

**CROSSING BOUNDARIES:
PATIENTS' EXPERIENCES OF USING
A DIABETES EHEALTH SYSTEM**

BY

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Know then thyself, presume not God to scan;

The proper study of mankind is Man.

Alexander Pope 1688-1744: *An Essay on Man: Epistle 2* (1733)

STUDENT DECLARATION

I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution

I declare that no material contained in the thesis has been used in any other submission for an academic award and is solely my own work

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Signature of Candidate

Type of Award : PhD

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ABSTRACT

This thesis is concerned with exploring patients' experiences of using a diabetes eHealth system. The context of the study is the growth of interest in eHealth systems that focus on patient needs, alongside increasing home computer use and the rising incidence of chronic diseases, such as diabetes. I aim in this thesis to make a novel contribution to knowledge about how eHealth technology is experienced by patients with diabetes. The study takes the form of a qualitative enquiry into the use of a diabetes eHealth system by a group of patients and their healthcare practitioners at a primary care general practice in Northern England. Using symbolic interactionism as a methodological perspective and taking elements from grounded theory the study produces a theoretical framework based on a thematic analysis of participants' descriptions of their experiences of using the eHealth system.

A diabetes eHealth system was designed and built for the study, and 38 patients were recruited from a single GP practice using purposive sampling. Participants used the system for six months and were interviewed at the beginning, middle and end of the study period. Issues of surveillance, automation, endorsement and interaction influenced use and experiences of the system. Results from the study indicate that participants use and perceive the eHealth system as part of their diabetes management experience. My thesis is that the eHealth system is a boundary structure through which boundary objects, such as electronically formatted blood glucose readings, are created and shared across different social worlds. The eHealth system crosses the boundary between two spheres of an individual's diabetes management experience, the personal sphere of self-management, and the external sphere of seeking and receiving support from medical experts and others with diabetes. The co-location of these two spheres exposes participants to scrutiny but also opens up new possibilities for collaboration and learning.

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ABBREVIATIONS

GP	General Practitioner
HbA _{1c}	Glycated Haemoglobin (see footnote on p.12)
HIV	Human Immunodeficiency Virus
IFIP	International Federation for Information Processing
IT	Information Technology
NHS	National Health Service
PCT	Primary Care Trust
PDA	Personal Digital Assistant
SMS	Short Message Service (text messages)
TAM	Technology Acceptance Model
UK	United Kingdom
URL	Uniform Resource Locator
USA	United States of America

1. THE INVESTIGATION OF AN EHEALTH SYSTEM: INTRODUCTION

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The web is more a social creation than a technical one. I designed it for a social effect – to help people work together – and not as a technical toy. The ultimate goal of the web is to support and improve our web-like existence in the world.

Tim Berners-Lee *Weaving the Web* (1999)

1.1 Introduction

In this thesis I explore patients’ experiences of using a diabetes eHealth system. The context of the study is the growing interest in eHealth systems that focus on patient needs, alongside increasing home computer use and the rising incidence of chronic diseases. Recent UK statistics indicate that levels of home computer ownership are increasing at a steady rate, with 67% of households owning computers in 2006, rising to 70% in 2007, 72% in 2008, and 75% in 2009. Similarly the proportion of households with Internet connections rose from 61% in 2007, to 66% in 2008, and 71% in 2009 (Office for National Statistics, 2010). However, these figures only tell a small part of the story. As home computer ownership has increased, computing technology has extended into many areas of life, such as study, social networking, games, travel, and shopping. Health is one of these areas, and there is evidence that people are increasingly using technology at home to access health information (Ayantunde et al., 2007, Larner, 2006) and to monitor and manage their health (Viera et al., 2008, Harver et al., 2010, Farmer et al., 2008).

Health is an interesting area through which to investigate the social impact of technology for a number of reasons. Although the widespread use of digital technology in the field of health is a recent phenomenon, the modern disciplines of medicine and health science have been

inextricably connected with developments in technology since the beginning of the last century (Howell, 1995, Brodsky, 2010). The current state of health technology provides us with a foretaste of the potential for new applications, many of which are currently only concepts, or in the early stages of development. Also, health is a subject in which there is much interest at many different levels: individually, politically, socially and culturally. Health problems are intensely personal, but also reflect the social world in which they arise. Therefore, just as there are many differing ways to view health issues, there are many differing ways to view health technologies.

New technology has been introduced into every aspect of healthcare, from complex embedded systems to electronic patient record systems (Waneka and Spetz, 2010, Oh et al., 2010, Ludwick and Doucette, 2009). Many recently-developed health technologies are work-based systems designed to be used by healthcare practitioners and health administrators. Such systems aim to improve information sharing and aid decision making for practitioners in clinical settings. These technologies have an impact on the working practices of professionals as well as on the experience of patients. At the same time however, more health technology is becoming available for use directly by patients. As these technologies become increasingly available, more people are becoming aware of them and are interested in trying them out. These health technologies have a direct impact on people, and can change the way in which they experience healthcare, and it is this use of technology that is the focus of interest for this study.

1.2 The challenge of chronic disease

At the beginning of the twenty-first century healthcare providers all over the world face a range of challenges that put pressure on their limited resources and that require careful strategic planning (World Health Organization, 2008a, World Health Organization, 2008b). There are concerns about epidemics such as HIV and influenza (Montaner et al., 2006, Bennett et al., 2008, Coburn et al., 2009), the emergence of drug-resistant strains of TB and malaria (Shah et al., 2007, Plowe, 2009), the problems of chronic disease and increasingly sedentary and aging populations (Daar et al., 2007, Hill et al., 2007, Parker and Thorslund, 2006), as well as concern about the difficulty of dealing with disasters such as earthquakes, floods and droughts (Watson et al., 2007). At the same time there is a need to focus on developing public health systems that can provide equitable and cost-effective healthcare to wide sections of the population (Labonte et al., 2007). Amongst these challenges the rising

incidence of chronic disease has emerged as a major problem with global reach (Shaw et al., 2010, Narayan et al., 2006).

Chronic disease impacts on patients' lives in numerous ways, causing long term complications and lowering life expectancy (Stewart et al., 1989). Many of the factors that have contributed to the increasing incidence of chronic diseases such as diabetes and cardiovascular disease have been linked to changing lifestyles: most particularly rising rates of obesity, unhealthy diets, low levels of activity, and high levels of alcohol consumption (Mokdad et al., 2003, Hu et al., 2003). Of these chronic diseases diabetes is expected to become the fourth leading cause of death in high-income countries and the seventh leading cause of death globally by 2030 (Mathers and Loncar, 2006). As the incidence of chronic disease has increased and more effective treatments have become available, so has the emphasis on patients themselves playing a key role in managing their own care. Consequently 'self-care' has become a major theme in discussions about the effective management of chronic disease. As well as self-care being a practical measure that helps patients with daily living, it is part of the wider public discourse about health. Two related aspects of that discourse that are particularly relevant to this study are first, the public discourse suggesting that people should take some personal responsibility for the state of their health (Roy, 2008, Steinbrook, 2006), and second, the discourse amongst health practitioners about the beneficial effects of 'patient empowerment' (Anderson and Funnell, 2009, Anderson, 2005, Virtanen et al., 2007).

In addition to the challenges posed by the increasing incidence of chronic disease, other aspects of healthcare provision are currently undergoing major changes. One radical change has been the increasing use of technology in every aspect of life which has also affected healthcare provision at all levels over the last three decades. Computerised systems are being developed and implemented in all areas of health organisations, with the aim of transforming manual systems and integrating technology into every aspect of medical care. However, in addition to having an impact on organisations, technology is also being embedded into our personal lives and is increasingly being used by patients themselves, changing the way they seek for and access health information and health support.

All the themes introduced in this section are discussed in greater detail throughout the thesis. In the next section the term 'eHealth' is defined and discussed.

1.3 eHealth: definitions and scope

There is a long history of technology being used in medicine and healthcare, although recent developments in computing and networking technology have resulted in a rapid growth of technical systems for healthcare. As a consequence many terms are used to describe health-related technology. The term ‘telemedicine’ is possibly the most commonly used term to describe medical care that is delivered from a distance (Sood et al., 2007). Telephones started being used by physicians to enhance medical care soon after they came into popular use in the early 1900s (Zundel, 1996) and telemedicine has become increasingly diverse and sophisticated as technology has developed. While ‘telemedicine’ refers quite specifically to the provision of remote clinical care and ‘medical informatics’ to the use of data and information in understanding health and biomedicine, the terms ‘telehealth’ and ‘eHealth’ are more general and refer to the provision of a range of healthcare services. The term ‘eHealth’ was chosen for this study as it is the most generic term in use.

In a review of peer-reviewed literature Oh et al. (2005) found 55 different definitions of eHealth, indicating that it has become a widely used concept. The Oh review identified eight themes within definitions of eHealth of which two were universally mentioned; health and technology. Six other themes were found that were mentioned in some definitions but not others; commerce, activities, stakeholders, outcomes, place and perspectives. Some of the definitions found were brief and general – ‘eHealth is all that’s digital or electronic in the healthcare industry’ (Tieman, 2001) and others were more specific – ‘eHealth is an emerging field in the intersection of medical informatics, public health and business’ (Eysenbach, 2001). Interestingly a number of authors identify eHealth purely with the use of the Internet rather than with the use of a wider range of technologies (McLendon, 2000, Wyatt and Liu, 2002, Watson, 2004). For the purposes of this study I shall use Silber’s definition “eHealth is the application of information and communication technologies (ICT) across the whole range of functions that affect health” (Silber, 2004). This definition does not confine it to the use of Internet technologies alone but encompasses a whole range of technologies that enable health-related activities to take place.

1.4 Information systems: the social study of technology

The work presented in this thesis lies in the field of Information Systems research. The area of interest in this field is the study of the complex links between the technical and social aspects of information systems. Information systems are not fixed and static as both

technical and human systems are subject to change. Researchers in this field are interested in exploring the complex interplay between social systems and information technology. This field is multi-disciplinary and draws on theories and concepts from social science, business, management, computing and other related fields.

As Information Systems is a multi-disciplinary field, Information Systems researchers have drawn from a wide range of research approaches. In the 1980's most empirical research in the Information Systems field tended to be positivist and quantitative. Over the last three decades however this has gradually changed and there has been an increasing move towards qualitative, interpretive research with a particularly strong use of field studies (Flynn and Gregory, 2004). There has also been an increasing tendency to use social and philosophical theory as frames through which to explore the phenomena under investigation (Mingers and Willcocks, 2004). The rationale for these shifts in approaching research is that taking a positivist, quantitative approach only provides a limited way to explore the entanglement between technical systems and the social and cultural phenomena in which they are embedded. In contrast, qualitative approaches allow researchers to investigate some of the subtle complexities involved in technology use and explore the tensions and contradictions that lie behind attitudes and behaviours.

1.5 Research motivation

The system explored in this thesis is a diabetes eHealth system used by patients and healthcare practitioners in the context of primary care. I started with an interest in exploring the impact of personalised eHealth systems. The decision to investigate a diabetes-related system was made during a group discussion with academics and health practitioners, when a GP in the group suggested working on a diabetes system to support patients in primary care. These early group discussions were a vital part of setting up the research study and clarifying the approach to be used. The project gradually took shape as the preparation work continued through the processes of obtaining ethics approval, securing funding, designing and building the software and working with the GP practice to set up the study. There have been few interpretive studies of patient-focussed eHealth systems, as most previous empirical studies have been positivist studies undertaken by health teams looking to quantify the benefits that technical systems can bring to patient care.

The research question for the study was developed through the course of the study, but the primary aim was to explore patients' experiences of using the eHealth system through investigating what aspects of the system they were interested in using, how their use of the system influenced their health management and how they responded to the system. As the motivation for this research study was to explore the rich variety of patient experiences of using a diabetes eHealth system from an Information Systems perspective I decided to use qualitative research methods for this study.

1.6 Overview of the thesis

The eight chapters of the thesis are structured as follows.

In Chapter One I introduce the study. First, I give an overview of the context of the study. I then discuss eHealth and related terms, and the information systems research setting within which the study is set. I discuss the motivation for the research and provide an overview of the structure of the thesis.

In Chapter Two I review the literature that is relevant to this study. First, I outline the three major themes of relevance to the study. These are the rising incidence of chronic disease in general and diabetes in particular; the focus on self-care as a key way of preventing and managing chronic disease and the impact of Information Technology on healthcare. Following this, I review published studies of diabetes eHealth systems. These are categorised into educational systems, communication and social support systems, mobile systems and personalised Internet-based systems. In the final category, personalised Internet-based systems, I look particularly at studies of interventions that are similar to the one devised for this study.

In Chapter Three I discuss the methodological approach taken in the study. This chapter starts by outlining the main research question and the sub-questions, and provides a rationale for the development of the research questions. I go on to discuss the methodological and epistemological position taken in the study, within a contextualised discussion of the different approaches commonly taken in Information Systems research. I outline the research design, and provide a rationale for each element of the study. Further, I discuss the data collection methods and the data analysis approach. Finally, I discuss the approach taken to ethics and research governance and outline the procedures followed for ensuring patient consent, confidentiality and anonymity, security and freedom from harm.

In Chapter Four I discuss the set up and running of the study. First, I explore the two guiding factors for the design rationale. Following this, I discuss the features found in previously reported Internet-based diabetes eHealth systems and describe the features implemented in the system developed for this study. Following this, I describe the research setting and the recruitment process. Finally, I give an overview of the patients and healthcare practitioners recruited to the study.

In Chapter Five I present the results of the study for each of the three categories identified during the analysis. I present the content of each category by sub-categories and I illustrate the content of each sub-category with narratives and quotations from participants.

In Chapter Six I present and discuss a conceptual framework of the diabetes eHealth system developed through the data analysis. First, I present a diagrammatic model of how the categories identified through the analysis relate to each other. In this model participants' diabetes management experience is modelled as a cyclical process which consists of a self-management process and a support-seeking process. The eHealth system sits between these two processes and provides support for both of them. Second, I introduce and discuss the concepts of boundary objects and social worlds as concepts that help us to interpret aspects of the system in use. I discuss the eHealth system as a boundary structure that enables the sharing of boundary objects between users who inhabit different social worlds. Finally, I discuss the system qualities of surveillance, automation, endorsement and interaction.

In Chapter Seven I discuss the main points made in the thesis. Starting with the conceptual framework I review how the concept of boundary objects has been used in Information Systems literature particularly in relation to health Information Systems. Second, I revisit the research questions and outline the insights gained from the study in relation to each research question. I contrast the outcomes from this study with those of other studies of similar systems. Third, I discuss the experiences of diabetes revealed by participants during the interviews, and highlight similarities between the findings of this study and that of other qualitative studies. Next, I discuss the findings from the study about the use of technology in the home. Finally, I consider the usefulness of applying Information Systems adoption models, such as the Technology Acceptance Model to this research.

In Chapter Eight I conclude the thesis by drawing out the key findings. I start with an overview of the key points made in the thesis. I follow with a summary of the contributions

made by the study. These are broken down into three sections, theoretical contributions, practical contributions and methodological contributions. Then I discuss the limitations of the study. Finally, I make suggestions for further research and draw conclusions.

1.7 Summary

This chapter has introduced the research study undertaken for this thesis. The context of this study is the globally increasing incidence of diabetes, and a growing interest in the potential of eHealth systems to improve care for those with chronic disease. The aim of this research study is to explore the experiences of patients using a diabetes eHealth system in a primary care context. In the next chapter the literature relevant to the study will be reviewed.

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Where is the wisdom we have lost in knowledge?

Where is the knowledge we have lost in information?

T.S. Eliot 1888-1965: *The Rock* (1934)

2.1 Introduction

As the aim of this study is to explore the experiences of patients when using a diabetes eHealth system, the first task is to investigate the context in which diabetes eHealth systems have been developed and to look at similar work that has been undertaken in this area. In this chapter the three major themes of relevance to this study will be outlined. These are a) the rising incidence of chronic disease in general and diabetes in particular, b) the focus on self-care as a key way of preventing and managing chronic disease and c) the impact of Information Technology on healthcare. This is followed by a detailed review of recent literature that assesses interactive technological systems for patients with diabetes and interventions devised for use with those systems.

2.2 Diabetes management

The 2008 World Health Organisation World Health Report (World Health Organization, 2008b) reported that although globally people are healthier and wealthier than ever before,

there are new health challenges being faced that have only been partially anticipated. The report stated that “ageing and the effects of ill-managed urbanization and globalization accelerate worldwide transmission of communicable diseases, and increase the burden of chronic and non-communicable disorders”. The four non-communicable diseases identified for particular concern by the World Health Organisation are cardiovascular diseases, diabetes, cancers and chronic respiratory diseases (World Health Organization, 2008a). Alongside these are four shared risk factors — tobacco use, physical inactivity, unhealthy diets and the harmful use of alcohol. Ischaemic heart disease and cerebrovascular disease were globally the two leading causes of death in 2002 and are projected to remain so in 2030 (Mathers and Loncar, 2006). Diabetes was ranked eleventh in 2002 but is expected to become the seventh leading cause of death globally by 2030, and to become the fourth leading cause of death in high-income countries (ninth in low-income countries); so its prevalence is already high and is expected to increase. Population growth and population aging are both factors contributing to this increase in all regions, although population aging is generally perceived to be more important (Mathers and Loncar, 2006, King et al., 1998). Other factors implicated in the rise are urbanisation and the increasing incidence of obesity and physical inactivity (Wild et al., 2004).

These global trends are reflected in the UK. In the 2009 Health Profile for England (Department of Health, 2009) it was reported that while there was a general increase in life expectancy and a decline in mortality rates from cancer, circulatory diseases and suicide in the UK, there were also rising rates of diabetes and chlamydia, increasing rates of obesity and a continuing problem with geographical health inequalities. Recent studies have charted an increasing incidence of Type 1 and Type 2 diabetes in the UK with an estimated doubling of the incidence of Type 1 diabetes in children under five by 2020 (Patterson et al., 2009). This trend has also been noted in other European countries (Onkamo et al., 1999) and the USA (Bell et al., 2009). Reasons for the increase have been linked to obesity and rapid growth in children (Hypponen et al., 2000), but other environmental factors have also been implicated and further studies need to be undertaken to understand this phenomenon (Dabelea, 2009). Also in the UK the prevalence of Type 2 diabetes has increased both in the population at large (de Lusignan et al., 2005) and amongst children (Haines et al., 2007). Reasons for the increase are linked to lifestyle issues such as rising obesity, low activity levels and unhealthy diets (Mokdad et al., 2003, Hu et al., 2003, Parillo and Riccardi, 2004).

Diabetes mellitus (generally referred to as 'diabetes') is a condition in which the amount of glucose in the blood is too high because the body cannot adequately process it and turn it into fuel for energy. The two main types of diabetes are Type 1 and Type 2 alongside gestational diabetes which is less common. Type 1 diabetes is an auto-immune disease that develops when the pancreas is unable to produce any insulin. It usually occurs under the age of 40, often in young children, and has a strong genetic component. It accounts for about 5-10% of the all people with diabetes (Daneman, 2006). Type 1 diabetes is treated with insulin injections, maintaining a healthy diet and taking regular exercise. Type 2 diabetes develops when the body either does not produce enough insulin or becomes insulin-resistant (Kahn et al., 2006). Type 2 diabetes is often linked to patients being overweight and is usually diagnosed in those over 40 in the white population, and the over-25s in the black and South Asian populations, although it is increasingly being diagnosed in younger age groups (Diabetes UK, 2010, Shai et al., 2006). Type 2 diabetes can be treated at the least severe end through lifestyle changes such as by improving diet, losing weight and increasing activity levels. However, in many cases it needs to be treated with medication to help the body achieve normal blood glucose levels, and some patients move onto needing insulin injections (Diabetes UK, 2010). Gestational diabetes occurs during pregnancy and affects about 2% of pregnant women, in most cases it develops in the second half of the pregnancy and disappears after the baby is born, but it is sometimes a precursor to Type 2 diabetes (Buchanan et al., 2007). Short term complications for those with diabetes include hypoglycaemia (extremely low blood glucose which may lead to loss of consciousness), diabetic ketoacidosis (high ketone levels which can lead to coma and death), hyperosmolar hyperglycaemic state (high blood glucose levels can lead to loss of consciousness and death). Long term complications are almost all made worse by prolonged poor blood glucose control. They include increased risk of cardiovascular disease (poorly controlled blood glucose levels increases the furring up of blood vessels), retinopathy (blocked blood vessels in the eye and damaged vision), neuropathy (nerve damage), kidney disease, necrobiosis (skin lesions), mastopathy (fibrous breast tissue) and musculoskeletal conditions (Diabetes UK, 2010).

Patients with diabetes in the UK are treated either through their GP or a specialist diabetic clinic attached to a hospital or a combination of both. Although Type 1 and Type 2 diabetes have different causes and some different treatment requirements, many underlying healthcare needs are similar for all people with diabetes. Current NHS advice to patients with diabetes is

to keep blood glucose levels stable and as close to normal as possible (between 3.5 - 8 millimoles per litre), to eat healthily, to take plenty of exercise, to stop smoking, to cut down on alcohol consumption and to have regular check-ups (NHS, 2010). Check-ups should include monitoring of HbA_{1c}¹, blood pressure, lipids, feet and eyes (Diabetes UK, 2010). While stable glucose levels are recommended, there have been controversies about the benefits of intensive control of hyperglycaemia. Studies of the benefits of normalising glycaemia have produced inconsistent results (Dokun, 2010). However, there is evidence from the UKPDS study that control of blood pressure and lipids are important for those with type 2 diabetes (Adler et al., 2000, UKPDS Group et al., 2000). The current view is that there is no need for a 'special' diet for diabetes – it needs to be a healthy, balanced diet low in fat, sugar and salt and with plenty of fresh fruit and vegetables (Diabetes UK, 2010, NHS, 2010, Diabetes UK, 2003). Eating regularly is important, as is making sure that each meal contains carbohydrate foods with a low glycaemic index (such as whole grains) which release their energy slowly and help keep blood glucose levels more stable (NHS, 2010).

Once medication or insulin regimes are established and stabilised (if required), the focus is to manage the combination of medication, diet and activity as positively as possible as part of daily life. The responsibility for this lies heavily with the patient and the healthcare practitioner can only act as advisor in this respect (Jarvis et al., 2010, Aschner et al., 2010). Additionally, the patient's care regime often involves regular blood glucose monitoring with a portable blood glucose meter. There are many such devices available on the market, and they are now an integral part of the management routine of many patients with diabetes. They provide an instant blood glucose reading which may be required to inform the dose of insulin they are to inject or as part of the patients' own monitoring regime. Although some patients with Type 2 diabetes, who treat their condition purely through improved diet and exercise, may not need to meter their blood glucose levels regularly, many patients with Type 2 diabetes use a meter as do most patients with Type 1 diabetes. Evidence suggests that self-monitoring of blood glucose is effective for patients with Type 1 diabetes (Bode et al., 1999) and those with Type 2 diabetes who are using insulin (American Diabetes Association, 1998). For those with Type 2 diabetes not using insulin it may be effective in improving blood glucose control, but evidence is not conclusive (Welschen et al., 2005).

¹ The HbA_{1c} (glycated haemoglobin) test measures the amount of glucose being carried by red blood cells, and is used to indicate blood glucose levels for the previous two to three months.

