Mobile technologies for chronic condition management.

Owen, Thomas

Mobile Technologies for Chronic Condition Management

Thomas Owen

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Swansea University
Prifysgol Abertawe

Department of Computer Science
Swansea University

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Abstract

The management of long term chronic conditions is a complex and challenging task. The process relies on individuals engaging in regular recording of factors that affect their health. Yet currently, the mobile tools that people carry with them are not being fully utilised to assist in this process. This Thesis reports on research that has been completed to understand the role that mobile technologies can have in supporting people with chronic conditions. An individual engaging in personal monitoring is concerned with the data they collect, not the process used to capture the data.

The results of the research conducted contribute to an advancement of knowledge around how mobile technologies can assist in personal reflection on health information to provide greater understanding of chronic disease management This understanding of the role of reflection in chronic condition management can then be used as a platform to improve the mobile interventions in future implementations.

These findings are arrived at by conducting an initial investigation into the usage of existing health monitoring devices and an evaluation of these devices is detailed. The results of this early work suggests there exists a gap between real practice and the role that mobile technologies can play in assisting with the process. A deeper understanding of the management practices of people with diabetes is then achieved through a set of interviews with individuals with diabetes. The findings then define a model of chronic disease management, named the 'Diabetes Management Cycle.'

Following the definition of the cycle, a mobile application was implemented and deployed during a four week evaluation with individuals with type 1 diabetes. This system was designed to support existing management practices and implemented simple methods of information capture.

A second application was then developed to enable increased monitoring and subsequent reflection amongst individuals with cardiovascular conditions. The application was deployed in a six week in-situ evaluation and it was discovered a personalised 'tagging' mechanism allowed for the discovery of patterns affecting health.

Based on the findings of the studies, the Thesis concludes by presenting definitions of ready-to-hand in the short- and long-term contexts of mobile health management. These ready-to-hand guidelines provide a platform for future research projects to build upon.

Acknowledgements

My PhD could not have been achieved were it not for the support network that I am extremely fortunate to have. To all my colleagues, friends and family, thank you.

I would like to thank my supervisors Dr. George Buchanan and Professor Harold Thimbleby for all of their help and support during the course of my PhD. Thank you for being there when I knocked on doors and sent emails, both on a personal and professional level. The insights you have provided into my work have guided me to the conclusions I have reached, once again thank you so much. Thanks also to the Swansea University Computer Science Department for accepting me onto the PhD scheme.

Thanks also to those on the CHI-Med team who have provided advice and allowed me to grow as a researcher. The meetings and training days have built me into a stronger researcher than I was previously. Being part of the project has allowed me to form my own research ideas, and thank you for allowing me to follow the path I chose. Thanks also to the "Bridging Global Engagements for Research" body at Swansea University, for funding the project"Design and Evaluation of Cross Cultural Personal Medical Devices for Chronic Disease Management." Thanks also to my colleagues on this grant whom have been great to work with: Karen Li, Na Sun and Patrick Rau.

I have thoroughly enjoyed meeting new people and getting to know others better during my PhD studies. Patrick, Simon, Ben, Emma, Liam and Matt, thanks for the social events, hanging out and being around. Days in the office would have been far more unbearable without you all there. Thanks also to Vicky for your insights into diabetes, and partying.

Thanks to my family who have provided me with the platform to achieve where I am today. Like many people, my parents told me to get a good education, as it is always something to fall back on. I took that advice literally and have stayed in education for far longer than I ever thought I would. Thanks Mum and Dad. Kris and Joe, now that I am finished maybe we can start our music escapades that we have often talked about. Ann, Phil and Laura, thanks for all you have done too, I am lucky to have you guys around.

Finally, I have saved the best for last. Jen you have been great, not only have you kicked me on when it needed to be done, you have also provided love and support in every way you could. I love you to bits.

For those that I have mentioned, and those that I have not, thank you. I am fortunate and grateful to have you all around.

Preface

At the start of 2010, I was offered the change to join the CHI+MED project as a PhD student. The chance to put off moving into the real world and instead stay in education was too good to turn down. But, this was not the only reason I accepted the position as on the project.

CHI+MED was a large EPSRC funded project that focused on the design of safety critical devices used in healthcare. I came onto the project with little background in the area, I had previously been a researcher looking at digital document navigation. I saw this shift in research as both a challenge, and an exciting opportunity. Developing techniques that could potentially improve healthcare was a hugely worthwhile cause.

Whilst searching for a topic to investigate, I trawled through the various documents I had about the CHI+MED project, and what the project was investigating. A lot of work had already been established, and there was already a research strand looking at devices used in hospitals. I was keen to find an idea that was 'mine' and look at the project from a slightly different angle. I spotted that 'glucose monitors' were mentioned as a device that potentially carried problems, and this is where my PhD journey truly began.

After conducting an initial critique of these glucose monitoring devices, I attended *'Advanced Technologies and Treatments for Diabetes'* and it was here I had my eureka moment. One of the presentations highlighted the wide variety of factors that a person with diabetes must consider, glucose scores were only ***a part*** of the overall story. From here, I became greatly interested in how people currently keep track of that data, and how technology could support people in the management of their conditions.

Whilst diabetes is a condition that affects a great number of people (figures for this are given in Chapter 1), recruitment for the studies in this thesis proved to be challenging. As will be mentioned, the percentage of people who have Type 1 diabetes makes up 10% of all cases. While this is still a significant number, it drastically reduced the potential participant pool for the studies conducted in this thesis. Unlike much research conducted in the HCI field, the general population was not suitable to recruit from as individuals from that pool would not have provided true insights into the research domain.

Being part of the CHI+MED project enabled me to refine this idea, and the investigations I conducted. The project held regular meetings in which I presented both my ideas and work to high profile academics and health clinicians. Thanks also to the team for allowing me the freedom to attend the conferences that I have had the fortune to attend and present my peer reviewed works.

Now I have completed my studies and submitted this document, I feel that being part of the project has truly helped me to grow as a researcher. I have enjoyed my time as a PhD student, but, I look forward to never having to hear the dreaded question *"How is the thesis going?"* ever again.

Style

The research content in this thesis is written using a 3rd person narrative. This is a personal decision, as I feel it allows for my writing to be more objective, and less subjective, in the findings I present.

Ethical Considerations

The user studies documented in this Thesis involve human participants recruited from staff and students at Swansea University, University College London and the following diabetes groups based in London, UK: Juvenile Diabetes Research Foundation, Enfield and Hammersmith and Fulham.

Following best practice in the domain, careful consideration was given in the planning of each study concerning the ethical issues associated with each of the experiments. Prior to any study being conducted, ethical approval was sought from the relevant body (for studies based in Swansea, the Swansea University Computer Science Department's Ethics and Risk Assessment Committee. For studies in UCL, the UCLIC ethics board).

Prior to all studies, each participant was asked to complete a consent form and was informed of their right to terminate and withdraw from the study at any time, without penalty. Monetary incentives were given in specified cases in return for the participants' time.

The comfort and well-being of the participants was paramount to each study especially as the research was based upon health and well-being. Where interventions were made, such as the in-situ studies in Chapters 7 and 8, participants were advised that the systems being evaluated were there to assist and enhance their existing routine and not a replacement. All data that could identify participants has been removed from this thesis and in relevant publications to maintain anonymity. All data collected from studies has been stored securely in a locked cupboard or under a password protected file system.

Refereed Publications

Conference Papers

1. **Tom Owen**, George Buchanan, Harold Thimbleby: Understanding User Requirements in Take-Home Diabetes Management Technologies - *BCS Conference on Human Computer Interaction, (HCI 2012)*, Birmingham, UK.

2. Yunqiu Li, **Tom Owen**, Harold Thimbleby, Na Sun, Pei-Luen Patrick Rau; A Design to Empower Patients in Long Term Wellbeing Monitoring and Chronic Disease Management in mHealth - *Context Sensitive Health Informatics, Human & Sociotechnical approaches (CSHI 2013)*, Herlev, Denmark.

Doctoral Consortium

1. **Tom Owen**: Don't Let Me Down: Using Contextual Information to Aid Diabetics - *International Conference on Ubiquitous Computing (UbiComp) 2011*, Beijing, China.

Poster Presentation

1. **Tom Owen**, Parisa Eslambolchilar, George Buchanan, Richard Bracken: Anticipating Error: Analysing Blood Glucose Monitors for Potential Patient Use Errors - *Advanced Technologies and Treatments for Diabetes (ATTD) 2011*, London, UK.

2. **Tom Owen**, George Buchanan, Harold Thimbleby: Using Contextual Factors to Assist Diabetes Management - *Balancing Creativity & Evidence for Patient Safety, 2012*, Bradford, UK.

Workshop Article

1. **Tom Owen**, George Buchanan, Harold Thimbleby: Investigating the Influences of Contextual Factors in Condition Management - *MediCHI 2013 Safer Interaction in Medical Devices*, Paris, France.

Table of Contents

List of Figures

List of Tables

Chapter 1

Introduction

The World Health Organization has stated that chronic diseases accounted for 36 million deaths globally in the year 2008, comprising mainly of; 'cardiovascular diseases, cancers, diabetes and chronic lung diseases' [145]. Within the United Kingdom, 85% of all deaths can be directly attributed to these conditions and diseases [144]. The prominence of chronic disease also carries financial concerns, with the National Health Service (NHS) spending increasing amounts on treatment. Conditions such as diabetes account for 10% of the total spend on the NHS [135], equating to an estimated £286 spent per second on the condition. The total spend is a combination of the diagnosis and treatment of diabetes, as well as the complications that can arise from the condition.

Long-term management of these conditions is a burden to those who suffer from them, requiring constant maintenance and treatment. Procedures such as; taking and recording measurements, or calculating medication dosages, are frequent activities undertaken during an average day. Various interactive devices are used in this process, providing vital information back to patients, and aim to assist in supporting people in their ability to control conditions within a healthy boundary. Many chronic conditions require tight control of measurable factors to ensure both the short-term health of an individual and a reduced risk of long-term complications of a condition. There are several artefacts that support the monitoring, recording and visualisation of health information. However, rarely does a single device or medium (e.g., paper) cover every aspect that affects a person's condition. The research in this thesis is concerned with understanding how technological tools can assist in the management practices of individuals with chronic conditions.

Mobile devices have recently become an essential part of everyday life: phones, tablets and e-ink devices are a frequent and common sight. As a result of the ubiquity of these devices, attempts have been made to utilise their functionality and incorporate them into the support of people with long-term conditions. Several recent applications have delved into providing well-being support on the mobile platform. In general these applications could be assigned into three categories: exercise, weight loss and health management. The potential for mobile technologies to have an impact in these areas is suggested by the fact that applications of this description are hugely popular on mobile app stores (a full description is presented in Section 4.5.1).

One emerging theme within these applications is to provide support for people with chronic conditions, such as diabetes, Parkinson's disease and mental health conditions [161]. Recent movements within the NHS [143] have seen greater focus on treating people outside of the hospital setting where possible, placing greater emphasis on people being involved in their own treatment. This focused capture of information can be used by both health clinicians and the patients themselves to make reasoned decisions on how to progress with factors affecting health.

Smartphones are now the dominant handset in developed markets and offer more capability than those of previous generations used in earlier works (such as Mamykina [114, 115]). It is therefore timely to investigate whether the new technologies accompanying smartphones have the potential to further enhance additional device roles in the management of chronic conditions. It is possible to build upon the previous research in this area and advance the understanding of how these 'everyday' devices can form a more useful role in a person's life.

The management of chronic conditions is a complex process, involving a multidisciplinary team, as well as care-givers and families. Yet it is a process worth undertaking for those affected by chronic conditions:

> *"The long-lasting nature of chronic illness makes record-keeping and long-term analysis of diagnostic and evaluative measures both extremely important and also very challenging."* [71]

There exists opportunities to support those with chronic conditions to manage their record keeping and interpretation of that information. At the time of writing, there is currently little empirical evidence regarding the success of mobile interventions into personal management of chronic conditions. Previous research (described in full in Chapter 4) has primarily concerned itself with external interventions into an individual's management practices. This thesis reports on how these mobile interventions can be utlisied without the need for external support, and instead support individual's in their everyday management. The technologies can facilitate meaningful information capture for management purposes and determine how this information is then interpreted to better understand factors affecting personal conditions.

1.1 Background

It would be infeasible to develop strategies for all chronic conditions and therefore a wiser strategy is to investigate a subset. There are conditions that require more management than others, such as diabetes and hypertension, which require people to take frequent measurements and form their own treatment decisions. These conditions are becoming increasingly prevalent and are affecting a greater number of people, it is therefore timely to conduct research into this area. As the number of people affected by these conditions increases, so will the need for support in the management of the conditions.

This section gives information about these conditions and outlines the importance of facilitating good management. As stated, chronic conditions are an increasing problem on a global scale with greater numbers of people being affected. Such widespread concern makes investigations into how Human-Computer Interaction (HCI) techniques can assist in the management of these conditions especially relevant. Specifically, this thesis first investigates the existing practices and support of diabetes, a condition which requires heavy patient involvement and severe complications can arise from poor management. Additionally, in the later stages of the thesis the focus shifts to cardiovascular diseases relating to blood pressure management. Such conditions affect a great number of individuals making the described investigations a potential benefit to a large user group.

1.1.1 Diabetes

Diabetes is a condition affecting millions of people worldwide, with estimates that in the year 2000, 2.8% of the global population were sufferers [183]. The prevalence of the condition is anticipated to increase up to 4.4% by the year 2030 due to an increase in both the number of older and obese individuals. These figures equate to the total number of people with diabetes increasing from 171 million to 366 million by 2030. At the time of writing, within the United Kingdom, it is estimated that 1 in every 20 people have diabetes (either diagnosed or undiagnosed) [138].

The potential increase will not only impact health, but also place a heavy burden on health service resources [134]. In total, diabetes is estimated to currently account for 10% of total health resource expenditure in the UK, potentially rising to 17% over the next 20 years [76]. This large percentage is due to both the continuous treatment of diabetes, along with the complications that can arise from the condition. Diabetes itself is: the single most common cause of end stage renal disease, the leading cause of blindness in the working population and the most common cause of lower limb amputations [137]. However, such complications are less common, as well as less severe, amongst those who have well managed and tightly controlled blood glucose levels.

Diabetes is an incurable condition in which an individual's body cannot control the level of glucose in the bloodstream. This is a result of the pancreas not performing the key function of producing insulin effectively. Insulin is a hormone that the body uses to regulate the amount of glucose that is in the blood stream. There are two main forms of diabetes:

- Type 1 - In which the pancreas does not produce insulin, meaning there is no insulin to break down the glucose in the body
- Type 2 - There is not enough insulin produced by the pancreas, or the insulin does not function properly in processing the glucose.

Type 1 diabetes is also known as juvenile diabetes or early-onset diabetes due to the fact that it typically emerges in people under the age of 40. Type 2 diabetes, otherwise known as insulin-resistant, is often diagnosed in people over the age of 40, although increasing numbers of younger people are being diagnosed. Type 2 diabetes can be attributed to lifestyle choices, such as poor diet leading to obesity. In the UK, roughly 90% of the diabetes population are Type 2.

Diabetes management relies on patients taking an active role in the monitoring and treatment of their condition. Processes such as daily checking of glucose levels and carbohydrate counting form an essential part of maintaining a healthy level of blood glucose. Using these values, people with diabetes are able to make informed treatment decisions, whether this be an intake of insulin (via injection) to enable the body to process glucose, or to eat food in order to raise the blood glucose. Failure to successfully stay with healthy boundaries can lead to conditions such as:

- Hypoglycemia - which arises when there is too little glucose in the bloodstream. Consequences of this condition include confusion, dizziness and poor coordination. More severe complications include the loss of consciousness or even death.
- Hyperglycemia - occurs when too much glucose is in the blood. Symptoms include fatigue and blurred visions with more severe complications such as nerve damage and ketoacidosis (breakdown of fat in body leading to a rise in toxic acids in the bloodstream) [137].

These levels of blood glucose can lead to reduced cognitive ability, seizure, loss of consciousness and, in extreme cases, death. As mentioned earlier, there are also chronic complications of the condition as diabetes is a degenerative disease. It is therefore essential that the condition be tightly controlled to reduce the magnitude of effects on ageing patients. In order to achieve a constant healthy level of blood glucose, patients must be heavily involved in the processes of monitoring and treating their own condition.

1.1.2 Cardiovascular Conditions

Cardiovascular conditions are an increasing problem, with estimates that between 1990 and 2020, the proportion of worldwide deaths from cardiovascular disease may increase from 28.9% to 36.3% [74]. Of these, complications of hypertension currently accounts for 9.4 million deaths worldwide every year [146].

In England, 32% of men and 30% of women, aged 16 years or over, have hypertension. The equivalent figures for Scotland are 33% of men and 28% of women. There are no exactly comparable figures for Wales or Northern Ireland. However, 15% of adults in Wales reported being treated for high blood pressure. In Northern Ireland, 19% of men and 27% of women reported having been diagnosed with high blood pressure [139].

Hypertension, which is often referred to as high blood pressure, is a condition in which the arteries in the body have a blood pressure which is above healthy bounds. Blood pressure readings are measured in both two forms:

- When your heart beats, it contracts and pushes blood through the arteries to the rest of your body. This force creates pressure on the arteries. This is called systolic blood pressure. A systolic blood pressure number of 140 or higher is considered to be hypertension, or high blood pressure.

- The diastolic blood pressure number indicates the pressure in the arteries when the heart rests between beats. A diastolic blood pressure number of 90 or higher is considered to be hypertension or high blood pressure [184].

Those diagnosed with hypertension are often required to take daily readings of their blood pressure, as well as keeping a record. With personal interventions, such as diet choices, quitting smoking and exercise, the aim to is lower blood pressure towards a more normal range. It is often the case that people are also given medication to assist in the maintenance of high blood pressure.

1.2 Problem Statement

There has been a recent trend towards patients being more involved in the management and treatment of chronic conditions. Those required to be involved in the maintaining of their own conditions have a wealth of information and factors to process and understand [31]. For example, those affected by diabetes are faced with a constant challenge to maintain their glucose levels through tight management of food intake and insulin dosing. Devices such as glucose monitors form an essential part of this process by allowing patients to check the current level of glucose in their blood stream. This information can then be used to make future treatment decisions, such as adjusting insulin injection levels. However, the results that these monitors provide are the end result of the previous hours' activities. Important contextual information such as food consumed and exercise performed (whether planned or completed) are also involved in the patients' treatment decisions and condition management.

Successful management of long-term disease is dependent on a number of contributing factors. As stated by Clark et al. [32] an individuals' management is part of a network, and patients potentially rely on family, colleagues, clinicians and neighbours for support. When parts of this network are not successfully achieved, good management and control of the disease may be negatively impacted. Factors such as low self-efficacy, poor family support and poor communication between patient and physician are a few of the most frequently noted barriers to active self-management of chronic conditions [68, 84].

One further factor is the technology that supports users in managing their condition. The majority of chronic disease management applications available, regardless of which conditions they target , provide some sort of health data logging mechanism [27, 113, 126]. However, monitoring and tracking well-being signals can only be considered as subsets of self-management. Such applications should also offer additional mechanisms, such as enhancing patients' experience and improving the applications acceptance among the chronic disease patient community [172]. Current research on this topic in the HCI community is currently limited, however, there are examples of previous work conducted in this area.

Mamykina et al. [114] described findings of their investigations into management practices of people with diabetes and developed a tool to provide support, titled 'Continuous Health Awareness Program' (CHAP). Through their investigations, it was determined that there exists a health management decision cycle. This notion specified that those with diabetes frequently make decisions on their previous health related information. They also describe the 'Mobile Access to Health Information' (MAHI) system which allows for mobile collection of information. During their work, they put forward the idea of "reflective thinking" based on information gathered by an individual. Yet much of the work sought to leverage support from external sources (such as clinicians and peers) rather than focusing on individuals' actions while acting alone. This thesis aims to build upon this notion and understand how individuals currently engage with their health related information and where the potential for mobile-based support may exist. To achieve this, this thesis aims to:

- **Research Aim 1** - Understand devices currently in use and how they are used in practice.
- **Research Aim 2** - Design appropriate support for health condition management practice.
- **Research Aim 3** - Capture the impact of new technology solutions on people's understanding and management of health conditions.

1.3 Research Contribution

This thesis aims to resolve whether the addition of on-demand and ready-to-hand contextual information through a mobile application can improve a patients' awareness and understanding of their condition. Specifically, the work focuses on improving patient knowledge of results to better inform treatment decisions and to create a greater sense of involvement with the information. Initially, the work is focused on diabetes before moving onto blood pressure management. By using mobile applications to capture information in real-time it is possible that those suffering from long-term chronic conditions will be able to make more informed immediate decisions, as well as being able to fully appreciate data when reviewing at a later date.

This thesis makes the following contributions in this area:

1. A model of diabetes management processes.
2. An evaluation of lightweight and ready-to-hand methods of information capture to enhance diabetes record keeping.
3. An evaluation of personalised tagging of health information to promote awareness of points of interest in health information.
4. A set of properties for mobile interventions into chronic condition management applications.

1.3.1 Scope

The HCI community has been engaged with investigating requirements and designs for digital solutions within healthcare, an area of concern that has the potential to genuinely impact people's lives and lead to tangible benefits for individual users. The existing research in this domain has emerged into three broad strands, which reflect different approaches to the role of digital systems in individual health.

First, and perhaps the predominant approach in the current literature is the use of 'persuasion' or 'nudge' interactions to encourage patients to adhere to specific behaviours or outcomes that contribute to good health or wellbeing (e.g., [13, 132]). Research in this theme benefits from a wide contemporary interest in persuasive interaction and 'nudge' in HCI generally. There is also a clear potential benefit in helping individuals take specific actions that are likely to improve their wellbeing. However, there are concerns that this technique unavoidably imposes normalised models that may be a poor clinical match to an individual patient: in the long-term, adoption and maintenance of nudged behaviours can fail. This style of research relies on encoding guidance or advice from medical experts into tools, games or other interactive experiences that encourage adoption of the expert opinion.

This thesis however, does not investigate issues surrounding persuasion, rather, it seeks to understand the naturalistic way in which people with chronic conditions manage their own information. Persuasion techniques present a very different set of challenges and research questions, ones which are beyond the boundaries of this work.

A sharply different, but complementary range of interaction research, is remote monitoring. This family of research brings the clinical expert more directly into the foreground. Rather than extracting and encoding expert guidance, results of the patient's readings, or records of their behaviour and actions, are gathered via sensors and (usually) some form of internet communication (e.g., [113]). The experts then review individual data and behaviour, and from their expertise diagnose problems, respond to critical events, or provide tailored guidance. This approach promises a good connection between patient and clinical expertise, and enhances treatment by improved information gathering with refined and personalised advice. There are countervailing concerns that the level of monitoring that this approach requires may appear intrusive or depersonalising, or may increase the scope for conflict between patient and clinician, particularly when the level of advice is found to be overly prescriptive. The scalability of the costs inherent in this approach, particularly of the availability of sufficient volumes of expertise, is also a practical concern.

The use of health data in a social or remote context is not the focus of this thesis. However, during some of the system evaluations, participants describe their own theories on how the applications could be used to gather support from other people (such as clinicians). Where these situations arise, the implications will be discussed but they play a secondary role to the main research focus.

The research in this Thesis has followed a third tradition: to enable individual management of a condition by the patient. This has potential economic benefits of avoiding the need for the routine involvement of clinicians, though it can also enable a more detailed discussion between patient and clinician when required. The sense of intrusion or compulsion in the other two routes is also avoided. However, the technique does not directly address the concerns of conformance that typically occurs in persuasion and remote monitoring. This particular setting of health-management has been labeled as *'unanchored'* [95], in that activities are often away from the influences of external (hospital or clinical, even family) sources.

The research landscape across all of these different approaches has been substantially altered by the widespread adoption of smartphones, allowing for mobile and convenient interaction beyond the scope of the desktop or laptop computer. While some substantial research has been undertaken in both persuasive and remote monitoring techniques, the third, self-management, field lags behind in terms of both research and practice. It is within this space that the work conducted in this Thesis has been focused.

This work focuses solely on users' preferred personal strategies and to determine how contextual information impacts current management practices. Over time, patients are likely to develop their own approach to how they manage their condition. This thesis specifically investigates strategies already in place, rather than prescribing advice and guidance.

Therefore, in this work the notion of *'unanchored'* settings [95] is a key motivating factor. These unanchored settings are those that typically exist away from external interventions, such as clinicians. The proportion of time in which individuals are in unanchored settings is likely to form a high percentage, making it a key area to address.

1.4 Thesis Outline

In this Section, the format of the Thesis is outlined and the studies that have been conducted are described.

1.4.1 Thesis Structure

While approaching the research conducted in this Thesis, a background understanding of the problem area was required. As a result, this work is presented in the chronological order that the research was completed in. Figure 1.1 illustrates the structure of the Thesis and where each research contribution (as described in the previous section) is addressed and presented within the text.

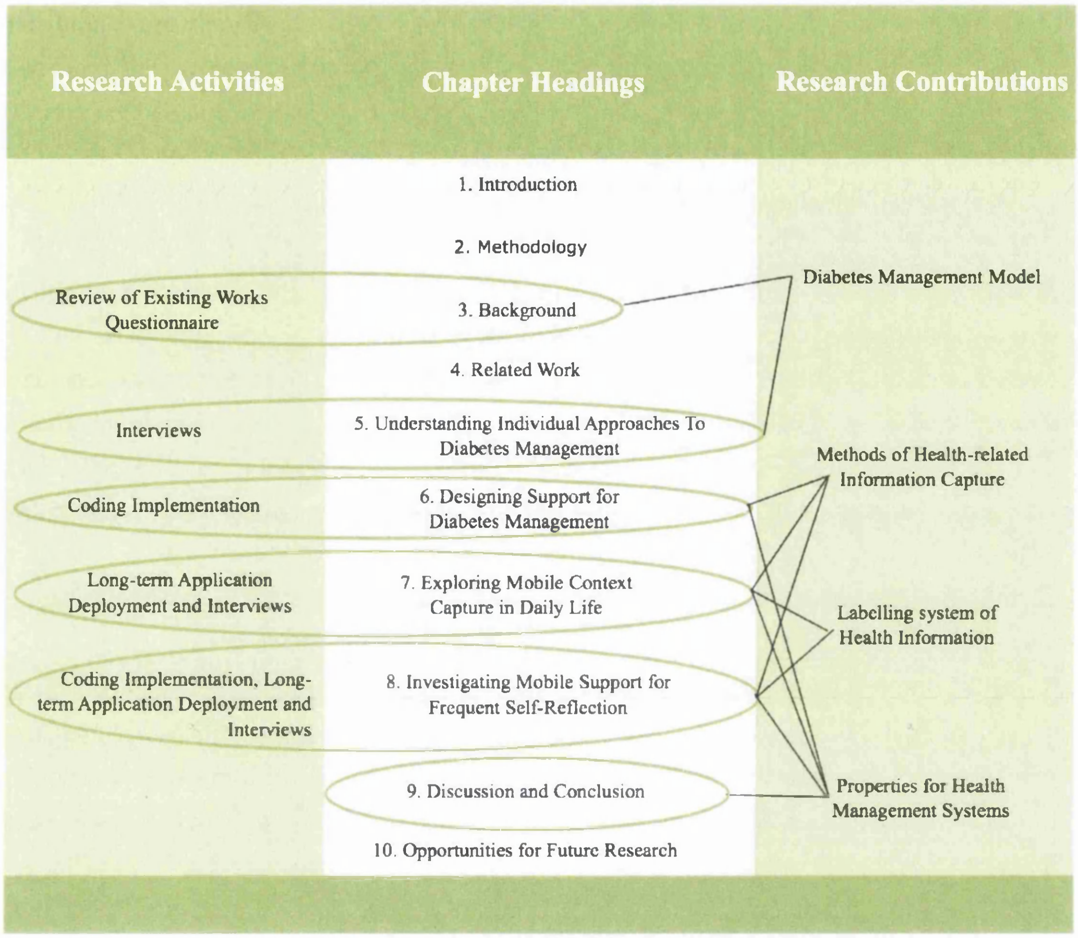


Figure 1.1: Thesis Structure.

1.4.2 Studies Completed

Study 1 - In order to achieve a deep level of understanding in both current practice and the impact of two mobile applications on individual's health management, four user studies have been conducted. These have taken the form of a survey (Chapter 3), which was designed to provide an initial baseline understanding of the processes involved in diabetes management though glucose devices. This study forms part of research aim 1, and contributes to the Diabetes Management Model

Study 2 - To further probe the issues and practices involved in diabetes management, a series of interviews were conducted. This set of interviews (Chapter 5) were designed to understand how participants dealt with the challenges of diabetes management during daily life. Through this understanding, opportunities for design were identified that informed the subsequent two studies. Studies 1 and 2 form the activities to achieve Research Aim 1 (as described in Section 1.2). The results of these two studies then inform the first research contribution (as described in Section 1.3), which presents a model of diabetes management.

Study 3 - In this study, the first technological deployment in this Thesis was evaluated (Chapter 7). Through a longitudinal deployment study, a mobile application was used by participants for a four week period. The application was designed (see Chapter 6) to offer several lightweight methods of information capture and attempted to alleviate elements of the burden of recording health information. The data presented from this study is largely the feedback received from participants during interviews conducted at the pre- and post-deployment phases of the research study. The results of this study form part of the research activities to achieve the research aims 2 and 3, and form the second contribution described in Section 1.3.

Study 4 - The final study presented in this Thesis was again a longitudinal deployment of a mobile application (Chapter 8). The application used for the study was designed to give participants a new labelling system for health related information to promote higher level of understanding in results through reflection.The results of this study form part of the research activities to achieve the research aims 2 and 3, and form the third contribution described in Section 1.3.

The information gathered from all four studies is then used to determine a set of generic principles for mobile based health management systems (research contribution 4). Throughout the Thesis, a deeper level of understanding regarding both existing practice, and impact of new technology, is achieved. Though this understanding, key design considerations are determined and presented in Chapter (9).

1.4.3 Chapter Descriptions

In the following Chapter, the methodological approach used in this body of research is described. Chapter 3 then outlines the motivation for undertaking this research. Through an analysis of devices used in the checking and recording of glucose monitoring data, and an initial pilot study, there exists an opportunity for further support. The current devices are focused on the important task of accurate measuring of glucose scores, yet there is a great deal more information that is highly relevant to good diabetes management. The existing devices capture a subset of this information and there is potential to enhance management practices.

Following this, Chapter 4 details relevant literature to the proposed research agenda. Here, an investigation into the key concepts and literature around recording and understanding of personal information are included. More in-depth literature reviews will be conducted within each following Chapter where they are most relevant.

Following on from the survey of existing work, Chapter 5 introduces work carried out to understand existing management practices of people who have diabetes. Here, the research builds upon existing work outlined by Mamykina et al. [115] to arrive at a detailed understanding of key stages during the management of chronic conditions.

Chapter 6 uses the findings of the previous Chapter to create a tool which attempts to capture information essential to the management of diabetes. The design of the 'ConCap' application is outlined before Chapter 7 details four-week long evaluation of the application by people with diabetes. The application allowed for the capture of simple forms of information that contained rich sets of detail and presented them alongside more important factors, such as glucose scores.

Chapter 8 introduces the application 'VCTag' which further builds on the findings of Chapter 5 and introduces a personalised tagging mechanism on health information. This system was used to investigate whether personal contextualisation of health results can assist in discovery of factors in condition management from patients. This application was tested during a six week user evaluation, where people were asked to make regular use of VCTag and 'tag' their health results based on their understanding of the factors contributing to the result.

The above Chapters all detail investigations and implementations that have been evaluated through rigorous user studies, which have provided insight into answering the earlier research questions. A full discussion of the implications of the results of each study are discussed in detail in Chapter 9. An outline of the conclusions and findings from each Chapter are presented and the contributions of the work conducted are aligned with previous research, as well as the other Chapters in this thesis. The final Chapter outlines the potential for future work which can be built upon the research conducted in this Thesis.

1.4.4 Author's Contribution

All of the work in this thesis has been undertaken by the author, with the exception of the research described in Chapter 8. This work was undertaken as part of a research grant awarded by the 'Building Global Engagements in Research'[1] project at Swansea University. In addition to the author, the project involved colleagues from Swansea University: Professor Harold Thimbleby, Dr Karen Li, and Tsinghua University in Beijing: Professor Patrick Rau and Na Sun. For this work, the author coded the implementation of the software and contributed to the system design along with Karen Li and Na Sun, with the user study being conducted by Karen Li. The write up for this Thesis includes the author's own analysis and interpretation of results from the six-week in-situ field study conducted.

[1] Building Global Engagements in Research - `http://www.swansea.ac.uk/bger/`

Chapter 2

Methodology

This Chapter outlines the methodological approach undertaken in the research conducted in this Thesis. As described in Chapter 1, this body of work focuses on individual management of chronic conditions during *"unanchored"* settings, and therefore away from external interventions. In order to accurately understand all of the factors that are involved in this process, current practice will need to be studied to allow for appropriate technological interventions. Section 2.1 outlines methods to achieve an understanding of real-world everyday practice.

2.1 Real-World Understanding

A key aim during the early stages of this Thesis is achieving an understanding of the existing management practices and challenges encountered by those who have diabetes. This approach is aligned with current practices in HCI research which seeks to fully understand existing context to enable more suitable interventions:

> *"The emphasis has been very much on understanding ordinary living and designing technologies that extend this."* [148]

This is very much the approach taken in this body of work, especially as the research has been conducted within the sensitive domain of healthcare. A major concern during the construction of a research agenda was to ensure the well-being of potential participants. To ensure all interventions were appropriate within the context and situations of individuals' health management, work was carried out that focused solely on the understanding of existing management practices were conducted.

Likewise, understanding how the developed mobile interventions fit in with individuals' daily lives was a main focus. As a result, two long-term in-situ user evaluations were conducted. Rogers et al. [149] state that traditional lab-based methods of evaluation are unsuitable in this domain:

> *"Traditional evaluation methods...fail to capture the complexities and richness of the real world in which the applications are placed"* [149]

2.2 Probes

Recent movements amongst the HCI community have seen researchers seeking to move work from the laboratory setting and into the domains of the individuals who will use implemented systems. Primarily, the research in Chapters 6, 7 and 8 are concerned with methods of capturing information relevant to health management, rather than the mobile applications that are utilised. The systems developed are tools that allow further investigation of proposed methods of support in chronic condition management. This approach has been based on previous research methodologies, such as the notion of *'Cultural Probes'* put forward by Gaver et al. [58]. In this approach, artefacts are given to participants inspire them to reflect on their everyday activities.

Similarly to the practices of real-world understanding, Barab and Squire's notion of *'Design-Based Research'* [11] emphasises the importance of achieving a full understanding of existing processes and practices. Additionally, a similar approach should then be taken to understand how an intervention has impacted on users' processes:

> *"The goal of design-based research is to lay open and problematize the completed design and resultant implementation in a way that provides insight into the local dynamics."* [11]

Hutchinson et al. [81] use *'Technology Probes'* to understand how devices are using during longitudinal studies. By utilising this approach, they state that researchers are able to gain valuable insight in subsequent feedback sessions which could then be used to motivate discussions with target users of a system regarding system designs:

> *"Provide real-life use scenarios to motivate discussion in interviews and workshops."* [81]

Therefore, this Thesis adopts an approach which is based on all of the above methodologies. By firstly understanding the domain of chronic condition management, appropriate probes were introduced to participants which encouraged reflection and past thinking on previous actions.

2.3 Study Techniques

The work in this Thesis is targeted at supporting existing practices, rather than introducing new sets of behaviours and management strategies. It is, therefore, logical to first determine what practices are already employed by individuals. To achieve this, the early parts of this thesis form a heavily user-centered research approach. Firstly, a questionnaire method is used to gather individuals' use of glucose monitors and the information they provide. Following this, more detailed semi-structured interviews are conducted to provide a broader understanding of individual management of diabetes.

Using the findings of these user-centered investigations two mobile applications are developed whose design is heavily grounded in the responses gathered from the earlier studies. These applications are evaluated using in-situ, long-term deployment with participants who are representative of the group that the applications are targeted at. The participants in these studies were not prescribed a set target of interactions as it was key that the typical, everyday usage of the systems was captured. Interviews were conducted both before entry into the longer term studies, and once the study had been completed.

Motivated by the study methods laid out by John Rieman [147], the deployment of the mobile applications in Chapters 7 and 8 were evaluated with longitudinal studies in which participants logged their own data. By also allowing for the capture of information in-situ, participants were able to contextualise their own results and provide feedback as to the reasons behind the captures they made. This approach has been defined as an 'elicitation study' [23], which is defined as an approach where participants only capture aspects of the event when it occurs which is used in later interviews to prompt a fuller description of an event.

The research in this Thesis has been conducted using a variety of evaluation techniques (questionnaires, interviews and in-situ studies) to achieve the highest possible understanding of the domain. By adopting an approach which is heavily focused on user feedback, the conclusions of the evaluations present real-world findings that inform future design.

2.4 Challenges

Throughout the process of conducting the research in this Thesis, a recurring theme was the difficulty in the recruitment of suitable participants. As with all research projects, the target pool of participants should form sufficient representation of real-world users. To achieve this, the participants in this Thesis are all individuals who have the conditions that the research is focused on.

Therefore, the participant pool available to conduct research with was greatly diminished. In the quest to ensure valid research data, participants were recruited from several outlets outside of the author's university institution (Swansea University). This involved travelling to and recruiting from alternative locations outside of Swansea University.

A second challenge encountered was how to gather meaningful data during the in-situ deployments. The focus of the research was to gather how an application would be used in a real-world situation. Therefore, the participants in the study were not assigned any prescribed interactions and instead requested to use the applications as they felt. This led to the potential of participants disengaging with the study completely, which itself may be a research finding regarding the suitability of the application. To ensure real usage was represented, contact with the participants during the study periods was kept to a minimum. During Chapter 7 this contact took the form of brief weekly telephone conversations and in Chapter 8 participants attended bi-weekly interview sessions. While these are still interventions that may have influenced participants' real-world usage, they were essential mechanisms employed in the studies to gather meaningful data both in terms of application functionality and participant feedback.

2.5 Ethical Issues

Due to the potentially sensitive issues arising from health related information and management, a great deal of consideration regarding participant well-being was given before approaching the research studies in this Thesis. During the evaluations of the two mobile applications developed, participants were advised that the applications were not a replacement for their existing health practices, and instead should be used as a supplement.

All of the participants that took part in the research studies conducted were informed of their right to not answer questions which they were not comfortable providing answers to. While the questions were designed to not be unnecessarily intrusive, there were instances when an individual's health formed a crucial part of the research.

Prior to all studies initiating, ethical approval to conduct the research was requested from the an advisory and regulating body at the location research was being conducted (for studies based in Swansea, the Swansea University Computer Science Department's Ethics and Risk Assessment Committee. For studies in UCL, the UCLIC ethics board).

2.6 Analysis

Analysis of longitudinal deployment studies presents challenges in terms of obtaining a representative sense regarding how a system was used by individuals. In keeping with the methods employed by Nicholas Chen in his PhD work [24] and in the CHI publication by Chen et al. [4], one of the evaluations their research relies on individual participant accounts of experiences whilst using a mobile system. Similarly, the analysis of the longitudinal in-situ study in Chapter 7 uses individual accounts to present the variety of ways the system was used during the study period. To ensure the anonymity of participants was maintained, false names were used during the presentation of results in Chapter 7.

A Thematic Analysis [18] approach was employed to collate and interpret results obtained from an interview study conducted in this Thesis. This allowed the findings from qualitative studies with study participants to be generalised. Additionally, statistical tests have also been used to ascertain the significance of subjective ratings provided based on a Likert scale ranking system.

2.7 Summary

This Chapter has outlined the methodological approach to be taken in this Thesis. The research methods described have been chosen as they best fit the requirement to understand both the current practice of health management while not intruding or interfering with processes.

