi-cultural populations, but all three had very different healthcare infrastructures that impacted how their experience and practice with T1D technologies.

The idea of "*Clichés of the West*" is brought up in Mol's (2008) work separating the logic of care from the logic of choice. Mol states that her studies are local, but says "*that does not mean their significance is local*" (Mol, 2008). She explicitly states that the west is not and never has been homogeneous, however, she frames her work looking at diabetes care in the Netherlands as part of 'the West' which is associated with an ideal of autonomy and individualism. In conducting a bottom-up study of the situated use of T1D technologies, substantial differences in how the healthcare systems influenced participants in each of the three 'Western' cities emerged in relation to their individual use of T1D technologies,

London participants were living in a country that has a fully publically funded healthcare system. LA participants were living in a country where healthcare was provided for privately or through insurance plans. In Toronto, participants were living in a country where there was a mix between private and public healthcare. This impacted the coverage people got for the care of their Type 1 Diabetes and influenced how devices were adopted, used, and carried by individuals.

7.1 Knowledge of UK Healthcare System Bred Expectations

In the London interviews, participants who were diagnosed with T1D in the UK had immediate access to medication and medical devices which were provided free of charge. Even those who were diagnosed in different countries were able to get

prescriptions and medical devices free of charge if they were legally living in the UK and therefore covered by the National Health Service (NHS). These devices and prescriptions are given by general practitioners (GPs) and diabetes specialists according to national best practice guidelines. In the UK at the time of the study, this meant that glucose meters were free and easy to obtain from both GPs and diabetes specialist units in hospitals, and strips are prescribed for free. However, to obtain an insulin pump, a GP or diabetes specialist had to show that a patient's glucose levels are variable and justify through paperwork that patients would benefit from a pump and related prescriptions. CGMs are not covered at all and they have to be paid out of pocket along with their supplies so consequently, were not commonly used by participants.

Despite the blood glucose meter and the strips being covered by the NHS, people were still aware of how expensive the strips were. Although MU2 said she took 8 or 9 tests per day, she was *“still conscious of cost”* and chose a glucose meter that she could continue to add blood to without gaining an ‘Error 5’ and wasting a strip. Many participants were aware of the prices of supplies, with MU6 saying a specialist dietician once suggested putting extra supplies for sale on eBay, and MU4 replying that she had done this herself. Other than these supplies, the participants generally felt that the glucose meter itself held little monetary value to them. MU2 said *“I have thrown the blood glucose meter across the room in frustration”* with MU6 agreeing that they have no value. Most participants knew that they could be obtained for free, either through the GP, diabetes specialist services, or through manufacturers willing to send them for free in the hopes that they will profit from the proprietary strips used:

“There are, like, heaps of companies who will send you their meters because they want you to buy the testing strips.” – DS1

Some participants did not trust their GP's suggestions, as they only prescribe strips from some manufacturers because they are cheaper for the NHS and MU10 described that it *“scares me, luckily not mine yet.”* A GP once questioned her use of many strips, but she fought back against them saying it was *“not your business, I'm Type 1 and I want to test a lot”*. The participants were aware of the differences in knowledge between the GPs and the clinicians who specialised in diabetes care. DS9 said that she *“tend[s] to use whatever I'm given by the hospital”* which is through diabetes specialist groups she trusts, but does not trust her GP's suggestions:

“he obviously did some deal with some one of the companies, and my boyfriend went and picked up my prescription... my repeat prescription. And some new strips had been added onto it without me knowing [...] I was like, “what the hell are these?” So, the doctor had come to some arrangement with some one of the companies [...] So, I just called and was like, “what the hell?” And he kind of confessed, then. He was like, “oh, I think that was my fault”.” – DS9

CGMs are not covered by the NHS so many participants did not adopt them because of out of pocket cost concerns: *“I'd love a continuous glucose monitor but they're so expensive”* – DS1. MU6 was also conscious of the costs of using technology that there was no health service coverage for: although he wanted a CGM to monitor his BG levels because he is a *“control freak”*, he considered the cost of CGM *“a ridiculous amount of money.”*

MU6 didn't qualify for an insulin pump immediately either, so he got a second hand pump that still required £100 pound to be spent on supplies, so he originally was *“stretching it out”* as much as possible through overusing and off label use of the supplies. The infusion set attached to the torso is supposed to be changed every three days, but he was changing it every 5-10 days. MU6 said that *“everybody does it”* and the people at the meet-up then started comparing brands in terms of possibilities for misuse, discussing which can last the longest. He told the group of his personal limits: *“an extreme money saver is reusing the same infusion set in a different area, but that is too extreme even for me”*. MU6 eventually got funding for the pump, but when he told the doctor that *“I have one, I just need funding,”* this did not fit into the NHS funding model so he had to get a brand new Medtronic pump.

The participants understood the NHS will cover basic needs, but it is quite hard to qualify for more advanced technologies, such as the pump (*“I was on the waiting list for 3 years”* – MU2). For instance, it has to be shown that someone's blood glucose levels are erratic in order to qualify for an insulin pump to be covered and the NHS will not pay for continuous glucose monitor. Some participants learned about how to 'game' the system and they would find GPs who *“care”* (MU2) or are *“flexible”* (MU6), and *“that know”* (MU5) how to get around the guidelines, including MU4 who said she would *“go into London”* as soon as her flexible diabetes consultant retires to get another flexible consultant.

Another way to game the healthcare system was with research, and some participants became armed with knowledge, such as MU6 who thinks he is “*probably at a degree level with diabetes*” and “*far surpass[es]*” his GP with regards to knowledge of the condition. He suggested to the meet-up that the GP will back off if you use the right language. MU7 suggested the problem was that they see far more Type 2’s and therefore don’t care about Type 1 needs.

There is the option to buy these technologies out of pocket or get private coverage for them, but the CGM is not covered at all in the UK and they are not very common (MU1 said there were 127 Dexcom CGMs in the UK at the time of the meet-up in 2013). Covering it out of pocket is “*so fucking expensive*” (MU6), yet some technologies such as the Dexcom were described by participants as “*so enticing*” (MU4). MU1 joined a research project at a university in London and this is where she became familiar with the CGM. She decided to buy one for herself out of pocket, but has to look elsewhere for support in using it because her GP was not familiar with it:

“[the manufacturer] is helping me,” – MU1

“they shouldn’t be!” – MU5

MU12 also bought a CGM out of pocket and was using it “*intensely for a while*” as it helped immensely with overnight hypos, but could not justify the cost (£65 for ten days) when she got too busy to use it. After seeing the devices at the meeting, MU10 and MU4 both described having “*CGM envy*.”

7.2 Knowledge US Healthcare System Influenced T1D Device Use

In LA, all participants had an understanding that their healthcare is something that must be paid for out of pocket, through an insurance plan, or ‘too bad’:

“This girl that I met there she was telling me that her job stopped covering for her because it got kind of expensive [...] And she was like “it is ridiculous dollars per month, and it adds up, and now I can’t afford it, so I can barely afford test meter strips, I can barely afford the strips.” It is a harsh world out there.” – CI7

The insurance plans are usually provided through a parent’s job for children and young adults, and then through a person’s university or job past age 26. However, not all jobs offer health insurance and insurance plans can vary widely.

Even some participants in other places had experience with US healthcare or had heard from people in their social networks who live somewhere in the US. MU6 in London had an insulin pump and went online for support, including support from his peers in the US as the use of pumps was much more prevalent in the States. He also spent some time in the US at a diabetes physical activity event with attendees from the US with T1D. When discussing how to suck insulin out of the pump instead of bringing an extra vial with MU4 and MU5, MU6 said that in the US people suck out insulin to save it more and suggested *“we don’t have to pay for insulin so it isn’t a problem.”*

An instance of misuse to deal with the costs of self-care was described by CI6. He had just got a new job and was transferring his insurance from his father’s plan to his new company’s plan. He knew that there would be some time between the overlap so he stocked up on supplies so he would not have to pay out of pocket for self-care supplies. He was running low on supplies, and knew he wouldn’t be able to make the *“like gold”* strips last, so he started sucking the blood out of the strip to reuse it, and was quite proud to tell me that he only got one error whilst doing this:

“Yeah, so I was basically sucking the blood out of used ones. My own used ones. And started saving them. And normally it works, but then there was that time. “500, woah, I didn’t even eat anything” [...] Losing another strip. Closer to not having any. [...] They are like gold.” – CI6

Insurance plans widely varied, which influenced the adoption and use of the devices in different ways: CI7 uses *“whatever is covered by my insurance.”* Insurance plans are very different with some participants quite liking their plans and other getting onto secondary plans: *“As a type 1 diabetic, basically you got to be covered under two insurances, or you are going to have a bad time at the end of the day” – CI3.* CI6 was actually told to test less because his insurance didn’t cover the quantity of strips he was using in his glucose meter, so started getting strips from a friend with Type 2 diabetes:

“I take it too much anyway. My doctors said I take it too much [...] he would love for me to take to all the time, the insurance company told him to tell me I was taking it too much. Basically, I was taking it like 8-12 times per day, and he was like you should aim for 4-6. I was like, man, yeah, that’s how it works. [...] I do get strips from another source. Like someone I know who has diabetes, just gives them to me. Type 2 diabetes. Um, so they don’t really have to budget them, or they don’t need to, so they get like as many as I do, but they don’t

need that many so they are like “hey, are you running low?” So I am lucky to have that connection. So. [...] That’s’ what you gotta do with health insurance.”

– CI6

Some of the participants were young enough to still be on their parents’ plans, but were unable to get adequate insurance from their universities or their jobs. This meant that some supplies had to be paid out of pocket:

“I have really really crappy insurance because I can’t get it on my own, so I have to get it from my step-Dad because my Mom, the hospital that she works for [...] won’t cover me in California. [...] out of all the plans they have, only one will cover me out here, and it is a really awful plan where I have to pay \$5000 out of my own pocket for anything. [...] So, yeah, so it gets really expensive. Testing strips are \$1 a strip and if they were cheaper, it would be so much better but... so I am paying probably around \$250 for one month of testing strips. So it ends up being a lot of money but eventually, they will cover stuff. So it’s not a very good insurance plan and my work doesn’t offer benefits, so... if they did, I would not be on my parents’ plan.” – CI1

CI2 was without insurance at the time of the study and used the devices given by her health providers as her doctor would give her free strips for it: *“I usually use the one I can get free strips for”*. She had a pile of glucose meters at home because of the times in her life where she didn’t have insurance and had to get cheap supplies: this can be done by ordering the devices free from the manufacturer which comes with a few free strips as well or getting a cheap one from a pharmacy that comes with free strips. She also would take supplies off her sister who also had diabetes and had insurance:

“Because they do give them out for free, if you don’t have insurance. Like, there have been times when I am like, without insurance, and I have bought the one from Walmart that comes all in one. They are kinda handy actually. They have a strip canister. [...] They are ok.” – CI2

“I actually don’t have any [insurance] right now. So it’s not..[...] My sister also has diabetes has given me some, um yeah, because I lost my coverage” – CI2

CI2 had graduated with a fashion degree. Although she had originally wanted to pursue a career in fashion, she decided that she couldn’t because she needed to “*secure benefits*”: *“It is the only reason why I didn’t really go into fashion too seriously because the coverage isn’t that great.” – CI2*. She was looking for jobs in “more standard 9-5

jobs, things like that” because she thought it was “*more likely from a larger company to cover better*”.

Similarly when CI6 did not have coverage, he tried to get any job that he could that had coverage. Eventually he settled for one in part because of its insurance plan:

“I was working at a company for 7 months, for \$10 an hour with no insurance, and anytime I wanted to go see any doctor, I had to pay, and I didn’t get paid for time off. It was like absolutely brutal, and I was lucky because I was on my father’s insurance, but I was looking for any job I could find that would get me benefits. And this job had it down.” – CI6

The transition from university or parental coverage to people’s own coverage was daunting for those still in university or had recently had to deal with graduating. CI3 was not able to have a break (“*wasted time for a couple years or something having fun*”) between degrees as he needed coverage for his diabetes supplies and CI4 felt held back from pursuing art because of insurance, but also was thinking about marriage and coverage:

“Well I hope to have a full time job at that point, or even if I am married. My boyfriend or whatever. [...] With the art, if I was going to be an artist, and that’s the thing that is holding me back from doing art more, more full time, is that I need an insurance plan to cover my diabetes supplies and cover my health and whatever. And that’s why I am thinking more along the lines of finding something that is more marketable.” – CI4

CI5 had group insurance plan through her teaching job that she liked, so her out of pocket costs per month were only \$55 per month: “*I am a teacher, I have great insurance [...] it could be \$40,000, remember, you know. And your prescription could be \$55 each.*” – CI5. At the end of the interview, she wondered “*Now will my sons have great insurance? I don’t know.*” Although her sons do not have a chronic condition such as diabetes, she did think that people with Type 1 had to make decisions about their future careers that involved thinking about their salaries but also thinking about their healthcare insurance:

“So I think people coming up need to think of the money they want and the health insurance.” – CI5

Many participants used the devices that were given to them by their healthcare provider: *“I am going to ask him next month for another one like this one. And they are very good about it. Very good about it.”* – C15. They adopted these devices for numerous reasons, for instance trusting that their doctor would give them the latest model when it became available:

“So once he got the new ones in, and he gave that to me, I have been using it ever since. I have had this meter for a couple years. But he will give me a new one every year or so, or if I just ask him for new one, he just gives it to me, so.”
– C11

“I don’t think I have ever chosen a glucose meter. They have always been given to me, and then every time I go to a doctor, I’m always, “hey, do you have something smaller than that?” And it has gotten to the point where it is like, super small. I haven’t really asked for a new one at this point.” – C16

They also trusted the ones given by their healthcare professionals because they would give them devices that had consumables that were definitely covered by their insurance plans, even if they weren’t the ideal devices for them:

“My doctor got it for me for free because the test strips that you have to be refilled, the ones you put your blood sugar in, that, my insurance only covers certain types of test strips. So she gave me the meter the insurance covers for the test strips.” – C17

“My insurance changed and it didn’t cover that one anymore. I tried so hard to get that one back, but they said I can’t” – C17

Many of the participants from the US also suggested that these devices were given to them by their doctors because these models could be accessed by their doctors: when they visited their health care provider, the doctor was able to attach a data cord to the device, download their results, and sometimes print them out. Because of this clinical need, they had to use the device more suited for the doctor’s information needs:

“Whenever I go see my doctor, he’ll print out, because I see him every three months, he’ll print out from my meter what have my sugars been. There’ll be a little graph, it will show, like “Oh, you get consistently low at this time and you keep getting high around this time” [...] There are, there’s a computer program you can hook them up to, um I know Accucheck has one. I know several other

meter brands have 'em. Um, like, my meter will wirelessly, they have like a little sensor and they'll set it next to it. And they'll use Bluetooth to basically connect to it and send all my blood sugars to it and it will show times, dates, everything. [...] Well a lot of doctors offices do it." – C11

"Yeah, they do that with it, like at the doctors office, I don't actually have the software for it at my house. But the one I used to have that went to my pump, that was like, you could download it, it was like really pretty, so haha! [...] Yeah, yeah. They do with my pump too, to see the patterns" – C14

In fact, the knowledge that the doctors were looking at these numbers could change participants' self-care routines leading up to appointments with them, which was mentioned by many participants, including when they were reminiscing about having clinical appointments as children and filling out the older blood glucose level log on the way to the appointment. This was the case for C17 who only tested once a day normally. When asked if there were any times her use of the glucose meter changed, she answered:

"Yeah, when I am about to go see my doctor! Hee hee! I try to test more often because she has numbers to compare to, because if she doesn't have numbers, she can't really adjust my insulin levels. So a week before, I go to the doctor's, it changes a little bit. Like two or three times more per day. Most times I test once a day, so you can't really use those numbers to do, to change my insulin levels." – C17

Beyond the familiarity with health providers and the US health system, there was some shared general knowledge among participants about the pharmaceutical industry. Many participants were familiar with the fact that the manufacturers were not making money off the devices themselves, but from the consumables associated with the devices, such as the strips used for the glucose meters:

"Like the meters aren't expensive, but they make sure to make the testing strips expensive" – C11

"Everyone knows that the money that the companies are making are not on the meter but on the test strips" – C13.

"They will offer you a lower price because you have to buy those strips!" – C15

As such, many participants were comfortable getting in contact with manufacturers directly when something went wrong with their devices, because they knew that they would want them to keep using their devices with their consumables:

"I had one time where my meter just wouldn't turn on at all. Um and that's when I called the company and told them. They said "did you try new batteries?" and I said "yes I bought brand new batteries, put them in the meter, it still won't turn on" They even had me reverse the batteries because I had them in wrong, didn't work! I had them in right, but it still didn't work. Um, and, that's when they sent me the new one and I choose the backup that I have. So. It wasn't too bad." – C11

"Any time I have ever had a problem, Minimed can basically ship a pump the next day" – C13

"It self checks itself every time I turn it on. I have never had any problem with it, and if I did, they offer great customer service with a care number, if I had any questions, I can call them" – C15

Despite issues with health insurance and because of the lack of it, many participants were used to paying out of pocket for some parts of their health and many considered it a commodity, wanting to buy the best for their health. C12 said that she would pay for a pump out of pocket knowing that it would provide her the best results: *"I think that if I only had basic coverage and stuff, I would buy the pump out of pocket. And insulin."* – C12.

7.3 Knowledge of the Canada Healthcare System Varied

In Toronto, all participants were being covered by the publically funded Ontario Health Insurance Plan (OHIP). Although medical care such as routine check-ups and medically necessary operations are fully funded under this plan, not all types of healthcare are fully covered. This plan does not cover prescription medication or healthcare technology, so when people are diagnosed with Type 1 Diabetes, they immediately have to pay out of pocket or are given supplies by the hospital they were admitted to. They can get extra coverage from an organisation connected to the government (Assistive Device Program (ADP) or Trillium in Ontario), but in order to qualify for an insulin pump, glucose levels must be controlled to make sure that the people on pumps are getting value from them by adhering to medical advice. This is in

direct contrast to the UK NHS, which needs to see that glucose levels are variable in order to justify that the pump is needed.

MU3 was a recent immigrant to the UK from Canada, and discussed her experiences in relation to others' at the meet-up. She disclosed that she paid out of pocket for her first pump at it cost "\$500 Canadian" and was well aware of the cost of strips in Canada: "\$1 Canadian a strip." She described coverage as being different in every province, and the doctor had to write her a letter of support to get coverage of "\$600 every three months" for prescriptions and technology. She recently got a new Minimed pump and the company gave her two months of supplies for free: *"without funding, I estimate that it would be \$12,000."* Although she would prefer a Dexcom CGM, it was not available in Canada at the time and she would be unable to source supplies. CI11 talked about a friend she considered to be "captain diabetes" who would drive down from Toronto to the US to get supplies that were not covered in Canada for the Dexcom.

When participants were first diagnosed in Toronto, they were usually brought into hospital and given emergency care. This was covered by the health services and so was some of subsequent follow-up care. CI10 discussed getting diagnosed two years prior to the interview and the care that was provided by the health services that followed, where she learned how to conduct self-care practices:

"I stayed there for two nights, they did a whole bunch of testing, then I think it was Friday morning, I went to the diabetes education centre right after so they could teach me how to use it, and all that fun stuff. [...] I was there for a couple hours, like one-on-one, and then I had workshops for the following month. It was once a month, sorry, once a week, we had workshops, people who got recently diagnosed with me, so it was a support system. Which was really nice, um, yeah. So, calling each other, and reporting my insulin levels to her and what I ate. So there was a lot of support" – CI10.

Beyond the medical care provided by professionals, not much else was covered immediately in the care of Type 1 Diabetes, including devices and consumables:

"No. Type 1s get nothing. Well, no, that is not entirely true. Insulin is not covered, diabetes test strips are not covered, visit to the endocrinologists are."

– CI9

This was a tough reality for people who grew up in Canada where their healthcare, such as trips to the emergency room or annual doctor check-ups, was covered, but

they were diagnosed with a condition that immediately cost a significant amount of money out of pocket:

“From the ER. [...] I had to pay for the strips, they gave me the meter for free. They usually do a deal like that, and then I was basically in the ER and my dad was like, the doctor gave him all the prescriptions, everything I need, and my Dad went to [a local pharmacy], got everything, and brought it back. [...] It would be out of pocket for that part [...] we didn’t know, is it covered by OHIP? My parents insurance was like “oh, where did this come from? Um, we need to investigate this.” So, the first, probably the first two months were largely out of pocket, and I didn’t realise how expensive diabetes was. I was really shocked. I think that my parents insurance ended up claiming quite a big portion of it, I lost a little bit of money.” – CI8

On-going costs could be a problem for some people, particularly if their work at the time did not cover the cost of the strips and the insulin. Both CI9 and CI10 were diagnosed in recent years and had times where their jobs did not cover the cost of self-care, with CI9 having a time where he was unemployed and CI10 having an employer at the time of the study with no benefits:

“Currently, well, we are getting insurance at our work, but until now I haven’t been, so it is very expensive. I just got a pack of [...] night shots yesterday, and three packs of the test strips and it cost me 420 bucks, so. I think I have the receipt on me, right, so we have to wait until we get out insurance at work so I can claim it. But it is very expensive. [...] For about a year, because I was working somewhere else where I had benefits, um, and I ended up getting laid off, and so for the past, a little bit over a year, I have been covering it by myself.” – CI10

“At the time when I got a free one, I didn’t have any health insurance, or anything like that so I was kind of just doing Google searches for like free test strips. And something came up, like uh, “300 free test strips and a free meter” and I was like “duh, get it”. So I did that. I used it at home, I didn’t really like the meter, I found it bulkier, and so I didn’t stick with it. I used the 300 strips, and then stopped using it. [...] Fortunately, I was never at a point where I was like, out of work for too long, and also on the insulin side, I had some really good nurses on my healthcare team and they knew I didn’t have any coverage, so

they gave me samples. And the samples really carried me through. Because if you are not, you know, if you are not covered, you are spending about \$5000 a year based on what I use, about \$5000 a year. Or was in those days. I use less medication now.” – CI9

There were some programs run by charities to help some people who were out of work: *“they have special program through Canadian Diabetes Association, where um, if you are not on insurance, they will cover you up to \$800 per year on the strips. You keep the receipts, and they reimburse you for 75% of them.” – CI9.*

Qualifying for advanced technology required quite a lot of effort on the part of the patient and differed from the UK in that it needed to be shown that people’s glucose levels were in control. To get qualified for programs to get the insulin pump covered required a certain maximum income (*“I think you need to be below a certain income level to take advantage of those things” – CI9*), but also it required quite a lot of information from the participants, and there were still some costs out of pocket, which CI8 experienced:

“I think on average, I usually pay about \$100 over [...] for the three months. Usually the \$600 covers the majority of it, like 90%. And like \$100, which we try to push through my parents’ insurance. Sometime it covers, sometimes it doesn’t. A little tricky, but it is a lot cheaper than paying \$600. [...] You have to get your doctor to sign a report saying, “this therapy will be a better option for patients” I had to give them the eye exam, because they want to see are your eyes still working alright, because that’s the first thing that tends to get damaged with diabetes. And what else? I think they asked for my A1Cs and my blood sugar average.” – CI8

Unlike in the US, many of the participants did not accept that paying for healthcare is part of everyday life, rather they thought that this was unfair: *“And I find to be very expensive. I also find it to be kind of unfair. You know, it is unfortunate, but it is very expensive.” – CI10.* This was apparent in how CI11 described how she was able to get on an insulin pump despite not being covered at first:

“When I was 17 I left my home, and I needed a pump, [...] but I was living like hand to mouth kind of thing, like pay check to pay check. So that wasn’t working out. So I met this lovely couple that actually bought my pump for me. And, then to afford supplies, they weren’t covered at that time, I was paying out of pocket,

and that's like \$300 a month just to stay alive, not even talking about rent or anything like that. So ended up opening a line of credit and putting it on that line of credit, hoping that the government would pay for them. And they did introduce that ADP program here, that Assistive devices program, but when they first introduced it, so ass backwards, they wanted you to meet this list of criteria before, so you had to go to your [endocrinologist], and your dietician, and all these appointments. They wanted your A1C in a certain range, before they would give it to you, which is ridiculous, because you need the device to get your A1C in that range! So I remember I went to see my dietician, and in order to get ADP, I struggled for six years to get ADP approved. Six years of racking up debt. And the stress of that of course made my diabetes insane, and I went to my dietician, and she's like, "in order to get ADP, you have to fill out all these food logs" which is such a bitch, well anyway. And I said "there is no point in me filling out the food logs, because right now I am going to the food banks and right now all I am eating is white pasta and butter" and she's like "well you have to fill it out to get ADP" so I filled it out honestly, and I came back to her, and she's like "well I can't approve this, like you're eating horribly." And I was like "I know, well we talked about that. It is because I can't afford both insulin and food" like you know what I mean, and that is a really hard choice I had to make and you are not going to be able to control diabetes in that situation. Um which is why I am happy to talk to you, because I think the government, um people like me are sitting on \$15,000 debt on top of student debt that they are racking in." – CI11

Although the US system and the Canadian system were similar in their out of pocket costs and the need for insurance, people in Canada had a shared understanding that healthcare should be universally available and so they found the experience of getting diabetes technology to be unfair.

7.4 Unfamiliarity with Health Systems Required Changes in Routine

Some of the participants who were involved in the user study were either immigrants or had moved within a country, and had to prepare for the change in their diabetes care. Unlike above where participants had appropriated over time their experiences within a healthcare system, these participants were not necessarily aware of the healthcare systems that they were moving into. Some took a lot of precautions as they were not

aware of how these moves would influence their self-care in their new city, whether within the same country or in an entirely new country.

MU3 is a teacher from Canada who moved to the UK to work. She did not think she was going to permanently stay in the UK, so she said she continually brings her supplies over from Canada. Although she thought she probably qualifies for healthcare coverage in the UK, she is afraid she *“might lose Canadian funding.”* The last time she brought supplies, she *“brought a stash to use until Christmas”* which was about 7 months worth, taking up almost a suitcase, which she described as *“excessive”*.

CI6 also did not fully accept the health system he moved into, although he had just moved one state over from Massachusetts to New York. He felt he was not going to stay there for long, so he ended up keeping his old health insurance that he was comfortable with and did not want to lose. In order to get self-care supplies, he would bus back home to pick them up:

“I was actually still on MASScare while living in New York. I would just go, take a bus every time I needed to go to the doctor [...] They would have kicked me out. I wasn’t really, I wasn’t living in New York. I was living in New York, but I knew I wasn’t there permanently. I was only there 9 months, and then I moved back to Mass.” - CI6

CI6 moved again, this time across the country to where his parents had moved to in California. He was able to get some coverage because of US federal healthcare system changes, but knew there would be a time that he was without insurance. Knowing this was the case, he ended up stockpiling supplies for his self-care:

“When I came here, switching from my Dad’s insurance to the company insurance, there was like a brief period where like I had to cancel that, and like had to wait for the rollover period or whatever, to get on the company one. So there was a brief period where I was like stocked up on medication and like trying to make it last. Until I got to talk to doctors and get my prescriptions.” – CI6

When CI4 moved across the country to California, she had to get on the one plan that covered her through her father’s work. She knew there were issues that would be hard to resolve with getting her supplies in California, so she instead got them sent from back home by mail:

“Although they have your stuff, they aren’t here so you have to get it all mail ordered. [...] For the most part I mail order [...] Yeah, we have, like... for a three month supply of strips, it is like \$80 that we have to pay” – C14

Although there is some familiarity with healthcare systems that people have had experience with for many years or are able to research before moving to a new place, there still can be unexpected situations that change self-care practices.

When MU1 bought her CGM out of pocket in the UK, she knew that it was not a common medical device. What she did not foresee was that her doctor had no familiarity with the device at all and would not support her, so she had to look up American internet sources to supplement her knowledge on using the device.

DS1 moved to London to work as a primary school teacher. She had a glucose meter at home that she really liked (*“I don’t feel embarrassed taking it out because I think it looks awesome”*), but when she arrived she found she could not get strips for it here. Her doctor gave her another that she didn’t like, so she had to do some research to get the one that she liked again:

“I had the same one in New Zealand, but they have different size testing strips. Like, you can’t bring your New Zealand meter, and use English testing strips even though it’s the same meter. So I’ve had this one for, like, I don’t know, three months maybe [...] I’ve been here for ten months, but my doctor gave me a different one. It was, like, the size of a brick, so I just had to do some research to find a cooler one.” – DS1

7.5 Healthcare System Discussion

As described in the introduction, it is estimated that approximately 6% of people with Type 1 Diabetes in the UK use pumps, whereas almost 15% of people in some places in Europe and about 40% of people in the US use an insulin pump for self-managing their Type 1 Diabetes (Diabetes UK, 2013b). Although it could be argued that adopting diabetes technology is obviously connected to the availability of devices through healthcare system infrastructures, it was found that the healthcare systems influenced use and adoption in more complex ways than this. People who have experience with an infrastructure conformed to the practices that were available to them, adapted their use in order to get the most out of the resources they had available, and sometimes had to adapt their lifestyles in order to accommodate the care of T1D. This was in

direct contrast to those who were unfamiliar with these systems because of moving or buying a device outside the healthcare system had to change their routines to adapt to unfamiliar health system infrastructures.

In the UK system, many participants were still aware of the cost of the supplies that were needed for their medical devices and the costs to the NHS and the ability to get coverage. They had expectations of what would be covered by their health system, and often trusted the health service to be able to provide self-care technologies to support practices that would benefit them in the long run. In essence, the participants in London were able to anticipate the type of care and devices that they would have access to based on their previous experiences in the system that they had appropriated (McCarthy & Wright, 2004).

In the US, participants grew up knowing that healthcare was something that needed to be paid for, and changed jobs or paid out of pocket to get the best healthcare they could. Because of their experiences, participants were able to anticipate what would be required for the care of their condition, and valued the potential health benefits of supporting costly technologies over the money it cost to sustain their use, similar to the value judgements that occur in the emotional thread of felt experience (McCarthy & Wright, 2004).

In Canada, there was a hybrid system where health service providers were free but prescriptions and devices were not, and this divide caused some financial issues for participants, as they were surprised that they would not be covered and thought this was unfair. Participants described how their expectations were not fulfilled, leading to sometimes very immediate negative emotional experiences when they found this out (sensual thread of felt experience), and then had to connect their health to financial concerns, a value judgement that they did not have much experience with (emotional thread of felt experience) (Wright & McCarthy, 2008).

These emotional experiences led to very different actions and reactions that influenced the situated adoption and use of the diabetes technology. For the case of the person in between insurance plans and reusing strips in LA, this was a hack that he was proud of. For the meet-up in London, discussions involved elements of disgust in how people in the US had to work around the system to get the supplies that were needed for T1D self-care. The hybrid system found in Toronto meant that participants did not expect to have to deal with these issues until they were confronted with them face-to-face.

The importance of choice can be considered a “*cliché of the west*” (Mol, 2008), but it was found throughout the dataset that people’s choices were very much influenced by the healthcare environment that they were familiar with. Very few participants had insulin pumps in London and only one had paid out of pocket for a used one, yet some of the participants without jobs in the US still had these very expensive devices because they wanted to have the best healthcare that money could buy. In this case, seeing health as a commodity influenced the way participants made choices about their T1D devices and their self-care practices. Participants in London and Toronto were used to systems where they knew that there was universal healthcare, but in Toronto this system does not extend to prescriptions and technology, the most expensive parts of healthcare for people with T1D. Similar to the US participants, some were paying out of pocket to get the best healthcare for them, but only under the assumption that these expenses would be returned to them eventually by a governmental program.

These cities are very similar in many ways, including their multi-cultural makeup, their size in relation to the countries they are in, and the languages that they use. In many different ways, they are ‘western’ cities that have many similarities. However, despite these similarities, the differences in the healthcare infrastructure meant that the participants were adopting and using technologies in very different ways. Mol (2008) frames her criticism of choice in self-care within the “*Cliché of the West*.” Her work was conducted in the Netherlands, which she situated as part of the western world and within its ideals of personal choice and individuality. Even in one western country like the Netherlands, there can be a wide variety of care that can influence diabetes self-care (de Bakker et al., 2012).

Despite the similarities between the western cities the contextual interviews were conducted in, situated methods uncovered that these universal ideals did not carry over to influence the adoption and use of the devices in the same way. However similar these cities are in comparison to cities in different parts of the world or non-western cities, there were still remarkable differences found, which was very apparent when participants moved to places different healthcare systems. This has implications for the design of technologies that are designed for a global market, can be brought across borders, and can be available online to a wide variety of people with diabetes worldwide.

8 - Cultural Environment

From a bottom up approach to the data, culture has emerged as a recurrent influence on how people adopt, use, and carry their T1D mobile medical devices in the situations that they find themselves in. Culture has been of growing interest to the HCI community, with a push to recognize how technology design influences culture, with Balsamo (Balsamo, 2011) arguing that all design innovations rearrange culture. The influence of culture on the use of interactive technologies has begun to be discussed in HCI in work such as Dourish's on context (Dourish, 2004b) and Fitzpatrick's Locales framework (Fitzpatrick, 2003), and its influence has started to be explored within the participatory design field (Hakken & Maté, 2014; Mainsah & Morrison, 2014). For this chapter, I use the same definition of culture that has been used in the participatory design field (Mainsah & Morrison, 2014) from Hall (Hall, 1997) (emphasis added):

*“Culture, it is argued, is not so much a set of things – novels and paintings or TV programmes and comics – as a process, **a set of practices**. Primarily, culture is concerned with the production and the exchange of meanings – the ‘giving and taking of meaning’ – between the members of a society or group. To say that two people belong to the same culture is to say that they interpret the world in roughly the same ways and can express themselves, their thoughts and feelings about the world, in ways which will be understood by each other. **Thus culture depends on its participants interpreting meaningfully what is happening around them, and ‘making sense’ of the world, in broadly similar ways.**”*

Within the technology design domain, culture has been defined in a similar way, as “a socially shared symbolic system of signs and meanings” (Balsamo, 2011). For the purpose of focusing on culture as shared meanings between a group of people, I differentiate it from the shared meanings between two specific people face-to-face, which is described in the next chapter on the social contextual influences. Culture in this sense is about framing experiences to “bring structure and meaning to them”, which is line with the compositional thread of felt experience (McCarthy & Wright, 2004). Through a bottom up approach to the data, numerous instances were identified where the culture that the T1D devices were used in influenced experience and

practice. This is in line with Hall's assertion that *"Above all, cultural meanings are not only 'in the head'. They organize and regulate social practices, **influence our conduct and consequently have real, practical effects**"* (Hall, 1997).