2.3 The focus on self-management

For diabetes, the establishment of a good self-management routine, a healthy lifestyle and steady glycaemic control are generally viewed to be important for effective management (Song, 2010, Boule et al., 2001, Currie et al., 2010, Diabetes Control and Complications Trial Research Group, 1993, Albers et al., 2010). Despite some controversy about the effectiveness of certain measures (Coster et al., 2008, Cao et al., 2008) and recent new evidence (Currie et al., 2010), good self-care is still considered to be an important cornerstone of diabetes management.

2.3.1 Self-management and patient education

In order to practice good self-management, patients with diabetes need to know what actions to take and be motivated and able to undertake them. Hence, effective and accessible patient education is essential. Because of the importance of self-management, patient education programmes for diabetes patients can be viewed as interventions in their own right (Cooper et al., 2001). Over the last thirty years patient education practices have shifted from a focus on experts teaching medical facts in the 1980s, to care providers facilitating patients in learning how to learn in the 1990s, to patients themselves being actively involved in their own education in the 2000s (Adolfsson et al., 2007).

There is a large literature reporting the design, content, practice and effects of education programmes for patients with diabetes. Stated aims of such programmes include improving attitudes and feelings of self-efficacy, improving knowledge about the condition and how to manage it, improving practical daily self-care skills, managing feelings, and improving interactions with healthcare providers. Elements used within programmes vary widely and include lectures, audio-visual presentations, discussion groups, skill development sessions (Mazzuca et al., 1986), video presentations, workbooks, individual coaching (Frosch et al., 2011) and printed literature (Hill-Briggs and Smith, 2008). Some programmes use theoretical models as a basis for structuring interventions. Examples are the use of theories of adult experiential learning, theories of health protective behaviour (Cooper et al., 2003a, Cooper et al., 2003b), self-efficacy (Lorig et al., 2001), the transtheoretical model of change and social action theory (Griffin et al., 1999).

In the USA Kate Lorig pioneered the use of peer-led self-management programmes for people with chronic health problems. As a post-graduate in the 1970's Lorig started

developing a self-help programme for patients with arthritis (Lorig, 1982). She now runs the *Patient Education Research Center* at the Stanford School of Medicine where a range of self-help programmes have been developed both for use face-to-face and on-line (Lorig et al., 2001). They cover a range of specific illnesses such as diabetes, back pain, and HIV, but they have also developed a generic chronic disease self-management programme. Based on Bandura's theory of self-efficacy (Bandura, 1977, Bandura, 1986), the programmes aim to build people's self-confidence in their ability to manage their symptoms and to control how their health problems affect their lives. As well as helping patients with knowledge and skills they aim to help patients to manage negative emotions and to improve their confidence. The programmes are based on the twelve self-management tasks identified by Lorig as common to any patient with a chronic disease (see Table #1 below).

- | |
|---|
| <ol style="list-style-type: none"> 1. Recognising and responding to symptoms, including monitoring symptoms and controlling triggers to symptoms 2. Using medication 3. Managing acute episodes and emergencies 4. Maintaining good nutrition and an appropriate diet 5. Maintaining adequate exercise and physical diet 6. Not smoking 7. Using relaxation and stress-reducing techniques 8. Interacting appropriately with healthcare providers 9. Seeking information and using community resources 10. Adapting work and other role functions 11. Communicating with significant others 12. Managing the negative emotions and psychological responses to illness |
|---|

Table 1: The 12 Self-Management Tasks in Chronic Disease (Lorig et al., 1996)

These programmes were adopted by some healthcare providers such as Kaiser Permanente in the USA which uses the chronic disease self-management programme (Lorig et al., 2005) and the NHS in the UK who developed the Expert Patient Programme (Department of Health, 2001b). In the UK the Department of Health created a not-for-profit social enterprise in 2007 called the '*Expert Patients Programme Community Interest Company*' which took on the Expert Patient Programme and continues to develop a wide range of other courses in line with the approach at Stanford including the *X-PERT Diabetes Course* (Expert Patients Programme Community Interest Company, 2010). The Arthritis Self-Management Programme was adopted by *Arthritis Care* (before the advent of the expert programme), and was named the *Challenging Arthritis Programme* and this is still delivered by Arthritis Care (Arthritis Care, 2010). However, there have been criticisms of such programmes on the

grounds that there is weak evidence for their effectiveness. (Greenhalgh, 2009, Griffiths et al., 2007, Taylor and Bury, 2007). Four UK-based randomised trials of lay programmes showed an increase in patients' confidence, but no reduction in hospital admissions or the use of other healthcare resources (Griffiths et al., 2007), and a meta-analysis found evidence of publication bias (Warsi et al., 2004).

Work in a similar vein to that of the Stanford group has been undertaken by a team working at the *Michigan Diabetes Research and Training Center* at the University of Michigan Medical School. In particular their work has focussed on the importance of improving patients' self-efficacy and the concept of patient empowerment. As well as developing patient empowerment education programmes (Anderson et al., 1995, Anderson, 2005), this team has also worked on training medical professionals to allow patients to make autonomous, informed decisions about their diabetes management (Anderson and Funnell, 2009).

Research assessing the success of such programmes indicates that outcomes are varied. In a second stage descriptive meta-analysis of chronic disease patient education, Cooper et al. found that benefits from patient education programmes were often small and were only assessed for six months after the intervention (Cooper et al., 2001). They also found that educational interventions were often inadequately described and were not grounded in theoretical models. The outcomes measured by studies included knowledge, psychological effects, physical effects, and self-care behavioural outcomes. Results showed that effects were largest for knowledge then physical effects (including glycaemic control), and smallest for psychological effects and self-care behaviours. Conclusions were that although much research has been done on patient education, the methodological rigour has often been poor, and hence there is insufficient evidence to judge the efficacy of programmes undertaken. Other, more recent, systematic reviews have likewise indicated some modest improvements from patient education interventions (Ellis et al., 2004, Duke et al., 2009, Lager et al., 2010), but a general lack of methodological rigour (Warsi et al., 2004). Loveman et al. (2003) found that education interventions linked to intensive treatment interventions for Type 1 diabetes may result in significant and lasting benefits, but educational programmes for those with Type 2 diabetes did not yield consistent results. Following Cooper et al. they also note that there have not been enough high quality trials to make effective judgements about the efficacy of educational interventions.

In the UK the National Institute for Clinical Excellence have published recommendations on patient education for diabetes (2003). The report recommends that all patients should be offered structured patient education on diagnosis and further opportunities should be provided as required. The report acknowledges that there is insufficient evidence to recommend particular interventions but suggests that interventions chosen should reflect established principles of learning, be provided by a trained, multi-disciplinary team (including a diabetes nurse and a dietician), be accessible to the broadest range of people and use a variety of techniques to promote active learning.

Additionally, the Medical Research Council has published (in 2000 and revised in 2008) a framework for the design, implementation and assessment of complex interventions, of which patient education is an example. Such interventions are multi-faceted and are therefore difficult to design, control and assess. Moreover replication is not easy, as it is difficult to quantify, describe and control all the elements in a complex intervention. The recommendations are that the development of complex interventions should be systematic, using best evidence and theory; and iterative, including the following phases, feasibility and piloting, evaluation, implementation and development. The 2008 framework recommends the use of experimental designs for assessment whilst acknowledging that when it is not possible to use them, researchers should use the best available methods. Understanding processes is considered important, but should not replace evaluation of outcomes. As the interventions are complex, the measurement of a range of outcome may be more appropriate than single outcome variables. Additionally, the interventions may work best if they are tailored to local circumstances rather than completely standardised (Campbell et al., 2000, Craig et al., 2008).

2.3.2 UK Guidelines for diabetes self-management

The trend towards emphasizing “self-management” as the focus for chronic disease healthcare has been growing gradually over the past several decades. Part of this focus is an acknowledgement that, by definition, a chronic disease is a lifelong burden and a patient will spend far more time looking after themselves than they will in the clinic or discussing their condition with a healthcare practitioner. What the patient does for themselves and how they approach the management of their disease has an impact on their experience of the disease (Paterson et al., 1998, Paterson et al., 1999) and potentially on any related complications they may experience (Kerr et al., 2007).

In the UK the National Service Framework for Diabetes guidelines currently in use were first published in 2001 (Department of Health, 2001c) and updated in 2010 (Department of Health, 2010). The National Service Framework includes “standards, rationales, key interventions and an analysis of the implications for planning services”. The framework includes standards for prevention, identification, empowerment, and clinical care of people with diabetes. It also contains standards for managing emergencies, hospital care, pregnancy and long term complications. Two standards are of interest to this discussion. First, Standard 3, ‘*Empowering People with Diabetes*’ (Department of Health, 2010) states:

All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.

Then Standard 4 ‘*Clinical Care of Adults with Diabetes*’ (Department of Health, 2010) states:

All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes.

Both these statements emphasize the importance of healthy lifestyles, shared decision making and self-management for diabetes management. The National Service Framework for Diabetes is important in the UK as it drives the clinical agenda and sets the standards against which practice is audited. The establishment and expansion of the Expert Patient Programme (discussed in the previous section) and the development of the National Service Framework for Diabetes are both strategic responses to the increasing incidence of Type 2 diabetes in the UK, and both emphasise the importance of diabetes self-management.

2.3.3 The discourse of health and personal responsibility

The emphasis on ‘self-management’ for chronic conditions also needs to be seen as part of a wider discourse in public health that emphasises the importance of individuals taking active responsibility for their health. There are several elements to this discourse: the view that

individuals' lifestyles contribute to their health outcomes, the increasing individualisation in society, the need to cut the cost of healthcare, and the view of individuals as consumers of health services.

A particularly strong element is that individuals are increasingly being encouraged to consider their own actions as a major contributing factor to their health. In this discourse 'healthy lifestyle' practices, particularly those relating to diet and exercise, are seen as issues of individual choice. Such choices are the responsibility of individuals who are free to change them if they wish. News stories reporting results from medical research indicating how people should modify their lifestyle are frequently published in the media. Recent examples are a report in *The Scotsman* suggesting that vegetarians are less likely to suffer from heart disease, diabetes or a stroke than meat eaters (Newbury, 2011), and another in *The Telegraph* suggesting that children who eat 'healthy' diets are more intelligent than those who eat 'junk food' (Alleyne, 2011). The implication is that individuals can minimise the risk of certain illnesses (such as heart disease, cancer and diabetes) or improve their life chances, by leading a 'healthy lifestyle' (Patterson and Chambers, 1995). This discourse focuses on the active and self-disciplined individual who is able to manage their health in response to perceived risks (Nettleton, 1997).

This discourse can be seen as a reflection of the increasing individualism found in modern western societies (Beck and Beck-Gernsheim, 2002). When it is applied to public health it has ethical and social implications, particularly in countries such as the UK, where there is a publically funded health service. Taking responsibility for your health is implicitly equated with 'being good' and not doing so is equated with 'being bad'. As a result, the actions of individuals become subject to either moral approval or approbation. There have for instance been public discussions in the media about whether individuals who are perceived to have been irresponsible (by being obese, drunken or drug-dependent) should be allowed to receive expensive and limited services, such as hip-replacement or liver transplants, while other more 'responsible' citizens are on waiting lists for them (Garnsey, 2009, Donnelly, 2008). These discussions sit alongside the question of how to cut rising healthcare costs. The health-conscious citizen can not only improve their quality of life but also help to reduce healthcare costs, by not making so many demands on an over- stretched service. Here there is a close link between the notions of 'responsibility' and 'blame'. This type of reasoning tends to

stigmatise those with chronic disease in a way that ironically may make a positive approach to self-care more difficult to attain.

Another part of the discourse on personal responsibility is the concept of the ‘empowered consumer’ of healthcare services (Grace, 1991). This notion of patients as health consumers, as major stakeholders in healthcare services is very different from that of the passive patient who receives treatment from a medical expert (Anderson, 1996, Nordgren, 2008). In the UK the ideas of patient choice and consumer-driven services have recently been employed as rationales for new initiatives (NHS, 2010). This discourse is increasing in importance as a justification for the design and delivery of new services, with the intention of creating competition between providers in order to increase efficiency and improve quality (Dixon et al., 2010).

However, although initiatives such as the Expert Patient Programme (discussed earlier), appear to challenge the status quo in the doctor-patient relationship in which the doctor is the ‘expert’; the policy focus has emphasized patients taking responsibility for their health rather than clinicians allowing patients to take more control (Wilson, 2001). There is evidence that medical professionals find it hard to allow patients to make their own decisions, as their culture and training habituate them to expecting to be in control of clinical decisions (Anderson and Funnell, 2009). Additionally, the focus on taking personal responsibility for health and lifestyle does not take into account the fact that the increasing incidence of chronic disease is not solely caused by poor lifestyles, but also by other factors such as the rising numbers of the elderly in the population, urbanisation and other environmental factors, social inequalities and improvements in medical treatment. The focus on individual responsibility in healthcare can therefore be seen to shift the emphasis away from other important views of chronic health problems such as the structural inequalities that may lead to poorer health outcomes for some populations (Marmot, 2005, Taylor and Bury, 2007) and the vulnerability of those with chronic conditions that may make self-help more difficult (Gonzalez et al., 2008).

In this context it is worth distinguishing between health promotion and health education. Health promotion has been defined as “the process of enabling people to increase control over their health and its determinants, and thereby improve their health” (World Health Organization, 2006). In order to achieve these aims a range of strategies are required both at

an individual level - through the development of personal skills and the strengthening of community groups, and at a structural level, through the creation of supportive environments for health and the development of effective public policy (World Health Organization, 1986). In health promotion there is an acknowledgement of the reciprocal link between human behaviour and the environment in determining health outcomes for populations (Green et al., 1996). Changing social and economic conditions can have broad effects on health outcomes and social policy may be used as a tool to mitigate negative outcomes (Stuckler et al., 2009). Health education is focussed on influencing the health behaviours of individuals. It can be seen as one of the strategies used for health promotion. Most particularly it seeks to improve health by encouraging voluntary health changes. Health education may take place at an individual or group level or through the mass media. Health education initiatives that use mass media such as television, radio and newspapers, often aim at increasing public awareness and creating a climate of opinion about issues. They are non-personal and provide fairly generalised health risk information and advice. Individual health education, implemented in individual or group settings, is more specific and is aimed at promoting individual health changes (Catford and Nutbeam, 1984). Much of the work in this field has been on improving the effectiveness of health education programmes through the use of theoretical models that attempt to understand individual health behaviours (Glanz et al., 2008).

2.3.4 Health behaviour change models

As the discourse of personal responsibility for health has become more dominant, health change programmes have been developed to encourage individual behaviour change. Health change programmes are often underpinned by theoretical models about behaviour change. Many models exist, but the most commonly used ones are the Health Belief Model, the Theory of Reasoned Action, the Theory of Planned Behaviour, Social Cognitive Theory and the Transtheoretical Model (Redding et al., 2000). The Health Belief Model (HBM) was originally proposed in the 1950s and contains the four constructs: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers (Rosenstock, 1966). Other constructs have since been added such as perceived efficacy, cues to action and health motivation (Glanz et al., 2008). The Theory of Reasoned Action (TRA) proposes that an individual's attitude towards a behaviour and the prevailing subjective norms (or social influences) surrounding that behaviour influence their intentions to perform the behaviour and the likelihood that they will actually perform behaviour (Fishbein, 1967, Fishbein and

Ajzen, 1975). The Theory of Planned Behaviour (TPB) is a development of TRA and proposes that behavioural intentions are influenced by three factors; attitude, subjective norms and behavioural control (perceptions of the ease with which the behaviour can be performed) (Ajzen, 1985, Ajzen, 1991). In a similar vein, Social Cognitive Theory (SCT) (Bandura, 1986), identifies three factors: personal factors, behaviour, and the environment as influencing behaviour. Self-efficacy theory (Bandura, 1977), focuses on one particular facet of SCT, that individuals' perception of their ability to plan and take action to reach a particular goal influences their ability to reach that goal. The Transtheoretical Model (TTM) (Prochaska and DiClemente, 2005), identifies change as a process of progress through a series of stages: pre-contemplation, contemplation, preparation, action, maintenance and termination. Other core concepts that have been used in the model are the decision balance sheet and self-efficacy.

These models have been widely used to understand health behaviour and behaviour changes (Armitage and Conner, 2000, Bandura, 1991). Lorig's patient self-management programmes, for example, were particularly influenced by Bandura's theory of self-efficacy (Lorig, 2001). More specifically, a number of diabetes interventions have used these models, particularly to encourage changes in activity, diet and self-management (Jackson et al., 2007, Sharifirad et al., 2009, Boudreau and Godin, 2009). However, some authors have commented that not enough diabetes interventions are grounded in theoretical models (Cooper et al., 2001).

2.4 eHealth and the impact of Information Technology in healthcare

Another changing aspect of healthcare provision has been the growing use of Information Technology systems to support and extend healthcare provision and management (May et al., 2005). New technology has been introduced into every aspect of healthcare, from complex embedded systems in the operating theatre to patient record systems in primary care practices (Waneka and Spetz, 2010, Oh et al., 2010, Ludwick and Doucette, 2009). However, Information Technology is not just transforming the work of healthcare managers, administrators and clinicians it is also increasingly being used by patients and its use is gradually transforming the way that patients seek for and access health information (Sillence et al., 2007, Kivits, 2009).

The introduction of Information Technology into healthcare services in the UK has been a gradual process over the last four decades. A co-ordinated Information Technology strategy

for the NHS in the UK was developed during the 1990s, and eventually came to fruition in the development of the National Programme for Information Technology in 2002 (Department of Health, 2002). Its history can be traced back to the 1992 Information Management and Technology (IM&T) Strategy (Department of Health, 1992). This document noted the problems of having an uncoordinated approach to Information Technology delivery which would hinder any attempts to integrate data and systems. The main thrust was to design systems that would enable information sharing across the NHS network. In the Department of Health's 1998 strategy (Department of Health, 1998) commitments were made to ensuring electronic health records for all patients, online access to patient records for clinicians and shared electronic information about best clinical practice. The NHS Plan, which set out the government's plans for the development of the NHS (Department of Health, 2000), was followed by a supporting document "Building the Information Core: Implementing the NHS Plan" (Department of Health, 2001a). Following the 2002 publication of the Wanless Report (Wanless, 2002), the Department of Health finally published its new strategy for developing Information Technology "Delivering 21st Century IT Support for the NHS – A National Strategic Programme" (Department of Health, 2002). This laid the strategic foundations for the National Programme for Information Technology (NPfIT) which was formally launched in October 2002. The two key elements of this strategy were a central infrastructure and the replacement of local systems at hospitals and GP practices with centrally selected software. The process of implementing the National Programme for Information Technology, which has been overseen by NHS Connecting for Health since 2005, is currently still underway, but many facilities have now been implemented.

The National Care Records Service was the core aspect of the National Programme for Information Technology, which was designed to manage and improve the quality of patient information and to help clinicians. However, some services have been developed that patients can use directly. NHS Direct is an example of such a system. NHS Direct is an Internet and telephone-based information service, which has now also expanded to include freeview television. The service was launched in England in 1998 (NHS, 2011) and provides information in the form of self-help guides and health and symptom checkers on the website, along with a telephone-based help line through which individuals can receive personalised advice. The number of telephone calls handled has been gradually increasing with 6.4 million calls received in 2003/04 (Office for National Statistics, 2006).

While the NHS concentrates on implementing Information Technology systems that support clinicians and administrative processes, patients are increasingly turning to the Internet for health information. A number of studies have confirmed that many people use the Internet to search for medical and health-related information (Cline and Haynes, 2001, Gray et al., 2004, Bundorf et al., 2006, Schwartz et al., 2006). For instance Pew found that in the USA 80% of the Internet users they surveyed sought health information online (Fox, 2005); and in Europe a study of seven countries found that 71% of Internet users used the Internet for health purposes (Andreassen et al., 2007). In the UK, the Oxford Internet Survey found that 68% of Internet users sought health information online (Dutton et al., 2009). Evidence also shows that the use of the Internet for seeking health information has increased rapidly in the last few years. A longitudinal survey carried out in Birmingham found that in 2000 only 16% of respondents used the Internet to seek health information whereas by 2006 the percentage had risen to 55% (Trotter, 2008). Similarly the Oxford Internet Survey found that in 2005 35% respondents said they used the Internet to seek health information and by 2009 this had risen to 68% (Dutton et al., 2009).

Evidence indicates that most of those using the Internet for health purposes are seeking practical health information for themselves or for a close relative or friend (Shuyler and Knight, 2003, Atkinson et al., 2009). From the point of view of patient use therefore the Internet is currently largely being used as an information resource (Atkinson et al., 2009). This reflects the general trend of the Internet being used as an information resource and its increasingly widespread availability in home and work environments (Dutton et al., 2009). There is also evidence to suggest that those who perceive the Internet to be more embedded in their lives are those who use it more frequently as a source of health information (Leung, 2008, Rice, 2006). However, the Internet is not just used as a place to passively read health information. There are interactive communication facilities such as health chat rooms and online health forums where individuals can give and receive emotional support and share experiences. There are also interactive interventions available such as on-line decision aids and health and fitness programmes which provide facilities such as exercise regimes, diets and quit smoking programmes and self-management programmes.

The widespread use of the Internet and other computer-based systems for health purposes has a number of repercussions. Most significantly the Internet provides ways of accessing health information without the direct mediation of healthcare practitioners. This means that

patients are potentially not as dependent on one-to-one discussions with clinicians for health information, which can be interpreted as beneficial or problematic, depending on one's point of view. A number of benefits can be seen to follow from the increased availability of health information on the Internet: patients can read information in their own time which may help them understand it better, patients may feel more positive about taking responsibility for their health if they are more proactive in seeking health information or if they have easy access to it, also it may make consultations more focussed and effective if they do not have to concentrate on the passing on of basic information (Gustafson, 1999). However, a number of concerns have been expressed about patients' use of the Internet to obtain health information, especially by healthcare practitioners: the more informed patient can appear to be a threat to the clinician's expertise (McMullan, 2006) and as a consequence the physician-patient relationship may be damaged especially if clinicians have difficulty adjusting to the change (Murray et al., 2003b, Murray et al., 2003a), also the information that patients access online may lead to confusion, distress or detrimental self-diagnosis and self-treatment (Ahmad et al., 2006). Much research in this area has focussed on the issues of the quality of and trust in health information on the Internet. This is because it has been widely acknowledged that the quality of the information available on the Internet is variable and much of it is poor (Hesse et al., 2005, Cline and Haynes, 2001, Maloney et al., 2005). There is also concern that those who are most vulnerable are most likely to be susceptible to believing information from less credible sources (Kalichman et al., 2006).

This shift towards greater patient use of online health information can be seen to mirror the shift discussed above in the discourse of individuals taking responsibility for their health (Lewis, 2006). It is certainly the case that many people now have access to a wide range of health resources over the Internet, and that as a consequence they are accessing health services in ways that have not been previously possible. However, although many people have easy access to health information, it does not necessarily follow that they find it easy to understand, relevant or helpful, nor does it necessarily follow that they will take more responsibility for their health as a consequence of having easier access to information. Whether these developments are interpreted as beneficial or problematic, they nevertheless represent an important change for healthcare, by which it moves outside the confines of the health-practitioners consulting room and crosses the boundary between the surgery and the world outside. The shift away from reliance on a specialist 'place' at which one receives healthcare, which has also occurred in other spheres (libraries, banks shops), as a result of the

Internet being accessible from people's homes has had a subtle but pervasive impact on the way healthcare services are perceived.