Once a required level of understanding has been achieved, appropriate technological interventions are designed. To test the applications' suitableness to health management, longitudinal deployment methods have been used. A large portion of the information gathered from these studies is based on the feedback received from the participants. Therefore, qualitative methods of analysis have been employed to extract common themes of behaviour amongst the participant groups.

Chapter 3

Background

This Chapter outlines the motivating factors behind the research chosen for this thesis. It begins by outlining the case for investigating issues in chronic disease management and introducing a series of existing devices that are presently used during the process of self-management of chronic conditions. The majority of the work in this thesis is focused on diabetes, and hence this survey is heavily related to the devices used to monitor glucose (blood sugar) levels. Issues surrounding the management of blood pressure conditions are introduced in Section 3.4 of this Chapter.

This Chapter describes Study 1 (as outlined in Section 1.4.2), which is adopts a survey based approach to elicit findings that contribute to the research aim:

- Understand devices currently in use and how they are used in practice.

The study was aimed at understanding real usage cases amongst people using the devices on a regular basis is then described. The results of this Chapter contribute to refining the scope of this Thesis and clarifying the research space that the remainder of this thesis is concerned with.

3.1 Current Practice

Over the past 20 years, the attitudes within the healthcare domain have moved towards patients having greater involvement in their own treatment. The *'Patient Empowerment'* [55] movement has seen practitioners attempt to move patients from being 'passive recipients of services' to 'being active and self-determining parts of their health care' [142]. The aim is to ensure that patients are more prominently involved in their own treatment, from decision-making to an increased role in daily maintenance.

Patients are no longer be educated purely about the regimes they must follow for good condition management. Instead, clinicians aim to provide individuals with chronic condition problem solving skills [17]. By enabling patients to solve problems that they encounter, they are able to take more complete control of their own conditions and become a key decision-maker in their overall treatment. Patient input into their own medical records is also being realised. Systems such as Partners Healthcare [178] allow patients to provide content in their own health records.

3.1.1 Benefits of Increased Patient Involvement

Michael Weiss [182] who had been living with diabetes for 22 years and experienced the shift in focus spoke about his own experiences with the notion of empowerment, stating that:

> *"This approach has enabled me to take a much more active role in and increased responsibility for my personal health. I am now in a much better position to celebrate my successes. And when I fail to hit a target, I am more likely to analyze the reasons for it and make adjustments, rather than to feel the sense of failure that once accompanied my inevitable misses."*

Whilst Weiss was a recipient of the increased level of involvement, those giving care have also expressed their support for the movement. The role of the patient in higher level decisions about their treatment is becoming increasingly important:

> *"Patients take greater responsibility and accountability for their own health with clinicians often acting more as expert consultants than the primary caregivers"* [165].

> *"Now that chronic disease has become the principal medical problem the patient must become a partner in the process, contributing at almost every decision or action level.*

This is not just because patients deserve to be partners in their own health care (which, of course, they do) but also because health care can be delivered more effectively and efficiently if patients are full partners in the process." [80]

Those with chronic conditions can gain useful insights about their own condition from self monitoring. Lora Burke et al. [22] investigated the impact that instrumented paper diaries would have on the self-monitoring habits of people involved with a behavioural treatment study for weight loss. Participants in the study used the diaries to record information about their eating habits and weight measurements over an 18 month period. The results indicated that there was a positive correlation between self-monitoring habits and the rate at which weight loss was achieved.

3.1.2 Challenges of Increased Patient Involvement

Weiss [182], while highlighting the benefits of his own increased involvement, also notes that patients making their own decisions can sometimes create situations that have *"devastating consequences"*. This suggests that those in control of their own treatment are not immune to errors in judgement in relation to healthy maintenance of their conditions. Placing more control into the hands of people has been described as a 'burden' [167]. Situations can arise where the one in control of their condition can become overwhelmed with the pressures of family and clinical concerns. Conrad et al. [36] noted a case where a young female had taken to faking her personal health records in an attempt to appear healthy, without the negative impact of self-testing and self-evaluation.

Placing greater responsibility onto patients can therefore occasionally create cases where there is cause for concern in condition management. Causes for such instances can be as a result of a lack of literacy or knowledge of a condition. In the case of diabetes, these factors have been noted as a limiting factor in the treatment of those who do not fully understand their condition [151]. Patients require guidance on how to successfully control and manage their own condition. Clinical interventions during early phases of condition management must be applied, as it is unlikely that patients can simply learn about their conditions fully without the assistance of professional help. Providing generic written instructions rather than attending tailored group sessions for example, leads to *'unacceptable inaccuracy'* [180].

Such access to clinicians has been highlighted as the leading concern amongst those with chronic conditions [84]. In a set of ten focus group interviews involving 54 participants, all of whom had chronic conditions, perceived 'barriers' to self-management were discovered. Issues such as poor communication with physicians and lack of support from family members were cited as a main concern amongst the participants involved.

Depression appears to be another factor that acts as a barrier amongst those with chronic conditions. Those who are considered to have depression are more likely to give up on self-care sooner [65]. After conducting a study asking patients about their previous week of diabetes self-care, it was found that those likely to suffer from depression spent less time monitoring their blood glucose, less time exercising and were less likely to maintain a healthy diet.

Such negative emotion can also affect the quality of self-reporting. The information obtained from the self-monitoring process is only as good as the individual entering the data. Forgetting to record an event means that information is potentially lost forever. More deliberate omissions can also occur:

> *"I went through a phase of only recording what I perceived as 'good' results and wouldn't want to commit the 'bad' ones to paper to be scrutinised by my doctor later! Of course, this didn't get me anywhere, as it's the 'bad' ones I most needed to pay attention to and get help from my doctor."*[1]

Yet successful management is not purely a result of technological interventions. There are in fact, several personal relationships that can affect the success of chronic disease management by providing support. Clark et al. [32] state that while the primary entity in achieving good management is the individual, other factors such as family, clinical, work and community support, all assist the individual, as do broader policies set by governing bodies.

3.1.3 Strategies for Supporting Patients

It is possible to further extend the self-monitoring practices of people by using technology that is already available to them. Research has indicated that collection by an individual of information

[1] User 'Jen Nash' commenting on `http://www.diabetesdaily.com/` in the thread "How to Appreciate Your Blood Glucose Meter"

about their health has proven to be more successful on digital devices rather than paper based formats [82]. By using pervasive technologies, it is possible to utilise the capture of information to promote greater awareness about an individual's behaviour. Such awareness is useful should a person be interested in altering their own habits, to lead to a healthier lifestyle [37].

Speculations have been made that in the home of the future, true capture of healthcare [98] will be achieved by using wearable health sensors to record vital pieces of information. The aim of such systems would be to then aggregate this data which will then be used to better control disease by enabling greater knowledge in both clinicians and patients. However, presently such systems are not widespread, but several less complete systems are being used to monitor health.

Technological assistance in healthcare may not be required at all times during an individuals' own management. The need for interventions may alter over time depending on the needs and health of individuals. Subsequently patients may not be concerned with their interacting with assistive devices at all times:

> *"technological support should change based on the patient's disease severity"* [186]

In the above quote, the severity of disease is being considered, however the same sentiment can be applied to fluctuations in chronic conditions. Recording of information during long-term conditions may have varying levels of intensity as an individual's confidence or health changes. When a patient reaches a level of confidence and satisfaction with their condition, they may engage less with monitoring. Interventions that require input from individuals at frequent prescribed times may not be the optimal solution.

An individual's recording of information over a long period of time may encounter problems. Patients with chronic conditions have to deal with their own care not only within their own home. Information that is potentially valuable in deriving a long-term understanding may need capturing in adverse circumstances. For example, when an individual is in pain or experience treatment side effects, or when opportunities to manage information are impaired [96]. Long-term conditions such as diabetes and hypertension often require patients to play a key role in the management and maintenance of symptoms and information. In the case of diabetes, glucose monitoring devices provide patients with access to information about their body that is essential to maintaining a healthy state. However, people with diabetes have commented on the complex nature of dealing with information that the devices present to them:

> *"On the surface, it seems like a very fast task, it takes less than a minute. But when you have to deal with the results and think about it, it's a lot more than that."* [2]

The checking of glucose results is usually the first step in understanding the current state of the body, and then what the next steps should be. The level of glucose is determined. These devices capture and record some of the information that is essential to patients and the following section describes some of the more popular models.

> *"The process of understanding self is long and overwhelming because patients are required to not only observe the nuanced details of their life, but to understand the balance of various influential factors with glucose levels"* [25]

Over time people with diabetes become increasingly aware of factors that affect their glucose levels. Achieving such a level however, requires assistance from clinicians and the devices that are used in the process of managing diabetes. These devices offer insight into the state of an individual and provides information that would not otherwise be available.

3.2 Current Devices

The method of attaining good glucose readings has evolved from using urine strips (to give a general indication of glucose levels) to blood testing (which gives a much more precise value). The first devices to use blood samples began to see widespread usage in hospitals during the early 1970s [33, 122]. However, diabetes is a condition that requires frequent monitoring and more accurate measuring tools were required within a patient's home. The first monitors were marketed to the home market in 1981 and the leading two models were the Glucometer (Bayer) and Accu-chek meter (Roche).

[2] User 'mkkd,' a 29 Year old Type 1 since 1991 commenting on `http://www.diabetesdaily.com` in the thread "Judgmental Numbers: Are You at War with Your Meter?"

Current meters are able to provide a glucose value result in as little as five seconds once a blood sample has been taken. Patients are required to prick their skin (often fingertips) and apply blood onto a test strip, which is inserted into the monitor. The device then presents a reading to the user, as well as storing the result for later reference.

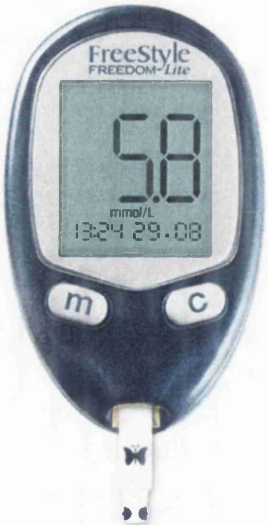
As the glucose monitors transferred from being primarily a hospital based device, to one used throughout everyday life, the need for more practical form factor increased. Presently, these devices are now smaller than most mobile phones and fit easily into a pocket. However, Figure 3.2 displays the numerous artifacts that are often carried by a person with diabetes at all times. For a blood test to be performed, an individual must use a lancet to break the skin, in order for a sample to be obtained. The monitors then require testing strips to take the blood sample from the person. As such, several of these supplementary tools are usually kept to-hand at all times for convenience, leading to wallets and covers often being supplied with monitors for storage of all artifacts.

Despite evolving over time into smaller devices, glucose monitors have increasingly started to include several other features and selling points aside from accuracy of results. Factors such as speed of result and blood sample size are frequently used as selling points by manufacturers and suggest greater convenience and suitability to everyday life. In such a dense market[3] it is essential that monitors offer a stand out feature in order to succeed amongst the competition from other manufacturers. It is worth considering, however, that the manufacturers of the devices rarely make profit from the sale of the monitoring devices; instead the income comes from the test strips that are used to take blood samples. This approach sees a primary component either priced cheaply or given away for free, but the consumables are aggressively marked up. This technique is known as the 'razor blade business model' [164] after the approach was adopted by shaving manufacturers in the early 20th century.

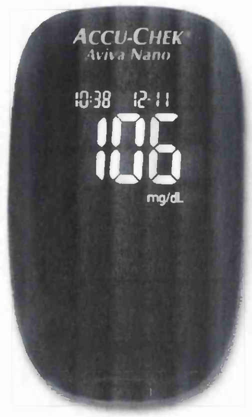
Advances in technological capabilities, and the competition in a consumer market, have seen other features added to the devices. Functions such as wireless transmission, cloud storage and contextualising of results have become frequent features of the current range of glucose monitors.

Understanding the situation in which a glucose result happened can allow a patient to make more accurate future decisions. Contextualising of results has been typically achieved by allowing users

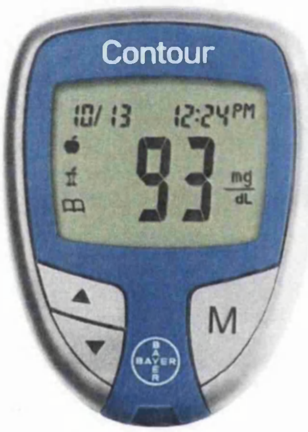
[3]diabetes.co.uk list over 40 devices on their 'Blood Glucose Meter Guide' - available at http://www.diabetes.co.uk/diabetes_care/blood_glucose_monitor_guide.html



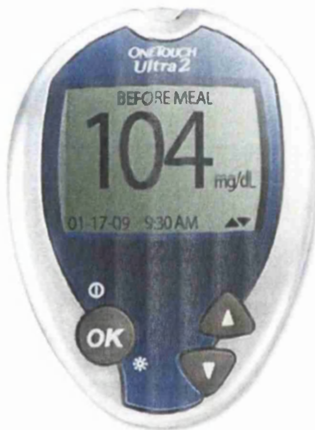
(a) Freestyle Freedom Lite



(b) Aviva Nano



(c) Bayer Contour



(d) Ultra OneTouch

(e) Bayer Contour USB

Figure 3.1: Examples of popular glucose monitors

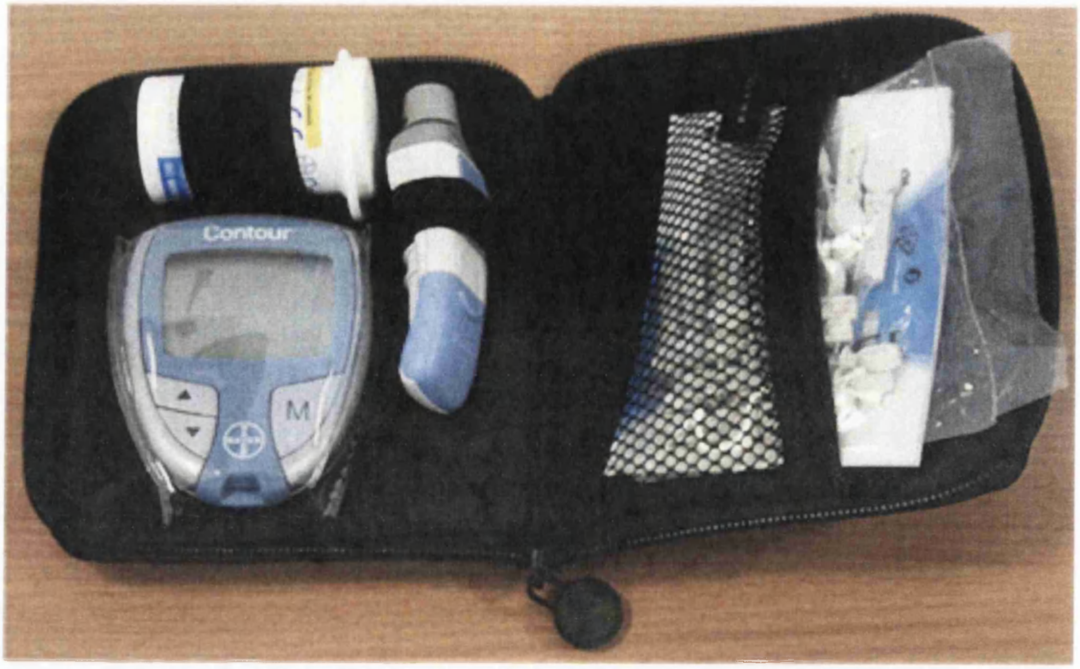


Figure 3.2: A typical glucose monitor setup

of monitors to 'tag' glucose results in relation to the event that they occurred. For example, the Bayer Contour (Figure 3.1c) monitor offers a user the opportunity to note whether a glucose reading was taken before or after eating a meal and therefore may offer an explanation why a result was higher than expected (glucose level increase after eating a meal). This information is potentially crucial when a user is looking back upon their own results [6]. Looking back upon data is a key process in diabetes management and being able to accurately frame in which situation a reading was taken can clarify whether a misjudgement may have occurred:

> *"Be sure to write down each glucose reading and the date and time you took it. When you review your records, you can see a pattern of your recent glucose control. Keeping track of your glucose on a day-to-day basis is one of the best ways you can take charge of your diabetes."*[4]

Additional factors, such as exercise or illness, may well have played a role in explaining why

[4]Center for Diabetes Control and Prevention (CDC) article 'Take Charge of Your Diabetes - available at `http://www.cdc.gov/diabetes/pubs/tcyd/ktrack.htm`

a glucose score was perhaps lower than expected, or if an insulin dose was incorrect. Clearly then, the context of a reading is a key factor. Yet current devices offer only a small subset of the information that may be relevant to a greater understanding of a reading.

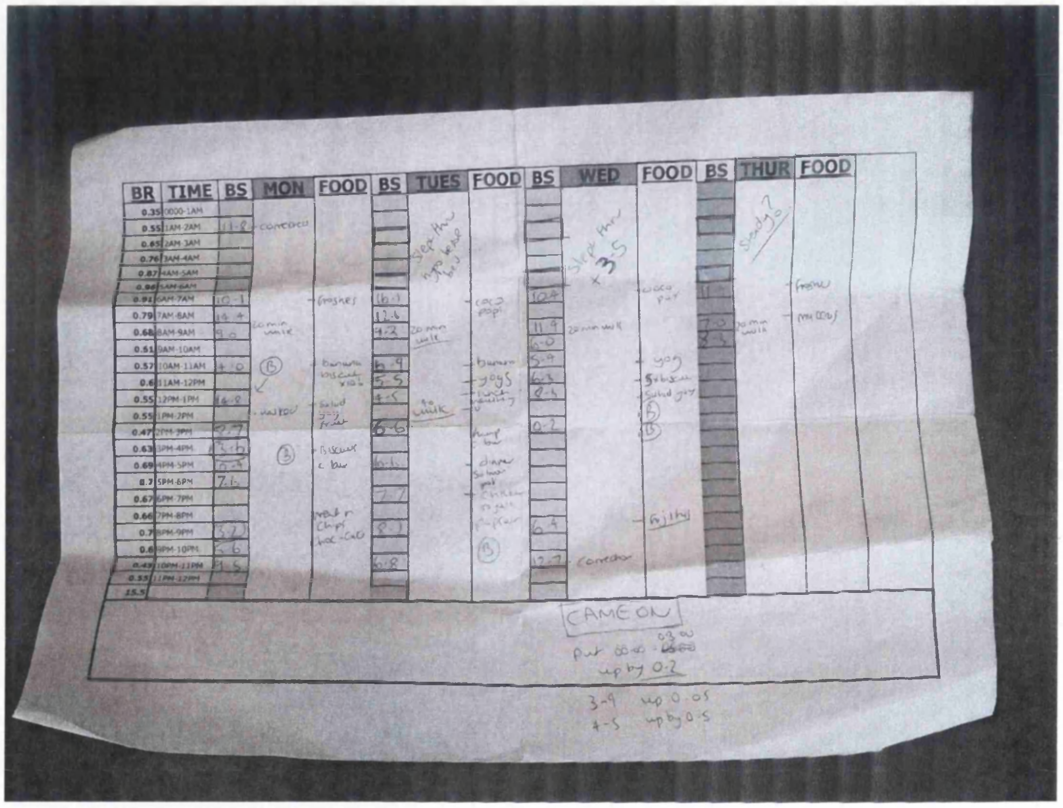


Figure 3.3: Example paper diary log for diabetes management

Figure 3.3 is an example of an artifact used by people with diabetes to log and monitor a variety of information that contributes to their well-being. The paper log of activity shows four days of annotations made highlighting points of interest along the diabetes management process. The patient who created the log has noted, in addition to glucose values, occasions such as walks taken and their length, food eaten and the fact that they had slept through a hypoglycemic episode. Whilst there appears to be a complete set of information exhibited, this piece of paper represents only four days worth of activity. This suggests that this type of logging being performed over several days and weeks will yield a vast quantity of paper. Being able to process and understand all of the pieces of paper in order to spot important information (such as trends) would become increasingly difficult. Pieces of key information exist on different physical objects, and being able to collate and organise the objects is an extremely challenging one. Potentially, the overload of information may result in some of the challenges discussed in Section 3.1.2.

People with diabetes have a huge interest in their results, good control ultimately benefits them in the longer term, but this also places a great burden onto the individual. Diabetes potentially places great restrictions onto people, limiting the foods they can eat and activities they can take part in. Additionally, the management of recorded information can potentially be challenging, with a vast amount of data to potentially be recorded and viewed.

3.3 Investigating Current Practice

Glucose monitoring is a complex process, due to the number of factors that can potentially influence a result. Those with diabetes face daily decisions regarding their health using information obtained from their glucose monitors. To gain an understanding of some of the experiences that people have had whilst using glucose monitoring devices, an exploratory small scale study was conducted. The aim of the study was to provide early insight into the experiences of individuals frequent use of glucose monitors. While the benefits of greater patient involvement have been discussed (Section 3.1.1), there is little understanding of the attitudes of individuals to the technology used to support this process. The results of this study assisted in understanding the scope for supporting individuals in their management, and potentially enhance the capabilities for users to capture meaningful information.

A questionnaire that was designed to probe some of these experiences was distributed to six people with type 1 diabetes from the Swansea area to take part in a study. This initial exploratory study aimed to provide early insight into the issues encountered whilst using glucose monitors, as well as gaining initial concerns regarding the daily usages of the devices.

3.3.1 Procedure

Questionnaires were distributed to six participants attending a diabetes trial at the Swansea University Sports Science Department. The individuals attending the trial had been selected because of their interest in an exercise program being conducted at the department. The participants had well controlled diabetes in order to meet the criteria of the study.

The questionnaire consisted of thirty questions which were created to further the understanding of interactions with glucose monitors. The questions focused on topics such as; existing glucose monitor features and display, interactions with the monitor, management of results and personal perception of the monitors. No incentive was offered for completion of the questionnaire. The ten participants were recruited through an email list used by the Sports Science Department at Swansea University. Of the ten questionnaires sent out to participants, six were completed and returned.

3.3.2 Participants

The six participants (5 female, 1 male) completed a series of questions to gain insight into their background and glucose monitor history. Rather than request specific ages of participants, groups of ages were used: three of the participants were from the 18-25 age group, and one from each of the 36-45, 46-55 and 56-65 age groups. The participants were asked to provide information about their glucose monitor history, and number of years using monitors in their disease management. The average number of years using a glucose monitor was 14.92 and the average number of monitors used in that time was 6.2 (sd = 3.27).

Participants were also asked about their current monitors and the number they were using. Four of the participants stated that they only used a single monitor. The remaining two each owned two monitors, but stated that one of these monitors was used as a primary device during everyday life.

3.3.3 Results

Participants were asked what reasons they had for changing glucose monitors. The responses included a variety of answers: the new monitor was free of charge, the new monitor had additional features over previous device (e.g., measuring ketones), wanting the latest glucose monitor model, smaller size of device, and failure of old device. One of the participants also started that a major factor in deciding to change monitors was the possibility that newer technology may be more accurate when calculating glucose levels.

A change in glucose monitor could potentially lead to new and unfamiliar features and testing procedures. Participants were asked what process they used to become familiar with the monitor: one participant admitted they learnt by trial and error, four learnt from hospital clinicians or representatives of manufacturers. The remaining participant had simply upgraded the monitor from an older model where the features were largely similar.

When asked about ensuring the time and data on the monitors was accurate, all but one participant stated that having accurate time and date on the monitor was not important. One participant stated *"I have my phone for checking the time"*, suggesting that the mobile phone was a more convenient method of checking for time. Another participant suggested that awareness of the time was of little concern: *"Time and date - Not of any great importance to me - although when checking precise results it is more important - not updated them yet (on the monitor)."*

Participants were also asked about their personal methods of recording results, which is often an integral part of the management of diabetes. None of the participants made use of the software provided from manufacturers for uploading data from monitor to computer. One participant had created their own spreadsheet using Microsoft Excel with the other five preferring to use paper based records.

Frustrations with the monitors were also reported, with one participant stating that the monitor was frustrating when *"I have really low sugar and haven't had a clear head whilst testing my sugar."* Another participant stated that it was frustrating that the monitor lacked lighting to allow them to test in situations such as the cinema. A third stated that there was simply *"too much stuff to carry round."* Glucose monitors currently available typically come with a wallet to store all the elements needed to perform a glucose test. Participants were asked whether they leave the meter in the wallet when testing, or if they prefer to take the monitor out of the wallet. Only one preferred to use the monitor in hand as they felt this method was a more discreet process. The remaining 5 preferred to leave the monitor in wallet with most describing it as less hassle than constantly removing the monitor and reduced the risk of dropping it. However, one of those five described testing with the meter in the wallet as a more discreet method, showing a difference in attitude to the participant who preferred holding the monitor in the hand.

3.3.4 Discussion

From the responses received from the questionnaires, it is evident that the amount of information being recorded by the participants is limited. Five of the participants stated that they made use of paper records to record glucose results, time and dates. It would be difficult for these participants to track the trends of their glucose levels using this method. The one participant who made use of Microsoft Excel has the potential to create graphs that may enhance their understanding of their condition.

Concern was expressed by three of the participants that the monitors were negatively impacting on their daily lives. Two described the desire for discreet interactions with the device, with another stating that a lack of functionality had forced them to alter what they were doing (having to leave a cinema).

Participants were also asked to describe situations in which they had found their monitor to be frustrating. The most interesting comment described how the impact of low sugar had a negative effect on the interaction with the monitor. As previously stated in Chapter 1, the result of suffering from low glucose can lead to problems due to the low supply of glucose to the brain. Users encountering such a scenario are in even more need of clear and concise feedback from their meter, yet this is not always the case:

The questionnaire also asked participants to describe how they had received the meters. Interestingly, four stated that they received their monitors from diabetes clinics while attending training courses in the management of their disease. This suggests that the patients had little input on the decision which devices they were to use and are now using the monitor because they had been recommended. Those that had at some point changed their meter themselves gave a variety of desirable features in monitors such as size and colour, as well as a newer meter having a simpler process when calibrating the monitor, thus reducing the workload when performing a test.

The feedback received from the study indicates that users of glucose monitors have concerns about the design of the devices. Participants mentioned the devices came with *"too much stuff"* and were not always sufficient to their needs. More interestingly, however, was the lack of contextual information being recorded by the participants, meaning they were potentially missing data that could help to improve their condition.

Despite the study being relatively small, the results indicate caution must be taken before creating any intervention. It became apparent from participant feedback that they were not largely concerned with changing monitors, with one participant stating they already had too much stuff to carry around. Therefore the research space for this thesis was shifted towards the external activities that occur during self-management, in addition to glucose monitoring tests.

3.4 Blood Pressure Management

The management of blood pressure conditions presents different challenges to those of diabetes management. Whilst those with diabetes take several readings of their health information each day, those with blood pressure concerns typically test less frequently and at more fixed times of day. Advice from the British Medical Journal (BMJ) states that blood pressure should be checked in the morning and evening [118].

There are also several factors that can impact on a blood pressure reading score. Issues such as arm position, posture, arm support and arm tested, can all influence a blood pressure score [123]. Therefore, the procedure of performing a blood pressure test is perhaps more complex that taking a glucose reading.

Figure 3.4 displays an example blood pressure monitor that is used by individuals during their home monitoring schedule. The monitor takes blood pressure readings using the same mechanism that is typically used during clinical visits. An individual places the cuff onto the upper part of their arm before pressing the start button to activate the monitor sequence.

Once the monitor has completed a reading, the results are displayed on the screen at the front of the device. Systolic and diastolic measurements are given, with the addition of pulse information. Those who are actively monitoring their blood pressure would then usually enter their information onto a blood pressure chart. Figure 3.5 displays an example chart that is often provided to individuals. In the table, the blood pressure readings can be entered, along with data and time data. Additionally, an individual can include notes that they feel are relevant to the reading taken.

The addition of notes in the table suggests that there are localised factors that can impact on blood pressure reading. However, as has been discussed earlier in this Chapter, individuals are unlikely to regularly comply with paper based record keeping.

3.5 Constructing a Research Scope

It is clear that glucose monitors are an essential element of the diabetes management process. Without these devices, people with diabetes would not be able to accurately treat their own conditions. Yet, glucose scores form only one part of the decision making process undertaken by patients, there

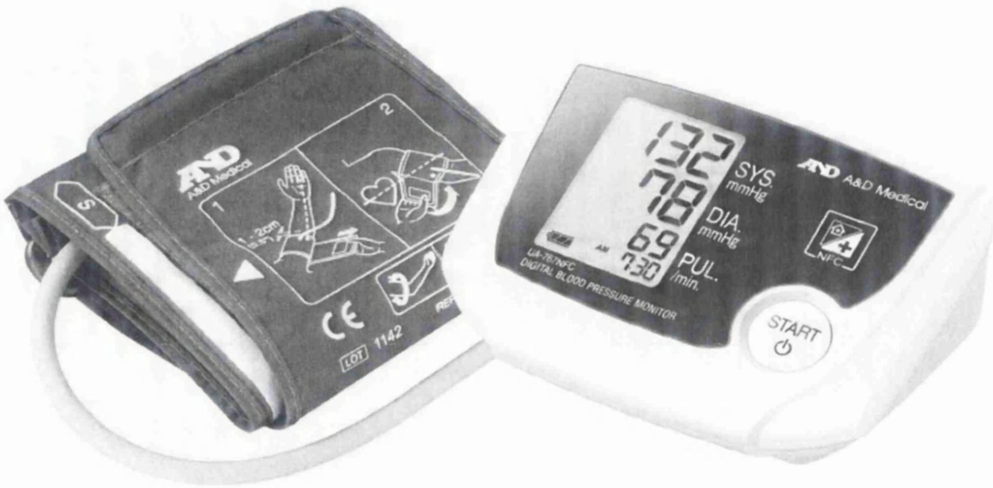


Figure 3.4: A&D blood pressure monitor given to participants during the six week long study period

are several other factors to consider. Daily activities such as; food eaten, exercise performed and insulin taken all contribute to the overall picture of a person's diabetes. An individual must collate and aggregate all of the information into a meaningful set of actions that will allow tight control of blood sugar. A blood glucose reading is potentially meaningless without some form of background context. Current glucose monitoring devices have made attempts to enhance the information they provide (such as tagging of glucose scores with pre- or post-meal), but there exists the potential to provide greater support and information.

While the participants in the pilot study discussed issues surrounding using glucose measuring devices, such as problems testing in low light and interactions in social situations, there are perhaps more interesting issues which have emerged from the early steps. Those with diabetes, either in internet support forums or in Section 3.3 have suggested greater issues in the wealth of information

MEASURING YOUR BLOOD PRESSURE AT HOME

Blood pressure table

Use this table to record your blood pressure readings over time. If you make changes to your medicines, or if there is anything happening that could affect your readings, keep a note of it in the 'Notes' section.

Blood pressure readings

Date	Time	Systolic (top number)	Diastolic (bottom number)	Notes

Figure 3.5: Blood pressure monitoring sheet included in the 'Home Blood Pressure Monitoring' booklet published by Blood Pressure UK [a]

[a] Blood Pressure UK http://www.bloodpressureuk.org/

they have to manage. Collating, understanding, processing and acting on a variety of factors is an extremely complex challenge, especially when normally only a single factor is usually recorded.

The past ten years has seen access to powerful technology becoming available on everyday devices which could potentially provide a greater role in the general well being of their owners. Examples of how mobile devices can assist in diabetes management include Hee-Seung Kim's [94] interventions where diabetes patients were provided with short SMS messages from their clinic nurses. Patients of the clinic were asked to upload their glucose results by either using a mobile or computer which allowed nurses to view the data. Based on the information provided, the nurses were able to send recommendations. The feedback to the patients was extremely successful, with patients having lower glucose by 1.15% generally, with a greater effect on post-meal scores (-4.7mmol).

Similarly, Franklin et al. [50] developed the 'SweetTalk' application for children (8-18) with type 1 diabetes. Text messages were sent to the patients with general suggestions to patients with the aim of improving glucose levels and self-efficacy and medical adherence. Upon completion of the study, 82% of patients felt that Sweet Talk had improved their diabetes self-management and 90% wanted to continue receiving messages.

While both of these examples involved interventions from medical staff, there perhaps exist a greater set of challenges around people who have to deal with their conditions without external help. It is potentially unreasonable to rely on clinical staff to be able to review and contact every individual diabetes patient with tailored advice. As such, individual is required to become the expert through both external education and their own understanding of their own condition.

Providing this support could potentially be of great benefit to an individual's ability to accurately manage their condition. This could be achieved using devices that people either already possess, or are extremely familiar with to capture elements of information that are relevant to their management. The ability to capture rich content in a variety of formats, on a single mobile device is potentially a highly useful tool in assisting self management:

> *"Mobile applications can enhance self-monitoring by providing real-time feedback"* [35]

Klasnja et al. [95] through a study of individuals with cancer and their management of their own information found that much of the process was performed in *'unanchored'* settings. The notion of unanchored relates to the important care-related needs that arise while patients are away from the expertise of clinicians and desktop based systems. Much of the information relevant to chronic condition management occurs throughout everyday life and potentially while away from specialised systems offering support. Through their work, Klasnja et al. define a set of properties that healthcare related systems should adhere to:

> *"Tools for unanchored patient work should support easy capture of a range of more informal information than what health information has traditionally been taken to mean."*

It is in this area that the remainder of this thesis will concentrate on. The focus of the research is to understand how are people currently managing the data related to health and the potential that everyday technology could support, and enhance their ability to achieve healthy states successfully.

3.6 Summary

This Chapter has described the early stages of the research direction that this thesis concerned itself with, and how through these preliminary steps, a much richer design space was uncovered. It became apparent that there are challenges that exist in the management of chronic conditions. Recalling and reflecting on that information for the purpose of ensuring healthy states could potentially be enhanced with the tools that already users already make use of. By using devices that patients already have access to, they will not be burdened with extra equipment nor any outlay of expense.

3.6.1 Next Steps

An early understanding of the management strategies employed by individuals with chronic conditions has been reached though the study and related works described in this Chapter. However, there is scope for further investigation to achieve a much deeper level of knowledge. Through the work in this Chapter, the focus of the Thesis has been narrowed and the following Chapter outlines the related works in this area.

Chapter 4

Related Work

The research that has been conducted in this Thesis follows a user-centered research and interaction design approach and builds upon prior research in these areas. This Chapter begins by describing the existing research into current methods for supporting the capture of personal information and how access to that data is provided. Typically, such systems aim to supplement and enhance an individual's own experience and recollection of activities and events they have engaged in. To understand how these systems achieve this, the following section describes previous literature which describes how human memory operates. Reflection, which is a subset of human memory, is then investigated in more detail before systems which support individuals in the management of chronic conditions are explored.

4.1 Capture and Access

Systems allowing for the automatic capture of personal information have been thought of and developed since Vannevar Bush first put forward the notion of a capture system. In his 1945 article *"As We May Think"* [175] he describes the benefits that a general capture and access system may offer and sets out his vision for a device which can:

> *"store all his books, records, and communications, and which is mechanized so that it may be consulted with exceeding speed and flexibility. It is an enlarged intimate supplement to his memory."*

Systems to facilitate capture have been considered ever since Bush's proposed system. For example, the 'Stuff I've Seen' [43] application builds upon Bush's expectations of a system that tracks viewed content on a computer and provides access to the artifacts later. The system captured a variety of media, viewed whilst at an office workstation, from emails and documents, to presentations and videos. Forty-five participants completed a questionnaire after using the application for 6 weeks and generally, it was found that the Stuff I've Seen system allowed for easier retrieval of content over traditional browsers.

Devices and applications have sought to record personal information for a wide range of purposes, such as office works, meetings and money. However, before describing these, it is logical to define the term 'capture' and how it will be used in this thesis. Truong et al. [170] state that:

> *"capture occurs when a tool generates an artifact that documents the history of what happened"*

The capture phase is typically the live experience duration to be preserved, while the access phase happens when these records are reviewed. Truong also seeks to define the finer nuances that exist within the broad concept of capture and access. The specification of 'who, what, where, when and how' must be considered while developing capture and access systems.

- **Who** are the users during capture and access?
- **What** is captured and accessed?
- **When** does capture and access occur?
- **Where** does capture and access occur?
- **How** is capture and access performed?

Clearly the process of designing a capture tool is not one that should be undertaken without deep consideration of the processes involved to achieve successful capture and access mechanisms.

As described in Chapter 3, the patient empowerment movement has seen greater focus on individuals tracking their own health information. The capture in this context will be performed primarily by the patient who will be recording information about their specific health condition. *Where*, *when* and *how* will likely be defined by the requirements of their particular condition. For example, someone with diabetes will likely need to record information every time they perform a glucose reading, however someone with cancer may not necessarily record any information relating to specific readings, but perhaps more general feelings of well-being at less frequent intervals.

More generally, collection of information about oneself can be achieved through the use of personal informatics systems. Li et al. [103] state that personal informatics systems assist people in the collection of information that is relevant to themselves. The reasons for performing the collection is for the purpose of self-reflection on past actions performed. By engaging in the self-reflection process, people will be able to gain knowledge about themselves that may otherwise have been missed.

Mik Lamming and Mike Flynn suggest in their 1994 piece that technology could become ever present on a person and that this would carry great benefits. They argued that by wearing a computer constantly, the information gathered would be specific to the individual. This would allow the device to become intimately involved in the activities performed. In turn, the computer would be able to provide more meaningful feedback to the user of the system [99]. Yet continuous capture, while offering comprehensive accounts of activity, may also create an intrusive feeling amongst the user. Knowing that all activities are being logged create an increased amount of self-consciousness in everyday life. Systems that are less invasive, yet still capture meaningful experiences, are more likely to be adopted [101].

Whereas Bush's view of capture involved large, perhaps cumbersome desk space, more recent attempts at the logging of personal data has shifted into more mobile settings, fitting with Mark Weiser's belief that computing should *"get out of the way"* [181]. These ubiquitous systems should not interfere with an individual's ordinary activities, and should allow people to *"go about their lives."*

Various capture systems have been created to record information from a variety of situations, such as classroom learning [169, 170], work meetings [119], conversations [77] and more continuous personal capture throughout a day [60, 79].

Gordon Bell, in his 2001 work [15], describes his own efforts to record as much of his daily life as possible. Great effort was made to collate vast amounts of information about everyday events, from photos, to documents and videos. Bell described the issues arising from storage, highlighting that the increase in data leads to challenges in the presentation of data.

The vast amounts of data that could potentially be gathered may exist of many images, hours of audio and/or several documents. There may only exist a few points of real interest to a user amongst such a large dataset. Kientz [93] states that capture is becoming ever more ubiquitous and subsequently an increasing part of everyday life, yet access is often more of a problem. Being able to present the potentially huge amounts of data is a challenge to achieve in a meaningful way. An overload of information is unlikely to present anything to a user. If meaningful access were to become more readily available then people would be more likely to use the information that they have recorded. The participants who responded to the survey described in Section 3.3 illustrated that they never made use of the accompanying software that came with their glucose monitors. The information gathered by these devices represents several daily recordings and when uploaded in a single large batch to a desktop system, the dataset is likely to be extremely large.

However, research has been conducted into how to address such a problem. By using the information that Gordon Bell described in his 2001 work [15], a visualisation tool was developed and evaluated using the data. The 'MyLifeBits' system [59] provided a variety of visualisations of digital documents based on user generated queries. The research investigated how such a wealth of information can, and should be presented. A timeline visualisation of a set of documents, images, audio files and videos are presented to a user in chronological order. Subsets of this data can be obtained by user-generated queries which are based upon the tagging and categories which have been pre-defined by the user.