Essentially, the importance lies in how systems and situations are similarly interpreted by a group of people. The participants shared these meanings in their routine lives where they are familiar with the culture through numerous and on-going episodes with them, ultimately anticipating their experiences (McCarthy & Wright, 2004). However, there are times that they go to places with cultures that they are not familiar with, whether they expect it or not. In the case of T1D technologies, it was found that the cultural contexts where the participants grew up, lived, and visited influenced how the devices were adopted, carried, used, and misused. The culture impacted their experiences, and it was found that their familiarity with the culture influenced their carrying, use and adoption of devices. Depending on their familiarity with the cultural context and their preparedness for that culture, they employed different self-management strategies with their T1D devices if they knew they were going somewhere new or if they were reacting to finding themselves in an unfamiliar culture.

8.1 Cultural Familiarity Resulted in Regular Self-Care Styles

In situations where people were familiar with the culture that they were going to be using their devices in, they were able to prepare and adapt their self-management styles. These styles of self-management ranged from strict adherence to keeping blood glucose levels balanced, to taking calculated risks based on familiarity with the possible outcomes of their actions. Familiar cultural contexts included shared meanings of technology trends, social norms, and cultural events.

8.1.1 Consumer Technology Trends Led to Expectations for T1D Devices

People are becoming more and more familiar with interactive technologies with the rise of affordable consumer technology. In the UK, the use of smartphones continues to rise every year with 76% of adults in the UK owning or having ready access to one, up from 52% in 2012 (Deloitte, 2015). Consumer technology is something that is constantly in the news, with the newest release from Apple getting to the front page of newspapers and websites discussing and reviewing the newest releases of smartphones, smartwatches, and other interactive technologies. With this increased access to information about consumer technology as well as mainstream media coverage, people form opinions and expectations about the technology that they choose to acquire or

buy. For the participants, this influenced the way they carried their devices, adopted them, and used them, based on shared understandings of device aesthetics and expectations of functionality.

8.1.1.1 Aesthetics of the Devices Were Compared with Consumer Electronics

The way some of the devices were described was linked to the language and the aesthetic of current, or sometimes out-dated, consumer technologies. Often T1D devices were described in negative terms associated with older consumer electronics, such as describing a part of a glucose meter with *“this little flippy thing, like an old cell phone”* – CI1. CI1 also described how she stopped using an older model because of its out-dated consumer electronics aesthetic: that *“like an early 90s cell phone”* – CI1.

MU1 paid for a CGM out of pocket after trying it during a research trial in London and liking its functionality and its aesthetics. She described its look as *“like an iPod. It’s smaller actually”* and seemed quite happy about its looks, but because it was a wireless system she was able to carry it in her pocket or bag and she did not have to wear it on her person, in contrast to insulin pumps which are usually attached to the torso or arm.

Many participants did not adopt an insulin pump, even whilst knowing that it might be better for their overall health. This aversion to adoption was explained in different ways, one of which was an aversion to the aesthetics of the insulin pumps that the participants were familiar with. Even the people who adopted the device described the devices in dated technology terms such as an *“80s pager”* – CI1, and knew others saw it this way too:

“I think like a lot of people think it’s a pager, so people make jokes, “is it 1980s?”, ha! And I’m like “it’s my insulin pump”” – CI4

“It kind of looks like a beeper or a pager, and sometimes people ask if they see it on my waist.” – CI8

CI8 had a glucose meter and an insulin pump that came together as a set and were able to connect to each other, which she spoke about as useful functionality for her needs, but she also was grateful for their more modern aesthetics:

“I like that they are both in colour as well. Like whereas some of the pumps are still in black and white, like an old Nokia phone is what we always think of!” – CI8

"I like the colour screen. I don't understand why some meters don't have colour screens, like it's 2013." – C18

The aesthetics of blood glucose meters varies quite significantly and some participants discussed the aesthetics of the meters that they used and the ones that they were aware of that were available. Some chose a glucose meter because it was a cute looking electronic device: *"I like the one touch ultra better because it is so small, it's like a little, it looks really cute"* – C17. Others commented on the medical aesthetics of meters, choosing to get the *"the coolest"* one that had aesthetics that were *"quite sleek and modern"* [DS1]:

"That it looks really cool and modern. Yes, it looks like a cool piece of technology" – DS1

Although one glucose meter that MU2 used *"does it all"* she lamented it does not *"have the European looks about"* it, meaning stylish and modern. C15 described her ideal glucose meter as *"modernized"* rather than dated:

"It would be sleek, thin, very modernized, very colourful. When you open it, it feels good to open it, it is not some old grey and black computer" – C15

On the other hand, because of the rampant use of consumer mobile electronics, some people benefited from the devices looking like other electronics because they didn't stand out:

"It is just like a laptop or a little purse for a phone thing, so nobody really notices and I don't really care" – C16

8.1.1.2 Functional Expectations of the Devices Linked to Consumer Technology

With experience of a growing range of mobile interactive technology, people's expectations of their mobile medical devices have changed. Everyday interaction with a wide variety of technology means that there are associations, and anticipations (McCarthy & Wright, 2004), of features and functionality with medical devices. For instance, C11 described her glucose meter as *"really big because it is older"*, as she has expectations that newer technology can be made smaller and expects it to be available in the near future with the features she wants: *"I am still waiting to find the tiny size, with the USB port, and a barrel of testing strips would be great."*

Additionally, people are used to having certain features available on their mobile phones; participants mentioned these in relation to what features they would want on future devices and also their frustration about what is currently lacking despite being available for other technology:

"I don't know, kind of like the iPod Shuffle's, the tiny square ones, that you can kind of just put against your skin. You know, maybe make that into kind of a watch, where it's constantly on you and it is monitoring your levels." – C110

This was particularly the case where participants compared the devices to their mobile phones both with regards to preferences, and also the wish to carry fewer devices, as phones were sometimes considered more important to carry:

"I mean ideally, I wish I didn't have to carry it, I wish I could just do it on my cell phone, because everything else is on my phone" – C16

"It would be in my phone. Because it is always with me. [...] I think my blood sugar would be more under control if it did. Just because I carry my insulin everywhere I go, so if I had a blood sugar, if I am randomly bored, blood sugar "oh, 300!" [...] I think it is more of the boredom thing. Because I don't want to go upstairs to test my blood sugar, because I am lazy, so this would be a way for someone, just playing around on my phone, because I always do that. If I am at the gym, on the elliptical machine or something, I would be "let's check my blood sugar, I might as well" – C17

MU12 discussed at length what her preferences would be for an ideal mobile phone application. She *"couldn't find any one that is all"* and she wanted to combine CGM, glucose meter, pump, food, and exercise information: *"one program. I want it."* She wanted to be able to add data categories such as menstrual cycle and look at the information in the way that she wanted to: *"I want to look at what is happening that day, that's the kind of level I need to control my blood sugars."* She knew that the ability to collect all this information is *"all out there, but not integrated"*. She posed the question to MU6 *"if it isn't hard, why aren't there more of them?"* and MU6 agreed that a solution would need *"millions of variables,"* with MU2 interjecting that she would need photos of food, which she was used to having through her use of the Carbs and Cals application: *"life is much easier"*. The theme of having all the technology needs met with one device was also brought up by DS9, who still wanted to have an all-in-one device that is small and neat, but she was disappointed by the size and separate functions of current

devices. When discussing the future of the artificial pancreas, she lamented “*can’t imagine what size that will be*”. MU12 also thought this technology had “*a long way to go*”.

Most participants were aware of the possibilities that new technologies would open up for them, and there was a mix of hope and expectation for these new features:

“I just want something, like the only reason that this is big is because I have the needles for this in here, if like if that wasn’t there, it would be a lot smaller, it is not bad, because I like, I have to carry it, you know. That is why I wish it was on my phone, because I always have my phone, so. Someday!” – C16

8.1.2 Social Norms Influenced Expectations Around T1D Device Use

The nature of the recruitment for the user studies meant that almost all of the participants lived in an urban area, either in the major cities of Toronto, London, or LA or in nearby suburbs. As such, on their commutes in their day to day lives and well as during everyday activities, such as grocery shopping, there were other people around who influenced their actions and behaviours. This type of everyday encounter with strangers carried with it social norms that people had developed over time with exposure to different situations. Norms are closely connected with shared cultural meanings as they “*are measured by perceived social pressures and one’s motivation to comply with them. Norms correspond to expected social outcomes for a given behaviour*” (Bandura, 2004). Participants described how different situations out in public influenced how they carried their devices and adopted devices, relating them to familiar social norms.

8.1.2.1 Participants were Aware of Strangers Observing their Device Use

Overall, a variety of experiences with strangers were brought up by the participants. MU4 said that most people didn’t really know what Type 1 Diabetes was and what was required for self-management. She said her age sometimes confused people into thinking she had T2D, joking to the group that she might clarify “*yes, it’s the really bad one [...] lucky I’m still alive!*”, which received laughs for.

Some participants did not care about strangers noticing if they were using their devices or that they have T1D. Many described how they were oblivious to the general public: “*Honestly, honestly I don’t care. Everybody’s got something*” – C16. Others explained that they did not care if strangers were squeamish about blood: “*They’ve got a problem*

with it, they've got to deal with it." (D6) and *"If it's strangers, I'm not really that bothered. They'll just have to look away"* (D9).

Other participants tended to be more private with their device use and self-care in routine encounters with the public: *"I just do it in my lap not to make it obvious."* – C12. One participant described it as *"secrecy in a way"* and she did not want the attention of strangers: *"I won't want to do anything too out in the public that might create, sort of, someone looking at me or something."* – DS2.

Another participant said that although she doesn't care if strangers know she has a medical condition, sometimes she just doesn't want to risk having to bother answering any questions about it if someone noticed and is curious:

"Sometimes that's fine and sometimes I'm, like, kind of a bugger to explain, whereas if you're obviously trying to do it discreetly, they're less likely to ask a question." – DS9.

8.1.2.2 Participants Used Devices on Public Transport Despite the Audience

Many participants described how their normal routine would often involve use of their devices on public transport (see Figure 30). DS8 described herself as *"always late for something"* and said that she would wait until she got on public transport to use the devices as she considered it *"dead time"*, and did not bother to try to hide her glucose meter or insulin pump: *"People usually stare at me on the tube if there's anyone around when I pull that out but, again, I think I'm so used to it sort of, it's like, I don't know no one's... [It doesn't matter someone will see?] Yes."* - DS8.

D9 cycled to work, but would often take the train to visit her boyfriend who lived outside London and although she would be comfortable to test on the train, she said she would test in her pouch quickly and hide it slightly with her body: *"Probably, I might kind of do it, like, put my knee up, and, kind of, maybe do it there. I don't know. I think that's... yes, I think that's more than likely what I would do"* - D9.



Figure 30: DS7 taking her blood glucose level in the tube

8.1.2.3 Restaurants, Cafes and Bars had Different Social Expectations

There was a wide variety in how people would regularly use their devices in specific public settings, such as restaurants cafes and bars. As visits to these establishments almost always included digesting carbohydrates, T1D devices often had to be used. For some though, their familiarity with the restaurants and cafes near their homes made them more comfortable about not self-managing their condition in ways that would be beneficial to their health:

[About delaying testing and insulin shot] *“Starbucks, yeah, I’ll get insulin when I get home”* – CI7

Unfortunately, eating food that is not personally prepared can be an issue for self-management. As MU5 describes, when glucose and carbs are hard to calculate her *“radar goes off”*. Restaurants cannot be relied on to actively give this information out, with MU2 saying a popular pizza chain changed their menu and *“don’t have carbs anymore.”* CI8 is more comfortable going to a *“chain restaurant”* than one-off restaurants because she is able to use her mobile phone to help with her self-care practices:

“Like a mom and pop kind of thing, I’m just a little more hesitant, because I have to figure out the carbs exactly. Because the big ones, they will have the

nutritional facts, or I look online on my phone [application for Canadian and American restaurants], so it makes it a little more enjoyable, like “will I go high at the end?” “will I go low?”” – C18

Unfortunately, some devices that are helpful for people’s individual self-management routines were not socially acceptable to bring to or use in restaurants and bars. MU2 usually uses a scale at home in order to calculate carbohydrates, but finds it quite difficult when out, and MU12 wants a miniature food scale to bring around with her, with MU6 mentioning a mobile scale device called the “*i-scale*”.

In restaurants and bars, people would adopt consistent strategies to deal with the social norms that they had become accustomed to. DS9 took photos while out at a restaurant having drinks and a pub during the diary study where she was testing above the table where other people could see her glucose meter use, seen in Figure 31 below.



Figure 31: D9 testing above the table when out at a restaurant and a pub

However, some pubs and restaurants had different social norms for DS9: in restaurants “*I’d probably do it on the table unless I was very close to other people*”, but in pubs she would do it above the table consistently as it “*doesn’t bother [her] at all.*” Participants visited a variety of different establishments (see Figure 32), and different cultural expectations in different types of establishments were brought up by some of the participants (“*the ambiance*” – C17). This meant that in some restaurants, devices would be used differently than in others:

“For the most part, but it kind of depends on where I am. If I am at a nice restaurant, I am not going to like whip it out and do a blood sugar at the table, ha! But, back here [in coffee shop] I would be comfortable doing it.” – CI4

“[In a fancy restaurant?] I would probably go to the bathroom and do it.” – CI4



Figure 32: D6 testing above the table in a familiar and popular chain of cafes

For some participants, it was about the proximity of blood to food: *“I feel a bit weird when everyone's eating, and you're, like, squeezing blood out of your finger” – DS1*. CI3 was never influenced to not use his glucose meter in restaurants, but does think there is etiquette when dealing with the used strips with blood on them and had experienced committing a social faux pas in the past:

“I ended up getting it out in the restaurant, the needle and put it on the table for the trash, and then they saw the bio-hazard thing and they got really scared. I thought that was hilarious. It probably wasn't nice in retrospect. [...] sometimes diabetics are really bad with meters, with not picking up their test strips. You gotta pick up the test strips, that is unacceptable to leave them around. But otherwise I use it anywhere I feel like. I have never thought like “I shouldn't use this because there are people around” or anything.” – CI3

This was of course different for different devices and people's comfort level with showing off their devices. During the meet-up, although most of the people in the hotel bar had T1D as they were there for the technology meet-up, MU1 still did not want to show her CGM patch: *“I won't bare my stomach here” – MU1*.

8.1.2.4 Running Errands and Routine Outings

The mundane act of running errands was mentioned by many of the participants, but particularly by those in the diary study as their diary entries captured these dull but necessary everyday acts. How participants used their devices during these times varied significantly, as did how and if they carried their devices, although there was a consistency to their routine use of devices while on routine outings.

DS1 brought her devices everywhere even while running local errands: *“I guess, like, you depend on it. It's everything. You can't really live without it. [...] I never am without it. I've always got it on me even if I walk round the corner to the shop.”* – DS1. DS4 also often had it with her for errands, such checking quickly in line at a grocery store in London, seen in Figure 33. This contrasted with CI9 who did not bring his kit with him when running regular errands:

“I typically will, but if I am just going out to pick something up or just out of the house for like an hour, um I will leave the insulin and leave the meter at home”

– CI9

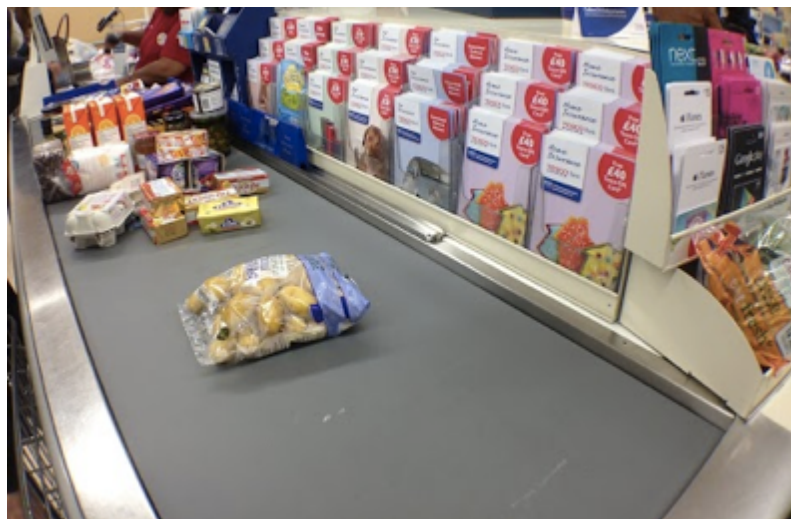


Figure 33: DS4 testing while in line at a local large grocery store

Many participants mentioned going to the cinema as a normal outing, and this is when many of the complaints about lighting arose, as discussed in Chapter 6. However, these film outings became routine in some people's lives and they developed self-care strategies around them. For instance, CI6 had to test his blood glucose levels during the film because he routinely consumed cinema candy. CI5 was usually very careful with eating sweet food as part of her normal self-care strategy, but this changed when

she went to see a movie in the cinema as a social outing, when she had to deal with the consequences of not knowing how many carbs she has ingested from cinema snacks:

"I will eat that popcorn. There is no question about it. And I like to put the candies in the popcorn [...] so I have this ideal, ok what's in the popcorn. They don't know." – C15

Nights out drinking could also influence blood glucose levels, so people would change their habits to deal with these routine outings: *"if I go out socially, I definitely check before drinking"* – C12. Alcohol was brought up by many participants as an influencing factor on their self-care. Drinking could influence how people felt physically and their ability to tell their blood sugar without the meter could be off:

"You can tell by the colour of your pee what your blood sugar is. That's how is used to be done. Exactly, more or less, before they came up with meters. [...] The thing is when you drink, obviously the alcohol is a diuretic, and so what this means is if you have to pee a whole lot and you aren't drinking that much alcohol, then you can figure it out without the meter. If you are drinking alcohol, you can actually have low blood sugar and think you are high. So that can throw you through a loop. [...] Yesterday was my birthday, so you can give me a break, but basically I thought, I was basically 120 when I thought I was 300. That was interesting." – C13

"If I'm, like, out in town clubbing is the only other time it changes because if you're... well, any party or thing where you're drinking you have to keep a really close eye on it because your blood sugar goes a bit crazy" – DS1

DS1 talked about the dangers of dropping low after a night of drinking. Although she hangs out with a lot of others who have Type 1 Diabetes, she is still confident that her friends without T1D will still want to eat after a night out because eating drunk is part of the culture:

"I eat on the way home, and I think it's, even when you're not with your diabetic friends, if they're drunk they would probably want to get food anyway, and I have to get food before I go to bed, so it doesn't really matter. [...] [Drinking] drops you. So you've got to eat something to stay up, but I think I ate too much because I woke up too high." – DS1

8.1.3 Cultural Events Influenced T1D Device Use in Expected Ways

Special events happen throughout the year that are associated with a person's culture. Often these events include traditions and routines, and more often than not, some sort of dining. The participants were asked about the times where they might be overeating, and the example of Canadian Thanksgiving was used to illustrate a cultural event that involves overconsumption. Participants described how these events influenced how devices were carried and used, and sometimes avoided.

8.1.3.1 Overindulgent Holidays Could Lead to Overuse and Non-Use

Thanksgiving and Christmas were both holidays that many participants brought up with regards to eating a large meal or consuming large amounts of food and drink. These holidays are often seen as times of overindulgence (*"That is what the holidays are for"* – CI3), and participants planned for this overindulgence in different ways.

Some participants avoided testing their blood sugars during the day, as they valued enjoying the holiday over thinking about their health. DS9 suggested that she would *"just do a lot of insulin and then do a kind of a catch-all test at the end of the day"* as she didn't want to know the numbers and actively avoided them. DS1 did not want to feel bad about the high numbers that were bound to occur because of the overindulgence:

"Because if you're, like, stuffing yourself all day it doesn't matter what you do you're going to end up high, so I think I test less often because you know it's going to be high anyway, and it just makes you feel bad if you look at it and you get all these high readings. But, yes, if it's, like, being overindulgent then I use it less." – DS1

Some participants decided to not test very often as they would be consistently consuming carbs, and the readings would be all over the place, but compensated by taking more insulin than they normally would require. This was the case for DS8 who had a pump and would take insulin for the entire day and avoid the blood glucose levels that would be all over the place because of overindulgence:

"What I'll do is give myself insulin for the whole day because I know I'm going to be eating continuously, so if I take my blood sugar in the morning, I probably won't take it again until the next... just because I'll be eating so much that my blood sugar is going to be all over the place anyway." – DS8

Like DS8, CI8 was also on a pump but she found she used the glucose meter more often, but would not interact with the pump as much. She found it easier to load up on insulin before overindulging, as she had grown familiar with overeating at her parent's house around holidays, and used the glucose meter to check that her levels were in line with the insulin she injected:

"So I find when I go to my parents house, especially, I test too much, around the clock partly because I know how holidays are with this. And I have found the pump has made it a lot easier. My dietician probably wouldn't like that! [...] I might think, Ok for the next three hours I'll eat 13 carbs or something, different snacks, so I'll tell the meter, for the next four hours, give me this much insulin to cover all that. So I am not, like going back to the pump everything time I want to munch on something. It kind of makes it a lot more easier, it's a convenience thing." – CI8

Like CI8, some participants dealt with the overconsumption influencing their blood glucose levels significantly by testing more so that they could monitor the situation more closely. CI1 is also overindulgent at Thanksgiving, and changes her self-care routines to deal with the additional carbs consumed:

"Well, I usually test more often when I know I will be consuming three times the amount of food the normal person should, ha! So usually I would just test, you know, before, and then I will wait a couple hours after and I will test and then maybe I will test again another hour later if my blood sugar is a little higher, but I definitely make sure I test a lot more during the holidays" – CI1

Some participants mentioned the need to be more careful during these types of overindulgent holidays as their intuition of what their blood glucose level is can be way off of their normal sense of the levels. This can be an uncomfortable situation if they take too much insulin and yet they are still full, so eating something to bring their levels up is a major annoyance:

"I have a sort of sense of my blood sugar. But when you are eating that much, you sort of like "oh my god". And those senses don't tell you as correctly [...] The problem with that is if your blood sugar is low, you have to eat. And then suddenly, you are like "no, I've made a mistake", ha! [...] My ability to guesstimate my blood sugar just by feeling "I feel high or low" it just doesn't work in that situation, I don't know. Everything feels different." – CI3

Cultural events also can mean celebrating with close family and friends, and this means that they can be more involved in self-care during these overindulgent times as they are aware of some of the consequences of overindulgence. C14 found that being around family was like a reminder to use her blood glucose meter:

“I kind of test more during holidays, if I’m, either in Minnesota or here, um, most holidays I have been with family so it is easy to kind of remember my schedule. So I will just test before I eat, and test right after, and then two hours after, because with the massive amount of food, you don’t know what it is going to do!” – C14

8.1.3.2 Weddings and Celebrations Required Adjustments to Routines

Celebrations like weddings can vary significantly with in terms of the family and friends who will be attending, but there are some general social norms that can be judged from having experience with the atmosphere and knowing general cultural traditions, and this can influence the use of diabetes technology.

C15 was very private about her glucose meter use, and a wedding would be no different in her hiding her self-care practices, although the context differs slightly: *“Same thing, I would find a quiet spot. In a hotel, there is always a sofa or something, where you can go.” – C15*

For others, it mattered who was around at the time of testing. Even those who were very open about their diabetes and their device use, the context of the wedding might make them modify their open routine practices. For instance, D9 tells of different self-management strategies she has employed at weddings, depending on whether she is at the dinner table with people she knows or not:

“I’d probably just take it out and do it on the... it’s partly, there are going to be many, if I’m at a table of people I don’t know, I’d probably maybe even go to the bathroom at a wedding. But then, likely, I’d probably just do it.” – D9

C14 was also conscious about who was around at the time of the wedding, but also the timing. At different parts of the cultural event, different social norms apply that C14 was aware of:

“I guess it would depend on how busy it was around. Like, if there were a lot of people around, like doing other things, I would just do it, like, under the table. If it is like, quiet, and someone is giving like a speech, and I am like going to do my blood sugars, I would go to the bathroom or something.” – C14

Although C13 does not often goes to weddings, he is aware that they will be happening a lot more often and is prepared for dealing with the social norms that are accepted at these cultural events:

“It has definitely been a while since I have been at a wedding, but I am starting to get to the age where people are getting married, it is scary. I probably do it before or after, because, I can see pulling out a meter is, you know, watching the vows being made, that could be, kind of, kind of, strange. Yeah, I probably would do it afterwards.” – C13

For weddings, people tend to dress differently and tend to dress up more. This can influence what kind of bags can be brought with people and the spaces available for carrying the diabetes devices. C110 usually has the devices on her wherever she goes, but likes to bring a small purse to these types of celebrations, so she leaves her glucose meter at home:

“Usually at weddings I say, I don’t check my sugars that frequently because I am more active. I check it, I mean, once there. But I, it is so hard to bring the equipment with me, that I don’t. You know, in that purse. I really bring it to family, like weddings and baptisms, or some type of event, because it is hard to carry it with me.” – C110

8.1.4 Summary: Familiar Cultures

The participants in all the studies were generally urban dwellers who had to deal with a variety of people day-to-day, and these experiences in a variety of different cultural settings with collectively shared meanings meant that their experiences were appropriated, and they developed expectations for their self-management with T1D devices. With the ubiquity of mobile phones and the experience of using different consumer electronics for a number of years, participants were acquainted with technology trends and applied this familiarity to their diabetes devices, which influenced not only their practice, but also their user experience. Their day-to-day lives and interactions in different but usual settings made the participants aware of different social norms, and they applied this knowledge consistently based on the place they were in. Cultural events, although with some variety, had different culturally appropriate atmospheres that would influence eating patterns and self-care practices, and participants changed their use of the devices in anticipation of these instances. Cultural familiarity meant that they were prepared for these different conditions and were

inherently prepared for the self-management practices that suited each of these systems, trends, norms, and events.

8.2 Known Unfamiliarity Led to Self-Care Seeking and Preparation

There are situations that people find themselves in where they will be going to a place where they are not completely sure of the culture of shared meanings, or they know that there was information out there that might be of benefit to them. In these cases, the participants prepared for these unknown cultures by researching self-care options, modifying their self-care strategies in advance, or equipping themselves for the worst-case scenario. These known unfamiliar shared meanings were raised when participants discussed actively seeking out online diabetes communities to improve their T1D devices knowledge, preparing for travelling to unknown cultural situations, and over preparing for air travel.

8.2.1 Seeking out the Unknown Through Online and Offline T1D Communities

There are many online and offline groups and communities of people with diabetes: *“parents of diabetics, T1, T2, people who don’t like bananas! [...] think of a group and you’ll find it!”* – MU5. Many of the participants were recruited for this research through online sources. This included through existing communities such as the Reddit r/diabetes forum, but also through word of mouth: MU3 discussed her *“online friends who have diabetes”* and C12 said *“I am part of a group, we haven’t met lately but we all have each other on Facebook”*. Many people posted information about the study to their personal social media accounts such as Facebook, which caused a snowball effect in recruiting for the diary study as many people had made friends with other people with Type 1 Diabetes. These connections through established groups and through connections online sometimes led to real life meetings, such as the one attended for the third study: *“all you have to say is that you will be at this pub [...] huge amounts of people will join”* – MU5. Many participants brought up their use of social media and connections with diabetes groups to get information about their diabetes, to connect with others that have similar experiences, and to find out about new devices, ultimately influencing how they adopted used, and carried new technology.

8.2.1.1 Interest in Research Informed Participants about New Devices

By joining these offline and online groups, participants were more aware of the research being conducted around diabetes technology: *“there is so much information*

on Twitter and Facebook” – MU5. They also discussed using this information to do their own personal research.

At the meet-up, personal research was discussed, with MU6 saying that when he first got a pump, that he *“did some experimenting”* to try to understand the different variables and get accurate results. MU2 and MU12 also said they tried doing this with the same meals, but found the results still variable. MU10 said that it was *“fun”* to try these things, and sometime it works. MU5 says that she can forget what works for her day-to-day, explaining that she deals with this by writing notes on what works to remember. MU6 suggested that the pump can help with this type of experimenting, and he liked how the same dose can already be filled in.

Additionally, knowing about research on diabetes influenced how participants viewed their current technology and how they see future technology: *“we’re getting close, we’re missing 5 hormones, we only get one”* – MU5. Although D9 said that her brother was the one into research, she could hear about new devices from him: *“I’ll ask, like, my brother if there’s something that I need to know about, he’ll probably have.”* MU6 also seemed to be aware of research that wasn’t even published yet, telling the meet-up that *“new [insulin] research is about to be released.”*

Being part of these communities also encouraged these participants to get involved in research themselves, which could be in turn beneficial. MU12 was able to get into an artificial pancreas research trial because of a *“patient connection”*. She was very knowledgeable about the technology coming down the line, and was able to argue with MU6 about the different algorithms used.

MU1’s involvement in a research project got her initially interested in the CGM and when her GP could not help her with it, the researchers were able to help her get started with it. CI7’s involvement in a research project influenced her expectation for future blood glucose level monitors:

“and it would be like touching a button or something. Blood sugar. Or scanning my finger [...] The study I did before, you put your thumb on a thing and it measures your blood sugar. And I thought that was kinda cool.” – CI7

8.2.1.2 Sharing Tips, Tricks, and Support Online Influences T1D Device Use

All the participants were diagnosed with diabetes more than 6 months before the study, and most had the condition for a number of years. With the responsibility of self-care

mainly on their shoulders, many had come up with routines and tricks in order to make self-care easier or to get the most out of their devices. A number of these were shared among the group at the T1D tech meet-up.

When participants were discussing the use of their glucose meter, tips and tricks for conducting tests were exchanged: *“what’s your regimen for your finger?”* – MU6. MU5 shared that she tests on odd fingers and then even fingers every second day in order to minimize any damage to finger tips, with MU6 describing he does *“round robin”* on all of his fingers. MU5 further suggested that instead of squeezing a drop of blood out of her fingers, she tends to pull the skin apart to release the blood, which she finds to cause less damage.

Support for current technologies can be found on the Internet, and many participants described reaching out to different communities to gain technical support. When MU1 CGM use was not being supported by her GP, she resorted to watching American YouTube videos. MU4 was having trouble with her pump, so she used the internet to meet people who were at the meeting to help her learn how to change the intensity of the basal rate *“I am quite new at it, but I am getting better at it”* – MU4. MU4 also protested against MU1’s assertion that she was *“alone”* with the lack of CGM support in the UK because there were plenty of resources and people online she could engage with: *“there is no way you are alone”* – MU4.

Many participants discussed finding out about these suggestions and others by engaging with diabetes communities, both online and offline. These tips varied in their usefulness, but many participants engaged in these communities just in case there might be some personal use in what was being shared:

“I was actually reading somewhere about what people name their pumps the other day” – CI2

8.2.1.3 Peer-to-Peer Emotional Support Can Influence Adoption

Frustration with the condition itself can arise: T1D can lead to *“burnout”* (Polonsky, 1999) has been described as a *“relentless condition”* (O’Kane et al., 2013). This type of frustration can be relieved by sharing it on social media (*“that’s why Facebook is useful”* – MU5), where T1D friends can support people by reaching out and getting encouragement to *“get on with it”* – MU5.

Even just being able to commiserate with self-management routines seemed to be useful. At the meet-up MU4 said it was “*weird no longer injecting*” after she got her pump, with MU10 agreeing “*so weird*”. When talking about the pump, MU6 said that the “*pump fixes all of it*” and MU4 asked herself “*what was I thinking?*” by not adopting it earlier.

Stories from other people with diabetes can also influence the self-care activities of people reading or listening to these stories. CI1 got fed up of constantly self-managing the condition, but even by lurking on some of these websites, she was motivated to focus again on the use of her devices for self-care:

“Can’t really skip out on that kind of thing. And once I’ve seen some people, because there’s some people that, I mean, I don’t know them personally, but you know, on the diabetes subreddit, there are people that talk about problems that they are having and they are like 27 years old. And it is like “how is it that you have neuropathy so bad you can’t do much of anything anymore?” and its just, I don’t know. It’s kind of, it’s a wake up call when I read stuff like that, so I really try to stay on top of it. So.” – CI1

Emotional support was not always the consequence of people sharing over social media though. Sometimes access to diabetes information was not helpful during times when blood glucose levels were harder to control, as seeing more reminders of the condition in addition to bad levels on the glucose meter could get to participants. As DS1 was sick for a few weeks before Diabetes Week, the posts of other people were upsetting for her:

“I think it was, like, everyone posts on Facebook in Diabetes Week about, like, looking after yourself and blood and all that stuff and complications and people going blind, and I’m like, “oh my God, my readings haven’t been in range for, like, three weeks”, so I think I was a bit depressed.” – DS1

This also occurred more consistently with CI10 who would actively avoid looking at diabetes related things on the Internet as she found it overwhelming, and consequently she did not look online for new or upcoming T1D devices:

“To be honest, I try to stay away from... [...] when I read about diabetes, I get very upset, and I make sure I do it on my own time and I am not in front of people because it puts me, it kind of ruins my day. You know, you look at the long term effects and stuff, which I usually look at. So that’s why I never really

looked into other monitors, or about diabetes. In the past year, it's very emotional." – C110

8.2.1.4 *Misuse and Off Label Use of T1D Devices Can be Encouraged by Peers*

Misuse of diabetes devices is a popular topic among the online and offline communities, according to the participants. Much of the interest in off-label use was about trying to get the most out of the technology, particularly if the person was paying out of pocket for care. MU1 who bought a CGM and felt the expense of it cost *"a bloody arm and leg"*, found out a component that had to be changed every few days could be used for longer: *"I read online that people can make them last 21 days."*

Finding out about new technologies from these online and offline communities can influence people to adopt them against medical advice and misuse them. After a trip to the US where pumps were very popular, MU6 *"saw insulin pumps and said "wow, this is fantastic!"* He decided to buy his first pump second hand online as he was not able to get it covered based on clinical guidelines in the UK until *"after two to three years, the NHS covered it"*. He was therefore paying out of pocket for the consumables that were required in order for it to function properly, which cost about £100 per month *"if you use it how you are supposed to"*, which of course he wasn't doing: he was *"stretching it out"* as much as possible. Instead of changing the infusion set every 3 days, he was changing it every 5-10 days. He said to the group that the reservoir was supposed to last 3 days, and he read that it could last a year, which got a laugh from the meet-up attendees. With regards to misusing the devices to make them last longer, MU6 thinks *"everybody does it" and the conversation turned to comparing brands to how much their supplies could be stretched out. For instance Dexcom was considered better because their supplies could last longer: although supposed to last 7 days, "I heard people use it for 20-30 days"* – MU6.