2.4.1 Theoretical frameworks for understanding IT adoption and use

As IT systems to support healthcare provision and management have become more widespread both within clinical environments and outside, it is worthwhile looking at some of the theoretical frameworks that have been used to understand the processes that occur during IT system adoption and use. While most of the theories and frameworks discussed in this section have been developed to understand general issues of IT innovation and adoption, they are nonetheless useful for framing discussion about innovation and adoption in eHealth.

Some models and theories from social psychology about attitude and behaviour have been particularly influential in this field. Of these, the most notable are the Theory of Reasoned Action, the Theory of Planned Behaviour, and Social Cognitive Theory, which were discussed above in relation to health behaviour change. In some studies these models have been used to understand behaviour in relation to IT use (Brown and Venkatesh, 2005, Marakas et al., 1998). However, they have been most influential in that they have been adapted and incorporated into IT-specific models.

Looking at models of technology adoption and use, the Technology Acceptance Model (TAM) (Davis, 1989) is one of the most widely used frameworks. It is based on the Theory of Reasoned Action, and proposes that perceived ease of use influences perceived usefulness, and that both determine an individual's intention to use an IT system which in turn influences actual system use. Various extensions to this framework have been proposed. The extended Technology Acceptance Model (TAM2) (Venkatesh and Davis, 2000) adds social influence processes (subjective norm, voluntariness, and image) and cognitive instrumental processes (job relevance, output quality, result demonstrability, and perceived ease of use) as influences to user acceptance. Another extension, TAM3 (Venkatesh and Bala, 2008), develops an integrated model of determinants drawn from the literature on the Technology Acceptance Model. The Task-Technology Fit model (ITF) is another model which also looks at factors that enhance user acceptance. It proposes that IT systems are more likely to be used and have a positive impact on individual performance if their capabilities match the tasks that the user must perform (Goodhue and Thompson, 1995, Zigurs and Buckland,

1998). These models have been used to look at health technology acceptance. For example, the Technology Acceptance Model has been used to investigate patients' intentions to use ehealth (Wilson and Lankton, 2004). In a recent review of studies found that the Technology Acceptance Model predicted a substantial portion of health IT use and acceptance by clinicians, but there were some inconsistencies (Holden and Karsh, 2010).

Another influential and widely used framework for understanding technology adoption is Diffusion of Innovation Theory (Rogers, 1995). This theory looks at the spread and adoption of any type of innovation; however it has been used extensively to investigate the acceptance of technology. The theory models individuals as having different degrees of willingness to adopt innovations. Rogers identifies five categories of individuals from earliest to latest adopters: innovators, early adopters, early majority, late majority, and laggards, and observes that the portion of the population adopting an innovation is approximately normally distributed over time. This theory has been widely used to understand, plan and predict the diffusion of ehealth and telehealth initiatives (Helitzer et al., 2003), although often with a focus on clinicians rather than patients.

The Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al., 2003), is an attempt to develop a unified theory, based on the four constructs, performance expectancy, effort expectancy, social influence, and facilitating conditions. These constructs are moderated by gender, age, experience, and voluntariness of use. It is based on a consolidation of the constructs of the Theory of Reasoned Action, the Theory of Planned Behaviour, Social Cognitive Theory, the Technology Acceptance Model, the Motivational Model, the Model of PC Utilization, and Diffusion of Innovation Theory. A few studies have used this model to look at the adoption of particular health technologies (Hsu et al., 2011, Cranen et al., 2011).

Finally, Normalization Process Theory (NPT) is a theory developed to understand the process of implementing and evaluating health care innovations (May and Finch, 2009). It is different from the other theories discussed in this section as it looks particularly at healthcare innovation, and in supporting the development of new innovations. NPT makes three core propositions, a) that complex interventions become routinely embedded in their organizational and professional contexts as the result of people working to implement them, b) that successful implementations can be characterised using four generative constructs:

coherence, cognitive participation, collective action, and reflexive monitoring, and c) that the work of integrating a complex implementation requires a continuous investment that takes place over time and space. These constructs were developed through identifying and mapping elements of interventions through empirical research studies (May et al., 2003, May et al., 2007), many of which looked at technology-enabled interventions such as telecare (Mair et al., 2008). The aim of the theory is to help health practitioners and managers to understand the processes and structures required when implementing complex interventions with the aim of improving practice.

2.5 eHealth systems for diabetes

This section reviews recent literature reporting and assessing interactive technological systems for patients with diabetes, and interventions devised for use with those systems. The focus is on systems that incorporate patient involvement, rather than systems that primarily support clinicians. This encompasses interactive systems in which patients use technology to communicate with healthcare practitioners or other patients with diabetes, upload or share personal medical readings with practitioners, or take part in interactive education programmes.

At a basic level information-providing websites are beneficial technology-driven tools that enable patients to access information at anytime without having to go into the clinic or GP surgery. Additionally, blood glucose meters enable patients to monitor their blood glucose level by taking a pin prick of blood, and placing a drop of blood on a test strip inserted into the meter in order to obtain a reading. Assessments of such simple, and commonly-used, information-providing artefacts are not covered by this review, although many of the systems reviewed incorporate both information provision through web pages and/or the use of blood glucose meters as one of the facilities offered.

This review has been undertaken by searching a series of electronic databases (PubMed, ACM Digital Library, Ingenta Connect and Science Direct) in order to find journal papers that report results from empirical investigations of such systems. The purpose of the literature review is to overview existing work and to highlight gaps in the research. This review is not comprehensive as so many studies have been published. However, this overview aims to highlight the key features of the published work, and provides the background to the empirical work undertaken for this study. The searches were initially

undertaken in spring 2006 and updated in spring 2011. Keywords used for the search were “diabetes”, “internet” and “self-management”. Studies chosen for inclusion were those that described: software systems designed to help patients to improve their diabetes self-management outside the clinical environment, the intervention framework within which the software was used, and the results of a research study into the effectiveness of the intervention. While many of the studies included in this review report the results of randomised controlled trials, not all do. This is because the aim is not to systematically review the success of interventions that meet certain criteria, but to examine a range of a) software systems, b) interventions, and c) research studies. The purpose of the review is to map out the work being done, and to highlight gaps within the field.

The structure for the review is based on a grouping of the types of system that have been developed. These groups were devised after reading the literature and clustering the systems found according to features they exhibited. Although the groups were found to be a useful structuring mechanism they are not entirely discrete and some systems apportioned to one group may exhibit features that overlap with another group. The groups are:

- Educational systems – focus mainly on providing interactive self-management education for patients with diabetes, improving their knowledge and approach.
- Communication and social support systems – provide social support through technical means, so that patients can communicate and share their experiences with others.
- Mobile/Personal Digital Assistant (PDA)-based Interactive systems – use mobile technology to provide patients with a range of interactive services, most often the transmission of data and advice between patients and experts.
- Personalised Interactive Internet-based systems – provide patients with a number of interactive facilities that enable them to undertake a range of activities such as: uploading, viewing and sharing relevant data (blood glucose readings, dietary data, medication taken, activity levels) with their clinicians; asking questions and sharing experiences with others, taking part in learning activities and supporting others. Details of the papers reviewed in this section are summarised in table format in Appendix #1.

2.5.1 Educational systems

Educational systems are those which focus primarily on providing patients with educational programmes and information about managing diabetes. As diabetes is a complex disease, there is much for patients to learn, both in terms of understanding the condition itself and in terms of learning how to manage it in their daily lives. However, most of the educational systems discussed here also provide some sort of social support alongside the educational input. As diabetes educational systems provide such a wide range of facilities, there is a question about what outcomes should be measured when evaluating them. Some studies discussed in this section assess biological outcomes, particularly improvements in glycaemic control (HbA_{1c}). Indeed the trend in all assessments of diabetes interventions is to measure biological outcomes. However, Cooper et al. have suggested that educational interventions may benefit patients in ways other than improving biological outcomes, for instance by providing educational or psychological benefits (2008). They suggest that diabetes education can be regarded as providing broad, patient-based positive outcomes that may not include lasting benefits to glycaemic control. Other studies have similarly found that where patient education interventions find no improvements in biological outcomes there are other valuable outcomes such as positive improvements in beliefs about illness (Davies et al., 2008) and treatment satisfaction and empowerment (George et al., 2008).

Most prominent amongst the various educational programmes devised are the Stanford Self-Management Programs which are the work of team at the *Patient Education Research Center* at the Stanford School of Medicine led by Kate Lorig. These are tightly structured programmes, originally designed to run as face-to-face peer-led group workshops, run for two and a half hours once a week for six weeks in community settings such as churches, libraries and hospitals. The programmes were designed for a range of chronic conditions such as arthritis, diabetes and back pain and the rationale behind their development has already been described in some detail in section 2.3. Internet-based versions were subsequently designed for the 'Healthier Living with Diabetes' program and the Chronic Disease Self-Management Program' (which is appropriate for people with a range of chronic diseases including diabetes) amongst others. A randomised controlled research study of the Internet version of the 'Healthier Living with Diabetes' programme is currently under way but the study of the Chronic Disease programme has been completed (Lorig et al., 2006). This intervention provided participants with access to a password controlled website that contained interactive instruction on the course content and a discussion board. Patients were also given a book

containing the course content. Participants agreed to log in at least three times a week for six weeks and participate in the suggested activities. Activities included reading the week's content, posting an action plan on the discussion board, checking in with a buddy via email and participating in self-tests and activities. The moderators assisted participants by reminding them to log-on, modelling action planning and problem solving, offering encouragement and posting to the discussion board. The study was run as a randomised trial for 958 patients with chronic disease (heart, lung or Type 2 diabetes), of whom 457 participated in the intervention and 501 received usual care. The outcome measures were quality of life (seven indicators), health-related behaviours (four indicators), health service use (three indicators) and perceived self-efficacy. One hundred and seventy-eight patients dropped out of the research study before completion. Statistically significant improvements for the intervention group were found after one year in only four quality of life indicators, and one of the health behaviours. The study was therefore inconclusive in finding statistically significant differences across the outcome measures for the intervention group. Improvement in self-efficacy (an important factor in Lorig's work) was not statistically significant, but was better in the intervention group than in the usual care group.

Glasgow et al. (2011) report on a large study conducted in primary care clinics in Kaiser Permanente Colorado on the use of a diabetes self-management website by patients with Type 2 diabetes. In this study 270 participants took part in a three way randomised controlled trial, in which they either used the website alone, or used the website plus human support or had usual care. The intervention program was designed to provide support for medication adherence, exercise and food choices by offering a number of interactive and multimedia features, including video, animation, and audio-narration. They found that usage of the website was reasonable but decreased over the four months of the study. Outcomes were measured at four months and the study found no statistically significant improvements in biological outcomes associated with website engagement.

A number of studies of Internet-based educational systems have also shown inconclusive findings, some of which are discussed here. A Norwegian randomized control trial investigated the usefulness of self-efficacy as a moderator in a tailored Internet-based educational system, for patients with Type 1 or Type 2 diabetes, that provided information, quizzes with feedback, videos, and behaviour exercises (Wangberg, 2008). Outcomes were measured at one month, and the results of the study were not statistically significant although

mean target behaviour improved slightly more for the group who started with the highest self-efficacy. An eight week randomised study of an intervention designed to encourage patients with Type 2 diabetes to engage in more physical activity using the D-Net system which enabled them to set goals and receive personalized feedback, contact a personal coach and use a peer discussion board (McKay et al., 2001), also found no statistically significant beneficial changes at the end of the study period. In Chicago, an Internet self-management education programme trialled with 19 young adults with Type 1 diabetes for six months provided information, goal-setting activities with feedback, role-playing, group discussions, empowerment activities, and communication skills training (Gerber et al., 2007). The study found that although using an Internet system was feasible, maintaining participant motivation was not easy and relied heavily on human input. It was found that participation generally declined over the six month period and participant involvement relied heavily on reminders and encouragement from educators and families.

Other innovative approaches have been tried, such as using interactive games, photography and multimedia stories. In a randomized controlled trial, 59 young diabetics aged 8-16 with Type 1 diabetes used an interactive Nintendo game for six months (Brown et al., 1997). In the game, players took the role of animated characters who manage their diabetes by monitoring blood glucose, taking insulin injections, and choosing foods, while setting out to save a diabetes summer camp from marauding rats and mice who have stolen the diabetes supplies. Results from the six month trial showed improved self-efficacy, communication with parents and self-care behaviour although not HbA_{1c}. In two studies involving participants taking digital photographs to augment the data coming from their blood glucose meters Smith (2007) found that using visualisations of activities (especially eating) helped patients to reflect on their health-related behaviours. In an American randomised study run in Nashville, Tennessee with 72 adolescents with Type 1 diabetes, the YourWay Internet-based self-management intervention (Mulvaney et al., 2009) used multimedia stories depicting psychosocial barriers to self-management and approaches to coping and problem solving. Results showed statistically significant improvements in self-management in the treatment group, but no other significant benefits. In Scotland, a novel support network based on text-messaging, called 'Sweet Talk', was designed to deliver individually targeted messages and general diabetes information to young people with Type 1 diabetes (Franklin et al., 2003). Theoretical models of social cognition and the health belief theory were used to underpin the development. Findings from a randomized controlled study in found that after a year of use

it was associated with improved self-efficacy and adherence; but that it was not on its own associated with improved glycaemic control. The study also found that use of Sweet Talk was associated with a greater number of clinic visits and use of the emergency hotline contacts (Franklin et al., 2006).

A recent systematic review of web-based educational interventions for the management of Type 2 diabetes concluded that goal-setting, personalised coaching, interactive feedback and online peer support groups were amongst the successful strategies used in such interventions (Ramadas et al., 2011). Findings from a systematic literature review of technology-based patient education interventions for young people indicated improvements in knowledge, psycho-social well-being and possibly improved self-care behaviours, but not in biological outcomes (Cooper et al., 2009). Approaches used by the five studies included in the review were self-instruction, information feedback, online forums and an interactive game. However, the review found a number of confounding variables in the studies such as the heterogeneity of the interventions, changes in treatment and increases in health care professional contact that make it difficult to clearly assess the outcomes of the interventions themselves.

The studies reviewed in this section show that interactive educational interventions can vary considerably in design, content, intended and measured outcomes. Although results show their use may bring about some health improvements, the evidence is far from clear cut. Another aspect of the systems reviewed in this section is that most of them contain social support features in addition to educational features. In the next section, systems specifically designed to enhance social support are reviewed.

2.5.2 Communication and social support systems

Chat rooms and bulletin boards have been used since the early days of the Internet, and as technology has developed more sophisticated social spaces (recent examples being Facebook and Twitter) have developed to enable people to seek and maintain social contact. The distributed nature of the Internet makes specialist social spaces viable as they are not limited by physical location, and features such as password-protected access and anonymity can make them useful arenas for safe exchanges. In addition to communication with other patients with diabetes, moderation or input from health practitioners can be provided.

A systematic review of studies evaluating health-related (not just diabetes-related) virtual peer-to-peer communities indicated that generally there were no beneficial health effects from their use. The most commonly measured outcomes in such studies were depression and social support (Eysenbach et al., 2004).

Little research has been undertaken on open diabetes chat rooms and discussion boards. Zrebiec and Jacobson (Zrebiec and Jacobson, 2001) report on a 21 month longitudinal study of an open access online diabetes community discussion board mainly used in North America. They found that the most common subjects for posts were nutrition, the emotional impact of diabetes and managing high or low blood glucose levels. Participation in the discussion board was rated as being beneficial by 79% of their questionnaire respondents.

Research on password-protected or moderated diabetes communities has been more detailed, but as with the educational studies, results have been far from conclusive about benefits to patients. Iafusco reports briefly on a study of 43 young patients with Type 1 diabetes using a moderated chat line, which found a statistically significant improvement in mean HbA_{1c} results over a period of three months (Iafusco et al., 2000). In contrast, a pilot study in the UK (Jennings et al., 2009) assessed a virtual diabetes clinic that included facilities for patients to communicate with health professionals, interact with peers and access information. Results from the study of 17 patients using the system for six months, all insulin pump users, found no statistically significant benefits for any of the assessed measures (HbA_{1c}, quality of life and self-efficacy). A qualitative study of a secure Web 2.0 diabetes portal for young people with Type 1 diabetes that included social networking tools such as message boards and blogs, found that using it enhanced information retrieval and facilitated feelings of security and being in control. However, use dropped off, login procedures were problematic and use was low for young people unwilling to self-identify with the disease (Nordfeldt et al., 2010).

Although receiving social and psychological support is acknowledged to be an important aspect of managing chronic disease (Funnell and Anderson, 2002), the studies discussed in this section suggest that there is potential for more research into social support environments for patients with diabetes.

2.5.3 Mobile/Personal Digital Assistant-based interactive systems

A wide variety of interactive systems for use by patients with diabetes have been developed and trialled over the last decade. The focus of these systems is that they provide facilities to

enable the input, viewing and sharing of blood glucose readings, other forms of data interchange, and communication with health practitioners. Effective blood glucose control is important for patients with diabetes as it has been shown to delay the onset and slow the progress of disease complications (The Diabetes Control and Complications Trial Research Group, 1993). These systems can be broadly grouped according to the type of technology they use: first, systems that use mobile technology and second, systems that use home computers. This section is concerned with systems that use mobile technology.

The increasing use of small portable devices, most particularly mobile phones but also Personal Digital Assistants (PDAs), has led to the development of eHealth systems that take advantage of the constant availability and ease of use of such devices. The core facility provided by mobile systems is often the viewing and sharing of blood glucose readings, as this is an area of disease management that many patients struggle with, but various other facilities are also offered. Some systems involve the synchronised use of mobile devices and computers in order to provide a wide range of facilities to patients. In contrast, some telemedicine systems are often used to provide patients with phone advice from healthcare practitioners as an alternative to face-to-face communication. In this section interactive mobile systems will be reviewed, but systems that provide phone advice as an alternative to face-to-face communication will not.

Looking first at PDA systems, in the CenTexNet study a PDA with pre-installed software was given to patients that enabled patients to enter blood glucose, insulin and food data and provided trend graphs and views (Forjuoh et al., 2007). With this system however there were no facilities for communication with health practitioners, so the intervention was solely aimed at supporting patient self-management practices. Data from nine of the 45 participants who enrolled and used the PDA for six months showed a statistically significant decrease in HbA_{1c} levels although complete results were not available from the trial.

Other PDA systems include facilities for data sharing with healthcare practitioners. In Poland a PDA system was developed that integrated a blood glucose meter with a simple electronic log book and enabled automated uploads to a computerised system that clinicians could view and respond to. In a randomized clinical trial of 30 pregnant patients with Type 1 diabetes in Warsaw, all participants received three days training after which 15 intervention patients were provided with the system (Ladyzynski and Wojcicki, 2007). In the intervention group

patients' blood glucose data was automatically stored and food data was manually entered by patients. The data was automatically uploaded so that clinicians could view the data and adjust treatment if necessary. In contrast, non-intervention patients were treated on the basis of three-weekly clinical examinations. After six months, results for blood glucose control and insulin adjustment were very similar in both groups, despite the more frequent reporting in the intervention group. In a study of the DIABTel system, patients with Type 1 diabetes were provided with a PDA which enabled them to input data into an electronic logbook, send messages to consultants, and review their treatment plans. Data could be uploaded to the clinical unit at any time by connection to a phone network (Gomez et al., 2002). Clinicians could view the patient data on their system, perform data analysis and send messages back to patients. Results from a six month cross-over trial with ten patients found a trend towards improved HbA_{1c} but no statistically significant results. The study also found that clinicians performed more adjustments to patients' treatment during the DIABTel phase than the control phase, but patients did not use the full range of facilities provided, and appeared to be quite passive in their interactions with the clinicians. A six month crossover study in Hong Kong, in which 19 patients who required insulin used a monitoring system based on a hand-held, touch-screen electronic diary, found statistically significant improvements in glycaemic control (Tsang et al., 2001).

A variety of interactive systems using mobile phone technology have been developed. Some systems are designed to use mobile technology primarily as an effective way to transmit data, but then use computer-based systems to generate useful views of the data for clinicians and patients to view. For instance a software system called DiabMemory was designed so that patients with Type 1 diabetes could enter data using a mobile phone, but then view statistics and trends through a web-based interface. A study of the system found that ten patients who used it for three months experienced improved HbA_{1c} results after use (Kollman et al., 2007). In a similar study run in Oxford, patients used a blood glucose meter linked to a mobile phone. The phone automatically transmitted blood glucose data, and additionally patients could send data through the phone about food intake, insulin intake and activity levels. When run as a randomised trial, patients in the intervention group received immediate feedback to their readings on their phone and could also view their data on a web-page as well as receiving regular tele-medicine advice from a specialist diabetic nurse who was reviewing their data. The nine month trial with 93 young 18-30 year old Type 1 diabetes patients found that although those in the intervention group had improved HbA_{1c} compared with those in

the control group, the difference was not statistically significant (Farmer et al., 2005). In Taiwan, a system was designed to which data could be sent by SMS (short message service) text messaging or that could be used purely as a web-based system. The SMS system was the same as the web-based system apart from the means by which the data was transmitted and results from a trial with 185 patients with Type 1 and Type 2 diabetes found that mean HbA_{1c} improved over three months (Kwon et al., 2004a). This study found that family members often helped (both younger and older) patients by entering data into the mobile device for them.

Other mobile phone systems have been designed more exclusively around the phone itself. When using the VIE-DIAB system for example patients entered data (blood glucose, carbohydrate intake and insulin intake) directly into the mobile phone, this was sent to a server and viewed by specialists who sent weekly text messages to patients containing management advice. A six month crossover study of this system with 36 adolescent patients found that glycaemic control improved (but not to levels of statistical significance) when using the system and deteriorated when using a manual system (Rami et al., 2006). Likewise in an eight month study run in Tenerife, patients were able to send blood glucose data by SMS message from their mobile phones and received monthly reports of their glycosylated haemoglobin on their phones. Results found that the system was largely acceptable to users, but no health outcomes were presented in the paper (Ferrer-Roca et al., 2004a).

One qualitative study of a mobile phone system was found which explored mobile phone communication between parents and young people with Type 1 diabetes (Gammon et al., 2005). In this study, a prototype system was developed that automatically transferred blood glucose readings from a young person's blood glucose meter to their mobile phone and thence to their parent's mobile phone. The aim of the trial was to investigate the feasibility of the technology but also to investigate issues that arose from its use in a family setting. Fifteen children (aged 9-15) with Type 1 diabetes used the system for four months. Results found that depending on how regularly children used their blood glucose meters the system decreased or increased subsequent parental reminders ('nagging'). Although this may be perceived as a positive outcome, some parents felt that as children moved towards adolescence the perception of surveillance could fuel oppositional behaviour and hence be counter-productive. In addition to these results nine themes emerged from the interviews: 1) a sense of security and reassurance, 2) nagging and scolding, 3) control, responsibility, and

independence, 4) surveillance and opposition, 5) learning and age-phased appropriateness, 6) focus upon illness, 7) automation, 8) system functionality and 9) it depends on how you use it. Again, as with the previous example of qualitative research about interactive systems for patients with diabetes ((Ralston et al., 2004) discussed at the end of section 2.5.3), this study uncovered a rich view of user experience that reveals a range of issues that need further investigation if the potentials and drawbacks of such systems are to be more fully understood.