Brown et al. [21] sought to understand the reasoning behind capture. It was found that the reasons for performing capture within a digital domain vary according to a situation. During a diary study, 22 participants were asked to photograph information that they felt the need to capture. The participants were split into two groups, with 11 asked to capture any form of information and the remaining 11 asked to only capture from paper documents. Participants completed a seven-day diary study and analysis of the information gathered focused on images gathered by participants and the response given during a semi-structured interview session upon completion of a study. Through this analysis, ten categories of capture were discovered [21]:

1. **Capture to be discussed** -A document of information captured to be discussed during a later conversation.
2. **Capture to distribute** - Information to be distributed, but without the need for conversation.
3. **Capture to post in a common information space** - Items that can be placed into a common place, to facilitate 'incidental viewing' (noticing information without specifically looking for it)
4. **Capture to archive** - Capturing information which might be useful in the medium to longer term, but without a specific reason in the short-term.
5. **Capture to collect and collate** - Items which are captured to add to a collection of similar items.
6. **Capture to read and reflect** - Information that is gathered for the purpose of later reflection.
7. **Capture for task management** - Capturing data to act as a reminder to complete a task in the future.
8. **Capture to refer to** - Information deliberately captured to be referred to at a later date.
9. **Capture to re-use** - Items which are captured in order that they can be re-used in the production of something else
10. **Capture to a living document** - Items which are captured and used within a structured information repository.

Based on the findings of Chapter 3, the capture processes that patients are likely to engage in fit within the points 2, 4, 5, 6, 7, 8 and 10. The omission of points 1, 3 and 9 are as a result of patients being unlikely to send information to others without seeking feedback (e.g., from a clinician) and that they are not 'creating' an artifact, rather that they are maintaining an existing picture of their health.

Additionally, during the previous Chapter it was noted that participants were not engaging in the recording of information as frequently as they perhaps had been advised to (Section 3.3). The cost of physical capture may be a cause, with the process of obtaining glucose results already a complex task. With glucose monitors also storing results automatically, logging yet more information onto paper based records may be a further, unfavourable detraction. The use of ubiquitous technology to facilitate further logging has been viewed as a potential solution:

> *"One goal of using video and audio records in some cases is to prevent some of the departure from reality that can be inherent to documentation manually recorded at the time of an incident or later"* [171]

Providing such support will allow for individuals to focus their attention on their main task. In the case of diabetes this task is the overall control of their condition and not on the manual entry of information. By providing more ready-to-hand forms of capture, then a greater amount of information will be available to patient's to use in the understanding of their condition.

4.1.1 Life-Logging

An extreme form of capture and access is the practice of life-logging. This is a process where a person makes use of an interactive device to capture their entire life, or at least a large portion of it. Life-logging research has become a well established concept with various systems tracking several aspects of daily lives [14, 52, 101, 129]. Life-logging can exist in two forms:

1. **Passive** - one stores the by-products of the life one would have lived anyway
2. **Active** - one surrounds oneself with sensors and information capture tools to create as rich a picture of one's life as possible [1]

The most mature method of continuous life-logging is the Microsoft SenseCam[1] device [26, 79]. The SenseCam is a small camera that is typically worn around an individual's neck in order to provide a similar viewpoint to that of the eyes. The camera takes pictures automatically using a fisheye lens at regular intervals throughout a day. Fleck and Fitzpatrick [48] conducted an evaluation of the SenseCam system and developed a method to present the images captured by the system for the purpose of reflection. The study found that the image data collected during a study enabled the participants to:

[1] Microsoft SenseCam - `http://research.microsoft.com/en-us/um/cambridge/projects/sensecam/`

- Remember something they had forgotten to talk about earlier
- Confirm or disconfirm a comment made earlier from memory
- Become aware of something they had not even noticed, at the time of the image capture

The images collected in the study were taken during an observation task by pairs of participants, who then engaged in group discussions after the event. The images appeared to not only support memory of the viewed events, but also as a tool to enhance *'collaborative reflective discussion on experience'*.

Automatic capture of information has been implemented in other scenarios to assist in the recollection of events. For example, the 'Cook's Collage' system [168] consisted of hidden webcams placed within a kitchen that captured performed actions during cooking, such as ingredients added. The system was designed to act as a 'memory aid' and allow for an individual to accurately remember at their place in a recipe. Using the data collected from the webcams, an LCD display placed at eye level showed video-stills of the six most recent events.

Other methods of continuous logging have varied from automatic recognition of activity through heat rate and accelerometer data using sensors on an individual [162], to tracking location using WiFi sensors worn by individuals to provide information about location history [133]. Yet, systems that support recollection of past events should consider that, unlike machines where memory is objective and procedural, memory for humans is far more complex [100]. Methods to support meaningful interpretation of information are required and tools to visualise the wealth of collected data are needed.

Life-logging technologies have also sought to support older adults in ensuring completion of essential everyday tasks in their health management [102]. By adding sensors to a 'pill-box,' which is used to dispense medication, a system was able to record interactions with the box, and therefore indicate which pills had already been taken. Yet, in subsequent interviews it became apparent that the participant using the system used the collected data to spot anomalies (such as missed pills). Once such an event had been detected, participants would first attempt engage in a recollection process in an attempt to understand the reasons behind the error. Should this first pass fail to draw a satisfactory conclusion, the participant would then resort to their daily habits in an attempt to resolve the issue.

Brown et al. [20] designed the *'FotoFit'* application to support reflection on health by students, specifically relating to diet and exercise. The application consisted of a mobile phone that captured image data, and a distributed system in a gymnasium that allowed for exercise sessions to be recorded.. This data could then be collated into a desktop based visualisation which provided both calendar and timeline based navigation through the information.

Concerns have been raised, however, as to the impact capture may have on the recipient of the information. Ubiquitous computing techniques designed to support, and potentially enhance, a person's memory during daily life potentially create more sensitive experiences [70]. By recollecting the past in a visual way, people may find a series of challenging thoughts. Issues arising from perceived personal poor behaviour and missed opportunities to make full use of a situation may not be seen favourably by users. Yet, in the domain of personal health management, spotting these opportunities for improvement may be of great importance, and a useful tool in understanding the overall outlook of a condition.

Life-logging technologies must be conscious of not only the information they provide, but also of the context in which they are capturing information. Technologies should be aware of the context in which systems are used, and provide support at every iteration:

> *"As the boundaries between technologies used for personal and professional reasons become less clear we anticipate an increasing need for applications that support the multiple roles people hold"* [66]

Pervasive technologies will not only be used in the privacy and comfort of the home of users. These ubiquitous technologies can be used in every scenario, from the workplace to home, and gym to social events. Through this continuous capture, situations that users may not wish to be recorded, either through concerns for their own privacy or others, and such systems should be aware of the user's needs at different times.

Further criticism exists of capture and access systems, with arguments that exhaustive personal logging of information may not serve a practical purpose [154]. Instead, smaller personal records should be used to promote cues for the purpose of memory, which is a more complex notion, rather than a singularly explained concept. Rather, memory is made up of five Rs: recollection, reminiscence, retrieval, reflection, and remembering intentions.

Therefore, rather than asking patients to capture every aspect about their daily lives it is perhaps more appropriate to only capture information deemed important by the individual. The findings of Chapter 3 suggested part of what this information might be, but currently little is known about what information patients would choose to store about themselves and if such information is indeed useful in reflecting for the purpose of enhanced management.

4.2 Memory

Before embarking upon a project concerned with collection and presentation of personal information, an understanding of how user‘s memory may impact ability to recall previous events is explored. Memory that provides information relating to one's self has been defined as 'autobiographical memory' [19] and it is in this domain that this section is focused. Recalling information about activities is an essential part of personal disease management, as multiple factors need to be taken into account before treatment can be accurately administered.

Endel Tulvig [173] claims that there are two forms of memory: semantic memory and episodic memory. Semantic memory relates to a general knowledge of several factors, such as someone with hypertension knowing that stress will push their blood pressure to a higher level. Contrasting the notion of semantic, episodic memory occurs when specific instances are recalled, for instance someone with diabetes remembers a meal from two hours previous for the purpose of insulin calculations.

Gardiner and Richardson [57] further expanded upon this notion and categorised the actions of remembering and knowing. Remembering is specified as the process of recollection of a variety of contextual factors (e.g. 'when' and 'who with') which falls into Tulvig's [173] classification of episodic memory. Knowing is more reliant on familiarity without the need for recollection and uses semantic memory.

The notion of supporting episodic memory has been investigated by Kalnikaite et al. [85] who described how image data was much more likely to promote genuine and detailed recall and support episodic memory. Alternatively, locational information was found to promote inferencing, allowing users to deduce likely scenarios based on where they had been throughout a period of time.

Willem Wagenaar [176] put forward the notion that people are very unlikely to recall sufficiently unpleasant experiences and are in fact much more likely to accurately remember pleasant experiences. Examples of such behaviour were given in Chapter 3 where patients had either tampered with, or omitted from, their own personal health records.

Wagenaar also argues that context such as location is important in cueing recollection about events and providing narratives about past activities. Locations are well remembered and provide cues for later reflection. Systems adding locational information to digital mementos support the reflection on past events [87]. The 'Memory Lane' application provided the ability to log personal mementos with factors including people, places and the home setting. Users of the system were able to contextually bind multimedia data (images and audio) with digital mementos.

Photographs have also been viewed as the effective cues towards past memories over other artifacts such as crafts, textual documents and videos [129]. By using technology to capture information, the burden on relying on human memory will be lessened. The daily activities that people engage with create a vast amount of information relating to events that happened, people spoken to and places travelled to. The utilisation of ready-to-hand mechanics, such as photographs, can act as a supplementary method of capture in addition to an individual's own memory:

> *"The sheer quantity of the information we create and use combined with the limitations of human memory means that we cannot rely solely on our memories to recollect precisely what information we have seen, where we may have stored an object, or how we can find it again."* [44]

> *"Narratives of the past captured by these technologies are not just collections of facts for users to record, store, and remember, but reconstructions of experiences subject to multiple interpretations and perspectives."* [38]

Clearly, then, technology has a role to play in supporting an individual's ability to recall previous activities. By providing effective memory cues, digital interventions can assist recollection of potentially important information. However, consideration must be given toward how to successfully implement systems within this domain of memory support:

> *"Effective memory support requires situation-appropriate information."* [40]

However, SenseCam images occasionally contradicted users' memory during a long-term deployment of the system [107]. Participants were able to determine reasons behind the conflicts and the diagnose of the factors was straightforward for users to resolve. Yet the perceived ambiguity was noted by participants of a longer term study as having the potential to increase engagement with the images and create a deeper understanding of the context an image was representing.

It is not simply enough to capture and greater consideration must be given to supporting accurate recall of past events. By ensuring relevant information is captured, the recall of an activity is more likely to be a true indication of the past events. It is possible even, to support those with memory deficiencies in being able to recall events [16].

Concerns have also been raised about the ability to successfully implement life-logging technologies:

> *"Life-logging technologies currently require both a significant investment in infrastructure and/or access to unusual hardware."* [153]

Currently, the devices to perform life-logging (both in terms of capture and access) only exist in specialist formats. Life-logging is not yet a widespread process and as those with chronic conditions are not concerned with additional hardware (section 3.3), it seems unwise to follow this approach. More meaningful capture of information, using hardware that is currently in the possession of a user may appropriate. Enabling users to capture information which they deem to be important to their chronic condition management is perhaps a more suitable approach.

4.3 Reflection

By using past events that are remembered, individuals are able to dissect and interpret events through consideration of what happened. The practice of performing this action is known as *'reflection'*. Reflection has been a long standing topic of interest from researchers, but before discussing approaches to supporting reflection, it is worth considering what is meant by the term 'reflection' in a more formal manner. John Dewey [41] defines reflection as:

> *"the kind of thinking that consists of turning a subject over in the mind and giving it serious and consecutive consideration."* [41]

The process of reflective thinking has the potential to enhance an individual's practices by gaining insight from past experiences, which in turn offer the opportunity for more informed, and better choices [150].

Dewey's definition indicates that when a person is engaging in thought about a past event, they are doing so whilst considering the possible alternatives that may have occurred. Donald Schon [152] further defines reflection by specifying two contexts in which reflection is achieved:

- Reflection-**in**-action is described as using feelings, emotions and prior experiences to contribute to the resolution of a present situation.
- Reflection-**on**-action happens when a person analyses a response to a situation and understand the reasons for and consequences of performed actions.

Reflection-on-action is usually performed through a documented reflection of the situation. Using the earlier definition of capture, it is clear that this approach has the potential to support this type of reflection. Those with conditions that require continuous management are likely to be required to analyse their personal information in order to understand where potential causes of concern may lie. Within self-monitoring of personal conditions, the ability to engage with this process may prove to be a valuable tool. Determining where the potential for improvement in disease management may be, will ultimately allow for greater control of a condition and therefore more positive long-term forecasts of well-being.

A hierarchy of technology that can support reflection has been defined by Fleck and Fitzpatrick [49]. They state that there exist tools for:

- **Revisitation** - Description or statement about events without further elaboration or explanation. Not reflective.
- **Prompting explanation** - Description including justification or reasons for action or interpretation, but in a reportive or descriptive way.
- **Seeing more** - Looking for relationships between pieces of experience or knowledge, evidence of cycles of interpreting and questioning, consideration of different explanations, hypothesis and other points of view.
- **Transformation** - Where social and ethical issues are taken into consideration. Generally considering the (much wider) picture.

Those with long-term chronic conditions who are actively managing their conditions are likely to engage in each of these levels at different stages of their management. Factors such as their own expertise and the severity of their condition are likely to affect at which of these stages they engage in.

In fact, a broader definition of stages of reflection has been defined by Li et al. [104]. They stated that there exist two phases of reflection; maintenance and discovery. The maintenance phase occurs when an individual is not actively seeking change in their behaviour or management. However, should an individual wish to introduce change into their management they would change into a discovery phase of reflection. Within the phases of reflection, there exist questions that individuals will ask of their data to further their own self-knowledge:

1. **Status** - data that revealed their current status.
2. **History** - seeing their data over the long term.
3. **Goals** - what goals would be appropriate to pursue.
4. **Discrepancy** - once people know their goal, they compare their current status with their goal.

5. **Context** - what other things were happening at or near the same time as their current information-seeking context.

6. **Factors** - what influences behavior over a long period of time.

Those engaged with the maintenance phase of reflection will only be concerned with points 1 and 4, whereas the discovery phase encompasses the remaining questions. Li et al.'s model complements that of Fleck and Fitzpatrick as both suggest that there are varying levels of investigation an individual will engage, depending on the management status.

Li et al. [105] then furthered their research agenda to discover if the inclusion of context in addition to automated data collection provided individuals with the opportunity for more meaningful reflection. By allowing participants to annotate data from a pedometer, greater insight and knowledge was given in understanding which activities provided the greatest physical benefit. Systems that support reflection provide a platform for individuals to act on, and do not offer suggestions of behaviour change:

> *"Reflective learning tools are not geared towards enforcing a specific behavior but aim at creating awareness and a cognitive dissonance to identify possible improvements."* [120]

It is in this context in which this thesis concentrates its research and outlook: supporting a patient's ability to understand and process information related to their own health. Facilitating the capture of meaningful information in a fashion that is decided by the individual potentially allows for opportunities in health management and a sustained usage, such as determining where potential concerns lie in everyday management. Prescribing interactions and behaviour through a system is not the approach taken in this work. Instead, supporting a person's existing practices to an extent that they find beneficial appears to be a fruitful avenue of investigation.

4.4 Personal Health Behaviour

Interventions into personal healthcare must be aware of the potential responses of the individuals meant to use them. Theories regarding personal health behaviour have long been researched, with many prominent variations attempting to predict how active people will be in their own health and well-being.

The most widely discussed theory of personal health behaviour is the Health Belief Model (HBM) [61]. The HBM was originally devised in the 1950's as a method of understanding why there was high prevalence of people failing to engage with programs to prevent and detect disease [78]. The core concept behind the model is that personal health behaviour is determined by personal perceptions about a disease, and the possible strategies to decrease the likelihood of being affecting by health conditions. The model is typically used as a predictor of how likely a person is to engage with behaviour that affects their health, as well as providing possible reasons behind poor engagement.

The model initially composed of four elements; *perceived susceptibility*, *perceived benefits*, *perceived barriers* and *perceived seriousness*. As the model matured over time, three additional elements were added to the model; *Modifying Variables*, *Cues to Action* and *Self-Efficacy*:

Perceived Susceptibility - Refers to beliefs about the likelihood of getting a disease or condition.

Perceived Severity - An individual's feelings about the seriousness of contracting an illness or of leaving it untreated. Possible consequences could be for example, medical (e.g. disability, and pain) or social consequences (e.g. impact on working or family life). The elements susceptibility and severity are often labelled as an individual's perceived threat.

Perceived Benefits - Even if a person perceives personal susceptibility to a serious health condition (perceived threat), whether this perception greater engagement in health management will be influenced by the person's beliefs regarding perceived benefits of the various available actions for reducing the disease threat. External factors such as potential financial savings related to quitting smoking may also influence behavioral decisions. It is possible therefore, that even if an individual perceives a high threat level, they may not act on their health behaviour if the benefits are not prominent enough.

Perceived Barriers - The potential negative aspects of a particular health action may act as barriers to undertaking recommended behaviors. Individuals may carry out cost-benefit analysis of a potential action, to determine whether a practice is worth investing time and effort into. For example, someone with hypertension may find the need to perform a test 3 times, and calculate an average, to be a time-consuming task and therefore, avoid or alter the procedure.

Modifying Variables - Cultural factors will also influence an individual's perceptions and therefore, their likelihood to engage in health-related behaviour. For example, educational levels, are believed to have an indirect effect on behavior by influencing the perception of susceptibility, severity, benefits, and barriers.

Cues to Action - Cues to action are events, people or things that move people to engage more with health related activities. These events however, are difficult to quantify as they can be as brief as a glance at a poster, or over-hearing a conversation. However, more concrete examples of cues to action could be having a family member suffer from negative affects of a condition, allowing for an individual to respond to their own condition and act.

Self-Efficacy - Self-efficacy was first defined by Bandura [10], and is defined as a person's belief in their own ability to carry out an action. If someone believes that a health action is beneficial and useful, but they are not capable of doing it, the likelihood of completing the action is low.

The HBM therefore, determines factors that explain engagement into health related actions and the potential barriers and beliefs that may impact on a person adopting a health behaviour. Within the scope of this Thesis, it is highly important to be aware of these existing notions.

Those individuals that have long had a condition may be wary of using a new intervention, the perceived benefit of using a system may be low. It is likely that the participants recruited for studies will have already formed beliefs relating to their existing health behaviour, and could be entirely satisfied. Any new technological intervention could therefore, be seen as an extra burden.

Instead, the design of any interventions should be mindful of ensuring a genuine reason for using a new digital system. The systems should address genuine issues that will benefit the individuals. For example, Free et al. [51] conducted a large scale survey of mobile-based health messaging delivery and found that there is a mixed success rate. While surveying 75 controlled studies, they found only two instances where patient adherence to good health practices as a result of mobile based health message delivery. Systems targeting adherence to diabetes and hypertension practices were also included in the research and found to not have generalisable results across factors such as demographic and cultural influences.

4.5 Healthy Living Support

Chapter 3 noted the increase in the patient empowerment movement, and a key part of that is patient self-care. Self-care has become a key component of current policies in the management of long term conditions [109]. The pervasive nature of computing has seen many applications become key components of the process. This change has been brought on by a variety of factors, such as patients taking charge of their own conditions and government initiatives pushing the health system towards a self care model [8].

It was found in Section 3.3 that participants were not engaging in logging of information on specialised desktop applications. The previous sections in this Chapter have described existing research in supporting the capture of perceived relevant information of an individual. Recent research has become focused on how mobile technology can supports this process, due to its increasing ubiquity and widespread usage. The technological capabilities of modern mobile devices mean an increasing array of data can be easily captured, facilitating both management and reflection on information. Patients are able to record information such as health measurements, diet intake and exercise statistics. Incorporating this data into an affective health record for a patient means that information should be meaningful and contextualised. This type of recording has been viewed as a 'personal health record' with the data being collected by patients becoming an integral part of their treatment [161].

The inclusion of data gathered by patients themselves forms a crucial part of the understanding of their own condition, both personally and by those treating that person, such as doctors or nurses:

> *"The long lasting nature of chronic illness makes record-keeping and long-term analysis of diagnostic and evaluative measures both extremely important and also very challenging."* [165]

4.5.1 Commercial Products

While traditional recording of health related data has taken place on paper, recently greater numbers of systems are taking a digital approach. The capabilities of mobile phones has seen several apps designed for the purpose of well-being management. Additionally, several specialist devices have been marketed for the same purpose. In the following, a selection of these devices is outlined to understand the existing methods of capture and access in the commercial field.

Bayer Didget [2] is marketed as the world's first and only device that rewards children for good control of their diabetes. The glucose monitor acts in a standard way in terms of measurements of blood sugar, but additionally it can also be attached to a Nintendo DS [3] gaming device. The device is targeted at children aged from four to fourteen and aims to encourage good glucose control by offering rewards. The meter will connect to Bayer's Didget world, a password protected, online community where children are able to 'spend' the points they earn by consistently measuring their blood glucose levels. It comes with an adventure game and a mini game arcade.

Jawbone [4] is a wristband based system that continuously tracks movement and sleep without requiring input from the user. The information is then synchronised with a mobile application which allows for contextualisation of the information displayed within the application. Personal interpretations of the data can be added to reflect food eaten and mood at the time of reading. The wristband is also able to track sleep patterns and offers a 'smart alarm' system designed to wake a person at a time that a user feels the most rested. The system claims to:

> *"discover hidden connections in the way you live to deliver powerful insights. Over time, insights lead to new behaviors and new behaviors become new, healthier habits."*

Fitbit One [5] is a device that allows people to record a variety of information, such as: steps, distance, calories burned, stairs climbed and sleep quality. The device allows for wireless syncing of information onto desktop based computers, as well as mobile devices (such as phones and tablets). Based on data collected from the user, the Fitbit system sets targets that are to be achieved and provides feedback to the user on daily progress towards those goals. Users are given suggested goals in the form of: daily steps taken, number of floors climbed and calories burned. The Fitbit system also adds another form of motivation by allowing sharing of results between friend groups.

[2] Bayer Didget - `http://www.bayercontour.com/Blood-Glucose-Monitoring/Didget`
[3] Nintendo DS - `http://www.nintendo.com/ds`
[4] Jawbone Up - `http://jawbone.com/up`
[5] Fitbit - `http://www.fitbit.com`

Scosche MyTrek [6] is a pulse and heart rate monitor that is worn by users on their wrist in the form of a watch. The watch then transmits the data to an iPhone to provide feedback on the information collected. Similarly, the Polar RCX5 [7] is another watch-based system that offers feedback to ensure users are training at the right intensity. It also offers support during water based activities. Based on past performance, the system also suggests race pace in order to assist casual runners progress at a suitable rate during race conditions.

Withings Blood Pressure Monitor [8] is controlled by the iOS family of devices. Users are able to plug the monitor into an iPod, iPhone or iPad to initiate the blood pressure reading, the iOS device then takes the readings and stores the results. Visualisations of offered within the application of the blood pressure trends over time and results are contextualised based on time of day. The data can be exported and presented to clinicians for feedback and advice.

BETAPLUS [9] is an assistive tool for people with Multiple Sclerosis that allows them to log their injection schedule. The application can run on either a mobile device or on a computer and allows users to input their injection schedule. Notifications or alarms when injections are due can be created, as can a rotation schedule for injection sites on the body.

GoMeals [10] is a mobile application which allows for the recording of food, activity and blood glucose. It offers a large database of both restaurants, and the nutritional information of the food served. Users are also able to tag glucose results with information such as pre-dinner reading or post-exercise. Users sign up with an account that is synced between the mobile application and a web based system. The online tool offers visual representations of the data that are not supported on the mobile application.

All of these applications capture differing streams of information, but there exist potential problems in the interpretation of multiple streams of information [166]. Issues such as collation of information and the ability to accurately understand information across multiple platforms make the task of management yet more challenging. To support aggregation of this information, the mobile application 'Mobile Mash-Ups' was designed and created. The application gathered data from

[6] Scosche - `http://www.scosche.com/rhythm`
[7] Polar RCX 5 - `http://www.polar.com/rcx5/`
[8] Withings Blood Pressure Monitor - `http://www.withings.com/bloodpressuremonitor`
[9] myBETAapp - `http://www.betaseron.com/betaplus/mobile-app`
[10] GoMeals - `http://www.gomeals.com/`

a weight scale, sleep tracker sensor, location sensor and user generated information. The information was then presented to a user in a single application and participants involved in an evaluation of the system were

> *"able to learn new facts about how aspects of their long-term well-being are affected by their context that they could not discern from the visualizations from each sensor alone."* [166]

4.5.2 Research on Data Capture for Well-being

It has been previously noted in this thesis that participants do not appear to be engaging with current logging mechanisms. Currently the manufacturers of glucose monitors offer desktop based visualisation tools for glucose data. However, none of the participants in the survey conducted in Section 3.3 made use of these systems. Earlier in this Chapter several examples of mobile systems to capture personal information have been described. While those systems were concerned with capturing information about meetings, conversations and daily activities, the following investigates systems that are specifically focused on well-being on a mobile platform.

Ubiquitous technologies have provided a platform allowing patients to take monitoring of their conditions into their own hands. Several applications on mobile devices and home based sensor systems have opened up new avenues in terms of forming an overall picture of a patient's current condition. Klasnja and Pratt [97] outline several applications developed to support various chronic conditions. They outlined 5 key areas in which technological interventions have made efforts to improve patient care: tracking health information, involving the healthcare team, leveraging social influence, increasing the accessibility of health information and utilizing entertainment. This thesis is concerned with the role that technology can play in the tracking of information by those with long-term chronic conditions.

Capture of every detail of events that occur during daily life may provide little, or no benefit in aiding better reflection in chronic condition management. Instead, much more focused capture may be necessary to facilitate more meaningful reflection on the information. By recording information that is useful, patients will be more able to determine factors that require greater concentration to improve their management.

Some interventions have found that usage, over time, decreases due to users no longer finding use for a system [163]. Problems including patients' mastery of their own condition, fitting additional workload into daily life and a balance between accuracy and meaningfulness in results.

Whilst there do exist concerns over the use of reflective technologies for well-being support, there also exist arguments for its implementation. The following outlines the arguments for using ubiquitous mobile support for patients' own health management. Developing systems that will have a successful long term usage by users is not an unrealistic goal, for example:

> *"For ubiquitous computing systems to gain acceptance, they must be functional, flexible, robust, easy to use, and meet demonstrated user needs within actual user physical contexts and usage patterns."* [47]

Additionally, the ubiquitous systems that are designed to empower patients in the control of their condition should not seek to replace the expertise of clinical staff. Instead, they should:

> *"step in to take care of the standard, repetitive tasks of monitoring vital signs and promoting compliance with medical advice, performing analysis, and requesting medical assistance only when required."* [157]

The systems developed to support the patients should also empower them to have more effective communication with health care professionals [174]. Clinicians will ultimately be the decision makers in longer term treatment decisions, due to their expertise. Yet, patients will offer insight into the finer details of their own experiences and should be provided with tools to facilitate this. The role of personal health records maintained by the patient has been discussed in several outlets([39, 161, 177, 178]) with many researchers stating that the approach can contribute to better health management and understanding.

Matthews and Doherty [116] developed a system to assist teenagers suffering from mental health problems to capture their mood and experiences. By using a mobile application, participants were able to enter daily information regarding their emotions and general mood. Participants captured information relating to their emotions during every day life. This data was then to be used during the teenagers' regular therapist sessions where the information was used to track progress towards a therapeutic goal. It was found during this study that adherence to completing the diary logging was improved when the participants were using a mobile phone as opposed to paper based logging.

Henricksen and Viller [75] used the Evernote Food[11] application to assist in the diagnoses of food intolerances and/or allergies in children. The mobile application offers several features such as: recipe storage, restaurant picks and food diary. Entries into the Evernote Food application require a title, notes and tags, as well as optional photographs and/or images. This information is then presented in a scrollable timeline view. Required information that entered into the system, with additional contextual factors that enhance the entry

Mattila et al. [117] developed and evaluated the Wellness Diary mobile application in the context of weight management and general well-being. The application itself automatically generated objective graphical feedback based on the measurements inputted by the user on a calendar style interface. The application did not give instructions back to the user on how to proceed, instead relying on the user's own responsibility in making wellness management decisions. In contrast to the Evernote system and the Matthews and Doherty's system were external support and feedback were offered, Wellness Diary application relied on a individual's personal judgment as to what further action may be required.

Similarly, Takeuchi et al. [160] sought to apply the Wellness Diary concepts to a broader context beyond weight management. Given the wider range of conditions a greater variety of information was recorded into the system. The application *'MedData'* allowed patients to enter information from both clinical settings (such as blood pressure) and home settings (medication intake) into the system. Visualisation tools such as graphs and calendar based interfaces were then used to present feedback to a user. However, the system described in the research article had yet to be formally evaluated through a user study.

This section, so far, has described interventions in healthy living support that have involved clinicians and peers. However, there is an emerging theme of research around an individual's own understanding and interpretation of their information, without outside assistance.

[11]Evernote Food - `http://evernote.com/food`

Mamykina et al. [115] set out to understand the diabetes management practices. This work led to the creation of systems which made use of mobile phones to support 'reflective thinking' of results. Systems such as 'CHAP' [114], a desktop application which combined entered and capture data, and 'MAHI' [113], a mobile application that received glucose results via bluetooth signals from a monitor, established that such probes are affective in enabling reflection on health information.

Fish n' Steps [106], informs individuals of their own physical activity levels through a visualisation of a digital 'pet.' The system took inspiration from the Tamagotchi[12], which is a small digital device which requires users to look after a digital pet. In a similar fashion, Fish n' Steps used virtual fish which grew in size depending on a user's physical activity. Participants in an evaluation were able to reflect upon their own activity based on the size of both their own fish, and the fish that their friends were in control of. Likewise in a different context, the Ubigreen [53] application was a deployed on a mobile phone. Data from a GSM device, a MSP device (which includes accelerometer, light, compass and temperature sensors) [30] and participant feedback was sent to an animated wallpaper on the phone. The display illustrated the impact of frequent travel in cars, which is contributing to CO2 emissions. The wallpaper showed items such as trees (which grew leaves if a user used their car less frequently) and polar bears (whose iceberg melted on poor green activities). Participants were then able to reflect on their own habits.

The method of presenting information back to a user in these systems used abstract visualisations that represented the progress towards either a personal goal, or towards a social groups standing. However, while the visualisations provided are successful in their respective studies, it is perhaps not suitable in chronic health management. More accurate feedback is likely to be required as precise calculations are often required to form treatment doses (such as insulin).

4.5.3 Limitations to Interventions in Well-being Support

Careful consideration must be given while incorporating technological systems into a person's care. Those who have lower technical confidence and a lack of exposure to recent technology are less likely to be accepting of medical technology use [187]. Likewise, assurances must be given towards the security of systems, and that patients' privacy is not violated. Trust in a system is a key factor in long term usage of a personal medical information system [42].

[12]Tamagotchi - http://tamagotchilife.com/

Yet, interventions into assistive technologies must take care to not develop tools for which there is not a need [121]. Tools that may appear to be useful in the role of management must be thoroughly considered to ensure that they are indeed solving a problem that a group of individuals may be having. Similar concerns have been raised by other researchers:

> *"ensure that the proposed technical solutions address specific problems experienced in providing effective support for disease management."* [45]

> *"the data collected is of little value, unless it informs individuals and enables educated choices."* [115]

There must be a clear aim of any intervention into well-being support. The information gathered must be relevant to a user's personal goal, whether it is achieving a higher fitness level or obtaining tighter glucose control.

While the early part of this section has investigated previous research into general well-being applications, the remaining text will focus on systems that have targeted diabetes support. Gaining an understanding of the previous work in this area will help to further refine the research space defined in Section 3.5

4.5.4 Diabetes Support

Having looked at a number of different approaches to data capture in the general and well-being domains, it is now timely to investigate systems relating to diabetes and its management.

Integrating mobile phones into the management of diabetes has been viewed as a "logical progression" [110]. Systems which are based on a mobile platform have been found to improve average glucose scores over desktop based systems [128]. Mobile systems such as MySugr[13] and Cellnovo[14] are offering methods to assist in the management of the condition. MySugr provides users with a 'monster' which the users must 'tame' by achieving goals relating to glucose scores. The Cellnovo takes a different approach, and is more focused on offering seamless integration between

[13] MySugr - http://mysugr.com/
[14] Cellnovo - http://www.cellnovo.com/

glucose monitors, and insulin pumps. The device is both a glucose monitor and a pump control, removing the need for separate devices. The use of mobile phones in diabetes management offers two benefits, namely that the devices offer technically capabilities to record vast amounts of data and that users will not have to purchase new equipment to enhance their logging:

> *"Mobile technology is widely accepted in today's society and can be an effective tool for managing diabetes."* [110]

Mobile phones are not only useful within the context of logging. Froisland et al. [3] state that only 17% of teenagers in Norway with diabetes meet international guidelines for HbA1c[15] tests. Two mobile applications were given to 12 teenagers (between ages 13-19) over a 3 month period. One of the applications used photo imagery to represent exercise and food, while the other offered an SMS guidance system. Participants preferred the photo based method in the mobile diary which was found to be an important educational tool through reflections in action. This led to a change in participants' applied knowledge about the management of their disease. Accurate and controlled management of diabetes is also a concern:

> *"It can be difficult to remember to measure blood glucose when being busy at work, when playing with friends or when being at an exciting football match. The diabetics also pointed out that it is difficult to remember if, when and how much medicine has been taken."*[88]

Research has been conducted into methods of supplying education to those with diabetes via SMS messaging [46, 56]. Children and teenagers who are in the process of taking on greater involvement in their condition at times need support. Providing them and their families with information regarding the disease and adherence to monitoring and treatment eases the minds of everyone. Wangberg et al. [179] constructed an SMS messaging service that contacted parents of young children with diabetes. Those contacted were able to choose 'themes' of information to receive, with the parents regularly requesting information on how to deal with teenagers 'sabotaging their parents attempts

[15] HbA1c measures the amount of glucose that is being carried by the red blood cells in the body and indicates blood glucose levels for the previous two to three months. These tests are performed at a specialised clinic by professional staff

at diabetes monitoring.' Conrad and Gitelman [36] encountered a similar circumstance where a seventeen-year-old individual who was diagnosed with diabetes at the age of four, had grown tired of their condition. Subsequently the patient refused to perform glucose tests and instead used a control solution to fake the results.

Beyond monitoring, another common approach to managing diabetes is the control of food intake. An investigation into educating children on the relationship between carbohydrates and their diabetes, coupled with carbohydrate estimates contained in food was conducted by Glasemann et al. [62]. Estimating carbohydrate counting is challenging even for adults, with applications such as the 'Carbs and Cals'[16] application providing detailed libraries of estimations of carbohydrate content in food. Aware of the challenges of accurate carbohydrate counting, Glasemann et al. hosted a workshop attended by children with diabetes to gain insight into how children believe information could be presented back to them. The aim of the design session was to determine methods to provide better education of both the importance of carbohydrate knowledge and good estimations to values contained in food.

Using personal inputs is only one method of discovering possible influences of food. One approach [90] is to use the user's current location, through a mobile app, to identify nutritional information on food served at their location. This will in turn enable dietary decisions to be better informed.

Additional work has been conducted using mobile phones to aid people with diabetes during regular activities. Kanstrup et al. [89] developed 'Living Laboratory' which consists of a database that can provide immediate information on topics such as the food a particular restaurant serves.

Exercise is a third factor in the management of diabetes. Intense exercise, or uncharacteristically low exercise, can have a marked influence an individuals glucose levels. Research has been conducted on how mobile phones can assist in monitoring regular exercise activities.

Preuveneers and Berbers [131] are using mobile phones to capture location and activity to predict future exercise activity and alert patients to the potential impact on glucose results. For example, the system is able to detect that a person will regularly walk to work at a same time every morning and alert the patient that they will need to prepare for the trip by increasing their glucose levels.

[16] Carbs and Cals - `http://www.carbsandcals.com/apps`

The tracking of exercise is one approach to spotting long-term trends or repeating patterns in glucose levels. However, a broader approach can also be taken.

O'Murchu and Sigfridsson [126] are building an iPhone application for diabetes patients to assist in the process of spotting trends in their glucose results. They believe that it is the trends that are important to understanding the condition, rather than a list of result. Their future work will focus on integrating social network support and facilitating patient-doctor sessions to allow for more community support for people with diabetes, and a valued second opinion.

Contextual information about glucose results forms an essential part of the management of diabetes. Simply knowing a result is meaningless with knowing the situations that occurred around it. To provide a greater understanding of glucose results, a study [156] that introduced photography as an additional method of recording information was carried out. Patients were asked to take pictures of the food they were eating around the time a test was performed. An interface was then designed which colour-coded results (between low, normal and high) and allowed users to match food choices with resulting scores. The use of image data mirrors that of research conducted in Sections 4.1, 4.1.1 and 4.2. While this system was based on a desktop system, there is potential to extend the approach into the mobile device domain.

4.6 Summary

This Chapter has outlined the key research ideas surrounding the capture (a tool that generates a record of activities) and access (the process of presenting personal information back to a user) of personal information. The process of capture and access has also been used in general life-logging situations, and more specifically has seen interventions in long term chronic condition support. It is clear that many researchers believe mobile technologies have the potential to play a key role in assisting people with chronic conditions [3, 110, 126].

Yet there still exists gaps in the existing knowledge of the role mobile technologies can play in chronic condition management. Many of the previous systems and studies have concerned themselves with educational feedback or external support from peers and clinicians. It is perhaps unrealistic to rely on these support mechanisms to be immediately available to an individual at all times. There is a need then, for systems which allow for those with chronic conditions to capture then own information for the purpose of reflection on their own data.

However, capture of relevant information at convenient times has been viewed as a challenge (Section 4.5.3) and there exists a need to contextualise glucose readings (Section 4.5.4). Overall, mobile devices can contribute to long-term management but commercial systems (Section 4.5.1) lack scientific analysis of any published form, and indeed seem to ignore key issues identified in the literature (irregular entry (Section 4.5.3) and meaningful capture (Sections 4.1.1 and 4.2).

4.6.1 Next Steps

Having defined a research scope and begun to address the research aims set out in Chapter 1, this Chapter has reported on the existing works within the domain. While Chapter 3 has provided a base knowledge of management practices and the existing work has built upon that, there is still scope for deepening this knowledge. Therefore, the next Chapter will conduct further investigations into management practices of individuals with Diabetes before technological interventions can be designed in later Chapters.

Chapter 5

Understanding Individual Approaches To Diabetes Management

This Chapter builds upon the motivation set out in Chapter 3. There exists a potential to support people with diabetes in their management of diabetes by utilising the mobile tools that are ready to hand. While there has been previous research conducted into diabetes management within the HCI community, it is on a limited scale. This Chapter describes a user centered study in which individuals with diabetes were interviewed. The interviews sought to gain insight into the practices and processes involved in the management of diabetes. Obtaining a greater understanding of existing practice will allow for more informed design choices in future interventions into condition support.

5.1 Introduction

There has been a recent trend towards patients becoming more involved in management and treatment across a wide variety of conditions [55]. Those required to be involved in maintaining their own conditions have a wealth of information and factors to process and understand. For example, those affected by diabetes are faced with a constant challenge to maintain their glucose levels through tight management of food in- take and insulin dosing.

Chapter 3 described how devices such as glucose monitors form an essential part of this process by allowing patients to check the current level of glucose in their blood stream. This information can then be used to make future treatment decisions, such as adjusting insulin injection levels.

However, the results that the monitors provide are he consequence of previous dietary choices, exercise and other factors. Important contextual information such as food consumed and exercise performed (whether planned or completed) are also involved in the patient's treatment decisions and condition management.

As evident from Chapter 3, regular logging of information by people with diabetes appears not to happen on a frequent basis. In the previous Chapter (Chapter 4), existing interventions into personal health management were described. However, there currently appears to be a lack of full understanding into existing management practices. Understanding how people currently approach their own management is key to any successful future interventions. Therefore, the research conducted in this Chapter aims to gain a detailed insight into the existing management practices of people with diabetes. The potential for supporting these practices exists and to achieve this we have conducted a series of interviews with people who have diabetes. The interviews were targeted primarily at understanding the management strategies when treating diabetes and what challenges are faced.

5.2 Background

At present there is a lack of HCI research that directly investigates the understanding of management practices by people with long-term chronic conditions. HCI research into the management practices of patients who are involved in monitoring their own conditions has focused on diseases such as asthma [186] and diabetes [114, 115]. That specific research has revealed that patients often monitor their own actions in order to better manage their condition. Within the monitoring processes, there exist clear models of behaviour that individuals regularly exhibit.