Getting over the frustration of poor numbers could be dealt with by breaking a cheap glucose meter, as discussed in previous chapters. Along with the cheap price and bad levels influencing this sensual reaction, online and offline communities could encourage this behaviour as well. MU2 shared with another participant that she had thrown her glucose meter in frustration and MU5 responded with familiarity: *"I've done it too!"* MU5 said that an American blogger suggested when frustrated, you should drive over it with your car: *"Yes it helps"*.

8.2.1.5 Online Sources can Suggest T1D Technology to Adopt

Beyond looking to social media for tips and tricks with regards to current self-care activities, participants also mentioned hearing about new technologies and new research from online sources. This influenced the way that people adopted new T1D technology and used it:

"[Did you go on the internet looking at models?] No I haven't, and that is actually my next step. I have gotten to the point where I am like ready to try something new." – C110

"I just, like, look it up online. [...] So, like, I've got so many meters at home. Yes, I just try them out." – DS1

DS1 was very active on social media and was aware when new technology would be released. She was an active iPhone user, and so she would try out new apps when she heard that they were released, although she did not end up adopting any in the long term (*"They just didn't cater to what I wanted"*):

"I've had, like, Glucose Buddy, D Sharp; there's probably a few other ones. I, kind of, like, try everything and when they come out" – DS1

Based on MU6's trip to the US for a diabetes wilderness 10 day trek event where *"everyone had an insulin pump"*, he said he thought *"this is fantastic"* and adopted a second hand pump when he could not get coverage for a new pump. Based on internet research, MU6 thinks that there are *"no Dexcom problems [...] it is also surprisingly resilient, considering the needle looks like a hair [...] it is also pretty accurate"* and would adopt one based on this internet research, if it wasn't a *"ridiculous amount of money."*

8.2.2 Preparing for the Unknown when Travelling with T1D Devices

In some cases, participants were travelling to places that they were not familiar with, and this influenced what they carried with them when they travelled. Often times this meant participants were bringing extra kit 'just in case': *"I usually am a little bit worried about bringing it because, you know, if it breaks or something"* – C11. MU6 described to the group that when he goes on holiday, *"you need all the stuff"*, which includes a spare pump and huge amounts of *"backup"* but he fortunately had not had to deal with any adverse events in the past. He said he packs so much stuff *"you only have a bit of room for clothes!"* MU10 described taking spare kit on holiday, especially after once catching her insulin pump tube on something when on holiday. MU4 agreed and said

“that’s what I am paranoid about” and agreed that she also takes spares. CI7, a participant who generally only tested her blood sugar once or twice a day and did not bring her glucose meter with her during her daily routine, even admitted that when travelling, she definitely brought her glucose meter with her:

“On trips especially, it is the first thing that comes to my mind. Like when I go out during the day, I don’t remember it at all, but on trips I have my insulin, my glucose meter, and my meter. Just to like have it. I don’t think it is a drag or anything to think about, because it is always in the back of my head.” – CI7

When going away, MU12 also brings backup, but called the guidance *“rubbish”* that you would need a backup for something as minor as a night away. CI2 and DS1 also changed their practices based on what type of travel they were doing and for how long:

“If I am going local, I take some extra needles, if I am going abroad, I take extra everything.” – CI2

“Overnight stays I don’t usually worry too much because that’s like, there’s always pharmacies around and stuff if anything happens, but it is a pain when you’re going overseas because you have to have batteries in case it dies, you need, like, all the lancets to go with it, and I always have a backup meter as well, in case it gets taken or you drop it or, like, I’ve lost my meter before, and it’s, like, meltdown, panic mode, so I always have a backup one. Yes, it’s a lot more stressful when you’re going overseas.” – DS1

It is not only the unfamiliarity with the healthcare system culture that people prepared for. It was also that they were unsure of what food they might have access to, which might get them in trouble if their levels were dropping. This led to CI6 bringing more supplies as he was testing more on road trips, which was the opposite practice to when he was familiar with a beach trip:

“If I am in a place where I don’t have access to orange juice if I go low and stuff, I will usually test more often, that’s usually on road trips. I also pack extra strips and stuff, because know I am going to end up using a lot more when travelling.” – CI6

“You know on vacation, I said that I would check more, but I didn’t take into account going to a beach or like place like, Miami Beach, where I am on the beach all day. Surfing, or skateboarding or something, and when I am doing

that I just don't test at all. Because my blood sugar's going to be low anyway, because I am doing so much activity is going on, so I usually, yeah, I only test when I am about to eat usually, so I would say I test a lot less. [...] Because I know that it's not going to be high, and when it's not high it's not bad, and I can catch my low a lot easier than a high, so if I know I am low, I will go get a beverage or something, and just skip out on testing all together" – C16

Furthermore, when travelling, some participants described being more careful with their devices. MU4 explained to the group that in the past she has taken a break from the pump when she was on holiday. A few people were astounded, with MU10 asking *"for more than an hour?"* and MU4 explained that with kids, a beach, a waterpark, etc, she would need a waterproof pump, which are not covered by the NHS according to MU5. MU4 did concede though that she couldn't *"see why you would take a fortnight off"*. This was also the case with D9, who brought some spares on holiday, but feared that the heat in Morocco would destroy her insulin so she did not take too much of it:

"I'd bring two spare pens just in case I lose a pen. But insulin, because you've got to... like, in a hot country, it's difficult because it's meant to be refrigerated, and so, I wouldn't bring two." – DS9

Being on holiday also meant that routines were not the same (see Figure 34) and there could be a bit of unpredictability with what self-care would be needed: *"On holidays, it kind of depends on the holiday. Like a ski holiday, I probably would do extra tests because, again, it's active, and it can just be kind of unpredictable."* - D9. On the other hand, similar to some overindulgent times where participants mentioned that they would avoid doing tests because they wouldn't want to have to deal with the numbers, on holiday people might avoid testing or forget about it:

"But on kind of a summer holiday trip, I think they'd be mostly similar to a... if it's an active day, I'd probably be doing quite a lot of tests. If it's not an active day, I'd probably be, maybe, avoiding doing tests if I'm eating a lot, and... yes, and don't want to have... and don't want to identify a reason to, if you know what I mean." – D9

"Especially like when I was in Las Vegas because I was up really late, really late and then, like the whole thing would be thrown off [...] kinda of like just when I remember to do it because I'm usually thinking about the trip or whatever is going on" – C14



Figure 34: D8 checking her blood glucose levels poolside at a hotel

CI11 said that her control is actually better when she is away on holiday and away from the stresses of everyday life, but she is also more careful during these times:

“Yeah, typically when I am away from my own environment, because I am less stressed and I don’t have the option of doing my to do list, that you have relocated yourself away from your busy life, I actually do improve with the glucose use, so I check more, and just yeah. And also you don’t want something to happen when you are further away from home.” – C11

Some participants adopted devices just for travelling. CI5 travelled a lot to Bridge tournaments and would try to enjoy the new cities she visited, including some sweet delicacies. For these travels, she adopted a glucose meter that did not have the same functionality as the one she left at home, but was easier to use more often privately because it was smaller:

“No problem, that’s why I have one of the portable ones. When I travel, it is once every other month, in April in Virginia, in May, Seattle, and also the weekends. You can get in trouble on holidays. [...] I test more often. [...] I test more [...] you are walking around different places, and you are not going to get anything? Not even a bon bon? So it makes it very hard, so that is why on vacation I test more often. And you need adjust your insulin so you don’t have a problem.” – CI5

8.2.3 Uncertainty in the Airport and on the Flight

Most participants were quite dismissive about having to go through airport security, despite some of the dreadful stories that can be found online about issues with security agents. For instance, not allowing an extra medical bag on with T1D supplies because it did not look medical enough (an anecdote from a diabetes technology conference I attended). Participants were generally aware that they might have a variety of experiences with airport security, and prepared for these possible situations:

"Airport security, I haven't had any issues. I bring a letter from my endocrinologist, just in case." – C19

"It was actually, they didn't stop me at all. So, I had my carry-on with my needles on me, and all that stuff, and I was ready to bust out the paper saying "no, no, I am a diabetic and I'm allowed to bring some food onto the plane with me because..." I have a paper that says so in case I have a low, but um, they didn't stop me at all. [...] they didn't even stop me." – C110

MU4 was prepared when flying through Hong Kong and had a letter explaining her condition. She had to show the authorities the letter as they were being "a bit fussy". MU5 doesn't worry about going through security at the airport as her pump's aesthetic looks medical and she can show it and "they are "woah! A medical device!" though she mentioned that she is "waiting for the day where a terrorist says they are diabetic".

This level of preparedness could be a source of annoyance for some of the participants, but they still made the effort just in case:

"Sometimes it can get annoying if I am going places where you have to get a doctors note or something. At the airport they are usually pretty ok, but um, sometimes it feels like it gets annoying." – C12

C11, who usually travels by plane to visit her parents across the US, also has had issues in the past with airport security:

"it's a little bit stressful because going through an airport with it you know, I've had them yell and scream at me before about my insulin pump thinking it was a cell phone or a pager, that I just didn't take off. And I always bring my all my pump stuff through, carryon and everything and my meter and everything. And I haven't really had too many problems with it, They have never questioned me about what it is or anything. Just, it's not really that big a deal, I do worry sometimes about like, you

know, somebody does say something, like, it would be fine, I have had tons of people question me about it before, and it doesn't bother me, it is just that, you know, if you are giving stuff to the TSA and trying to deal with them. They are very... they are not knowledgeable about people. Let's put it that way, ha! They are not knowledgeable about diabetes and diabetes management, which I wouldn't expect them to be, but they should know what to look out for.” – C11

Beyond security, participants also discussed self-care with devices on the plane (see Figure 35). Flying can involve eating, as flights that are of a certain length usually have a meal served on them. This of course means that participants have to use their devices on the flight to account for the carbs ingested. C16, who described himself as quite open with self-care in normal social situations, felt that he had to be a bit more discreet on the flight itself:

“So like, if I am on a plane, next to somebody, I'm usually like, if it's needle I'm more, you know, hide it, because I don't want to freak anyone out, but if I am just pricking my finger, nah. Don't care.” –C16



Figure 35: D8 using her blood glucose monitor on a flight

8.2.4 Summary: Unfamiliar Cultures

Unlike for familiar cultures, there were cultural settings that participants were aware of or were visiting that they had to adapt their self-care practices to. Although they were unsure of the exact situation that they were getting into, they prepared themselves so that they would not have to deal with any surprises and get the most out of these unknown situations. This was the case for online and offline diabetes communities. Participants were unaware of some research, tips, emotional support, tricks, and suggestions that were out there, but the knowledge that they were out there influenced

their actions. They lurked on social media, signed up to online communities, and attended events to meet with other people and learn more about their condition. This influenced the way that some participants conducted self-care with their current devices, how they adopted new devices, and what their expectations and hopes were for future devices. Different cultural contexts in different locations were also known to be unknown, for instance when participants travelled to new places. Although they were uncertain about exactly what their circumstances would be like for self-care practice, they were able to prepare in advance by bringing back up supplies or bringing along medical letters that were rarely looked at. Knowing that there might be unexpected events influenced people to prepare with resilience strategies just in case, and most often these participants were over prepared, which they considered to be a bit annoying but better than being underprepared.

8.3 Unexpected Unfamiliar Cultures Leading to Reactions

The majority of instances of self-care occurred in cultures that were familiar to the participant, or which they expected to be unfamiliar and were able to prepare for. Although far less common, there were instances that the participants found themselves in an unknown cultural setting that they were not expecting. These surprises led to changes in the way that they would normally conduct self-care as the participants had to think on their feet, relying on expertise that they had gained in other situations and apply in these situations, or just deal with the consequences of the unexpected situation.

8.3.1 Unexpected Public Situations with T1D Devices Led to Reactions

Although the participants became familiar with the social norms of the general public, there were cases where the general public became a lot more uncertain. This is where their previous experiences did not prepare them or allow them to anticipate the results of using their devices. For example, DS1 was in an area of London she was unfamiliar with and did not feel comfortable showing off her iPhone to interact with the diabetes mobile app. Whilst at a hotel bar that MU2 was unfamiliar with for the meet-up, she went to get a drink and encountered a “close call” when she asked for a diet Coke and got a regular, full-sugar Pepsi. These situations required both vigilance and also for participants to be more flexible with their normal T1D device use.

Although many participants did not describe major issues caused by their use of the devices in public, some had the misfortune of dealing with interactions with strangers. Some were able to confront them to control the situation, such as CI9: *“I’ll use it in public, I’ll test, you know, if you are looking at me and find that interesting, “hey buddy, what can I do for you””* and *“if anyone said anything, they would have a negative social experience”* – CI9. Some participants brought up instances where public use of the devices have actually caused issues for them:

“I was at a carnival once and you get tickets and you trade them in for a prize, and a bunch of my friends wanted FunDip packets, and I was like “alright, give me all your tickets, I’ll go get ‘em” and the guy refused, absolutely refused to trade the tickets in for this candy, which wasn’t even for me! And he said “no, I can see your insulin pump. I know what you are” and he refused! He was like “I will not be held responsible for your life decisions.” He refused, and I was like “really? Really?” And this happened, I want to say, 3, 4 years ago. [so when you were in your twenties?] Yeah! I was like 23, 22 at the time, something like that, yeah. I was in college and I couldn’t believe it. I was like “really? Really?” So, yeah.” – CI1

8.3.2 Reacting with T1D Devices to Unexpected Social Events

Usually social outings were planned in advance for participants, or at least they had some sort of expectation of how they would unfold based on prior experience. However, there were cases where participants were out and about with friends, and did anticipate the activity would influence their self-care practices. For instance, drinking too much at a friend’s house and sleeping over, and choosing not to use their T1D devices in that situation:

“If I stay at someone else’s house and I happen to drink a lot and sleep over there, I’m not even going to take my blood sugar.” – CI6

CI6 also encountered this when going out with friends and not expecting there to be a meal involved. In this case, he abstained from eating so that he wouldn’t have to deal with high blood glucose levels as he did not bring his kit with him:

“I went out with my friends, I forget where we were going, but I was under the impression that we weren’t going to eat, so I just left it at home, because I was like, I think it was warm out so I wasn’t wearing a jacket, so was like, “eh, we

aren't going to eat, so I'll just leave it here" and then we ended up staying out longer, and everyone wanted to eat, so I guess I skipped eating, or skipped that meal. I ate later." – C16

Social events could also turn into unknown cultural situations. C13 was prepared for a Christmas meal based on his experiences of the past, but was not prepared for an on-going feast when he was invited over to celebrate with a new set of people:

"It was going to be something between a lunch and a dinner and then it turned into a big lunch that was more dinner, and as the afternoon progressed. The thing is that, that, I tested my blood sugar before I started eating, and then, I'm on a pump. Start eating, take insulin, eat more, take more insulin, eat more, take more insulin. Just constantly. Disgusting in retrospect, man. Ha ha!" – C13

8.3.3 Visiting Places with Unexpected Norms Could Influence Use

In some cultural settings, people had a lot of experience with different possible situations and could identify with cultural norms easily, but in others they were not prepared for different cultural norms. This occurred with unknown people and also in unknown places, influencing how devices were adopted, carried, and used when participants travelled.

Known cultures can change unexpectedly to unknown cultures very quickly after a major event, which is what happened in the air travel industry in 2001. MU4 flew relatively soon after the September 11th airplane hijackings where all hand luggage was banned, and she had to *"fight"* to get her supplies on.

There were other unfamiliar situations people found themselves in, such as taking public transport when on holiday. One participant, who had earlier described herself as not caring about strangers, found herself hiding behind her boyfriend as she was uncertain of the social situation:

"Maybe in Morocco, I might be more particular about... I'd maybe get my boyfriend to just stand there and I'll do this, you know." – DS9.

When in different places, you can be unprepared for some of the cultural shared meanings that exist because of lack of experience. This was the case for C14 where she was not that familiar with the culture of visiting casinos, and the ban they have on recording instrumentation. By just the act of wearing her pump in a partially visible

manner, C14 attracted the attention of security guards who were unaware of the device having a medical purpose:

“I was in Las Vegas once, and I was wearing a red dress, and they came up, because I had it stuck in the back of my dress right here, and they came up and they thought it was like a recording device, like, they were going to take me out of the casino!” – C14

There were also cultural situations that were not only surprising, but could not be prepared for. When visiting an ex-boyfriend’s extended family abroad, C10 was not able to adequately communicate her health concerns as she wanted to keep her condition private from them. Although she was able to hide her self-care practice, she could not control the food that was being bought for her as a show of welcome in this unfamiliar cultural setting. She was expected to consume it to show her gratitude, so her control of her levels was very poor for that month:

“It was kind of difficult because I tried to hide it from them all the time. [...] It was friend’s family, and I just felt like you know, I kind of didn’t want to explain it to them because, they would kinda look at me differently, so I...and it was definitely hard because they would be buying food all the time for us and it’s like, I can’t eat that but I’m going to, you know, so that really threw me off last year. [...] it was definitely challenging when you know, your meals are being prepared for you or you know, surprise, here’s breakfast, everyone love a feta cheese pie. Or spinach pies and stuff, well you know. It was very hard to manage last summer and it was a learning experience for me because I came back and I wasn’t feeling well, um so I did feel some numbness in my toes and all that” – C10

C10 had recently come back from travelling again, this time to Jamaica to a beach resort. Again she expected there to be drinks that she could order, but she was unprepared for the resort culture of offering its guests very sugary drinks:

“I recently went to Jamaica, came back a few weeks ago. It was still very difficult to maintain, because most of the drinks that they cater for on the resort were sugary coladas, and it is so hot, so you want to have a drink, but what are you going to drink. It was really challenging to get them to make a different drink. So it is difficult all around.” – C10

8.3.4 Summary: Unexpected Unfamiliar Cultures

People would expect situations in familiar cultures and unfamiliar cultures to influence their self-care practices, but participants discussed times where there were unexpected cultural issues that they had to deal with. These occurred both at home and abroad, and participants had to use expertise gained in more familiar circumstances or just deal with the consequences in relation to their self-care practices with T1D technologies. Public situations could be unexpected even in the cities people lived in, and social situations could also be unexpected even though participants had experienced similar situations many times before. In different places, situations could occur that influenced a person's ability to use or adopt their Type 1 Diabetes technologies, but also the user experience of having to carry the devices on their person could also be impacted by an unexpected situation. In these cases, people had to rely on expertise that they have gained over the years or improvise a solution on the spot.

8.4 Cultural Context Discussion

Similar to the last chapters discussing environmental influence and healthcare systems' influences on the use and adoption of self-care technologies, this chapter on cultural influence has uncovered that there are variable practices among adults with T1D in routine situations.

In familiar cultures, participants experienced technology trends and knew what the social norms were in different situations through appropriating their past experiences in similar situations, leading to expectations (McCarthy & Wright, 2004). They have developed these shared meanings, and have adapted their self-management styles and preferences with T1D technologies to suit these cultural practices and inclinations.

They were frustrated by the lack of features that could be seen in other available technology, and they were also very aware of what was culturally appropriate with regards to the aesthetics of commercially available technology. They also had expectations of familiar situations, and sometimes chose to not carry or bring devices as they felt comfortable running errands locally. From past experiences, participants were able to determine what was appropriate at weddings and celebrations with regards to self-care and also how adapt T1D self-care practices around large celebratory meals. Overall, the participants were familiar with these recurring cultural

situations and knew what to expect, and therefore had routines for their self-care practices with their diabetes technologies.

Participants also encountered situations where they knew that there was something unknown. This occurred in two major ways: knowing that there was self-care information out there that they were unfamiliar with and knowing that visiting an unfamiliar culture would have different influences on their normal self-care practices. The nature of the recruitment for the user studies meant that many participants were Internet savvy and may have found the study through an existing social network of people with diabetes and related sites, so they knew where seek out knowledge on T1D devices. There were other situations where participants delved into the unknown, but were prepared for it: when travelling or moving to a new place. Participants weren't exactly sure what to expect in these situations, but they did know that they needed to prepare for them, and sometimes over-preparing in the process. Although this could lead to minor issues, such as uncovering too much negative information on the internet about side effects or losing too much luggage space because of additional devices, most participants were willing to practice these resilience strategies in order to get the best self-care or to maintain their normal level of self-care.

In some cases, participants encountered unknown cultures that they were not prepared for. Although these did not occur very often, these instances could have major effects on self-care, quality of life, and user experience with the devices. Participants did not expect to have issues with the general public until they found themselves scared to use a diabetes iPhone app on an unfamiliar street or almost kicked out of casino because of what their insulin pump looked like. They didn't expect to be uncomfortable testing on public transport abroad and had to use the resources available to them in innovative ways in order to feel comfortable. Being caught in an experience that they did not anticipate, participants had to improvise when caught in a situation that influenced their self-care.

This chapter discusses how people's familiarity with the cultural contexts in which they are conducting their self-care influences their use, adoption, and carrying of their mobile T1D devices. This range of situations is eloquently put in a controversial quote from Donald Rumsfeld (Rumsfeld, 2002), the US Secretary of Defence in 2002, justifying the lack of evidence linking the Iraq war with weapons of mass destruction:

“there are known knowns; there are things we know we know. We also know there are known unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns – the ones we don’t know we don’t know.”

Through a bottom-up approach to the data, it was found that the culture that people grew up in, were living in, and were often visiting influenced how they would routinely use their devices, as it was a known known. This familiarity over time allowed for participants to build individual styles and expertise when it came to self-managing their condition with the help of T1D devices. On the other hand, cultures that were not experienced previously and not completely familiar to the participants provided both opportunities to learn more and influenced preparedness. This known unknown influenced self-care strategies to be resilient and also be anticipatory. Finally, the surprises came when the participants didn’t know that they didn’t know the surrounding culture, and found themselves in situations that they did not suspect. This unknown unknown culture meant that participants relied on quick fixes or dealing with the consequences, and improvising and exploiting the resources that they had on hand and relying on their own expertise.

Overall, familiarity allowed for anticipation of situations, and sometime controlled risks, and although over preparing for an unfamiliar context could be ‘annoying,’ this was not nearly the negative sensual experience of being caught in an unknown unknown. These surprise situations could have influences on non-use of devices but also negative user experiences with them, independent of their functionality.

9 - Social Situations

The results in this chapter have been published as a Paper in the Proceedings of CHI 2015 (O'Kane, Rogers, & Blandford, 2015).

As Type 1 Diabetes devices are mobile, they are brought into a variety of different social situations every day, during both routine and non-routine times. These social contexts were found to have a major influence on how the participants carried the devices, which devices were adopted, and how they were used. Some of the most major misuses of these medical devices were discussed by participants in relation to face-to-face interactions, specifically who they were around at the time of use. Through taking a bottom up approach to the data, it emerged that the social context influenced the use of these devices. Although both cultural influences and social influences are about shared meanings, for the purpose of this chapter, a social situation differs from a cultural influence as the social deals with face-to-face encounters with small numbers of people, rather than a culture at large influencing use.

A number of specific issues with adoption of devices, carrying devices, and use of devices were identified, and these often occurred in social situations. They included encounters with family, friends, colleagues, romantic partners, people in different countries while travelling, and strangers. This concerns the spatio-temporal thread of felt experience (McCarthy & Wright, 2004), in that distinctions are made with regards to the social setting that influences how the participant experiences self-management with T1D devices. Everyday normal routine involved a broad range of self-care practices in front of familiar people and social situations, but non-routine times led to uncharacteristic use of the diabetes technologies. These self-care practices differed from the participants' usual interactions with their technologies, and instead involved uncharacteristic hiding in uncertain social situations and showing off in social situations where there was something to be gained.

9.1 Normal Use in Familiar Situations Varies Widely

Participants showed a wide range of practices in how they handled their devices in their everyday routines, which involved their routine work lives, and their personal lives.

Despite these variances between participants, normal routines allowed fairly consistent interaction styles with the diabetes devices in familiar social situations.

9.1.1 Familiar Use at Work

Although a few participants were currently unemployed or were students, most had full-time jobs. As going to work was part of their weekly routine, they developed habits for dealing with self-care in front of colleagues and people they encountered at work.

Different jobs were in different types of social environments, so people picked up routines that were appropriate to those situations and conducted self-care in ways that they felt comfortable with. C14 worked part-time in a bar, and therefore had to handle food and drink on a regular basis, so she hid her self-care away from colleagues and customers as she thought that was appropriate:

“I would go in the back where no one can see me, and do it under the counter there, probably. That’s usually where I do it, or go to the bathroom and do it. [...] Yeah I think so, because I am trying to be more professional, I guess. It is funny, because people have seen my pump at work, and they are like, “oh I am a type 1 diabetic too” but I feel like I have to hide it more at work because people are eating, and I am handling their plates, and like doing my blood sugar with blood on my fingers, I don’t know. Even if I wash my hands, I feel like people might feel weird about that.” – C14

Some people were quite protective and secretive about their diabetes when with colleagues. C19 said *“I mean it is not a secret, but I don’t go out of my way to do it in front of them.”* One participant discussed how she had to tell her boss when she started for health and safety reasons, but avoided conducting self-care activities when co-workers were around:

“There’s no one that walks past me, you know. And maybe I just pick it when it’s quiet. Although people over the other side of the desk won’t see me.” – DS4.

Others were far more open with their self-care activities and use of their devices: *“because of my comfort zone, I will check it at work [on top of the desk]” – C110.* One participant travelled to different construction sites as part of her job, as well as having a desk in an open office. She routinely tested herself at her desk (see Figure 36) and *“on site”* with no concerns about being seen by her co-workers: *“I would have told most*

people [...]. And then, because you're doing blood tests and doing injections, people will just figure it out or they'll ask you or whatever.” – DS9.



Figure 36: DS9 testing visibly at her open office desk

9.1.2 Familiar Use Around Close Family, Friends and Partners

Participants' everyday lives involved regular contact with family, friends, and romantic partners (see Figure 37). This regular contact allowed for self-care regimes to become routine, but how open people were in front of close family and friends differed quite significantly.



Figure 37: DS7 testing in front of her husband and small child

Some people were very comfortable with their romantic partners and did not hide their self-care from their view. One participant (DS5) described an inside joke among insulin pump users that their *“partner knows when they're going to get lucky because, you*

know, you're snuggling in bed and then you're, like, "let me just disconnect my pump.""

She was very comfortable showing her devices in these intimate situations:

"We've got to disconnect the insulin pump because we don't want to get the tubing wrapped up in any awkward places. And sometimes... well, not sometimes, it's, kind of, like, clockwork there will be some buzz or some vibration from the table while we're... you know." – DS5.

Some participants incorporated their partner into their self-management, such as C14 who will call up her boyfriend to bring her meter to her if she forgets it:

"There's been a couple times, where I am, like if I'm out for a couple hours and I forget it [...] if I am at work or something for awhile, I will like call my boyfriend and get him to bring it to me. And he's cool with doing that. So." – C14

C17, a university student, was also very open with her self-care regime in front of her live-in partner, so he was familiar with the devices and how she used them and encouraged her self-care practices. She was so comfortable with him being involved in her self-care, that if she passed out drunk, he would use her glucose meter to test her BG levels and then would inject her if necessary:

"He always makes me test before I fall asleep and he reminds me every time. Even when I am like, even when I go drinking, um, I like pass out when I go home, and he tests my blood sugar for me and gives me insulin for me. He does it, he tries to make me do it once a day, and he tries to make me do it twice a day but sometimes, sometime we both forget because we are like watching TV, or doing something. Minimum, once a day." – C17

C17's partner is so involved in her self-care, that he often is the person testing and injecting her:

"So when we are in fights and stuff, and he hears the test meter going off [...] he even gives me my insulin, and if he hears the machine go off, "he's like, are you giving insulin?" "yeah, without you" ha!" – C17

Some participants were very open with their use of the devices around close friends who also had T1D or who worked in diabetes care: *"If I am at a friend's home, I am probably pretty comfortable with them. So I will probably do it just there" – C14.* For example, DS5 described a glucose meter drinking game they made up called *"blood glucose bingo."* C16 described borrowing insulin from a co-worker who also had T1D

saying *“I have loaned him insulin before though, so we’re even”*. DS1 described testing together with a close friend who also had T1D: *“If she’s testing and then I’m like, I may as well and then try and see who gets the best reading”* – DS1. DS1 said that different friends sometime required different strategies, including her friends with diabetes:

“I think if I’m with my diabetic friends then we just, like, you’re just so used to everything you just do it on the table or, yes, but if it’s with the other friends then you don’t want to gross them out by like bleeding everywhere and stuff.” – DS1

This was also the case for some participants that were very comfortable using their devices in front of family, including DS6 who lived at home with her parents (see Figure 38).



Figure 38: A diary entry by DS6 testing in front of her parents before a family meal

In other cases, participants concealed their routines from their friends and families:

“No. I don’t think you ever get comfortable [...] It makes people uncomfortable [...] they know I have it, but they never see me. I do it away from people.” – CI5. Although her family knew about her condition that she had from childhood, CI5 never felt comfortable conducting self-care activities in front of even her closest family members: *“My husband says he can do it, and I say “no you can’t.” It is a personal thing. It is a very personal thing.”* – CI5. She was so secretive about her self-management, that she wouldn’t even involve him when she once forgot the devices while travelling:

“I did forget it one time, we were going to Chicago, last summer, we were going to Minneapolis, my friend works in Minneapolis, [...] I forgot my meter [...] in the glove department. My feeling was, I called up some friends of mine who were going also, who were going to Chicago, and I told them to overnight it to me. I didn’t want to tell my husband so I got another one” – CI5

Some participants incorporated knowledge from prior experience about how people react to their self-management practices. One participant knew that her sister was quite squeamish about blood, and chose to hide her use of the glucose meter from her: *“It’s a weirder, sort of, social thing to do, and then others might be a little bit squeamish, a little bit... because testing of blood in front of someone, some people... my sister, she’s just like, “ooh!””* – DS7. For some participants, this did not occur often but they were sensitive to people who were squeamish:

“there are some people that I can tell that they are uncomfortable with me using it in front of them, so then, like that’s like three or four people over my entire life, where I have been like then I will go to the bathroom and do it, or like go in the other room. For the most part, like, people are more interested in it or they go on with whatever they are doing” – C14

C110 was very private about her self-management in front of her parents, who she lived with. She knew that her diagnosis from three years ago was very upsetting for her parents and that they still got upset when reminded of it: *“anything related to my diabetes, I feel like my family gets emotional.”* She tended to go to her bedroom where she could keep her self-care and devices away from her parents’ eyes, including before every family meal: *“I do keep it away from them”* and *“in front of my parents, I just won’t do it.”*

On the other hand, she was more than comfortable conducting self-care in front of one her best friends:

“One of my best friends, she actually can’t stand watching me inject myself and I try to make her watch sometimes. It’s funny! But um yeah, or poking my finger, she cringes at the sight of that, but that’s about it. Because we are in a comfortable relationship, you know.” – C110

9.1.3 Summary of ‘Normal Use’

The findings highlight variety between the participants in how they practice self-care in their day-to-day lives, leading to varied use of the mobile medical technology. People ranged from open use, to slightly hidden use, to going into different rooms to conceal device use. Routine social situations influenced how people use their devices, dependent on their preferences, past experiences, and the social situations they regularly encounter. Although they were accustomed to the social situations, they were

still aware of the other people around them and adjusted the ways they used their T1D devices accordingly, despite their familiarity.

9.2 Uncertainty in Social Situations can Lead to Hiding

Familiarity with a social situation enabled some participants to adopt consistent management strategies, while unfamiliar settings led to a sense of uncertainty among participants, which influenced their use of the devices. Several participants described situations where they felt uncomfortable using their devices out in the open. DS2 described the link between uncertainty and the personal aspect of the condition: *“When you take it out you feel like you’re exposing something about yourself for people to, sort of, either, sort of, judge that it’s good or bad, in a way, and then I more, sort of, fear someone’s reaction”* – DS2.

9.2.1 Uncertainty in Romance and Attraction

When asked about times they may have benefited from using their devices, but chose not to, people described instances related to their romantic lives. Even chance encounters in public could lead to hiding devices:

“It sounds really silly, but if you see someone, like, attractive or on the bus or something, you don’t really want to do something potentially, like, weird, and they’d be like, “ugh”” – DS2.

I met CI20 in a cafe where he ordered a sandwich and proceeded to test and inject visibly in front of a busy line of people at the counter. He was very relaxed in describing his self-management habits, but looked uncomfortable when asked if there were times when he should have used his glucose meter and didn’t. He went on to describe a time he did not use his glucose meter for an entire day. He was on a first date and they spent the day at the beach. As there were no washrooms or places to hide his use of the glucose meter, he decided not to use it at all, leaving it in his backpack. He did not want his date to see his medical device kit, nor want her to know about his condition that early in their courting.