Various issues are raised by these studies. Although many systems provide similar core features, the detail is varied as are the interventions in which they are used. It is therefore difficult to make direct comparisons between them. In mobile systems the focus is usually on frequent, automated data transmission, and timely but basic communication (by text or phone). Mobile systems generally provide few facilities for information provision, education, peer-to-peer communication, or support groups. The take up for studies is often low, and those who express an interest in taking part are often a quite different group from those not wishing to take part (Forjuoh et al., 2007).

2.5.4 Personalised Internet-based interactive systems

Over the last decade, a number of Internet-based eHealth systems have been developed with the aim of providing interactive, personalised services that patients with diabetes can access from their home computers. A number of such systems have been built and trialled in a variety of different settings in different parts of the world. They typically provide facilities such as blood glucose input and sharing, and communication with health practitioners. Additionally, such personalised systems provide ways to direct individualised information and educational material to patients and to provide personal support. Such systems offer novel opportunities for improving health outcomes.

The core component of this type of interactive personalised system is usually a facility for patients to share personal health data (usually blood glucose readings) with healthcare practitioners and to communicate with them about the data. For example a Korean Internet-based system developed for a specialist diabetes clinic in Seoul provided facilities for patients to enter blood glucose and medication information and to ask questions of healthcare practitioners using electronic messaging (Kwon et al., 2004b). Healthcare practitioners could view this data, as well as other health data about participating patients, send electronic

recommendations to patients, and reply to their queries. In a randomised trial of the system 110 patients with Type 2 diabetes either used the system in addition to usual care, or had usual care only for 12 weeks. For the intervention group, two endocrinologists reviewed the system daily and made personal recommendations to patients. In addition three nurses made comments on lifestyle modification and exercise and two dieticians gave individually modified medical nutritional advice. The aim of the trial was to ascertain any health benefits for patients, which was measured by changes in HbA_{1c}. Results showed statistically significant improvements in HbA_{1c} levels among patients in the intervention group (Kwon et al., 2004b). A follow up study in which 80 patients used the system for 30 months, found that although low HbA_{1c} results were sustained in the intervention group compared to the control group they were no longer statistically significant below a 1% level (Cho et al., 2006).

In addition to the core features of health data interchange and communication with practitioners, such systems often include features for information or education. The University of Washington's MyUW portal enabled patients to access their electronic medical records, upload and view blood glucose readings, use an online diary, communicate with practitioners by email and read practitioner-endorsed information (Goldberg et al., 2003, Ralston et al., 2004). In a more recent trial of the portal, 83 adults with Type 2 diabetes were randomised to receive usual care or usual care plus using the system for one year. Results from this study showed improvements in HbA_{1c} levels amongst the intervention patients that were statistically significant, although no difference was found in blood pressure, cholesterol levels or healthcare service use (Ralston et al., 2009). Further developments to the system have included the introduction of mobile phone system for uploading glucose meter data and providing graphical and tabular data feedback. However, participants reported mixed reactions to this system (Harris et al., 2010). In a different randomised controlled trial, also based in Washington, patients used a system that included educational and information elements alongside communication with a nurse and the input, viewing and sharing of personal health data. This intervention resulted in statistically significantly lower HbA_{1c}, cholesterol levels and weight (Bond et al., 2007).

Some studies however have produced less conclusive evidence of benefits for patients. The MyCareTeam system provided facilities for blood glucose and blood pressure uploading and viewing, messaging between patients and the care manager, and educational modules and resources. In a 12 month study, conducted in Boston, Massachusetts, 104 patients with

poorly controlled diabetes were randomised to take a diabetes education class and use the system and receive usual care or to take a diabetes education class and receive usual care only (McMahon et al., 2005). Results found statistically significant improvements in HbA_{1c} levels for both groups, but although the improvement was greater in the web-based group, it was not significant. The study also found that participants with less diabetes distress were more likely to use the web-based system, but also that system users experienced statistically significant lessening of diabetes distress over the period of the study (Fonda et al., 2009).

A few studies have evaluated such systems by using measures other than biological health outcomes. One study, undertaken in Tenerife, was of a primary care-based system that provided blood glucose input and viewing, educational resources and messaging with physicians (Ferrer-Roca et al., 2004b). The system was trialled for nine months with 12 patients and outcomes measured were system use and patient perceptions. It was found that effectiveness relied on regular system use, but many patients reported not having sufficient time to use the system. Positive responses were made about ease of use and efficient care. The limited Information Technology knowledge of patients and doctors using the system caused problems. Also a major factor detracting from the success of the project was the lack of messages sent from doctors to patients. In an American study, Selecky discusses the implementation of the LifeMasters system in Massachusetts that provided blood glucose upload and viewing, patient coaching and education and physician decision-support (Selecky, 2001). The main outcome measures reported here were cost reduction and patient satisfaction.

Some systems add the potential for peer support as well as other features. In Arizona the Diabetes Network (D-Net) intervention provided facilities for blood glucose input and viewing, interactive education resources, goal setting and contact with a dietician, and a moderated peer-to-peer discussion forum (Barrera et al., 2002, McKay et al., 2002). A randomised trial was conducted with 160 participants with Type 2 diabetes being separated into four groups – a) information only, b) personal self-management coach, c) social support and d) personal self-management coach and social support. Results after three months showed little change in biological measures (HbA_{1c} and cholesterol) but improved dietary practice and slight improvements in quality of life across all four groups.

Automated decision support systems can provide a different type of support for patients with diabetes. The DIASNet computer system enabled users to input blood glucose, food and insulin data and could produce simulations enabling patients to learn how particular combinations of food and insulin affect their blood glucose levels (Plougmann et al., 2001). Here the aim was to use the simulation capabilities of the software in order to learn about how best to behave in response to a particular situation. In a study DIASNet was trialled with six patients with Type 1 diabetes for six months (Cavan et al., 2003). Findings were that although well-motivated patients used the system to derive useful information, manual data entry was cumbersome and off-putting.

Only one qualitative study was found. Ralston and Goldberg conducted an interview study of the nine patients who used their MyUW portal in the early stages of its development (Goldberg et al., 2003, Ralston et al., 2004). Six themes were identified in the study a) feeling that non-acute concerns were uniquely valued; b) an enhanced sense of security about health and healthcare; c) frustration with unmet expectations; d) feeling more able to manage; e) valuing feedback; and d) difficulty fitting the programme into activities of daily life. Of these, the first three were considered by the researchers to be particularly relevant to patients' experience of system use. These results are interesting as they indicate that patients' perceptions of such systems are not solely focussed on their role as tools for improving biological health outcomes.

In the studies reviewed in this section, most of the systems discussed contain a variety of features. The core features provided are data interchange (data input, viewing and sharing with practitioners) and electronic communication with practitioners. Additional features provided by a number of systems are endorsed information provision, educational provision and peer-to-peer support. However, there is a considerable difference in the ways these elements are implemented by the various systems. Additional differences between the systems are found in provision of free equipment, length of training required, health practitioner input provided, type and frequency of interaction available, automation of services and length of time for which the studies were run. Further details of the studies discussed in this section are provided in a table in Appendix #1. The variations in the software features and the design of the interventions used by these studies make it difficult to make sustained comparisons between the systems.

2.6 Discussion

The wide variety of personalised Internet-based interactive systems reviewed above show the diversity there is in the field. A set of core features can be identified from the systems, these are: data interchange (input, upload, viewing, sharing), communication, education, information provision. However, the ways in which these features are implemented varies considerably from one system to another.

In addition, a distinction needs to be made between the technical ‘systems’ that are built and the ‘interventions’ that are used with those systems. The technical ‘system’ here refers to the computerised artefact – for example a website and its associated software programs, or a PDA linked to a blood glucose meter and associated software. An ‘intervention’ is the way in which the system is used – the people who are selected to use it, the context in which they use it and the processes they follow when using it. The same technical system could be used in a number of different interventions. For example a technical system could be used on the one hand during a 12 week intervention run with a clearly stated purpose (for example to increase physical activity) with weekly input from several healthcare specialists. On the other hand, the same technical system could be used during a year-long intervention with no single clearly stated purpose and infrequent input from healthcare specialists. The outcomes from these studies may be quite different even though the computerised element was the same. Because the research studies reviewed in the previous section use such a variety of technical systems and intervention designs, it is not possible to compare them. The design of the interventions in the reported studies was particularly varied. For instance variety was found in the clinical situations in which the systems were embedded, the type of patients selected to take part, the amount of training provided for participants, the amount of extra clinician time provided during interventions, the length of time interventions ran for, the quantity of free equipment provided, and expectations of patient expertise with computing systems.

Most of the studies reviewed in the previous section were run as quantitative studies in which the main outcome measured was patient HbA_{1c}. Other outcomes commonly measured by studies were cholesterol and blood pressure. Some interventions also measured outcomes such as self-efficacy, depression and health service use. Although many of the studies were randomised, the pool of potential participants was often limited by the fact that the study required patients to have access to an Internet-connected computer at home and enough expertise to use it. Also although many of the studies reviewed were controlled, the control

condition was most often 'usual care' whereas the intervention delivered such a variety of extra facilities to patients it could not be clear which elements were instrumental in providing benefits and which were not. For example patients under intervention conditions were often provided with increased access to personal data, information, education, and personal advice from clinicians compared to patients under control conditions.

Additionally, only one paper was found that reported a failed system (Keshavjee et al., 2003), and most other papers reviewed focussed on positive results. In a meta-analysis of educational and behavioural interventions for patients with Type 2 diabetes (but not just technical ones) Gary et al. (2003) suggest that there is a publication bias that results in fewer studies than one might expect being published with findings that are statistically non-significant or negative. This indicates that the benefits in actual practice may be less than suggested by the literature.

Such comments do not detract from the value of the studies undertaken or the systems on which they are based. Indeed, although results from previous studies do not decisively show that use of diabetes eHealth systems results in improved health outcomes for patients, they indicate that patients can benefit from using them and that it is worthwhile investigating them further. Although improving HbA_{1c} may be the ultimate goal for many diabetes interventions, it is not the only useful finding that may come from studies. Increased understanding about how and why technical eHealth systems are used is also worth pursuing. Given the inconclusive findings of the quantitative studies, there is a need to understand in more depth what happens when patients use systems, what motivates them, how they perceive the systems, and how they embed their use into their daily diabetes management regimes. The use of eHealth systems is still relatively uncharted territory and much more groundwork is needed to map out the terrain. Only the qualitative studies reviewed in the previous section (Ralston et al., 2004, Gammon et al., 2005, Goldberg et al., 2003) give any indication of how people experienced using the technical systems under investigations, or produced concepts that indicated what aspects of systems or interventions were relevant to how they were used.

Having looked at the literature and identified a lack of qualitative research in the field, I decided to undertake a qualitative investigation of a diabetes eHealth system, on the grounds that it is only through gaining a deeper understanding of patients' experiences of using

technical health systems that we will move forward in our understanding of how to make them more effective for patients. Furthermore it was evident from looking at the few qualitative studies that had been undertaken that there was a complex picture underlying technical health system use that had not been uncovered by quantitative studies, but that could provide new insights into how and why they are used by patients.

2.7 Summary

This review started by looking at the contextual factors that have had a bearing on my research study. First, the rising incidence of diabetes was considered. This has not only affected wealthy countries but has had global reach, with diabetes set to become the seventh leading cause of death globally by 2030. Second, I looked at the way in which Information Technology systems have been developed to support healthcare provision and management. The computerisation of healthcare is a work in progress in the UK, with major new systems still being developed and implemented. However, most of these systems are work-based systems that support clinical and administrative processes. Patient-oriented eHealth systems have not yet been developed to their full potential.

As part of this discussion the discourses that are currently influencing patient health behaviour were considered. Particularly influential is the idea of the ‘responsible patient’ – an active and self-disciplined individual who is able to manage their health in response to perceived risks. Another new but influential discourse is that of the ‘empowered health consumer’ who is a stakeholder in health services and who looks for quality and choice. Alongside these the more traditional discourse of the ‘passive patient’ still holds considerable sway.

Finally, the literature on empirical studies of eHealth diabetes systems was reviewed in four groups: educational, communication and peer support, mobile and PDA-based interactive systems, and personalised Internet-based interactive systems. The systems reviewed exhibit a wide variety of features making direct comparisons difficult. Most of the empirical studies undertaken have been quantitative and have assessed improvements in HbA_{1c} as a measure of success. The few qualitative studies that have been undertaken indicate that there is a rich patient experience that has not been taken into account in quantitative studies. For this reason it was decided to undertake a qualitative study for this research project, and to focus on investigating patient experiences of using an eHealth diabetes system.

3. A QUALITATIVE APPROACH: STUDY METHODOLOGY AND DESIGN

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Every art and every investigation, and likewise every practical pursuit or undertaking, seems to aim at some good: hence it has been well said that the Good is that at which all things aim.

Aristotle 384-322 BC: *Nicomachean Ethics*

3.1 Introduction

Following on from the literature review presented in the previous chapter it was decided to undertake a qualitative investigation of patients’ perspectives of using a diabetes eHealth system as this was highlighted as an under-researched area. The aim of the study was to investigate how patients experienced using an interactive Internet-based eHealth system, similar to those described in the last section of the previous chapter, which included facilities for viewing and sharing blood glucose readings with healthcare practitioners, communicating with practitioners and other patients, reading information about diabetes, and learning through an interactive email system.

In this chapter, the methodology and methods chosen for the study are discussed. The chapter contains seven sections; with section one introducing the chapter. Section two reviews the research question, discusses its original format and the way in which it developed

during the course of the study. Section three contains a discussion of the philosophical and methodological lens used for the study and a contextual overview is given of how the methodology used for this study fits in with recent developments in information systems research. As part of this section the historical background to symbolic interactionism is reviewed, and an explanation is given of how and why a symbolic interactionist approach was chosen for the study. In section four the design of the study is explained and discussed, particularly the key design decisions made and sampling and recruitment strategies. In the fifth section there is a detailed review of the data collection methods used, and a discussion of the design of the patient interviews. In the sixth section there is a discussion of the theoretical approach taken to the data analysis. This is contextualised by a discussion of alternative qualitative analysis methods, and a rationale for the choice of a flexible grounded theory approach to analysis is given. In the seventh section there is a discussion of the ethics and governance issues that arose from the study and the ways in which they were addressed.

3.2 The research question

The focus of the study was to concentrate particularly on patient experiences of using an eHealth system in order to uncover rich data about how and why it was used and what role it played in their diabetes management activities. The focus was particularly on whether using the eHealth system changed any aspects of patients' diabetes management or their views about diabetes management. The research question for the study can therefore be stated as:

- How do patients experience using a diabetes eHealth system?

This broad research question can be broken down into three more detailed sub-questions that focus on system use, perceptions of the system, and changes in response to the system. These were the three key elements of patients' experience that needed to be explored:

- How and why do patients use a diabetes eHealth system?
- How do patients change in response to using a diabetes eHealth system?
- How do patients view a diabetes eHealth system?

These questions were developed during the course of the research project as it became clear that patients' experiences were broader than those that had originally been anticipated. At the

beginning of the research it was envisaged that the study would focus on changes patients made in response to the eHealth intervention. The final version of the research question was developed after it became clear that patients used the system in ways that had not been anticipated. For instance, it had been envisaged that patient participants would use most parts of the system; however many only used selected elements of the system and some did not use the system at all. It also became clear that patients' experiences of the system were intricately enmeshed with their wider experiences of diabetes. The focus of the initial research question, on exploring changes in response to system use, reflected the focus on outcomes that had been found in the literature. Initially the primary research question was:

- What changes to the attitudes and behaviour of patients and healthcare practitioners occur as a result of using a diabetes eHealth system?

In order to investigate this research question several sub-questions were devised and used as the basis for data collection:

- What attitudes do patients have towards their health and the system before, during and after using the system?
- Do patients change their health behaviour when using the system?
- Do patients' HbA_{1c} readings change after using the system?
- How and why do patients use the system?
- What attitudes do healthcare practitioners have towards the system before and after using the system?
- How do practitioners use the system?

However, these research questions were substituted for the final research questions (listed on the previous page) as it became clear that it was not practical to focus on practitioners as well as patients, and that the research questions needed to be wider.

The refinement of the research question was an important part of the process of the investigation. In a qualitative study it is essential for the researcher to remain sensitive to the

research picture as it emerges. Thus the final research question represents both a focussing in on, and a development of, the original research question. The focus in the final question is on patients alone rather than both patients and practitioners. The development of the final version of the research question reflects the decision to focus on exploring patients' experiences of using the eHealth system rather than to concentrate solely on the changes they made during the study. Also, as most of the data collected in the study was collected from patient participants, and only three practitioners had regularly used the system, the decision was made to focus the analysis on patients' experiences. This development of the research question reflects my learning experiences during the study and was influenced by an emerging understanding of what was important to patients through the process of interviewing them.

3.3 Methodological approach

As stated above, the purpose of this research study was to investigate, describe and analyse patients' experiences of using a diabetes eHealth system. In order to make sense of these real-life experiences it was important to gather data in the form of patients' accounts of their own experiences. As well as containing descriptions of diabetes management activities and attitudes, these accounts also contain patients' explanatory frameworks and are embedded in a mix of contextualising stories, explanations and chat. During analysis the researcher interprets these accounts through a methodological lens, a lens which itself needs to be made clear.

This research study lies within the discipline of Information Systems research which takes as its area of study the social and organisational context of information systems design and use. As this is a multidisciplinary field linking various disciplines such as computing, business, management, health and social studies amongst others, those working in the field have adopted a variety of research approaches which have been a matter of debate over the years.

In a review of information systems research publications conducted during the 1980's Orlikowski and Baroudi (1991), following Chua (1986), identify three broad categories of research – positivist, interpretive and critical – distinguished by their underlying epistemology. They go on to discuss how these methodological approaches are used in Information Systems research. The epistemological perspective of positivism suggests that phenomena can be understood by being observed and recorded and that the researcher can

be an objective observer. This is based on the underlying realist ontological perspective of positivism, that realities and their meanings exist external to the mind and there are a priori and fixed relationships between phenomena. Concepts uncovered by investigations should be amenable to testing and should have qualities such as repeatability and predictive value. In contrast, an interpretive perspective is based on an epistemology which considers that meaning is created by people through their interaction with the world and researchers attempt to understand phenomena through accessing those meanings. In interpretive studies, the researcher is not viewed as an objective observer, but seeks a shared understanding of events. Whereas many interpretive studies take an uncritical stance, critical enquiry aims to critique the status quo through an exposure of contradictions in social systems, and in doing so seeks to uncover conflict and oppression. In critical studies the researcher questions assumptions made about the role of information systems in order to reveal the historical, ideological and contradictory nature of practices surrounding their design and use. In their review Orlikowski and Baroudi (1991) found that the majority of Information Systems research papers in the 1980s took a positivist approach, a few took an interpretive approach and none took a critical view. They conclude that if a wider diversity of research approaches were taken, encompassing interpretive and critical perspectives as well as the well-trodden positivist approach, more insight could be gained into different aspects of Information Systems phenomena.

The 1980s was a period of lively debate about Information Systems research methods and the discussion started at this time signalled the beginning of a change in the approach adopted in many subsequent Information Systems studies. The 1984 IFIP (International Federation for Information Processing) 8.2 Colloquium “Information Systems Research, a Doubtful Science” held in Manchester can be seen as a turning point (Mumford et al., 1985). At this conference there was a call for researchers to be bolder and more diverse in their approach to research. By the early 1990s some Information Systems researchers were starting to shift their methodological lens and were seeking to explore in various ways the interaction between information systems and the social processes into which they were embedded. As a result there was a gradual change in the way in which IT artefacts were studied, with an increasing number of research studies using qualitative methods and a wide number of social theories being used to explore the context of Information Systems use (Jones, 2000). Although there have been some criticisms about the lack of theory generation (Klein, 1999a) and the lack of generalisation (Hirschheim and Klein, 2000) from qualitative Information

Systems studies, recent studies indicate that research approaches are continuing to diversify (Flynn and Gregory, 2004), and that such diversification has been considered beneficial (Robey et al., 2008).

Whilst Orlikowski and Baroudi (1991) offer a useful critique of the primacy of the positivist paradigm in Information Systems research until the late 1980s, their tripartite division of research paradigms is not universally agreed upon. A variety of nuanced ways of categorising the epistemological, ontological and methodological positions taken in social research studies can be found in the literature. For instance Lincoln and Guba (2000) identify five paradigms: positivism, post-positivism, critical theory, constructivism and participatory/cooperative, Schwandt (2000) discusses three contrasting epistemological positions in qualitative research: interpretivism, hermeneutics and social constructionism, and Crotty (1998) distinguishes positivism, constructionism and subjectivism. Whereas Orlikowski and Baroudi (1991) and Crotty (1998) describe interpretivism as being founded on social constructionism, Schwandt distinguishes them. He agrees that interpretivism and social constructionism are both based on a rejection of the “empiricist, logical, atomistic, designative, representational account of meaning and knowledge” (Schwandt, 2000 p.196). However, he goes on to argue that interpretivism draws on the neo-Kantian concept of ‘*verstehen*’, taking as its basis the view that a) human action is meaningful, b) the intersubjective world must be respected and c) it is also possible to see human knowledge in an objective manner while acknowledging human subjectivity in knowledge. In contrast, social constructionism takes a perspectivist view that humans mediate reality by constructing concepts, models and schemes in order to make sense of the world. The pluralistic nature of reality is thus emphasized in the constructionist view, and many constructionists do not believe in an objective reality. Crotty (1998) discusses similar issues but draws his categories with different boundaries. He distinguishes between the epistemological position of constructionism, that meaning is constructed through our engagement with the world, and that of subjectivism, which denies interplay between subject and object, and suggests that meaning is entirely subjective.

Whilst it is not necessary in this thesis to unpick the details of these categorisations in any more depth, it is important to state the position being taken in the research. Following Crotty’s model (Crotty, 1998 p.4) the epistemology, theoretical perspective, methodology and methods chosen for this research study are identified. The epistemological view taken in this study is social constructionism, and the theoretical perspective is interpretive using a

symbolic interactionist approach. The methodology is a qualitative enquiry using elements of grounded theory, and the data collection methods chosen are interview, document collection and web page monitoring.

The constructionist epistemological position taken in this thesis is that meaning is constructed by social actors rather than an inherent property of objects themselves. This view does not deny the existence of the world independent of the human mind, but advocates that the act of generating meaning is a dynamic construction resulting from humans interpreting the perceived world. The implication for this research project is that I did not see the eHealth system as a neutral object whose use could be understood by measurement alone, or whose purpose was defined by me and those I worked with when we designed and built it. The eHealth system needs to be understood through investigating the meanings of those that use it. By taking this epistemological position it was expected that the set of understandings that patients brought to the eHealth system would differ from those of healthcare practitioners or policy makers. It was also expected that these meanings would not necessarily be static but may change over time. I anticipated that patient participants would overlay the technical artefact with personal, social and cultural meanings that would need to be explored in order to build a picture of how the system was used and therefore what benefits its use may bring.