Mamykina et al. [115] suggest that there exists a decision cycle which patients will proceed through when detecting changes in their condition. In her work, Mamykina describes the results of a series of interviews and long-term observations of a diabetes support group. Through a Grounded Theory [63] approach, it emerged that patients' must deal with a complex set of information relating to their health and that:

> *"patients often try to negotiate the compromise between the health and the desired actions."* [63]

Whilst these results are useful, they perhaps do not provide a deep enough understanding of daily, normal and unremarkable life with diabetes. There are perhaps more lessons to be learnt with the HCI community about how those with diabetes monitor, interpret and reflect on their personal health information in a maintained and frequent manner.

Axelrod et al. [7] conducted a series of interviews with patients, carers and stroke therapists, as well as 3 focus group sessions with members of stroke clubs. Their findings suggested that patients' motivation is a key element in repeating rehabilitation exercises that support recovery from stroke. The motivating factors varied from enjoying the activity, a necessity to maintain health and satisfy a partner's concerns. In the case of diabetes, depression amongst sufferers is a key concern. Gonzalez et al. have shown that those with diabetes who suffer from depression are more likely to give up on self-care sooner [65]. Their study asked patients about their previous week of diabetes self-care, and it was found that those likely to suffer from depression spent less time monitoring their blood glucose, less time exercising and were less likely to maintain a healthy diet.

Teenagers also demonstrate the interaction between management, personality and psychology. Toscos et al. [167] encountered a 'diabetes management battle zone' between teenagers with diabetes and their parents who were keen to ensure control of the disease was correct by the child. Efforts to bridge this gap and provide parents with reassurance and children with independence have been investigated by Wangberg et al. [179]. The authors developed a system which would alert parents to glucose monitor results via text message once a child had completed a task. This is particularly useful when the parents and child are separated, such as school times when parents must rely on other people to deal with the diabetes. So, a patient's life circumstances play a major overarching facet in their management strategy, and their personal experience of their condition.

However, local factors are also significant. The interpretation of individual results has been established as a context-sensitive facet during the everyday life of diabetes. The results from a glucose monitor are a 'snapshot' into how the body is currently acting. No indication is given of whether the glucose levels are increasing or decreasing, or how previous activities have impacted on the score. To provide a greater understanding of glucose results, one study [156] introduced photography as a means of capturing information to give context for glucose meters. Patients were asked to take pictures of the food they were eating around the time a test was performed. A software implementation for those with diabetes was then designed that colour-coded results (between low, normal and high) and allowed users to match food choices with resulting scores. However, this system was desktop based and as has been discussed in Chapter 3, those with diabetes are unlikely to regularly engage with such systems.

The contextual information is not only important to patients: clinicians also form a part of the management process. Providing information to clinicians can provide a platform for further education to patients regarding their diabetes management. Hela et al. [73] proposed a monitoring system for patients' houses that monitored activities such as activity and the times at which food has been eaten. From this data, clinicians will be able to determine adherence to health plans set out to the patients and highlight areas which are not being followed.

As described in section 4.5.4, the management practices of diabetes patients are not limited to the home. Systems to assist with the challenges of daily life, such as carbohydrate counting in restaurant food have been developed [89].

One caution we must bear in mind is that these ongoing research programmes, such as [89], are not yet complete, and results are not canonical. Others, such as [179] have been completed and indicate that the technologisation of diabetes self-management is not inevitably successful. Given the popularity of mobile phones, and of text messaging in particular, among teenagers and young adults, text messaging may seem to play a potentially useful role in managing diabetes. However, Franklin et al's 'Sweet Talk' SMS system, that explored this approach, did not improve compliance or control [50].

The existing literature, then, suggests that context of lifestyle, psychology and recent events all play a role in how a patient interprets each reading. The broader concerns of self-image and management strategies also apply across sets of readings, and previous research in other conditions suggests that issues of doubt and motivation influence effective management. However, this body of knowledge does not yet give sufficient insight to design and build predictably and provably effective tools that assist a patient's ongoing management of their condition. Indeed, the lack of successful final summative evaluation suggests that this is very much an open research agenda.

The goal of this work is to extend research on the role of context in managing diabetes, to arrive at a better view of how different contexts interact, and contribute to effective strategy. However, the existing literature in the area does not give a complete view of the existing practices that people with chronic conditions, such as diabetes, currently utilize. Mamykina et al.'s work [115] concerns itself with the monitoring habits of people with diabetes, rather than the broader concepts of day to day management. The work detailed some of the existing practices, but lacked detailed accounts of why these approaches were taken.

Therefore, before introducing an intervention into individuals' disease management, a more complete understanding of the complexities of the task are required. To achieve this, a user study has been conducted to reach this level of understanding. The following sections describe both the design and findings of the study, which informed the direction of this thesis.

5.3 Study Design

When approaching the design of the following study, several different methodologies were considered. Section 3.3 yielded useful early insights into approaches to diabetes management by people with the condition. While the data collected was useful in suggesting a research avenue, the information provided did not provide an understanding of *why* participants were engaging in the described activities. Previous work in the area by Mamykina et al. [115] used interview sessions and observations of support groups gather information, whereas Yun et al. [186] introduced technology probes to collect data from participants.

As diabetes is a condition that individuals must deal with throughout daily life, continuous observations are unfeasible. To constantly follow a participant would require significant time from the observer and extreme invasion of a participant's privacy. Technology probes could potentially gather information, however, a key concern of the participants in section 3.3 was the lack of desire for further technology to be introduced into their management. Finally, interviews appear to be the most suitable approach due to balance between time constraints and meaningful data collection from participants.

A semi-structured approach was used for the interview sessions to allow systematic addressing of the key issues suggested by the previous literature [104, 114, 186]. Additionally, the approach allowed for exploration of issues that appeared to be important for each interviewee, and also participants' own elaborations on the questions. As the work being conducted at this stage is focused with understanding existing practice, introducing probes may create an unnatural set of behaviours. While it would be useful to observe the tasks performed by individuals, it is both time-consuming and intrusive to the individual. Mamykina et al.'s [115] method of employing an interview strategy offers the benefits of focused discussions and less time commitment on both the researcher's and participant's time.

The research focus in this Chapter was to understand the role existing technology, particularly the glucose meter, played in the participants' self-management; how the interviewees decided and monitored where and when to check their glucose levels; how those strategies had emerged, what threats and changes disrupted them, and how they responded to, and managed, changes in their condition. By understanding these factors, a clearer picture will emerge of where opportunities for support may exist in regular management practices. The findings of this study will then be used in the future Chapters as a platform for designing appropriate interventions in personal management.

5.3.1 Procedure

In order to recruit participants for the study, emails were distributed amongst staff and students of Swansea University. The email requested people who had diabetes and made regular use of glucose monitors or if they knew someone who met the criteria. We also included a brief description of what the study would entail, such as; length of study and topics to be discussed (glucose monitoring habits and experiences). An incentive of a £5 gift voucher was offered to participants for taking part in the study.

Before attending the interviews, participants were asked for a location that they would feel most comfortable completing the discussions in. Personal offices and coffee shops were the preferred option by all participants. Given the potentially intrusive nature of the discussion (a participant's health condition) it was deemed that allowing the participants this option was most suitable. In order to maintain a feeling of an informal discussion, it was also preferred to conduct interviews in person as opposed to discussions over telephone or teleconference. This approach was also motivated by practical issues relating to the ability to facilitate data capture. The sessions lasted around 30 minutes on average.

5.3.2 Participant Information

13 participants (seven male, six female) attended the interviews with ages amongst the participants ranging from 19 - 65 (average age 46). Participants were asked which type of diabetes they had, nine had type 1 diabetes and four had type 2 diabetes. It is estimated that 10% of people with diabetes are sufferers of type 1, whereas the remainder suffer from type 2. The high proportion of

Participant	Gender	Age	Years with diabetes	Type
P1	Male	65	6.5 years	2
P2	Male	53	2.5 years	2
P3	Female	47	36 years	1
P4	Female	55	29 years	2
P5	Male	64	12 years	2
P6	Female	64	35 years	1
P7	Female	40	36 years	1
P8	Male	54	45 years	1
P9	Male	30	19 years	1
P10	Female	23	21 years	1
P11	Male	19	6.5 years	1
P12	Female	21	12 years	1
P13	Male	20	9 years	1

Table 5.1: Details of participants that attended the interview sessions

type 1s in our participant pool is likely to be a result of the request for people who make regular use of glucose monitors. Those with type 2 diabetes are not required to monitor their sugar levels as tightly; their body is resistant to insulin and their sugar levels can often be corrected through lifestyle choices. However, those with type 1 diabetes are unable to produce insulin at all and so to accurately dose themselves with the correct insulin amount, they require the glucose results to inform treatment choices.

In the results section, participants are referred to by using an anonymous numbering system. A list of participants with demographic and health information can be seen in table 5.1.

5.3.3 Analysis Method

During the interviews, extensive notes were taken by the researcher conducting the sessions. In additional to this, participants' consent was requested to allow for the audio from the session to be recorded for further investigation. Each interview was subsequently listened to again to both confirm the accuracy of the notes taken during the session and provide an opportunity to detect potentially interesting points that were missed during the initial note taking.

Once a complete data set had been obtained, the information was analysed using a thematic analysis [18] approach. Sections of individual transcripts that had similar meaning were condensed into smaller descriptions, which formed the coding process. Once all transcripts had been coded, similarities across participants were highlighted then grouped together to form themes. The themes that emerged from this process were then validated by again comparing to the original data gathered from the interviews.

5.4 Results

Upon completion of the study, several consistent themes emerged across the individual responses from the interviews. This section outlines the five most prominent themes that were discovered. Together, these themes cover the main elements of the participants' experiences during their own management of diabetes.

5.4.1 Monitoring

All thirteen participants stated that they performed some form of monitoring, yet the level of monitoring varied greatly. Participants P4 and P5 never looked back at previous results, whereas P6 would only check back on previous results if they *"lost track of what is going on"*. The majority of our participants, however, undertook some form of diary logging at some point, most notably in the lead up to a clinic visit.

For example, P2 stated that his monitoring intensified at particular times in the year, often for a week. These intensive monitoring spells were brought on by a personal desire for more information, or his partner's concern that P2's health may be worsening, and when GPs requested additional testing on the lead-up to a scheduled clinic visit.

P10 made use of a 'tagging' feature that her monitor provided; she had the ability to mark results as pre-meal and post-meal. She was then able to upload her scores into a computer program which enabled her to compare different results with each other. Other participants appeared to only engage in reflection of a sequence of results when they experienced unexpected results from their meters:

> *"If I can't decide why it was high, just keep an eye on it for a couple of days to see if it is a recurring problem."* - P6

P6 also expressed a wish for an ability to mark results which are unusual to themselves, rather than labelling a result as good or bad based on a clinical scale.

Attitudes towards dealing with glucose results varied throughout our participants, P5 had particularly extreme views on his own condition:

> *"I have more pressing health issues, so I tend to ignore the diabetes, even though I know it will be a problem in years to come."* - P5

Alternatively, P12 was extremely keen to log all aspects of her activity from glucose results, to food eaten and unusual situations that occurred. P12 noted that situations such as exams greatly impacted on her glucose levels factors such as stress and adrenaline are known to alter body chemistry sufficiently to impact blood glucose levels.

P12 described that moving onto a continuous insulin delivery therapy had greatly impacted on the frequency with which she monitored. She described how, when first using the continuous pump, tight glucose control was necessary, and this led to regular testing every 2-3 hours. P12 stated that they *"Never really got out of the habit"* of this intense regime. So, the demands of complying with clinical procedures, and the repetitive nature of this regime, leads to the formation of supporting habits.

5.4.2 Habits

The participants frequently described their own personal habits and rituals that are involved in, and emerge from, their management processes. P8 went to the extremes of tightly controlling the types of food he ate, portion sizes and times of the day at which he eats, *"I don't get any surprises this way."* Despite being offered a more flexible meal plan by his clinic , after forming his own management style over 45 years he felt that his current style was predictable and he suffered fewer *"surprising sugar results."*

P3 also noticed changes in management style, stating that using injections led to a strict food schedule. Types of food eaten and the time at which they were consumed were based on the insulin injections that had previously been performed. Food intake was also a concern of P5, who had eliminated foods with high carb values as a method of controlling glucose levels.

Intensive monitoring was described by P2 during the interviews, and they indicated that they had been recommended to use monitor less. P1 stated that

> *"Monitoring is a bad way of controlling diabetes, this is responsive whereas it should already be controlled through good eating and exercise"*

Perhaps this is why P2 has been discouraged from monitoring as frequently. As stated in Chapter 3, glucose results are the end result of previous activity and purely dealing with glucose results is similar to dealing with a problem once it has already occurred, rather than preparing.

5.4.3 Confidence

When asked about whether they had a good idea of their glucose levels before performing a test, only participant P5 stated that he was rarely sure what his result would be before testing. The remaining twelve participants indicated that the majority of the time, they had a good idea of what the result would be. Performing glucose tests at specific points during the day has resulted in participants being in tune with how their body is feeling and translating that into glucose scores.

Participants then changed their insulin doses and manipulated their glucose levels in anticipation of future events. Such an example was described by P13, who discussed his approach to preparing for visits to the gym, indicating that to account for the body using up sugar during exercise, he would knowingly push up his glucose levels to prepare.

Yet this confidence in the control of their condition is only maintained providing 'normality' continues and there are several factors that can remove the confidence from participants. For instance, P2 has a consistent glucose 'spike' during late morning that is unexplained by both him and clinicians despite his attempts to determine the problem. He described this as a disappointment, a sentiment which was echoed by P4:

"sometimes when I haven't eaten anything I shouldn't have, I still get a bad result and I get disappointed."

Yet this participant could handle bad scores when she had eaten known bad foods, as this provided an explanation that she could attribute the scores to.

Twelve of the participants described that after a prolonged time dealing with diabetes, their bodies become tuned to undesirable situations and that often they sense something is wrong, and consequently perform a glucose test to confirm that belief. However there are situations where this sense can be lost. P3 had been suffering from diabetes for 36 years, and had achieved an extremely tight control of glucose. Sadly. her body became acclimatised to sugar levels which were slightly low, but healthy. Subsequently she her symptoms did not present themselves so noticeably when her sugar was approaching dangerously low levels, and she now has to rely entirely on a glucose monitor to indicate where her sugar levels are. As a result of long–term diabetes control and keeping sugar low, P3 has now lost Hypoglycemic symptoms, Hypoglycemia is a situation that arises when blood glucose reaches dangerously low levels (the opposite condition, Hyperglycemiais a result of sugar levels which are too high). The loss of these symptoms has removed a safety barrier that the participant previously had and to compensate for this loss, they have greatly increased the number of glucose tests they perform in a day.

The breakdown of long-term habits would often cause participants to lose some of their confidence in managing their condition. P9 described attending a session aimed to improved glucose control, but with a different approach to what he had been used to. While he felt comfortable with the changes, he noticed stress amongst other attendees who were intimidated by performing new calculations to their insulin doses. He described that people who had diabetes for several years were able to form their own management style and that the new approach would represent a major change in their daily monitoring and treatment. Concerns about insulin doses and calculations were also highlighted by P4:

"I have problems with the insulin calculations, they scare me a bit in case I get them wrong."

5.4.4 Unusual Situations

Perhaps the main issue that caused the greatest shift in participants' management of their condition was when they were put into situations that differed from what they described as normal days. P1 indicated that

> *"the weather can affect testing, humidity and heat give the same impression as a hypo so I perhaps test more frequently than is needed."*

P7 experienced problems with glucose control during a walking holiday. In order to prepare for the holiday, P7 sought advice from her clinicians as to how best to alter her insulin treatment to account for the increased exercise from walking. An increase in activity leads to glucose in the bloodstream being used up as energy, hence lowering glucose levels at a faster rate. Therefore, an individual will need to account for the lower glucose levels in their insulin dosage calculations. Subsequently she was advised to halve Basal[1] doses and keep Bolus[2] doses as normal. Yet during the holiday P7 found that this style was not suitable for her and her sugar levels were frequently too low. As a result she experimented with her treatment until she found an optimal strategy. P7 expressed regret that she had not kept a record of what solution she found, as she had since forgotten it and would likely have to go through the same process during the next holiday.

One participant took great care to log unusual events, P12 stated that exams caused her great amount of nerves and stress, which in turn increased her adrenaline levels. This change in body reaction greatly affected her glucose scores and in order to account for the changes, P12 kept detailed records of what had been previously done to correct glucose levels to ensure that she did not lose her glucose control during these times as she could employ strategies that she had already created.

Whilst holidays and exam periods are infrequent and easily remembered, everyday situations that occur can sometimes be overlooked. P13 had concerns about casual exercise, such as rushing to a lecture that had already started. Running or cycling fast to make up for lost time would use up

[1] The role of basal insulin, also known as background insulin, is to keep blood glucose levels at consistent levels during periods of fasting.

[2] A bolus dose is insulin that is specifically taken at meal times to keep blood glucose levels under control following a meal.

more glucose than an ordinary trip would, yet insulin levels would rarely be adjusted to account for this. P11 echoed similar sentiments:

> *"Sometimes when I play football I don't correct my insulin injections after meals as I forget that played sports earlier in the day."*

Therefore, variations, regular or occasional, occur within an individual's treatment management, and this leads to uncertainties that focus the patient's immediate attention on diagnosing and correcting erroneous glucose scores, before refining their management practices. Where patterns are established in the patient's mind – e.g. P11's experience of football – reassurance is easier to find. However, when P7 faced a new situation, interpretation was more difficult, and she now has lost the knowledge that she had gained. Such omissions to capture previous experience led to feelings of regret and some anxiety about future episodes.

5.4.5 Concerns

P1 was worried that high glucose levels are harder to detect in terms of how their body was feeling, but *"perhaps this is where the most damage is occurring."* Conversely, P1 saw the opposite – low sugar scores – as an opportunity for a potential treat *"Low glucose scores means I get to have a chocolate bar!"*

Performing glucose tests in public was a worry for several of participants, with P12 finding the greatest difficulty. Testing whilst in the company of friends and family was not viewed as a problem. However, being in public would often cause her to hide her test as much as possible, usually performing inside a handbag to give the illusion of looking for something. Situations such as being in a lecture hall caused further problems, as the lecture theatres she attended had sloped seating, the people behind her could potentially see what she was doing leaving her feeling self-conscious. An additional factor that discouraged her from testing in public was people around her having bad reactions:

> *"lots of people will ask what I am doing and I tell them I have diabetes, then they get a bit embarrassed and don't know what to say."*

Participants P2 (*"it is a fiddle"*) and P4 (*"people look at you"*) also shared concerns about performing glucose tests in public. This suggests that some participants may in fact prefer discreet and hidden interactions with their devices that are simple to perform in order to avoid standing out from the crowd.

P2 was one of the participants who took a high interest in his results and would regularly perform trend-spotting in previous results. Whilst this made him feel comfortable most of the time, he felt that too much testing is not an optimal strategy and was subsequently having a negative impact on his health:

> *"the constant worry about results can push up my blood pressure."*

The issues of worry, and potentially depression amongst people with diabetes were discussed in Chapter 3. High blood pressure was also highlighted as a general concern for everyone, but P2's worries were a result of the risks of high blood pressure being increased in those with diabetes and that the risk of complications from either condition are raised.

5.5 Discussion

Monitoring styles are usually born out of recommendations from clinicians. Various participants made reference to the impact that doctors and nurses at their clinics had on the number of times they performed glucose tests each day. P12 highlighted the point that once the clinicians had suggested a monitoring structure to her, she felt it was easier to just carry on with the regime as it was simpler than discovering something for herself. She described this behaviour as *habit* that provided her with confidence that she was in control of her condition. However, all participants described situations where results were not as they expected. Factors such as weather, food, illness, stress and holidays were all highlighted as scenarios that would force them to re-evaluate their treatment decisions.

It became apparent that there was a sequence throughout the management practices undertaken by participants. Monitoring would (almost) always be the starting point, as it is the key factor in the management of their condition. Some participants also undertook more intensive monitoring, such as taking note of food intake and tracking levels in preparation for exercise. The repetition of

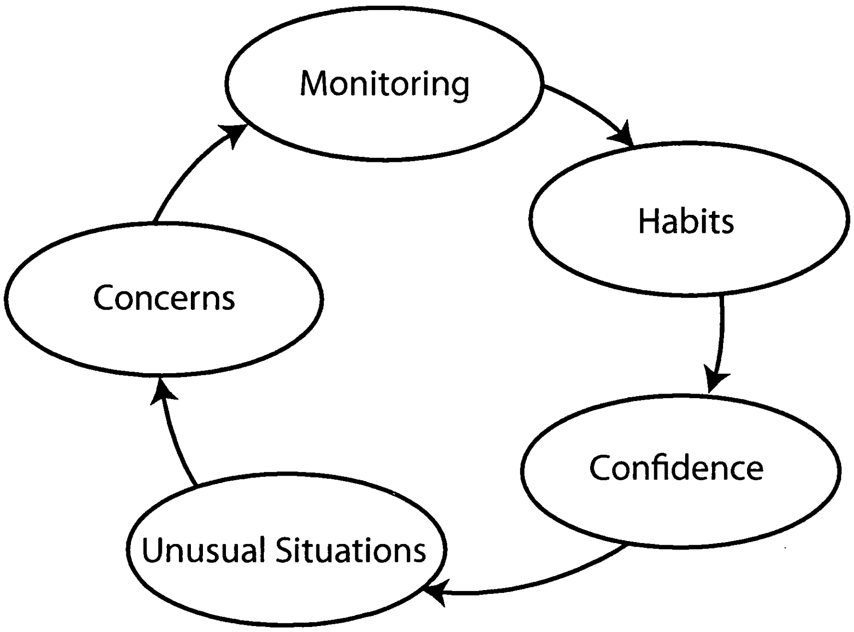


Figure 5.1: Diabetes Management Cycle.

everyday situations led to habits being formed, from testing at set times in a day through to having a rigid meal plan. These habits presented participants with a feeling of confidence that they were in control of their sugar levels and that they could deal with 'normal' days and events that would affect their glucose levels.

However, *unusual situations* outside the patient's normal routine would often produce unexpected glucose results and in turn, potentially unknown treatment requirements. Small factors – such as a particularly hot and humid day – could give the illusion of the body having low sugar levels, which would lead to more frequent testing as the usual safety barrier that participants had become accustomed to had been removed. Such exceptional circumstances undermined confidence, and led to a desire to explain and understand the situation. This often included referring back to previous events, and comparing to similar readings or contexts in the past.

Following the definition of the themes, and the relationships that exist between them, the *Diabetes Management Cycle* was defined. This model of behaviour during the management of diabetes is based on the findings conducted in the study described earlier.

Through every stage of the management cycle (Figure 5.1), some form of self-reflection occurs. The participants described situations at each of the five points of the cycle where some form of monitoring was being either recorded, or earlier situations and glycemic measures recalled. In turn, this information was used to judge and interpret the current context. This pervasive reflection shaped the future behaviours and progression through the cycle, with the most pointed need for evaluating the information occurring in the 'unusual situations' phase.

Mamykina et al. [115] suggested that the decisions undertaken by people with diabetes were the result of monitoring and attributing changes to particular actions before modifying behaviour based on observations. The feedback from the participants in this Chapter suggest that there are more factors involved, such as habits, confidence, unusual situations and concerns.

The data that collected during the study in this Chapter indicates that there are two significant behaviours when reflecting on previous glucose scores. Results taken from an ordinary day are often recorded and rarely checked back on, instead the more intensive reflection occurs when unusual situations arise. These exceptional situations could be simple things such as illness up to more complex scenarios including holidays.

Li et al. [104] suggested that there are two main phases of reflection: maintenance and discovery phases. In the 'Diabetes Management Cycle' (Figure 5.1), habits and confidence would fit in the maintenance phase, whereas unusual situations and concerns would present a shift into a discovery phase. The monitoring theme of the proposed model may bridge the two phases of Li et al.'s phases depending on what level of confidence or concern patients would be experiencing.

Li et al also suggest methods to support each of their two phases. The recommendations for supporting their discovery phase are particularly relevant to the research agenda of this thesis. The key suggestion for supporting discovery is to collect and retain as much data as possible at a low cost to the user. Based on the responses from the participants in the interview sessions, and the past research in the area, a set of requirements for mobile interventions in self-management can now be defined.

5.5.1 Requirements for Self-Management

The study revealed a cycle of activity within diabetes self management, and the issue of measuring their glucose level naturally pervades the entire cycle.

One key constraint that emerged from the discussions was the need for privacy. Most of the participants noted issues arising from conducting glucose tests in public and therefore any technology aimed to support diabetes management should be discreet and unobtrusive. Due to the extensive and ubiquitous nature of mobile phones, an everyday object that would not raise issue from surrounding people, they provide a suitable platform to facilitate and support the management process.

As highlighted in Section 4.5.4, systems have previously been developed for mobile systems targeted at providing support for diabetes management. However, these systems largely consist of those that lack empirical evidence [126] or were based on devices that pre-date the current smartphone era [131].

A further argument for using such an approach is the outcome of research conducted to assist teenagers suffering from mental health problems, that helped capture their mood and experiences [116] (described in more detail in Section 4.5.2). This data was then to be used during the teenagers' regular psychotherapy sessions, to understand progress with their condition. A key finding was that adherence to completing the diary logging was improved when the participants were using a mobile phone as opposed to paper based logging. Hence, despite the earlier failure of diabetes mobile services [50], this route still seems to be viable, and to match participants' need for discretion.

There is existing work on using mobile phones to support 'reflective thinking' of results conducted by Mamykina et al. [112, 113]. As discussed in Chapter 4 the research focused on providing support to diabetes patients in their understanding of information through assistance with peers and clinicians. Data gathered by participants was reviewed by clinicians together with the patients, to facilitate a formal review of the patient's management strategy. Whilst this is a crucial point in the learning process of diabetes, there exist opportunities to support patients when they do not have access to external support. As seen from the results of the study in this Chapter, reflection occurs when a patient is dealing with the daily streams of information they gather, between clinical sessions.

The key moments around *unusual situations* appear to be the crux of the management of most interviewees. Their interpretation of the situation requires a capture of recent and past context. and interpretation of both experience and knowledge. Logging, mental- and written-notes all contribute to this, but being systematic is a challenge. Mamykina [111] defines this process by considering the notion of *"breakdowns"*

> *"Individuals are forced to 'problematize' many of their established routines, such as shopping and cooking, participating in social events, and attitudes toward stress or exercise. With time, new behaviors become settled as new routines, which no longer cause breakdowns. However, the time of transition between one set of routines to another presents considerable challenges to the individuals and opportunities for support with technologies."*

There exists, in fact, an extensive basis of existing work on mobile tools for self-management on which the research in this thesis can build (Section 4.5). Those with diabetes need to reflect on events from some time previously, but this requires regular logging and other forms of context-capture. The original information capture is secondary to the immediate management task, and must, consequently, be conducted with a minimum of effort. Extensive capture enhanced by the interpretative support of medical specialists can be helpful - but this may omit the contextual information that people with diabetes use to interpret their current circumstances. Making sense of various factors like place, time, and trends all need support.

5.5.2 Changes to Research Approach

During the early stages of the interviewing sessions, concerns were expressed by participant P2 regarding the terminology used by the interviewer. The term *'diabetic'* was seen as labelling people by their condition, rather than someone who simply has a condition. Based on the feedback from this participant, great care was taken to eliminate such terms from all future studies conducted and forms of writing resulting from the work. This was viewed as an issue of great importance in order to maintain a good relationship with participants and avoid the potential for offending individuals.

5.6 Conclusions

This Chapter described a series of interviews that sought to further knowledge and understanding of the management practices employed by people with diabetes. After analyzing the comments made by participants, five themes were identified that form key stages during the management process: monitoring, habits, confidence, unusual situations and concerns. It also became apparent that there exists links between each of the stages and Section 5.5 described the 'Diabetes Management Cycle' (Figure 5.1) which demonstrates the progression through each theme that has been discussed.

It is possible that technology can provide a supportive role during this cycle to enable further logging of actions and reflection on the impact changes will have on glucose control. Having explored the possibility of employing mobile technology to fulfil this role and suggested a set of requirements that any system should adhere to for successful uptake by individuals. Participants in both the study described in this Chapter and in Chapter 3 have discussed the issue of dealing with multiple devices. The transfer of information between glucose monitors to paper or computers adds an extra burden. Additionally, interventions which highlight a person's condition are also to be avoided.

The ultimate aim with this research is to understand what impact the addition of contextual information will have on patients' self-reflection during unanchored settings. To achieve this, future interventions must fit within an individual's own comfort levels, both in terms of physical handling and allowing for discreet methods of interaction.

5.7 Summary

The work in this Chapter has contributed to the research aim "Understand devices currently in use and how they are used in practice" as introduced in Section 1.2. The research conducted built upon the earlier study described in Chapter 3 and further extended the understanding of the management processes that people with diabetes are frequently engaged with. The study concludes the formal investigations into management practices with diabetes and the research focus for the remainder of the Thesis will now focus on technological interventions that support chronic condition management.

5.7.1 Next Steps

This Chapter has outlined work undertaken to understand the challenges faced by individuals during the diabetes management process. The feedback received from the participants suggested a workload burden when having to constantly deal with glucose testing, insulin calculations and logging of information. While it is unfeasible in this body of work to change practices in glucose testing and insulin calculations, it is possible to provide support in the final aspect of diabetes management.

When considering the Health Belief Model [78] (full discussion in Section 4.4), there exists barriers to active health engagement. With logging of information potentially being seen as having little benefit, and a cumbersome process, it is likely to be rarely carried out. As can be seen from the participants in this study, few of the individuals commented that they frequently record results, or look back upon them. If a potential barrier to this process is the cumbersome nature (writing on paper, storing paper etc.), then there is a design opportunity to improve this process.

The following Chapters (6, 7 and 8) describe the design and evaluation of mobile based applications targeted at providing lightweight methods of recording and interpreting health related information.

Chapter 6

Designing Support for Diabetes Management

This Chapter describes the design of a mobile application, named *'ConCap'* and this activity forms part of the research aim "Design appropriate support for health condition management practice." By using the findings of the previous two studies described in Chapters 3 and 5, the application ConCap has been designed and implemented to provide the most suitable methods of information capture that are relevant to health management.

6.1 Introduction

Several themes emerged from Chapter 5 suggesting the potential need for greater capture of information relevant to diabetes management. Those with diabetes need to reflect on events from some time previously, but this requires regular logging and other forms of context-capture. The original information capture is secondary to the person's immediate management task, and must, consequently, be conducted with a minimum of effort.

Extensive capture enhanced by the interpretative support of medical specialists can be helpful - but this may omit the contextual information that those with diabetes use to interpret their current circumstances. In this chapter, the idea that on-demand contextual information has the potential to support immediate self-reflection for people with diabetes is thoroughly investigated. As mentioned previously in Chapter 5, there are several streams of information that affect the overall control of glucose values, but typically, only a handful of types are permanently recorded. Whilst glucose values are permanently stored on the designed measuring devices, other highly relevant information is less likely to be recorded. Capturing more of these relevant streams of information has the potential to allow patients to quickly spot factors which are affecting their glucose levels and both correct their levels and make note for future occurrences of the same problem.

6.2 Background

As described in Chapter 3, people with diabetes have a limited set of tools that facilitate accurate recording of the variety of factors that are important to their management. Glucose monitoring devices capture blood sugar results and individuals often resort to paper based logs to record a vast array of information. This process can lead to a large collection of paper which may make interpreting the data into something meaningful a difficult task.

Perhaps a key factor in the apparent lack of logging of information is the difficulty in the maintenance and entry of paper based records. As noted in Chapter 5, not everyone who has diabetes completes a comprehensive history of their own information. It is likely that the time and effort to maintain such a record is just too much of a burden. Add to that the challenge of many instances of information across many different physical objects, processing the data may also be a daunting prospect. It is possible then, that the process of entering data onto paper is detracting from the main aim of management, to understand the data:

> *"may also detract from organic memory processes by compromising how we process incoming information"* [86]

Frequent and complete recording of information has been found to not always be put into practice by individuals. Despite patients reporting that they comply with set practices, in actual fact few people actually engage in the process. Research has suggested that adherence to paper based recording of health information is not always optimal. After surveying 80 participants with chronic pain, it was found that full paper diary logs were reported to be completed by 90% of adults, but in fact only 11% of participants in a study adhered to advice [159]. Adherence to logging of personal information is potentially highly dependent on the attitudes of individuals:

> *"One could argue that only the most compulsive would actually complete a 7-day diary"* [12]

Paper, while useful for writing, is problematic when large quantities of records are kept. As seen in Figure 3.3, the amount of information that can be entered onto paper is often limited, in an attempt to keep a sufficient level of legibility on the paper. The space on the paper is finite and to avoid cluttering, which could lead to mis-interpretation, only four days‘ entries are able to be entered on each sheet. This contributes then, to a large set of paper once a period of logging in undertaken. Additionally, paper requires writing implements, such as pens, which increase the amount of things an individual must keep on them at all times. An increasing practice is to replace paper based systems with mobile devices, such as using mobile phones to write and manage shopping lists.

Mobile phones are becoming increasingly ever-present on a person, and are now considered as a personal trusted device [117]. The technology capabilities also offer opportunity to support the logging of information. This potential could be realised by making use of the devices people already keep on their persons, mobile phones could offer support in this context. As highlighted in Chapter 3, several modern glucose monitoring devices are offering more support in the capture of relevant information. This further extends to allowing for the contextualisation of information, stating whether readings were taken before or after a meal. However, there is potential to extend this capture further. By using the devices that people have on them increasingly, such as mobile phones, a much richer record of factors relating to diabetes could be achieved.

It has been noted that clinical success should not be the only measure of an appropriate intervention into personal healthcare [9]. The clinical perspective should be supplemented with considerations on how technology may impact on a person's everyday life. Patients who have been managing chronic conditions are likely to have formed their own routines, the observations in Chapter 5 defined this as 'habits.' Habits provide individuals with reassurance and predictability, however disrupting good routines by introducing technology may cause a lack of uptake in their usage. Adding in a large scale tertiary device seems inappropriate and perhaps, interventions must be made on a smaller scale.

One approach that has been attempted to capture rich information in a lightweight form was to use photo imagery alongside glucose reading results. Smith et al. [156] developed a visualisation that

Design Choice	Supporting Evidence
Chart Visualisation	Matching with existing presentations of health information as discussed in Chapters 3 and 5
Use of Pictures	Previous HCI research [54, 112, 156] have integrated photos as a means of health management support for the purpose of discussion with external sources (such as clinicians)
Use of Location	[133] Location data has been found to support episodic memory [85, 87], and this may be necessary for individuals to attribute causes behind glucose scores
Icon Design	Designs for Glucose and Insulin buttons based on real-world representation, remaining icons follow general conventions for icon design
Platform Choice	Participants in the studies described in Chapters 3 and 5 stated that they rarely used desktop based management systems, and instead often used their monitors to view information. The immediate availability of these devices is potentially a key reason for this action and therefore, the platform of choice was mobile based.

Table 6.1: Design decisions take as part of ConCap development.

displayed a timeline of images and glucose results, which had been colour-coded based on their healthy status. Similarly, Mamykina et al. [112] used a mobile intervention to allow for people with diabetes to gather data about their condition for the purpose of feedback from peers and clinicians. Both systems were well received by those who were involved in trials, and recording of information onto the systems was in keeping with the monitoring participants performed. However, both of the applications required a desktop based system to present information back to the user, and as such still required some form of aggregation from a participant. The work conducted by Mamykina et al. was also made use of pre-smartphone era mobile phones and modern devices offer far more functionality than that of their predecessors. There is an opportunity to provide immediate feedback to a user on the same device that is performing the data collection.

6.3 System Design

Previous research ([54, 112, 156]) into the area of supporting management of long-term chronic conditions has used technology which requires centralisation of information to be conducted by the user. Therefore, there exists an avenue of exploration around how to provide meaningful support in a suitable, single device platform.

In order to assess the potential impact that rich media data may potentially have in supporting patients' reflection, the application 'ConCap' was designed and implemented. ConCap is a system that allows a user to enter glucose scores and insulin units before presenting the information onto a visual graph. In addition to this, the system also allows for photographs to be taken using a device built-in camera and gather location information which is presented as a map snapshot. Rich media such as images and location have been implemented in self-reflection systems previously, with responses from participants being favorable [67, 133]. However, these systems were not focused on chronic disease management and the systems that made use of these features [112, 156] in this domain were desktop based.

As mentioned, ConCap allowed users to take photos using the camera on their mobile phone. Including images in diabetes has been successful in previous research [54], yet the images captured in previous studies have typically been on separate devices, and required collation on a central device, such as a desktop computer. ConCap will allow for the images captured by users to automatically stored and displayed alongside the health data entered.

As well as including imagery data, the application also offers the ability to capture a user's location at regular intervals during the day. Location data has been seen as a useful tool in pervasive health applications [92]. By using such data, people will be able to track where they have been throughout a period of time, which in turn may allow people to recall what activities were performed. For instance, if an application indicates that a user had been close to a gym address, the user may then be able to recall that they had performed an hour of exercise.

Paper based record systems typically present data using a table visualisation, as seen in Figure 3.3. Research has shown that graphical representations of data outperform those that are in a tabular format [5]. As discussed in Chapter 3, many glucose monitoring devices manufacturers are creating desktop based systems for data management. These systems show data in a graphical format, using a line chart approach of glucose values over time. In order to maintain consistency and align with the concepts that people with diabetes are already familiar with, the ConCap system uses a similar approach.

Likewise, the devices that individuals use frequently offer averages of glucose scores over set periods of time, typically 7, 14 and 30 day averages. These ranges match the existing features available on glucose monitoring devices as described in Chapter 3. These features were included to align the feature set to that in which participants would already be familiar with. ConCap also provides a feature that allows users to define their own range to view averages over. Users of the system can enter a number which will present the average glucose scores for the given number of previous days.

The ConCap application created not designed to replace existing habits that participants already had in their management, or to provide clinical assistance. Instead, ConCap acts as a platform to capture daily activities and to display information relevant to diabetes management in an appropriate fashion. The system was designed to be an extension to the practices already performed by people on a daily basis and to also act as a supplementary glucose reading logging mechanism. The aim of the application was to assist in the trend-spotting and understanding of causes behind glucose scores by capturing daily activities and using media data.

6.3.1 Scenarios

To represent how the application ConCap may be used, the information gathered from the study in Chapter 5 was used to compile potential usage scenarios. The usage scenarios were used as guidelines throughout the design of the ConCap application.

Lucy has had type 1 diabetes for 15 years and checks her glucose values typically around four times a day. She has recently decided to start attending the gym, in an effort to improve her fitness. Unsure of how the increased level of exercise will impact on her need for insulin, she begins to keep a record of her glucose scores and location on her mobile phone. Using this data, she can correlate the occasions that she was at the gym and how much it affects her glucose scores. She can then make more accurate future decisions about how much insulin is required on days she attends the gym.

George is a type 1, he has had diabetes for 7 years. He feels his control is very good and has reached a level where he rarely has any unexplained glucose events. He recently attended a paint-balling session with his friends and has another similar event approaching. His glucose control on the previous occasion had been almost perfect, he had estimated his glucose requirements correctly when calculating his insulin dose. Using his mobile application, he cycles through his history and finds an image of his friend in paintball gear. He can now view both his glucose and insulin values for that day, and has an accurate guide on how to approach the upcoming event.

While the scenarios suggest how the applications may be used in a real world setting, they are not expected to be a comprehensive indication of the expected outcomes. As seen in previous Chapters (3, 4 and 5), each person is likely to have an individual approach to their own management. Therefore, accurately predicting how the application may be used is perhaps unfeasible. Yet, the scenarios provide a crucial link back to the research conducted previously. The design of the application relied heavily on both the previous literature in the area and the data gathered from the interviews in the previous chapter.