A first date can be a nerve-racking experience where you might not want to reveal everything about yourself. The beginning of a relationship is a time when people can be quite uncertain, as they do not know where the relationship will lead, and do not want to mess it up. Although one participant did not personally agree, she said many friends concealed their conditions and devices: *“I have lots of friends that go out with guys,*

and they don't even tell them they're diabetic for, like, months. I don't even know how they hide it" – DS1. Another participant said that she did not want to make it an issue too early: *"I try to keep it secret but not secret as in I don't ever want them to know; it's just whether it comes up or not because I don't want to make it a big deal."* – DS2.

Even when relationships are established, there can be uncertainty over time with regards to attraction and how stable the relationship is: *"I am more open with my current boyfriend than I have been in the past, but yeah. It's still a little uncomfortable, but it is better than it's been in the past, so it is slowly getting there."* – CI10. Attraction can change with life changes, including the addition of a new mobile medical device. A lot of participants avoided adopting an insulin pump, as they said they did not want to feel physically attached to something and mentioned it looked unattractive to be physically hooked up to a device. An married participant (MU1) initially said she was interested in getting an insulin pump, but revealed to the group at the meet-up that she was concerned that *"it is not very sexy"* to use during intimate situations and also that she was concerned about *"what it will be like to use it in the summer with tighter and more revealing clothing?"*

9.2.2 Furthering Jobs and Careers

Uncertainty in jobs or careers was also found to influence participants in hiding their medical devices. DS8 was very open about her glucose meter use and wore an insulin pump quite openly. She was quite adamant that there were no times where she would hide or not use them. However, in one of her entries, there was a photo of what looked like a trade show (Figure 39) and I probed further on how she used her devices at this time. She said she hid them when there were potential clients around. She went on to explain that even when in the office, if she had a face-to-face meeting with a client *"I normally schedule it around a time where I don't necessarily have to take my blood sugar."* This was because she felt a certain level of vulnerability with regards to her career, saying that only *"if I were very senior in my position I'd feel comfortable doing it."*



Figure 39: DS8 hiding her meter use at a trade show

In the case of changing jobs or trying to get a new one, there was even more uncertainty about the situation. A participant in the diary study had changed jobs recently, so was more private at work. Another participant was unemployed at the time of the study and was going for job interviews. In one case, the participant did not want to risk being seen with her medical devices, so she used her glucose meter in the building beside where her interview was to take place:

“Something like that could possibly sway them to take someone else rather than me. Because yes, as much as people say the discrimination doesn’t happen, it does happen.” – DS2.

In other situations, the reason for participants hiding their devices was not based on conjecture, but on past experiences. A participant who was a substitute teacher described a situation where she was at a new school and went to the staff room to test and inject, because testing during school was important to her: *“I’m teaching primary school I don’t want to have to like treat hypos and things while I’m teaching. That’s why I test a lot during the day”* – DS1. The principal at the school saw her and told her that it was a health and safety concern, which she believed led to her losing that job. Even after leaving that place of employment, the experience had a lasting effect preventing her from again openly using her devices or injecting in front of people at work:

“I’m more careful about injecting when I’m in a new school, like, in the staff room and stuff. I don’t really just, like, flash all the syringes around. I just do it really quickly, you know.” – DS3.

9.2.3 Unfamiliar Acquaintances

The participants discussed times when they changed their normal practice because of who was around. CI4 and CI6 were both very open with their use of their glucose meters, and CI4 with an insulin pump, but this could change based on an uncertain social situation:

“Most of the time I will just pull it out and do it where I am, if it’s, if I don’t feel comfortable doing that, because of other people around or if they are giving me a weird look or something, then I will go to the bathroom and do it. Or kind of try to do it behind my backpack or something.” – CI4

“Pricking my finger, it doesn’t matter who it is, it can be a complete stranger, it can be in Disneyland in front of children, but if it is someone I know that has a fear of needles, or like someone I am not sure of, and I’ll ask first, yeah. I will be a little more cautious.” – CI6

“I would, most likely, if I was with my friends, I would just do it publically. If it was with people I hadn’t met before, I might go to the bathroom.” – CI6

Some social situations involved uncertainty with people at arm’s length. For example, DS9 referred to a “group of people who I know but I don’t really know” influencing her self-care practices. Many participants discussed how they were either comfortable or uncomfortable using their devices among the public, friends, and family at meals as part of their more regular routines, but sometimes meals involved engaging with new people, such as meeting friends of friends for dinner. This kind of new encounter also influenced participants to hide their devices:

“The under the desk or under the table or whatever scenario. It’s people who I’m just acquainted with rather than friends with or don’t know at all.” – DS9.

“I guess I can usually find a window sometime within like at a dinner party, or if I know I am going to eat soon, I do my blood sugar right before I get there.” – CI4

9.2.4 Summary: Hiding Devices

Most of the participants discussed times where they hide their medical device use, time when they do not use their medical devices, and reasons for not adopting medical devices even though it would be useful for them to do so. Many of these situations were linked to the nature of the social situation that they were in. Specifically, that they

felt uncomfortable using the devices because of the presence of other people they were not familiar with or were unsure about their relationship with them. Such situations made them feel uncertain, leading them to actively hide their self-care and their mobile medical devices rather than show them off, not knowing what might happen.

9.3 Showing Off to People can Achieve a Purpose

There were situations described by participants where they actively showed off their devices to other people. This has recently become a trend on social media as described in Chapter 2 with a model posting bikini pictures showing the colostomy bag and Miss Idaho 2014 showing off her insulin pump during the bikini competition, causing #showmeyourpump to trend on Twitter leading to more people posting photos of their devices (Diabetes UK, 2014).

These situations where devices were shown off to achieve a social purpose were not as common as instances where participants felt they needed to hide their devices, but there were numerous instances where participants used their devices to achieve a purpose.

9.3.1 Making it Normal in Front of Children

There were several instances where participants went out of their way to show off their self-care activities in order to make it seem normal. This included trying to educate children about T1D: *“There was another kid there, I’d kind of talk them through it. I’d say, “oh, I’m going to do a blood test. This is how I, you know, manage...” you know, to make it so I’m not sick”* – DS9.

In another case, a participant who was normally quite private with her self-care went out of her way to show a newly diagnosed child that it was normal: *“At a friend’s house today. Her 16 month olds just been diagnosed weirdly with type1 so we tested together!”* – DS2 (diary entry).

9.3.2 Showing Off to Get Perks

There were also cases where the purpose of showing off the device was not as noble as educating people about T1D self-care practices: where the devices were shown off in order to get personal benefit. For example, during the tech meet-up, participants talked about instances where they used their condition and the devices to achieve something.

One participant described how she used the condition, including her mobile medical devices, to get a disability pass at a large amusement park. She was even able to get her brother a caregiver pass so they could skip lines for popular rollercoasters:

[Sheepishly] “I get the Alton Towers [amusement park] Priority line. Me and my brother for years never lined up. Not even a sob story needed: given right away.” – TM5.

This instance steered the conversation at the table towards times where they used their condition for gaining benefits in other ways. This included a participant proudly telling the table that she had been bumped up twice to first class when flying. MU1 had *“made a fuss about it”*, including showing off her mobile medical devices to the airline staff in order to benefit from a better seat on the plane. When asked by MU6 *“word for word, what did you do?”* MU1 suggested *“lay it on thicker next time!”*

9.3.3 Controlling a Social Situation

There were times when a participant wanted to have more control over the social situation, and used their devices to achieve this. In these cases, their mobile medical devices became props in these outward displays. This was the case for one participant who perceived that a woman was being disdainful of her and her mother on a train. In order to elicit a reaction from the woman, the participant, who is normally quite private about her condition, actively used her glucose meter when she didn't need to. She made sure that the woman saw what she was doing in order to 'wind her up':

“A snooty woman that was sitting opposite us and she didn't like the fact that we were sitting opposite her, and so I, like, got it out of my bag, and was, like, “really, why not? Bet she's not going to like this.”” – DS2.

There were also situations where participants wanted to make a certain impression on new people, which sometimes involved showing devices off. MU10 was discussing that she had been online dating and *“tried to get out of one”*. She wanted to deter the unsuitable suitor, so she made a big deal about her medical condition. She warned how she got crazy when hypo and tried to make her self-management activities seem overwhelming:

“It didn't turn him off, but it didn't turn him on!” – TM10.

New romantic situations that were going well also meant that some of the participants were showing off their devices, however to achieve a different purpose. DS1 described

first dates where she was using the glucose meter more often than usual to test a potential partner:

“I, kind of, almost do it more, [...] like, the first date; just get it out of the way, and if they can't deal with it then too bad.” – DS1.

9.3.4 Summary of Showing Off for a Purpose

There were fewer cases mentioned of showing off than of hiding, but some participants described times when they used their mobile medical devices as props in social situations. The reasons behind this included showing that T1D self-management is normal, getting perks because of the condition, and controlling social situations. In these cases, the medical devices were not being used as per adherence plans and the medical aesthetic of the device was important for the social situation.

9.4 Social Situation Discussion

Across the data set, participants described and showed a range of everyday self-care behaviours that indicate the influence that individual differences had on the use of mobile medical devices socially. Some adults typically preferred to hide their devices in their everyday routines, indicating that a device designed to be inconspicuous might be ideal. However, others were very open about their everyday device use, indicating, in contrast, that the design should be eye-catching. These divergent everyday uses of mobile medical devices point to a need for designs to accommodate different styles of interaction, as per Storni's findings (Storni, 2010). However, this analysis also shows that even for one person, their use of the device is socially situated and a device that might be appropriate in one situation might not be appropriate in others.

Although the approach taken to data analysis was bottom up, Goffman's theatre metaphor of how people present themselves to others can help make sense of the behaviours that people engage in during T1D self-management in social situations (Goffman, 1959). This conceptual framing provides insight into the nuanced ways adults with T1D conceal or reveal the use of mobile self-management devices in social situations, impacting on their adoption, use, and carrying the devices. This has parallels to the spatio-temporal thread of experience, which taken into account timing and social settings as a part of the overall felt experience (McCarthy & Wright, 2004).

Goffman's theoretical framing uses the metaphor of performance at the theatre to express the ways that people present themselves in their daily lives (Goffman, 1959).

Goffman uses the metaphor of theatre to explain face-to-face interactions where people attempt to control the impression they give: *"Sometimes the individual will act in a thoroughly calculating manner, expressing himself in a given way solely in order to give the kind of impression to others that is likely to evoke from them a specific response he is concerned to obtain"* (Goffman, 1959). He describes three different stages, onstage, offstage, and backstage. People perform in front of others as if they were actors, choosing the props, and costume they present *onstage* to their audience. In their *offstage* life, while still in a social context, they can set aside the performance and interact with others without performing, yet still managing the impression they give. *Backstage* is when people can put down their 'front' and be themselves, for example when they are alone. In social settings, people present themselves to others either offstage or onstage. For the presentation aspect of Goffman's metaphor, the setting and the appearance of the act are influenced by the props the player is using or, in the case of diabetes, the technologies used.

The participants described concealing and revealing behaviours with their T1D devices, during both onstage and offstage times. During normal times, they would participate in offstage presentation: with knowledge of their social surroundings, they would participate in fairly consistent self-care practices, concealing or revealing dependent on the situation and their personal preferences. During non-routine times, participants engaged in practices of hiding the devices in times of uncertainty, such as in new romantic situations, starting a new job, and meeting unfamiliar people, which are examples of Goffman's *"protective practices"* (Goffman, 1959) during what he calls *"impression management"* onstage (Goffman, 1959). For instance, similar to the participant that did not want to use her T1D devices in the same building as an interview, Goffman describes: *"the interviewee will pay much attention to his appearance and manner, not merely to create a favourable impression but also to be on the safe side and forestall any unfavourable impression that might be unwittingly conveyed"* (Goffman, 1959). Also during non-routine times, there were instances where participants would show off their devices to achieve a purpose, with some situations akin to Goffman's notion of *"misrepresentation"* (Goffman, 1959) of a disability.

A participant who is quite private and would normally hide their devices from friends and family (offstage), wanted to show off their devices in order to make it normal for a child who was just diagnosed (onstage). A person who wears their medical device visibly outside their clothing to work everyday (offstage), wanted to actively hide it from

a potential external client (onstage). The use of these mobile medical devices is socially situated, and Goffman's notion of presentation of self frames these behaviours: there is no one practice and there are multiple 'fronts' people put on dependent on the social situation.

Normal offstage behaviour with devices was consistent, but dependent on the individual. Onstage behaviour occurred in situations that were not part of everyday routines: where the participants were conducting self-care activities in front of audiences that influenced the way they used their devices (or props (Goffman, 1959)). These were situations where the social context impacted the person's use of the device so that they were hiding them or showing them off in ways they normally would not. These included situations that were not everyday occurrences, such as first dates or trying to get upgraded to first class on a plane.

In addition to the variety of situations that influence device use including culture, healthcare system and physical environment, as discussed in the previous chapters, this chapter uncovers the impact of the social situation. People have different self-management strategies in their everyday social routine life that would indicate a choice of designs for T1D devices might suffice, but the uncharacteristic self-management behaviours in non-routine social situations means that one type of device would not be appropriate for participants all the time.

10 - Personal Styles, Lifestyles and Circumstances

Within health psychology research, personality (Skinner, Hampson, & Fife-Schaw, 2002) and personal models of diabetes (Hampson, Glasgow, & Toobert, 1990) have been shown to be associated with self-care activities among adults and adolescents with diabetes. Individual differences influencing the use of technology in HCI have been discussed since the early 1970s, first regarding the differences between manufacturing process operators (Umbers, 1979). However, little attention has been paid to how individual differences lead to varying uses of self-management technologies. McCarthy and Wright (2004).discuss these individual differences in relation to how technology is experience:

“Simple observation demonstrates that technology gets mixed reception in people’s lives. Different individuals, or even the same individual at different times, may experience technology in quite different ways.”

Unlike medical devices that are used by professionals, mobile medical devices can be used by anyone with a chronic health concern that requires self-care to self-manage. This means that a variety of different people have to use the same medical devices for similar health issues, but have very different lives and personalities. Individual differences in style and circumstance impacted self-care practice and experience with T1D devices throughout the data set. People are unique in their preferences for other technologies, and from the data set, it appears that people are unique in their preferences for Type 1 Diabetes technologies as well. Using a bottom-up qualitative approach, personal differences arose as a major influence on how Type 1 Diabetes technologies were carried, adopted and used by the participants, particularly emotional and physical responses, aesthetic preferences, lifestyle choices, and past experiences.

10.1 Emotional and Physical Responses to T1D Technology

People had different psychological relationships with the devices, along with different physical responses to their T1D technology. These impacted people’s choices in their technology use and adoption.

10.1.1 Emotional Responses to Technology Can Impact Use and Adoption

People's responses to the technology was not always as expected, considering some of the devices were quite cold and practical: there was a connection with these devices that could be "*sensual and expressive*" (McCarthy & Wright, 2004), in line with the sensual thread of felt experience. As previously discussed in the Culture chapter, people at the meet-up and online would encourage others to vent their frustration by breaking their replaceable diabetes devices. Devices can be linked to these negative emotions and feelings: "*High readings. That is a negative experience.*" – CI5. These numbers could be directly associated with the device that gave the numbers, and participants sometimes 'shot the messenger':

"Even though you rely on your meter you, kind of, hate it a bit because it's just annoying." – DS1

Experiencing high blood glucose levels could have an emotional toll on the participants, and the results of using a glucose meter could make participants feel bad about their lifestyle decisions:

"Yeah, there have been times where I have been, had a lot to eat, binge eat, or had a regular soda, instead of a diet and spiked. And, yeah, I always get bummed about it. I try to keep it in track. Tough." – CI6

This frustration can influence people's use of their devices in different ways. As diabetes can be described as a "*relentless condition*" (for expanded discussion, see (O'Kane et al., 2013)) and leads to "*burnout*" (Polonsky, 1999), some participants could grow sick of constantly taking care of it. CI1, who was quite careful about her condition still sometimes had to force herself to conduct a blood glucose meter test:

"I know that before, like, I've woken up and I know that I am low and I've gone straight for the juice, you know, and just drank juice and like "I'm fine" and I'll test later. And I did that...a couple weeks ago. I woke up in the morning to get ready for work, and I was like "I know I am low, I can feel it. I feel shakey and awful. I'm just going to go drink some juice and get in the shower." And that's how." – CI1

This frustration could lead to people not carrying or using the device when it might be beneficial for their health. CI10 talked a lot about the emotional toll that diabetes had had on her life since she was diagnosed two years ago, and said that if she had to

name her device she would call her pink glucose meter “*Lucifer*”. This emotional response to her diabetes influenced the use and adoption of T1D devices. She was averse to adopting an insulin pump that would be on her all the time everywhere she went: “*I don’t want to do that. It is too permanent*” – CI10. She also did not want to have to be reminded of the condition and sometimes did not bring her meter with her to avoid the emotional response to the condition:

“To be honest it is a burden. It’s a burden. I can make spaces to bring it, but I choose not to. Knowing that it can harm me in the long term, I know it is sad to say, but sometimes I just want to go out and not worry about it. So I would rather not bring it with me.” – CI10

For other participants, their devices were a source of positive emotions. Some used their meters to feel better about their condition, and to feel more in control. CI5 wished she checked more often for this reason, rather than as a direct health concern:

“All the time. Sometimes I wish I checked in the middle of the day. It makes me feel better. And that is worth more [...] because you know you are on track” – CI5

However, sometimes these positive feelings led to a kind of emotional reliance on the technology, beyond relying on its functionality for health related reasons. DS1 was very dependent emotionally on her glucose meter, and its presence and constant testing made her feel better about her levels. She talked after about panicking if it wasn’t with her, and going to buy a blood glucose meter out of pocket if she forgot it at home when going to work:

“Keeping good control of my blood sugars and making me feel at ease. Like, if I didn’t have it with me I’d panic, yes.” – DS1

“I always have it with me. If I don’t have it with me then I freak out because I don’t like... Like, I rely on it. I don’t like not having it with me because I can’t rely on feeling my blood sugars. Yes, I mean, I’ve done it plenty of times. I’ll, like, walk out of school, and I’ve left it on my desk or something, and I’ve left it there for the holidays and had to go buy a new meter. I couldn’t not be with it.” – DS1

DS1 had suffered from an illness throughout the diary study and this massively impacted her numbers, which she described as much higher than normal. As the diary study required her to use a diabetes app, a glucose level tracking application, she was

repeatedly confronted with those numbers. This had a negative emotional toll on her and she relived those feelings going through the exit interview where she was confronted with the numbers again:

"I think that, like, sometimes if you know you're high it's all right, but then if you're... like that's the thing [with the diabetes mobile phone application], like, if you have a couple of weeks of absolute crap blood sugars and you keep seeing them, it's like, when is this going to end? Like, it makes me, kind of, feel worse looking at them." – DS1

"I was gutted. I had a whole day of, like, almost perfect readings and then [a high reading]" – DS1

The graphs that the diabetes app produced were supposed to provide more information to the users about their overall control, but because the illness was wreaking havoc on that control, she started associating the shape of the graphs on the diabetes application with a goal that she just couldn't reach:

"See, all I want is, like, a nice straight line [...] It's so psychological." – DS1

10.1.2 Physical Comfort (or Perceived Comfort) Can Influence Adoption

The devices themselves had different effects on people's personal sense of physical comfort. This physical comfort was brought up by many people who had not adopted the insulin pump, but, surprisingly, by none of the people who used one or had experience with it. Like CI10 above who did not want to adopt something that was permanently attached to her, there were some emotional barriers to adoption for other participants as well, but physical comfort was also mentioned:

"There are a number of reasons why I am disinclined towards it. [...] I don't want to be attached to something all day. [...] like I have no interest in like having, being connected to something. Like, I do not find the needles inconvenient, so, I stick with it." – CI9

Physical freedom from the pump was also mentioned, which can be attributed to both psychological concerns, but also a sense of just not wanting to deal with a tube attached to the torso, with one participant saying that a CGM sensor being attached would be fine because it did not have the tubing:

“You know, they have tried to offer it to me, I am intrigued, but like I don’t really, I don’t want to carry the thing around, you know. I don’t want a tube in my body when I am doing stuff so.” – C16

“I don’t want a pump because I don’t like being attached to stuff. Even though I want a constant glucose monitor it doesn’t having the tubing and stuff. Like, I just have pens because I like being able to, like, ditch it all and just do what I want.” – DS1

Physical comfort issues for people who did adopt the devices were easily relieved through experimentation (also discussed below with regards to clothing). No participants in this study suggested that they had not ended up adopting a pump after trying it, but rather they adjusted to them by changing the way they wore them:

“I keep it in my pocket because that is more comfortable. I find that, there’s this metal clip, so when I put it on, it is sort of uncomfortable” – C13

The physical nature of the blood glucose monitors was also brought up by the participants. This was mentioned with regards to ‘Error 5’, as the participants would normally have to poke or prick their finger again. Testing blood glucose a lot meant that participants had to prick their fingers a lot and *“like, it makes my finger go all callousy”* – C17. Also, not controlling BG levels carefully sometimes meant that people had to correct with a lot of insulin to deal with a high level, and this consumable could also cause physical discomfort:

“Giant shot! And then had to deal with it in my skin, work it in. I usually get, it can bubble up and stuff sometimes.” – C16

10.1.3 Personal and Changing Healthcare Needs Impacted Device Use

Although the focus of this research is on the use of the devices themselves and participants’ health was not a consideration in the studies, they cannot be completely considered in isolation as T1D technologies are tools to help with a health concern: *“I check it more when I don’t feel well. Or when I am hot or cold, and I feel like something’s up, that’s when I tend to check it.”* – C110. People’s health influenced their use and adoption of these devices, both from a perspective of how they prioritised their health and also with regards to how different health concerns could change their self-care practices.

10.1.3.1 Different Attitudes to Health, Different T1D Technology Use for Self-Care

The use of most T1D technology is to generally give people more control over their blood glucose levels by giving them information and tools to balance them, and in the long run, to influence their health positively. Most participants knew this, but overall health concerns could sometimes be prioritised lower than other concerns in their lives. CI7 does not test as often as she should, but said she decides to not bring around her glucose meter because she says *“I know my body well enough”*:

“[The doctor] tells me, ‘the more you test your blood sugar, the more controlled it is. If it is high you give insulin, if its low you eat. So the more aware you are of your numbers, the better you control your diabetes.’ She said you should test 5 to 6 times per day. But. I don’t carry my meter around, and it is hard for someone to test their blood 6 times per day, and prick your finger 6 times per day, so.” – CI7

This of course was not the case for all participants, as different people have a different sense of what their blood glucose levels are and this can change over time (Mol & Law, 2004). For instance, DS1 doesn’t trust her sense of blood glucose level and needs her technology to determine health needs:

“If I just went on feelings instead of using my meter I’d have, like, awful control. I wouldn’t know what I was on. I wouldn’t know if my insulin was working or whether I was eating something that was making me high. A big mess.” – DS1

Some participants described themselves as lazy, and did not attend to their self-care as much as they should. This lack of prioritisation of health needs included not dealing with replacing the consumables or prioritising other activities, even when the meter was at hand:

“If my battery went down or if I ran out of actual glucose monitoring sticks I will sometimes be really lax about replenishing the battery.” – DS8

“Out of laziness, I just don’t want to bring it. Even when I am at home, I don’t check my blood sugar when I should, and it’s just like I would watch TV or rather surf the internet. [...] It’s usually in my room. Or play with my dog. And I’m just ‘I’ll check my blood sugar later.’” – CI7

In other situations, some participants prioritised immediate health concerns over using their devices. CI8 said that she would prefer to know exactly what her levels were

before treating herself when she is feeling low, as what she would ingest would be based on the number. However, sometimes she prioritised the risk of being hypo over the risk not treating the low properly:

“I don’t want to sit around waiting. I want to get some sugar in my body.” – CI8

10.1.3.2 Caring for Sicknesses Changed Self-Management Styles in the Short Term

Physical sicknesses on top of diabetes can have major bearing on blood glucose levels, as well as influencing the person’s personal wellbeing. Both of these aspects can change routine self-management practices with T1D devices in order to deal with a health condition along with a chronic condition.

For some participants dealing with some sicknesses, they felt that they were not as active and they were not eating very much, so they didn’t need to monitor their levels as much. As such, some participants ended up testing much less frequently than they normally would during these times of sicknesses:

“I don’t use it as much at all, because normally when I am sick, I stay in my bed and don’t eat, or do anything. I mean, so I test it right when I wake up, and then I usually make myself go back to sleep, and don’t test for the rest of the day.” – CI6

On the other hand, the variability in blood glucose levels can be caused by sicknesses that are not in line with what the participants usually expect of their levels. This meant they were in less control of their levels as they could not anticipate when the levels changed, which caused some participants to worry (*“Because it is confusing, I didn’t eat, why is my blood sugar high?” – CI7*), and they used their meter more often to keep an eye on the levels, ultimately to try to gain control and to alleviate anxiety:

“I tend to test a bit more when I am sick, um just because my blood sugar tends to run a little bit higher and I’ve got to keep a closer eye on that.” – CI1

“I probably would still do the breakfast lunch and dinner times, but I would check it more often in between there, kind of on a whim, or if I am not sure about it, kind of like an anti-anxiety thing” – CI4

CI8 also uses her glucose meter more often during times of sickness, but her insulin pump use also changed, perhaps related to anxiety. During times of sickness, she sometimes stops using her insulin pump for boluses of insulin and reverts back to

injecting insulin with “*old fashioned shots*”. She tries to keep the levels under control by testing more and injecting, as she feels more in control of how a shot works rather than leaving it up to the pump, which could have its own issues:

“Definitely, I check a lot more frequently. And like, whenever I was sick in December, I couldn’t understand why my sugar wasn’t down so, I finally said like, for my pump, I’m just going to let it do the background insulin, and I’m just going to go back to old fashioned shots. Because at least that way I know for sure, like, if it is problem with my pump, or my site, like my site is tired so it isn’t absorbing, so I find I do the shots with a little extra insulin, and keep a little record of it next to my meter so I know exactly how much is going in my body. And what my blood sugar is. And I found when I started to do that, it started to slowly come down a bit.” – C18

DS1 had an illness right before the entry interview and this continued throughout the diary study. As mentioned previously, her levels caused her emotional distress and she felt she had to test a lot more to keep an eye on her balance. She did not trust her ability to reflect on the state of her body and her feelings because of the symptoms of the sickness, so she tried to take control by using her glucose meter more often than she normally would:

“I’ve been off for, like, three weeks, so I use it heaps because, like, often when you’re sick you’ll either go really high, like, if you’ve got infections and stuff, or the symptoms you have will mask your feelings. Like, you can’t feel if you’re high or low, so because I was so tired I couldn’t feel what my readings were at all, so I used it a lot more. A lot more, yes.” – DS1

The participants also mentioned that different types of sicknesses required different self-care strategies, dependent on how they felt and the symptoms of the specific sicknesses. DS8 discussed two different strategies, dependent on if the sickness made her feel high or low:

“It’s funny because if I feel like I’m spiking when I’m sick I’ll probably take it more often. I generally check more often when I feel like I am very high. If I feel like I am low, I don’t usually [inaudible]. Shaky. I’d probably say I take it less often if I’m sick because I don’t have the energy to do it.” – DS8

Certain symptoms of sicknesses could be major causes of concern for self-management. Although C13 usually wouldn’t check very often if he was staying in bed

and not eating much when he was sick, if it involved vomiting, that changed his self-care completely:

“The only times really change is when you are throwing up. Um, that’s a completely different question because then there’s a whole function problem. You take 5 units for food you just ate, and then you throw it all up, then you have got serious issues that are not easily dealt with, and then you are going to be checking your blood sugar for the next 5 hours. So cases, like that, then you have to, like everything that you basing your assumption on is no longer true, so the whole game has changed.” – C13

This was also the case for C11 in Toronto. Her past experiences with sickness involving vomiting led her to not trust her self-care practices and not trust the tools available for her because of unexpected reactions her body was having to the sickness. She did not try to self-manage her levels at all, but instead chose professional interventions in a clinical setting:

“For something like a flu though, I usually just check myself into the ER. Because, you know if you are throwing up, you know, if you go low, you can’t drink sugar and all that. Typically, when I am throwing up or have the flu, I am in the 30 range, really high. And so that’s when you just want IV insulin, you are not resistant to IV insulin, the way that you are like, to subcutaneous insulin, so.” – C11

10.1.4 Summary of Emotional and Physical Responses

It emerged that participants’ emotional states influenced their use of the devices, if they carried them, and if they adopted them. Personal physical comfort was also mentioned by the participants, which in the case of insulin pumps is probably linked quite closely to emotional responses to the technology. Personal wellness was also a major impact on the device use and adoption by the participants, with people reacting differently depending on personal practice and also on sickness, ranging from using the glucose meter less to checking oneself into the hospital to get on an insulin drip. These physical and emotional concerns impacted people differently, but across the participants, they impacted routine self-care practices with the devices.

10.2 Personal Style and Aesthetics Influenced T1D Device Choices

Technology trends emerged as a shared meaning of what consumer electronics should look like previously in the Culture chapter, and this was mentioned by the participants in how it influenced how they experienced their devices and how they adopted them. Beyond some of the universal aesthetics brought about with popular consumer technology and people's appropriation of those trends, people's personal sense of aesthetics also influenced use and adoption of these devices. People valued different aesthetics, and made value judgements on the aesthetic qualities of their devices and devices they have encountered, similar to the value judgements that are occurring in the emotional thread of felt experience (McCarthy & Wright, 2004). This was most salient with regards to their aesthetic taste for their devices and their aesthetic taste for their clothing, which was influenced by the use of these mobile medical devices as they were brought around in people's day-to-day lives.

10.2.1 Clothing Style Influenced Adoption and Experience with T1D Devices

Some people's sense of style and presentation influenced their use of the devices, and their devices in turn influenced their style. As with any group of people, the participants had their own personal sense of style and clothing habits, and this interacted with how they used, carried and adopted diabetes technologies.

Many of the participants who had the financial option of adopting the insulin pump did so for a variety of reasons. As these are worn devices, they were not adopted into day-to-day lives in a consistent manner because clothing style was not homogenous among the participants. These participants did not all carry the devices in the same way, with some wearing them in different places on their bodies and on their clothing:

"I keep it in my pocket, some people always have it on their waist" – C13

"I just clip it to my pocket and the cord kind of hangs out" – C11

Both insulin pumps and glucose meters could cause clothing to not sit properly on people's bodies, which was more of an issue for some than it was for others. Many females with insulin pumps talked about wearing their devices *"on my bra"* [C18]. C18 preferred the model with tubing compared to other insulin pumps that are attached in different ways such as on the back of the arm. She preferred this option so that she could easily hide it with different clothing styles she chose to wear, because *"if I am wearing a dress, I can stick it in my bra or something"* [C18]. Although wearing the

device on a bra did not work for all participants: *"It doesn't really work, it just makes it look lumpy, ha!"* – C14. C16 found that carrying the glucose meter could also cause aesthetic issues with clothing, and chose wearing it in a pocket that made him look like he had a larger belly rather than fitting the device in slim fitting jeans:

"In the little front pouch, yeah. It is not an ideal place, it looks like I have a little belly, but like whatever. It is better than, because I wear slim jeans, kind of, so it's a little tighter in the back pocket, but if I have no choice, I have no choice." – C16

For insulin pumps, there was an issue of accessibility with regards to the clothing choices that participants made. For instance, accessing it could be awkward: *"If it is on my bra, it's a little awkward to, you know, dig down my shirt, ha!"* – C18. C111 discussed a recent incident caused by clothing when on a date versus the jeans that she was wearing to the interview:

"Like today, you know, if it is in your jean pocket, it is so easy to whip out. I went on a date on Friday night, and I was wearing like a really nice size 2, I don't know how I fit into it, pencil skirt, and um, I had just put the pump up against my stomach, it wasn't sitting on anything, and it just kind of held it there. And so, but, then every time I ate or did anything, I had to excuse myself to the bathroom, and I kept thinking "this guy is going to think I'm bulimic, because I just keep running away to the bathroom", but I would have to undo my whole outfit to get to my pump. So that's when it become more of an issue, pump accessibility I suppose." – C111

Glucose meters generally were not carried on a person's body, but rather had to be carried separately because of the size of the kit. Participants dealt with this constraint in many ways, and sometimes did not end up carrying it because of the bag, or lack thereof, that they wanted to use. C12 said that she sometimes would not carry her glucose meter if it did not fit into a purse that matched her outfit, while prioritising her cell phone:

"Sometimes I guess, if it going to match an outfit, ha! [...] yeah, you know there are some times it doesn't fit. [...] It was a lot easier before cell phones! The cell phones are actually bigger than these now" – C12.