The theoretical perspective taken in this study is broadly interpretive. This approach seemed appropriate given that the aim of the research was to uncover how patients experience an eHealth system, the views they develop of it and the meanings they ascribe to it. Interpretivism has a long tradition starting with the empiricism of Kant (1724-1804), and developed through Dilthey's emphasis on 'verstehen', or interpretive understanding. Dilthey (1833-1911) argued that the focus of social science is to understand the meaning of events for the social actors involved in them. This is set in contrast to a natural science (or positivist) approach which focuses on objectively observing the outside patterns of a phenomenon and looking for evidence of causes and effects. Weber (1864-1920) was another strong influence, particularly on developing the idea of explanatory or motivational understanding in social research. The interpretive approach emphasizes the importance of both observation and explanation in social research, and leads researchers to study the meanings actors attribute to their action and to gather data in natural settings. A number of 'schools' and different theoretical positions have emerged from the broad base of this tradition such as ethnomethodology, structuration theory, constructivism and symbolic interactionism.

Symbolic interactionism has its roots in the intellectual tradition of pragmatism, a tradition in which theorising is considered integral to human practice. The position of Charles Peirce (1839-1914), considered the founding father of pragmatism, was that the meaning of a concept could be found in the entire set of its practical consequences (Burch, 2009). The core view of Peirce's pragmatism was his maxim:

“Consider what effects, which might conceivably have practical bearings, we conceive the object of our conception to have. Then, our conception of those effects is the whole of our conception of the object.” (Peirce, 1992 p.132)

William James (1842-1910), who was working at the same time as Peirce, argued from the position that pragmatism provided a way of overcoming the clash between scientific and religious ways of thinking. These ideas were developed by John Dewey (1859-1952) and Clarence Lewis (1883-1964). Dewey considered that ideas and actions should be judged contextually according to the situations that gave rise to them. He was particularly interested in the nature of enquiry, and the way in which it is grounded in practical questions and concerned with transforming and understanding the situations in which we find ourselves.

Drawing on this pragmatist heritage, the ideas of George Herbert Mead (1863-1931) are considered to provide the foundations for symbolic interactionism along with the social research of W. I. Thomas (1863-1947) and the sociological framework of Robert E. Park (1854-1944). One of Mead's most significant contributions was his distinction between the “I” that is the spontaneous non-reflective self and the “Me” that is the reflective self. Mead states that individuals become self-conscious through the constant process of the “Me” monitoring the “I”. He also states that individuals shape themselves through an internalised conversation between their concept of the ‘generalised other’ and the self.

The sociologist Herbert Blumer (1900-1987) developed the work of Mead and coined the term ‘symbolic interactionism’ (Blumer, 1962, Blumer, 1969). He contends that symbolic interactionism rests on three premises:

“1. Human beings act towards things on the basis of the meanings such things have for them

2. the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows

3. these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters.” (Blumer, 1969)

The focus of Blumer's view is that meaning is central to an individual's interaction with the world. The meaning of a thing is not given, but arises through a process of interaction with the thing and through the ways in which other people react to the thing. Two stages are involved in the act of interpretation, first the person 'indicates to himself' the things towards which s/he is acting. This is an internal social process in which the actor communicates with her/himself. Second, as a result of this the actor transforms the meaning in the light of the current situation and acts accordingly. Action and interpretation are therefore always emergent and ongoing.

Blumer's symbolic interactionism is based on a number of "root images" (Blumer, 1969). Most fundamentally he views human society as existing in action and society as consisting of individuals interacting with each other. He takes Mead's concept of two forms of interaction – the conversation of gestures, and the use of significant symbols and calls these 'non-symbolic interaction' and 'symbolic interaction' respectively. Symbolic interaction is the most interesting form of interaction as through this interaction individuals interpret the actions and meanings of others. Objects in the world are defined by the meanings that people associate with them. Objects therefore may have different meanings for different people. However, it is also possible for common objects to emerge through a process of mutual indication. It nevertheless cannot be assumed that objects are seen in the same way by different people even if they inhabit the same social group. The meanings of objects, social process and the interlinking of those objects and processes that occur in organisations and institutions are not static but are subject to reinterpretation and change. The task of social research is therefore to investigate and uncover the interpretations that people have of the objects, social processes and people around them. Blumer holds a strongly empiricist view of research and argues that it is vital to ground research in a close exploration and inspection of empirical data. Exploration is a way of forming a close acquaintance with the empirical life under study through methods such as observation, interviewing, discussion and reading diaries and records. Inspection involves theoretical analysis in order to develop generic relations. This

analysis however should not be routine but should be flexible, imaginative and creative and should keep returning to the core data.

Symbolic interactionism colours the approach taken in this study in a number of ways. First, there is an emphasis in this study on uncovering the meaning patients ascribe to the diabetes eHealth system through an analysis of the ways in which they talk about the system. Using this theoretical stance entailed starting the data analysis with an open mind and rigorously and iteratively reading through the transcribed patient interview texts. The aim was to uncover and interpret the range of views patients expressed about the diabetes eHealth system. This emphasis on careful ‘inspection’ of the raw empirical data, and regularly returning to that data during the process of interpreting the findings from a study is central to the symbolic interactionist approach. Additionally, in symbolic interactionism individuals’ actions are considered as important as their interpretations, so as well as looking at what patients were saying about the eHealth system the research study also carefully investigates what they were doing with the system and what other diabetes management activities they were engaged in. The in-depth nature of the study ties in with Blumer’s notion of ‘exploration’, in which a researcher aims to “form a close and comprehensive acquaintance with a sphere of social life” (Blumer, 1969). The intention here was to get a good feel for what patients were saying about the eHealth system over a period of time, not just at one point in time. Although this process involved some repetition of questions and discussions it was an important part of getting to know the patients, and attempting to gain insight into their ongoing interpretation of the role the eHealth system had in their health management practices.

3.4 Research design

3.4.1 Study overview

Running a research study that involves working with patients in a primary care setting requires careful organisation and planning. Before commencing the study it was necessary to gain permission to carry out the work and to raise funds. A considerable amount of paperwork was required in the early stages. This section gives a brief overview of the activities undertaken.

First, there was a need to establish contact with GPs at one or more primary care practices in order to find someone who was interested in taking part in the research project. Having

made contact with a GP who wanted to run the study in their practice, and found another GP practice prepared to get involved if necessary, detailed planning could begin. Planning involved a number of steps: undertaking a thorough literature review, deciding on the features to be implemented in the eHealth system, ensuring that it was feasible to implement the key features of the system, deciding on the primary research question, designing the study, planning patient and practitioner information material and consent forms, and getting CRB (Criminal Records Bureau) clearance. Additionally, approaches were made to a number of blood glucose meter manufacturers in order to request support for the project. Roche² expressed an interest in the study and agreed to donate their Accu-chek Aviva blood glucose meters and Compass software to all the patient participants.

Having completed the background planning, a detailed research protocol was written along with patient and practitioner information leaflets. Funding was required in order to cover some of the study costs, so two small funding requests were submitted to, and approved by, the Mersey Research and Development Consortium³ and Diabetes UK⁴. The research protocol and associated patient and practitioner information material and consent forms were submitted along with the NHS Research Ethics Committee application form in order to apply for NHS ethical clearance. This process also required attending a meeting at which the NHS ethics board asked questions about the research process. During the waiting period the diabetes eHealth system was developed and tested. Additionally, during this period contact was made with the GP practice and I attended a patients' group meeting at the practice and discussed the proposed study with patients. Once NHS ethical clearance was obtained, it was necessary to get RM&G clearance⁵ and also to obtain ethical clearance from the University of Central Lancashire for the study. I also needed to obtain an honorary contract of employment in order to work as a researcher in the GP practice. Once all these procedures were completed the website went live and the study commenced, and ran from September 2006 until March 2008.

² Roche is a multi-national company that specialises in pharmaceuticals and health diagnostics (www.roche.com). They manufacture a range of products for diabetes care such as blood glucose monitors and insulin pumps.

³ The Mersey Research and Development Consortium is a primary care research network set up in 1999.

⁴ Diabetes UK are a UK charity that works for people with diabetes, funding research, campaigning and helping people live with the condition (www.diabetes.org.uk).

⁵ RM&G (Research Management and Governance) clearance for research projects is managed through a local delegated officer. The aim of RM&G clearance is to ensure that each research project has appropriate research governance arrangements in place, and that these are appropriate for local needs.

3.4.2 Study design

The setting chosen for the study was primary care as it is the setting in which a large proportion of patients with diabetes in the UK receive their care (Pierce et al., 2000). In the UK, even patients who receive much of their diabetes care from a specialist hospital-based diabetic clinic often maintain a reasonable degree of contact with their GP. Additionally, very few empirical studies of diabetes eHealth interventions have been undertaken in the UK, in which there is a publically funded health service, and those that have, have not been undertaken wholly in a primary care setting (Franklin et al., 2003, Farmer et al., 2005, Franklin et al., 2008, Jennings et al., 2009). Many diabetes eHealth studies have either taken place in specialist clinics (Kwon et al., 2004b, Bellazzi et al., 2002, Ladyzynski and Wojcicki, 2007, Gomez et al., 2002), or in the USA in the private healthcare sector (Ralston et al., 2009, Selecky, 2001, Forjuoh et al., 2007, Bond et al., 2007). During the planning stage for this study two GP practices were identified from which participants could be recruited and ethical clearance was applied for and obtained for both sites. Two practices were chosen in case an insufficient number of volunteers were recruited from the first practice; however in the event it was not necessary to use the second GP practice. The practice chosen for the study was a large practice of about 12,000 located at two sites with a mixed urban/suburban population. At the time of the study the practice had eight partner GPs and two practice nurses. If the study had been run in more than one practice, it would have been possible to access a more diverse population of patient participants. However, it was decided to focus the study on one GP practice as would have been difficult to ensure that the eHealth system was used in exactly the same way in different practices, and also the study time would have been lengthened, as it would not have been practical to run both studies concurrently. The study focussed on individual participants, however they were studied in context and the introduction of an element of comparison at a different level (by situating the study in two different GP practices) would have added extra complexity to both data collection and analysis. Stake argues that there is a danger in comparison studies that *'uniqueness and complexities will be glossed over'* (Stake, 2000), and Lewis that *'qualitative samples structured around comparison can easily become over large'* (Lewis, 2003).

Given the research aim, a variety of research methods could have been used to gather data, such as observational methods or interviews, or a combination of both. Direct observation methods would have allowed a closer focus on the context of eHealth system use in participant's home environments. However, observing the system being used in its natural

setting would not have been practical as the intention was that patient participants could use it when they wanted to. Also the focus of the study was not on the home context in which the system was used, nor on participant interaction with the software at a technical or interface level (Lewis, 2003), although those issues in themselves would have made interesting studies. In this study the research question focussed on participants' experiences, and the interpretations and meanings that they attached to those experiences, so it was decided that qualitative interviews were the most appropriate method of data collection.

In the study each patient participant used the system for six months. This time period was chosen because it was practical for the participants, and the General Practice in which the study was set. It was also long enough to allow participants to have a reasonable experience of using the system. This study length is roughly mid-range compared to that of other studies reviewed in the literature review. Some intervention studies have run for a very short time, such as the Norwegian educational study based on self-efficacy that ran for one month (Wangberg, 2008). The shortest time length of a similar personalised Internet-based intervention the D-NET study in Oregon which ran for three months (McKay et al., 2002). Other studies have run for longer periods such as the 2009 Washington study (Ralston et al., 2009) which ran for a year. Of the qualitative studies reviewed the Washington study ran for six months (Ralston et al., 2004) and the Norwegian study ran for four months (Gammon et al., 2005).

I chose a research design in which participants were interviewed several times, as one of the aims was to investigate the changes that occurred as a result of using the system. I decided to interview participants at the beginning of the study, after three months, and at the end of the six month period, so that as well as investigating participant experiences before and after the study, there was an opportunity to talk to participants while they were still immersed in using the system. This approach had the added advantage of providing an interim view of how participants were using the system and what their views were. Other qualitative studies reviewed in the literature review had either interviewed participants at the end of the study (Gammon et al., 2005) or at the beginning and the end (Ralston et al., 2004), so this particular study design was novel in comparison. As well as providing a view of change over the period of time of the study, the three interviews gave me an opportunity to get to know the participants during the study.

I decided to conduct all the interviews at the GP practice rather than in participants' homes. This was partly decided as a practical safety measure as I was working alone on the study. However, it was also considered that participants may find it easier to come to a quiet and private room in the practice to talk about the system rather than having me visit their home where it may have been difficult to find a quiet and private place to conduct an interview without interruptions. Additionally, as a visiting researcher to the practice, the participants did not know me, and some may have been reluctant to take part in the study if it involved a stranger coming into their home. However, there would have been advantages to conducting the interviews in participants' homes. Visiting participants' homes would have provided a better sense of where and how their computers were set up and would have given me opportunities to help with any technical problems. Additionally, from the participant's viewpoint, being in the home environment during the interview may have elicited more stories and recollections about how it felt to use the system at home. Locating the interview sessions in the GP practice possibly associated the diabetes eHealth system in participants' minds as belonging to the domain of the GP practice. Attending interviews for the study was probably similar to attending the surgery to see a healthcare practitioner to talk about diabetes, and it is possible that participants may have talked about the system and their diabetes differently if the interviews had been located in their homes. However, it is speculated that the advantages and disadvantages of each approach balanced each other out. This was therefore an informed decision made about the research for pragmatic reasons (Bechhofer and Paterson, 2000).

3.4.3 Patient sampling and recruitment

The sampling approach chosen for the study was purposive sampling, a common non-probability approach often used in qualitative research (Bryman, 2001, Silverman, 2005, Ritchie et al., 2003a), in which participants are chosen on the basis of certain characteristics. As the aim of the study was to implement the system in an 'ordinary' primary care setting, it was important to access a mixed range of patients of the type who would normally use primary care for their diabetes. Therefore a heterogeneous approach was applied. A heterogeneous strategy deliberately samples phenomena which vary from each other (Robson, 2002). The sample frame was therefore chosen to ensure variety across certain criteria, which were: gender, type of diabetes, length of time since diagnosis, last HbA_{1c} reading and medication regime. Socio-economic factors were not used because appropriate data was not available. However, some limiting factors applied to the approach taken. Most

fundamentally participation was voluntary, therefore although the sample frame was broad; it was not possible to control the types of patient who would agree to take part in the research. Additionally, all participants were required to have a home computer and access to the Internet. Initially it had been planned to address technology inequalities by offering computers and Internet connections to some participants. However, as funding was tight and offering computers to participants would have involved considerable extra time in training and home visits, it was not practical. As the study took place in one GP practice, all participants had to be registered at the practice. Finally, it was decided that all participants should be over 18, as the extra ethical and organisational issues raised by working with young people would have been too complicated to handle within the scope of such a study. As a result of these decisions the practice's records were used to generate a heterogeneous list that included patients with a range of attributes along the criteria chosen, and recruitment was subsequently undertaken from this list.

The size of the study was calculated to be manageable for one researcher to undertake whilst being large enough to include a range of different participants. The aim was to have a sample size of 30 patients, plus all the healthcare practitioners who used the system. Thirty-eight patients were recruited of whom six completed two interviews and 32 completed all three interviews. This sample size yielded 108 patient interviews. It is normal for sample sizes in qualitative research to be small (Bryman, 2001, Ritchie et al., 2003a), and Ritchie suggests that as a general rule sample size for a single study involving individual interviews will often lie under 50 (Ritchie et al., 2003a). In this case the study yielded three interviews for each participant. However, given the heterogeneous nature of the population being sampled it was considered important to maintain a reasonable sample size. After four patients dropped out from the first recruitment group of 27 patients, it was decided to supplement the sample by another round of recruitment. This second sampling added extra time to the length of the research study but it was considered important to ensure that the sample size did not drop much below 30 so that key constituencies from amongst the population were included and there was sufficient diversity in the data to explore during the analysis.

3.5 Methods of data collection in the study

3.5.1 Interviews

The primary method of data collection was the semi-structured qualitative interview. This method of gathering data was chosen to provide an insight into participants' perspectives of

the eHealth system and also give an understanding of the meaning participants attached to the system.

In semi-structured interviews key questions are asked of all participants to ensure that the main topics under investigation are covered. However, such interviews are structured so there is still room for further probing and discussion of unplanned issues (Arthur and Nazroo, 2003). For this study topic guides were prepared for all three interviews. These were written at the beginning of the study, but I revisited and reworked them as each stage of interviewing approached. Part of the reason for using guides was to ensure that I did not forget anything during the interview. However, the topics only acted as a guide during the interviews and I did not always follow them exactly (see Appendix #4 for interview topic guides). Digressions or added subjects of discussion occurred in most interviews and the interviews became more like conversations in these cases (Bryman, 2001). Additionally, as I had contact with each participant over a six month period, I developed a rapport with the participants during the study period which was beneficial to the interviewing process. I recorded all the interviews with an audio recorder, with participant permission. All the recordings were then transcribed into word processed documents. This process was essential as the conversations were so long and detailed that it would not have been possible to gather enough detail by taking written notes. Although using a tape recorder may have made participants self-conscious in certain circumstances (indeed some participants mentioned the recorder during the interviews), the advantages of recording the data far outweighed any disadvantages.

The first interview took place during the first meeting with the participant. As this was the first face-to-face contact I had with the study participants several activities needed to take place during this meeting. These included demonstrating the eHealth system, providing the Aviva blood glucose meter and a copy of the Compass software, and filling in the study consent form and demographic form. These activities were completed before I conducted the interview. The aim of the first interview was to obtain some background context about the participant in terms of their healthcare, their approach and attitude towards diabetes management and their expectations of using the system. During the first interview I asked participants about their current health, their current healthcare experience, their information seeking behaviour, their approach and attitude towards diabetes self-management, their

relationship with their GP, their expectations of the research project and their competence with IT.

The second and third meetings were entirely interview-based. I contacted participants three months after their previous interview and made an interview appointment. Each meeting usually lasted 30-40 minutes and consisted of a semi-structured interview with discussion of any particular issues raised. The aim of these interviews was to discuss changes since the previous meeting, which parts of the system participants had used and why. I asked participants about the benefits and disadvantages of using the system, and changes to their self-management practices, attitude to the GP practice, learning, information-seeking and approach to diabetes.

3.5.2 Textual data

In addition to the interview data, other textual data was collected and stored through the eHealth website. This consisted of posts on the discussion board, messages between patients and their healthcare practitioners through the messaging system and targets inputted by patients into the system. This data was stored in the server and downloaded and saved at the end of the study period.

In addition, demographic data was collected through a brief paper-based questionnaire that participants filled in during the first interview. This data was used, along with information gathered from interviews and the practice records, to put together a profile of each patient participant who had taken part in the study.

3.5.3 Numerical data

A certain amount of quantitative data was collected during the study. The eHealth website was designed so that it could collect and store data about how often participants logged in, which pages they viewed and how many blood glucose readings they uploaded to the site. During the study I accessed these statistics every week and put them in a spreadsheet in order to generate a long-term view of how participants were accessing the website. Also a summary of Alive email system use (see Chapter 4.3.3) was sent from NutritionQuest at the end of the study.

Patients were verbally asked to have Hb_{A1c} readings taken at the beginning and end of the project if they did not have recent readings. Patients' Hb_{A1c} data were then gathered from the

GP practice administrative department for the date closest to when the patient started the project and the date closest to when the patient finished the project.

3.6 Data analysis

3.6.1 Primary analysis

Although there are a number of ways of analysing qualitative data, analytical methods are often associated with a particular type of data, such as narrative analysis for personal accounts, ethnographic analysis for observational and descriptive ethnographic data, and conversation analysis for conversational data. As the primary data collected for this study was a set of interview transcripts the analysis approach taken needed to be suitable for this type of data.

The process of qualitative analysis necessarily starts with reading the raw data that has been collected. This raw data is often messy, and with transcribed interviews, will often include sections such as introductory chat or diversions in the conversation which are not required for the research. In this study the primary set of data consisted of 108 interview transcripts each between four and 23 pages long. The stages of qualitative analysis from collecting raw data to developing an explanatory interpretation of the data have been described by Spencer et al. (2003) as an analytical hierarchy, and similarly by Miles and Huberman (1994) as an abstraction ladder. Spencer et al. identify the three broad stages in the analytical process as data management, descriptive accounts and explanatory accounts. Each stage represents a movement up the analytical hierarchy away from the detail of the raw data and towards an interpretation of the topic under investigation. In the data management phase, codes or themes are identified from the data and elements of the data are tagged and sorted. During the descriptive phase, themes are developed and refined and form the basis of descriptive accounts. In the explanatory phase patterns are identified in order to develop interpretations of the phenomena. The movement through these phases is often iterative as there is a constant need to go back to check the data and to synthesize themes and concepts in order to develop theoretical interpretations. The idea of the researcher moving upwards through the analytical hierarchy during the process of qualitative analysis provides a good metaphor for the qualitative analysis process whatever particular technique is used.

A number of techniques for qualitatively analysing interview data have been described in the literature with varying degrees of detail. In some descriptions the precise analytical method

used remains implicit, a fact that has been noted by some authors (Bryman, 2001, Attride-Stirling, 2001). However, a number of detailed accounts are available. The approaches that were considered for this study are discussed here.

In the framework approach (Ritchie and Spencer, 1994, Ritchie et al., 2003b), a conceptual framework is first developed by analysing a sample of the raw data and this framework is then applied to the rest of the data. Broad themes are then synthesized from sub-themes through thematic charting and typologies are developed. Finally, associative analysis is undertaken in order to interpret the data. Template analysis uses a similar approach (King, 1998, King, 2004). In template analysis a coding template, part of which may be a priori, is used to code data. Emphasis is put on a hierarchical coding framework in which broader themes subsume narrower themes. Neither of these approaches was chosen, as they were considered to focus too much on the development of a fixed hierarchical coding framework based on a small sample of the data and not sufficiently on being sensitive to the variety present in the data.

In the thematic network analysis approach (Attride-Stirling, 2001) salient themes are uncovered from the text and organised into a network structure. This approach draws on argumentation theory, which provides a structured approach for analysing negotiation, in order to explore the meaning in people's discourse (Toulmin, 1958). Three classes of theme are developed, each at a higher level of abstraction: basic themes, organising themes, and global themes. Once constructed, a network can be used as an illustrative tool for interpreting data. An advantage of this technique is that it provides a clear set of processes to follow. However, as with the framework and template approaches discussed above, it was found to be overly prescriptive about the outputs. Using this technique, themes must be placed in a hierarchical structure and the output produced must be a network diagram. As the aim of the analysis was to explore participants' experiences of using the diabetes eHealth system without a priori assumptions, it was important to choose an approach that allowed the researcher freedom to develop ideas in an unfettered manner.

Schema analysis is an approach that focuses on the linguistic features of collected text, such as metaphors, proverbs, repetitions, transitions and interruptions. The aim is to uncover the mental models that motivate action. Schank and Abelson (1977) for instance proposed that schemas, or scripts, can be used to infer hidden meaning from text. Quinn likewise

approaches texts by looking for “clues in ordinary discourse for what they tell us about shared cognition” (Quinn, 1997, p.140). There is however very little notion of a method in schema analysis, apart from a general approach similar to the one described above of reading text carefully, uncovering themes and linking themes into a theoretical model (Ryan and Bernard, 2000). The focus on linguistic analysis and the heavy reliance on interpretation make this approach more appropriate for a cultural study rather than a study of IT use as was the case here.