6.4 System Implementation

A key design consideration that was at the fundamental during the creation of the application was the findings of Fishkin and Wang [47]. They put forward that in order for ubiquitous systems to gain acceptance, they need to be functional, flexible, robust and easy to use.

ConCap allows for the input of 4 distinct types of information:

- Glucose values - A numeric input which is plotted as a line graph
- Insulin values - A numeric input which is plotted as a line graph
- Photographs - Using the phone camera, users are able to capture moments they feel are important enough to remembered, small thumbnails are added to the graph
- Location - Regular location updates illustrate a user's travels during the day. Users can also force a location update and small thumbnails are added to the graph.

Type 1 diabetes accounts for at most 10% of people with diabetes (Chapter 1). While Apple's iPhone device is popular, it is less prevalent than the Android platform [34]. Given the challenge of obtaining suitable participants, choosing the more popular platform will reduce the risk of finding too few participants for a study of our application.

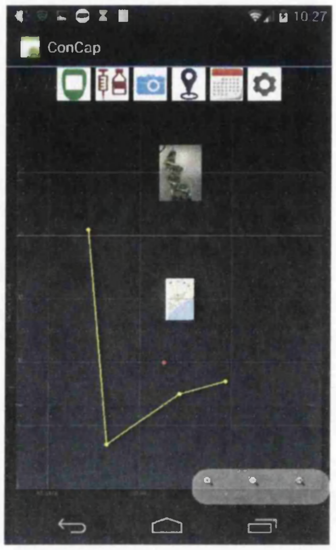
The main screen of the application can be seen in Figure 6.1a, the displayed graph makes use of the achartengine [1] open source graphing library for Android. Several modifications were made to the library in order to support the addition of thumbnail images in the correct location on the graph. The thumbnails could be viewed by pressing on the graph at the location of the image, this would then change the view of the application to a full screen version of the image captured. An example of this process can be seen in Figure 6.1c which displays a map and indicates the location of the participant using a pointer.

By including the image and location information, accurate representation and relationships between a glucose score and captured image could be achieved. Graphs of information are employed by glucose monitor manufacturers in both their home-based applications, and the ones used within a clinical setting for the visualisation of glucose scores. In order to maintain consistency with expected features from the participant pool, a similar approach was used in the ConCap application. However, unlike the systems currently in use, the ConCap application allowed for further forms of information deemed relevant by a user to be captured alongside glucose and insulin information.

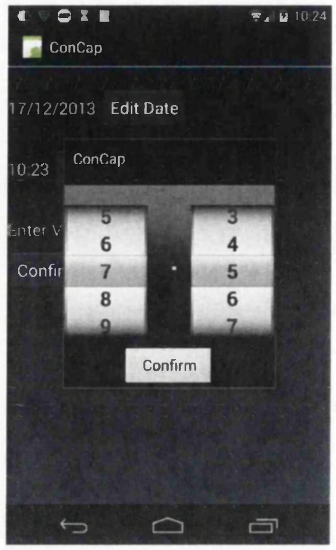
The ConCap application also provides additional functions beyond the presentaiton of a chart. As seen in Figure 6.1, above the chart are six buttons which each perform key functions within the application:

Glucose Entry - A screen which allows users to enter blood glucose values into the application. Data entry is achieved by using spinner class containing numeric values. A spinner class allows for a rotating display of numeric values achieved by swiping through the available values. Such an approach aligns itself with previously conducted research into number entry [125], suggesting that this method is both accurate and sufficiently quick to enter. An example of the input method can be seen in Figure 6.1b.

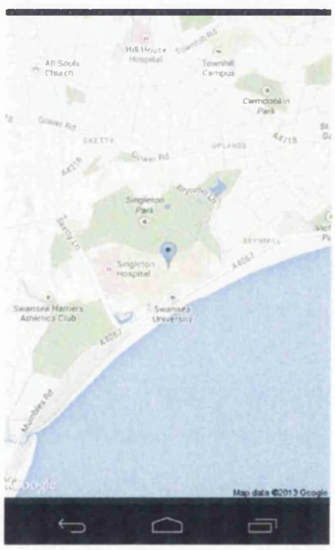
[1] achartengine available at `http://www.achartengine.org/`



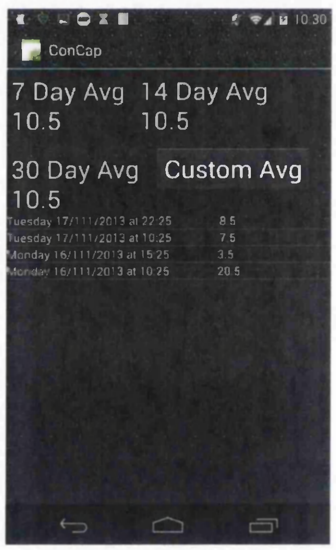
(a) Entry screen used to input information



(b) List of all entries made in chronological order

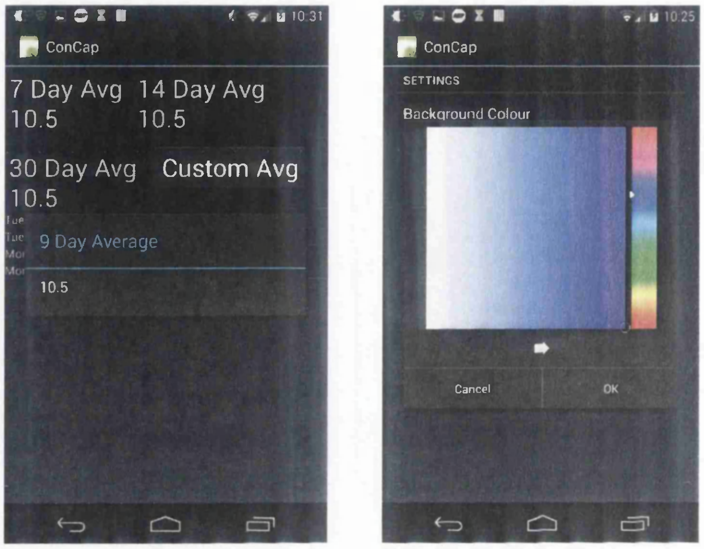


(c) Chart used to visualise information



(d) Screen to present statistical information

Figure 6.1: Screenshots of ConCap application



(e) Visualisation of user tag information

(f) Chart used to visualise information

Figure 6.0: Screenshots of ConCap application continued

Insulin Entry - Like the glucose screen, the insulin entry system uses a spinner widget to allow users to select a number of units of insulin that they have taken. However, unlike the glucose entry class, the insulin input offers values up to 2 decimal places.

Camera Entry - By pressing the camera button, the application opens the native camera system on the mobile phone. Once an image is captured, a smaller scaled copy of the image is created to be displayed on the chart. The original image is stored for full screen viewing.

Location Entry - Should the user wish to capture their location outside of the automatic location tagging, the system will retrieve a map representation of their location. Similar to the camera, a smaller version of the location image is shown on the chart, with a larger version stored for viewing.

History - This view shows a list of entered glucose values in a textual form and can be seen in Figure 6.1d. In addition to this, the 7, 14 and 30 day averages are constantly displayed. This view also includes a button to view an alternative number of days average. Once this number has been picked, a pop-up with the result is displayed (Figure 6.1e).

Settings - Customisation of the chart is offered in the settings page, with users able to edit the colours used for the graph background, glucose line and insulin display. The colour is picked using a widget, which can be seen in Figure 6.1f.

The system also has support for a list of previously entered glucose values and a range of average values. This visualisation of the information matches closely with the sequential nature of viewing past results on a glucose monitor.

Location information was polled at hourly intervals during the study between the hours of 7am and 11pm. However, map thumbnails used to represent the location were only downloaded while the mobile device was connected to a Wifi network. It was considered that frequent pulling of online images would have too large of an impact of participants‘ monthly data allowance, potentially incurring additional costs. The background capture of location information acted separately to that of user entered location actions.

6.4.1 Initial Pilot Study

Prior to deploying the system into a full user study, a small pilot study was conducted in order to ensure the stability of the application while under real use. The application was used by a test participant over a 7 day period. The participant was a 34 year old female who had been diagnosed with type 1 diabetes at the age of 14. During the 7 day trial, the participant made use of the application to ensure the robustness of the system. Any bugs or errors that occurred were reported back to the researcher so that a solution could be implemented as they happened during the trial period. In response to the feedback received during this pilot, several fixes were issued to ConCap, leading to a more robust application. Issues such as errors during data entry and duplicated images upon saving were rectified during this period.

6.5 Summary

This chapter has described the design of the mobile application ConCap. The implemented system was motivated in its design by the findings from both the study results in Chapters 3 and 5 and the research literature that exists in the area. ConCap has been designed around the idea that immediate capture of information can assist in chronic condition management. Specifically, through the use of rich media, in a lightweight fashion, the application should fit within existing management practices. In the following chapter, the ConCap system is deployed in a field study to asses the usage of the system in a real world context.

6.5.1 Next Steps

As this Chapter has introduced work to meet the research aim "Design appropriate support for health condition management practice," it is now logical to change focus to the final research aim: "Capture the impact of new technology solutions on people's understanding and management of health conditions." The following Chapter outlines Study 3 (as described in Chapter 1) and presents the findings of a longitudinal evaluation of the ConCap application with a set of individuals with diabetes.

Chapter 7

Exploring Mobile Context Capture in Daily Life

This Chapter introduces the first of the two longitudinal technological deployment studies described in this Thesis. The previous Chapter described the design of the ConCap application, a system that provides lightweight methods of information capture for diabetes management. The study in this Chapter forms part of research aim 3: "Capture the impact of new technology solutions on people's understanding and management of health conditions."

Diabetes management is a complex task, that takes place across variety of situations and locations. This means that employing lab-based evaluations of the ConCap application may not capture a true representation of real-world usage. This Chapter describes a longitudinal field study in which the ConCap application was deployed with 12 people with diabetes. The participants used the application over a 4 week period and included the application in their existing management strategies towards their diabetes.

7.1 Introduction

The ConCap application was designed to support the highly complex management of diabetes during everyday life. Therefore, to understand how the ConCap application would be used in real world situations, a long-term deployment in which the application would be used frequently was undertaken.

By conducting a longitudinal study, several insights can be gained regarding the use of the ConCap system in a real world setting. Firstly, an understanding will be gained as to whether the ConCap application can meet the needs of people with diabetes. Although an understanding was gained in Chapter 5 about existing management practices, it is unclear how an tool such as ConCap will be accepted into the daily habits of people with diabetes. Through a field study, a clearer understanding will be gained about how mobile interventions are accepted as a tool in the management process. Finally, it may also be the case that the mobile system may introduce new behaviours from the participants in their recording habits of their information.

The previous work in supporting individual well-being (Chapter 4) has largely focused on systems that require some form of external interventions, such as clinicians or family members. There currently exists little knowledge regarding how mobile applications can support a person's own reflection on their health information. From the responses gathered from participants in Chapter 5, it is clear that people with diabetes often have to deal with challenging situations outside of clinical appointments. In these cases, people with diabetes have to calculate their own treatment decisions based on current, and past information.

The motivation behind this study therefore, is twofold. Firstly, the primary aim of the research is to approach an understanding of how mobile interventions can support self-reflection on personally gathered health information. Secondly, the study sets out to contribute additional knowledge to the domain of mobile well-being support without external intervention.

7.2 Study Methodology

To evaluate and understand the affect of the ConCap application in the management practices of people with diabetes, a four-week user study was conducted. This section outlines the design and approach taken to this study.

7.2.1 Procedure

In order to evaluate the appropriateness of ConCap in assisting diabetes management, the study will take the form of a four-week longitudinal study. Participants were asked to use the application to both enter data (such as glucose scores and taking pictures) and reflect on the data presented back to them (such as location and images). Data collection through the course of the in-situ study was obtained through from a database that stores values throughout the application. This database, along with images captured during the study, was collected at the end of the study. By capturing this data, it was possible to determine what factors participants considered to be important to the management of their condition. Participant consent was sought before accessing images taken using the application. In order to protect participant anonymity, the names that appear in this section are not those of the actual participants.

Only experienced users of mobile phones were recruited onto the study, in order to avoid learning effects and general unfamiliarity with devices. Although these technologies affords individuals an opportunity to increase their health literacy, a minimum level of proficiency is necessary before users can effectively use the system resources to manage their illness [91].

In order to ensure participants remained active during the study, regular contact 'checkpoints' were used. In addition to entry (start of week 1) and exit interviews (end of week 4), contact was made with participants at the end of weeks 1, 2 and 3. The weekly contact involved short telephone conversations, arranged at a time convenient to the participant and in all except one instance, exactly seven day after the previous contact.

At all times throughout the course of the study, participants were informed that any subject they are not comfortable with discussing would be omitted from the study and that they should not feel embarrassed at any stage during the discussion. Participants were informed that the study was not an evaluation on their ability or knowledge, instead it was an evaluation of the impact the application may have on the management of their condition.

During the interviews, note-taking and audio recording were used to capture data. Permission was requested from participants for audio recording to take place for the purpose of later analysis. On one occasion during the entry interview sessions, a participant requested for the interview to be stopped, due to the individual experiencing a hypoglycemic event. In this instance the audio recording was suspended and the researcher accompanied the participant to a local convenience store to allow them to purchase some food. Once the participant felt they were able to carry on, the participant was led back to the study room and the session resumed. The audio recording was resumed at this point and the discussions that took place outside of the recording have not been included in the results. The primary concern at this time was to ensure the well-being of the participant and not to gather research data.

7.2.2 Entry Interview

The individuals who replied to the recruitment emails were requested for an hour of their time and to attend an initial interview session at University College London Interaction Centre (UCLIC). In three instances this was not possible and the session was conducted through a video call. When participants first arrived at the session, a brief outline of the study was described. Following this participants were asked to read through a series of rights they were entitled to during the study, as well as signing a consent form indicating that they were willing to take part.

The entry interview session aimed to understand the current management practices of our participants. Participants were asked for evidence of their existing recording habits (whether this be paper, computer or none). This provided an understanding of the habits already in place for each of the individual participants. During the analysis of the feedback obtained at the end of the study, the information from the entry session provided a foundation to build upon. Demographic information was also collected at this stage and an introduction session as to how to use the application was also held.

Participants were then asked about their own diabetes management and the approach that they undertook and how the artifacts they presented were a part of the process. These questions formed part of a semi-structured interview style which allowed for both detailed accounts of specific parts of interest from the researcher's perspective, and allowed for embellishment by the participants. As had been discovered in Chapter 5, there exists a wide variety of approaches to diabetes management and there was a risk that a rigid question format may have missed highly relevant information relating to the study. By allowing participants the freedom to continue discussions in a manner in which they were able to lead part of the discussions, a clear picture of their own practices was achieved.

7.2.3 Exit Interview

As with the entry interview, participants were requested to attend UCLIC for a post study interview. Four participants were unable to attend this session and alternative arrangements were made. Three interviews were conducted using a video conferencing system and the final session was conducted at the participant's place of work.

The exit interviews focused on participants' perceptions of how useful the application was in the

Date 28/12/2012 Fri

	BGM	Bolus	Site	Carbs	Food / Comments
00 - 01					
01 - 02					
02- 03	11.5				
03 - 04					
04 -05					
05 – 06		8	6	100	Noodles
06 – 07					
07 – 08					
08 – 09					
09 -10					
10 – 11					
11 – 12					
12 – 13					
13 – 14	7.9	5		60	3 toast Jam
14 – 15					
15 – 16					
16 – 17	13.4				
17 – 18	9.0				
18 – 19	9.4				
19 – 20					
20 – 21	13.4	8	L	200	Pizza (160) + yoghurt, choco
21 – 22	9.1	9	L		
22 – 23	7.2				
23 - 24					
	Total	30		360	

Basal time	21.00
Basal dose	19
Injection site	B

Sleep hours	[illegible]
Total sleep	7
Trimovate	
Amitryptaline	
Contact lenses	

Figure 7.1: Participant 5 method of recording information at entry interview.

management of their condition. This session again took the form of a semi-structured interview. Questions focused on obtaining qualitative feedback from participants about the application features, ease of use and perceived impact on management on condition. In addition to these factors, participants were also be asked to describe how they used the features of the application. The use of images could vary from capturing food intake, to symbolising activities or well being. Likewise the location system could be used as a passive assistive tool for reflection, or a diary of places visited.

Participants were asked to explain each of the images that they had captured during the four weeks of the study. By requesting participants to detail the reasoning behind individual images, an insight into context that an image represented was achieved. Additionally, the meaning that the image represented to the participant at the time of the interview session was also understood. By gathering this information, it was possible to gain knowledge into the role that images played in participants' diabetes management. As images are a simple form of capture, the participants could capture a

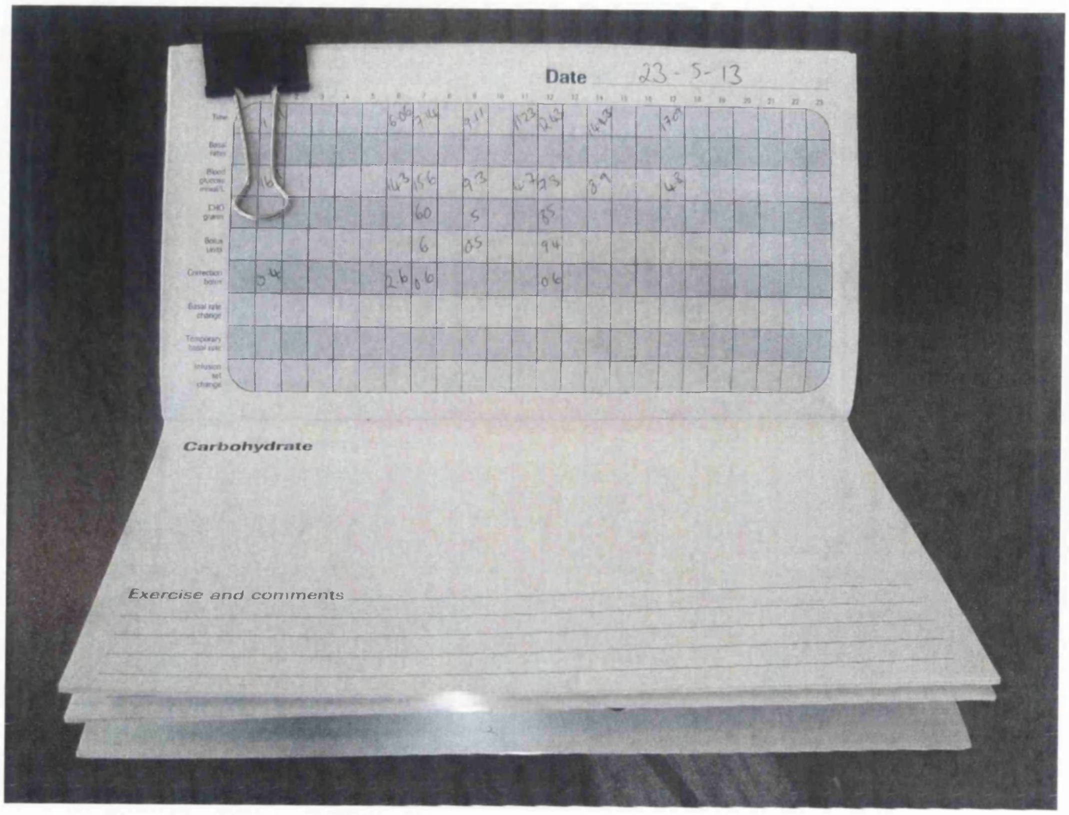


Figure 7.2: Participant 7 method of recording information at entry interview.

wide range of information that they deemed relevant to their blood glucose levels.

7.2.4 Research Questions

The aim of the application is to answer the research questions posed earlier in this document:

RQ1 - To what extent does the immediate availability of a mobile phone and subsequently our application impact on the recording of glucose results (compared to paper based diary logging)?

RQ2 - To what extent does the addition of contextual factors to glucose scores allow for greater understanding of the cause of individual glucose scores?

RQ3 - Does an immediate visual representation of glucose scores highlight points of interest to participants (such as unexplained trends)?

RQ4 - Will the application be used most heavily during 'unusual' situations that are outside of ordinary activity?

RQ5 - To what extent can the he application prompt users of forgotten previous activities / clarify information about activities?

These research questions will be used in order to evaluate the impact the ConCap application might have on patients' diabetes management. During the later discussion of results, the outlined criteria above will be reflected upon.

7.2.5 Participants

A total of 12 participants were recruited for the study, all of whom had had type 1 diabetes for a period of 2 years or longer. There were 7 female and 5 male participants, whose ages ranged from 21 - 56 (average age of 32.25). In total, the participants in the study had been living with diabetes for a total of 201 years (average of 18.27, standard deviation of 10.4).

All of the participants were regular users of glucose monitoring devices and had access to mobile phones with the Android operating system. All of the participants had been regular users of the Android system for at least one year. To protect the anonymity of the participants, they have been assigned false names which will be used during the remainder of this section. A full overview of the participants who took part in the ConCap study can be seen in Table 7.1.

7.2.6 Analysis

The interview sessions formed the primary area of analysis, with each serving different purposes. The entry session was designed to understand an individual and their existing attitudes and management practices of diabetes. During the exit interview session, participants were queried regarding their usage of the ConCap application during the four-week long study period.

During each interview session, notes were taken throughout which acted as both logging of important pieces of information, and as pointers towards notable points in the audio recording. Upon completion of the study, the first step in processing the data involved returning to the notes to gain a brief understanding of how each participant used the ConCap application. To enhance this understanding, the audio recordings of the interview session were listened to in an attempt to gain further

ID	Name	Gender	Age	Time with Diabetes	Insulin Pump	Actively Records
1	Joe	Male	37	20 years	Yes	No
2	Naira	Female	28	27 years	No	No
3	Sarah	Female	44	18 years	No	No
4	Paul	Male	37	7 years	No	Yes
5	John	Male	34	21 years	Yes	Yes
6	Hayley	Female	27	12 years	No	No
7	Matt	Male	56	44 years	No	Yes
8	Ruth	Female	25	22 years	Yes	No
9	Julie	Female	23	13 years	No	No
10	Holly	Female	21	7 years	No	No
11	Lauren	Female	28	15 years	No	No
12	Mark	Male	27	17 years	No	No

Table 7.1: Details of participants that took part in the ConCap four week field study.

insights. This process also allowed for double-checking of the accuracy of the notes, and to obtain exact quotations, which were transcribed from the relevant sections from the audio recordings of the interviews. Using a similar method employed by Chen et al. [4] during their own long term deployment of a system, each participant was treated individually and their own use of the system was kept separate from that of the other participants. As had been found in Chapter 5, there exist several different approaches to diabetes management. As such, participants were kept separate and individual stories of usage were created.

ConCap also logged a variety of information during the study which allowed for confirmation of the descriptions given by participants. The application recorded all of the glucose and insulin information entered by the participants, as well as the images captured and the locations (either manually or automatically). From this captured data, participants' daily interactions with the application can be determined. The application also logged instances when participants opened the application without entering any data. This provided a database with a set of log data which enabled triangulation with reported incidents and behaviours discussed by participants in the interview sessions.

7.3 Results

Over the four week study, participants entered a significant amount of data into the application. A summary of individual behaviours can be seen in Figure 7.17. There were, in total, 1008 glucose entries and 593 insulin values entered, as well as 106 images captured and 144 locations tagged during the course of the study. Daily inputs to the application averaged across all participants are as follows: glucose 36.00, insulin 21.18, images 3.79 and 5.14 locations were entered into the system database.

Unfortunately, information from Participant 10 (Holly) was partially lost from the database stored on their mobile phone. The information presented in the rest of this section is based on the limited amount of information retrieved from this particular device along with the feedback provided during the interview sessions.

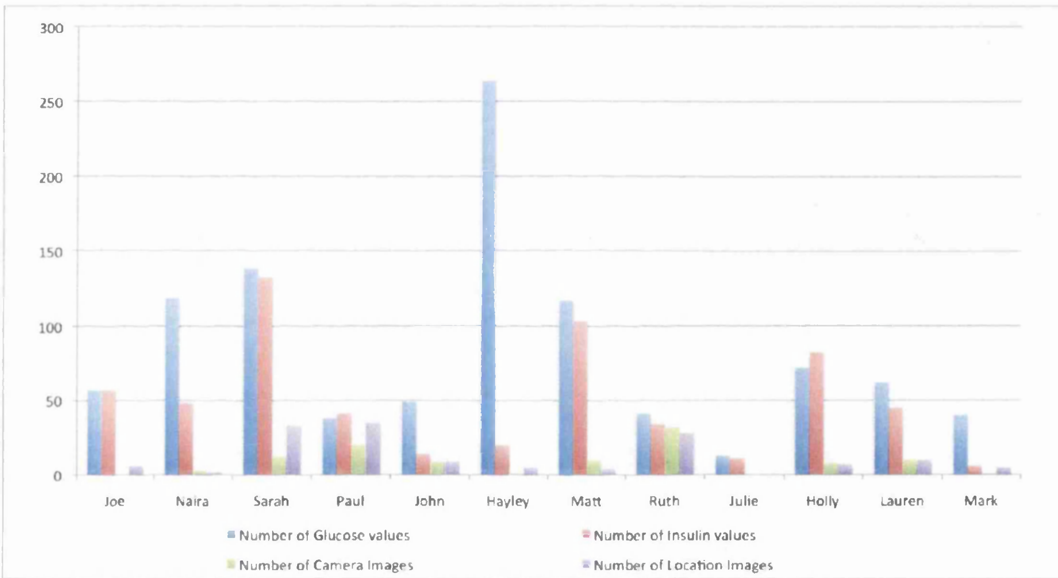


Figure 7.3: Participant total data entries during the ConCap study period.

In the remainder of this section, an overview of each individual participant is given. The subsections briefly outline the findings from the entry and exit interviews, as well as the data retrieved from the application. There were a variety of behaviours observed and recorded and it is important to illustrate how such an application is used by different people. Once the participant summaries have been concluded, I then look into the potential similarities that exist across multiple participants and how the application may be used more generally.

7.3.1 Joe

Joe was a 37 year old male children's diabetes nurse who considered his personal control of his own diabetes to be *"perfect."* He had been diagnosed with type 1 diabetes for 21 years and had been using glucose monitoring devices throughout that period. Due to the longer term impact of diabetes, Joe had been moved onto a regime of using a continuous insulin delivery system and had been using this system for 10 years. This system had contributed to Joe's confidence in his diabetes control, for instance his continuous monitoring system sounded alerts if his blood sugars were approaching a level that is too low.

Typical glucose monitors, as a result, saw their daily usages be reduced to twice a day due to the continuous delivery system also offering blood sugar readings. However, more accurate readings acquired from a normal blood glucose monitor were still required. Joe performed blood sugar tests before his breakfast meal in the mornings and an before evening meal. While seemingly used not that often, the twice daily uses provide more accurate data at highly important times of day and readings taken at fingertips typically provide more accurate readings. These results were then added to the continuous monitoring system that Joe wore. However, Joe also mentioned that he would perform additional glucose tests if he felt unwell, or if he disagreed with what his continuous system was indicating.

Joe also stated that his continuous monitoring device allowed him to upload his results to a cloud based storage mechanism. The upload of this data is automatic once he plugs his continuous monitor into his computer, though he admits this service isn't used as frequently *"as I probably should."* This suggests that his checking back of results does not occur as often as would be deemed 'correct,' yet this may be because of his own assertion that he was satisfied with his knowledge of diabetes, which is likely to be extensive due to his profession.

During the study period, Joe generally entered his glucose readings into the application twice a day, as that matched with pre-existing testing regime. The information was entered at the time of a reading, to avoid the potential of forgetting to enter the data at a later point in time.

Joe didn't find the location information that useful as a result of only using a glucose meter twice a day. These tests were typically performed in the morning and after an evening meal, which resulted in the tests being conducted within the home *"99 per cent of the time."*

Joe mainly used the application for the 7, 14 and 30 day averages that were provided. This feature was the most commonly used by Joe, who had previously stated that he relied on the information gathered by his continuous monitor which was uploaded onto a cloud based storage. Joe stated however that this information was rarely used by himself and was primarily a tool used to collect information for clinic visits.

> *"Averages are definitely something I should be concerned with, as they are indicative of what my HbA1C is going to be."*

Joe stated that the averages were usually under 10, which is Joe described as a *"pretty standard month."* So, the application may not have been used as frequently due to Joe being in a comfortable period of diabetes management.

7.3.2 Naira

Naira was a 28 year old female who had been diagnosed with diabetes in 1986 and started using glucose monitors in 1992. She described herself as being a housewife at the time of the study, as a result of her having a young child to look after. The recent addition to the family had shifted her personal focus away from her diabetes management, to the care of her child. As a result of this, her current control was not as good as it had once been and her glucose levels had been creeping upwards.

Figure 7.4: Participant 2 (Naira) captured an image of a Thai takeaway. The image assisted in the understanding of the impact the type of food had on blood glucose levels and insulin requirements.

> *"During the day I test test test and then once the little one went to bed I entered information into the app."*

Naira was described herself as being *"mostly at home"* during the study period, as a result of looking after her child. As a result, the location tool on the application was rarely used as it did not provide information that was unknown or likely to be useful at a later point in time.

Naira stated that she took several pictures using the application. Unfortunately however, she had accidentally deleted several of images during the study, so at the exit interview only had 6. The feedback gathered during the exit interview suggested that she mostly took pictures of food and meals:

> *"I thought it was nice, having the food next the glucose and insulin. I could figure out the carb ratios later on."*

By engaging in the process of aligning food content with insulin values, Naira was using the application to determine whether insulin intake was the correct amount for specific meals.

> *"For instance, one time I had Thai and took too much insulin. The next time I had Thai I knew to take less. I've got it now, I have sussed it out."*

Naira saw this as the primary role that the application could play in her own diabetes management, stating that *"it helps in that way"* while describing the understanding of relationships between meals and insulin requirements. Additionally, the application was used to assist in the understanding of how exercise was impacting on blood sugar values:

> *"I went to the gym and took pictures of the equipment I was using, that way I knew how the exercise was affecting my sugar levels."*

During the study period, she felt she was able to spot trends in her glucose results, mostly based around insulin calculations. Additionally, Naira also felt that it was easier to perform trend spotting on the application over paper, with the images providing information regarding meals. Naira felt the benefits of using the application were the ability to enter information on the go, in her own time and supporting her own memory of previous activities

Naira used the application on her husband's phone which led to restricted times of use. This led to interactions typically happening in the evenings. However, Naira stated that should she have access to a suitable phone her interactions would have occurred more frequently, typically at the time of a glucose reading or insulin dose. Another factor that would have seen Naira continue to use the application was the advantage it held over paper based forms of recording:

> *"The little one couldn't get her hands on the application like she could with paper."*

During the exit interview, Naira expressed her eagerness to carry on using the application and suggested that her application had become the point of envy for a friend of hers:

> *"I showed it to my friend and she was jealous, she really liked the graphs and I said yeah they are great, but you can't have it!"*

Naira spoke positively about the visualisation used to represent the glucose and insulin values entered. However, she did not make great use of the camera and location functions offered, stating that she was usually engaging in similar activities day on day, and that it was not worth highlighting occurrences that were frequent and repeated.

7.3.3 Sarah

Sarah was a 44 year old working as a production director at a book publisher. Her diagnoses of type 1 diabetes came in 1995, meaning she had had diabetes for 18 years at the time of the study. She described herself as having *"pretty good control"* prior to the application development. Her most recent visit to the diabetes clinic appointment had resulted in a HbA1C value of 6.7, which she was pleased with.

During a typical day, Sarah performed glucose tests usually four times a day; in the morning, at lunch, before dinner and before bed.

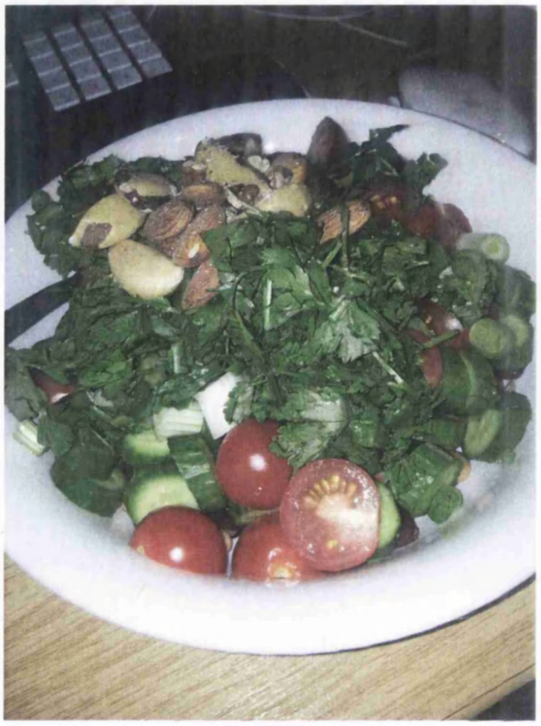


Figure 7.5: Participant 3 (Sarah) captured an image to represent lunch time meal, which was represented a typical meal for that time of day.

Whilst using the application, Sarah noticed that the average on the application (6.8) differed from the average on her monitor (6.2). However, during the session Sarah stated that she used a second monitor whilst at work, and that may potentially be the reason for the discrepancy between the data. This highlights the challenge of making sense of information across several data platforms as information could potentially be stored on multiple devices.

> *"I entered results every time, except when it was rude to get my phone out and then I would retrospectively add them in."*

Sarah initially used the image feature during the early phases of the study, however her use of the tool decreased. As Sarah had a well established routine, the addition of further information provided little value to her. During the entry session, Sarah stated that she regularly controlled what she ate and this subsequently impacted on her use of photographs during the deployment phase:

> *"I tend to eat the same foods, so it wasn't information that was useful to me."*

However, Sarah did find value in reviewing the glucose information in a graphical format:

> *"Sometimes when things are going well, you don't really realise it. When you see it on the graph, you are kind of please with yourself."*

Sarah was the only participant who stated that the graph provided her with a sense of satisfaction in her diabetes control. But, the graph also highlighted points where her glucose scores were not so well controlled:

> *"I had one score of 32 which went off the chart and that was scary."*

Sarah described how the application was useful to her during times that were outside of the ordinary, such as going out and visiting friends:

> *"If I was anywhere off my usual routes, I did try and put those in. I did mapping much more at weekends, when I was doing something unusual."*

The location service was used to assist in the process of remembering activities performed and Sarah also stated that she used the graph in this process:

> *"I have a good memory. But sometimes I might forget when I last took insulin or when a particular hypo was. It was useful to see those on the graph."*

7.3.4 Paul

Paul was 37 year old male who was the most recently diagnosed of the group of participants in this study, having be diagnosed with type 1 diabetes in April 2006. He described himself as having *"very good control,"* yet expressed concern that this was getting worse. Paul's worked as an Auditor and stated that he was fascinated by numbers and took great interest in his glucose values. Very good hypo-awareness and generally a good idea of where his blood levels were.

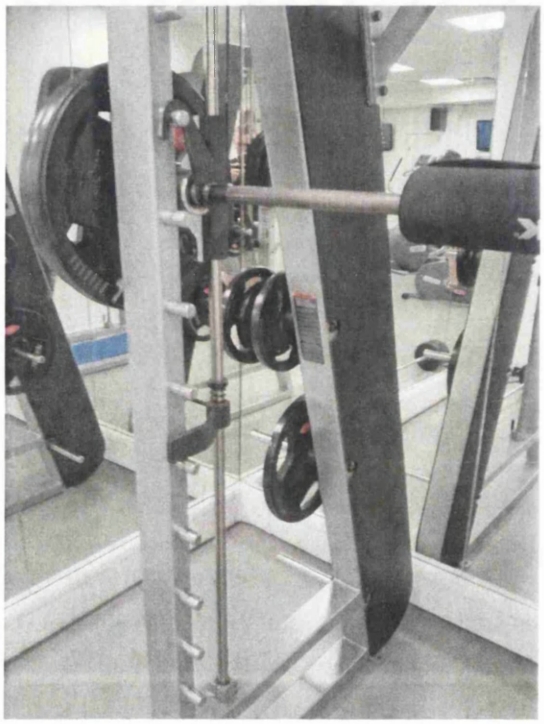


Figure 7.6: Participant 4 (Paul) captured an image of gym equipment, used to illustrate exercise.

Paul captured a variety of images with ConCap for several different reasons. For instance, Figure 7.6 shows the inside of a gym, and in particular a piece of equipment. During the exit interview, Paul stated that this image was used as a reference to the physical activity that had been performed. He had a general routine that he followed whilst at the gym, so had a firm idea about the amount of energy he expended. The image was taken to highlight the reason for particular insulin dosing decisions were not erroneous, but in preparation for the increased levels of activity.

During the study however, Paul's level of monitoring altered due to alterations in his lifestyle:

"I certainly did more testing the first two weeks than I did in the preceding weeks, and the weeks following."

During those first two weeks, Paul stated that he had typically performed *"between 2 and 4 tests a day, closer to 4."* and during this time he achieved averages between 5.4 and 5.6. However, the following two weeks of the study saw Paul *"revert to type a little bit'* and reduce his testing to once a day. During the interview, he stated that his averages had increased in the lead up to the exit interview: 30 day average 5.6, 14 day average 5.9 and 7 day average 6.8. The numbers had increased due to a change in Paul's monitoring habits. Due to a busy period of time at work, rather than testing at random times during the day, Paul had only tested to confirm his own feeling that his sugar was at a high level.

"I wanted to give you as much information as I could. But also, I had become a little blasé about testing my blood sugars and I relied on what I felt rather than what the machine was telling me. It's always good to reset that bias."

Paul also highlighted that the platform the application was deployed on had an impact on the frequency of his entering of information:

"I entered my results at the time, your phone is always with you so it's easy to do."

By having his phone on him at all times, Paul did not need any additional devices or artefacts to carry with him at all times. Yet, Paul did not make use of the photograph or location information often during the study period:

"I didn't use it that often, but occasionally when something interesting happened I took a photo."

The few times that Paul used the photographing capabilities of the application, he had done so to capture information that he had deemed interesting. These interesting instances include the hypoglycemic event illustrated by the images in Figure 7.7

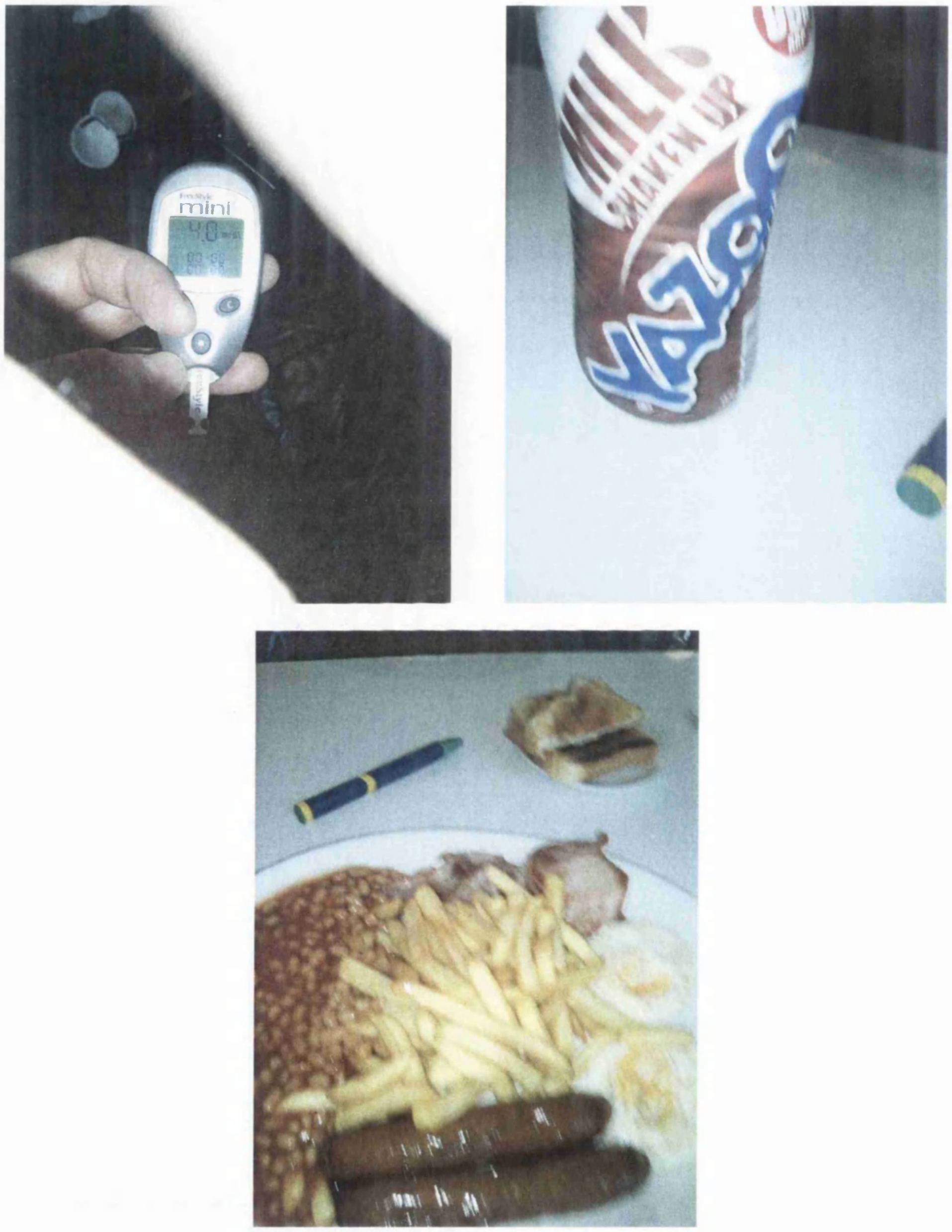


Figure 7.7: Participant 4 (Paul) illustrating the process of dealing with a night-time hypoglycemic event and the steps taken to correct blood glucose values.