CI8, who sometimes also went out dancing with friends and wanted to wear a smaller purse had to really plan what went in it, including prioritising her mobile medical devices:

"If I go out at night, I use a smaller...If I am going out dancing with my friends, like I've gotten into diabetes Tetris, where I like take everything out, and I am like, "I'll know I need this this this, and maybe some sugar pills" I will make it fit in that wristlet, ha! I might not be able to open in and scrounge around but you know, at least I got it there and with me. [...] I finally found a small dressy purse I can fit it in no problem. It's the wristlets that are more troublesome" – CI8

Some participants did not want to carry separate bags or were not used to bringing purses with them, particularly some male participants. CI3 did not usually carry a bag, and therefore either did not bring the device with him so he would leave it in his car:

"Well I don't have a purse, I don't have a 'murse'. That's the thing, I don't really have a carrying anything at the end of the day, and so if I am going somewhere it's going to be in a car" – CI3

Some participants discussed how they had to adapt their sense of style or sartorial choices based on their medical devices. This included CI6 who wore a jacket or hoodie all year round to carry a glucose meter unless it was really too hot wear a hooded sweatshirt, and CI4 who bought dresses with pockets and sometimes adapted them for her insulin pump:

"Sometimes yeah, exactly I cut holes. Like I try to buy dresses with pockets so I can put it in there, and then I have to cut a hole because the tube is right here. Then, if I am wearing like short dress or a tight dress, then it's like, I don't even know where to put it." – CI4

"Every jacket I own has an inner pocket that I choose just for the meter, because it is small and slim and stuff." – CI6

Others chose not to adopt medical devices because they prioritise their sense of style and clothing choices over perceived health benefits. CI7 was very open about her opposition to adopting the pump because of clothing choices, despite her family encouraging her:

"Yeah. My mom wants me to. I don't like it. Being a girl, it is hard to carry, to have something attached to you all the time. If I am going to the beach, or if I

am wearing a dress, or something so. I'd rather just carry my insulin in my wallet. [...] I don't have a purse, I just carry this [Coach wallet]. And my insulin is as big as my Coach wallet." – C17

10.2.2 Personal Aesthetic Taste Influenced Taste in T1D Devices

People have different aesthetic tastes and associated judgements of values: this is clear in people's different choices of hair, fashion, etc. and increasingly so in their choice of consumer electronics. This also carried into Type 1 Diabetes technologies, where participants were able to have some choice of which devices to adopt.

The colour of the device was brought up by a few participants. Purple was a popular colour choice for insulin pumps ("*Purple makes me happy*" – C12) if that option was available, and C11 said that she wanted a pump in her favourite colour:

"They have purple, blue, green, pink. They have ones that are blackish grey, they have clear. They have tons of colours. I, I really like purple, I mean so. Got my case, got my glasses, like everything is purple!" – C11

C18 had a glucose meter and insulin pump that worked together, so she was not able to choose what colour (see Figure 40), but has plans for future T1 D devices:

"They come together. I would have liked a purple one but maybe later down the road! [...] I wanted a purple one, but this one unfortunately does not come in purple" – C18



Figure 40: C18 with a matching glucose meter and green insulin pump

Colour choice turned out to be very important for some participants, and purple was a controversial choice for some participants: "*blue is the best colour. Everyone knows that blue is the best colour. Haha!*" – C13. Beyond the pumps, C15 who wasn't using an

insulin pump yet still chose purple when she was getting a portable glucose meter for her travels. *"You can choose a colour, so I picked purple"* – C15

Some participants would go out of their way in order to make their devices more aesthetically pleasing for them, including DS1 who carried them in *"pretty bags"*: *"I hate the black bags they come in so I'm always, like, shopping for, like, new little bags to put my meter in to make it look cool"* – DS1. In the case of C110, a Louis Vuitton bag was used for her kit (see Figure 41).



Figure 41: C110's Diabetes kit carried in a Louis Vuitton bag

Making self-care more aesthetically pleasing could also include the use of stickers or skins. C14 got an insulin pump in black, but *"did this whole like buy a skin thing, pay \$12 for it"* to get a skin that was zebra print. This was a purchase that she prioritised and valued what she got for the money she put in, because she later explained that she broke the clip for it and so would just wear it in her pocket because *"the clips are really expensive, they are like \$25 for it,"* pointing to the importance of aesthetics to her. Not only did C111 choose a colourful pump, but she special ordered a free Toronto skyline sticker for her pump: *"It's cute"* – C111 (see Figure 42 below).



Figure 42: C111's pink pump and glucose meter with a sticker

C18 talked at length about how it is important to her that her devices looked aesthetically pleasing, and about what she saw others do to their devices to make them more personally visually appealing or “fun” compared to them having a medical aesthetic:

“It’s making it more a fun thing, in a sense. Well not fun, just like, it’s not making it such, like when I think of medical, or hospitals, I think of plain white, silver, that kind of idea in my head. Even it being a colour, like green, orange, it just adds a little extra fun, something you can personalise to yourself. I see little kids wearing pumps, and they got drawings and everything, so it is kind of making it your own. And I think because this is something that you are stuck with for the rest of your life, have a little fun with it. It goes a long way. Maybe something cool, like accessories! But like, having cool little things to put on it, I’ve seen some girls get the sticky rhinestones and put it on it. It’s really cute. It’s a little more fun, and less, less you know, scary.” – C18

10.2.3 Summary of Aesthetic Preferences

A range of devices were adopted and used by participants, and these devices all had different aesthetics. People chose certain devices and certain colours of devices because of the way they looked, and these aesthetics could influence the user experience with these devices. Furthermore, as T1D devices are meant to be kept on a person at all times of the day, the devices influenced what clothing people could wear and also where the devices could be carried. This sartorial choice influenced more than just user experience, as they also influenced if the device was going to be carried with a person and in some cases, impacted people’s choice to not adopt insulin pumps that would be awkward to wear with some clothing choices.

10.3 Lifestyles Choices Influenced T1D Technology Choices

Lifestyle influenced the adoption, use and carrying of the devices for every participant involved in these studies. How people chose to live their lives influenced the technologies they used, and the technologies in turn influenced their lifestyles. This could be seen through different aspects of their lives, including their mundane work routines, their weekends, eating and drinking, and activities.

10.3.1 Schedules and Routines Led to Routines Around T1D Device Use

For some participants, the role that self-care played in their lives set up the lifestyles that they chose. C15 had a very routine schedule during the week and even the weekend was planned around self-care activities: *“it is usually about the same, it kind of sets up the structure of my day”* – C14. For C15, it influenced the classes that she was going to take at college:

“I guess like if I am in school and I have a class over when I would normally eat, it might change a little bit. I try to schedule my classes so that they are not like that, but there have been some of the classes in the past that, I would either have to test before or sometimes I forget to test, and then I like go straight to dinner” – C14

On the other hand, some people’s self-care activities were prioritized after their lifestyle. Although most of the participants acknowledged that it would be wise to test their blood glucose levels in the morning (*“I always test when I wake up before I get in the shower because you can’t really lock yourself in and room and be low where no one can get to you”* – DS1), many people skipped this step as they thought that this part of their morning routine could be either pushed back or skipped (C17’s *“I don’t test in the morning, because I am always in a rush to get out”* compared to C15 who had a strict morning routine to *“eat breakfast before I leave home I take my insulin and everything”*). Some people self-identified as not ‘morning people’ and others developed a routine around not eating right in the morning so that they could leave these activities until they arrived at work.

“Yeah, I check right, usually, because sometimes I wake up, I am really not sure how I am feeling and I will check immediately right when I wake up. Usually I wait until I get to work, because it is right before I eat my breakfast” – C11

People's routine varied considerably based on their values, their self-care needs, as well as their daily routines. Some had weekday routines that were in stark contrast to other people's routines based on their work life, personal life or their student life. For instance DS1, would go out after work *"every day. I go and hang out with friends and go to cafes and stuff"*. C17, a university student, only tested her blood glucose levels once a day because she only ate once a day as a student:

"I don't test during the day because I don't eat til 5 o'clock, until I get out of class. From 1 -5pm, I don't' eat anything, If I do it's probably a latte from Starbucks. And when I get home at five, I am always running around at Costco or something, to buy groceries, so when I actually do get home, at 5:30, 6 o'clock, I eat dinner with him, and then I test my blood sugar, I give insulin for how much I ate, and then we like to go to McDonalds or Starbucks at about 8 [to study]...sometimes I test twice a day like before, like, before I actually fall asleep at night just to make sure my blood sugar is ok, um, but yeah, usually it is one time a day." – C17

Different lifestyles were observed among the participants in the study, and where they were living had an impact on this. For instance, participants from London seemed to take public transportation more than participants in LA, and therefore their self-care practices varied because of these different commuting cultures (although Figure 43 shows DS9 in her car in London). C11 really liked her all-in-one glucose meter, as she was able to test very quickly at red lights in LA:

"I really like the fact there's not a bottle of strips that I have to pull out. [...] If I am driving somewhere, and I am at a stop light, I don't have to try to deal with the little bottle of testing strips, I just need to hit the button and it come out, so."
– C11



Figure 43: DS9 taking her blood glucose levels before driving

Another Californian, CI3, left his glucose meter almost exclusively in his car: *“As long as I have my car, that is like the ultimate southern California thing to say, I can leave it in my car”* – CI3. This is in direct contrast to Londoner DS8 who consistently conducted self-care on the tube or bus. It was important for CI3 to check his blood glucose levels before driving: *“I can drive when I’m 300, I will have to pee a lot, but you know [...] but driving while 40 is like driving while drunk”* – CI3. With the use of his car and his personal, work and social life revolving around the university, CI3 would not take the glucose meter with him:

“Most of the time, I am a block or two away from where I live, and if I am going to be perfectly honest, I wouldn’t have it with me. If I am nearby, my meter is back at home, if it is far away the meter is in my car.” – CI3

Work life versus student life was brought up by a few participants, as they can be very different in their routines and flexibility. C11 had experience with working and as a student, so was able to compare the two lifestyles:

“It is hard to describe because as a student, there is no typical, which I think is one of the hardest challenges with diabetes because there is no typical. [...] I was really good at it when I was working 9-5 and that’s all I was doing. Like when I worked an office job or whatever, blood sugar management is a lot easier. It is when you are throwing in classes, the erratic schedule, it is harder to do it.” – C11

Lifestyle difference influencing device use could also be caused by non-human reasons, such as pets. DS4 mentioned her cat playing with the device and being in the way when testing (see Figure 44 of a glucose meter test), and CI4's cat knocked it off the table so much that she had acquired different functional preferences for glucose meters, and would prefer not to have a touchscreen:

"Like my cat plays with it. Like I would leave it on the table, and he will knock it off the table. Sometimes I will leave it open, or sometimes like this. [...] He bats the thing around. That's why I break these things all the time. [...] The touchscreen thing would be nice, but so many people drop their phones and their phones shatter" – CI4



Figure 44: DS4's cat sits on her while she uses her meter

10.3.2 Weekends and Breaks in Routines Disrupting Regular T1D Device Use

Weekend routines were different from weekday routines for most participants. Participants also described that their routines can change from the weekdays to the weekends, so their use of their devices also changes slightly. Many participants discussed the change in eating patterns on the weekends influencing use:

"on the weekend I might not eat lunch and dinner, I might just eat lunch or whatever I eat, so I'll definitely check" – CI2

Activities on the weekend also differed significantly from weekday activities, which influences self-management. CI1 discussed different sleeping patterns and sleeping in causing her blood glucose levels not to go low, so therefore testing less:

"I would say I test, usually on the weekends more like exactly around 4 times, I will always test breakfast, lunch, dinner, and before bed, regardless. But,

usually I don't get low as often or anything. Um, just because, you know, the day... I sleep in so, my day tends to be shorter, but um, yeah, I don't tend to get low on the weekends as much as I do during the week. It's weird, I don't know why." – C11

Other participants described their weekends as filled with a variety of activities and plans, and sometimes this busyness would influence their testing routines. C16's weekend activities would mean that he would also be testing less because of scheduling rather than sleep influencing blood glucose levels:

"Weekends, I don't test as much because I am normally out doing things. Beach. Band practice." – C16

Similarly, DS9's weekend generally involved a few different activities out and about, and although she would carry her kit with her, she often wouldn't bother testing during these times:

"Out and about, go and kind of visit friends, or go shopping, or something like that. Probably again, I wouldn't use it all...it's likely I wouldn't use it all day. I'd likely have it with me, but more as a just in case. Just in case I don't feel right, but not in a way that I would think to use it to just do a normal kind of check. [...] I'd probably do less tests than on a typical weekday on that kind of a weekend day." – DS9

Disruptions to schedules could also change people's routines with self-management and the use of their devices significantly. DS1 tried many mobile phone applications, but her use of these apps changed greatly when she lost the structure of weekday working. Her normal schedule was quite structured as a teacher, so she was able to find time to enter in data, but when she wasn't on that strict schedule, she described it as a "mission".

"When I was teaching because it's so structured, I would use it every time because you get breaks, so you can just put it straight in, but, like, in the weekends and stuff when you're busy and running around it is, kind of, a pain to stop and put your readings in. Like, because just getting it out and testing and stuff is a mission as well. You don't want to have to get your phone out and put it in." – DS1

CI3 was a PhD student (*"I have a meter in my lab"* – CI3) and at times had deadlines that he had to meet, which also changed his schedule and routine significantly. During these stressful times, his routines would change and his self-care activities would also change:

"Maybe if I am doing an all nighter, yeah, because if you are still writing up that thing I really needed to finish at 3:30 in the morning, you can't be doing that with a low blood sugar because it is not going to come out well. Well at 3:30 in the morning, it's not going to come out well anyway. But, you come out with a bunch of words, but your blood sugars are way out of whack. Um, my ability, my my enjoyment, my ability to read things and comprehend them well below 60, or 50 turns off. And so, that has to be, that has to be kept in check." – CI3

On the other hand, self-care practices could be the disrupting factor in normal routines. DS1 caught a time during the diary study where she was feeling hypo as she was in a rush to get ready before a night out seen below (*"Getting ready to go out. It always happens at the worst times when you have to test."* seen in Figure 45) and recalled a time *"I've been hypo in the middle of dyeing my hair. That's got to be the worst."* – DS1.



Figure 45: DS1 testing in the middle of straightening her hair

DS1 also talked about cooking, which is a fairly regular occurrence and built into a daily routine for many people. She found that cooking can sometime unexpectedly lower

blood glucose levels, which need to be dealt with but could be annoying and could cause the food to be ruined:

"I was helping cook, and then I had to test in the middle of it when I was cooking, which is annoying. [...] if you're, like, frying stuff you can't just, like, walk away and leave it and test. [...] I'd just do it. I'd just turn around and do it, but because I had to do the other thing as well, I don't know, I might burn something especially when you're cooking for someone else." – DS1

10.3.3 Eating and Drinking Habits (and Binges) Influenced Use of T1D Devices

Eating habits were also very different among participants. CI7, who usually only eats one large meal a day and her self-management with her T1D technology is based around this, said that *"whenever I do eat, it is always carbs at the end of the night. My blood sugar is always [tested] before I go to sleep."* Both CI7 and CI6 admitted to occasional eating habits that may not be considered the healthiest:

"I would say I am not like the healthiest person. I binge eat on occasion. I typically, when I am doing something like that, I test specifically, I'll test before I do it, I'll get my shot, I'll eat a bunch, and then I'm like "Oh, I think I've had more than I shot for, so maybe I should get more" and I'll test again, and I'll keep doing it. [...] Yeah, I'll keep an eye on it. More eye than I would normally." – CI6

Three times a week, three times out of the seven days, we eat 3000 in one sitting. Because I love sweet things, I love sweets, and he loves meat and savory. We eat whatever he wants during dinner, and we eat whatever I want during dessert. So if you combine all those foods that we do eat, and we are watching Game of Thrones or something, it is an obscene amount of food." – CI7

In contrast, some participants discussed the ways that their eating was in line with their self-care activities, and how self-management of T1D influenced their diet. For instance, CI5 made sure that she did not ingest too many sweet things, even going so far as avoiding certain venues: *"coffee houses are not good diabetics, it is difficult"* [CI5]. However, some participants did not think that banning foods should be part of self-care activities. CI3 thought that making up these rules was going to far:

“There are all sorts of rules that are associated with diabetes, like “you can’t have candy”, or “you can’t have cake.” These are all bullshit. I just take more insulin.” – C13

Even if some participants were careful about their eating habits because they wanted to keep their blood glucose levels in line, *“sometimes you just want pizza” – DS1.*

Pizza, Indian food, and other ‘takeaways’ can influence blood glucose levels significantly as they have levels of carbohydrates and fat that interact with how glucose is dealt with in the body and how insulin reacts to it. Often, these types of foods produced blood glucose levels that were not predictable, so this could lead to more testing, or testing at inopportune times:

“There are certain groups of food that I don’t eat anymore, or eat rarely, not because I don’t like them, but because it is just not worth it. The carb content and then the fat content, it slows down the insulin absorption, so next thing you know, I have to wake, I have to wake myself up at 2 o’clock in the morning, test my blood sugar and then correct it. It’s bad, so sometimes it is not worth the hassle.” – C19

10.3.4 Activity and Hobbies Shaped Device Adoption and Use

Activity is associated with lower blood glucose levels, and some participants would be especially careful with using their blood glucose meter at times when they knew that they might be doing more exercise than they normally would:

“Like if I am doing anything that might make me lower, even something like walking around the mall or walking around with my family, I always carry my meter with me” – C12

“I tend to go really low if I’m doing exercise or sports or, like, running around doing stuff, so I use it a lot more” – DS1

Similar to eating different foods, people could be doing different activities every day and would have to adjust their self-care strategies with their T1D devices accordingly:

“Everyday is a different day. You never know where you are going to end up. One day I will play kickball. The next day I won’t. Some days I do exercise. Some days I do not exercise. So I am very careful.” – C15

Some participants led very active lives, for their own health but also because their personal lives influenced their level of exercise. C18 has a group of friends that are very active and their social meet-ups likely involve some sort of physical activity. As physical activity tends to drop her levels, she tends to test more often:

“My friends are really active, so we might go to the beach and play a game of soccer or something, and like, for me, exercise where I am going going going, tends to drop me, so I find that I need to check maybe a little more frequently, especially in the summer with the heat as well. So my meter is always close by.” – C18

The intensity of the activity also influenced levels in different ways, which in turn influenced how devices were used for self-management. For C18, different levels of activities influenced her blood glucose levels in different ways, and she would adjust her self-care practices accordingly. For instance, for her, the distance that she ran meant different self-care practices with her devices:

“I go on a lot of runs in Toronto [...] and I find that even between 5 and 10 k runs, I use my meter and pump a lot differently. With the 10 one, I tend to check a lot more, it is more of a long term kind of thing, I will probably be running for at least an hour if I do the 10k, so that constant motion and...the first 10k I found, I only drank the water, and I went so low, because even after I turned my insulin down on my pump, to prevent that, I still went really low. So the second time around, I only drank the Gatorade, and was like 5.8 by the end of the race, so I was like, wow, this is very impressive. I find I check a lot more, especially pre race because I’m worried about going low, and if you go high your muscles won’t perform as well.” – C18

Participants that were active ranged in what they brought with them when being active, such as C18 who wore her insulin pump in a waist bag at a waterpark, to C19 who did not bring his glucose meter with him because he was asthmatic, and couldn’t fit everything he needed in his running bag and didn’t prioritise his meter: *“It’s pretty bad, I run with a backpack” – C19.*

Hobbies were another aspect of people’s lives that really changed the way they used their devices and conducted self-care practices. C11 did quite a lot of hiking in and around LA, so she said *“if I am like, going hiking all day, I will test every couple hours and make sure depending on what is going on.”*

CI3 was an avid hang glider, and this influenced the routines he made for himself with his self-care practices. Although he could tell without the meter and admitted sometimes he didn't test and *"shouldn't do that"*, he made strict rules for himself around dangerous activities, including his hobby, and the type of device needed to fit into these rules:

"I test my blood sugar before I drive, I test my blood sugar before I fly, I test my blood sugar before I do anything that is notably potentially dangerous. That is, that is essentially the rules that I have come up with for myself. Those are the rules I have to follow." – CI3

"And then when you fly you got to fit it in the harness, so small is important. It is not usually important, but again it fits in my car somewhere" – CI3

Hobbies and activities also influenced how the participants could carry their devices and if they were able to carry them. DS1 decided not to adopt large glucose meters because of running, and DS9 sometimes did not bring her meter when she was mountain biking, because she didn't want too much stuff in her backpack:

"They're really big. Like, some of them are about that big. You don't want to fit... if you want to go for a run or something, and you've got your phone and your glucose meter you're just like, "okay, where's this going to go?" [...] like, my one is tiny. It's the Nano, so I can just fit it anywhere on me and it's not annoying" – DS1

Hobbies could influence the adoption of certain diabetes devices as well. Although CI9 mentioned psychosocial and physical comfort reasons not to use a pump, he also did not believe it would be physically possible with his practice of martial arts:

"I mean, for instance I do martial arts, I take a lot of kicks to the area where the pump would be, you know, it's... you know I have mentioned it, mentioned that to my endocrinologist, I'm like, "yeah da da da physical activities" and he's like "well they are designed for athletes" and I'm like "are they designed for athletes who get kicked in the exact spot where they are?" and he's like, "I guess not" So" – CI9

There were also hobbies that were not physical that influenced the way people used their devices. CI5 was an avid Bridge player and travelled about two times per year to tournaments across the US, which is why she bought a portable glucose meter to bring

with her. As she needed concentration to play Bridge, she was more conscious of her blood glucose levels during these times: *“there is no way I am going up to the table without testing.”*

10.3.5 Summary of Lifestyles

As expected, with the variety of people that were interviewed from three different studies and in three different cities, there was a huge variety in their lifestyles. For weekday everyday routines, some people varied massively, even when it came to their morning routine. Differences in preferences meant that they had very different weekends, and their self-care practice usually varied for them during these disruptive times. Eating and drinking was also very specific to the person, and people used their devices in different ways depending on their eating habits and the cuisines they liked to eat. Hobbies and activities differed significantly as well, and even some activities could cause a person to change their self-care practices based on variables within it. Overall, individual lifestyles had a massive impact of self-management practices and therefore influenced the ways that people used, carried, and adopted mobile T1D devices.

10.4 Past Experiences and Insider Knowledge Lead to Expectations with T1D Devices

Although some participants were diagnosed in recent years, quite a few participants had had diabetes for a number of years, including since they were children. The nature of this chronic condition with on-going self-care needs meant that participants had made many connections with people who knew they had diabetes and they gained quite a lot of experience with different treatments and different technologies (*“I remember using a strip where you wipe it off and read it on the side of a bottle”* – C14). These past experiences meant they were able to appropriate their experiences and anticipate or expect new similar experiences with T1D technologies, and their relationships that they built up or were lucky enough to have access to influences the spatio-temporal thread of felt experience (McCarthy & Wright, 2004). This past experience influenced how they viewed technologies, how they adopted them and how they trusted them, and building up insider connections also influenced their self-care practice.

10.4.1 Past Experiences Form Expectations for T1D Self-Care with Devices

The variety of people interviewed meant that some people had been diagnosed 6 months ago, which was the case for DS2 and some participants, like 65-year-old CI15, were diagnosed as children. As such, people had a range of experience with self-care over the years, and some instances influenced their self-care practices.

CI1 was on an insulin pump seven months after she was diagnosed at the age of 12, and had a lot of experience using this technology. In high school when a new treatment option came along for all day insulin, she went off her insulin pump with some fairly serious consequences. She believes that the 24-hour medication that she went on in high school caused her to have a serious car crash, and this influenced her decision to go back on the insulin pump, and stay on it for another 13 years:

“I got an insulin pump about 6 months after I got diabetes, um and... [...] I was off of my pump for I think, two or three month period when I was testing out Lantis, [...] I actually ended up passing out one time, because of it, so that wasn't fun and wrecked my car another time, so. After that I was like “I'm done with this” [...] I actually love my pump. I don't think I would ever trade it for anything else.” – CI1

Seeing other people with diabetes go through medical issues related to diabetes could also influence how people saw their own condition, and could influence the way that they used their T1D devices. These past experiences also influenced CI1, where an ex-boyfriends' family who had Type 2 diabetes did not take care of their health with physical consequences to their legs, a teacher from her high school needed an amputation because of his Type 1 Diabetes, and a friend of hers that did not take care of herself needed to go on kidney medication. These past experiences seeing others with health conditions made her more strict with her own self-management using T1D devices and more open, because she thinks hiding self-care activities with T1D devices might be the source of these healthcare issues:

“It was just seeing that in person, just made it even clearer: “I don't want my legs to be like his” [...] I don't want to... Once I have seen people, who just haven't taken care of it, it is just like....I don't want to end up like that. I want to live to I'm 90 years old, which a lot of people with Type 1 Diabetes, they tend to die a lot earlier because complications from it. I want to keep my kidneys, and not have liver problems, and everything. [...] it's the friend of mine that I told you

about who, she doesn't like...she...I've never seen her test her blood sugar and she tries to kind of hide it, and I think because she tries to hide it, she doesn't test as often, so she's [...] going on kidney medication. That's huge, you know. So I don't want that to happen" – C11

Some participants had experiences over the years that they have reflected and recounted, ultimately to have an understanding of what their strengths and weaknesses were and have expectations for future events. These experiences could also colour how they saw themselves in relation to their T1D devices. For instance, C13 knew that he was always losing things and leaving things behind when he was out *"partying"*. With this experience of other items in his life, he translated that expectation to his T1D devices. He thought it was safer to leave his glucose meter at home instead of it falling to the same fate as sweatshirts in college, being left behind at parties:

"This is something I've learned, because, undergrad, I lost my share of everything partying. [...] And then the sweater is gone forever, and that happens with glucose meters also, if you take that to the party, so the conclusion I gained through "I'm not going to take my meter with me" [...] then I don't lose my meter, because like, having a high blood sugar once is a much better thing than losing your meter and then having to scrounge around for meters, um. I do have a secondary, but, it is much better to not risk losing it in my experience, I am terrible at losing things." – C13

Many participants were well aware that they were lucky that they were born at the time that they were, because previously, as one participant described, *"One hundred years ago, it was a death sentence"* – C13. Some participants expressed this gratitude for the advances in the technology that they able to use to better manage their levels with, and this coloured their impression of their current devices:

"I mean I am really thankful for these devices. I could be testing with urine. [...] the technology is great. [...] I am thankful that they are so much better now" – C12

Even small advances in the technology were appreciated by the participants who had previous experiences with other older technologies. This included C16 who was diagnosed in 2001 and remembered what it was like to have a huge meter and C17 who remembered having to wait with her mother for results to appear on old

technology. These advances in making the meters smaller and faster made participants more grateful of the technology that was currently available:

“Yeah you know, there was a point in time where I was a little embarrassed, I did have a larger meter when I first got diagnosed. This is like considerably smaller in comparison.” – C16

“It is fast. Yeah that one...we didn’t have 5 second meters before, when I was like 8 or whatever. And it was this big block, basically like a Nintendo thing, 45 second to get your blood sugar. “Ok, mom, I’m going to go, I’m going to go after this” “no, I need to give you insulin, stay here” “mom I want to go!”” – C17

Participants’ past experiences with current T1D technology would also influence their future choices with their T1D devices. This was particularly apparent with regards to how participants trusted their devices and what devices they would adopt in the future, with some participants showing some brand loyalty. For instance C13 trusting a particular manufacturer for his insulin pump and glucose meter, after trying another insulin pump:

“Eventually I stopped using it. The meter was also, they weren’t as good honestly than the ones I am using now, these test strips are better, I think I honestly trust the manufacturer to have an accurate meter more, they don’t mess up. Like, I never use Accucheck, because their accuracy, in my experience they have been absolutely terrible.” – C13

There was a level of comfort that could be obtained over time with the continued use of a specific device or a specific method. Through continued experiences with a device, how it would react could be anticipated by the participants and through reflection and recounting, they formed a sometimes unnoticed connection with the self-care devices and tools, not unlike the compositional thread of felt experiences in that they lost their “sense of the separation of self, objects, and events.” This was seen with C14’s loyalty to her glucose meter and C15’s reluctance to adopt an insulin pump:

“The drum one? I used that one briefly, my brother had that one for a while. I like this part, this one better. I don’t really know why. It’s just what I used for a long time and what I feel comfortable with.” – C14

“I like having control, really good control. I am thinking of going on the pump. I think. I think. [...] I prefer these for a lot of reasons. I am comfortable with it. [...]

I guess I am kinda old fashioned because I know it works for me. I don't mind doing it, although I do mind doing it. But I know it works for me! I don't mind doing it. No." – C15

10.4.2 Insider Connections and Knowledge Can be Beneficial for T1D Device Use

Many of the participants were recruited for these studies through snowball sampling. Some people found out about the studies through social media, through active use or lurking of online communities, or through being a part of charity mailing lists. Many of these people were attached to these social networks because their social lives or their jobs related to diabetes. Generally these people had more knowledge about diabetes technology, and this personal insider knowledge influenced their technology use and adoption.

In addition, some people had personal relationships with people in the medical domain, and were therefore able to benefit from insider knowledge. C11's mother was a nurse, so when she was diagnosed, she was able to benefit from her mother's medical knowledge immediately when learning to use her glucose meter, and was able to learn younger than other people who went with the instructions from the clinicians:

"They moved me down to the paediatric unit and um, my mom had me testing my own blood sugar level. So you know, "you are going to have to do this on your own sometime", and the nurses got really angry with her. [...] They wanted my mom to do everything. [...] You know I was 12 years old so, that's old enough to learn. [...] She, she's a nurse, and also, she had gestational diabetes with one of my brothers so, she, she knows all about diabetes. So she's had first hand experience with it." – C11

This insider knowledge that she has been able to gain from her mother being a nurse and also having gestational diabetes meant that she tried to manage her diabetes as best she could through testing often. Despite not having very good insurance in LA and the cost of strips being so high, C11 does not cut down on her testing even with the financial concerns attached to the use of many expensive strips. She explains it has to do with her mother's advice very early on:

"My mom was straightforward with me with what would happen if I didn't test or if I didn't take my insulin [...] many people don't want to scare their kids. And my mom, being a nurse, was very straightforward and said "If you don't take care of

it, you will get amputations, if you get a cut, it will get infected and will peel. You will go blind. You will have all this nerve damage problems.” [...] so it is something I definitely make sure to do, because I don’t want to end up being 30 and in a wheelchair because I had to have my legs cut off.” – CI1

Having a connection to clinical sources was also helpful with regards to the supplies that participants had access to, as well as the number of devices. This ease of access could influence use, and in some cases misuse, because the devices were very easy to replace. CI4’s mother also worked in diabetes as an educator, so she had access to a number of devices and was able to replace devices easily when they were broken:

“On the fourth of July, it got stuck in the cooler and then it got submerged in water, ha! Yeah, but, so that doesn’t work anymore. My mom’s a diabetes educator, so she gets them for free all the time. And it uses the same strips as the one I used before.” – CI4

Other connections outside the realm of diabetes could also be personally beneficial to the participants with regards to supplies and devices. For instance, CI7’s parents own a store that she can take supplies from related to her glucose meter. There were always extra batteries at home, so she was able to find a replacement circular battery that can be sometimes hard to find in other stores:

“The battery was dead, like six months ago. Luckily my parents have a hardware store, so they always keep batteries in the house, and I had to change the battery, and luckily we had the circular battery.” – CI7

DS1 was not as lucky as CI7 with replacing the circular battery from a stash. She had run out and had to wait in the pharmacy to get the special battery, because the primary school she was currently working at did not have them: *“No. There were none there. I checked.” – DS1*

10.4.3 Summary of Past Experience and Insider Knowledge

As T1D is a chronic condition, some participants had to live with it over a number of years and have had numerous experiences with self-care and self-care technologies. Personal experiences, knowledge of previous practices, and experience with older technologies meant that many participants were dedicated to self-care and many appreciated the technologies that were available to them. Over these years, people developed trust for certain technologies and preferences, because they felt comfortable

with them. In addition, the nature of the long-term condition meant that people gained relationships with people with diabetes connections or insider knowledge over the years, or they were lucky enough to have a parent with a clinical connection, and that influenced their use of devices and what they had access to. Although each participant was unique in their personal experiences, over the data set, it emerged that these personal experiences influenced self-care practice and experience.

10.5 Styles and Circumstance Discussion

As part of the organisation of these user studies, a variety of recruitment methods were used that helped to ensure that a wide variety of people with Type 1 Diabetes were accessed. From the use of physical advertisements in grocery stores and pharmacies to going to different cities in different countries, these user studies ensured that participants came from a range of backgrounds and had different experiences, which would not have been the case if only one of these methods were used or if a specific health care clinic helped with the recruitment. The success of this recruitment strategy can be seen with the variety of perspectives gained on the use of these mobile medical devices for the self-management of Type 1 Diabetes.

In previous Chapters, the different contextual factors influencing use and adoption emerged, but even in those chapters, the differences between individuals emerged in-situ. In this Chapter, I laid bare the massive differences that people's styles, lifestyles and circumstances have on their choice of T1D devices to adopt, use and even misuse, but also, the influence that the T1D devices had on these different aspects of people's lives. Emotional responses and physical responses to these devices differed significantly, from one participant calling her pink glucose meter "*Lucifer*" to another describing a reliance on it such that forgetting it could lead to near panic attacks. Personal style varied so much that some would not adopt an insulin pump because of what they look like under dresses and some had already planned their next BG meter to be the colour purple. Lifestyle varied massively, with a Bridge player checking before every game and someone not adopting an insulin pump because they will get kicked during martial arts. Past experience and circumstance also allowed some participants to access batteries or glucose meters at their parents' homes while others assumed they would lose a BG meter just like they lost sweatshirts while drinking so did not bring either with them while partying.

Medical devices are designed to certain medical usability standards in order to deal with common problems that might occur, such as human error. However, there is no guidance in the medical usability standards to deal with the huge variance of adoption and use caused by the fact that the users could be anyone and they are not trained for a specific job with the medical device as a tool to use: people are using these in their everyday, messy lives. Education has also been used as a tool to combat 'non-adherence' to self-management plans, with programs such as DAFNE (DAFNE, 2013) being prescribed and education available on how to deal with psychosocial issues that arise in self-management of diabetes. However, education is not going to stop people from living their lives, and sometimes that includes drinking to the level of forgetfulness or using small evening purses. Participants were often choosing quality of life, as they perceived it, over quality of health, how medical device designers or clinicians might perceive it. Furthermore, what quality of life means to one person is not the same for everyone. People's individual attributes, styles, lifestyles, and circumstances dictate what quality of life is, and they make emotional value judgements on what they prioritise.