After some consideration, I chose to use a grounded theory approach to data analysis. The set of techniques described by Glaser and Strauss (Glaser and Strauss, 1967, Glaser, 1978, Strauss and Corbin, 1998) formed the basis of the approach taken. However, the study did not completely follow the grounded theory method as I considered it rather prescriptive to be followed in its entirety. Indeed Charmaz (2000) has noted that the positions taken by Glaser, Strauss and Corbin, although conflicting in later years, were imbued with positivism. However, she also notes that grounded theory methods can be used as flexible strategies rather than formulaic procedures, and this is the approach I took in this study. No single guiding method was used for the whole research process, but I selected and used techniques as appropriate. For example I used purposive rather than theoretical sampling as it was more practical to run the study with a cohort of participants.

I adopted grounded theory analysis for a number of reasons. First, I chose it because it provides a set of well-documented techniques that are well-suited to analysis of textual interview data. Additionally, I found the detailed descriptions and examples of analysis techniques provided in the literature were useful to me as a novice qualitative researcher. The grounded theory approach provides a style of doing analysis that is not linked to a particular disciplinary perspective (Strauss, 1987). Also I considered that by using grounded theory in a flexible way, as originally proposed by Glaser and Strauss (1967), I could both stay close to the data and develop theory without being unduly constrained by method. I therefore decided to apply grounded theory techniques as “a set of principles and practices not as prescriptions or packages”(Charmaz, 2006a, p.9).

This flexible approach to analysing the data also fits in with the symbolic interactionist approach taken in the study. From a symbolic interactionist perspective it is important to

ground one's analysis carefully in the empirical data but also to ensure that analysis is not routine, but can be imaginative and free to take new directions if necessary. Blumer states:

“one goes to the empirical instances of the analytical element, views them in their different concrete settings, looks at them from different positions, asks questions of them with regard to their generic character, goes back and re-examines them, compares them with one another and in this manner sifts out the nature of the analytical element that the empirical instances represent.” (Blumer, 1969)

During grounded theory analysis, the analyst becomes engaged with the data by paying close attention to detail in the data and by making subtle observations in order to gain analytical insights. This process starts with the coding of raw data and the identification of concepts, and iterates between coding and categorisation until theory is generated. This process is similar to that described in Spencer et al.'s (2003) analytical hierarchy in which the analyst starts with the raw data, moves on to identifying themes or categories in the data, and then finally moves to interpretation and theory building. This is an iterative process that involves the analyst regularly returning to read and compare elements in the raw data. The grounded theory techniques utilised during this analysis were a) the simultaneous involvement in data collection and analysis, b) the construction of analytic codes and categories from the data, c) use of the constant comparative method, and d) the development of theory during data collection and analysis (Charmaz, 2006a).

I started the process of data management and analysis early on in the study. I sent interviews for transcription as soon as they were downloaded on return from interviewing sessions. On the completion of each set of interviews I typed a summary of answers to key questions into a spreadsheet and read the interview transcripts for emerging themes. By the end of the data collection period a set of spreadsheets were completed (one for each interview – first, middle, and final) that contained data about participants' use of the system during each phase as well as selected quotations from interviews. I also read through and coded the second and third interviews. This initial line by line examination of the data was time consuming, but was an important step in helping me to fracture the data analytically and to start developing concepts. During this coding process constant comparison was used (see Table #2 below), in which coded incidents were compared with previous incidents coded in the same way, in

order to start considering the theoretical properties of codes (Glaser and Strauss, 1967). At this point the codes were reviewed and an initial set of sub-categories were identified from the codes.

Although spreadsheets proved to be a useful tool for summarising data and providing an overview of participants' point of view at each stage of the study, I did not find them to be a manageable way of coding the data. This was because it was not possible to input the entire interview text into the spreadsheet, or to link codes to text so that they could be subsequently reviewed and refined. At this stage I decided that in order to manage the large amount of data and the large number of emerging codes, some data management software was required. After trialling two software systems (NVivo and Atlas Ti), I chose Atlas Ti and input the interviews into the software and re-coded them. The advantage with using Atlas Ti software was that the codes could be linked to the text and viewed either participant-by-participant or code-by-code. As the work progressed codes could easily be refined or split or merged and memos could be written relating codes to each other and to higher categories.

Stages	Stage description
Stage 1	Comparing incidents applicable to each category
Stage 2	Integrating categories and their properties
Stage 3	Delimiting the theory
Stage 4	Writing the theory

Table 2: Stages in the Constant Comparison Method (Glaser and Strauss, 1967)

Although time-consuming, the second coding period was invaluable as it involved a sustained process of constant comparison. This helped with the refinement of the analysis. It helped to confirm some previously made coding decisions and to encourage the review of others. A large number of codes resulted from this coding process. These were then refined in detail and grouped into sub-categories and categories. This process equates to the first and second stages of Glaser and Strauss's description of constant comparison, shown in Table #2 above. Stage three was accomplished by grouping sub-categories and modelling them diagrammatically in order to develop and refine the theory. As with the previous stages this was an iterative process. In the early stages of theoretical modelling I used post-it notes to help me try out different configurations of relationships between sub-categories (interim versions of the conceptual framework are provided in Appendix #8). I found this approach

helpful as it allowed me to remain open to trying out a number of different ideas. During this phase I iteratively developed the model, and improved it through discussions with my supervisors before the final theoretical model was developed. These discussions took place throughout analysis, but key moments were a) after coding, when my supervisors read and checked the coding for all the interviews of three selected participants, and b) during analysis, while establishing the three main categories in relation to the sub-categories and the conceptual framework.

3.6.2 Supplementary analysis

In addition to the primary analysis of participants' interview data, I carried out supplementary analysis on the other data that was collected. This analysis involved a range of techniques. For example some basic personal data and system use data, collected from participants and the web site, was analysed numerically and is presented in the thesis in descriptive tables. Although statistical techniques cannot reliably be used on this data, due to the sample size, it is nevertheless possible to interrogate and present the data in ways that serve to supplement the primary analysis.

3.7 Ethics and governance

Several ethical clearance procedures were required before being able to undertake the research study. First, I needed to obtain CRB (Criminal Records Bureau) clearance, followed by NHS ethics clearance through a Research Ethics Committee using the COREC (the Central Office for Research Ethics Committee) process. This procedure involved submitting an online form along with accompanying documentation and attending a meeting at which questions were asked about aspects of the research. This was followed by RM&G (Research Management and Governance) clearance and the provision of an honorary NHS contract. I also needed to apply for ethical clearance from the University of Central Lancashire. The purpose of these procedures was to ensure that the research study was undertaken in an ethical manner so that participants' interests were protected throughout the study and that the data would be collected and managed in an appropriate manner. The advantage of going through these procedures was that it enforced clear and thorough planning before the study commenced. The COREC form in particular required detailed decisions to be made about all aspects of research governance including the manner in which the data would be collected, anonymised and stored.

A number of the ethical concerns had to be addressed as the study involved managing data collected from human subjects. Issues here were informed consent, anonymity and confidentiality. Informed consent was obtained through a series of measures. First, information leaflets were provided to patients and practitioners detailing how the study would be run, what would be expected of them and what data would be collected. Participants were given time to consider whether they wanted to be involved before being contacted and asked whether they wanted to take part in the study. Consent forms were then signed during the first interview. Additionally, it was made clear to patients that they could withdraw from the study at any time. Because participants were interviewed several times, patient consent was effectively revisited at each interview stage, as they could decide not to attend the interview. Patient anonymity and confidentiality were preserved by providing each participant with a pseudonym for the purpose of the study. Apart from a patient list that was maintained in order to be able to contact patients, all patient data was collected using patient pseudonyms.

Additional ethical concerns needed to be addressed as the study involved patients using and uploading personal data to a live computer system. Particular issues here were anonymity, security and protecting participants from harm. All access to the web site was password protected. Additionally, all patient and practitioner access through the web site was anonymised using patients' pseudonyms. No personal details linking data to real individuals were stored on the web-server. Practitioners using the system were provided with a list of pseudonyms so that they knew who was who on the website. The web-server was stored in a secure room in the School of Computing, Engineering and Physical Sciences at the University of Central Lancashire. As the system was designed to help patients and provide them with extra information and support there was no concern that using the web site itself may cause patients harm. However, there were two additional issues that needed to be considered. First was the use of the Alive email system. This system was devised and run by an organisation founded by Dr Gladys Block, Emeritus Professor of Public Health Nutrition and Epidemiology at the University of California, Berkeley. Before the Alive email system was used its data was read through by the study GP in order to check that the information provided was in line with current UK advice about nutrition for people with diabetes. Additionally, there was a news page on the web site that was regularly updated with new links to news stories. Before adding new links the stories were vetted by the study GP.

Finally, there was the question of fairness and equal opportunity for all patients. This was particularly important because the study took place within the NHS where the principle of healthcare being ‘free at the point of need’, is fundamental. Because of the nature of the study, it was only possible for patients who had a computer and access to the Internet to take part in the study. As discussed previously I had considered providing computers to a small number of patients, and using funding to pay for this, however in the event this was considered too much of an added burden for a single researcher. There were undoubtedly limitations to the study as a result of requiring participants to have access to a computer and the Internet at home. However, as the study was an exploratory enquiry, the issue of equal opportunity was not the same as it would be if a real service was being rolled out within the NHS. Indeed this type of investigative study, and others like it, are a necessary prerequisite to public healthcare bodies deciding whether and how to invest in patient-focussed eHealth systems. The issue of accessibility to all patients then becomes a matter of public policy decision making.

3.8 Summary

The aim of this study was to explore and conceptualise how patients experienced using a diabetes eHealth system and to develop an explanatory theory of this experience. The primary research question for the study was “How do patients experience using a diabetes eHealth system?” After reviewing the literature it was decided to conduct a qualitative study of patients’ experiences of using a diabetes eHealth system in order to provide insights into how and why patients used such a system and how their perceptions of the system influenced any changes they made.

The epistemological position taken in this study is constructionism and the methodological perspective chosen is symbolic interactionism. The study focuses on investigating the meanings participants assigned to the eHealth system and the variety of ways in which they used it. The methodology used is that of a qualitative enquiry with elements taken from grounded theory. The aim of the study was to make a novel contribution to knowledge about how eHealth technology is used by patients with diabetes by exploring in depth the ways in which real patients experience it.

The study was designed as an in-depth study in which each participant used the system for six months and was interviewed at the beginning, middle and end of the study. Altogether 38

patients were recruited from a single GP practice based in a city in Northern England, using purposive sampling. Patient participants had to be over 18, have either Type 1 or Type 2 diabetes and have access to a computer with an Internet connection from home. One GP, two practice nurses and a community nurse also took part in the study. They were interviewed at the beginning and end of the study. The study was carefully designed as a qualitative study which also collected some quantitative data. The primary method of data collection was semi-structured interviews, but data was also collected through the website and in addition HbA_{1c} readings taken close to the beginning and end of the project were gathered from patients. Interview data was analysed using an approach that drew heavily on grounded theory, but which used it as a flexible strategy rather than a formulaic procedure. Ethical procedures were carefully followed during the design and running of the study. Appropriate ethical clearance was obtained before the study commenced and the procedures identified for ensuring patient consent, confidentiality and anonymity, security and freedom from harm have been carefully followed.

4. SETTING UP AND GETTING GOING: THE SYSTEM AND THE STUDY

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We used to have lots of questions to which there were no answers. Now with the computer there are lots of answers to which we haven't thought up the questions.

Peter Ustinov 1921- : *Illustrated London News* 1 June 1968

4.1 Introduction

As discussed in the methodology chapter the research was designed as qualitative study, taking a symbolic interactionist perspective, aiming to explore patients' experiences of using a diabetes eHealth system.

In this chapter the setting up and running of the study are discussed. The chapter contains five sections; with section one introducing the chapter. In section two, the design of the diabetes eHealth system is discussed, and a rationale is given for the features chosen for it. In section three, the implemented features of the eHealth system are described. In section four, the study setting in a GP practice is described along with details of the recruitment procedures adopted, an overview of the patients and practitioners who used the system, and

some details about the way the study was conducted. Finally, in section five the chapter is summarised.

4.2 eHealth system design

4.2.1 eHealth system design rationale

As discussed previously, the purpose of the study was to explore how and why patients in a primary care setting used, viewed and changed in response to using a diabetes eHealth system. There was no existing system to use in the study, therefore some software was designed and built. Two factors particularly informed the design of the system that was built: first the design of systems used in previous studies and second the primary care setting in which the eHealth system was used.

Of particular interest during the design stage were which facilities to provide for users. During the literature review stage of the research I reviewed the literature describing previously implemented diabetes eHealth systems (presented in Chapter 2.5.4), and performed a feature analysis of the functionality provided by these systems (described later in this Chapter). Selected features from this list were then implemented in the system built for this study. Another design approach could have been taken, such as some form of participatory design in which selected end-users participate in the process of stating the requirements for a technical system (Schuler and Namioka, 1993). Participatory design has become a popular approach (Kyng, 2010, Muller, 2008, Schuler and Namioka, 1993, Greenbaum and Kyng, 1991), along with variants such as cooperative inquiry (Druin, 1999) and informant design (Waraich and Brna, 2007), as it is acknowledged that when systems are designed without the involvement of users there is a risk that the resulting technology may not adequately meet users needs. The development of particular approaches such as participant design can be seen as part of a broader trend that has seen increased inclusion of stakeholders and users during the design and development of new technologies (Karat and Karat, 2010). There has over the same period been an increasing tendency to embed user or client participation during the requirements gathering and design stages of Information Systems development methodologies over the years (Cockburn, 2006, Stapleton, 2003, Schwaber and Beedle, 2001, Mumford, 1995, Martin, 1991). However, although intensive user participation in software requirements gathering and design is a dominant theme in Information Systems development, some have argued that the benefits may only be minimal (He and King, 2008, Cavaye, 1995, Ives and Olson, 1984), and in some cases may hinder

development (Gallivan and Keil, 2002). Problems identified have included user-developer conflict (Howcroft and Wilson, 2003), and increased workload (Broadbeck, 1984).

It was decided that instead of using a participatory approach for this study, the design of the system would build on existing ideas and include features identified in related work and investigated in other studies. Users were therefore not heavily involved in the design of the system, but they were instead heavily involved in the evaluation of the system developed. Looked at from a broad viewpoint, this entire study can be seen as an extended piece of participatory evaluation and design. This is because the aim of the study was to undertake an in-depth evaluation of an eHealth system in order to gain insights about how patients responded to and used the system. The eHealth system built for the study was never envisaged to be a permanent system, and was only used for the duration of the study. The insights gained from this study could not have been gathered at brief meetings with potential users using the methods traditionally used for participatory design. However, the outputs from this study will provide a useful set of insights that can be used for the development of subsequent diabetes eHealth systems. The value of using longitudinal methods for technology design has been suggested by others as a way of uncovering a range of factors that influence systems use (Hartwood et al., 2008, Dourish and Button, 1998).

Second, the study was intended to run in a primary care setting and this affected the features included in it. The most important aspect of primary care from the point of view of this study is that it is a generalised rather than a specialist setting. A wide variety of patients with diabetes seek advice and treatment from their GP. These patients will exhibit a range of traits such as: type of diabetes, age, medication regime, length of time with diabetes, regularity of contact with the GP and co-morbidities (Khunti and Ganguli, 2000). One of the motivations for choosing primary care as the setting for this research was that this is the setting in which many patients with diabetes receive their initial diagnosis and much or all of their care (Pierce et al., 2000, Williams et al., 2002, Khunti and Ganguli, 2000). Primary care is the front line for many patients who need advice on how to manage their diabetes as well as being the place they go to for advice and treatment for other health problems that may or may not be related to their diabetes. Many patients with Type 2 and some patients with Type 1 diabetes receive much of their healthcare through their GP (Pierce et al., 2000, Khunti and Ganguli, 2000). Even those who do not regularly attend primary care will expect their GP to be aware of

their diabetes medication and treatment needs in as much as this may affect any other treatment they receive (Kerr et al., 2007).

The general nature of the primary care setting and the different needs of patients using its services influenced the design of the system in several ways. For instance some patients who control their diabetes through dietary and lifestyle improvements alone do not use a blood glucose meter (Hippisley-Cox and Pringle, 2004), and therefore would not be able to upload blood glucose readings, but may be interested in an interactive dietary support system and may also want to communicate with other participants. Other patients, particularly those with Type 1 diabetes, may want to focus on viewing and understanding fluctuations in their blood glucose readings. Additionally, some patients may want to share data and communicate electronically with their GP and the practice nurse. The primary care setting influenced the system design in the following ways: 1) the system needed to provide a range of functionality in order to cater for a range of patient needs; 2) the system needed to provide optionality so that patients could choose to use the elements that were useful and of interest to them; and 3) the system needed to enable patients to communicate electronically with their GP and the practice nurse.

After the overall system was scoped out, input was sought from a range of academics with an interest in the study, health practitioners and patients. As part of this process, feedback and suggestions for functionality were gathered from the lead diabetic GP at the practice in which the study was to take place, the practice nurse and the patient forum. During this process I met the GP at the practice several times and attended a patient forum meeting⁶. Additionally, I met with and obtained input from other local health practitioners.

4.2.2 eHealth system design review

In order to decide which features to include in the eHealth system built for the study, the functionality of the diabetes eHealth systems identified during the literature review was analysed. From this work two views were distilled of the features available in diabetes eHealth systems, first a user/functionality view, and second a data management view.

In the user/functionality view, which is illustrated in Figure #1, four generalised types of user are identified along with five generalised types of functionality. The user types identified

⁶ The patient forum at the GP practice provides patients registered at the practice with an opportunity to air their views at an open meeting arranged at the practice which is held approximately every three months.

were: individual patients with diabetes, medical practitioners, diabetes researchers/educators, and others (depending on the precise nature of the system this may be other patients with diabetes, or families and carers). The five general types of functionality identified were a) support and communication, b) medical consultations, c) patient data management, d) information provision, and e) education provision.

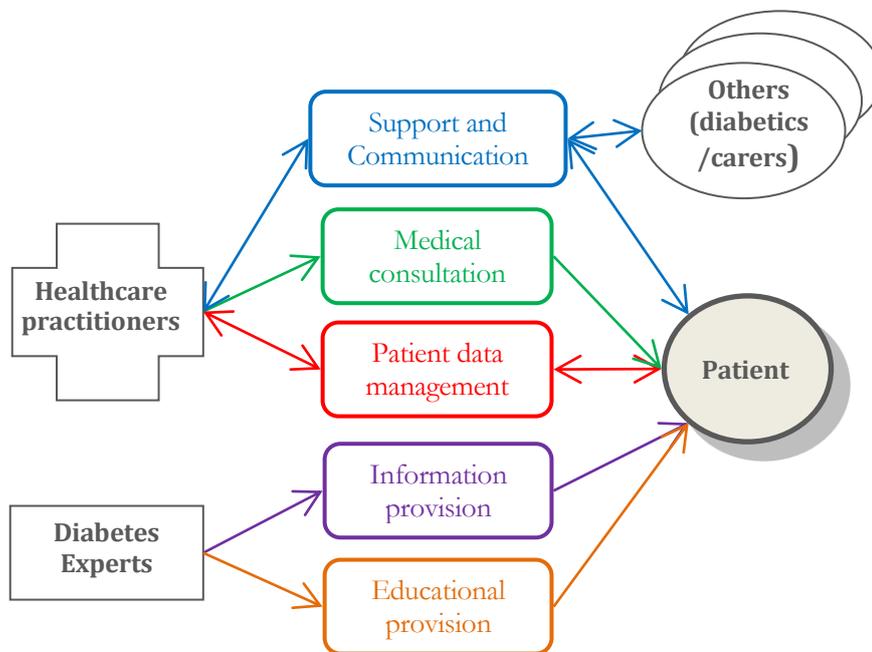


Figure 1: Users and Functionality in Diabetes eHealth Systems

In this model each of the five categories of functionality represents a group of facilities made available in Diabetes eHealth Systems. ‘Support and communication provision’ covers the type of facilities that enable patients to receive support, either through one-to-one or group communication. Typically communication provision in eHealth systems allows individual patients with diabetes to communicate with their healthcare practitioners and also allows patients to communicate with other patients with diabetes. Some systems enable patients’ families or carers to take part in communication as well. ‘Medical consultation’ covers facilities that enable patients to receive remote healthcare advice from healthcare practitioners. ‘Patient data management’ involves facilities that enable patients to input/upload/view their own personal medical or health-related data. With diabetes eHealth systems this typically involves inputting and viewing blood glucose readings and being able to share them with healthcare practitioners and/or being able to view them in graph or tabular format. Additionally, some eHealth systems allow patients to view their own medical records,

test results and manage other health-related data such as activity and diet-related data. ‘Information provision’ covers the provision of diabetes-related information to system users. This is usually provided through web pages that offer patients practitioner-endorsed information about diabetes, but it can also involve audio or visual material. ‘Education provision’ covers educational material or programmes that enable patients to learn more about diabetes or some other aspect of their health, such as healthy eating or becoming more active. These are often linked to the achievement of particular targets or changed behaviours such as improved diet or increased activity levels.

Additionally, the data management features of diabetes eHealth systems were analysed and categorised, as shown in Figure #2 below.

	<i>Personal data</i>	<i>Diabetes/health information</i>
<i>User-controlled processing</i>	Personal data storage/retrieval	Information storage/retrieval
<i>Automated processing</i>	Automated data processing & message exchange	Automated information provision

Figure 2: Data management in diabetes eHealth systems

The matrix in Figure #2 shows two different types of data along one dimension: personal data and general diabetes/health information; and two different types of processing along the other dimension: user-controlled storage/retrieval and automated processing. When personal data is held on eHealth systems, it needs to be kept secure and should only be accessed by those authorised to do so. It generally consists of personal medical data such as medical records, test results, blood glucose readings, medication data and food or activity diaries. The diabetes and health information that is made available on such systems is of a more general nature but is practitioner endorsed and often is carefully selected to be particularly beneficial to the target users of the system. Along the other dimension of the matrix there are two types of data or information processing. On the one hand, there are storage and retrieval mechanisms that enable data and information to be input, retrieved and viewed through the

control of those using the system. On the other hand, there are automated processes that manage data and information exchange such as automated uploading, insulin simulations, automated alerts, message exchange facilities and interactive educational features.

High-level features identified in Diabetes eHealth systems	Feature description	User/ Functionality view	Data Management view
Peer-to-peer messages	Send/receive messages to other patients with diabetes	Support & Communication	Automated personal data processing
Discussion board	Add/read messages to a diabetes discussion board		
Message exchange with expert	Exchange messages with health practitioners		
Medical consultation	Receive consultation from expert	Medical consultation	
Use blood glucose meter	Patient obtains blood glucose readings using a meter	Patient data management	
Automated data upload	Personal data readings (such as blood glucose readings) can be automatically uploaded for storage and sharing		
Automated data processing/simulation	Processing readings to provide information to practitioners or patients, such as recommended medication based on blood glucose readings		
View recent test results	Viewing test results – bloods etc.		
View medical record	View personal medical record		
Input blood glucose readings	Patients input blood glucose data to a central server so it can be stored, viewed and shared		
Input medication data	Patients input medication data to a central server so it can be stored, viewed and monitored		
Diet/exercise/other monitoring/diary	Dietary, exercise or other personal data can be input to an area where it can be stored, viewed and/or shared		
Target setting/plans	Targets are input so that they can be stored viewed and/or shared		
Diabetes information	View/read information about diabetes	Information Provision	Information storage /retrieval
Educational program	View/read an education program about diabetes	Educational provision	Automated information processing

Table 3: Features found in Diabetes eHealth Systems

These two abstract views were applied as broad groupings to the list of features found in diabetes eHealth systems. The resulting list is shown above in Table #3. The feature list on

the left-hand side of the table is generated at a coarse (i.e. use blood glucose readings) rather than a fine level (i.e. put test strip in blood glucose meter) of functionality, as the purpose is to provide an overview of major features made available to users rather than the fine detail of particular processes.