7.3.5 John

John is a 34 year old male who had been diagnosed with type 1 diabetes in May 1992. At the time of the study, John was working as a heating engineer. He described his diabetes control as good, but indicated that in the weeks prior to the study he felt his control has become *"less good."* Overall, he control over his diabetes had been so successful that while taking part in pharmaceutical studies, he had been described as an 'expert patient.'

However, John described the challenge of continually dealing with the management of his diabetes:

> *"It's always with you diabetes and unlike other conditions, it is very much down to the patient to treat themselves, rather that the doctor. You get guidance, but you have to do things everyday and make decisions relating to your blood sugars and insulin."*

> *"It (diabetes control) is often cyclical with me, when you have time to remember it or you go through a good patch and then other things take over and you can go through a less good patch. It's a 24/7 condition, that requires a lot of willpower and decision making the whole time."*

This suggestion by John of a cyclical pattern matches with the diabetes management cycle defined in Chapter 5 (Figure 5.1). He also described the process of self-treatment and the need to maintain a wealth of information to be able to make accurate decisions about treatment.

At the entry interview, John provided an example of the paper based methods of recording that he occasionally completed. However, the process was one that was not performed on a rigid basis:

> *"I don't do these everyday. My life would probably be better if I did"*

During the study period, John typically used the application to capture information relating to his food intake:

> *"I think where the application is useful for someone like me is when I eat at someone else's house or where nutritional information isn't available. The photographs and location can be used to verify what you have eaten"*

However, John also expressed concerns about fitting the application into his diabetes management:

> *"If I am being honest, I don't think the photographs and location are essential to me and the way I think about things. But I do think the photographs could be useful."*

> *"I think it takes a bit more time for something like this to become part of a routine, I have been using paper and an insulin pump since 2001."*

7.3.6 Hayley

Hayley, a 27 year old female has had diabetes since the year 2001, making a total of 12 years at the time of the study . Her profession was as an admin assistant and described herself as comfortable with her knowledge of technology. When asked if she had used any mobile applications previously to assist with her diabetes management, she stated that she typically only used applications which allowed for carbohydrate counting. These applications provide a library of foods with detailed information about nutritional information, with the carbohydrates being the most important to those with diabetes. The carbohydrates will eventually be broken down into glucose in the body, hence why they need to be careful considered in relation to insulin dosing.

Hayley described how she avoided extra workload introduced by the application by entering her entries in bulk once a week:

> *"I think because I've been on a strict schedule recently and writing lots of things down, it was extra effort to enter into the application."*

During the interview sessions, Hayley stated that she was in the process of trying for children and therefore had to achieve better level of control. This increased level of control was as a result of a change in her major change in her life. This impacted on the way in which Hayley used the application during the time of the study, as it was not a key part of her management processes. In other words, Hayley simply had more pressing issues to deal with. Yet, Hayley did state that:

> *"I thought it would be a good idea if I took a picture of every meal and check the blood sugars next to it."*

While Hayley was not the most prolific in capturing images into the ConCap application, she did see the value in using this feature. She commented that it would be useful to see the impact that different food types had on her glucose scores in a visual fashion.

Despite the intensive monitoring that Hayley was engaging with, she stated that she had logged all of her events into the application. She liked seeing the graphs the application produced as it was a similar feature available with her glucose monitor. However, her existing system required scores to be uploaded onto a computer and Hayley felt that the immediate display of her entered information was her preferred choice.

7.3.7 Matt

Matt, a 56 year old male had been living with diabetes for 44 years since being diagnosed in 1969.

Matt was keen to capture many aspects of his own diabetes management into the application. Figure 7.8 shows an image he took to represent an increase in his physical activity that he would usually have not recorded. He described how exercise such as walking and biking could be easily accounted for and defined for the purpose of insulin adjustments. Yet spending a day performing DIY tasks in the home was much more difficult to quantify, it is more work that he would usually be doing by he had no real concept of how much physical work he was actually doing, making insulin dosing tricky. By capturing the image of the DIY equipment, he had a permanent record of the fact this was done, the insulin treatment he took and the resulting glucose trend. This will allow him in future to reference the information and potentially learn from in order to make a more informed decision at a later date.

As well as the DIY, Matt also attended a large sporting event which he captured in the application

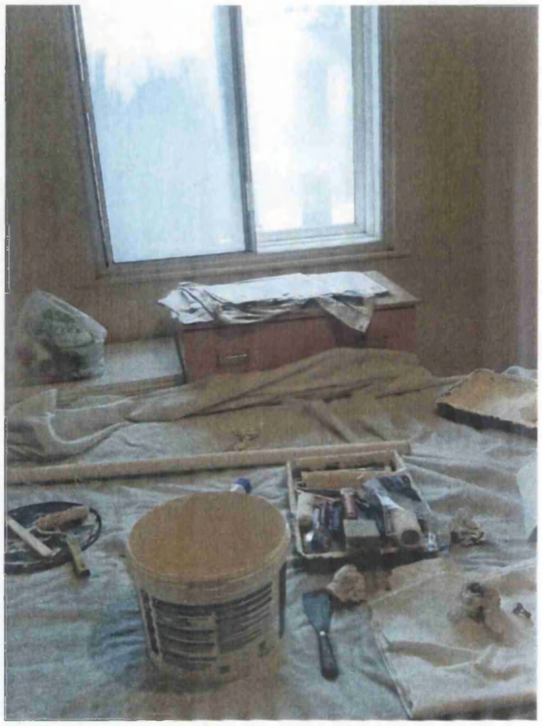


Figure 7.8: Participant 7 (Matt) captured an image of home decorating equipment, taken to represent the increased physical activity.

in the form of his match ticket (Figure 7.9). Knowing that during the day he would be experiencing things that were beyond what he perceived to be a 'normal' day, he felt contextualising the glucose results for that day was important. The amount of walking to and from the event would be an increase on the levels he would normally do, as well as the potential for increased levels of alcohol and fast foods over what he normally consumed. These alterations in diet and exercise would have a direct impact on Matt's glucose levels, but not in a manner than he could prepare for. His treatment for the day would be much more responsive, rather than planned. As such, making a record of this day would provide a reference should future occurrences of similar occasions happen again in the future.

Matt also described that during the study, he felt that his average glucose reading had decreased by 0.5 mmol/L (millimoles per litre). He was extremely pleased with this result, having expressed concern over his readings in the entry interview. However, Matt stated that he believed this decreased to be as a result of a *"halo effect"*. Yet this still suggests that as a result of using the

Figure 7.9: Participant 7 (Matt) took a picture of a Rugby match ticket, taken to represent a day of increased walking, alcohol and fast food.

application, Matt was becoming more interested in his data and was able to form judgements that had previously alluded him. For example, Matt made extensive use of the photograph and location functions within the ConCap application for the purpose of capturing setting of performed activities:

> *"I used the location button when I was somewhere out of the ordinary, I wouldn't use it at work for instance."*

> *"The location and photographs were interchangeable for me, they were both pretty good. They were good reminders of what I had been doing"*

> *"I did some DIY and if in a couple of weeks I look back at the results I can see the DIY was the reason for the score."*

Matt also expressed an interest for an expansion of the average settings to provide further breakdowns during the day. Matt stated that he would like to have the option of viewing averages at specific periods of the day, such as morning, afternoon and night-time averages. This would allow for a further understanding of control and the progression through a day.

7.3.8 Ruth

Ruth, a 25 year old female, had type 1 diabetes which had been discovered in when she was 3 years old, meaning she had had the condition for 22 years. At the time of the study she was working at the Juvenile Diabetes Research Foundation (JDRF), a charity supporting those with type diabetes and run by those with the same condition. Hence, Ruth considered her own knowledge of diabetes to be very good.

Figure 7.10: Participant 8 (Ruth) captured an image of bedsheets, taken to demonstrate an early morning glucose reading taken before breakfast.

In order to distinguish glucose readings taken before and after breakfast, Ruth took several images similar to that seen in Figure 7.10. These images of bedsheets illustrated where she was at the time of taking a reading. Therefore, the bedsheets were designed to show that she was still in bed in the morning and had not yet got out of bed to have breakfast. The image had now added an extra layer of context to the morning glucose results, and allowed to quickly distinguish results for the purpose of later understanding.

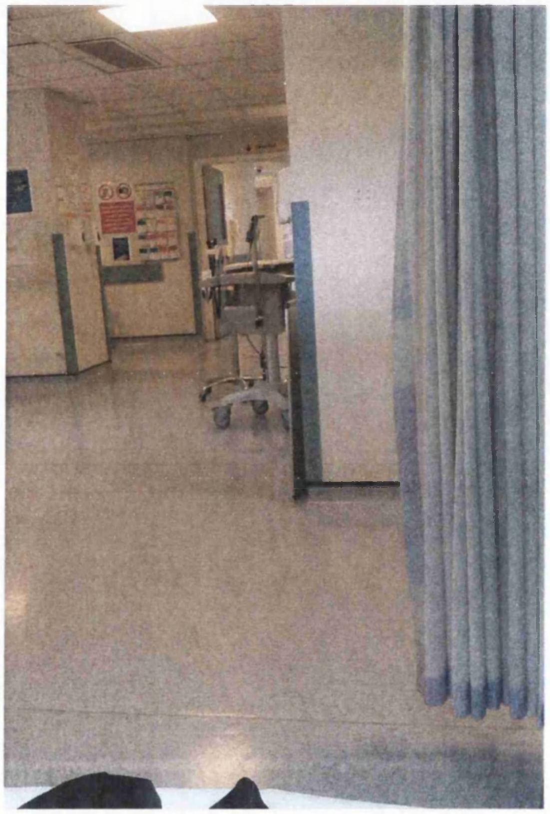


Figure 7.11: Participant 8 (Ruth) visited the diabetes clinic for a routine check-up.

In the exit interview, Ruth described how her usage of the application had decreased over time:

> *"To begin with I was pretty good and entered information a lot, but over the past week I haven't and that is mostly because it hasn't been at the forefront of my mind."*

> *"At first it was a novelty because I haven't recorded for so long, but as time wore on I just haven't used it."*

Again, it appears as though the addition of a mobile application had disrupted an existing routine, leading to a limited amount of usage from the participant. Despite this however, Ruth still provided insights into her use of the photograph and location functions.

Typically used the location and the photographs at the same time, but felt that the location information provided little insight during the study period. This reason was primarily down to Ruth stating that she was usually at her desk or at home and as such, location information didn't offer an unknown insights.

> *"I generally took pictures of what I ate, or where I was so I could look back and remind myself where I was when I took a reading."*

Ruth then, appears to have used the application to capture settings where she had taken a glucose reading, rather than capturing daily activities when they happened.

Figure 7.12: Participant 8 (Ruth) captured an image of train tickets to represent a journey taken during the study.

7.3.9 Julie

Julie, a 23 year old female, worked as a policy officer at the time of the study. She had been diagnosed with type 1 diabetes in the year 2000 at the age of 11. During her time with the condition, Julie had used around 10 different glucose monitors. Overall she felt her diabetes control was 'pretty good' and that she had only had two serious hypo episodes.

Of all the participants recruited for this study, Julie had the most frequent glucose testing habits described during the entry interview. She tested at least six times a day, at set intervals; when waking up in the morning, three hours later, before lunch meal, three hours before dinner and before sleep. There were additions to these tests if Julie felt that she was unsure of what her glucose scores were likely to be. However, during the ConCap phase of the study, Julie entered a total of 72 glucose values, equating at 2.6 entries per day. The added burden of transcribing data twice from glucose monitor to paper and the ConCap application may have been a factor:

> *"Because I went onto a pump halfway through the study I put the glucose values into the pump, which meant that I often forgot to enter them into the application as well."*

The change in her management had led to an increased burden on the attention she had to pay to her condition. As a direct result, Julie's interactions with the ConCap system were few and infrequent. Julie struggled to integrate the application into her routine and made no use of the photograph or location functions:

> *"I usually remembered to take a picture once I had already finished eating, so there wasn't anything to take a picture of."*

As Julie had more pressing concerns regarding her health during the study, it is only natural that the external intervention saw limited use. As has been stated throughout this Thesis, the application designed was intended as an assist where appropriate and in this instance, this was not the case.

7.3.10 Holly

Holly was a 21 year old female working as a carer. She had been living with diabetes since 2006 and described herself as not having 'the greatest control.' Her glucose checking regime involved checks around four to five times a day; morning, lunch, before dinner and at bed in the evening. During the entry interview, Holly stated that her she never really planned ahead in terms of her diabetes and instead preferred a more reactionary approach. She felt that this allowed her more freedom in her everyday life.

Figure 7.13: Participant 10 (Holly) took a photo of cakes that she had eaten.

During the study period, Holly stated that there had been little variation in her lifestyle during the four week deployment:

> *"I pretty much do the same thing everyday, so there aren't normally any changes."*

> *"I took a few pictures but not all the time because I was working and I thought they would all be the same. If there was a bit of variety I would have taken more pictures."*

Her usage of the functions therefore were limited, yet Holly highlighted that she took pictures if went out for dinner, or went out for coffee. These events signify those which are outside of the normal sequence and typically occurred at weekends, prompting an increase in picture taking:

"If I can see a picture of what I have eaten it gives me a better idea of what my blood sugars are doing and why. "

"I had a couple of hypos and I looked back at the photographs and saw that I had a coffee and a muffin and had really overestimated the insulin. "

By using the photographs in this fashion, Holly was able to determine that she had incorrectly calculated a dosage of insulin. During the exit interview Holly highlighted this issue with little prompting, suggesting that by viewing the glucose and insulin values alongside an image of the food, she had a distinct memory of the event. It is possible then, that the application may had facilitated a learning experience around this event.

Additionally, the application when viewed by Holly highlighted a trend which she had previously been unaware of:

"I looked at the application most days, it was interesting to see. I could see where I was going higher during the day, mostly in the afternoon, which I hadn't really realised before."

7.3.11 Lauren

Lauren, a 28 year old female was working as a librarian and was diagnosed with diabetes in 1998, making a total of 15 years a the time of the study. She described he overall control as:

"Quite good, not perfect. I'd say I have too many hypos at the moment, around 1 minor hypo a day."

The frequent occurrences of hypoglycemic events was as a result of Lauren making attempts to consistently lower her average glucose scores in order of a lower HbA1C tests in the future. The hypos were happening regularly in the mornings after Lauren had arrived at work. She described how her work was now based on two different office sites and that the method of getting to each was different. One of the locations was sufficiently close that she was able to walk and Lauren described how this may be a contributing factor to the low blood sugar pattern she was experiencing. Whilst not actively looking at the patterns, she was aware of the potential and whether they were isolated instance:

> *" Is that walk having quite an impact and do I need to take less insulin, or do I just need less insulin in general?"*

She expressed concerns that her insulin needs change over time and gave the example that during the summer months she may feel like she needs slightly less insulin. Lauren speculated that the reduction in the need for insulin may be as a result of increased heat levels, or the fact that she may be outside more often and subsequently be more active than in cooler temperatures.

Her glucose monitor was also the main record that she kept of her glucose monitor. Lauren didn't regularly check on previous results unless she was unable to remember her last reading. However, she did state that if she were to look for patterns, she would probably write things down as the blood sugar results aren't enough. However, day to day recording of results and information offered little benefit to Lauren:

> *"Because my diabetes changes so much, what happened, what happened earlier in the day doesn't necessarily mean anything later in the day. Unless I had a hypo, which would then cause problems later in the day. The only reason I'd want to look at sugars in great deal, would be to look for patterns. To do that, I'd look over a week of so."*

Yet there were occasions were Lauren engaged in more intensive logging of her information such as if she was experiencing a *"particularly bad couple of weeks."* Additionally, she stated that if she changed a factor in her lifestyle or she had an upcoming diabetes clinic appointment that she would also begin more detailed recording. These periods would usually last for about 2 weeks, which was a length of time that Lauren felt was the best comprise between the need for information and convenience. She did however state that perhaps this was not the optimal solution and that she could perhaps *"try and be more scientific about it and look over a month."*.

She stated her belief that It is useful to record information but stressed that the application wasn't the most intuitive application in the world. Her own attitudes to recording information were also a factor and that she only really things recently when she took greater interest. Lauren would only enter data if she was keeping a closer eye on her sugars.

> *" It takes a long time to enter data and diabetes takes a bit too much time as it is."*

The point made by Lauren here sums up her overall attitude to her condition, the challenge of ensuring day to day healthy levels of blood glucose was already enough of a workload. Anything offering potential benefits would need to offer quick and intuitive interactions, with meaningful output.

Figure 7.14: Participant 11 (Lauren) captured an image at a barbecue to represent the small, irregular intakes of food likely to complicate insulin dosing.

An interesting image captured by Lauren during that study was that of a barbecue scene, as seen in Figure 7.14. On initial sight, it appeared that this image had been taken to show the fact that

Lauren was eating food that was out of the ordinary, and perhaps needed careful consideration and focus in later reflection. However, upon discussion during the post-deployment interview, Lauren detailed that in fact, the image had been taken to show the irregular manner in which the food had been eaten. As is often the case, food at barbecues comes in small, infrequent batches. For instance, the first thing that has been cooked maybe sausages (perhaps one per person), but the salad was served 20 minutes earlier and the final thing cooked was burgers, 30 minutes after the sausages. This poses a challenge in terms of calculating insulin injections, and Lauren had marked this event as a reference point to assist in the understanding of her glucose trend that day.

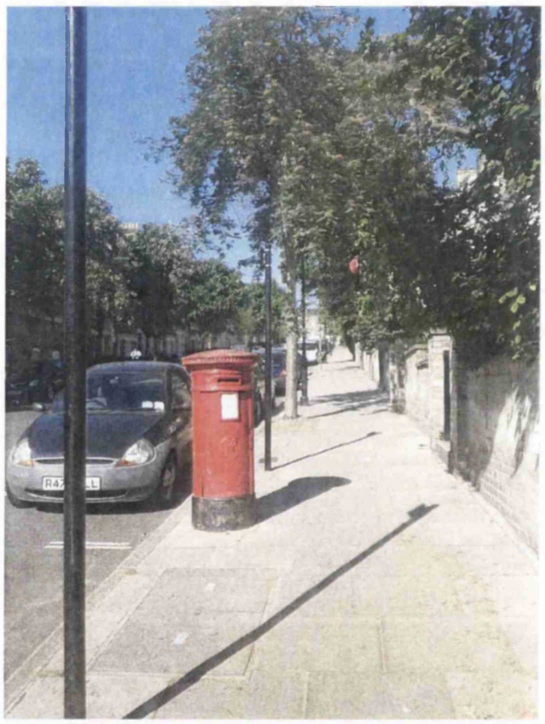


Figure 7.15: Participant 11 (Lauren) usually took public transport to work, but sometimes walked. To illustrate these days, she took pictures of street pavements to show which days she walked in.

Additionally, Lauren had recently been making attempts to use transport less on her commute to work and walk instead. This increased level of activity was going to impact on the rate at which her body used the glucose in blood, meaning adjustments would be needed to her insulin intake. However, at the time of the study, walking in daily had not yet become realised and instead was performed occasionally. It was therefore difficult for Lauren to accurately adjust her insulin injections, but in order to assist with this process she tagged the occasions she walked to work by taking pictures of the pavement on her route to work. This then allowed for correlation between walking events alongside her glucose and insulin values.

7.3.12 Mark

Mark, 27 year old human resources administrator was diagnosed with diabetes in 1996 and described his current control as *"OK, could be better."* At the time of the study, Mark was aiming to tighten his control, aiming for consistently good blood sugars, rather than patches of good values and spikes in his glucose results that he had been experiencing in the past. Mark described his overall knowledge of diabetes as:

> *"I think I know enough, more than the basics but I could probably do with knowing more. Over the past 2 years I've learnt a lot as the amount of information offered is different from when I was first diagnosed."*

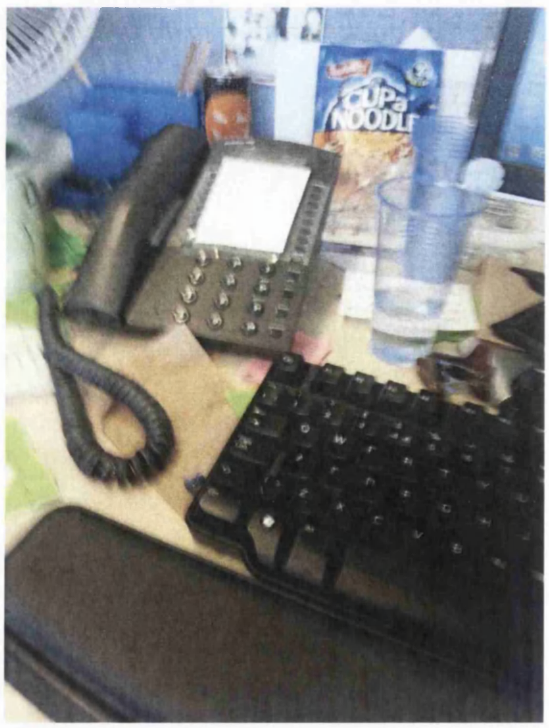


Figure 7.16: Participant 12 (Mark) took a picture of his of work desk, to illustrate a day in the office and distinguish it from weekend days.

Mark found that the averages offered within the application were of the greatest benefit to him. By viewing the averages data, it was stated that it was *"really useful in terms of just seeing where you are."* He discussed how he felt it was always good to see what his averages are and that when he opened inspect his data he primarily looked at the averages. In his own management, Mark was more concerned with getting averages down, rather than investigating the information to determine trends. The availability of averages was beneficial to Mark, he felt that it was easier to obtain this insight on an application, as on a monitor it would take lots of button clicking, whereas the app its just one button press.

> *"It was new, but easier to enter something, rather than writing down. Even though it is the same, its easier to do this (enter data onto the application) rather than onto paper."*

His frequency of entering the information was affected by his pre-existing habits, he described how he often forgot to enter a result as soon as a result was obtained from the monitor.

> *"I didn't always enter at the time, it's more to do with changing routine. I'm so used to leaving data on the monitor."*

However, information was typically back dated and entered retrospectively. This information tended to be more focused on glucose scores, with insulin readings be a secondary concern.

Mark made little use of the location feature, however he felt that he had taken pictures at a rate of twice a week, although this figure actually represented his total number of images over the whole study. The images Mark captured were of his place of work and were described as *"just a reminder that I took the test there."*. No pictures of alternative settings were captured as Mark felt that he was usually not in a situation he felt comfortable in taking pictures. In his entry interview, Mark stated that when out in public places, he would go to the bathroom to perform his glucose readings and insulin injections. As a result, he felt that capturing images related to his treatment would usually be of the inside of a bathroom, a situation that may cause offence to other people, and embarrassment to himself.

During the study, Mark experienced a routine month, which most of his days attending work. Regarding the camera images, he felt that *"It's more for the test outside work hours, it is probably more useful there."* When asked about longer term usage of the application, Mark felt he could keep on using application that offered similar features to ConCap, especially with the averages. Additionally, he felt that the images could be beneficial in carbohydrate counting of meals. By capturing the food as an image, a record of the estimated carbohydrates could be tagged with the image to provide a reference point for future instances of the same meal.

7.4 Discussion

The questions posed to participants during the entry interview session confirmed that few regularly logged their health information on a regular basis (3 out of 12). Those who stated that they engaged in this process were the most frequent users of the ConCap application.

During the four week deployment, all participants continued to enter data into the application and attended all sessions that were requested (including weekly telephone calls). The engagement throughout the study suggests involvement from the participants and that there was benefit in completing the study. Prior to the study commencing, concerns were expressed about participant retention during the trial. Participants had been using their own devices and so had no responsibility to the researcher conducting the study. Additionally, participants had been informed that should they wish to withdraw from the study at any time, they would be compensated for the portions of the study completed. For instance, attending the final interview session would have provided participants with £7, but they would have already accumulated £107 by this stage and potentially the final sum may not have been incentive enough. Several of the participants had to travel notable distances in order to attend the interview sessions and make significant alterations to their everyday schedules (such as skipping a lunch hour or travelling earlier into work). The keenness to engage could potentially suggest their belief that the system had benefits to the management of their own conditions. All participants provided some form of feedback relating to how they believed the system could be improved or extended.

Yet not all participants felt they would continue to use such an application over a long period of time. Several spoke of their own contentedness towards their diabetes, both in terms of knowledge and management. They had reached a stage that they felt the balance between rigorous inspection of results and 'getting on with life' was right for them. Others however had found great benefit in using the application, with Matt stating his belief that his weekly averages had dropped by 0.5mmol/L. Amongst the participant pool, Matt had diabetes for the longest period, almost twice as much as the next closest participant. Matt's use of the imagery feature in the application was perhaps also the most interesting with his ability to capture complex events in a single shot.

7.4.1 Attitudes

During the entry interviews, it became clear that participants had a great deal of difference in their approaches to diabetes. The management of the condition had almost become a secondary consideration due to other life events, such as Naira's recent addition to the family becoming her main focus. Conversely, the study also observed people who had 'lost interest' in their management for alternative reasons. Some, having had the condition for a long period of time, had become comfortable with both their knowledge and daily approach to their condition and intensive monitoring of data was of little use to them. Finally, there were some who, for varying reasons, were eager to record and process data at a much higher rate. Reasons for this increased level of logging appeared to be for personal satisfaction (almost a safety blanket) , a keen general interest in numbers and of course, the knowledge that their condition had not worsened.

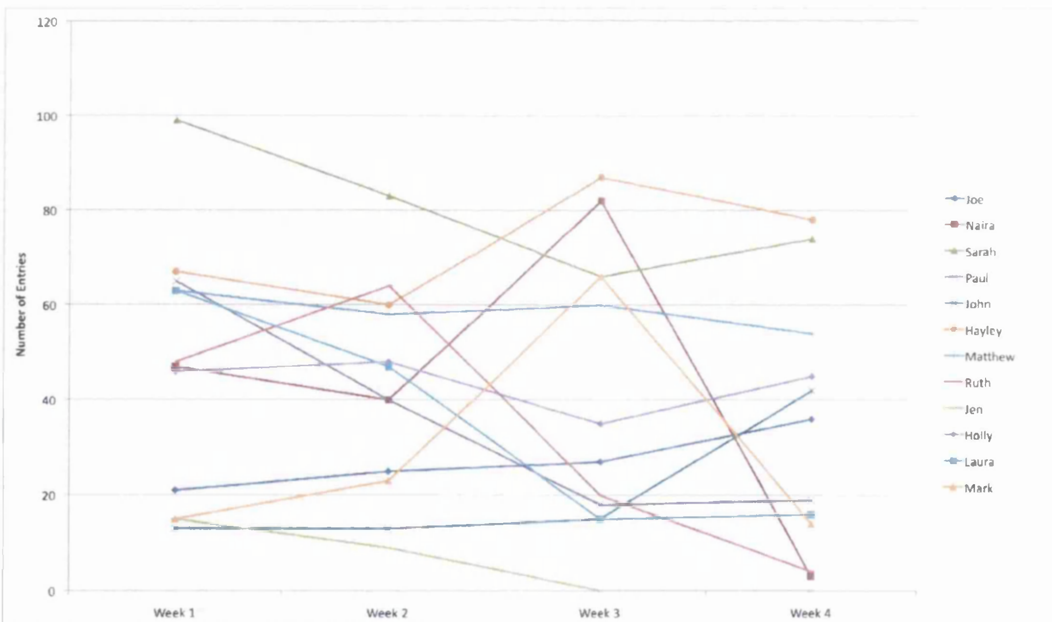


Figure 7.17: Participant weekly data entries during the ConCap study period.

Based on the information gathered in the entry and exit interviews, the participants were categorised into groups based on the current state of their health information management. Two main alternatives were 'Standard' conditions, where the participant's condition and practices were stable, versus, 'Change' conditions where the overall pattern was in the process of adjustment. This further broke down into standard (rigid), standard (fluctuating), change (voluntary) and change (forced), which we will now describe in further detail:

Standard – Rigid – Participants within this pool were determined to be at a phase of their management in which their condition was largely stable, due to their own strict control of factors. These factors include typically; the choice of food, times of meals and portion sizes. The participants assigned to this category were *Joe* and *Ruth*, who both described extremely tight glucose control through their planning and monitoring of a variety of activities.

Standard – Fluctuating – Individuals in this class are satisfied with their health status, yet experience moments of uncertainty in areas such a special events that disrupt the norm. The participants in this category were *Sarah, Paul, John, Matt, Holly* and *Mark*. Those in this category all expressed being largely happy with their control, but still experienced some areas of concern, such as Paul who had noticed an increase in his glucose levels and was determining what action to take.

Change – Voluntary – Those who are going through a change in either their condition or management through a choice that they have made. The participants in this category were *Naira, Hayley and Lauren*. Hayley, for example, had recently made the decision to try for a baby which required her to increase the level of control she had previously been performing.

Change – Forced – Those who are experiencing change which is out of their control, such as Julie who had to change treatment halfway through study and moved onto an insulin pump. Change was known before entry into study and likely explained low number of interactions early on, before a change in medication was required by their clinicians. The only participant included in this category is *Julie*, due to her change of treatment plan during the study.

When considering the Diabetes Management Cycle (Chapter 5), those who are in a rigid mode of management are at a stage which is heavily habitual. Therefore, it is unlikely that they will have broken their management styles to fully engage with the ConCap application.

However, those in the fluctuating category maybe be experiencing moments of concerns and unusual situations, but generally moving through those stages at a rapid pace and spending more time in the confidence, habit and monitoring stages. Their usage of the application will increase over the Rigid group, as they have more moments of uncertain.

The two Change groups are likely to be spending more time in the Concerns and Unusual Situations parts of the model. Those who are going through voluntary change are perhaps the more likely to use the application, as they are active changing their management processes and be looking for assistance. Yet, those who are going through forced changes are unlikely to engage due to the pre-existing issues they have, and the application not fitting with their practices.

7.4.2 Frequency of Use

The approach taken to entering information into the application was varied across all of the participants, with the two primary methods of entering information being: at the time of a reading and bulk inputs at set periods of times.

Four of the participants described how their interactions with the application had decreased over the study period. The reasons given for the decrease appear to correlate with the attitudes of the participants described in the entry interview. For instance, Ruth stated that she rarely recorded her glucose results and that the novelty of using the application had worn off during the study period.

It seems that those who used the application less as the study progressed struggled to integrate the system into their routine. John for instance, stated that he had been using paper records for at least 13 years and altering that habit over 4 weeks was a challenge.

Instead, those who had more concerns about their diabetes appeared to have used the application more frequently. Those who were in intensive stages of monitoring, or engaging in *'unusual'* activities attempted to capture far more information onto the application. Naira, Matt, Lauren and Sarah all described instances where they had engaged in activities that were beyond normal and had felt a need to capture those occasions.

7.4.3 Times of Use

Nearly all of the participants described that they were more likely to use the photograph and location functions during times that they were engaging in activities that were beyond they usual practice. Typically, these types of events occurred at weekends and activities such as eating out, alcohol consumption and increased physical activities triggered greater use of the application.

More routine events were also captured however. During the initial interview, Lauren highlighted a recurring problem that she was experiencing with minor daily hypoglycemic episodes at mid-morning. She speculated that the frequency may have been a result of her daily commute into her workplace. Her work was based across 2 different sites which she alternated between on different days. One of the offices required her to walk to the workplace, and Lauren felt that this may be a contributing factor to her recurrent problems in the mornings. In order to capture these instances, during the study Lauren used the camera to take pictures of pavements. These images represented the days on which she walked into work, meaning she could begin to see the correlation between days she had walked to work and days in which she had low blood sugars.

7.4.4 Illustrating Points of Interest

The primary aim of the inclusion of location and camera images in the application was to provide participants with a quick method of capturing a moment they felt was relevant to their condition. Location, for instance, illustrated a trace of where people had been throughout the day, and images visually displayed events that a participant had engaged in.

By far the most appreciated of the two features was the camera function. Issues arising from limitations in GPS positioning may have contributed, but the ability for participants to capture what they felt was relevant, in a fashion they understood, is likely to be the leading influence. Simple instances such as meals could be quickly captured, yet richer and more complex scenarios could also be represented. Matt highlighted that a day of home improvement is not easily quantified in terms of how the effort expended in the process, translates into physical activity allowing for a recalculated insulin dose. In his picture of his DIY equipment (see Figure 7.8) he created a record of a day's activities as a point of reference, which in future situations could explain an unusual set of glucose results, or as a guide for future similar instances.

Most of the time, the two functions were used to capture a setting. But the capture of the setting appears to have had two distinct meanings. Participants such as Ruth and Mark only took pictures when they were performing a glucose test, therefore contextualising the setting for a reading. However, other participants such as Lauren and Matt captured activities as they were happening.

Those who had captured images at the time of a reading were then able to infer why they were taking a reading and perform a process a back-tracking on activities. However, those actively capturing these activities while they were happening had immediate representation of the events.

7.4.5 Categorising Images

Participants used the camera feature on the application to depict several different situations, this section will determine categories for the images taken. By conducting this process, which scenarios images are best suited to in the context of chronic disease management will become apparent.

All of the images from participant's devices were collected for the purpose of coding. Each individual image was assigned a tag for what was represented (e.g., a plate of food as seen in Figure 7.5 was coded as 'food and drink'). Through this process, 4 categories of images were constructed: food and drink, location, scene and physical artifact.

Food and Drink – Based on previous research [156] participants were informed at the start of the study that images of food may be helpful. All of the participants recruited for the study took at least one picture that fits into this category.

Location – Rather than use the location maps offered on the application, several participants took pictures of their surroundings to represent where they had been during a day. This was the most prominent method of capturing location, potentially due to participant ability to contextualise a picture in a much more meaningful way than simply a map.

Scene – Scenes were specific events that happened during the study that didn't appear to fit into the location category. Items such as Lauren's barbecue picture (Figure 7.14), represented events that were not sufficiently covered by location. For instance, in the morning Ruth took pictures of her bedsheets and then knew that her tests would have been taken at home, but the photo represented at which point the tests were taken (i.e., on wake or pre-breakfast).

Physical Artifact – Participants also took pictures of objects that they felt were relevant to their condition. For example, Figure 7.9 displays a match ticket, representing a entire day of activity. Similarly, Paul captured his own monitor screen whilst he was having a hypoglycemic episode.

7.4.6 Research Questions

Early in this section, a set of research questions were defined relating to how the ConCap application would facilitate meaningful reflection on diabetes information. By using the results gathered from the field study, each question is responded to and an outcome is presented.

RQ1 - To what extent does the immediate availability of a mobile phone and subsequently our application impact on the recording of glucose results (compared to paper based diary logging)?

Of the participants recruited onto the study, three stated that they were using paper based logging of their glucose results. The remaining nine did not engage in any logging manually, instead using the monitors storage as their log. Eight of the participants commented on the immediate availability of a mobile phone being easier to enter information on rather than using paper.

While all of the participants entered information throughout the study, three participants entered very little information during the final phases of the deployment. Those individuals had either not been logging information previously, or had changed treatment which required specific clinical logging.

RQ2 - To what extent does the addition of contextual factors to glucose scores allow for greater understanding of the cause of individual glucose scores?

Location data was deemed to not be particularly useful by the participants, however, suggestions that the addition of images was indeed useful became apparent. Described by one participant as a *"unique selling point"*, the manner in which participants suggest there is a potential for a rich representation of key information relating to their own conditions.

RQ3 - Does an immediate visual representation of glucose scores highlight points of interest to participants (such as unexplained trends)?

Holly and Sarah both stated that the graph had provided insights to them regarding their diabetes control, suggesting that the approach could be further refined.

It appears that the visualisation used in the ConCap system could be enhanced in a future iteration. The current system allows for scrolling and zooming over the data set, giving a chronological view of the information. Perhaps an alternative method may be to allow for overlay of data, for example; plotting consecutive weeks on the same chart grid. This method would allow for immediate representation of weekly trends and offer quick and intuitive discovery of information. When asked about trend spotting practices, the participants in the study commented that they typically look at information over a month long period or less.

RQ4 - Will the application be used most heavily during 'unusual' situations that are outside of ordinary activity?

During the evaluation, there were very few instances of *'unusual'* situations. When asked the question "do you consider the previous month to be a routine one?" all of the participants replied positively. However, there were small instances where participants deemed a situation sufficiently out of the ordinary to capture. Situations such as Matt's attendance at a major sporting event, or Lauren's evening at a barbecue were removed from what was their normal day.

RQ5 - To what extent can the he application prompt users of forgotten previous activities / clarify information about activities?

Whilst there were no explicit examples of this criteria during this study, there were examples of photo-taking making events more memorable. The memorability of individual events was heightened by taking photographs, such as Holly's experience with insulin calculations after coffee and a muffin.

There were suggestions by participants that this is a potential likely scenario over a longer period of time. Had there been more situations that participants felt were out of the ordinary, they speculated that this may having imagery data may have assisted in diagnosing the cause of unexplained glucose events.

7.5 Emerging Themes

Through our analysis of the ConCap data and feedback received from our participants, similarities began to emerge amongst the individuals. In this section, we describe the key themes that arose.

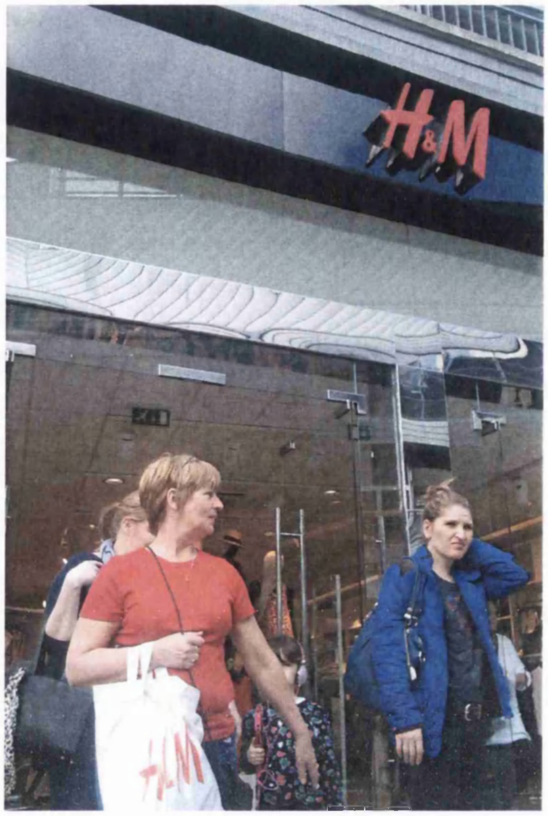


Figure 7.18: Participant 9 (Ruth) highlighted image during exit interview about a hypo experience whilst out shopping

7.5.1 Exceptions

All but two participants captured events that broke their regular routine. Accounting for or tracking unusual events was seen as important in pre-empting potential unusual readings later in the day. For example, Lauren took a picture of a barbecue scene, as seen in Figure 7.14. On initial sight, it appeared that this image had been taken to show the fact that Lauren was eating food that was out of the ordinary, and perhaps needed careful consideration and focus in later reflection. However, upon discussion during the post-deployment interview, Lauren detailed that in fact, the image had been taken to show the irregular manner in which the food had been eaten. As is often the case, food at barbecues comes in small, infrequent batches. For instance, the first thing that has been cooked maybe sausages (perhaps one per person), but the salad was served 20 minutes earlier and the final thing cooked was burgers, 30 minutes after the sausages. This poses a challenge in terms of calculating insulin injections, and Lauren had marked this event as a reference point to assist in the understanding of her glucose trend that day.