As discussed by McCarthy and Wright, people with diabetes do not just use technology but they live with it (McCarthy & Wright, 2004), and integrate it into their unique and personal lives. This of course makes the design of a mass produced interactive mobile medical technology difficult, as user requirements are not straightforward. What emerged from the data was a very complex and unique personal experience with these technologies, that indicates that a one-size-fits-all design will never be able to address adequately. As such, some participants are choosing not to adopt these technologies, choosing not to bring them on their person, or choosing not to use these technologies. Furthermore, when these technologies are adopted, carried, and used, they are having too much impact on a person's lived experiences. User experience is not often brought up with medical technologies, and issues of aesthetics are nowhere to be found in medical usability standards. However, the individual differences that emerged from the data show that user experience can have a profound effect on the use and adoption of these technologies in ways that are important for the long-term health of the users.

- Personal Styles, Lifestyles and Circumstances -

11 - Discussion

Part of this chapter has been published as part of a Paper in the Proceedings of CHI 2015 (O’Kane, Rogers, et al., 2015), has been accepted for publication as in the Extended Abstract Proceedings of CHI 2016 (Temir, O’Kane, Marshall, & Blandford, 2016), has been accepted for publication as a Workshop in the Proceedings of CHI 2016 (O’Kane et al., 2016), and is under review for publication in the Journal of CSCW (O’Kane, Park, Mentis, Blandford, & Chen, 2015)

The previous five chapters outlined the influence that contextual factors and individual differences had on the choices participants made to adopt, carry, use, not use, and misuse mobile medical technologies for the self-management of T1D. By taking a pragmatic situated approach, I was able to access how these devices are integrated into people lives, how these devices influenced everyday life and how everyday life influenced the use of these devices. As an exemplar from across the chapters, Figure 46 shows the same glucose meter used by DS9 in three very different locations and invoking different threads of felt experience (McCarthy & Wright, 2004).



Figure 46: A glucose meter at work, in a car, and at a bar

In the left picture, the device is being used in the participant’s car, in the middle it is being used on top of a desk at work, and on the right it is being used on top of a bar. With regards to the physical context, the lighting conditions are different in each context and in the car, it could be a range of different temperatures including very hot in summer and very cold in winter, causing the device not to work (causing immediate and engaged frustration, the sensual thread of felt experience). With regards to healthcare system, this device is one that was given to the participant for free, but she had to fight for in order to keep it when her GP tried to change it to another brand that

she suspected the GP had links to (brought on by connection to the device and a value judgement, the emotional thread of felt experience). The cultural context was ingrained in each of these situations, such the social norms in the pub making her feel comfortable to test on top of the bar (coinciding with the time and place of this interaction, the spatio-temporal thread of felt experience). Style and circumstance also played into each situation, from her choice of camera bag to carry the device, to her lifestyle influencing her use of a car, weekday routines at work, and social outings in pubs (ingrained in how the experience is composed in the situation, the compositional thread of felt experience).

Affective or situated experience can be hard to define and even harder to describe. McCarthy and Wright believe that *“the word ‘experience’ is simultaneously rich and elusive”* (McCarthy & Wright, 2004). This does not mean it can be ignored in the design of safety critical systems, even though it is incredibly hard to quantify. Throughout the chapters, it was found that these experiences were linked with people’s quality of life, which was sometimes prioritised over long or short-term health needs. Quality of life is something that also cannot be easily defined, and it is also not easily quantified, as discussed by (Mol, 2008):

“It is hard to judge something that is a part of yourself as if from a distance. It is even harder to make judgements about your own life. Health-care researchers ask us to do this. We are supposed to tick boxes on questionnaires on a scale of 1 to 5. How much does your diabetes bother you, 0 (not at all, 3 (a little) or 5 (a lot)? The numbers are added up, and the total is meant to represent our ‘quality of life.’ [...] You are inside your life, you live it. You cannot disentangle yourself from it and establish its quality from a distance.”

This research tried to take a holistic approach to experience with T1D devices from a bottom-up situated approach, letting themes emerge from the data. This approach pointed to the importance of respecting user experience and quality of life in the design of these devices, because ultimately their users are deciding on how and if to use this. These devices are mobile and meant to be used throughout people’s days, whatever the situation, and the threads of felt experience that materialise from these interactions emerged throughout the datasets (Wright & McCarthy, 2008). As such, context and individual differences had large influences on the experience and practice of these devices, and therefor their use.

11.1 Context Influences Experience and Practice

Mobile medical technologies are used by people for the care or maintenance of a health condition outside the clinical setting. Although the medical usability standards try to address all medical technologies, mobile medical devices differ from clinical healthcare technologies as their users are not trained professionals performing the tasks of a job: they are people who are ill and need to use this technology for their own personal health and safety, using these devices on their own bodies. In addition, the devices are mobile and therefore could be needed and used in a variety of different environments. Mobile medical technologies bring unique HCI concerns, including people's affective experiences of using these devices in different contexts. Affective experiences with technology have been linked to people's adoption and reliance on other interactive technologies (e.g. (Umbers, 1979)), but the influence of affect in context is not captured in the medical usability standards. Instead, an ideal use of these devices is captured, rather than the situated use, as the practice with these devices is the focus. However, *"by excluding or separating off people's felt experiences with technology in order to concentrate on the logic of practice, people's concerns, enthusiasms, and ambivalence about participation are abstracted or averaged out"* (McCarthy & Wright, 2004). In line with the Technology as Experience framework, this research has shown that people do not just use these mobile medical devices, but rather they live with these devices.

'Self-management' cannot be perceived as a singular activity in a box that can be easily studied in order to design and evaluate mobile medical devices. The findings of this situated exploratory study show that this is not the case; people's lives where self-care occurs are complex and dynamic. Although human factors evaluations of T1D devices have ensured that their usability (effectiveness, ease of use, ease of learning, and user satisfaction) was generally acceptable to the participants, when things did go wrong, this could evoke strong negative emotions, including annoyance and frustration.

Rather than independently determining behaviour and practice, the complexity of the physical environment, the healthcare infrastructure, the cultural context, and the social situation intertwined in how they influenced the use and adoption of T1D devices. This research takes a step towards expanding our understanding of the influence that context of use can have on the adoption and use of T1D mobile medical technologies. However, with this targeted scope, it did not access the full complexity of the context of

use, although it does provide useful insight into what pragmatic situated studies can uncover.

11.1.1 A Pragmatic Approach to Using a Situated Methodology

The approach to both the situated data collection and the analysis was flexible.

Although thematic analysis was used to guide the process, in order to get to the final themes presented in this paper, it required both the use of a qualitative research tool (Atlas.ti) as well as trial and error through writing the report. It was flexible and required iterations based on my own interpretations, but also input from my supervisors.

Although this might not be the most straightforward path for conducting analysis, I believe this bottom-up approach made the findings stronger than compared to using a more stringent top-down and inflexible framework, because the ultimate research question of examining user experience is not something easily put into boxes.

Additionally, the use of conceptual framing provided narrative for some of the thematic chapters, such as using Goffman's (Goffman, 1959) Presentation of Self framing for the social chapter and the more creative use of a Rumsfeld (Rumsfeld, 2002) quote for the culture chapter. However, these framings were only used near the end of the analysis and only used where they obviously helped with the flow of the chapter. Further conceptual framings could have been found for the other thematic chapters, but they would have been forced and this attempt at uniformity between the chapters could have negatively impacted the narrative of these chapters.

The data collection methods chosen to access 'in the wild' use of these devices are not explicitly listed in the medical usability standards, but autoethnography, contextual interviews, diary study, and observation of meet-ups applied flexibly can be useful at gaining access to the contexts that influence use, and therefore should be considered during the design and evaluation of these mobile medical devices. These methods are not the easiest to employ, as they require access to everyday life situations that are inherently private, which of course impacts the recruitment for these studies. There are benefits and challenges to each of these methods, which are summarised below.

11.1.1.1 Autoethnography for Empathy

Using Autoethnography, I experienced what it is to not only plan your day around the device, but sometimes even plan your outfit because of the shape of the device. I felt what it is like to have strangers look at me and experienced how my strategies to

minimize this were influenced by the design of the device. Through exploring the device with friends, I was able to informally test first time users and compare this with my experiences of understanding how to use the device and its affordances. Knowing that there were sounds that the device made was completely different than feeling the embarrassment of causing noise in a silent office.

Some of these insights might be gained through an ethnographic study or a contextual inquiry where HCI practitioners can observe users with their devices in context. Of course, they may not be captured as being an observer puts the researcher on the outside, whereas using autoethnography puts the researcher inherently on the inside of the experience. This method does not focus on analysing tasks or functions, but goes further to allow the researcher to comprehend the experience of using the device. As this is the case, autoethnography should be considered as an additional method that designers, evaluators and researchers in the medical usability domain could call on to acquire empathy for user experiences.

However, autoethnography is highly subjective: it is a very personal method that will give insights about some circumstances, but these results are dependent on the researcher, and situations can be inherently artificial. It should not be expected that the results are common across the very large and diverse group of mobile medical device users or that the results could be replicated. What it does allow is the designer, evaluator or researcher to experience *how it feels* to be a user, and it challenges assumptions that can sometimes be unavoidable when judging new technologies. Understanding and empathizing with the user is an important part of fully comprehending what it is like to be a mobile medical device user. Although it can be artificial and only analogous situations can be conceived, the method is an excellent surrogate for accessing part of the experience of using a mobile medical device in context.

11.1.1.2 Contextual Interviews in Public To Ground Answers

The act of having the interview in a public place added much depth to the context of the answers from participants about their T1D mobile medical device use. These interviews could have taken place in numerous locations where the devices are used, including participants' workplaces, homes, etc., but the influence of the general public in the autoethnography informed this decision for this inquiry. Although work and the home can influence use, less research has been focused on the public use of mobile medical

devices and this emerged as a powerful theme throughout the findings chapters, whether it was poor lighting in washrooms to avoid public testing, testing in line at grocery stores, or trying to gross someone out on a train with testing. Being in a public place that the participants were comfortable with provided much benefit in the richness of the interview data gathered. This was encountered in three ways. Firstly, the context itself was generally a café that had a certain number of other customers who may have been able to hear the conversation. It was interesting to see how this influenced people's body language and the level their voice was raised to. Secondly, it acted as an influence on how the participants would handle their technology in the situation. All participants were asked to bring their technology with them, but they were not all very forthright with putting it on the table and showing it to me. Although this was just one context where they might use their technology, it was enough to show how comfortable they were actually compared to how they described their comfort level in the interview. Thirdly, it was a very good way to prompt the participants into thinking about public instances of use, even beyond using it in a café. For instance, when probed about public transport use, I was able to use body language to indicate members of the public who might be around during use and participants would often look around themselves when answering.

As this study was conducted in three major cities, the possible impact of cultural norms became more apparent, despite the small sample size of 7 in Toronto, 7 in LA, and 6 in London. Through these contextual interviews, the level and frequency of misuse of the technologies became apparent. Contextual interviews grounded some of the interview answers that involved participants' past experiences in the context of everyday life, but they also acted as a prop so that participants could refer to situations and draw influence from the surroundings. I believe that this type of situated method is one that sheds light on the everyday use of current and future mobile medical devices, beyond the scope of T1D devices.

11.1.1.3 Diary Study to Access Glimpses Into the Mundane

The act of completing self-care requires a level of juggling and sometimes discretion that some people self-managing T1D might have grown accustomed to, but with the addition of the requirement to make a diary entry on a smartphone, the entire task has changed. Although this might not be routine for some people that don't use a smartphone application as part of their regular self-management practice, people with

T1D would have some expertise in how to carry out this task in a safe way. There is an additional burden on the participant when they have to use one technology and then switch to another type of technology to capture the diary entry. Although handling two devices at once can be awkward, the diary method used in conjunction with a user's smartphone was found to be relatively easy to maintain and did not gain too much attention, and it allowed details of the context to be quickly captured through photos and/or further fleshed out with text.

Simply getting a person to complete a diary study for one week will not give an idea about the breadth of use of the device. Some of the most challenging situations can occur during non-routine times, but these are the hardest to capture as they are less common and can be more invasive into a participant's life than getting them to integrate a diary study into a more regular routine. This method was the closest I believe I could get into the daily use of mobile medical devices. Although there have been criticisms of this method being truly situated (Brown et al 2013) as the diary entry is taken after the use of the device, it was a practical addition to regular self-management activities for the participants. It gave access to the places and situations that BG meter use occurs in, including the mundane testing that may not have been recounted by the participants using methods that rely on recall. Accessing the testing in the middle of the night or with a cat on your lap may not have been interesting enough to bring up in an interview, but it was captured with a diary entry. It was a good method for comparing what was said to what was done, and I believe rich data was collected from the situated nature of the diaries.

11.1.1.4 Observation of Meet-Up Provided Access to Different Opinions

Although I had previously heard many of the topics of conversation that arose during this 5-hour meeting from my other participants, the way they were approached using this method differed significantly. This is where individual differences were shown and were very clear in the agreements and disagreements of the participants about a range of topics, including sex, work, and exercise. Additionally, direct preferences of technologies were discussed in a way that I had not been able to access using other methods. Through the open conversation and the casual nature of the gathering, many people would share stories about their use of technologies, and also trade stories about their misuse, sometimes for the purpose of entertaining the others at the table. This gave rise to recalling and comparing past experiences, both positive and negative

that influenced current use and current adoption practices. As I was not facilitating the conversation nor asking interview questions, the conversation flowed naturally for them and I was able to listen and not interject any biases nor ask leading questions. Of course this resulted in conversations that were not all relevant to my research questions, but because the topic of the meeting was diabetes technology, a lot of the conversations were highly relevant.

In addition, people were very comfortable talking about a range of topics because they were with a peer group and many of them knew each other, either online or offline, including quite sensitive topics such as sexual relationships. The flow of the conversation also allowed for differing viewpoints to be shared and argued about, which offered some sort of validation that the other methods could not provide. As I was a visual presence at the group with a nametag and a notebook, there is the possibility that the conversations may have been steered to topics of situated technology use for my benefit.

Of course, this is a method that cannot be easily taken up by every researcher: I was quite lucky to be invited to a diabetes technology user meet-up as a diabetes technology researcher. There were also ethical issues with attending a group meet-up that had to be negotiated, such as wearing a nametag, visibly looking like I was taking notes, and introducing myself to people. Unfortunately, for many other mobile medical devices, there would not be this kind of social gathering and it might be harder to access. Other than this, it acted as a very interesting validation method for the other studies, and perhaps contextual focus groups could provide some similar function to this contextual group meet-up. The ability to see how different users discussed their use and adoption was very interesting, as it was quite different to how individuals talked about their own experiences, as I was not able to agree or challenge participants, as I was not a user myself.

11.1.1.5 A Note on the “Situated” Nature of These Methods

‘In the Wild’ has become a buzz term of late in HCI, but fieldwork has always been integral to accessing real world use, including being mentioned in the medical usability standards (ANSI, 2009). Mol’s (Mol, 2008) examination of both the clinical setting and in depth interviews with people with diabetes and carers concludes that for scientific research on diabetes, the focus should be where the activities are actually happening:

“Lived reality also needs to be better incorporated into scientific research. It is here, after all, that new interventions are developed and assessed”

Brown et al discuss two limitations of not taking a situated approach, and relying on retrospective methods such as interviews and diary studies (Brown, McGregor, & Laurier, 2013). Firstly there is a lack of coverage: these methods are unlikely to cover important situations of use as both interviews and diary studies are retrospective and interviewees will remember and prioritise some instances over others. Also, diary entries only focus on snapshots of an overall situation. Secondly there is a lack of detail: interviewees filter their retrospective accounts based on what they find important and diary studies are limited in how much can be asked of respondents.

I call my methods situated, but they were conducted in a pragmatic way in order to not intrude unduly on people's daily lives in-situ. Methods are not a binary choice between situated or not, but rather lie on a continuum between retrospective and real-time, and one between 'in the wild' and in the laboratory. Through the comparisons of three situated user study methods used, some of which were more real-time and situated than others, I was able to capture T1D mobile medical device use in context. While the 'in the wild' real-time methods of autoethnography and observation of a meet-up helped uncover broad but detailed contextual influences, the 'in the wild' retrospective methods of contextual interviews and diary study showed issues that were most important for each participant: a narrower range of problems that were repeatedly reported, and explained reasons behind adoption, carrying, use, non-use, and misuse of T1D devices.

11.1.2 Wider Implications for the Situated Studies of Devices

This research has pointed out the influence that context can have on the experience and practice of self-management of Type 1 Diabetes technologies by adults. Although the usability of these devices was generally fit for purpose, the physical, healthcare infrastructure, cultural, and social contexts in which they are carried, adopted and used influenced their use. This is an important concern for the designers and evaluators of T1D devices, and as such, situated methods that are beyond the scope of current medical usability engineering standards should be considered. Although this research focused on the self-management of one condition involving mobile medical devices, these concerns carry over to other conditions, other mobile medical devices, and perhaps beyond to other assistive technologies. Medical devices for the self-care of a

condition are chosen by adults to be used and adopted, despite the health concerns involved in not using, not adopting, and not carrying these devices. As such, situated user experience should be accounted for in the design and release of these devices.

There are also other approaches that would provide additional insight into the use of mobile medical devices. For example, examining GPS data, timestamps, and capturing video of smartphone application use could give a detailed account of where and how medical applications are used. Although this type of approach was not used in the diary study because of technical, practical and ethical challenges, this does not mean a different situated method might not be useful for examining the real world use of a mobile medical device.

Beyond medical devices, situated methods should be considered for other health and wellbeing mobile technologies. The use of personal informatics tools, including wearable technologies, are becoming increasingly popular (e.g. (Harrison, Marshall, Bianchi-Berthouze, & Bird, 2015)), and the lessons learned from the study of T1D devices that have been around for many years could provide insights into how these personal devices are used in context. This has already started to become a concern in the HCI community with studies being published on the situated studies of wearable technologies for exercise (Patel & O'Kane, 2015), and as the popularity of these consumer devices for health and wellbeing increases, it will likely grow as a research area. However, context should not be looked at in isolation, as it was found that individual differences impacted the situated experience and practices with these devices, as they were intertwined in people's day-to-day lives.

11.2 Individual Differences Influence Situated Experience

Throughout the situated mixed method approach, it became clear that issues beyond the usability of the technology were important: an affective experience could cause the misuse, inappropriate use, unintended use, and appropriate use of a Type 1 Diabetes technology. These affective experiences were dependent on many factors, including context as previously described, but they were also highly individual. They were different for everyone, but they are an important concern as these personal experiences could be quite negative; feelings such as frustration, annoyance, embarrassment, and discomfort were brought up time and again as influencing use in ways that could be contrary to best self-management practices, such as unintended use, not carrying technologies, not using them, and not adopting them. On the other

hand, positive experiences such as confidence in off-label use also led to some misuse and also unintended use. Although the participants who were recruited were not as varied as initially intended as described in Chapter 5, despite these similarities, there were still huge individual differences in how they experienced the devices during self-care in their everyday lives, dictated by style, lifestyle and circumstance.

People's emotional reactions to the condition influenced technology use and could be very different. They could also be temporal in nature, such as feeling out of control during sickness and not wanting to reflect back on a graph of glucose levels that were all over the place. Physical changes could also impact use and non-use of the device, ranging from not testing, often because a person was just resting in bed all day, to checking into a hospital because participants didn't trust their self-care practices when vomiting. Aesthetic sensibilities were also incredibly varied, from sartorial choices that could be made around the use of wearable CGMs and insulin pumps, to the colours that were chosen for the devices, with one person saying she can't wait to replace a green pump with a purple one, purely for aesthetic reasons. People's lifestyles massively impacted use and adoption and varied significantly based on myriad reasons. Simply being a morning person or enjoying a sleep-in changed the way the mobile medical devices were used, and hobbies and routines could interfere with adoption if a person's martial arts practice made kicks to the torso a common occurrence, or they avoided their glucose meter when binge eating. Lifestyle had massive influences on all aspects of people's lives including their device use, with even cats and cars getting in the way. People told me very personal and individual stories from their pasts that influenced their current practices, including gratefulness for technology that had progressed to a point where diabetes was not a "*death sentence*" and there was no need to "*be testing with urine*" [C13]. Over time, some participants gained what could be called insider knowledge about the condition, and who they knew could influence their practices with these devices, such as parents who were nurses.

11.2.1 Design Implications for Individual Differences?

So what are the implications for designers? It does not seem to be straightforward. The range of uncovered practices does not make for an easy one-size-fits-all solution to making these devices more suitable for people's personal everyday lives. For adults who prefer to hide their devices during their everyday routines, a device designed to be inconspicuous would be best. Currently, there are designs of devices that attempt to

mimic the style of other consumer electronics so that the medical devices do not look out of place. For example, an insulin pump that was designed to look like an inconspicuous mobile phone might suit those who prefer to carry their devices in a pocket and are discreet about their self-care activities. Or perhaps for people who choose to wear the insulin pump under their clothing and hooked onto their bra, the design of the insulin pump should include a remote that looks like (or is) a mobile phone so that they do not have to reach down or up their shirt or dress to operate it.

For others who are more open about their everyday device use, a design could be more eye-catching. For instance, an insulin pump that can be worn outside the clothing with different covers or stickers might be appropriate for some people with T1D who consistently use their devices in an outward way. Some people might want it to match the rest of their electronics in their favourite colour, or even their purple eyeglasses. Perhaps it should be an ostentatious colour so that when a person is practicing martial arts, their opponent will be able to see the area to avoid.

But could they be designed to accommodate all of these user requirements? We know from the discussion above that context could influence some to want a device that looks fashionable when showing it off in their workplace, but also one that is small and subtle for when they may want to try to hide their use during a job interview or a nerve wracking first date. In other situations, some might want a medical device to look clearly like a medical device so that they are treated preferentially: for example, in situations that were not everyday occurrences, such as trying to get upgraded to first class on a plane. In this case, neither a fashionable nor a subtle device would suit the person who is trying to 'misrepresent' their condition to get a perk, as it would benefit them most if it looked 'medical'. But this raises ethical issues for the designer to contend with. Should they be condoning this kind of behaviour, when the person does not really need to be upgraded?

Medical devices can be designed to be smaller and compact. However, this might not suit the needs of users. Such a move to miniaturization might reduce the participant's efforts to make it harder to find in a purse, harder to quickly grab when stopped at a stoplight in a car, harder to make the condition normal for a newly diagnosed child, or harder to present the condition in a way to repel a bad date. Moreover, it might cause self-care to fade into the background where it becomes invisible, increasing the potential for feelings of stigmatization (Kanstrup, 2014). This might lead people to feel

they need to perform self-care privately, such as not using a device all day during a first date. There is also a push towards making devices that are embedded into existing consumer products or making medical devices look like them, such as mobile phones and smart-watches. This of course brings with it all the issues of adoption, use and carrying associated with consumer devices, such as not wanting to show off expensive looking technology on holiday nor wanting to use a diabetes app on their iPhone in rough areas of London. Furthermore, neither of these trends to make devices smaller or more like mobile phones take into account the times when people are showing off the device to achieve a purpose, such as preferring a medical aesthetic when trying to get a disability pass in an amusement park or trying to bring a medical bag as extra luggage on a flight.

11.2.2 Wider Implications for the Personalised Design of Devices

It is clear that a one-size-fits-all solution is not appropriate: adults with chronic conditions have a variety of values, preferences, and past experiences, as well as different health concerns. The failure of a device to fit into a person's everyday life and also non-routine occurrences means that devices may not be adopted, carried, or used for self-care in all circumstances when they might be needed. Adults choose to carry and use mobile medical devices as part of everyday self-management. As such, they are both medical devices and consumer technology, and consumer needs have to be accommodated if they are to be adopted, carried, and used for self-management.

This has implications for the design and evaluation of current and future mobile medical devices used for self-management of chronic conditions. Approaches like using design probes with children (Tsvyatкова & Storni, 2014), using cognitive probes with people with T1D and T2D (Mamykina et al., 2006), and conducting participatory design and running a living lab with families (Kanstrup et al., 2008, 2010), that emphasise *user-driven design* might provide another way forward for self-management tools. This could involve using rapid prototyping and open-source hardware and software in creating bespoke mobile medical technology. Empowering people with T1D could help designers understand more how to develop devices that can serve multiple purposes in people's everyday and non-routine lives.

Beyond T1D devices, the impact of individual difference has research implications for the design of other mobile medical devices used for chronic conditions. Although these are medical devices, they can be perceived similarly to consumer electronics and if

they are at odds with the style, lifestyle, or circumstance of the user, they may not be used as intended, despite health concerns. This of course has wider implications for the growing field of personal informatics and wearable devices as well, as one-size-fits-all has also been shown to not be appropriate for the design of these technologies (Patel & O'Kane, 2015). Empowering people using these devices in a user driven design cycle may be the way forward, however, this is more of a research concern rather than something that a manufacturer might endeavour in order to deal with the variety of needs and the situated experience of adults.

11.3 Implications for Manufacturers of Mobile Medical Devices

A program of situated research to explore the use of future devices or the evaluation of current devices should be considered by manufacturers of mobile medical devices. However, in order to design the appropriate set of 'in the wild' studies, knowledge of these methods and the expertise to apply them must be in place, which might be outside the scope of some medical usability practitioners (see Appendix E). Moreover, based on the variety of individual differences found, it would be hard to use these methods to come up with design implications that would suit the majority of adults with Type 1 Diabetes. As such, I believe that manufacturers must both conduct situated evaluations and accommodate personal preferences by supporting moves towards end user customisation.

This is not to say that everyone with T1D would want to come up with a personalised technology, or want to put in the effort to making these devices perfect. There are a lot of participants that were satisfied with their current technologies, and would want to buy the model off-the-shelf. However, some of the very strong experiences relayed to me indicate that there are a number of people who would be willing to put in the effort to customise their mobile medical technologies for their particular needs and would be motivated to do so as well.

This is already occurring, in a sense, by the different technologies and brands that adults are already adopting. For instance, there are many diabetes applications available on the market currently, but people are not all flocking to one. MySugr (mysugr.com), which is a very popular diabetes app that allows people to feed their diabetes "monster" has had some great success and attributes a lower user HBA1C (a long term measure of blood glucose levels). However, those that do not want to gamify their diabetes self-management will not choose to adopt it. This is similar with diabetes

devices with different functionality, such as the Omnipod insulin pump that attaches to the back of the arm compared to an insulin pump that is attached with an infusion set and tube to a worn device on the waist. People are making choices about devices based on their personal preferences and individual differences, and this will continue whether manufacturers support them or not.

There is also a question of the level of customisation allowed and what people would want. The ability to customise the aesthetics of the device seemed to be an important concern for many participants, and this might not require that much investment from the manufacturers. Participants were already getting skins for their devices to customise them in a more superficial manner, and putting them in carrying bags that suited their personal sense of aesthetic style. However, different functions for the devices were prioritised differently for different participants, so the ability to customise aspects of a device might also be appreciated. For instance for a glucose meter, what type of battery was used, what type of screen, the size of the device, the ability to add other information to the device, the ability to send that information, the type of strips it could take, the strips being part of the devices, etc. This is not dissimilar to some types of products that can be customised for individuals, such as footwear or toys, nor dissimilar to some types of electronics that can be customised by their battery life and their hard drive size. However, the ability for medical device manufacturers to release these devices is hampered by the due diligence that they must observe in following medical standards and conducting randomised controlled trial, which can be time consuming.

Supporting end user customisation could be a way forward for manufacturers to develop mobile medical devices not only for adults with Type 1 Diabetes, but for other conditions that also require devices to be part of everyday self-care regimes. Although some self-care researchers have argued that these type of consumer practices must be levelled against levels of health and care (Mol, 2008), I believe the situated nature of this research captured the cultural expectations of consumer technologies that are trickling into the healthcare domain through shared meanings and cultural trends. Although healthcare and capitalism are controversial bedfellows, the entire interactive technology domain has been completely changed by the proliferation of mobile consumer electronics such as the iPhone which is now a household name. The current wave of wearable technologies (such as the Fitbit, Fuelband and Apple Watch) was not as ubiquitous when conducting these studies, but I believe that this consumer

technology will also influence expectations of mobile medical technologies and might influence the results of situated studies if I was to run the user studies again.

The use and acceptance of these interactive technologies for personal health cannot be viewed in a vacuum away from the influences of context such as changes in culture, and current trends do point to the anticipation (McCarthy and Wright, 2004) attached to consumer electronics and personal designs. They must be viewed as integral and intertwined in the lives of those who use them, with all of the messy contexts and individual preferences that go with them. This would require a fundamental shift for manufacturers: from designing for experience to designing an experience (McCarthy & Wright, 2004).

However, a new trend in the diabetes realm is changing the entire manufacturing paradigm of healthcare technology development. Motivated hackers and makers are building their own technologies and hacking into existing technologies to make them more useful and more personalised, and they are sharing these advances in an open-source way. The rate at which they are releasing these technologies is far surpassing the rate of consumer healthcare electronics, and this is something that should be followed up with in future research, along with further studies of the situated use of mobile medical technologies.

12- Conclusions

Healthcare technology is not often associated with first dates, job interviews, first class flying, and stickers of skylines, but this research shows that mobile medical technologies are different. They are brought with laypeople throughout their everyday lives, and this means that they are subject to a variety of contexts and a huge variety of users. Through using situated methods to understand the use and adoption of Type 1 Diabetes technologies by adults in the UK, Canada, and the US, it was found that the physical environment, the cultural context, the social situation, and individual differences had massive impacts on how this technology fits into people's lives.

Although human factors engineering methods have accounted for the usability of these devices quite well, user experience in the physical context with these devices was shown to impact the choices adults made while using them. Cultural contexts could be familiar or not, influencing whether people could fall back on routines with devices, prepare for the unknown, or just react when they found themselves out of their comfort zone. Using devices around other people was varied but consistent, until an unknown social situation caused people to hide their device or use it like a prop to gain control of the situation. Individual differences were stark among people who were in theory not that different from each other, greatly influencing adoption and use of the diabetes devices. This research shows the importance of conducting situated studies in order to access the everyday contextual influences on self-care with mobile medical devices for diabetes, but also for other medical devices that need to be carried throughout people's days and into different physical, cultural, and social contexts. Furthermore, this research uncovered the opportunity for end-user customisation that would account for people's personal preferences, but also their changing attitudes towards consumer electronics that are also being attached to mobile medical devices. This research focused on adults with diabetes and had a limited sample set, but its usefulness is broader, including for mobile health technologies that are increasingly being used as care moves away from clinical settings and into people's everyday lives. The future of mobile medical devices might be the shift in their design, manufacture, and dissemination from traditional medical device manufacturers to open-source grassroots communities, which have already had massive gains in the diabetes realm.

12.1 Future Work

12.1.1 Future Research Opportunities

McCarthy and Wright (2004) believe “*Writing ethnography is a process of displaying other people’s sense making in a language that we understand. Moreover, ethnographic inscription is always open to contest and debate; it is never finalized.*” With this in mind, I believe that I have not (and could not) completely encapsulated the contextual and individual differences that influence the use of Type 1 Diabetes technologies, and certainly not of mobile medical devices in general, which come with their own set of circumstances. However, this is a step towards understanding and there are inevitably further steps that still need to be taken. Using different methods, including quantitative accounts of situated use, there is much still to be learned about how mobile devices intertwine with people’s everyday lives and what can be done to design them so that they can be adopted and used for the immediate and long-term health of their users. However, all research on mobile medical devices needs to be situated in the real world culture that people are using these devices in as there are trends emerging outside the research space that will fundamentally change how these devices are designed and evaluated in the future.

12.1.2 Future Opportunities to Engage Manufacturers with Situated Studies of Mobile Medical Devices

Human factors engineering has made excellent strides in the past 20 years and continues to make great impacts on the design of mobile medical technologies. This has been seen in industry, but I also saw this emerging from my own research on mobile medical devices. There is great uptake of human factors processes and methods in industry, and there are over 250 British healthcare companies that adhere to these standards.

However, my research has pointed to an issue that is beyond human factors engineering: user experience. My research has pointed to the connections people are making between their mobile consumer technology and their mobile medical devices, and expectations are starting to form about the interaction design of these self-care devices. This trend is likely to trickle down further with the growing popularity of wearable consumer devices that have been designed with aesthetics and user experience in mind.

Through research activities, I have been in contact with a range of companies that are not only interested in my research, but also interested in bringing user experience into their design and evaluation processes. This has ranged from small start-ups to global pharmaceuticals, some of which have found out about my research through internet searches and have contacted me directly. I believe that there are other companies that would also be interested in academic quality research on the situated use of their mobile medical devices, and setting up a consultancy to allow these connections to be made is the basis for the commercialization of my PhD research.

Situated methods can be applied to inform the design of current and future mobile medical technologies, however they are currently not included in medical device usability standards, which are part of industry best practice, and they do require a level of expertise to be able to achieve user requirements from running them.

12.1.3 Future Opportunities from Grassroots Do-It-Yourself Health Communities

With the various types and brands of devices available, the choice of self-care technologies for managing T1D has never been as abundant, and tech savvy adults are making informed choices about their technology needs. A need for bespoke devices was uncovered through this research, where adults with T1D were observed to be choosing to adopt, carry, and use devices in various and individualized ways to accommodate their everyday practices.

For diabetes, where the condition pervades everyday life and the onus of responsibility for condition management is on the patient, a 'one size fits all' technology is not the answer. The current model of medical device development is top down and fails to accommodate these idiosyncratic needs, so instead I look towards the burgeoning open-source communities as a bottom-up solution. There has been a recent push towards open source hardware in the medical domain (Schubert, van Langeveld, & Donoso, 2014) and within this community, people have started to discuss the development of bespoke medical devices to meet individual needs (Niezen, 2014; Reynolds & Wyatt, 2011). In addition, there have been moves towards an open data approach to healthcare information (Walsh, Roberts, Morris, & Heinemann, 2015), particularly in diabetes where information from medical devices is being transferred to the users through open software solutions and dedicated technologies. Additionally, mobile phone companies are now looking towards incorporating medical sensors into hardware (Farr, 2014) and are opening themselves up to the open-source hardware

community (Brown, 2014). This same argument has been made for technologies to help people age in place, with a push towards technology that is easier to customize (Procter et al., 2014), and for assistive devices that can be 3D printed (Buehler et al., 2015). Despite concerns with “*creeping featurism*” (Norman, 1992) or “*bloat*” (McGrenere, 2000), bespoke personal health tools have the potential to be regulated as custom made medical devices (Medicines and Healthcare Products Regulatory Agency, 2014). There is potential to build on these advances and tap into chronic condition communities to support bespoke hardware/software solutions that suit the individual in their information needs relating to self-management.