Looking at the user/functionality view (see Figure #1 and column 3 in Table #3) it can be seen that many of the features provided by diabetes eHealth systems focus on patient data management. Examples are facilities that allow patients to view their blood glucose data, medical records and test results to personal and medication diaries. All are aimed at helping patients to gain greater understanding of their diabetes and their current diabetic control. The patient data management category in Table #3 contains the highest number of eHealth system features, followed by the support and communication category. Looking at the data management view (see Figure #2 and column 4 in Table #3), most of the functionality provided by diabetes eHealth systems focuses on personal patient data rather than general diabetes information – whether that is processed automatically or through user control. This feature analysis shows that the interactive manipulation of personal health data is one of the core elements of functionality provided by diabetes eHealth systems.

The diabetes eHealth system used for this study included elements from each of the five functionality categories identified in Figure #1 as well as each of the four types identified in the matrix presented in Figure #2. Certain features were not feasible to implement for this study, mainly because they involved complex technical or organisational solutions that were not practical to undertake in the timeframe for this project. Examples were the integration of blood glucose meters with mobile phone technology, and personal health record viewing. Although the integration of blood glucose meters with mobile technology (Farmer et al., 2005, Gammon et al., 2005), and the use of mobile phones to transfer meter data (Kwon et al., 2004a, Ferrer-Roca et al., 2004a) offer interesting ways of sharing or uploading data for this type of system, both would have required a considerable amount of development time which was not feasible for this study. Additionally, the development of simulation software based on insulin or drug intake was not considered appropriate for a primary care setting.

4.3 eHealth system features

Features that were implemented in the diabetes eHealth system devised for this study are described in Table #4 below.

Diabetes eHealth system functionality	Functionality description	User Functionality view	Data Management view
Discussion board	Read/post to a diabetes discussion board on the web site	Support and Communication	Automated personal data processing
Questions to specialist nurse on discussion board	Post questions to the specialist diabetes nurse on the discussion board – “Ask Trish”		
Private messages to/from GP and practice nurse	Send/receive messages to GP and practice nurse	Medical consultation	Automated personal data processing
Blood glucose reading (meter)	Use meter to obtain and store individual blood glucose readings		
Blood glucose reading upload	Upload blood glucose readings from meter to computer	Patient data management	Personal data storage/retrieval
Sharing blood glucose data with GP and practice nurse	Patients could share blood glucose data with the GP and practice nurse		
Graph/tabular view of input values	Graph and table views of blood glucose readings		
Target setting	Set and review personal targets for diabetes management		
Diary	Enter and review data in an electronic diary	Information provision	Information storage/retrieval
View information pages	View/read information about diabetes		
View news pages	Read recent new stories about diabetes	Education provision	Automated information processing
Alive email programme	12 week email education programme with a choice of 3 options		

Table 4: Features incorporated in the study eHealth System

The system was built during the spring and early summer of 2006 by a software developer (funded by Diabetes UK), using an iterative development approach that involved frequent testing by myself and the developer. Once the system was nearly complete it was tested by five other individuals, and further amendments were made. As ethical approval had not been sought for user acceptance testing with patients from the GP practice, system testing had to be completed before the study began. The testers were students, aged between 19 and 25, and with varied experience of computer systems. Each was given access to the system for a week and asked to provide feedback. Comments received from the testers were used to make further amendments to the system.

The system consisted of a number of integrated elements. Some of these were discrete elements that could be used on their own, such as the blood glucose meter. Other parts of

the eHealth system were integrated, such as the features that were implemented on the web site. The central hub of the system was the password-protected website. The different elements of the system are discussed in detail below.

4.3.1 The Aviva meter and Compass software

Patients participating in the research were provided with a Roche Accu-chek Aviva blood glucose meter⁷ (see Figure 3 below) (Roche, 2009). Some time was spent at the beginning of the project investigating different blood glucose meters and contacting providers to enquire if they were interested in donating meters for the study. The meters were provided free of charge by Roche for use by patients along with connection cables and CD copies of the Compass software that patients could install onto their home computers⁸.

The meters were supplied with a Multiclix finger pricker, a Multiclix lancet drum and Accu-chek Aviva test strips⁹. The Accu-chek meter is about the same size as a computer mouse, the Multiclix finger pricker is about the same size as a thick felt-tip pen. They were supplied with a carry case. In order to take a blood glucose reading a patient inserts a new test strip into the meter, takes a blood sample by pricking their finger using the Multiclix finger pricker and touches a small sample of blood onto the test strip. The meter then reads the amount of blood glucose in the blood sample and displays it on the small meter screen along with the time at which the reading was taken. The meter shows the most recent reading, however previous readings can be read one by one by scrolling backwards.

⁷ Many different types of blood glucose meters are commercially available. Despite the range of different makes available they are all very similar. They are small devices that allow individuals to test their blood glucose levels on the provision of a small blood sample. They generally consist of four elements, a) a finger pricker; b) sterilised needles that are used to prick the finger and produce a blood sample, c) sterile test strips onto which the blood sample is smeared, d) the meter itself into which the test strips are inserted and which have a simple screen that displays the blood glucose reading and the date and time at which it was taken. The sterile test strips and needles have to be bought in batches by patients (in the UK many patients can get these on prescription). Most meters have a memory that will store a certain number of readings, but as they are small, portable devices they only show one reading at a time. They are used by many patients with diabetes as a way of measuring their daily blood glucose levels.

⁸ During preparation for the study I had phoned around many suppliers of blood glucose meters. Roche agreed to provide meters and software for the study free of charge. Their Aviva Accu-chek meter came with the Compass software and an infrared reader that allowed individuals to transfer their readings from the meter and view them on a home PC.

⁹ The Multiclix lancet drum fits into the Multiclix finger pricker. The lancet drum contains 6 lancets that are designed for single use and are embedded into the drum so that they do not present a hazard for disposal.



Figure 3: The Accu-Chek Aviva meter and Multiclix finger pricker

Once the Compass software was installed onto a home computer, patients could upload all the stored readings from their meter onto their computer using the cable supplied. Once uploaded, readings could be viewed in graph format. This enabled a better view of the blood glucose readings than the one that was possible on the small meter screen. Additionally, facilities available through the software enabled patients to input data about when they had taken medication, exercised and had meals. The graph format also provided guidelines to indicate the ideal range within which readings should fall. An example of the graph format is shown in Figure #4 below, in which the horizontal axis shows the days of the week and the vertical axis shows the level of the blood glucose reading in mmol/L (millimoles per litre). The yellow band highlights a general target band for readings (set here between 3.9 and 7.8 mmol/L - although these could be changed). Each individual reading is shown as a red dot.

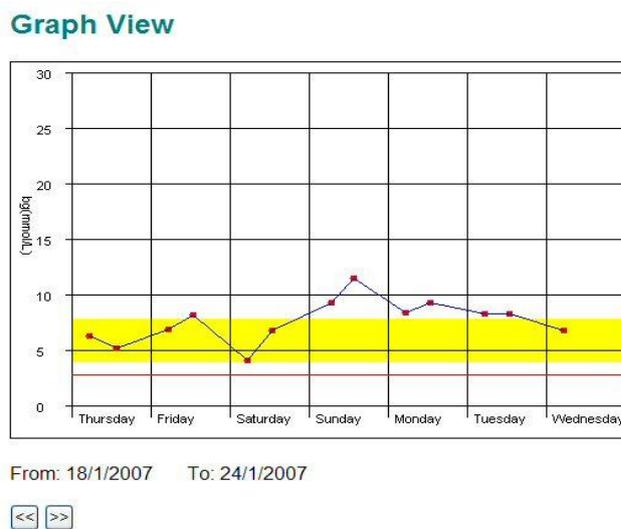


Figure 4: Compass graph view

4.3.2 The website

The website was the main feature of the diabetes eHealth system. Entry to the website was restricted to those who had a valid user-name and password combination. Three types of users could log into the website: patients, health practitioners and the administrator. In order to ensure security and confidentiality all patient users were given passwords that consisted of two unrelated nouns (such as Rosecandle, Catlily). No real patient names were used on the site and no personal data, that could be used to identify individuals, was stored on the site.

Each user type (patient, health practitioner, and administrator) had a different level of access to the website facilities and could use different sets of facilities. These facilities are described below.

4.3.2.1 Patient facilities

Once logged on patients could access their own personal view of the system. This enabled them to input, upload and view their own data, communicate with the practice, read general content and contribute to the discussion board. Facilities on offer were as follows:

- **Upload blood glucose readings**
 - Readings could be uploaded from Compass to the web server
- **View blood glucose readings**
 - Readings could be viewed in graph or table format. Graph format gave a weekly view. Table format allowed users to view within a specified date range
- **Send and receive messages to/from the GP/practice nurse**
 - Private messages could be exchanged with the practice
- **Make diary entries**
 - A diary facility enabled patients to enter data into an electronic diary
- **Add/view/edit/delete targets**
 - Patients could create a list of personal targets. Targets were date stamped by the system on creation. Patients could add comments about their progress.
- **Read information page**
 - This contained information about managing diabetes, details from the surgery about frequency and types of check-ups, and local information.
- **Read news page**
 - The news page contained web links to recent news stories about various aspects of diabetes
- **Read/post to the discussion board**

- The discussion board was set up with seven different topic sections: Healthy Eating; Exercise; Monitoring; Drugs; Heart, feet, eyes etc; Web site; General.
- During the project another topic was added called “Ask Trish”. Questions posted to this topic were answered by a specialist diabetes nurse.
- All patients could read and post to any topic in the discussion board
- **Make setup changes**
 - Patients could change their password and change their name as it was displayed in the discussion board. The default name used on the discussion board was the user’s login name.
- **View help**
 - A help page gave help information on each aspect of the website

4.3.2.2 *The health practitioner view*

Once logged on, health practitioners could access the practitioner view of the system. The primary activity that practitioners carried out was selecting a particular patient in order to view their blood glucose readings or to send them a message. Practitioners could also contribute to the discussion board and view the other general information available on the site. Facilities on offer were as follows:

- **Select a patient**
 - A facility enabled practitioners to select a particular patient so they could view that patient’s entries
- **View blood glucose readings**
 - Patient readings could be viewed in graph or table format
- **Send and receive messages to/from patients**
 - Private messages could be exchanged with patients
- **View targets**
 - Practitioners could view patient targets
- **Read information page**
 - Health practitioners could read the information page but not change it.
- **Read news page**
 - Health practitioners could read the news page but not change it
- **Read/post to the discussion board**
 - Health practitioners could post to the discussion board
- **Make setup changes**

- Practitioners could change their password and discussion board name.
- **View help**
 - A help page gave help information on each aspect of the website

4.3.2.3 The administrator view

Once logged on the administrator could access the administrator view of the system. The administrator carried out a number of activities during the course of the research study. Primary activities were adding new patients, adding news and information items and viewing the number of page hits that had occurred each week. Facilities on offer were as follows:

- **Select a user**
 - Any user given access to the system could be viewed
- **View user statistics**
 - Having selected a user the administrator could view statistics about how frequently each page on the web site had been used
- **View blood glucose readings**
 - Patient readings could be viewed in graph or table format
- **View messages between patients and practitioners**
 - Messages between patients and practitioners could be viewed
- **View diary entries and targets**
 - Diary entries and targets could be viewed
- **Add/edit/delete/read news and information entries**
 - The administrator could add, edit and delete news and information entries. All entries were checked by the GP before being added to the site.
- **Edit/delete discussion board postings**
 - The administrator could edit or delete discussion board postings if they were deemed unsuitable. The administrator could also add new topics to the discussion board
- **Read/post to the discussion board**
 - The administrator could post to the discussion board in the normal way
- **Make setup changes**
 - The administrator could add new users to the system. The administrator could reset passwords in cases when users had forgotten them.

4.3.2.4 Web site design and implementation

The web site was designed to be simple to use, and was implemented using a standardised template with a header along the top of the screen and a menu bar down the left side of the

page. The header and side bar were in the same position and contained the same content on all pages. The look and feel of the site was discussed with a number of healthcare practitioners and administrators at the general practice, as well as those who evaluated the early system prototypes. It was designed to be straightforward with an easy-to-read, 'clean' look. This resulted in the use of a plain white background and a sans serif font. The home page is shown in Figure #5 below, and further pages from the web site are shown in Appendix #10.

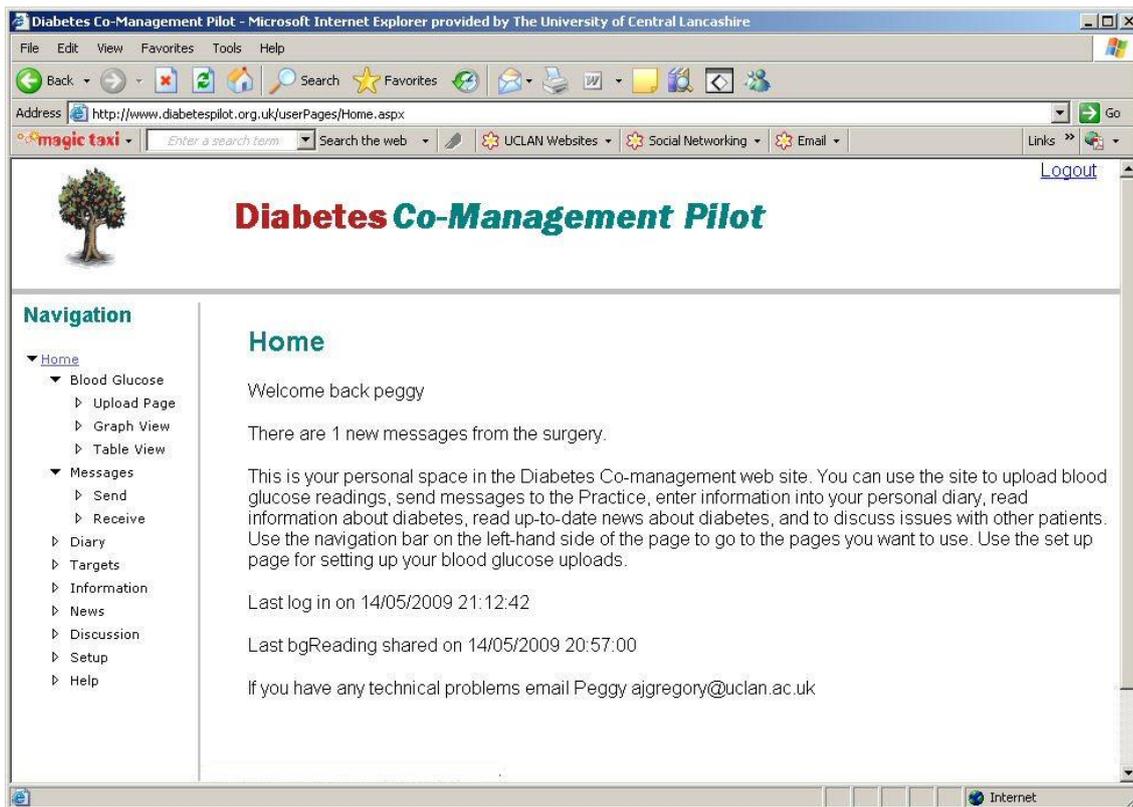


Figure 5: Web site home page

The web system was implemented using Microsoft technologies, with SQL Server Express for the backend database and .NET and Visual Basic for the web site. The primary technical design challenges were how to manage security and how to manage the output of blood glucose readings from the Compass software and their input into the system database. The challenges in dealing with security were addressed in two ways. First, all users were allocated user names that could not be used to identify individuals, and no information tying user names to individuals was stored on the system. Second, all potentially sensitive data was encrypted within the database such that even if the database had been inappropriately accessed, the data would not have been readable. The challenge with integrating output from

the Compass software with the web site software was that client-side scripting software (JavaScript) was required to read data from the Compass database to upload it into the server-side database. Alternative and technically neater solutions, such as reading directly from the meters' transmission, were not open to us as the transmission protocol from the blood glucose meters was not available.

4.3.3 Alive emails

The Alive emails were added to the eHealth system for several reasons: to provide a facility that encouraged and supported patients to make improvements to their diet and/or activity levels in a way that would impact on their diabetes, to provide an educational element to the system and to provide an automated aspect to the system. The Alive email system was not designed specifically for patients with diabetes but for the general population. However, its aims were consistent with dietary and activity advice given to patients with diabetes (Nield et al., 2007, Home et al., 2008), and it was considered a useful resource for the project by the GP at the participating surgery. The Alive email system contains three programmes, each of which lasts for 12 weeks. The programme "Choose Good Carbs and Fats" aims to encourage participants to reduce saturated and trans fats, decrease sugars, increase good fats and increase good carbohydrates such as whole grains. The aim of the "Eat More Fruits and Vegetables" programme is to encourage participants to eat more fruit and vegetables. The aim of the "Move More, Sit Less" programme is to increase physical activity.

The Alive system was developed as a result of collaboration between the research division of Kaiser Permanente and Block Dietary Data Systems (now known as NutritionQuest), and was a modification of Block's previous programme WIN (Worksite Internet Nutrition) (Block et al., 2008). It was designed as a corporate resource for use by companies aiming to support healthy lifestyles for their employees (Block et al., 2004), and has been used in a variety of organisational settings. NutritionQuest (NutritionQuest, 2009) was originally founded to provide services to health researchers by Gladys Block, who was developing dietary questionnaires at the National Cancer Institute, before being formed as a spin-off company. The programmes were designed to improve dietary behaviour and increase physical activity by providing weekly goal-setting, individualised feedback, tips and reminders. Results from trials of the programmes have indicated they can be instrumental in encouraging positive lifestyle improvements (Sternfeld et al., 2009, Block et al., 2008, Block et al., 2004). The advice in the programmes is in line with US national and international guidelines (US Department of Health and Human Services and US Department of

Agriculture, 2005). For the purposes of this study all the advice was reviewed by the lead GP at the practice before the programme was run.

In order to use the Alive programme, patients were asked to click on a link (which I emailed to them and which was also available on the eHealth web site). The link took patients to the Alive home page, from which they could start the programme. The programme starts with a baseline diet and physical activity questionnaire that ask a series of questions about the participant's normal diet and activity levels. As part of the questionnaire participants are asked to identify barriers that may deter them from improving their diet or activity behaviours, and these are linked to subsequent tips. After finishing the questionnaire, participants are given feedback about their intake of saturated fat, trans fats, added sugars, fruits and vegetables and amount of physical activity. They are then invited to join one of three different programmes. The three alternative programmes were: "Choose Good Carbs and Fats", "Eat More Fruits and Vegetables" and "Move More Sit Less". After selecting the programme, participants received the first of 12 weekly emails. Each weekly email included a list of suggested weekly goals as well as a list of motivators and barriers that may help or hinder the achievement of one's chosen goals. Participants were encouraged to select a weekly goal from the list and select motivators and barriers. Each weekly email also contained links to the Alive website that provided additional health notes associated with that week's topic, including reports on recent scientific findings. A reminder email was also sent each week. After participants had run through the programme once they were able to start again, either choosing the same programme or another.

4.4 Study setting and participants

4.4.1 The study setting

The study took place in a group General Practice located in a city in northern England. The practice is located at two sites in an area with a mixed urban/suburban population of about 12,000. At the time of the study the practice had eight partner GPs, two practice nurses, one supporting nurse practitioner and a healthcare assistant. Alongside the Practice Manager and Deputy Practice Manager there were eight administrators and secretaries and 14 receptionists.

Most of the registered patients at the practice come from one ward in the city with some coming from adjacent wards (the name of the ward is withheld in order to maintain the anonymity of practitioners and patients at the practice). The population of the ward in 2001

was 18,020. Data from the 2001 census (Office for National Statistics, 2001) provides the following details for the ward: 5.99% unemployment, 37.69% with no educational qualification, 11.04% registered permanently sick or disabled, 43.31% of households with no car, 5.45% of households overcrowded, 65.60% households owned by the resident and 10.88% of lone person households with dependents. The multiple deprivation index for the ward was 431, where one is the most deprived and 3,098 the least deprived. This places the ward within the bottom 15% of wards in the country using the multiple deprivation index. However, as the ward had a mixed population, there was potential for considerable variation in the population attending the surgery.

4.4.2 Recruitment

Recruitment for the study started in August 2006. I used the GP practice as a base, and recruited participants to the study with help from the practice administrative team. A heterogeneous list of patients with diabetes registered at the practice was generated, using the sampling guidelines discussed previously (Chapter 3.4.3). An invitation letter and explanatory leaflet about the research were then sent to patients on the list by the practice (see Appendix #2). I followed up the letters with recruitment phone calls. The process of phone recruitment involved a short conversation to ascertain whether patients had read the letter and if they were interested in taking part in the project. Patients who expressed an interest in taking part in the project were invited to come into the surgery for the first meeting and interview. Each patient participant who took part agreed to use the system for six months and to be interviewed at the beginning, middle and end of the six month period. Participants signed the consent form during the first interview.

Two phases of recruitment were undertaken during the study period. For the first recruitment phase in August 2006, a list of 89 patients with diabetes was generated. The first participants were recruited on a rolling basis starting in September 2006. By the middle of January 2007, 27 participants had been recruited and had completed their first interview. As four participants withdrew from the research before completing all the interviews, it was decided in the early summer 2007 to recruit another small batch of participants. Another list of 37 patients was generated in July 2007. A final 11 participants were recruited on a rolling basis from this list during August and September 2007. Details of all participant interview dates are listed in Appendix #3. The eHealth system was in use from September 2006 until March 2008 when the last participant completed their final interview.

Data collected during the recruitment process about how many patients were contacted and why patients did not want to take part in the research is summarised below in Table #5. Recruitment phone calls were generally short and the researcher did not probe respondents who said they were not interested. In Table #5 column 2 (shown below), those categorised as ‘interested’ were those who agreed to take part in the research. Those who are categorised as ‘interested at first’ initially said they would take part and booked an appointment, but subsequently cancelled or failed to attend appointments and later changed their minds about taking part. Respondents who said they did not have a computer, or did not have access to the Internet are categorised accordingly. Patients who could not be contacted because they had moved away or the phone number given was unobtainable are categorised ‘not contactable’. The category ‘not interested’ covers many different answers from a simple “*I’ve read the leaflet and I’m not interested*”, to more detailed answers such as “*I’ve just retired and we’re away a lot*” and “*I don’t take my blood sugars or take any medication so there doesn’t seem any point*”.