7.5.2 Habits and Routines

As seen in previous literature ([115]) and Section5, those engaging in diabetes self-management are likely to form methods to control their condition, which they implement recurrently. Therefore, the introduction of a new intervention would be a break in routine, and consequently not all participants successfully integrated ConCap in their management.

> Paul: *"I didn't use it that often, but occasionally when something interesting happened I took a photo."*

> John: *"I think it takes a bit more time for something like this to become part of a routine, I have been using paper and an insulin pump since 2001."*

Conversely however, Lauren was attempting to form a new habit of walking and therefore altering her routine. This increased level of activity was going to impact on the rate at which her body used the glucose in blood, meaning adjustments would be needed to her insulin intake. However, at the time of the study, walking in daily had not yet become realised and instead was performed occasionally. It was therefore difficult for Lauren to accurately adjust her insulin injections, but in order to assist with this process she tagged the occasions she walked to work by taking pictures of the pavement on her route to work. This then allowed for correlation between walking events alongside her glucose and insulin values. It appears then, that during moments of change ConCap was able to assist in the understanding of the impact new factors were likely to have.

7.5.3 Reflection

Support for reflection was a common requirement we encountered in our earlier research on diabetes self-management. Two thirds of the participants, none of whom were in the Standard/Stable condition, reported that ConCap was helpful in acquiring some understanding of their condition. The underlying reflection was helped in several different ways:

Sarah: *"Sometimes when things are going well, you don't really realise it. When you see it on the graph, you are kind of pleased with yourself."*

Sarah was the only participant who said that the graph provided her with a sense of satisfaction in her diabetes control, but the graph also highlighted points where her glucose scores were not so well controlled.

In order to distinguish glucose readings taken before and after breakfast, Ruth took several images which represented Scenes. She typically captured images of bedsheets illustrated where she was at the time of taking a reading. Therefore, the bedsheets were designed to show that she was still in bed in the morning and had not yet got out of bed to have breakfast. The image had now added an extra layer of context to the morning glucose results, and allowed to quickly distinguish results for the purpose of later understanding.

Ruth typically used the location and the photographs at the same time, but felt that the location information provided little insight during the study period. This reason was primarily down to Ruth stating that she was usually at her desk or at home and as such, location information didn't offer an unknown insights.

"I generally took pictures of what I ate, or where I was so I could look back and remind myself where I was when I took a reading."

Ruth thus appears to have used the application to capture settings where she had taken a glucose reading, rather than capturing daily activities when they happened.

Holly highlighted that she took pictures if she went out for dinner, or for a coffee. These events signify those which are outside of the normal sequence and typically occurred at weekends, prompting an increase in picture taking:

"If I can see a picture of what I have eaten it gives me a better idea of what my blood sugars are doing and why."

> *"I had a couple of hypos and I looked back at the photographs and saw that I had a coffee and a muffin and had really overestimated the insulin."*

By using the photographs in this manner, Holly was able to determine that she had incorrectly calculated a dosage of insulin. During the exit interview, Holly highlighted this issue with little prompting, suggesting that by viewing the glucose and insulin values alongside an image of the food, she had a distinct memory of the event. It is possible then, that ConCap can facilitate reflective learning around specific events.

7.5.4 Incongruity

During entry interviews, the issue of performing medical tasks in a public setting was highlighted as a concern. The process of piercing skin for a glucose reading, or carrying out injections for insulin, were described as out of the ordinary. Similarly, our participants expressed issues surrounding the use of mobile phones. Mark described not making use of the photo feature while using the bathroom (he typically performed his glucose tests there to keep away from people seeing what was happening). Sarah also commented on the challenge of ensuring data entry during social situations:

> *"I entered results every time, except when it was rude to get my phone out and then I would retrospectively add them in."*

Clearly then, there is a social concern regarding the use of mobile phones during certain scenarios. O'Kane et.al. [124] categorise these scenarios as *Unexpected Environmental Influences* and *Unexpected Social Situations*.

7.6 Conclusions

This Chapter described a long-term user study with twelve participants over a four week period. The participants were asked to use the ConCap application in a manner in which they felt best suited both their daily life, and diabetes management. By using imagery and location data, alongside glucose and insulin values, it was established that meaningful capture of rich data is an asset in diabetes management. Participants were able to capture daily experiences, that they felt were relevant to their condition, in a quick and lightweight manner. Images captured using mobile phone cameras were employed in a variety of strategies, such as capturing food, exercise or events attended.

The feedback provided from the participants during the exit interviews suggested that some of the individuals had regimented and near-perfect control, and subsequently felt that they did not need additional help. Conversely, however, those who had mentioned concerns about their condition, or had less regimented control used the app more frequently.

Therefore, the application ConCap appears to be most useful during times of uncertainty and unusual situations. By providing support at these times, individuals were able to attribute causes to their blood glucose results. By providing the ability to capture images alongside glucose readings, participants during the study suggested that the memorability of specific events increased.

7.7 Summary

This Chapter presented work to fulfil the research aim "Capture the impact of new technology solutions on people's understanding and management of health conditions." The methods for information capture utilised on the ConCap application provided moments for the participants to remember activities, or to make discoveries about factors that affect their condition. The most successful method of capture was the use of camera images. While previous researchers have also looked at this feature (e.g., [112, 156]), the work in this Chapter has contributed to the domain of unanchored settings [95] using lightweight, mobile methods of capture.

7.7.1 Next Steps

The ConCap application allowed for participants to enter data related to their health, but once the information had been entered they were unable to interact with it further. One of the participants in the study (Matt), suggested that it would potentially be beneficial to allow for tagging of health information. Such an approach is currently offered on some glucose monitors (Chapter 3) and it is perhaps where the idea of tagging was generated by the participant.

With smartphones offering the technological capabilities that they do, there is potential to extend the methods used in the ConCap application to allow for more interaction with inputted data. The following Chapter will investigate methods of tagging of health information and evaluate through a longitudinal deployment.

Chapter 8

Investigating Mobile Support for Frequent Self-Reflection

This Chapter describes research into how the utilisation of personal tagging on health information can lead to greater understanding of a personal condition. To understand how mobile technology can assist in this process, the application 'VCTag' was designed and implemented based on the findings of previous Chapters and existing literature. VCTag was implemented to support to people with blood pressure conditions in managing and engaging with information that they personally record relating to their health and well-being. The Chapter describes an in-situ field study of the application during a six week deployment in which twenty participants took part. The results and findings of the study suggest that participants were able to discover critical factors affecting their condition through using the application.

The work in this Chapter contributes to the research aims: "Design appropriate support for health condition management practice." and "Capture the impact of new technology solutions on people's understanding and management of health conditions." It makes a research contribution by introducing an evaluation of a personalised tagging mechanism for health information. Through this mechanism, participants are able to raise their awareness of factors that are impacting on their health.

8.1 Introduction

As has been described in previous Chapters chronic conditions such as diabetes require frequent measurements of factors relating to overall health. By engaging in this process, those with chronic conditions are able to gain an understanding of their condition and their level of control. A key part of achieving this level of understanding is the reflective process undertaken on both past data and previous activities. However it is not clear whether this frequent testing leads to the process of reflection of previously gathered relevant information.

Unlike diabetes, conditions such as cardiovascular diseases are monitored most often within a clinical setting. Those with illnesses such as hypertension (high blood pressure) and hypotension (low blood pressure) have their conditions monitored by clinical professions during appointments which occur over long term time periods. Rarely do these individuals engage in self-monitoring processes within their own home setting.

However, as has been stated in Chapter 3, there is a growing movement seeking to involved individuals' in the management of their own conditions on a greater scale. The control of blood pressure has also seen recent rises in the number of people undertaking the process [130].

Many current methods of supporting this process typically provide feedback based on clinical success. The primary aim is to inform an individual whether their readings fall within healthy or unhealthy boundaries. While this information is of high importance, there is perhaps an alternative form of feedback that could be employed.

During the interviews described in Chapter 5, a participant expressed an interest in the ability to contextualise their own readings based on their own interpretation. For example, people with chronic conditions are likely to experience readings that are considered 'unhealthy,' but regular occurrences for themselves. Those with diabetes may experience frequent high readings after eating that are high, but expected for their own individual management.

It is possible that simple labeling health information as health or unhealthy may not lead to an enhanced understanding of the data. This Chapter describes a method to allow for individuals to 'tag' their own information based on their understanding of the data.

In order to evaluate how alternative forms of logging information amongst chronic condition sufferers can affect understanding of results, it is logical to research condition that requires less intensive involvement from an individual. People with diabetes are involved with frequent test, injections and consideration about their condition. They are already required to be heavily involved in controlling their condition, the short-term implications of failing to do so are too much of a concern to ignore. Hypertension is treated primarily through lifestyle changes and medication [140]. Yet, testing procedures for blood pressure have to be performed in a specific and controlled manner as results can vary greatly if poor technique is implemented [69].

Hypertension is also known as high blood pressure and has been described as the 'silent killer,' due to the fact that the condition rarely exhibits any warning signs or symptoms [136]. The condition is also wide spread amongst the adult population, with 31% of men and 28% of women in England having high blood pressure [141]. Blood pressure is typically measured in two units, diastolic and systolic and hypertension is defined as a persistent raised blood pressure of 140 (systolic)/ 90 (diastolic) mmHg [184]. Those with hypertension or suspected borderline cases regularly take blood pressure readings at home, and make a record of the results. Their treatment is usually lifestyle based, such as stopping smoking or losing weight. However some cases of hypertension do require that medication is also taken.

Self-monitoring of blood pressure has been in existence for over 30 years, however it is only in the past 15 years that this practice has started to become widespread. Gallup polls[1] have indicated that the number of people with blood pressure concerns who regularly self monitor at home increased from 38% in 2000 to 55% in 2005 [130]. However, effective self-monitoring relies on patients taking an active role, yet there are potential pit-falls to this approach. Participants who took part in the study described in Chapter 5 suggested that they were aware of people who had lacked confidence in their ability to manage diabetes. This specifically orientated about calculations between carbohydrates and insulin doses. A lack of confidence can potentially greatly affect the engagement an individual has with an activity, such as self-monitoring:

> *"people with high self-efficacy - that is, those who believe they can perform well - are more likely to view difficult tasks as something to be mastered rather than something to be avoided."* [10]

[1]Gallup - http://www.gallup.com

Considering the opposite of the above statement, it is likely that a person who has a low self-efficacy may be overwhelmed by the potential of addressing a difficult task and respond poorly to the challenge of achieving the task. This thesis has illustrated the complex task of disease management in the context of diabetes. The collection and interpretation of vast amounts of personal information is not a simple task. Patients have expressed concerns with individual situations such as accurately calculating insulin units based on carbohydrates consumed.

8.2 Background

Adding greater meaning to recorded health information has been achieved in the past by utilising user *'tagging'* of information. Section 3.2 outlined how glucose monitoring devices are now allowing for users to mark results in relation to the situation they were taken in (such as before or after a meal).

Several of the mobile applications described in Section 4.5.1 further extended the marking of results by allowing for richer forms of tagging to be added. Systems such as the Evernote and GoMeals applications allowed for text-based annotations to be added to records. By facilitating this form of enhanced recording, participants are able to contextualise the events surrounding their health status.

Within the HCI community, the idea of tagging has been used as a method of retrieval in capture and access systems. The MyLifeBits [60] system used text based tagging entered by a user for the purpose of later search query support. The Tagliatelle [108] system further extends the tagging of information and introduced a social aspect to the records. Users within the Tagliatelle system were able to upload pictures of their meals to a social website where other users of the site were able to tag the images. This process gives an individual general feedback on the food choices they are making and their appropriateness in a weight loss program. However, during an early evaluation of the system it was discovered that frequent interactions with the textual based entry deteriorated over time.

The Wellness diary [117] also offered textual forms of tagging, however these were often shortened predefined tags. They formed part of a weight loss assistive application which allowed individuals to track their weight and contributing factors, such as exercise and food intake. This information was then presented on a calendar view which allowed users to view how specific factors were affecting their weight management. It seems then, that there is potential for moving away from the notion of 'healthy' or 'unhealthy' tagging of information. Previous systems such a Smith et al.'s [156] marked information as high, normal and low to participants, informing them of the clinical meaning of their results. However, alternative systems have begun to offer more personalised feedback on information.

Sota et al. [158] developed an application to support those in the recovery of kidney failure. Their approach involved indicating to an individual the current level of health information, whether improving or deteriorating. This was achieved by using an arrow visualising which indicating how their condition was progressing. Such forms of feedback may offer more opportunity for individuals to understand how the level of their condition.

Hypertension and hypotension conditions can be improved through both medication and lifestyle changes. By providing feedback to an individual regarding both individual readings and overall management, they may be able to make informed choices which improve their condition. Factors such as body position during a blood pressure test can have implications onto the accuracy of a result [2] and allowing participants to accurately contextualise these readings could be of benefit.

8.3 System Design

Participants in the study described in Chapter 7 found images to be a useful mechanism in representing activities. This lightweight method of information capture is again used in the design of the application VCTag. As with ConCap (Chapter 6), the new application, VCTag, allows for images to be taken and stored alongside inputted health data.

In order to match with the information provided by the blood pressure monitor, VCTag will allow for the input of all of the information displayed. While the systolic and diastolic readings are essential pieces of information, Figure 3.5 suggests that pulse readings are not frequently recorded. However, perceived lack of functionality in the application, the pulse readings are also included in the available input fields.

However, the primary feature of VCTag is a tagging feature. As discussed earlier in this Chapter, self-efficacy plays a crucial role in successful management of chronic conditions. By enabling a platform for self-reflection to occur, a patient's understanding of their condition may improve. The

Design Choice	Supporting Evidence
Chart Visualisation	A bar chart visualisation was used as to display blood pressure information on a timeline display as it offered the most suitable representation of the data.
Use of Pictures	Previous HCI research [54, 112, 156] has integrated photos as a means of health management support for the purpose of discussion with external sources (such as clinicians). This feature was also used in the ConCap application (Chapter 6) and found to be useful by participants during a longitudinal deployment (Chapter 7).
Tagging Feature	Previous research (e.g., [156]) has integrated tagging of health related information to provide feedback on information which may be required to be investigated more fully. The notion of tagging is also be using to label times of health readings (as described regarding glucose monitors in Chapter 3).
Colour of Tags	Blue, violet and brown as the colour of the tags based on previous studies in colour preference and colour emotions [83, 127] so to avoid stimulating any negative emotional response.
Platform Choice	Participants in the studies described in Chapters 3 and 5 stated that they rarely used desktop based management systems, and instead often used their monitors to view information. The immediate availability of these devices is potentially a key reason for this action and therefore, the platform of choice was mobile based.

Table 8.1: Design decisions take as part of VCTag development.

tagging function is designed to allow users to contextualise their readings based on their own understanding of individual results. The tagging mechanism allows the users to annotate their readings with one of three options, representing their perception of the reading itself and the patient-device interaction. The three tags that are available in the system are:

Expected Reading - The reading from the blood pressure monitor matches with the user's expectations. This tag illustrates that the reading has been considered and is understood.

Queried Reading - The reading does not match with what was expected. The user marks the reading as one that requires further consideration and expects to revisit the reading at a later date to determine reasons behind the reading.

Rejected Reading - The user disapproves the validity of device reading and marks the entry with this tag. Such a tag may be the result of a secondary individual using the monitor, or an incorrect method of taking a reading (such as placing a blood pressure cuff too low on the arm).

A decision was taken to avoid the use of colours that may have associated connotations indicating performance or achievement. A neutral colour palette was utilised to achieve colours that have a low chance of being associated with measurement of success. For instance, avoiding colours such as red and green, which are traditionally associated with 'wrong' and 'correct,' were avoided as the tagging of results was designed to reflect understanding of a result and not clinical success and to reduce the potential for emotional impact [83, 127].

The sum of these tags is also used to calculate the overall acceptance of measurements by the user, which is the second feature. This measurement is introduced to summarize and visualize tagging data collected throughout a certain period of time. The representation appears alongside a pie chart visualisation of the percentages of different tags that have been made.

8.3.1 Example Usage

To represent how the application VCTag may be used, the information gathered from the studies in Chapters 5 and 7 were used to compile potential usage scenarios.

Brian has been asked by his doctor to monitor his blood pressure, which has been diagnosed as being too high. Each day he takes a blood pressure reading using a monitor and then uses his mobile application to log the results. Occasionally, he notices that he did not perform his test correctly and that the result may have been false. In his mobile application he labels the entry as a false reading, but still enters the information as it may agree with a second test. Brian performs a second test and gets a new reading, which is lower than the previous test. He enters the new value and tags the result as understood.

Caroline is about to perform her evening blood pressure test and feels good, her blood pressure reading should reflect this. She performs her blood pressure test exactly as her nurse instructed her to do so. However, the result from the reading is higher than she was expecting. She enters the information into her application and labels it as a valid reading, but an unexpected one. Using the images she has previously taken, she attempts to reach a short-term understanding of the reading. However, she feels further investigation is need and turns to earlier dates in the chart and the statistic page for more detail.

8.4 System Implementation

Figure 8.1 shows a screen shot from the implemented VCTag application and displays the chart used to represent blood pressure and pulse values. The primary feature added to the VCTag application is the allowance for personalised 'tagging' of entered data by a user. Within the application, there are 3 possible tags which were described in the previous section.

The application allows for the entry of diastolic, systolic and pulse readings taken from the blood pressure monitor. Additionally, participants are able to use the camera on the mobile phone to add imagery into the graph, using a similar approach to that seen in Chapter 6. Both the device used to measure blood pressure, and the mobile phone on which data was entered, were issued to participants during the entry interview.

For the purpose of the study, there were three variations of the VCTag application developed:

1. **No Tag** - This version allows for the entry (Figure 8.1a) of blood pressure and pulse readings taken from a monitoring device. The results are then visualised in a list (Figure 8.1b) and graphical format (Figure 8.1c) on separate screens. Additionally, a screen to display brief statistics (Figure 8.1d), such as highest and low readings over specified periods of time, is also provided.

2. **Tag** - tagging of entered data is enabled with participants able to choose three different options to tag their data with. The tag chosen for a particular reading affects the colour that the representative entry on the list and graph screens appears as.

3. **Visualisation** - an additional screen is added to the application which provides a visualisation of the tag participants have made in the form of a pie chart. Additionally, aggregate

measures of the tags are provided in order to give feedback to the user about their overall interpretation of their measurements.

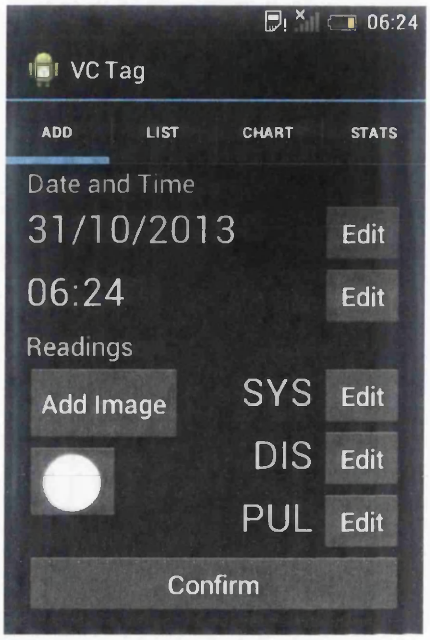
The 3 versions of the application were developed to provide a platform for the discovery of how tagging influenced participants' approaches to entering and interacting with their date. The NoTag system offered no form of tagging and acted as a baseline system, in which participants entered information as it would usually be recorded. The alternative 2 systems offered the tagging mechanisms with differing methods of presenting the information.

Data Entry - A screen (Figure 8.1a) that allows for a user to enter their blood pressure reading information. The date and time buttons when pressed display pop-ups which allow for the default values (which are set at the current values) to be altered using a spinner widget. Likewise, the values entered for the systolic, diastolic and pulse are also entered using a spinner, with the default value being set at an appropriate level for the type of information being entered. The camera button allows for an image to be taken, which will be added to the graph. Finally, the tag button opens a spinner which has 3 coloured options to represent a user's understanding and approval of the information entered.

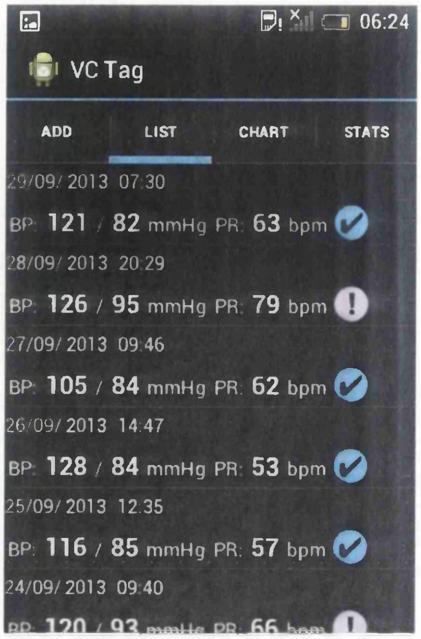
List View - All of the information entered can be viewed as a list on this screen (see Figure 8.1b). The data is presented in a chronological order, with the most recent values being at the top of the list. This screen also allows for the tags associated with an entry to be changed, allowing participants to update the representation of their understanding of a result. This is achieved by clicking on the relevant list entry which then presents the same widget as used in the entry screen for selection of a tag.

Chart - A more visual representation of the information that users enter (Figure 8.1c). The graph presents information by displaying a bar for each blood pressure entry, where systolic is the maximum value and diastolic the minimum. The bars reflect the colours that users entered as their tag of a reading, meaning that the bars can appear in 4 different colours. Additionally, the entered pulse readings are illustrated as a line graph and images taken appear on the chart.

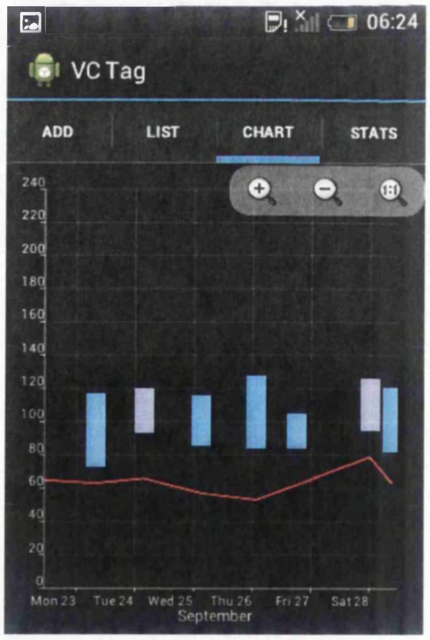
Statistics - A condensed presentation of information, allowing for users to see the highest, lowest and average readings over a set period of time (Figure 8.1d). Users can view information over



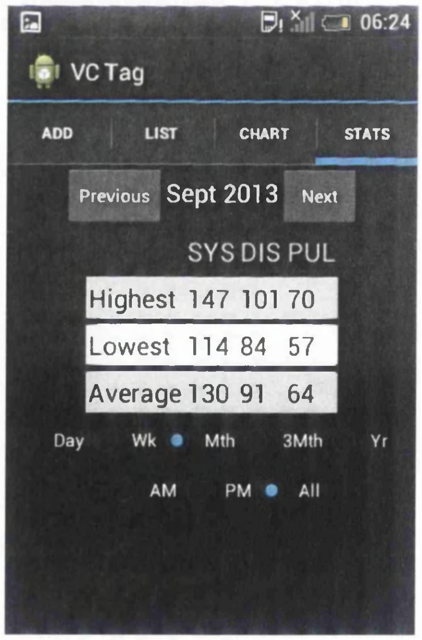
(a) Entry screen used to input information



(b) List of all entries made in chronological order

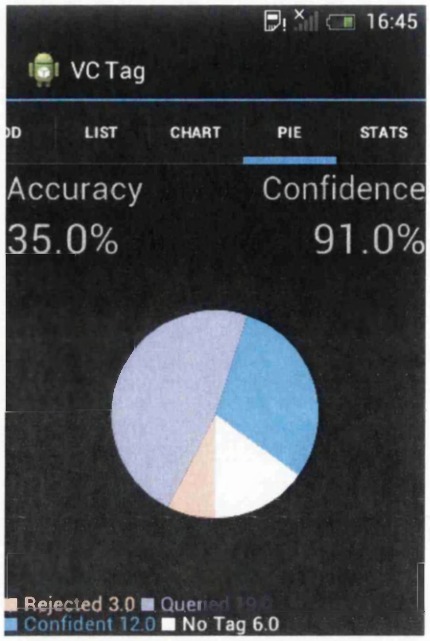


(c) Chart used to visualise information



(d) Screen to present statistical information

Figure 8.1: Screenshots of VCTag application



(e) Visualisation of user tag information

Figure 8.0: Screenshots of VCTag application continued

a single day, a week, month, 3 months and a year. This can be further refined by only viewing morning or afternoon readings. Users are able to cycle through each iteration and view aggregate information of previous periods of time.

Tag Information - Finally, this screen (Figure 8.1e) presents feedback to a user regarding the tags that they have made on their information. A pie chart displays the percentages of tags entered, to visualise how well a participant feels they are understanding their readings. A value is also presented indicating the percentages of the tags entered.

8.5 User Study

In order to gain an understanding about how the VCTag application would be used by people with blood pressure concerns, and how it may potentially encourage greater patient involvement and understanding in personally logged information, a six week user evaluation was conducted. This section outlines the design of the study and reports the key findings from the field evaluation.

8.5.1 Procedure

Participants were recruited through an email call sent to Swansea University student and staff email lists. The email briefly described the research being conducted, as well as the workload that participants would be asked to undertake.

To expand the potential participant pool, the hardware for the application was provided to participants in the study. For the purpose of the study, each participant was given a HTC Desire C android mobile phone (Figure 8.1). For this reason, all testing of the application took place using the same type of mobile phone. Additionally, participants were given a new blood pressure monitor (Figure 3.4) and those that completed the study were offered the opportunity to keep this monitor as they own.

Figure 8.1: HTC Desire C model phone given to participants during the six week long study period

Upon completion of the entry interview, participants were asked to use the application during a six week period. Throughout this time, participants were requested to use the VCTag application

Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6
Entry Interview	**Forming Groups**	**Week 1-2**	**Week 3-4**	**Week 5-6**	**Exit Interview**
All Participants	Group A (n = 10)	NoTag	Tag	Visualisation	All Participants
All Participants	Group B (n = 10)	NoTag	Visualisation	Tag	All Participants

Table 8.2: VCTag study deployment procedure

to log their blood pressure readings into the system. Depending on the variant of the application they were using at the time, this involved differing amounts of input, though none of the input was overly time-consuming and at most required six pieces of information to be entered (time, date, diastolic, systolic, pulse and tag).

Participants were asked to attend interview sessions at both the beginning and end of the deployment, with additional bi-weekly sessions during the study period. The bi-weekly sessions served as an opportunity to gather feedback from participants about the application they had been using, and to introduce a new variant of the application for the following two weeks. The new application given to participants at each stage closely matched the version they had previously been using, but with an alternative combination of features (as described in Section 8.4). Therefore, the application name remained the same on the mobile device, as did the pre-existing shortcuts participants had been using.

8.5.2 Entry Interview

Before entering into the six week study period, participants were asked to attend an entry interview. The sessions were conducted at Swansea University Computer Science Department in a bright, well-lit room. This interview focused on gaining insight into individual participants and their current perceptions of their own condition. In addition to this, a thorough knowledge of the participants understanding of existing management solutions that were available to them was also sought. The interview took a semi-structured approach and offered opportunity for more spontaneous discussions to happen. During the interview sessions, topics including self awareness of well-being and health management were also covered.

8.5.3 Exit Interview

Upon completion of the deployment period, participants were required to attend an interview session to provide feedback. The interview questions targeted an understanding about how the participants felt that had used the system over the trial. The data gathered from this interview was also to be used against that gather in the entry interview, to asses how each participants own attitude towards the management of their condition had altered, if at all. As with the first interview, this session took a semi-structured approach and covered issues such as the usage of the system, external strategy developed to motivate or maintain the patient-device interaction and the effect of weekly checking-in call as an additional intervention.

8.5.4 Bi-Weekly Sessions

As there were three variations of the VCTag application participants used each variant for an equal amount of time, each version was use by participants over a two week period. At the end of these two weeks, participants were asked attend a short session in which they would be introduced to an alternative version of VCTag. The new features of the application were introduced to the participants and they were also asked a short series of questions. These questions were focused on understanding the attitudes of participants to the features within the application. Measures of self-efficacy were also taken at each stage, in order to track any attitude changes that transformed during the study period.

8.5.5 Participants

Following an recruitment email to both Swansea University staff and the Swansea Over 50's network, a total of 20 participants were recruited for the study. All participants described themselves as having blood pressure conditions. There were 9 number of females in recruited, with the 11 males and participant ages ranged from 41 - 68. A detailed overview of individual participants can be seen in Table 8.3.

8.5.6 Analysis

During each interview session, notes were taken throughout which acted as both logging of important pieces of information, and as pointers towards notable points in the audio recording. Using the notes, a brief understanding of how each participant used the VCTag application was gained. To enhance this understanding, the audio recordings of the interview session were listened to in an

Group	ID	Gender	Age	Condition	Medicated	Time With Condition
A	P1	Female	62	Hypotension	No	3 years
A	P2	Female	55	Hypertension*	No	7 years
A	P3	Female	53	Hypertension*	No	5 years
A	P4	Female	55	Hypertension	Yes	9 years
A	P5	Male	56	Hypertension	Yes	2 years
A	P6	Male	56	Hypertension	Yes	10 years
A	P7	Male	60	Hypertension	Yes	5 years
A	P8	Male	56	Hypertension	Yes	1 year
A	P9	Male	55	Hypertension*	No	10 years
A	P10	Male	61	Hypertension	No	15 years
B	P11	Female	57	Hypotension	No	10 years
B	P12	Female	41	Hypertension	No	6 months
B	P13	Female	56	Hypertension	Yes	1.5 years
B	P14	Female	50	Hypertension*	No	4 years
B	P15	Female	57	Hypertension	Yes	6 years
B	P16	Male	51	Hypertension*	No	1 year
B	P17	Male	56	Hypertension	Yes	7 years
B	P18	Male	68	Hypertension	Yes	20 years
B	P19	Male	52	Hypertension	Yes	1.5 years
B	P20	Male	56	Hypertension*	Yes	5 years

Table 8.3: Details of participants who took part in the VCTag six week field study (* indicates a borderline case of hypertension)

attempt to gain further insights. This process also allowed for double-checking of the accuracy of the notes, and to obtain exact quotations, which were transcribed from the relevant sections from the audio recordings of the interviews.

An identical approach was taken during the bi-weekly and exit interview sessions. During these session, participants were asked to provide feedback on the application that they had most recently used using 7-point Likert scales. The Likert scales used during the interviews used 7 as a high or agreeable score, and 1 as a low or disagreed score. During the exit interview session, participants were also asked questions regarding their usage of the applications over the study period and for their preferred variation of VCTag.

VCTag also logged a variety of information during the study which allowed for confirmation of the descriptions given by participants. The application recorded all of the interactions that participants made, whether it be simply opening the application, or alterations made to the tag of an entry. Taking note of edits to tags illustrates that participants have engaged in the reflection of the data in order to alter their understanding of the information.

8.5.7 Predictions

Before entering into the study, a set of hypotheses were laid out which will be used to assess the impact of the VCTag application:

- **Prediction 1** - Though use of the VCTag application, participants' awareness of factors that impact on their condition will be raised.
- **Prediction 2** - The tagging mechanism employed in the application will promote moments of self-reflection around specific causes of blood pressure readings.
- **Prediction 3** - By regularly using the application, participants' confidence in their ability to manage their blood pressure will be raised.

These hypotheses will be used in order to evaluate the impact the VCTag application had on the participants' management of their blood pressure condition. During the later discussion of results, the outlined criteria above will be reflected upon.

8.6 Results

All twenty participants attended all interviews sessions and completed each stage of the application deployment during the study period. This section outlines the results of the study and presents a discussion of the impact the VCTag application had on participants' management of their own conditions.

The initial interview session revealed that six of the participants in the study were actively engaging in monitoring of their blood pressure prior to the study. Participants P3, P8 and P17 checked their own blood pressure at home in weekly intervals, with P3 and P8 recording their information on paper and P17 using an excel spreadsheet. P12 attended an occupational health clinic at their place of work every week for blood pressure readings. P7 stated that they checked their readings every

ID	Stage 3	Stage 4	Stage 5
P1	0.85	0.57	0.35
P2	0.69	0.87	1.15
P3	1	0	0.85
P4	0.65	0.32	0.34
P5	3.46	1.43	1.62
P6	1.31	1.14	1.68
P7	2	2.2	3.1
P8	2.46	1.36	1.37
P9	3.77	1.86	1.6
P10	0.5	1.16	0.63
P11	0.5	0.78	1.33
P12	1.23	1.32	0.87
P13	0.85	1.43	0.52
P14	1.93	1.58	0.67
P15	2.9	2.07	2.37
P16	0.93	0.41	1.5
P17	1.04	0.74	0.6
P18	1.43	0.81	0.11
P19	2.07	0.95	1
P20	0.93	1.41	0.87

Table 8.4: Average daily entries by participants at each stage of the study

other day and P19 took readings daily. Both of these participants recorded their results onto paper. All participants were regular visitors to health clinicians where blood pressure readings were taken. These visits typically ranged from intervals of 3 months up to 6 months.

8.6.1 Participant Usage

During the study period, participants entered a total of 1296 entries into the applications used. Across the participants, this makes an average number of 64.8 (standard deviation of 30.5, min = 30, max = 137, median = 59) entries. On average, participants made average daily entries of; 1.53 in stage 3, 1.12 in stage 4 and 1.12 during stage 5. Participant average daily entries across all stages of the study are presented in Table 8.4.

Participants also entered a total of 787 tags into the application, with rejected readings contributing 129, queried 84 and expected 574 to the total. A summary of participant's individual tagging of results can be seen in Figure 8.2.

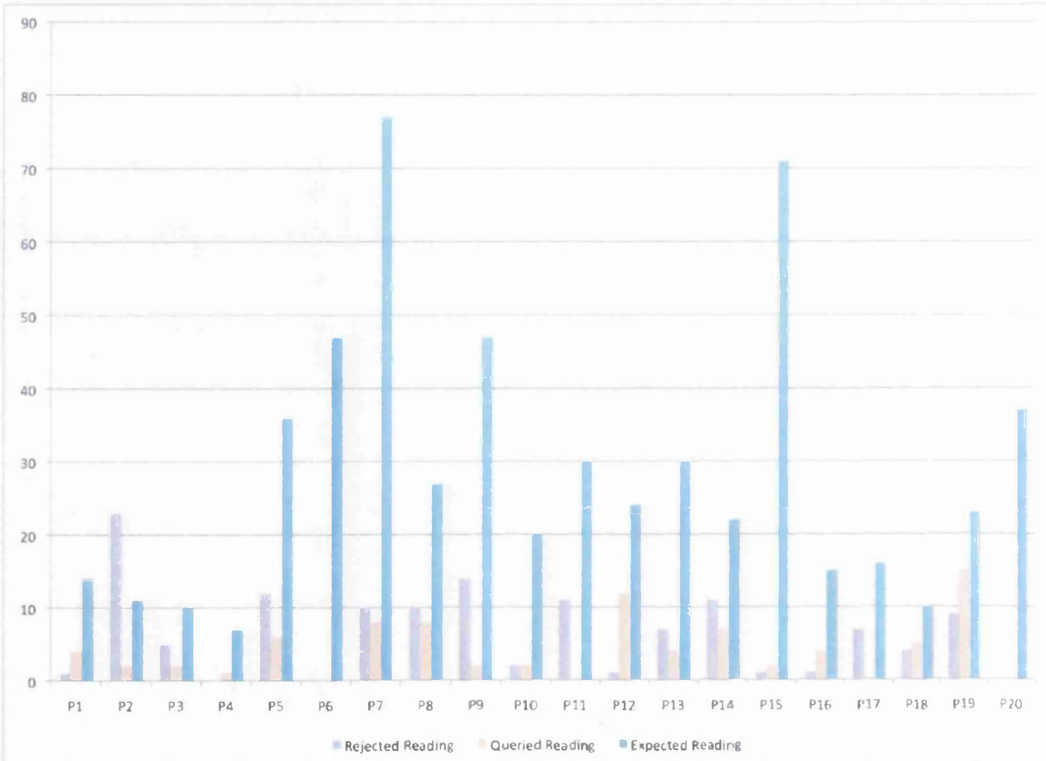


Figure 8.2: Tags made be each participant

8.6.2 Subjective Ratings

All of the results presented in this section were tested to determine whether the datasets were a normal distribution. A Shapiro-Wilk's Normality Test [155] was used on each collection of data and it was found that none of the data presented in this section formed a normal distribution. As a result, the Wilcoxon Signed-Rank tests performed report the W values.

During the entry interview sessions, participants were asked to score their confidence of managing their condition, with the average amongst participants being 5.05 (standard deviation of 1.53, min = 1, max = 7, median = 5). Participants were then asked the same question at the end of the evaluation period and the resulting average across participants at this time had risen slightly to 5.65 (standard deviation of 1.3, min = 3, max = 7, median = 6). A Wilcoxon Signed-Rank Test on the values provided by participants before and after the study period however suggests that this is not a significant difference ($W = 35.5$, $p = 0.16$). Over all of the participants, 5 stated that their

	Ranked Best Application		
Application	**Group A**	**Group B**	**Overall**
NoTag	2	1	3
Tag	4	7	11
Visualisation	3	2	5

Table 8.5: Participant preferred application rankings, provided during the exit interview session

confidence had not changed during the study, while 10 improved their scores and 5 gave lower scores. A full range of responses from participants can be viewed in Figure 8.3.