Beyond commercially available devices, there is a community of makers that are developing their own bespoke solutions to T1D needs. These makers personalize their T1D devices to varying degrees. At the lower fidelity end, they adopt and appropriate accessories such as luggage tags to carry their devices or order customized stickers or skins to decorate their devices (see Figure 47).



Figure 47: Luggage tag used as a case for a CGM

At the higher fidelity end, there are movements such as #WeAreNotWaiting who use their technical expertise to create and release bespoke technology solutions at a faster rate than manufacturers or research labs. #WeAreNotWaiting believe manufacturers are taking too long to release products that provide functionalities that they find important, such as being able to upload glucose meter data to the cloud. DIY groups such as Nightscout have modified CGMs to broadcast “CGM in the Cloud” and communicate with other devices that are not reachable using the commercially available CGM Bluetooth capabilities. This not only enables people to broadcast their results to their smartphones and smartwatches (Walsh et al., 2015) but also allows parents to monitor their children’s BG levels remotely and in real time, something they could not do with commercial devices (see Figure 48).



Figure 48: Three smartwatches running Nightscout (from: <http://bit.ly/1MBPOao>)

There have also been moves to use off-the-shelf CGMs and insulin pumps in conjunction with programmable devices such as Raspberry Pi to develop more advanced T1D technologies. The closed loop ‘artificial pancreas’, where a glucose monitor is connected to an insulin pump and balances glucose levels through automatic medication injection without human assistance, has not been released by any research group or manufacturer to date. However, there have been moves to release an open-source DIY closed loop pancreas (see Figure 49).

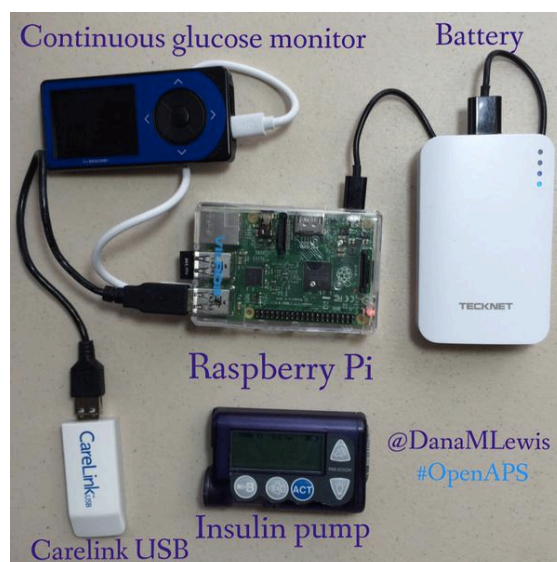


Figure 49: Open-Source Closed Loop Artificial Pancreas (from: <http://bit.ly/1LbldOQ>)

To solve this disconnect between needs and skills, there has been some informal technical knowledge transfer activities uncovered throughout my research: in meet-ups where tips and tricks are shared, in personal connections made online (e.g. a three hour Skype call to help someone set up a technology), or even more formalised instructions to hack devices. Despite the initial success of these initiatives, there is still a divide between those who are interested in bespoke technology and those who are able to create their own bespoke technology (e.g. over 14000 Facebook members of

CGM in the Cloud, but under 3500 Nightscout users in mid-2015). As such, there is an opportunity to support these technical knowledge transfer activities among online T1D communities and expand these findings to other communities with growing appetites for personalised care through bespoke technologies.

This future research is being taken up as an EPSRC Doctoral Prize to build on and expand the findings of this dissertation.

References

- Aarhus, R., & Ballegaard, S. A. (2010). Negotiating Boundaries: Managing Disease at Home. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1223–1232). New York, NY, USA: ACM.
doi:10.1145/1753326.1753509
- Aarhus, R., Ballegaard, S., & Hansen, T. (2009). The eDiary: Bridging home and hospital through healthcare technology. In I. Wagner, H. Tellioğlu, E. Balka, C. Simone, & L. Ciolfi (Eds.), *ECSCW 2009 SE - 4* (pp. 63–83). Springer London.
doi:10.1007/978-1-84882-854-4_4
- Alberti, K. G. M. M., & Zimmet, P. Z. ft. (1998). Definition, diagnosis and classification of diabetes mellitus and its complications. Part 1: diagnosis and classification of diabetes mellitus. Provisional report of a WHO consultation. *Diabetic Medicine*, 15(7), 539–553.
- American Association of Diabetes Educators. (2009). AADE guidelines for the practice of diabetes self-management education and training (DSME/T). *The Diabetes Educator*, 35(3 suppl), 85S–107S.
- ANSI. (2007). Medical devices - Application of usability engineering to medical devices. (A. for the A. of M. Instrumentation, Ed.) *ANSI/AAMI/IEC 62366:2007*.
- ANSI. (2009). ANSI/AAMI HE75: 2009: Human factors engineering: Design of medical devices. *AAMI, Arlington*.
- Arrnrich, B., Mayora, O., Bardram, J., & Tröster, G. (2010). Pervasive healthcare. *Methods Inf Med*, 49(1), 67–73.
- Årsand, E., Muzny, M., Bradway, M., Muzik, J., & Hartvigsen, G. (2015). Performance of the First Combined Smartwatch and Smartphone Diabetes Diary Application Study. *Journal of Diabetes Science and Technology*, 9 (3), 556–563.

- Arsand, E., Tatara, N., Østengen, G., & Hartvigsen, G. (2010). Mobile phone-based self-management tools for type 2 diabetes: the few touch application. *Journal of Diabetes Science and Technology*, 4(2), 328–36.
- Ballegaard, S. A., Hansen, T. R., & Kyng, M. (2008). Healthcare in Everyday Life: Designing Healthcare Services for Daily Life. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1807–1816). New York, NY, USA: ACM. doi:10.1145/1357054.1357336
- Balsamo, A. (2011). *Designing culture: The technological imagination at work*. Duke University Press.
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior*, 31(2), 143–164.
- Banks, S. P., & Banks, A. (2000). Reading “the critical life”: Autoethnography as pedagogy. *Communication Education*, 49(3), 233–238.
doi:10.1080/03634520009379212
- Bergman, E. (2000). Designing the PalmPilot: a conversation with Rob Haitani. *Information Appliances and beyond: Interaction Design for Consumer Products*, Morgan Kaufmann, San Francisco, CA, 81–102.
- Blandford, A. (2013). Semi-structured qualitative studies. In M. Soegaard & R. Dam (Eds.), *The Encyclopedia of Human-Computer Interaction*, 2nd Ed. The Interaction Design Foundation.
- Blondon, K., & Klasnja, P. (2013). Designing Supportive Mobile Technology for Stable Diabetes. In A. Marcus (Ed.), *Design, User Experience, and Usability. Health, Learning, Playing, Cultural, and Cross-Cultural User Experience SE - 40* (Vol. 8013, pp. 361–370). Springer Berlin Heidelberg. doi:10.1007/978-3-642-39241-2_40
- Blood Pressure Association. (2012). How to Use a Home Blood Pressure Monitor. Retrieved from <http://bpassoc-shop.org.uk/>.
- Bødker, S. (2006). When second wave HCI meets third wave challenges. *Proceedings*

- of the 4th Nordic Conference on Human-Computer Interaction: Changing Roles.* Oslo, Norway: ACM. doi:10.1145/1182475.1182476
- Boehner, K., Sengers, P., & Warner, S. (2008). Interfaces with the ineffable: Meeting aesthetic experience on its own terms. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 15(3), 12.
- Boots. (2012). Monitoring Blood Pressure. Retrieved from http://www.boots.com/en/Monitoring-blood-pressure_1211500/
- Brandt, J., Weiss, N., & Klemmer, S. R. (2007). txt 4 l8r: lowering the burden for diary studies under mobile conditions. *CHI '07 Extended Abstracts on Human Factors in Computing Systems*. San Jose, CA, USA: ACM. doi:10.1145/1240866.1240998
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. Qualitative Research in Psychology*, 3(2), 77–101. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brown, B., McGregor, M., & Laurier, E. (2013). iPhone in Vivo: Video Analysis of Mobile Device Use. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1031–1040). New York, NY, USA: ACM. doi:10.1145/2470654.2466132
- Brown, E. (2014). Mobile Customization Gets Boost with Jolla's The Other Half. *Linux.com*. Retrieved August 5, 2014, from <http://www.linux.com/news/embedded-mobile/mobile-linux/761693-mobile-customization-gets-boost-with-jollas-the-other-half/>
- BSI. (2008). *BS 7000-1:2008 Design management systems – Part 1: Guide to managing innovation*.
- Buchenau, M., Francisco, I. S., & Suri, J. F. (2000). Experience Prototyping. In *Conference on Designing interactive systems: processes, practices, methods, and techniques* (pp. 424–433). ACM. doi:http://doi.acm.org/10.1145/347642.347802
- Buehler, E., Branham, S., Ali, A., Chang, J. J., Hofmann, M. K., Hurst, A., & Kane, S. K. (2015). Sharing is Caring: Assistive Technology Designs on Thingiverse. In

Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (pp. 525–534). New York, NY, USA: ACM.
doi:10.1145/2702123.2702525

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167–182. doi:10.1111/1467-9566.ep11339939

Button, G., & Sharrock, W. (2009). Studies of Work and the Workplace in HCI: Concepts and Techniques. *Synthesis Lectures on Human-Centered Informatics*, 2(1), 1–96.

Cafazzo, J. A., Casselman, M., Hamming, N., Katzman, D. K., & Palmert, M. R. (2012). Design of an mHealth app for the self-management of adolescent type 1 diabetes: a pilot study. *Journal of Medical Internet Research*, 14(3), e70.
doi:10.2196/jmir.2058

Chen, Y. (2010). Take it personally: accounting for individual difference in designing diabetes management systems. In *Proceedings of the 8th ACM Conference on Designing Interactive Systems* (pp. 252–261). New York, NY, USA: ACM.
doi:10.1145/1858171.1858218

Choe, E. K., Lee, N. B., Lee, B., Pratt, W., & Kientz, J. A. (2014). Understanding Quantified-selfers' Practices in Collecting and Exploring Personal Data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1143–1152). New York, NY, USA: ACM. doi:10.1145/2556288.2557372

Clarke, S. F., & Foster, J. R. (2012). A history of blood glucose meters and their role in self-monitoring of diabetes mellitus. *Br J Biomed Sci*, 69(2), 83–93.

Clarke, S. F., & Foster, J. R. (2012). A history of blood glucose meters and their role in self-monitoring of diabetes mellitus. *British Journal of Biomedical Science*, 69(2), 89–93.

Clough, P. T., & Ellis, C. (1997). Autotelecommunication and Autoethnography: A Reading of Carolyn Ellis's "Final Negotiations." *The Sociological Quarterly*, 38(1), 95–110.

- Consolvo, S., & Walker, M. (2003). Using the experience sampling method to evaluate ubicomp applications. *Pervasive Computing, IEEE*, 2(2), 24–31.
- Csikszentmihalyi, M., & Larson, R. (1992). Validity and reliability of the experience sampling method. *The Experience of Psychopathology: Investigating Mental Disorders in Their Natural Settings*, 43–57.
- Cunningham, S. J., & Jones, M. (2005). Autoethnography: a tool for practice and education. *Proceedings of the 6th ACM SIGCHI New Zealand Chapter's International Conference on Computer-Human Interaction: Making CHI Natural*. Auckland, New Zealand: ACM. doi:10.1145/1073943.1073944
- DAFNE. (2013). Type 1 Diabetes: Less guesswork. More freedom. Better health. Retrieved October 25, 2013, from <http://www.dafne.uk.com/>
- de Bakker, D. H., Struijs, J. N., Baan, C. A., Raams, J., de Wildt, J.-E., Vrijhoef, H. J. M., & Schut, F. T. (2012). Early results from adoption of bundled payment for diabetes care in the Netherlands show improvement in care coordination. *Health Affairs*, 31(2), 426–433.
- Deloitte. (2015). Game of Phones. *Mobile Consumer 2015: The UK cut*. Retrieved from <http://www.deloitte.co.uk/mobileuk/>
- Department of Health. (n.d.). Ten things you need to know about long term conditions. Department of Health, Richmond House, 79 Whitehall, London SW1A 2NJ, UK, dhmail@dh.gsi.gov.uk.
- Dewey, J. (2005). *Art as experience*. Perigee.
- Diabetes UK. (2013a). Testing - Diabetes UK. Retrieved October 25, 2013, from <http://www.diabetes.org.uk/Guide-to-diabetes/Monitoring/Testing/>
- Diabetes UK. (2013b). UK lagging behind Europe for use of insulin pumps - Diabetes UK. Retrieved from http://www.diabetes.org.uk/About_us/News_Landing_Page/UK-lagging-behind-Europe-for-use-of-insulin-pumps/

- Diabetes UK. (2014). Diabetes UK gets behind #showmeyourpump movement. *Diabetes UK*. Retrieved August 31, 2014, from http://www.diabetes.org.uk/About_us/News/Diabetes-UK-gets-behind-showmeyourpump-movement/
- Diener, E., Larsen, R. J., & Emmons, R. A. (1984). Person x Situation interactions: Choice of situations and congruence response models. *Journal of Personality and Social Psychology*, 47(3), 580.
- Dix, A., Rodden, T., Davies, N., Trevor, J., Friday, A., & Palfreyman, K. (2000). Exploiting space and location as a design framework for interactive mobile systems. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 7(3), 285–321.
- Dourish, P. (2004a). What we talk about when we talk about context. *Personal Ubiquitous Comput.*, 8(1), 19–30. doi:10.1007/s00779-003-0253-8
- Dourish, P. (2004b). *Where the action is: the foundations of embodied interaction*. MIT press.
- Efimova, L. (2009). Weblog as a personal thinking space. *Proceedings of the 20th ACM Conference on Hypertext and Hypermedia*. Torino, Italy: ACM. doi:10.1145/1557914.1557963
- Farr, C. (2014). Apple, Google, Samsung vie to bring health apps to wearables | Reuters. *Reuters*. Retrieved August 5, 2014, from <http://www.reuters.com/article/2014/06/23/us-tech-healthcare-mobilephone-insight-idUSKBN0EY0BQ20140623>
- FDA. (2011). Draft Guidance for Industry and Food and Drug Administration Staff - Applying Human Factors and Usability Engineering to Optimize Medical Device Design, (1757).
- FDA. (2015). Medical Device Data Systems - Identifying an MDDS. Center for Devices and Radiological Health. Retrieved October 13, 2015, from <http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/GeneralHospitals>

talDevicesandSupplies/MedicalDeviceDataSystems/ucm251906.htm

- Fitzpatrick, G. (2003). *The locales framework: understanding and designing for wicked problems* (Vol. 1). Springer Science & Business Media.
- Flanagan, J. C. (1954). The critical incident technique. *Psychological Bulletin*, 51(4), 327–358. doi:10.1037/h0061470
- Franklin, V. L., Greene, A., Waller, A., Greene, S. A., & Pagliari, C. (2008). Patients' engagement with "Sweet Talk" - a text messaging support system for young people with diabetes. *Journal of Medical Internet Research*, 10(2), e20. doi:10.2196/jmir.962
- Funnell, M., & Anderson, R. (2000). The problem with compliance in diabetes. *JAMA*, 284(13), 1709.
- Furniss, D., Blandford, A., & Mayer, A. (2011). Unremarkable errors: low-level disturbances in infusion pump use. In *Proceedings of the 25th BCS Conference on Human-Computer Interaction* (pp. 197–204). British Computer Society.
- Furniss, D., Masci, P., Curzon, P., Mayer, A., & Blandford, A. (2015). Exploring medical device design and use through layers of distributed cognition: how a glucometer is coupled with its context. *Journal of Biomedical Informatics*, 53, 330–341.
- Furniss, D., O'Kane, A. A., Randell, R., Taneva, S., Mentis, H., & Blandford, A. (2014). Fieldwork for Healthcare: Case Studies Investigating Human Factors in Computing Systems. *Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies*, 3(1), 1–129. doi:10.2200/S00552ED1V01Y201311ARH005
- Furniss, D., Randell, R., O'Kane, A. A., Taneva, S., Mentis, H., & Blandford, A. (2014). Fieldwork for healthcare: guidance for investigating human factors in computing systems. *Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies*, 3(2), 1–146.
- García-Lizana, F., & Sarriá-Santamera, A. (2007). New technologies for chronic disease management and control: a systematic review. *Journal of Telemedicine and Telecare*, 13(2), 62–68.

- Gaver, B., Dunne, T., & Pacenti, E. (1999). Design: Cultural probes. *Interactions*, 6(1), 21–29. doi:10.1145/291224.291235
- Glasgow, R. E., Orleans, C. T., Wagner, E. H., Curry, S. J., & Solberg, L. I. (2001). Does the chronic care model serve also as a template for improving prevention? *The Milbank Quarterly*, 79(4), 579.
- Goffman, E. (1959). *The presentation of self in everyday life*. London: Penguin Books Ltd.
- Graham, F. (2010). MHealth: Mobile technology brings healthcare home. Retrieved from <http://www.bbc.co.uk/news/business-12068754>
- Grönvall, E., & Verdezoto, N. (2013). Beyond self-monitoring: Understanding non-functional aspects of home-based healthcare technology. In *Proceedings of the 2013 ACM international joint conference on Pervasive and ubiquitous computing* (pp. 587–596). ACM.
- Haire, M. (1950). Projective Techniques in Marketing Research. *Journal of Marketing*, 14(5), 649–656 CR – Copyright © 1950 American Marketing Association. doi:10.2307/1246942
- Hakken, D., & Maté, P. (2014). The culture question in participatory design. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2* (pp. 87–91). ACM.
- Hall, S. (1997). *Representation: Cultural representations and signifying practices* (Vol. 2). Sage.
- Hampson, S. E., Glasgow, R. E., & Toobert, D. J. (1990). Personal models of diabetes and their relations to self-care activities. *Health Psychology*, 9(5), 632.
- Harrison, D., Marshall, P., Bianchi-Berthouze, N., & Bird, J. (2015). Activity Tracking: Barriers, Workarounds and Customisation. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (pp. 617–621). New York, NY, USA: ACM. doi:10.1145/2750858.2805832

- Harrison, L., Skau, D., Franconeri, S., Lu, A., & Chang, R. (2013). Influencing visual judgment through affective priming. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13* (p. 2949). New York, New York, USA: ACM Press. doi:10.1145/2470654.2481410
- Hilliard, M. E., Sparling, K. M., Hitchcock, J., Oser, T. K., & Hood, K. K. (2015). The Emerging Diabetes Online Community. *Current Diabetes Reviews*.
- Holtzblatt, K., & Jones, S. (1993). Contextual inquiry: A participatory technique for system design. *Participatory Design: Principles and Practice*, 180–193.
- Höök, K. (2010). Transferring qualities from horseback riding to design. *Proceedings of the 6th Nordic Conference on Human-Computer Interaction: Extending Boundaries*. Reykjavik, Iceland: ACM. doi:10.1145/1868914.1868943
- Höök, K. (2012). Affective Computing: Affective Computing, Affective Interaction and Technology as Experienc. In (M. and D. Soegaard Rikke Friis, Ed.) *Encyclopedia of Human-Computer Interaction*. Aarhus, Denmark: The Interaction Design Foundation.
- Hutchins, E. (1995). *Cognition in the Wild* (Vol. 262082314). MIT press Cambridge, MA.
- IEC. (2010). 60601-1-11: 2010 Requirements for medical electrical equipment and medical electrical systems used in the home healthcare environment. IEC Geneva, Switzerland.
- International Standards Organization. (n.d.). ISO 13485:2003 - Medical devices -- Quality management systems -- Requirements for regulatory purposes. Retrieved from http://www.iso.org/iso/catalogue_detail?csnumber=36786
- International Standards Organization. (2001). 14971: 2001 Medical devices-Application of risk management to medical devices. *London: British Standards Institute*.
- Isomursu, M., Kuutti, K., & Väinämö, S. (2004). Experience Clip: Method for User Participation and Evaluation of Mobile Concepts. In *Proceedings of the Eighth Conference on Participatory Design: Artful Integration: Interweaving Media*,

Materials and Practices - Volume 1 (pp. 83–92). New York, NY, USA: ACM.
doi:10.1145/1011870.1011881

Jacobson, A. M. (1986). Current status of psychosocial research in diabetes. *Diabetes Care*, 9(5), 546–548.

JDRF. (2013). Continuous Glucose Monitors. Retrieved October 25, 2013, from
<http://www.jdrf.org.uk/life-with-type-1-diabetes/managing-type-1/treatments/cgms>

Jeon, M., & Zhang, W. (2013). Sadder but Wiser? Effects of Negative Emotions on Risk Perception, Driving Performance, and Perceived Workload. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, 57(1), 1849–1853.
doi:10.1177/1541931213571413

Kanstrup, A. M. (2014). Design concepts for digital diabetes practice: Design to explore, share, and camouflage chronic illness. *International Journal of Design*, 8(3), 49–60.

Kanstrup, A. M., Bertelsen, P., Glasemann, M., & Boye, N. (2008). Design for More: An Ambient Perspective on Diabetes. In *Proceedings of the Tenth Anniversary Conference on Participatory Design 2008* (pp. 118–127). Indianapolis, IN, USA: Indiana University.

Kanstrup, A. M., Bjerger, K., & Kristensen, J. E. (2010). A Living Laboratory Exploring Mobile Support for Everyday Life with Diabetes. *Wirel. Pers. Commun.*, 53(3), 395–408. doi:10.1007/s11277-010-9953-3

Kaufman, D. R., Patel, V. L., Hilliman, C., Morin, P. C., Pevzner, J., Weinstock, R. S., ... Starren, J. (2003). Usability in the real world: assessing medical information technologies in patients' homes. *Journal of Biomedical Informatics*, 36(1-2), 45–60. doi:10.1016/S1532-0464(03)00056-X

Kaufman, F. R. (2002). Type 2 Diabetes Mellitus in Children and Youth: A New Epidemic. *Journal of Pediatric Endocrinology and Metabolism*, 15(Supplement), 737–744.

Klasnja, P., & Pratt, W. (2012). Healthcare in the pocket: mapping the space of mobile-

- phone health interventions. *Journal of Biomedical Informatics*, 45(1), 184–198.
- Kohn, L. T., Corrigan, J. M., & Donaldson, M. S. (2000). *To err is human: building a safer health system* (Vol. 627). National Academies Press.
- Ljungblad, S. (2009). Passive photography from a creative perspective: “If I would just shoot the same thing for seven days, it’s like... What’s the point?” *Proceedings of the 27th International Conference on Human Factors in Computing Systems*. Boston, MA, USA: ACM. doi:10.1145/1518701.1518828
- Lowe, C. M. (2006). Accidents waiting to happen: the contribution of latent conditions to patient safety. *Quality & Safety in Health Care*, 15 Suppl 1, i72–5. doi:10.1136/qshc.2006.016071
- Mainsah, H., & Morrison, A. (2014). Participatory design through a cultural lens: insights from postcolonial theory. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2* (pp. 83–86). ACM.
- Malinowski, B. (1978). *Argonauts of the Western Pacific: An account of native enterprise and adventure in the archipelagoes of Melanesian New Guinea*. Psychology Press.
- Mamykina, L., Mynatt, E. D., & Kaufman, D. R. (2006). Investigating Health Management Practices of Individuals with Diabetes. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 927–936). New York, NY, USA: ACM. doi:10.1145/1124772.1124910
- Mamykina, L., Mynatt, E., Davidson, P., & Greenblatt, D. (2008). MAHI. In *Proceeding of the twenty-sixth annual CHI conference on Human factors in computing systems - CHI '08* (p. 477). New York, New York, USA: ACM Press. doi:10.1145/1357054.1357131
- Mamykina, L., Smaldone, A. M., & Bakken, S. R. (2015). Adopting the sensemaking perspective for chronic disease self-management. *Journal of Biomedical Informatics*, 56, 406–417.

- Manhattan Research. (2008). *The State of eHealth: Trends of Today's eHealth Consumer*.
- Marshall, P., Morris, R., Rogers, Y., Kreitmayer, S., & Davies, M. (2011). Rethinking "multi-user": an in-the-wild study of how groups approach a walk-up-and-use tabletop interface. *Proceedings of the 2011 Annual Conference on Human Factors in Computing Systems*. Vancouver, BC, Canada: ACM.
doi:10.1145/1978942.1979392
- Martin, J. L., Norris, B. J., Murphy, E., & Crowe, J. A. (2008). Medical device development: The challenge for ergonomics. *Applied Ergonomics*, 39(3), 271–283. doi:http://dx.doi.org/10.1016/j.apergo.2007.10.002
- Mayo Clinic. (2013). Diabetes nutrition: Eating out when you have diabetes - MayoClinic.com. Retrieved October 25, 2013, from <http://www.mayoclinic.com/health/diabetes-nutrition/DA00131>
- McCarthy, J., & Wright, P. (2004). *Technology as experience*. The MIT Press.
- McGrenere, J. (2000). "Bloat": The Objective and Subject Dimensions. In *CHI '00 Extended Abstracts on Human Factors in Computing Systems* (pp. 337–338). New York, NY, USA: ACM. doi:10.1145/633292.633495
- McMahon, B. T., West, S. L., Mansouri, M., & Belongia, L. (2005). Workplace discrimination and diabetes: the EEOC Americans with Disabilities Act research project. *Work: A Journal of Prevention, Assessment and Rehabilitation*, 25(1), 9–18.
- Medicines and Healthcare Products Regulatory Agency. (2014). Custom made devices. MHRA. Medicines and Healthcare products Regulatory Agency (MHRA), Market Towers, 1 Nine Elms Lane, Vauxhall, London, SW8 5NQ, UK. Telephone 020 7084 2000 (weekdays 0900 -1700), 020 7210 3000 (other times), Fax 020 7084 2353, E-mail info@mhra.gsi.gov.uk, Websit. Retrieved August 5, 2014, from <http://www.mhra.gov.uk/Howweregulate/Devices/Complyingwithlegislation/ActiveImplantableMedicalDevicesDirective/Custommadedevices/index.htm>

- Merton, R. K. (1975). Thematic Analysis in Science: Notes on Holton. *Science*, 188(4186), 335–338.
- Mianowska, B., Fendler, W., Szadkowska, A., Baranowska, A., Grzelak-Agaciak, E., Sadon, J., ... Mlynarski, W. (2011). HbA1c levels in schoolchildren with type 1 diabetes are seasonally variable and dependent on weather conditions. *Diabetologia*, 54(4), 749–756.
- Mol, A. (2006). Proving or improving: on health care research as a form of self-reflection. *Qualitative Health Research*, 16(3), 405–414.
- Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge.
- Mol, A., & Law, J. (2004). Embodied Action, Enacted Bodies: the Example of Hypoglycaemia. *Body & Society*, 10 (2-3), 43–62.
- Moore, J. O. (2009). CollaboRhythm: new paradigms in doctor-patient interaction applied to HIV medication adherence. Massachusetts Institute of Technology.
- Mynatt, E. D., Abowd, G. D., Mamykina, L., & Kientz, J. A. (2010). Understanding the potential of ubiquitous computing for chronic disease management. *Health Informatics: A Patient-Centered Approach to Diabetes*. *Health Informatics*, 85–106.
- NHS Choices. (2013a). Diabetes, type 1 - NHS Choices. Department of Health. Retrieved October 25, 2013, from <http://www.nhs.uk/Conditions/Diabetes-type1/Pages/Introduction.aspx>
- NHS Choices. (2013b). Diabetes, type 1 - Treatment - NHS Choices. Department of Health. Retrieved October 25, 2013, from <http://www.nhs.uk/Conditions/diabetes-type1/Pages/treatment.aspx>
- Niezen, G. (2014). Open source hardware (OSHW) and medical devices. *Thingscon*. Berlin. Retrieved August 6, 2014, from <https://speakerdeck.com/gerrit/open-source-hardware-oshw-and-medical-devices>
- Nolan, T. W. (2000). System changes to improve patient safety. *Bmj*.

doi:10.1136/bmj.320.7237.771

- Norman, D. A. (1992). Design principles for cognitive artifacts. *Research in Engineering Design*, 4(1), 43–50. doi:10.1007/BF02032391
- Nunes, F. (2015). Designing Self-care Technologies for Everyday Life: A Practice Approach. In *Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems* (pp. 215–218). ACM.
- Nunes, F., Verdezoto, N., Fitzpatrick, G., Kyng, M., Grönvall, E., & Storni, C. (2015). Self-care Technologies in HCI: Trends, Tensions, and Opportunities. *ACM Transactions on Computer-Human Interaction (TOCHI) Journal*.
- O'Hara, K., & Perry, M. (2001). Shopping anytime anywhere. *CHI '01 Extended Abstracts on Human Factors in Computing Systems*. Seattle, Washington: ACM. doi:10.1145/634067.634271
- O'Hara, K., Perry, M., Sellen, A., & Brown, B. (2002). Exploring the relationship between mobile phone and document activity during business travel. In *Wireless world* (pp. 180–194). Springer-Verlag New York, Inc.
- O'Kane, A. A. (2014). Using A Third-Wave HCI Approach for Researching Mobile Medical Devices. In *CHI 2016 Workshop: HCI research in healthcare: using theory from evidence to practice*.
- O'Kane, A. A., & Blandford, A. (2013). Recruiting Diabetes Patients: a Success and a Failure. In *CHI 2013 Workshop HCI fieldwork in healthcare: Creating a Graduate Handbook Workshop*.
- O'Kane, A. A., & Blandford, A. (2014). Reflecting on Empathy during Mobile Medical Device Research. In *CHI 2014 Workshop: Enabling Empathy in Health & Care: Design Methods & Challenges*.
- O'Kane, A. A., Hurst, A., Niezen, G., Marquardt, N., Bird, J., & Abowd, G. D. (2016). Workshop Proposal: Advances in DIY Health and Wellbeing. In *Submitted to CHI 2016*.

- O’Kane, A. A., & Mentis, H. M. (2012). Sharing medical data vs. health knowledge in chronic illness care. In *Proceedings of the 2012 ACM annual conference extended abstracts on Human Factors in Computing Systems Extended Abstracts* (pp. 2417–2422). ACM.
- O’Kane, A. A., Mentis, H. M., & Thereska, E. (2013). Non-static nature of patient consent: shifting privacy perspectives in health information sharing. In *Proceedings of the 2013 conference on Computer supported cooperative work* (pp. 553–562). ACM.
- O’Kane, A. A., Park, S. Y., Mentis, H. M., Blandford, A., & Chen, Y. (2015). “It wasn’t just me!” - Turning to peers: integrating understanding of the self, the condition, and others’ experiences in making sense of complex chronic conditions. *Submitted to Journal of CSCW*.
- O’Kane, A. A., Rogers, Y., & Blandford, A. (2014). Gaining Empathy For Non-Routine Mobile Device Use Through Autoethnography. In *Proceeding of the thirty-first annual CHI conference on Human factors in computing systems - CHI '14*.
- O’Kane, A. A., Rogers, Y., & Blandford, A. (2015). Concealing or Revealing Mobile Medical Devices?: Designing for Onstage and Offstage Presentation. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (pp. 1689–1698).
- Omron. (2012a). How to use an Omron. Retrieved from http://www.omron-healthcare.com/en/health_information/blood_pressure/#Howto.
- Omron. (2012b). R7 (HEM-637-E7). Retrieved from http://www.omron-healthcare.com/en/product/blood_pressure_monitors/All/HEM-637-E.html.
- Owen, T. (2011). Don’T Let Me Down: Using Contextual Information to Aid Diabetics. In *Proceedings of the 13th International Conference on Ubiquitous Computing* (pp. 523–526). New York, NY, USA: ACM. doi:10.1145/2030112.2030197
- Owen, T., Buchanan, G., & Thimbleby, H. (2012). Understanding user requirements in take-home diabetes management technologies. In *Proceedings of the 26th Annual*

BCS Interaction Specialist Group Conference on People and Computers (pp. 268–273). Swinton, UK, UK: British Computer Society.

Owen, T., Pearson, J., Thimbleby, H., & Buchanan, G. (2015). ConCap: Designing to Empower Individual Reflection on Chronic Conditions using Mobile Apps. In *Proceedings of the 17th International Conference on Human-Computer Interaction with Mobile Devices and Services* (pp. 105–114). ACM.

Palen, L., & Salzman, M. (2002). Voice-mail diary studies for naturalistic data capture under mobile conditions. *Proceedings of the 2002 ACM Conference on Computer Supported Cooperative Work*. New Orleans, Louisiana, USA: ACM.
doi:10.1145/587078.587092

Pantelopoulos, A., & Bourbakis, N. (2008). A survey on wearable biosensor systems for health monitoring. In *Engineering in Medicine and Biology Society, 2008. EMBS 2008. 30th Annual International Conference of the IEEE* (pp. 4887–4890).

Patel, M., & O’Kane, A. A. (2015). Contextual Influences on the Use and Non-Use of Digital Technology While Exercising at the Gym. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (pp. 2923–2932). New York, NY, USA: ACM. doi:10.1145/2702123.2702384

Peyrot, M., McMurry Jr, J. F., & Kruger, D. F. (1999). A biopsychosocial model of glycemic control in diabetes: stress, coping and regimen adherence. *Journal of Health and Social Behavior*, 141–158.