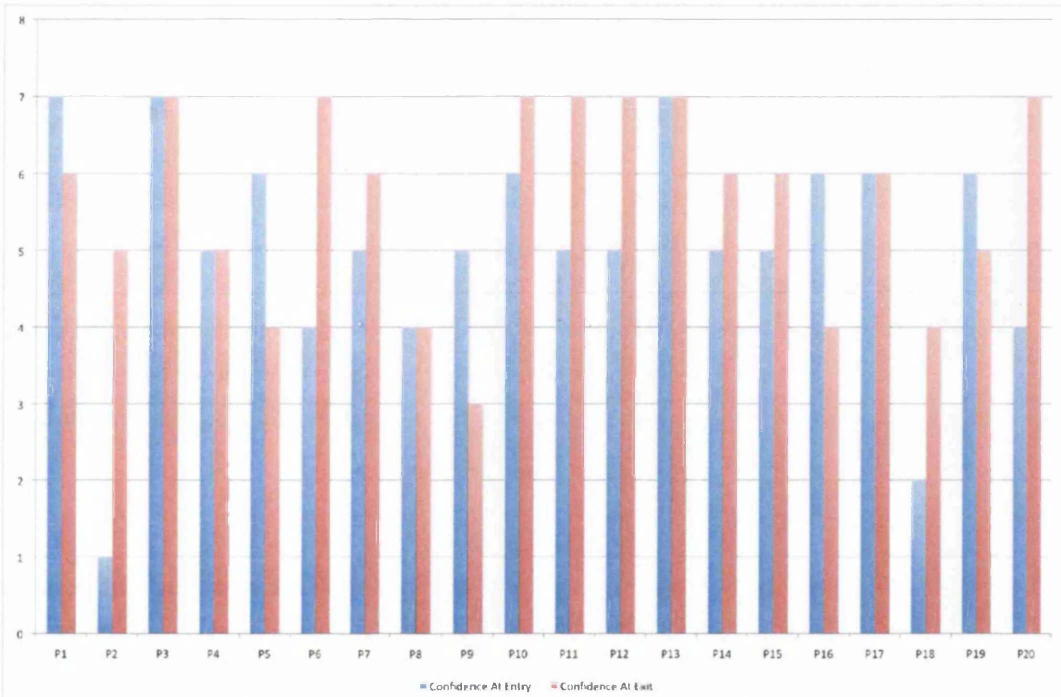


Figure 8.3: Participant's confidence to manage their blood pressure condition at the start of the study and after using the VCTag applications

Upon completion of the in-situ study, participants were asked to score their own likability of the tagging mechanism introduced. The average response from participants on a 7-point Likert scale was 5.25 (standard deviation of 1.74, min = 1, max = 7, median = 6). Similarly, participants were also requested to score how necessary they felt tagging was in the management of their condition. Participants provided an average score of 5.7 (standard deviation of 1.66, min = 3, max = 7, median = 6).

Participants were also asked to rate the usefulness of the features in the applications. Firstly, participants were asked to rate the list screen without the tagging information present, this yielded an average response of 4.42 (standard deviation of 1.95, min = 1, max = 7, median = 5). Once the tagging had been introduced, participants were asked the same question of the list screen which produced a slightly higher average of 5.10 (standard deviation of 1.7, min = 1, max = 7, median = 5). A Wilcoxon signed rank test suggests this increase is a significant result. However, the size of N (8) is not large enough for the distribution of the Wilcoxon statistic to form a normal distribution, and therefore an accurate p-value cannot be calculated. The result is significant in the W-value, (W = 2.5, W-crit = 3) at a level of p ¡= 0.05.

Perhaps surprisingly, the perceived usefulness of the chart decreased after the introduction of the colour coding from an average of 5 (standard deviation of 1.6, min = 1, max = 7, median = 5) to an average 4.25 (standard deviation of 2.1, min = 1, max = 7, median = 4.5). The visualisation of the tags in the final screen was rated by participants at an average of 5.25 (standard deviation of 2.07, min = 1, max = 7, median 6) for the question "How useful is the visualisation of tags?"

Finally, participants were asked how likely it was that they would recommend the application to another person. This results in an average response of 5.95 (standard deviation 2.06, min 1, max = 7, median = 7), suggesting that participants believed that was value in this form of monitoring.

8.6.3 Participant Feedback

During the interview sessions, the participants also provided feedback regarding both reasoning behind their scores for the Likert scale based questions, and their opinions and usage of the application during the study period.

Tagging

The addition of personalised tags to blood pressure readings was generally well received by the participants. For example, P14 stated that:

> *"it (tagging) makes you stop and think rather than just putting information in. It makes you look for reasons."*

The inclusion of tagging also appeared to add additional meaning to the information presented on the list view screen (Figure 8.1b). Comments such as *"it's now more useful than the list without those tags."* (P3) and *"It is more useful this time with the tags. It shows me that the reading is good and I understand why."* (P7) reinforce this claim.

Participants also described how the expected reading was a condition that was an achievement. P15 commented *"You are driven to get as many ticks as possible."*. P1 experienced a similar situation, but stressed the importance of considering past actions; *"When it was a tick, I was happy with the reading. Otherwise, it's useful to think back on what I've done."*

Participants also described the reflective process that they engaged with through the tagging mechanism:

> *"It does make you think about what you could have done differently."* - P3

> *"It certainly adds more interest, makes you think a bit more. The odd times when I questioned it, it flagged it up, and made you think it through why those figures appears."* - P7

> *"The tag allows you to keep a context of why it is what it is."* - P13

> *"What I found useful is to put something down on the day and go back and alter the tag when I figured it out."* - P19

However, while the tagging feature allowed the above participants to determine causes of individual results, it was not always the case that this process was perceived as a useful process:

> *"With the tags, it help you understand why your readings are what they are, but I'm not sure it's helping the management."* - P4

The causes of unexpected readings were not always immediately clear amongst all of the participants groups. The suggestion by P4 is that understanding the causes of results may not be a sufficient influence over the more general management of the condition.

Tag Visualisation

The visualisation of entered tag information (Figure 8.1e) was also generally well received by participants. The method of providing an overview of the tags made, provided participants with an understanding of how well they were understanding their results:

> *"Every time I see the pie page, I'm reassured that I was doing well."* - P1

> *"It just makes me think that I was in control."* - P4

> *"my confident level was quite high which indicates I have a good idea of what cause my readings. It reinforces that I was doing it right."* - P17

Attitudes towards the visualisation page also changed upon the removal of the feature, which participants in Group B experienced. Those in Group B were asked to rank the usefulness of the feature on a 7-point Likert scale after having access to the page, giving an average score of 4.4 (standard deviation of 2.5). However, after having the feature removed and using a version of the application without the visualisation page, participants ranked the usefulness of the page as 5.2 (standard deviation of 5.2). This increase suggests that participants felt that there did exist some insights that could be achieved through using this feature. For example, P15 highlighted their own experiences without the feature:

> *"I didn't think it was that useful before because my blood pressure level was quite high and I always knew why. But last week my readings were all over the place, so the visualisation became very useful but it wasn't there anymore."* - P15

Similarly, participants who did not make frequent use of the feature suggested that this was a result of them understanding their results. While P6 stated that they did not make use of the tag visualisation page, they did state that:

> *"if I haven't got 100 accuracy and confidence, I would pay more attention to it."* - P6

This approach towards interacting with the application suggests that P6 was in a period of control that they were satisfied with. A similar situation had been described by participants in the Con-Cap evaluation study (Chapter 7). An emerging pattern therefore, is potentially that applications that support chronic condition management may have varying levels of usefulness to individuals, depending on their own satisfaction of their condition. In the above quote, P6 suggests however, that should their own tagging have suggested a lower score from the application they would have focused more on the reasoning behind a result. Perhaps then, applications in this domain should be ready-to-hand in both the short-term and long-term. Ready-to-hand in the short term would deal with scenarios in day to day life (such as recording an incident as it occurred), whereas long-term ready-to-hand would allow for participants to vary their level of engagement depending on their situation.

8.7 Discussion

The application described in this chapter - VCTag - allowed for individuals to capture blood pressure levels and label the results based on their own understanding of the information. The application was designed to allow participants to personalise their health related information by allowing for 'tagging' of results obtained from blood pressure monitoring devices. All of the participants engaged with the application frequently over the study period, with the exception of one participant who, during one stage of the study, made no entries onto the application. In general however, the feedback received from the participants in the study suggested that they reflected on their blood pressure results more than they previously had before the study:

> *"If you get 100 it means you know yourself very well, but a lower percentage can trigger your self reflection."* - P11

"It's likable and leads you to identify, reflect and put in context (the readings). It gives you a level of control, I need to think about why." - P13

The increase in frequency of monitoring also led to participants being able to make discoveries about their own management:

"I was really disappointed with my readings when on holidays." - P19

Potentially, the activity of taking a holiday may have introduced behaviours which negatively impacted on the participant's blood pressure. Factors such as reduced exercise and increased alcohol, which are likely outcomes of a holiday, are removed from practice that is considered *'healthy'* in blood pressure management. However, by engaging in more frequent monitoring, the participant was able to detect the negative outcomes the change in behaviour had on their condition.

8.7.1 Usefulness of Tagging

Generally, participants appeared to feel that the tagging mechanism was a useful feature. On average, participants rated the tagging with a score of 5.25 in terms of it's usefulness. More specific comments give a clearer picture of how the participants viewed the utility of the feature:

"It makes you understand all of your readings and why it was like that. It makes you think why you got them in that particular moment." - P2

"It is useful, help you stop and think. You have to do something, to reflect." - P8

"I feel more relaxed, and in control now. Not as anxious as before, when I go to the doctors." - P14

Clearly then, some of the participants viewed the tagging mechanism as a method of achieving a greater understanding of both their individual results, and overall condition. P14 in particular described how the method of tagging had led to a more relaxed view of his condition, which assisted in this calmness while visiting a clinician's office for a regular check-up. The 'White Coat' effect has been noted by Blood Pressure UK[2] as a contributing factor to individuals receiving higher readings while at a clinical setting. Such instances could potentially mask the true level of an individual's condition and lead to incorrect records of health.

P2 and P8 illustrate how the application enabled them to think back of past actions and the reasoning behind their blood pressure readings. By facilitating this process, those who use the tagging mechanism could potentially make greater insights into their condition. Discovery of individual factors and causes of readings were noted by participants which in turn lead to alterations to both their daily lives and management of the condition.

8.7.2 Participants' Changes to Condition Management

The participants who took part in the study appear to have become more aware of factors that affect their condition. As noted in Section 8.6.2, ten of the participants felt their condition to manage their condition increased as a result of using the application, while five felt their confidence had decreased. There are several potential reasons behind the values provided by participants included the possibility that participants had the pre-existing attitude that there is nothing they could do for the management of their condition. Others however may have believed they were in control of their condition, but upon the further inspection provided by the application, they may have discovered that they needed to take a greater interest in their condition.

The combination of increased levels of monitoring, coupled with the usage of the VCTag application, led to participants making new discoveries about their conditions. The process of actively monitoring their conditions during the study led to several participants altering their behaviours:

> *"I'm now able to identify why it was out of range. It's beneficial for me to understand what's going on and allow an opportunity to change."* - P13

> *"I've learned to give myself 5 minutes to sit down first."* - P1

[2]Blood Pressure UK page on the effect of White Coat - `http://www.bloodpressureuk.org/BloodPressureandyou/Medicaltests/Whitecoateffect`

> *"It made me realise that taking my tablet is important. It has some effect."* - P4

P1 and P4 discovered that their procedures did in fact, have implications on their blood pressure readings. In the case of P1, the act of resting before taking a reading would have allowed for the blood pressure to reduce due to the rest period. P4's case however, is a greater change in behaviour. By tracking the readings on a more frequent basis, the participant was able to detect a trend relating to their medication. Similarly, P16 discovered the impact that exercise had on their blood pressure:

> *"I didn't expect exercise to change my readings that much, but it did. Occasionally when I didn't do any exercise, my readings get really high. And I wonder could it be normal, or could it be because of lack of sleep and exercise. But when it comes back to normal, I didn't pay attention to it anymore."* - P16

The suggestion that attention diminished once a situation had returned to a *'normal'* suggests a similar pattern to the Diabetes Management Cycle defined in Chapter 5. Likewise, the usage of the VCTag application appears to be similar to that of the ConCap application (Chapter 6) in that both were used most frequently during times that were outside of what a user felt was *'normal.'* Yet the VCTag application appears to have introduced new behaviours onto participants:

> *"I think it has a positive effect on me. Made me more disciplined."* - P8

P17 realised coffee was having a negative impact on their health and increasing their blood pressure levels at the time of readings. To resolve the issue, the participant *"switched to instant coffee for de-caff."* Rather than drinking regular coffee, the participant made a conscious effort to now only drink decaffeinated forms of coffee. Similarly, P3 became aware of the impact weekend activities had on blood pressure. Their blood pressure readings typically increased at weekend due to the decrease in physical exercise and the increase of alcohol intake.

P10 Became aware of raised blood pressure levels during study as a result of factors such as driving, gym session, stress and work around the house.

8.7.3 Possible Barriers to Engagement

The approach taken in this Chapter differed from the procedure conducted in Chapter 7. In the previous Chapter, participants used their own mobile devices to run an application during the study period. However, in the current study participants were given devices that they could make use of during evaluation of the VCTag application. Several differences have been noted between the two user groups as a result.

By using personal devices in Chapter 7, participants were not required to carry any extra devices or technology with them. Whilst most participants in the current study appeared to use the introduced phone frequently, some elected to associate it purely with the blood pressure monitor.

The tagging feature was not fully utilised by all participants. As can be seen in Figure 8.2 participants P6 and P20 marked all of their readings as understood and the logs of their interactions show no edits were made to their results.

P3 was a borderline case of hypertension, so may have been less likely to engage in frequent monitoring at all times during the study.

> *"For me inputting data and sometimes tag the unexpected ones just to flag out the abnormal is good enough. the more I use it the more I like it. But you need to analyse by yourself which I don't like. It's better if it helps you analyse the data and tell you what to look out for, because not everyone is an expert."* - P16

> *"I don't find it very useful because I need to tag more than one thing. My readings fluctuate a lot. Possibly because of my medical history."* - P9

Participants also highlighted concerns regarding external factors that could affect their blood pressure that was outside of their control:

> *"Most things that give you stress is beyond your control."* - P5

> *"There are things that I have no control of that can affect my blood pressure like my dog barking."* - P19

Stress is known to increase blood pressure and while these readings are important for a participant to be aware of, they may unnaturally push the values presented in the details screen (Figure 8.1d) away from a true representation of their overall health picture.

However, not all participants were satisfied that they were in fact able to gain a sense of their overall health from using the application:

> *"I think it's meaningless without a medical background. As long as you aren't medically qualified, you don't have a clue. It would be nice if the app comes with educational materials of blood pressure."* - P18

While a valid issue to raise, the purpose of this particular study was to facilitate users in their own understanding of their health information. There are inevitably individuals who feel uncomfortable with making decisions regarding their health without the assistance of expert clinicians. Such an intervention is beyond the scope of this particular study, but it raises a valuable insight into the concerns of some participants.

8.7.4 Affect of Additional Functions

While the tagging mechanism was intended to be the primary form of providing informative feedback to the participants, the other functions of the application also appear to have played a key role. The statistic screen (Figure 8.1d) is such an example:

> *"Every time I logged new information, I would review my history to see what affect the new data has on it, especially the stats."* - P19

The statistic screen allowed for participants to view their highest, lowest and average readings of the information they had entered, over a variety of time periods (such as day, week or month). This presentation of information provided a general overview of information and allowed participants to view the extremities of their information, as well as the general trend.

Unlike the statistic screen however, the photo tool was not generally used by participants. The feature was included as a result of the feedback from participants who took part in the study in Chapter 7, however the enthusiasm for the feature did not transfer across all participants. A potential reason for this is the introduction of a new mobile phone to participants, as this is unlikely to have become their primary device during the study period. As a result, participants described how the phone became associated with the blood pressure monitor and was often left at with the monitor. However, there were occasions when the feature was viewed as a useful asset:

> *"Photo is instant, and tagging requires thinking, the combination of photo and tag is good for me."* - P14

> *"I'm an excel pie kind of guy. Photo and tag is non relevant to me now, but in the future, if my blood pressure goes up, they will be very useful."* - P20

Here, P20 describes how should there be a need for further investigation into their own information, then the level of usage of the additional features would increase. The feedback from the participants in Chapter 7 similarly suggested that participants would make greater use of the application features during times of uncertainty.

This process appears to match with the Diabetes Management Cycle defined in Chapter 5. While this was not the primary target of this research, there does appear to be suggestions that those with cardiovascular conditions may undertake a similar process to those with diabetes.

8.7.5 Study Predictions

Early in this section, a set of hypotheses were defined relating to how the VCTag application would facilitate meaningful reflection on blood pressure information. By using the results gathered from the field study, each hypothesis is responded to and an outcome is presented.

Prediction 1 - Though use of the VCTag application, participants' awareness of factors that impact on their condition will be raised.

Several participants described instances where using the VCTag application had highlighted factors that impact on their condition. For example, P1, P4 and P13 described how they had become more aware of how their actions could affect their blood pressure scores (Section 8.7.2). Through use of the applications, it appears that the participants in the study were indeed able to become more aware of factors that were affecting their condition. Instances such as; correct testing procedure, proper intake of medication and affect of exercise were all described by the participants.

Prediction 2 - The tagging mechanism employed in the application will promote moments of self-reflection around specific causes of blood pressure readings.

Several participants (P3, P7, P13, P14 and P19) provided feedback during the study about how the tagging mechanism prompted them to think about causes of blood pressure results. P7 stated that the tagging feature made them think more their results, and P19 stated that the ability to change the tags informed them of where to focus their attention. Instances of self-reflection were therefore apparent throughout the participant group.

Prediction 3 - By regularly using the application, participants' confidence in their ability to manage their blood pressure will be raised.

As described in Section 8.6.2 and in Figure 8.3, 10 of the participants recruited into the study increased their confidence scores. While this makes up half of the numbers recruited into the study, the remaining participants felt their confidence levels hadn't changed (5), or had become worse (5). It seems that this prediction is partly true, but cannot be claimed to be conclusive during to several participants giving lower scores. It is possible however, that the visualisation of the results had indicated to the participants that their control was not as good as they believed it to be.

8.8 Conclusion

This Chapter has described the evaluation of the application VCTag, which was designed as a probe to investigate the affect mobile technology could assist in an individual's ability to reflect on health information. Twenty participants were recruited onto a six week study, in which time the participants entered information gathered from blood pressure monitors into the VCTag application. At each point of entry, participants were able to add a 'tag' to the entry, indicating their understanding of the result. Through this process, points of interest to participants were highlighted.

While all but one of the participants increased their level of self-monitoring, the tagging mechanism appears to have played a crucial role in highlighting points of interest to individuals. Several of the participants indicated that the use of the application was a leading factor in their decisions to alter aspects of their daily lives (such as taking up de-caff coffee, or stricter adherence to medication regimes).

By facilitating the personal contextualisation of health information, the individuals in the study were able to highlight points of information that were of interest to them. While many existing systems provide information based on clinician health measurements (e.g. Smith et al. [156]), those with chronic conditions at times require less formal forms of feedback. The individuals with the conditions become expert in their own personal health and can make decisions on their own treatment through their own understanding.

8.9 Summary

This Chapter presented a longitudinal evaluation of a new tagging mechanism for health related information. This formed part of the research agenda by contributing to research aims 2 and 3 (as described in Chapter 1). The main contribution of this Chapter is the evaluation of the tagging feature. Through this feature, participants become more aware of factors (such as correct procedure and exercise) that were influencing their health results.

By allowing participants to interact with their health data, they were promoted to consider the reasons behind health results and to determine the causes. Several of the participants in this study were subsequently able to learn more about their condition and improve their confidence in their ability to manage their blood pressure.

Chapter 9

Discussion and Conclusion

The preceding Chapters have detailed the research conducted and each has acted as a precursor to the following Chapter. The overarching outcomes of this thesis are described in this section by collating the results of Chapters 3, 5, 6 and 8 and aligning them with the previous research literature presented in Chapter 4.

This Chapter begins with a review of the problem that this Thesis has targeted its research towards. The general findings of each Chapter then follow, before a generalisable set of contributions are outlined. A deeper discussion of the role mobile technology may have in supporting self-reflection on personal health information then concludes the Chapter.

9.1 Overview of Problem

Chronic conditions are an increasing problem for both the individuals that are afflicted with them and the global community [144, 145]. There exist large financial concerns about the treatment of people with these conditions, and ensuring people adhere to good behaviours that will improve their long term health and reduce the financial costs of treating these individuals.

Chronic conditions are becoming an ever increasing global concern. The number of people who are afflicted by these long-term conditions is increasing causing both health and financial concerns. Developing support to assist those in reducing the longer term affects that the conditions may have is essential. In several of these conditions, strict and tightly controlled management helps to prevent severe associated complications. This thesis has concentrated on 2 diseases; diabetes and cardiovascular conditions, the potential complications of these include:

- Diabetes - problems with: eyes (retinopathy), heart (cardiovascular disease), kidneys (nephropathy), and nerves and feet (neuropathy). [28]
- Hypertension - stroke,heart attack,embolism (occurs when a blood clot or air bubble blocks the flow of blood in a vessel) and aneurysm (occurs when a blood vessel wall bursts causing internal bleeding) [29].

Individuals must be engaged with their own information, to be able to make informed decisions about how to treat their conditions. Collecting, interpreting and acting upon various amounts of information is crucial to ensure they are able to effectively manage their health. This Thesis has focused itself within this area. Specifically, the notion of assisting individual's during *unanchored* [95] settings has been the key research theme.

During the early stages of this Thesis, it became apparent that within the HCI community research into digital solutions for health-care was a rich area of interest. There have been several previous investigations into using mobile devices to assist in during personal health management (e.g. [97, 113, 115, 116, 131, 156, 186]) However many of the interventions relied on systems which connected individuals to external sources of information and little research has been conducted into supporting individuals during unanchored settings, while they are away from external expert or social guidance and advice.

Subsequently, the focus of this body of work has been targeted an achieving a deep level of understanding of how existing devices are used in practice and current management strategies employed by individuals. Following this understanding, studies were conducted to understand the impact of new technological solutions on people's understanding and management of their health conditions.

9.2 Summary of Chapter Findings

Chapter 1 set the scene for the research of this thesis, namely that the issues surrounding management of chronic conditions was to be investigated. The following Chapter further expanded upon the management of diabetes, and the devices that are used during the process.

Chapter 3 outlined the existing tools that people with diabetes presently use to manage and treat their condition. It emerged that devices were moving towards adding context to the results that they recorded from users. This contextualising of data is currently in a simple form, allowing patients to 'tag' glucose readings with information relating to the time of a result (i.e., pre- or post-meal). Given the wealth of factors that affect blood glucose control, it seemed logical that a wider reaching collection of information would be useful.

A review of the existing literature (Chapter 4) highlighted previous approaches in introducing capture and access methodologies into health management systems. However, it emerged that several previous projects had focused on systems which also leveraged support from external sources, such as clinicians. Yet, an individual's management of a chronic condition is one that is undertaken at all hours of a day, and typically away from access to expert opinions of clinicians.

To further enhance this argument, a series of interviews were conducted in Chapter 5 with individuals who had diabetes for long periods of time. From the discussion held with the participants, it became clear that there existed situations where the ability to capture a moment would provide a highly useful insight in future scenarios. Thirteen people were recruited onto the study and offered insights into their own personal experiences and strategies with their condition. Issues such as forgetting regular activities and the challenges around unusual situations were key outcomes of the interviews conducted. This data then informed the later design of applications in the subsequent Chapters. The 5 key components of the Diabetes Management Cycle are; Monitoring, Habits, Confidence, Unusual Situations and Concerns. The application ConCap appeared to have been most frequently used during times of unusual situations and concerns. VCTag however, seems to have been used during more normal times of management, which is perhaps due to the more prescribed nature of blood pressure management.

In order to resolve the earlier thinking in relation to providing contextual information, Chapter 6 described the development and evaluation of a mobile application aimed at offering this support. ConCap was used by 12 participants over a 4 week trial period. The system allowed participants to capture images and location data alongside inputted glucose readings and insulin dosage units. By providing rich media in the form of images, participants were able to add a greater context to the glucose readings that they were experiencing.

Building on the discoveries made in Chapters 5 and 6, a second mobile application was developed to support efficacy amongst people with high blood pressure. This system allowed for participants to add meaning to the results that they entered into a database, indicating whether they had a good knowledge as to the reasons behind a result. By allowing participants to mark results in this manner, they were able to target particular points of interest that they themselves had marked out as needing attention. The application was trialed with 20 participants over a 6 week study.

9.3 Research Contributions

This research in this thesis has been motivated by the potential to enhance the management of these conditions, through meaningful collection of both data already recorded and additional streams of information. Chapter 1 outlined the following key research questions that were to be targeted in this research, each research question is now responded to based on the findings of the studies conducted.

A model of diabetes management processes.

A deeper understanding of the management practices of people with diabetes was presented in Chapter 5. By obtaining this knowledge through a user study, the existence of a rich design space in which to provide support to people with chronic conditions was revealed. The results of this study extend the previous work of Mamykina et al. [115], who presented a model of the *'Diabetes Decision Cycle'*. While the previous work highlighted the processes that individuals perform when determining causes behind glucose scores, it omitted some external factors which became apparent in the study conducted in Chapter 5.

An evaluation of lightweight and ready-to-hand methods of information capture to enhance diabetes record keeping.

Chapter 7 presented work which built upon existing research ([113, 156]) to investigate how ready-to-hand methods of information capture could facilitate self-reflection on personal health information. The previous work had introduced imagery as a method of data capture relevant to health management. However, Mamykina et al. [113] relied not only on personal interpretation of information, but also of external sources.

Smith et al.'s [156] work was closer to the themes in this Thesis in that the images were used for personal reflection during unanchored settings. However, their system was desktop based, reducing the ability for people to check results away from a fixed point. The participants in the studies described in Chapters 3 and 5 stated that they rarely used desktop based interventions provided by their glucose monitor manufacturers. The approach in this Thesis (Chapter 7) found that the ability to capture imagery information on a phone and store alongside glucose results allowed participants to record meaningful information.

An evaluation of personalised tagging of health information to promote awareness of points of interest in health information.

Self-reflection relies on involvement from the individual, and the VCTag application introduced a 'tagging' mechanism to allow for users to place their own meaning onto data. Personalised tags of results created a greater sense of control over the information, people with chronic conditions are often aware that their own records may differ from clinical guidance, but are within their personal pre-determined safe zones. By allowing people to tag results with their own understanding, opportunities for greater focus on results were presented.

9.3.1 Memory

During the course of the deployment studies conducted (Chapters 7 and 8), participants have highlighted instances that enabled them to remember events that had taken place. As stated by Endel Tulvig [173], there exist two forms of memory: semantic and episodic. The instances of memory described by the participants in the ConCap study are examples of episodic memory, in that they enable participants to remember specific events.

For example, Matt recorded images into his application that would trigger recall of events that he had been engaging with, such as attending sports events (Figure 7.9). Likewise, Lauren captured images of roads to signify days when she walked to work, rather than taking public transport.

In contrast, the tagging mechanism used in the VCTag application appears to have enhanced participants' semantic memory, in that they were now aware of how more general factors might affect their blood pressure results. Several of the participants commented on how they had become more aware of factors that had affected their blood pressure scores. It is possible therefore, that the participants will subsequently be able to remember that information in the future.

From the responses gained from participants, it appears as though the lightweight capture methods of ConCap support episodic memory and the tagging feature of VCTag enhanced semantic memory. However, as these issues were not the core focus of this work they were not fully evaluated and will require further investigation in the future.

9.4 Mobile Technology for Reflection

The main motivation of this thesis was to develop techniques to support self-reflection on personal health information in a mobile context. From all of the studies and user evaluations completed, it became clear that mobile phones have a key role to play in the management of long term chronic conditions. Several participants that took part expressed an interest in sustained usages of the applications (or potential applications) in their everyday life. For example, the participants who used the 3 variants of the VCTag application requested that each app file be made available beyond the research study. The ability to capture situations in through a rich media format was seen as a simple, yet meaningful process. Participants also stated that the ability to personalise their results was also a useful asset.

However, the positive attitudes towards longer term usage were not expressed by all participants. Some of the participants were already comfortable with their management, and knowledge of their conditions. For these people, there appeared to be little benefit to a more intensive monitoring of their condition. As stated in Chapter 5, those with chronic conditions can, over time, develop habits which control their condition. Almost ritualistic patterns often remove the potential for unusual, or out-of-the-blue, situations to happen. Without these extraordinary occasions, participants largely know what will happen with their own conditions through a normal day. This is reinforced by ensuring that similar foods are eaten, at similar times of day and in similar portion sizes in the case of people with diabetes.

There appear to be two conditions which must be met in order for mobile technologies to be accepted into the daily lives of individuals with chronic conditions. Based on the findings of Chapters 5, 7 and 8 which have investigated diabetes and blood pressure management, this Thesis presents the notion of ready-to-hand in both the short- and long-term scenarios.

By using Heideggers [72] original presentation of *ready-to-hand* and advocated by Winogrand and Flores [185] as key considerations in designing mobile apps for chronic condition management. The notion of ready-to-hand promotes the idea that digital systems should be immediately available when required but at the same time, they should not be obtrusive in their nature.

This is a particularly appealing concept when considering the feedback received from participants in the studies completed. Many participants spoke of the burden of health management, with the need for continuous measurements being required, calculations of medication and logging of information forming crucial parts of the processes.

When also considering the Health Belief Model [78] (discussed in Section 4.4), the notion of ready-to-hand may alleviate some of the negative aspects of attitudes towards the health management behaviour. Existing health management systems provide barriers to the individuals who are intended to use them. For example, desktop based systems for glucose monitors typically require specialise software, cables and conscious effort from users to upload the information to a computer. When considering the already extensive set of health management processes that individuals are engaged in, the desktop systems are often a step too far.

By providing a system which requires less input from users, and is stored on a person at all time, it is possible to reduce the perceived barriers to recording health information. During the two deployment studies (Chapters 7 and 8), participants were requested to enter information as they believed was necessary. Yet, due to the immediate availability of the applications, a great amount of information was entered. Participants in the ConCap study took pictures, which were not central to their existing management, and the participants in VCTag described the process of editing their tags.

Therefore, the lightweight and ready-to-hand methods used in the designs of ConCap and VCTag have been defined as properties. The notions of *Ready-to-hand Short-Term* and *Ready-to-hand Long-Term* are presented below:

Ready-to-hand Short-Term

During the small study conducted in Chapter 3, participants provided feedback suggesting they were concerned with the number of devices they had to keep on themselves at all times. Additionally, in Chapter 5, concerns were raised about the unusual nature of interacting with glucose monitors and insulin injections, suggesting that these interactions brought unwanted attention. Therefore, a decision was reached to support management practices in an unobtrusive manner, on a *normal* platform.

Given the ubiquity of mobile phones and their unremarkable nature, they are a suitable platform to fit with participants' concerns. Another key attribute of the devices is their increased functionality and their ability to capture information using a variety of media. The ConCap and VCTag applications described in this Thesis employed methods of capture that required limited amounts of input from a user.

Typically, the interactions required were based on a few button presses, rather than longer forms of entry. As those with chronic conditions feel that chronic conditions can already take up too much of their time, requiring longer forms of interaction is unwise. Instead, it is far more appropriate to provide ready-to-hand mechanisms for quick capture of information. To achieve this, the ConCap application made use of image and location information, and the VCTag application allowed for personal tagging of health results.

Ready-to-hand Short-Term interactions should be unremarkable within their context and allow for quick, simple methods of interaction. By adopting this approach to the design of mobile applications for chronic condition management, users are more likely to engage in recording of health information.

Ready-to-hand Long-Term

Chapter 5 specified the Diabetes Management Cycle which suggests that those with diabetes move through times where their monitoring frequency changes. This change is typically due to a level of comfort being obtained, or as a result of change which leads to more intensive monitoring to determine causes. Therefore, applications which are designed to support the management of chronic conditions should facilitate infrequent interactions.

As all of the participants in the studies in this Thesis have described instances where their monitoring decreases. For instance, in Chapter 7 the participants were placed into groups depending on their current state of management (standard (rigid), standard (fluctuating), change (voluntary) and change (forced)). The current state of their management will directly impact on they engagement into logging of health information.

It would be unwise to develop applications which require frequent interactions on a continual basis. Systems which notify users after a period of inactivity may not be serving the best interest of the individual, and could potentially cause annoyance.

Instead, applications in this domain should offer timely support when the individual is in need. Few of the participants in the studies were actively engaging in frequent recording of information, instead dipping into such activities when their own personal interest in the information increased or when their situation changed sufficiently that they were forced to act

9.5 Research Scope and Limitations

9.5.1 Study Duration

While the in-situ studies described in Chapters 7 and 8 took place over a number of weeks, the results cannot be used as a reliable indicator for use over longer periods of time. As has been discussed in this Chapter, there are times in which those with chronic conditions engage in more frequent monitoring of their conditions. The studies in this Thesis took place over 4 and 6 week periods, which potentially may not have been sufficient periods of time to capture such instances of uncertainty.

9.5.2 Participants Recruited

The participants recruited in Chapters 3, 5, 7 and 8 potentially represent a subset of the general population of diabetes and those with blood pressure conditions. The individuals recruited may be those who are motivated in their management and have great interest in their own monitoring. It is possible that this is not a widespread sentiment and through all of the participants, only P5 expressed that his diabetes was not an issue that he paid attention to.

However, as the research was focused on supporting the management practices of those with chronic conditions, it may be the case that those who were recruited represent the population that engage with that process.

9.5.3 Number of Participants

The numbers of participants involved in each of the studies ranged from 6 to 20. There is potential that studies involving larger numbers of participants may uncover further discoveries regarding how individuals manage their conditions, and how they used the ConCap and VCTag applications. While new findings may exist, it is unlikely that they would change the findings of this Thesis dramatically and instead may offer further refinement. For example, the Diabetes Management Cycle defined in chapter 5 aligns itself with previous research conducted by Mamyikina et al.[115] and Li et al. [103].

9.5.4 Devices Used

A challenge discovered during the studies conducted in Chapters 7 and 8 was the segregation of devices used to monitor a condition, and a device used to capture and access information. All of the participants in the ConCap study had all previously made use of mechanisms to log their glucose information, while 3 of those in the VCTag study recorded health information on a frequent basis.

The introduction of the applications then led to a second repository of information, and potentially a duplication in the entry of information. All participants in the studies were advised that the applications were an assistive tool and were not intended to replace their existing methods of managing their own conditions. This caused issues amongst some participants, who viewed the additional entry of information as a burden.

Similarly, the study conducted to evaluate the VCTag application (Chapter 8) introduced both a blood pressure monitor and mobile phone to participants. The primary reason for introducing the phone to participants was to expand the participant pool, however this led to problems during the everyday usage of the application. At least 3 of the participants described how their associated the phone as an addition to the monitor and as it was not their own personal device, the phone was often left next to the monitor. This perhaps led to an undesirable state where participants were not engaging as frequently with the application.

9.6 Concluding Remarks

This body of work has attempted to establish the extent that mobile interventions can have in the support of chronic condition management. This has been by investigating the existing practices of those with diabetes and subsequent creation and evaluation of mobile implementations to aid individuals' management.

The current devices used to capture health information typically concern themselves with clinical factors such as blood glucose levels. However, Section 3 described how there is often a need for support in the capture of other factors. This type of capture was defined by Klasnja et al [95] as *'unanchored'* and is the process of the collection of more informal types of information that individuals believe to be relevant to their practice.

While there are several examples of mobile applications designed for this task there exists either little empirical evidence to support their suitability (Section 4.5.1 or they rely on clinical and peer support (Section 4.5). Such support may not always be immediately available, therefore individuals must have methods of capture and access that facilitate and extends their own management.

However, it was a key concern throughout this Thesis that the interventions created were fit for purpose. A survey of previous literature ([115, 186]) did not provide a sufficient understanding of how people are currently managing their conditions. Therefore, this Thesis built upon this existing knowledge and extended it further to ensure that the interventions served a practical purpose to the study participants.

From this core idea, two mobile applications were designed, implemented and evaluated that facilitate capture of information. As participants in Chapters 3 and 5 both expressed the burden that the management of diabetes can have on an individual, the methods that required little interaction from the user were implemented. Methods of information capture that fit this criteria and have been used previously in healthy living support (such as image capture [114, 156], location information [131, 166] and tagging [108, 117]). Unlike much of the previous research however, participants in the evaluations of the two systems were not prescribed frequency of interactions or topics to capture. Instead, the participants were asked to use the features in ways in which they deemed worthwhile.

The results from the evaluations determined that participants used the methods of capture for a variety of reasons. Most prominently, the features were used during times of *unusual situations* and *concerns*, as defined in the Diabetes Management Cycle (Section 5.5). By enabling the capture of *'unanchored'* [95] management, participants were able to move away from clinical measurements, to a more complete understanding of the factors that affect their health, and to what extent.

Mobile technology clearly has a role to play in the management of chronic conditions. The immediate availability of everyday devices such as mobile phones makes them a suitable platform for logging of personal health information. This Thesis has moved towards a deeper understanding of the role these devices can have when individuals are away from guidance provided from clinical and peer-related sources.

This Thesis has sought to understand the issues around health management practices and how technology can support them. In this body of work, the Diabetes Management Cycle (Chapter 5) was used as a basis for the design of applications to assist in these processes. By ensuring lightweight and meaningful methods of capture, the workload requirements for health logging were reduced, but still able to provide new insights into personal conditions.

The Diabetes Management Cycle, and subsequently the notions of short- and long-term ready to hand, can be used inform user requirements for application design, reduce the demand of the process of management of chronic conditions; and increase understanding about the external factors that influence unusual situations of management.

Chapter 10

Opportunities for Future Research

As is common with research undertaken as part of PhD studies, the process of conducting the work described in this thesis has prompted more research questions than could be answered during the time frame available. This Chapter outlines the opportunities that have arisen to further the work described in this body of work.

10.1 Extend The Diabetes Management Cycle

The results of Chapter 8 suggested that there exist similarities within the processes that those with blood pressure undertake and those who have diabetes. In Chapter 5, the Diabetes Management Cycle was defined and reinforced with the findings in Chapter 7 within the domain of diabetes management.

The findings of the VCTag evaluation suggested that participants felt that they would be more likely to use the application during situations that were outside of *'normal'* practice. This potentially matches with the Diabetes Management Cycle, however further investigation into the similarities between the conditions would be required. As this was not the focus of the research conducted in this Thesis, it would be unwise to claim that the Diabetes Management Cycle could be applied across a broader context. However, the findings of Chapter 8 suggest that there is potential to further explore this concept, potentially across a multitude of chronic conditions.

Extending the model would further provide a foundation for interventions into chronic condition management. Should the model be found to hold true across more conditions then appropriate methods of supporting the management could be achieved.

10.2 Mobile Intervention In Early Phases of Chronic Condition Management

A requirement placed onto the recruitment of participants throughout all of the studies conducted in this work stated that individuals were not newly diagnosed patients. Through requesting individuals who had been living with a condition for a minimum of 6 months, only those who had already established practices in their own management were recruited. A primary aim of the research was to support the existing management of chronic conditions. However, the potential exists to provide feedback during the learning phase of chronic condition management.

Those who have been recently diagnosed require a great deal of support in the understanding and treatment of their new condition. The applications ConCap (Chapter 6) and VCTag (Chapter 8) allowed for participants to make discoveries about their condition. Largely, the individuals in those studies could be described as *'experts'* and may have had fewer potential discoveries that could be made. By adopting an approach as described in this Thesis, those who are newly diagnosed with a condition may be able to make similar discoveries which will ultimately benefit their management.

10.3 Cultural Attitudes

The work conducted in this thesis has focused on participants who were within the United Kingdom during the studies described. However, attitudes towards self-management of chronic conditions are unlikely to be universal across countries and cultures. Understanding these differences could potentially, lead to more informed design choices. As has been seen in earlier parts of this thesis, participant attitudes to their own management differs between individuals. These differences between participants from the same country may be transferred to a different culture, however it is more likely that a new and different set of challenges may emerge.

In order to achieve an understanding around these differences, the study described in Chapter 8 is to be replicated in an alternative setting. At the time of writing, 20 participants have been recruited onto a replica study, using the same VCTag application. The study has taken the same approach and artifacts as the work included in this thesis. The only difference in the between the two has been the translation of various language related points, such as labels in the application and terminology used in interview sessions. The purpose of conducting a second study is to seek an understanding around how different cultures approach the management of their own health. As has been seen in this thesis, the management of health conditions is a deeply personal one, with attitudes towards the task differing greatly between people. As such, understanding the differences between western and eastern people, it will be possible to approach the design of mobile interventions in a more appropriate manner. There is unlikely to be a 'one-size' fits all approach to chronic disease management, but there will exist similarities between different user groups. Understanding the differences that exist will allow for better tailored applications.

Concerns have been raised about the varying attitudes of different cultures when it comes to reporting the prevalence of chronic conditions. Goldman et al. [64] states that there exist differing attitudes between the reporting behaviours of those in an Eastern country to those who reside in a Western country. By understanding the differences that exist, most suited interventions can be made in the future.

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