Phillips, R., & Madhavan, P. (2013). The Role of Affective Valence and Task Uncertainty in Human-Automation Interaction. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, 57(1), 354–358.
doi:10.1177/1541931213571077

Piette, J. D. (2006). The Impact of Comorbid Chronic Conditions on Diabetes Care. *Diabetes Care*, 29(3), 725–731. doi:10.2337/diacare.29.03.06.dc05-2078

Polonsky, W. (1999). *Diabetes burnout: What to do when you can’t take it anymore*. American Diabetes Association.

- Procter, R., Greenhalgh, T., Wherton, J., Sugarhood, P., Rouncefield, M., & Hinder, S. (2014). The Day-to-Day Co-Production of Ageing in Place. *Computer Supported Cooperative Work (CSCW)*, 23(3), 245–267. doi:10.1007/s10606-014-9202-5
- Rajkomar, A., Blandford, A., & Mayer, A. (2013). Coping with complexity in home hemodialysis: a fresh perspective on time as a medium of Distributed Cognition. *Cognition, Technology & Work*, 1–12. doi:10.1007/s10111-013-0263-x
- Rajkomar, A., Blandford, A., & Mayer, A. (2014). Coping with complexity in home hemodialysis: a fresh perspective on time as a medium of Distributed Cognition. *Cognition, Technology & Work*, 16(3), 337–348.
- Rajkomar, A., Farrington, K., Mayer, A., Walker, D., & Blandford, A. (2014). Patients' and carers' experiences of interacting with home haemodialysis technology: implications for quality and safety. *BMC Nephrology*, 15(1), 195.
- Reynolds, C. J., & Wyatt, J. C. (2011). Open source, open standards, and health care information systems. *Journal of Medical Internet Research*, 13(1).
- Richardson, L., & Pierre, E. A. S. (2007). A method of inquiry. *Collecting and Interpreting Qualitative Materials*, 473.
- Riddell, M. C., & Perkins, B. A. (2006). Type 1 Diabetes and Vigorous Exercise: Applications of Exercise Physiology to Patient Management. *Canadian Journal of Diabetes*, 30(1), 63–71. doi:http://dx.doi.org/10.1016/S1499-2671(06)01010-0
- Rieman, J. (1993). The diary study: a workplace-oriented research tool to guide laboratory efforts. *Proceedings of the INTERACT '93 and CHI '93 Conference on Human Factors in Computing Systems*. Amsterdam, The Netherlands: ACM. doi:10.1145/169059.169255
- Rijken, M., Jones, M., Heijmans, M., & Dixon, A. (2008). Supporting self-management. *Caring for People with Chronic Conditions: A Health System Perspective*, 116–142.
- Ritholz, M. D., Smaldone, A., Lee, J., Castillo, A., Wolpert, H., & Weinger, K. (2007). Perceptions of psychosocial factors and the insulin pump. *Diabetes Care*, 30(3),

549–54. doi:10.2337/dc06-1755

- Rodden, T., Cheverst, K., Davies, K., & Dix, A. (1998). Exploiting context in HCI design for mobile systems. In *Workshop on Human Computer Interaction with Mobile Devices* (pp. 21–22). Citeseer.
- Rogers, Y. (2011). Interaction design gone wild: striving for wild theory. *Interactions-New York*, 18(4), 58.
- Rozich, J. D., Howard, R. J., Justeson, J. M., Macken, P. D., Lindsay, M. E., & Resar, R. K. (2004). Standardization as a mechanism to improve safety in health care. *Joint Commission Journal on Quality and Safety*, 30(1), 5–14.
- Rumsfeld, D. (2002). *NATO Speech: Press Conference US Secretary of Defence - NATO HQ, Brussels - 6 June 2002*. Brussels.
- Russell, J. A. (1980). A circumplex model of affect. *Journal of Personality and Social Psychology*, 39(6), 1161.
- Schubert, C., van Langeveld, M. C., & Donoso, L. A. (2014). Innovations in 3D printing: a 3D overview from optics to organs. *The British Journal of Ophthalmology*, 98(2), 159–61. doi:10.1136/bjophthalmol-2013-304446
- Segal, L. D., & Suri, J. F. (1997). The empathic practitioner: Measurement and interpretation of user experience (Vol. 41, pp. 451–454). Human Factors and Ergonomics Society.
- Sengers, P. (2006). Autobiographical design. In *CHI 2006 Workshop on Theory and Method for Experience Design*.
- Sharples, S., Martin, J., Lang, A., Craven, M., O'Neill, S., & Barnett, J. (2012). Medical device design in context: A model of user–device interaction and consequences. *Displays*, 33(4–5), 221–232. doi:http://dx.doi.org/10.1016/j.displa.2011.12.001
- Skinner, T. C., Hampson, S. E., & Fife-Schaw, C. (2002). Personality, personal model beliefs, and self-care in adolescents and young adults with Type 1 diabetes. *Health Psychology*, 21(1), 61.

- Sony. (2012). Xperia Pro. Retrieved from <http://www.sonymobile.com/gb/products/phones/xperia-pro/gallery/>
- Spry, T. (2001). Performing autoethnography: An embodied methodological praxis. *Qualitative Inquiry*, 7(6), 706–732.
- Stawarz, K., Cox, A. L., & Blandford, A. (2014). Don't forget your pill!: designing effective medication reminder apps that support users' daily routines. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 2269–2278). ACM.
- Storni, C. (2010). Multiple forms of appropriation in self-monitoring technology: Reflections on the role of evaluation in future self-care. *Intl. Journal of Human-Computer Interaction*, 26(5), 537–561.
- Storni, C. (2011). Complexity in an uncertain and cosmopolitan world. Rethinking personal health technology in diabetes with the Tag-it-Yourself. *PsychNology Journal*, 9(2), 165–185.
- Storni, C. (2013). Patients' lay expertise in chronic self-care: a case study in type 1 diabetes. *Health Expectations*, n/a–n/a. doi:10.1111/hex.12124
- Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczek, B., & Wiener, C. L. (1984). *Chronic illness and the quality of life*. Mosby St. Louis.
- Suchman, L. (1987). *Plans and Situated Actions: The Problem of Human-Machine Communication*. Cambridge University Press.
- Swan, M. (2012a). Health 2050: The realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *Journal of Personalized Medicine*, 2(3), 93–118.
- Swan, M. (2012b). Sensor mania! the internet of things, wearable computing, objective metrics, and the quantified self 2.0. *Journal of Sensor and Actuator Networks*, 1(3), 217–253.
- Temir, E., O'Kane, A. A., Marshall, P., & Blandford, A. (2016). Mobile Apps and

Running: A Pragmatic Situated Study. In *Submitted to CHI 2016*.

Thieme, A., Wallace, J., Johnson, P., McCarthy, J., Lindley, S., Wright, P., ... Meyer, T. D. (2013). Design to Promote Mindfulness Practice and Sense of Self for Vulnerable Women in Secure Hospital Services. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 2647–2656). New York, NY, USA: ACM. doi:10.1145/2470654.2481366

Thin, A., & Gotsis, M. (2013). Game-Based Interactive Media in Behavioral Medicine: Creating Serious Affective-Cognitive-Environmental-Social Integration Experiences. In A. Marcus (Ed.), *Design, User Experience, and Usability. Health, Learning, Playing, Cultural, and Cross-Cultural User Experience SE - 52* (Vol. 8013, pp. 470–479). Springer Berlin Heidelberg. doi:10.1007/978-3-642-39241-2_52

Topouchian, J. A., El Assaad, M. A., Orobinskaia, L. V, El Feghali, R. N., & Asmar, R. G. (2006). Validation of two automatic devices for self-measurement of blood pressure according to the International Protocol of the European Society of Hypertension: the Omron M6 (HEM-7001-E) and the Omron R7 (HEM 637-IT). *Blood Pressure Monitoring*, 11(3), 165–171
10.1097/01.mbp.0000209078.17246.34.

Toscos, T., Connelly, K., & Rogers, Y. (2012). Best intentions: health monitoring technology and children. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1431–1440). ACM.

Toscos, T., Connelly, K., & Rogers, Y. (2013). Designing for positive health affect: Decoupling negative emotion and health monitoring technologies. In *Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2013 7th International Conference on* (pp. 153–160). IEEE.

Tsvyatkova, D., & Storni, C. (2014). Adapting Design Probes to Explore Health Management Practices in Pediatric Type 1 Diabetes. In *Proceedings of the 2014 Conference on Interaction Design and Children* (pp. 277–280). New York, NY, USA: ACM. doi:10.1145/2593968.2610471

- Umbers, I. G. (1979). Models of the process operator. *International Journal of Man-Machine Studies*, 11(2), 263–284.
- Verdezoto, N. (2013). Home-based Self-care: Understanding and Designing Pervasive Technology to Support Care Management Work at Home. Aarhus UniversitetAarhus University, Science and TechnologyScience and Technology, Institut for DatalogiDepartment of Computer Science.
- Vincent, C. J. (2013). PRODUCT DEVELOPMENT—SAFETY AND USABILITY OF MEDICAL DEVICES. In *Contemporary Ergonomics and Human Factors 2013: Proceedings of the International Conference on Ergonomics and Human Factors 2013, Cambridge, UK, 15-18 April 2013* (p. 127). Taylor & Francis.
- Vincent, J. C., Niezen, G., O’Kane, A. A., & Stawarz, K. (2015). Can Standards and Regulations Keep Up With Health Technology? *JMIR mHealth uHealth*, 3(2), e64. doi:10.2196/mhealth.3918
- Walsh, J., Roberts, R., Morris, R., & Heinemann, L. (2015). Device Connectivity: The Next Big Wave in Diabetes . *Journal of Diabetes Science and Technology* . doi:10.1177/1932296814568806
- Ward, J. R., & Clarkson, P. J. (2004). An analysis of medical device-related errors: prevalence and possible solutions. *Journal of Medical Engineering & Technology*, 28(1), 2–21. doi:10.1080/0309190031000123747
- Wilcox, S. (2012). Ethnographic Field Research For Medical-Device Design. *Biomedical Instrumentation & Technology*, 46(2), 117–121.
- Williams, A. (2002). Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine*, 55(1), 141–154.
- Wood, J. R., Moreland, E. C., Volkening, L. K., Svoren, B. M., Butler, D. A., & Laffel, L. M. B. (2006). Durability of insulin pump use in pediatric patients with type 1 diabetes. *Diabetes Care*, 29(11), 2355–60. doi:10.2337/dc06-1141
- Wright, P., & McCarthy, J. (2008). Empathy and experience in HCI. *Proceedings of the*

Twenty-Sixth Annual SIGCHI Conference on Human Factors in Computing Systems. Florence, Italy: ACM. doi:10.1145/1357054.1357156

Writtle, J. (2014). Colostomy bag bikini photograph seen by nine million people. *BBC News*. Retrieved August 31, 2014, from <http://www.bbc.co.uk/news/uk-england-hereford-worcester-28138485>

Wu, S., & Green, A. (2000). Projection of chronic illness prevalence and cost inflation. *Washington DC: RAND Health*.

Appendix A - Autoethnography Medical Instructions

1. Instructions from Boots (Boots, 2012)

- Always measure your blood pressure when you are relaxed. Sit down and do not cross your legs.
- Ensure the Velcro cuff is fastened comfortably without being too tight.
- Always take the reading on the same arm. Initially take the reading on both arms, but in subsequent readings always use the arm that had the higher reading.
- Sit still for five minutes before taking the first reading. After starting the monitor, remain still during the measurement, supporting your arm at heart level and do not talk.
- Where practical, try to measure blood pressure at the same time of day each time.
- The British Hypertension Society recommends ignoring the first reading and taking the average of the second and third readings. Remember to wait three minutes between these readings.

2. Instructions from the UK based Blood Pressure Association (Blood Pressure Association, 2012):

- When you first start, measure your blood pressure morning and evening, every day for a week. Discard your first day's blood pressure readings – they may not be accurate because you are not familiar with your monitor. At the end of the week you will have a useful picture of what your blood pressure is like normally. You can then take readings less often – once a week perhaps. Your doctor or nurse will be able to advise you.
- At times, you may want to monitor your blood pressure more regularly for a period. For example if you are given a new medicine or a higher dose of

medicine, then you could measure your blood pressure over a few weeks to see if this is having any effect.

- Take home blood pressure readings at the same time each day. This will mean that you are comparing 'like with like'. You could use your blood pressure monitor first thing in the morning or last thing at night before you go to bed.

3. Instructions from the Manufacturer Omron (Omron, 2012a):

- Sit down and relax. Do not cross your legs.
- Place the cuff approximately 2.5 cm above the wrist with the monitor on the inside or side of the wrist. • Fasten the cuff comfortably without it being too tight.
- Press the (O/I) button to switch the monitor on.
- Place the arm across the chest, with the wrist at heart level. • Remain still during the measurement and do not talk.
- Press START. • The cuff will inflate and then slowly deflate.
- Make a note of the measurement and the pulse rate.

Based on these instructions, I endeavoured to accomplish the following as part of the study plan:

1. After becoming familiar with it, use the wrist blood pressure monitor every day as part of the three stages
2. Test twice a day at 10am and 7pm, regardless of location
3. Don't drink coffee 2 hours before test
4. Sit for 5 minutes before test without crossing legs
5. Place the arm across the chest with my wrist at heart level and do not talk
6. Read the meter's result and take note of it
7. Record a diary entry on Android diary applications (varied in order to try different programs), preferably with a text or audio note but at the very least a picture of the context and the test result

8. If anyone asks about it, I will say it is part of my PhD research and explain the method

Appendix B - Recruitment Posters

Recruitment flyer given out in pharmacies:

Do you have Type 1 Diabetes?

You can contribute to glucose meter research through sharing your experiences with medical technology design researchers at UCL

University College London is conducting research on the design of glucose meters and we want to talk to Type 1 diabetes participants about their daily use of them.

Participants will be asked to meet a researcher at a coffee shop or café for a **one-hour interview** on their glucose meter use.

The participants can choose when and where to meet and they will be rewarded with any beverage of their choice at the café and a **£15 Amazon gift certificate**.

For more information, please contact us at:

Phone: **020 7679 0695**

Email: **mobiledmedicaldeviceresearch@gmail.com**

Website: **<http://mobilemedicaldeviceresearch.wordpress.com/london-studies/>**

This research is supported by the CHI+MED project, UCL, and the Engineering and Physical Sciences Research Council.



Recruitment poster put up at grocery stores:

[illegible]

Appendix C - Interview Questions

The same questions were asked of the participants from the contextual interviews and diary studies.

Inclusion criteria questions (phone or by email):

1. They were over the age of 18
2. They had Type 1 diabetes
3. They had been diagnosed
 - a. over one year ago for the contextual interviews
 - b. over six months for the diary study
4. They lived in or near
 - a. LA, London, or Toronto for the contextual interviews
 - b. London for the diary study

Pre-interview questions (phone or by email):

1. What age are you?
2. What type of diabetes were you diagnosed with?
3. When were you diagnosed with diabetes?
4. Where do you live?
5. The interview will be conducted
 - a. in café or coffee shop of your choice. Can you think of one that you have been to before that you would like to meet in? (contextual interviews)
 - b. at UCL. Can you make your way there? (diary study)
6. What day and time would be best for you?
7. The interview will last
 - a. one hour and should not be rushed. Is that time still ok for the interview? (contextual interviews)
 - b. one and a half hours and should not be rushed. Is that time still ok for the interview? (diary study)
8. Would you be comfortable bringing your glucose meter to show me?

Demographics questions (in person):

1. What age are you?

2. What gender do you identify as?
3. Where do you live?
4. What is your occupation?
5. When were you diagnosed with diabetes?
6. Do you have any family members with diabetes?
7. How would you describe your comfort with technology: very comfortable, comfortable, neutral, uncomfortable, or very uncomfortable?
8. How many years have you been using a glucose meter?
9. How good would you say your control is?
 - Can you tell without the meter?

Ethnographic Inspired Interview Questions:

1. Why did you choose this location? (diary study)
2. How often would you go to places such as these? (diary study)
3. How many times per week would you go to a place that isn't your home or your work?
4. What is a typical weekday?
5. Can you talk about your glucose meter use during a typical day?
6. What is a typical weekend?
7. Can you talk about your glucose meter use during a typical day?
8. Do you go any trips? See friends, family, conferences, holiday, business
9. What are the last three trips you went on?
10. How was bringing the glucose meter with you?
11. Can you talk about your glucose meter use during these out of town times?
12. Do you use it more often or less often?
13. Holidays such as Christmas, thanksgiving...
14. When you are sick, does your glucose meter use change?
15. Levels of sickness?
16. Can you think of any other times where your glucose meter use changed?
17. Are you comfortable using your glucose meter in front of close friends or family?
18. Are you comfortable using your glucose meter in front of acquaintances or colleagues?
19. Are you comfortable using your glucose meter in public?
20. What do you usually carry your glucose meter in?

21. Where did you get the glucose meter?
22. How did you choose the glucose meters?
23. How much shopping around did you do for the glucose meter?
24. Who paid for the glucose meter?
25. Who taught you how to use the glucose meter?
26. You do not need to take out the glucose meter. What is your current glucometer model?
27. Can you describe it to me?
28. How long have you used that model?
29. How many glucose meters have you used?
30. Do you prefer cassette or strip glucose meters?
31. Do you use any other medical devices?

Critical incident interview questions (in person):

1. What would you say is the primary purpose of using the glucose meter?
2. In a few words, how would you summarize the general aim of using the glucose meter?
3. Think of the last time you got a reading that surprised you. What were the general circumstances leading up to this?
 - a. Tell me why the reading was surprising.
 - b. When did this happen?
 - c. What was the consequence?
 - d. Were there other times that this occurred?
4. Think of the last time the glucose meter did not act as you expected it to. What were the general circumstances leading up to this?
 - a. Tell me why the reading was surprising.
 - b. When did this happen?
 - c. What was the consequence?
 - d. Were there other times that this occurred?
5. Think of the last time you had an issue with the glucose meter battery. What were the general circumstances leading up to this?
 - a. Tell me why the reading was surprising.
 - b. When did this happen?
 - c. What was the consequence?
 - d. Were there other times that this occurred?

6. Think about the last time you did not use your glucose meter even though it might have been useful. What were the general circumstances leading up to this?
 - a. Tell me why you didn't use it?
 - b. When did this happen?
 - c. What was the consequence?
 - d. Were there other times that this occurred?
7. Think of the last time that you did not bring the glucose meter with you even though it might have been useful. What were the general circumstances leading up to it?
 - a. Tell me why you did not bring it with you.
 - b. When did this happen?
 - c. What was the consequence?
 - d. Were there other times that this occurred?
8. Think of the last time that you had a negative experience with your glucose meter. What were the general circumstances leading up to this?
 - a. Tell me why it was a negative experience.
 - b. When did this happen?
 - c. What was the consequence?
 - d. Were there other times that this occurred?

Projective technique sentences to complete (in person):

1. If I am out at a cafe and want to check my blood sugars, I will...
2. If I am at a dinner party with friends and want to check my blood sugars, I will...
3. If I am on a long public transportation journey such as a train ride and I want to check my blood sugars, I will...
4. If I am at work/school and I want to check my blood sugars, I will...
5. If I am at a friend's home and I want to check my blood sugars, I will...
6. If I am at a wedding and I want to check my blood sugars, I will...
7. If I had to pick a gender for my glucose meter, it would be...
8. If I had to pick a name for my glucose meter, it would be...
9. If my glucose meter had an age, it would be...
10. If it had a clothing style, it would be...
11. If my glucose meter had a personality, it would be...

12. If my glucose meter was a celebrity, it would be...
13. My favourite thing about my glucose meter is...
14. My least favourite thing about my glucose meter is...
15. My ideal glucose meter would look like...

Appendix D - Example Summary

Mary is in her thirties and works at different sites as project manager for a large company. She has had Type 1 diabetes since she was a child growing up in another European country with her diabetic brother and she has used a glucose meter for “God, 20 maybe 25?” years. They used to swap supplies growing up, and he had a girlfriend who was a pharmacist, so they ended up with a lot of different of glucose meters. She says they use different ones currently and she “wouldn’t use his because he has strips that you’ve got to rip packaging off, and they drive me nuts. They’re always... the bits are always everywhere, and it just seems like an extra task to me.” It would also impede her ability to take a test while walking. Although her brother uses a pump, she chooses not to because “basically, aesthetics” but would consider one if it was much smaller. Mary wore a continuous glucose monitor for three day before it drove her “nuts” with knocking it off and feeling the tube on her waist. She has used a diabetes mobile phone app that her brother suggested once, but constantly loses phones so doesn’t bother with them. She also tends to forget things, so she leaves a glucose meter in her car and at her boyfriend’s place. She can also forget it when she changes rucksacks or bags.

She is quite open about her use of her glucose meter, but if she doesn’t know the person she’s with, she might hide it. She will hide from those that she knows that are squeamish, but says “But for some reason, if it’s strangers, I’m not really that bothered.” When asked if she would use a glucose meter on the tube, she answered “Oh, God, yes” and she often takes the injections through her clothing, even though she was told not to. This differs when she is in new places, and said she might get her boyfriend to cover her when she was conducting tests on public transport in Morocco, her last vacation destination.

She likes the glucose meter she currently used which replaces the one given to her by the hospital, because she says “I called them up about something to do with it. And they were horrified - that’s been out of use for a year, or two years, or something because it had some kind of fault or something”. She likes it because it is “quite small” but had troubles on holiday recently as she brought a very small evening purse and so she left the glucose meter at the hotel at night. She sometimes purposely doesn’t take

it mountain biking at the weekends as it takes up too much space, saying “But it’s one of those... I should take it, but I do sometimes and I don’t always.” On the other hand, she has only forgotten her insulin once on her first trip back to Ireland, but says “I might forget it, but it would be completely unintentional.” She would like an all-in-one system (with the strips and insulin injection included) that she can access the data from, as she tends to occasionally “just scribble them down somewhere.”

She has had problems with temperature changes, as the glucose meter occasionally will not work on a cold cycle to work or on a ski holiday, where she keeps it inside her jacket for body heat. In fact she read the booklet that comes with new glucose meters she says “For the temperature thing, I will check the temperature thing and see what... if they... if it’s in there. You know when they have, like, the frequent problems or the troubleshooting page at the back, it’s usually... that’s where you’ll find it.” When it’s warm, the insulin will not work the same way and she can get high readings, and be unsure of if she is just dehydrated or high. As she is into sustainability, she has mastered extending the battery life of her glucose meter by taking out the battery and rubbing it that she said the last time “it went so long that I thought, this is never going to die.”

She has not used her glucose meter when she’s in a hurry and will just eat something and ride high if she feels low, saying “even though I would say the whole thing... the whole process probably takes under a minute.” This includes when she first wakes up, where she won’t test unless she says she “was for some reason early or if I had some type of suspicion.” Riding high also occurs when she is sick, as she makes sure food stay down before taking insulin. She says she is “very hit and miss” with testing and goes through phases where she tests a lot or she says “I might go through a couple of days when I don’t do any at all,” but always tests a lot before mountain biking because of the amount of energy she expends. Days with no exercise can mean more sweet things, and Mary says “I think maybe I’m more in denial. I don’t want to check it because I don’t want to know that it’s high because I want to have another cake”. On these days, she says sometimes “Instead of actually checking what it is, I’ll just take some more insulin.” The same practice applies at other indulgent times, such as Christmas dinner.

Appendix E - Commercialization

Introduction

As part of the UCL Advances Enterprise Scholarship, this chapter outlines the potential commercialization opportunities that arose from my PhD course of study. The initial idea for a commercialisation project arose from my experience in human factors engineering consulting before starting graduate school, the contacts that I made in industry connected to my research, and the results of my dissertation showing the importance of conducting situated studies of mobile medical devices.

Situated studies are important for the design and evaluation of medical devices that are meant to be used in the context of everyday life, because changing contexts impact the way we use and adopt interactive technology. As an example, take the mobile phone. This is a device that is used in a variety of different physical contexts and its design needs to be sensitive to these contexts. The sound of it ringing will not be heard in the context of a loud punk rock concert and this sound is too loud for a quiet movie theatre. Its design also needs to be sensitive to the social contexts it is brought into. A Bluetooth headset provides hands free functionality, which is very useful when driving, but it also means that other people might perceive you to be talking to yourself, which is socially inappropriate. Even people wearing headphones with microphones that could make call without using their hands still often hold the microphone up to their mouths to give a social cue that they are indeed talking to someone and not themselves. Based on my research, these same types of concerns arise for mobile medical devices (see Figure 50).

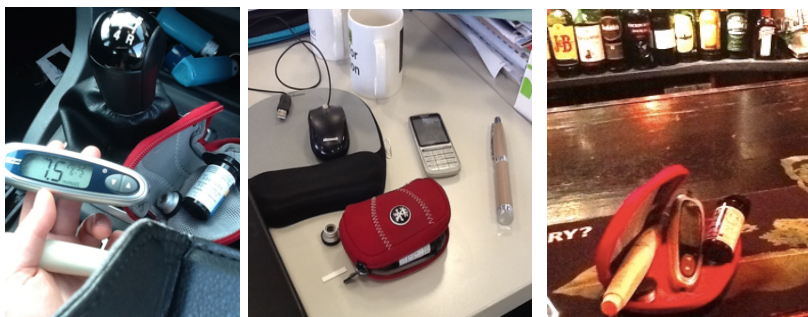


Figure 50: The same glucose meter being used at work, in a car, and in a bar!

Situated methods can be applied to inform the design of current and future mobile medical technologies, however they are currently not included in medical device usability standards, which are part of industry best practice, and they do require a level of expertise to be able to achieve user requirements from running them. Therefore, there is an opportunity to commercialize the research methods that I have become an expert in applying to mobile medical devices and to offer this as a consultancy service.

Background

Initially, the plan was to create a separate consultancy that would act as a mediator between small, medium, and large healthcare and medical devices companies in order to connect academic human-computer interaction researchers with relevant projects. In order to achieve this, a web domain was bought (academicinsight.co.uk) and initial starts at branding were made (see Figure 51) along with a company description to use on marketing material: Providing academic quality research for manufacturers of personal healthcare devices.



Figure 51: Branding for standalone consultancy

However, my intention was to treat this as a part-time venture whilst continuing academic research. In June of 2015, I was offered a two year EPSRC Doctoral Fellowship to continue my research on medical devices at UCL. As such, I did not need to develop a separate company to mediate between industry and academic consultants, as UCL Consulting is already in place to make these connections. This reduced the risk of starting a new business and also eliminated the start-up costs of insurance and accountancy. In order to pursue this route further, I looked to both UCL Advances and UCL Consulting for advice.

Business and Entrepreneurial Training

Although I had a vulgar competency on how a consulting practice might look, I expanded my business knowledge by attending courses and boot camps offered by UCL Advances and UCL BEAMS. The BEAMS business residential course was an intense three days of lectures on business essentials and a hands on activity of

bringing a start-up from ideation to pitch, where the team I lead as CEO, Concilium, won the business prize. The BEAMS The Enterprise Bootcamp covering topics over two days about business principles in general and also entrepreneurial pursuits. The Advance Idea Accelerator 8 week program focused on the process of ideation to start-up as an entrepreneur in an 8 week program, covering topics such as market and branding; pricing and positioning; market research and validation; sales strategy; product development; digital and social media; IP and business structures; and, finance for growth. These courses, lectures, and specific advice on starting the part-time HCI consultancy was used to come up with a plan to advance industry contacts into consultancy projects for both myself and the other HCI researcher in my research group, the UCL Interaction Centre.

Identifying the Problem

The first thing was to identify if there was a problem to be solved and what value might an academic focused consultancy might have. Human factors engineering has made excellent strides in the past 20 years and continues to make great impacts on the design of mobile medical technologies. This has been seen in industry, but I also saw this emerging from my own research on mobile medical devices. There is great uptake of human factors processes and methods in industry, and there are over 250 British healthcare companies that adhere to these standards.

However, my research has pointed to an issue that is beyond human factors engineering: user experience. My research has pointed to the connections people are making between their mobile consumer technology and their mobile medical devices, and expectations are starting to form about the interaction design of these self-care devices. This trend is likely to trickle down further with the growing popularity of wearable consumer devices that have been designed with aesthetics and user experience in mind.

Through research activities, I have been in contact with a range of companies that are not only interested in my research, but also interested in bringing user experience into their design and evaluation processes. This has ranged from small start-ups to global pharmaceuticals, some of whom have found out about my research through internet searches and have contacted me directly. I believe that there are other companies that would also be interested in academic quality research on the situated use of their

mobile medical devices, and setting up a consultancy to allow these connections to be made is the basis for the commercialization of my PhD research.

Soft Launch with Academic Partner and Freemium Model

My intention is to conduct a soft launch of this consultancy through conducting studies for other academic institutions that may not have the required skills to conduct these situated studies. I have been in contact with one London based institution that requires human factors engineering and user experience consulting on one of their research projects. As of October 2015, they have not received the funding to go ahead, but there has been an agreement that I will conduct the studies and I will be able to use the results of the studies to write up a case study that can be posted to the website. This will give a testimonial of the quality of the work, but also explain the type of academic research that can be conducted in an easy to interpret way by those not used to academic writing.

This will lead into a Freemium model of business. Essentially, if the work has academic merit and could possibly be published, then these studies will be seen as an extension of my research as a postdoctoral fellow and the opportunity to collaborate with other institutions, charities, and industries. Although money will not exchange hands, the benefit will be academic, and that will feed into the reputation of the consultancy having high quality academic work.

For many institutions, this will not be possible as there will be financial concerns about publishing sensitive material that may hurt their competitiveness. In the cases where non-disclosure agreements (NDA) are made and signed off, this will be work that is paid as consulting work. Based on the needs and requirements of these clients, they may or may not be asked to make testimonials that can be advertised on the consultancy website.

Competitors and Market Advantage

There are many different consultancies in the UK and especially in London that offer expertise in conducting user experience and human factors research, including Foolproof, Bunnyfoot, Amberlight, UserFocus, SUS, Spotless, and CxPartners. These companies have usually hired people with experience at a Master's level to work for them as consultants, and their expertise grows as they conduct more industry projects.

For this consultancy, it will differ on the expertise of the consultants. This academic focused consultancy will offer robust research rigor, expertise and professional qualifications that the competitors will not be able to offer. This includes the qualifications of a PhD, making me an expert in the field, and also the reputation of a professional engineer (PEng) certified through the Professional Engineers of Ontario, Canada, and recognized in the UK. Furthermore, the consultancy will be under the wing of UCL, and will be able to brand itself with the reputation of UCL's research brand.

This distinction does not necessarily mean that the consultancy will be competing with the more industry focused consultancies. My research into the industry has shown that these larger UX agencies often hire freelancers to provide expertise on projects. My intention is to build competitor contacts through attending UX industry meet-ups, keeping contacts with former UCL Master's students who work for these agencies, and contacting UX recruitment agencies through LinkedIn so that if a project comes along where special expertise is needed, they will contact us first.

Clients and Marketing

I have made contact with various potential clients already, including small start-ups, medium size manufacturers, large manufacturers, and also talked to current and former employees of large UX agencies. Meetings with some of these contacts have already taken place, and more are being planned currently.

I intend to expand this potential client list by through various marketing means, including attending conferences, updating personal social media, word of mouth, and publishing in trade magazines. I have also been given the head of department's permission to revamp the current static consultancy website for the UCL Interaction Centre and have taken over the LinkedIn profile for the research centre as well.

Marketing will be broad, but it has to be carried out very carefully. The brand of consulting is dependent on the success of the research, so the quality of the research cannot suffer or it will negatively influence the consultancy.

Costs and Contracts

As I have been awarded a personal fellowship at UCL for two years, I will set up the consulting through UCL Consultancy (UCLC). This means that I will not have to personally deal with indemnity or public safety insurance, contracts or accounting.

Although UCLC takes 20% of the costs of completing the work, there is very little risk up front if the consultancy does not do successfully and I will not have to pay personally out of pocket. In a meeting with Trish Greenan to discuss costs and contracts, I believe that for lead consultants, the day rate will be approximately £1000. I personally have the capacity to conduct about two to three projects per year, but it is possible to expand the consultancy to other researchers at the UCL Interaction Centre.

Expanding to the UCL Interaction Centre

There are currently consulting activities going on, however they are generally through personal contacts through the academics and segregated from the rest of the centre. Although there is an informal system where consulting projects are offered to others in the department, if the lead academic cannot take them, there is no formal process in order to encourage this transfer to researchers that are available. I discussed with UCLC about coming up with a finders fee model that would encourage people to share potential contracts. Furthermore, currently PhD students and postdoctoral researchers are not leading any consultancy projects, but rather are put on lead academic projects in an ad hoc manner, despite some expertise in conducting UX consulting prior to entering careers in academia. With clarifications from UCLC, I found it is possible to sign postdoctoral researchers up as lead consultants through an agreement with heads of departments signing off. This has been encouraged to postdoctoral researchers, but the PhD students still have to be under a lead academic consultant to conduct any industry studies.

Future Plans

A meeting will be set up soon to involve the researchers at the UCL interaction Centre in developing a fair and consistent finder's fee model. It is through this bottom-up process that I hope that a solution can be found that the majority of those involved accept and find appropriate.

The research centre's website is currently going through an overhaul. After this process is completed, I will look to revamp the consultancy wing of the UCL Interaction Centre's website so that it will be attractive to potential clients. I will also revamp the LinkedIn account for the UCL Interaction Centre in line with this. Depending on departmental funding, researchers that have signed up at UCLC consultants will be given business cards with links to both this website and the LinkedIn account in order to allow

marketing to occur naturally from researchers attending conferences, workshops and meeting potential clients through their day to day research.

Overall, this plan to start a consultancy for expert situated studies for mobile medical devices has arisen from the commercial potential of my PhD, but there is opportunity to expand the consulting wing of the department even further. This will benefit researchers who will be able to have real world impact by applying their research to industry projects, make further industry contacts that may lead to academic collaborations, and it will improve the reputation of these researchers and the UCL Interaction centre as a whole with regards to the high quality academic research that it can produce.