Recruitment Outcome	Reasons	Gender	#	%	%
Recruited	Interested	Male	26	20.6	30.2
	Interested	Female	12	9.5	
Not Recruited	Interested at first	Male	4	3.2	7.9
	Interested at first	Female	6	4.8	
	Not Interested	Male	29	23	32.5
	Not Interested	Female	12	9.5	
	No Computer	Male	10	7.9	19.8
	No Computer	Female	11	8.7	
	No Internet	Male	2	1.6	
	No Internet	Female	1	.8	10.3
	Not contactable	Male	12	9.5	
	Not contactable	Female	1	.8	

Table 5: Summary of phone recruitment data

The data shown in Table #5 indicates there was high uptake (30%) from those who were invited. A number of respondents discussed the project with their GP before deciding to take part. The gender profile of the uptake (male:female, 2:1) reflects the gender profile of the list generated by the surgery, so there did not appear to be a gender bias in terms of uptake. The number of patients with diabetes in the surgery at the time of the study was male:female 274:213 (approximately 5:4). The gender profile of those with diabetes in England in 2003 was that 4.8% of males had diabetes and 3.6% of females had diabetes, this is a ratio of 4:3 (male:female) (Department of Health 2007). National statistics from 2007 indicate that 61%

of households in the UK had Internet access (National Statistics 2007). Data gathered during interviews indicated that only 20% of patients phoned either did not have a computer or did not have access to the Internet, however it is possible that some of the respondents who said they were not interested also did not have access to the Internet.

4.4.3 The patient participants

Demographic data was collected from participants who agreed to take part in the research and was collated along with data collected about the patients' diabetes. Details are provided below in Table #6 below.

There were 26 male and 12 female participants. The age range of participants was from 21 to 77. When the age data is split into age groups by decade, the picture provided is as follows: 20's (1), 30's (7), 40's (11), 50's (16), 60's (2), 70's (1). The age profile of the participants was predominantly focused in the 30-59 age range. This is partly a reflection of the fact that many participants had Type 2 diabetes, which typically starts over the age of 40. Most particularly it may reflect the fact that as patients with diabetes get older they become more aware of the damage that poor diabetic control has on their long-term health. It is interesting to note that although a number of participants expressed the view that this sort of system was 'for young people who use computers all the time,' this was not reflected in the profile of recruits. It was difficult to recruit young people to the project and likewise older people. Of the participants recruited, 25 were in full-time employment (68%), four were self-employed (10.5%), and nine were either retired, students or at home (21.5%). These statistics reflect the census statistics for the area. The homogenous ethnic origin of participants is a reflection of the demographics of the area of the city in which the surgery is situated. Data from the 2001 census shows that 96.74% of the population of the ward is white British (Office for National Statistics, 2001).

User Name	Gender	Age	Ethnic origin	Occupation	Years with diabetes	Diabetes Type	Insulin User	Entry HbA _{1c}
frogbook	F	50	white British	Retired	1	2	N	6.7
greenfish	M	62	white British	full-time employed	7	2	Y	-
bluepurse	M	58	white British	Retired	3	2	N	5.8
rosecandle	M	77	white British	Retired	3.5	2	N	5.7
papercat	M	52	white British	self-employed	30	1	Y	-
hatfork	M	46	white British	full-time employed	0.5	2	N	6
treeswan	F	38	white British	Housewife	38	1	Y	9
boatapple	M	55	white British	Other	30	1	Y	12.6
catlily	F	54	white British	full-time employed	12	2	N	6.9
smilecup	F	51	white British	full-time employed	7	2	N	6.8
shoepen	F	33	white British	full-time employed	7	1	Y	7.2
chairtree	M	57	white British	Retired	17	2	Y	12.8
gardenpen	M	59	white British	full-time employed	12	2	Y	10.1
grasslake	M	55	white British	full-time employed	11	2	N	6.1
owlrose	F	40	white British	full-time employed	13	1	Y	-
greenmouse	F	47	white British	full-time employed	8	2	Y	7.5
shopbeach	M	33	white British	full-time employed	7	1	Y	9
poppymist	F	60	white British	self-employed	4	2	N	10.3
steelsky	M	35	white British	self-employed	7	1	Y	7.7
breezelane	M	43	white British	full-time employed	0.3	2	N	8.2
forestcircle	M	49	white British	full-time employed	15	1	Y	9.2
sandstar	M	54	white British	full-time employed	1.5	2	N	7.2
brightwater	M	42	white British	full-time employed	20	1	Y	8.9
berrybank	M	21	white British	full-time employed	2	1	Y	10
clearlake	M	41	Mixed	Student	8	2	N	10.2
roundocean	M	51	white British	full-time employed	7	2	N	8.1
hollybrook	M	33	white British	full-time employed	0.2	2	N	-
eastwind	F	56	white British	full-time employed	2	2	N	6.6
fairstream	F	32	white British	un-employed	0.5	2	N	5.3
palmstone	M	42	white British	full-time employed	7	2	N	6.2
lilyrose	F	42	white British	maternity leave	7	2	N	5.8
lionmoor	M	41	white British	full-time employed	7.5	2	N	9.4
friendsky	M	54	white British	full-time employed	3	2	N	7.5
fieldshine	M	39	white British	full-time employed	1.5	2	N	6.5
meadowsong	M	52	white British	full-time employed	2	2	N	7.5
waterlight	M	54	white British	full-time employed	2	2	N	6.8
orangenote	M	49	white British	self-employed	4	2	N	8.9
applehand	F	51	white British	full-time employed	6	2	N	8.2

Table 6: Summary of participant information

Twenty-eight of the participants (74%) had Type 2 diabetes and ten (26%) had Type 1 diabetes. At the time of the study 91% of the patients with diabetes at the surgery had Type 2 diabetes and 9% had Type 1 diabetes, so those with Type 1 diabetes were more heavily represented in the research group than in the surgery's diabetic population. The mean number of years participants had had diabetes was 8.6 years, with a range from two months to 38 years since diagnosis. A number of the participants with Type 2 diabetes were taking insulin. Some participants were not able to say whether they had Type 1 or Type 2 diabetes, especially those who were taking insulin. The range of HbA_{1c} results taken closest to the beginning of the project was from 5.3 to 12.8, with a mean of 7.96. The range of participants recruited reflects the research objective of ensuring that a diverse set of patients were represented in the study.

4.4.4 The practitioners

Practitioners who used the system at the study practice were two practice nurses and one GP. Additionally, a specialist diabetes nurse from the local PCT (Primary Care Trust)¹⁰ was involved in helping with queries posted on the discussion board. The assistant practice manager and team of receptionists helped with arranging meeting times and interview rooms.

The lead diabetes GP at the surgery used the system throughout the research. As well as having a special clinical interest in diabetes he also has an interest in child health and takes the lead role in the Practice on IT. This GP was involved in the project from its inception and contributed design ideas for the system. I maintained contact with the lead diabetes GP throughout the project, from the early planning and training stages, through the process of patient recruitment and during the study itself, through meetings, email contact and informal discussions about the study.

One of the practice nurses took the lead with patients with diabetes, and it was this nurse who was primarily involved in using the system during the study. Another, part-time practice nurse was also shown how to log onto the system and use it for occasions on which the lead nurse was not at the practice. The lead practice nurse was involved in the study throughout the study period, and was involved in providing help to patients with use of the meter and re-ordering strips and lancets for the meter. She used the system regularly throughout the study.

¹⁰ At the time of the study there were 151 PCTs (Primary Care Trusts) covering the whole of England, whose role was to manage all Primary Care Services in a particular geographical area.

A specialist diabetes nurse linked to the local PCT became involved in the study towards the end of the first phase of use in August 2007. Her involvement had been suggested by the lead GP as someone who could provide support for any questions that required knowledgeable input on the discussion board. Specialist input on the discussion board had also been suggested during the study by some of the participants.

4.4.5 The study

Participants who were recruited onto the study were shown how to use the system and interviewed in the first meeting; they were then contacted again about three months after the first meeting for a second interview and again after another three months for a final interview. I provided email and phone contact in between interviews so that participants could contact me if they had a problem. Of the 38 participants who started the study, 32 attended all three interviews and six dropped out during the course of the study. Reasons for dropping out were varied. Of the six patients who dropped out one was advised not to take part in the study by a hospital consultant because the consultant could not see the uploaded data¹¹, another was frustrated by failing to succeed in connecting the meter to his computer, two others lost access to a working computer, one became ill, and another could not be contacted for the last interview.

Practitioner use was fairly stable throughout the time period of the project. The GP practitioner used the system more at the beginning of the project, and then delegated the job of checking patients' readings and answering patients' messages to the practice nurse. The PCT nurse joined the project in August 2007 for the second phase. After her initial introduction to the discussion board she regularly responded to patient-initiated questions on the "Ask Trish" section of the board, but she did not actively instigate posts. Overall practitioner use was response-driven rather than pro-active, if patients had used the system more intensively the practitioners would have used the system more intensively.

4.5 Summary

This section discussed the design rationale for the diabetes eHealth system developed for this study. Two major factors were considered in the design of the system, these were the design features found in previous systems and the fact that the system was to be used in a primary care setting. The features implemented in the diabetes eHealth system developed for the

¹¹ The system was only designed to be used by patients and the health practitioners at the general practice.

study have been described and discussed. The study setting has been described and patient sampling and recruitment processes explained. Finally, an outline has been provided of the patients and practitioners who took part in the study. The details of the eHealth system and the study participants presented in this chapter provide the background for the next chapter in which the study findings are presented.

5. PARTICIPANTS' EXPERIENCES OF THE EHEALTH SYSTEM: FINDINGS

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Experience is the child of thought, and thought is the child of action. We cannot learn men from books.

Benjamin Disraeli 1804-81: *Vivian Grey* (1826)

5.1 Introduction

Following on from the discussion in the previous chapter about the process of setting up the research study, this chapter presents the categories and subcategories that were identified from participants' interviews. These categories were developed through a process of careful and iterative analysis of interview transcripts, using a grounded theory approach which

started with detailed data coding, followed by identifying subcategories and ending with an iterative process of category and theory development.

This chapter contains six sections. The first section introduces the content and the structure of the chapter. The second section provides an overview of the three categories presented in the chapter. The third section discusses the category ‘*Diabetes Self-management Experience*’, the fourth section discusses the category ‘*Diabetes Support Experience*’ and the fifth section discusses the category ‘*Diabetes eHealth System Experience*’. The sixth section summarises the main points in the chapter.

5.2 Category Overview

The results presented in this chapter are structured using the three categories that were identified during the analysis. These are summarised in Table #7 below:

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
Diabetes Management Outcomes	
DIABETES SUPPORT EXPERIENCE	
Support-seeking Approach	
Support Experiences	
Support Aids and Tools	
DIABETES eHEALTH SYSTEM EXPERIENCE	
Aims for System	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

Table 7: Category Overview

The first category identified is the ‘*Diabetes Self-Management Experience*’. This category describes the personal sphere of participants’ diabetes management experiences. This consists of three groupings. The first grouping includes contextual factors such as participants’ *health context*,

their *knowledge of diabetes* and their *approach to diabetes*, along with participants' *aims and intentions* for managing their diabetes, and the *barriers* that hinder them in that process. These subcategories represent layers of knowledge, experience and personal history that are built up over years, and together form a complex personal picture of the experience of diabetes. The second grouping relates more directly to self-management. This includes participants' *self-management approach* to taking medication, and managing diet and activity levels and their *diabetes symptoms and experiences*. This also includes the *self-management tools and aids* that they use such as blood glucose meters and diaries. These self-management activities, whether consciously or unconsciously undertaken, are embedded in participants' everyday lives and are acted and re-enacted on a daily basis. The final grouping consists of the *outcomes* participants experience as a result of their diabetes management activities.

In contrast, the second category '*Diabetes Support Experience*' covers the external sphere of a participant's management activities such as going to visit the GP, a dietician or the diabetic clinic. This category includes participants' *supported experiences*, their *support-seeking approach* and their *support aids and tools*. External support is more likely to be sought in a sporadic manner and often involves having meetings that occur at a particular place and time with someone who has specialist skills. Support-seeking involves looking outwards, communicating with others about diabetes and actively seeking help.

The third category '*Diabetes eHealth System Experience*' covers the experiences participants had using the diabetes eHealth system. This category was the focal category for the research, although it is intimately linked with the other categories. The eHealth system brought together and co-located various personal self-management and external support-seeking activities in a virtual system accessible from the home environment. This category covers how participants experienced using the eHealth system as a technical system to help them manage their diabetes. It includes participants' *aims* for using the system, their *experience of using technology* at home, and *barriers and facilitators* to system use. It also includes participants' *views of the eHealth system*. Finally, it covers *system use*, such as when and how they used the system, their *response to the system* and *unmet expectations* of it. All of these affect the outcomes achieved from using the system.

The three categories presented in this section are all intricately linked together. For the purposes of this research study the diabetes eHealth system experience is the key category

and the issues that arose during the use of the eHealth system are the focal point of the study. However, it is important to note that this category cannot be fully separated from the others as it is contextualised by them. Even while participants were using the eHealth system they continued to undertake activities and have experiences that were related to the other categories.

In the following sections each category will be discussed in turn. Each section is structured to include a short overview of the category, followed by a discussion of each of the subcategories identified within the category along with supporting interview data, and finally a brief summary of the key points. Participant vignettes are provided in Appendix #5. These provide a short description of each participant and the way in which they engaged with the eHealth project. Also a detailed list of each category with its sub-categories and associated codes is provided in Appendix #7.

5.3 Category One: Diabetes Self-Management Experience

This category covers participants' personal experiences of diabetes which includes both the personal context of their diabetes experience and their self-management experience. This is the realm of personal experience. The sub-categories in this section encompass contextual elements that form the backdrop for participants' diabetes management activities as well as elements that relate to self-management activities. These can be broadly divided into three groupings. First there are contextual factors. The health context, diabetes knowledge and diabetes approach of participants set the tone for the way in which they set targets for themselves and perceive barriers. The second grouping consists of the factors surrounding self-management. These include how participants approach and carry out their regular self-management activities including the tools they use to help them with those activities and the ways in which they manage their immediate symptoms. The third grouping consists of outcomes from self-management. These outcomes in turn affect participants' health context, diabetes knowledge and diabetes approach. The diabetes management experience is therefore a continuous process that develops and changes over time.

The ten sub-categories in this category are summarised in Table #8 below:

DIABETES SELF-MANAGEMENT EXPERIENCE

- | | |
|--|--|
| <p>5.3.1 Health Context</p> <p>5.3.2 Diabetes Knowledge</p> <p>5.3.3 Approach to Diabetes</p> <p>5.3.4 Diabetes Management Aims</p> <p>5.3.5 Barriers to Diabetes Management</p> | <p>5.3.6 Self-management approach</p> <p>5.3.7 Diabetes Symptoms and Experiences</p> <p>5.3.8 Self-management Aids and Tools</p> |
| <p>5.3.9 Diabetes Management Outcomes</p> | |

Table 8: Category One Overview

5.3.1 Health Context

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
Diabetes Management Outcomes	

This sub-category is about participants’ perceptions of their health context and the impact this had on their diabetes and their diabetes management. Participants

talked about the practical and motivational implications of their health context. Each participant had a unique health context, and held views about how that context affected them. Participants’ views about their health formed the basis of the narratives they constructed about their diabetes. These affected how they tackled their diabetes management, particularly their ability to focus on and prioritise diabetes.

Several participants talked about how they viewed their diabetes in the light of other conditions they had. For example Rosecandle was a 77 year-old man with Type 2 diabetes. He had recently had a stroke, pneumonia and had been diagnosed with dystonia, after which he was diagnosed with diabetes. He said that as far as he was concerned ‘*the dystonia is more a problem than the diabetes’ because ‘I get very serious cramps, or I will kick out suddenly’*. He felt there was not much he could do to manage his diabetes apart from taking his medication, being careful about his diet and monitoring his bloods. He could not for instance take much exercise, explaining

I do go out on my own, but I know my limitations there, I know when to sit down, when I have walked far enough, and I know spots where I can sit down either on a wall or I have got my walking frame.

On more than one occasion he expressed a clear view about his age and health saying ‘*as far as I am concerned the biological clock is running down, and there is nobody can wind it up again*’. Although he used the diabetes eHealth system frequently to upload and check his blood glucose readings and to communicate with the GP, he did not express an interest in any of the rest of the system. His use of the system seemed to be limited in line with his view of his health and his appraisal of what he needed to do to manage his diabetes.

Other participants talked about the distracting effect of having multiple health problems. Catlily, a 54 year old woman with Type 2 diabetes, said that after having a series of health problems she was finding it hard to control her self-management activities such as remembering to take her medication or eating properly. She explained:

The past few years I have had lots of medical things going wrong that sort of hamper me in lots of ways. Well I used to go to the gym twice a week with my niece and I went for a hysterectomy a few years ago ... and I have not got back to the gym since then. But then I had embolisation on fibroids, and I have had bowel problems and I am waiting to see someone, so it's yes, it seems to have been one thing after another, I have gone into the change, and the migraines are worse.

In addition to finding her health problems a distraction she also said, as did several others, that discovering she had early signs of diabetes-related damage helped her to focus more on looking after herself. She said that finding out she had early signs of diabetic retinopathy ‘*was good because it's like a wake-up call... it keeps me on track*’. Catlily used the system throughout the study, although there were some occasions when she forgot about aspects of the system or stopped using it for a while and these coincided with times when she was having other problems.

Some participants said diabetes was not their main priority. Smilecup, a 51 year old woman with Type 2 diabetes, explained that she felt her struggle to lose weight was her key problem saying ‘*my weight is far more of a priority, and that is part of the diabetes, but it's only a fragment*’. Additionally, she felt that in general she had good diabetes control, and hence the diabetes itself was not her main problem:

Yes, I think I don't see my diabetes as a real problem, I think if it wasn't as well controlled as it is, it would be different. I know that it hasn't been quite as well controlled this year, last year was excellent, this year isn't, so I think if it was having a greater impact on me that would be different.

Smilecup did not use the eHealth system at all during the study. Although there were other factors such as home computer problems and a stressful work situation that undoubtedly contributed to her not using the system, her view that diabetes was a low priority also seemed to contribute.

Some participants talked about the effect mental health problems had on their ability to focus on diabetes. Clearlake, a 41 year-old man with Type 2 diabetes and schizophrenia, said his mental health problems made it *'very hard to bring diabetes to the forefront'*. Instead his main focus was on *'what I have got to do in life, like studying and meeting people'* as these were aspects of life he struggled with. He said,

Hmm, to be honest with you, I mean I think, I don't know whether I am the right or the wrong person to ask, but the way my mental health has been I have, you know, my diabetes has gone on the back burner. It shouldn't do because that should be at the forefront I know that but, you know that is the reality of life.

Clearlake hardly used the system at all during the period of the study, although he talked about intending to use it at each meeting.

5.3.2 Diabetes Knowledge

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
	Diabetes Management Outcomes

This sub-category is about participants' diabetes knowledge. This includes their understanding of factual 'medical' knowledge about diabetes and their own

'experiential' knowledge of what it feels like to have diabetes. Factual diabetes knowledge was accumulated through a combination of reading from a variety of sources and talking with health professionals and others with diabetes. Experiential knowledge was built up over the

years of having diabetes and by learning to be sensitive to certain signs and symptoms. Participants said that both types of knowledge were important in helping them to feel confident about managing their diabetes effectively.

Participants varied quite widely in the extent of their knowledge about diabetes. They talked about accumulating knowledge over time, but were also aware that knowledge could go out of date as new medicines and management techniques were introduced. Some participants said they felt they knew enough about diabetes, such as Friendsky, a 51 year-old man with a three year history of Type 2 diabetes, who said *'I think I know all I need to know'*. However, most participants indicated they could learn more. Sometimes this was because the participant was recently diagnosed, such as Hatfork, a 46 year-old man who had been diagnosed with Type 2 diabetes six months previously, who said he had *'a lot more to learn'*. However, even after over a decade some participants considered they still had more to learn. For instance Gardenpen, a 59 year-old man who had had diabetes for 12 years, said *'you are always learning something else about it'*, and Forestcircle, a 49 year-old man who had had diabetes for 15 years, said *'there's a great deal more I could look into'*.

During the course of the interviews participants mentioned a variety of aspects of diabetes that they felt uncertain about. Sometimes uncertainties were about practical issues, for instance Smilecup said she was uncertain about some *'dietary things'* such as *'portion size'* and added that she felt she got *'conflicting advice'* from the dietician about obesity and diabetes. Some participants had specific queries that related to their own experiences such as Greenmouse, a 37 year-old woman with insulin-controlled Type 2 diabetes, who said she did not understand *'having high readings in the morning when you haven't eaten anything since late last night'*. Others mentioned quite fundamental uncertainties such as Sandstar, a 54 year-old man with Type 2 diabetes, who said he was not sure *'what actually builds up the blood sugar'*. Also Applehand, a 51 year old woman who had had Type 2 diabetes for six years, explained that she did not understand her blood glucose readings saying:

*Dr **** has said to me, "God you know that reading is really high", you know, "What have you been doing?" and I am like, "Is it?" you know, "I have had higher", type thing. It's like I didn't realise it's that bad.*

Lilyrose, who had Type 2 diabetes, explained how she had learnt about diabetes gradually, but that she had struggled to get the right information at the right time:

I think I got a lot more information about it when I was pregnant ... before we got married I said to the like the diabetic nurse, that you know, we were thinking of maybe having a baby and I asked to see if there was any leaflets. And one of the things I didn't know was that, you know, you should really monitor your sugar, your sugar levels should be well maintained before you get pregnant and obviously during the pregnancy. And I didn't know that I would have to go onto insulin. I didn't know that. It was only when I saw the consultant at 12 weeks, so in that respect it was a bit of a shock because I didn't, I wasn't even able to get any leaflets about it. Now, when I went actually was put on the insulin I was given leaflets then and I thought well I wonder why I couldn't have got these leaflets before, so in that respect, that was a bit frustrating. I tried to find things out on the internet and I couldn't, I couldn't really find anything.

5.3.3 Approach to Diabetes

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
	Diabetes Management Outcomes

This sub-category describes participants' approach towards diabetes. This includes participants' acceptance of their diagnosis, their focus on diabetes and

their emotional response to it. There was a high degree of individual differentiation in this sub-category. Although 'approach' or 'attitude' is a complex concept to grapple with in the context of a chronic disease, here it is seen as a factor that contextualises participants' diabetes management practices. In many cases a participant's approach to diabetes seemed to suffuse their whole experience of diabetes.

While most participants acknowledged their diagnosis of diabetes, some expressed doubts. Rosecandle said in the third interview '*I doubted that I had diabetes*' but went on to explain that looking at his blood glucose readings during the study had convinced him the diagnosis was correct. Lilyrose, a 42 year-old woman with Type 2 diabetes, said that a few years previously when she had lost weight her readings were such that the doctor '*thought I had been*

misdiagnosed'. Waterlight, a 55 year-old man with Type 2 diabetes, expressed great doubt about his diagnosis during interviews. He was particularly concerned about the irrevocable nature of being diagnosed with diabetes saying *'the label is stuck'*. He explained *'I failed the test and now I am a diabetic'*, but felt that *'on another day I could have passed'*. Having doubts about diabetes was likely to make participants less certain about the importance of looking after themselves. Waterlight for instance felt that changing his working patterns was more likely to affect his health than any other lifestyle change, saying:

See if I was to go back to a normal work pattern, would that change it, without changing my diet? Because in all honesty I haven't changed my diet, you know what I mean, there was nothing to change.

About a third of participants said that they tried to avoid thinking about diabetes much of the time. Certain phrases were regularly used by participants around this theme, such as *'burying my head in the sand'*, *'ostrich trick'*, *'hiding'*, *'in denial'*. The degree of avoidance that participants described varied. Grasslake, a 51 year-old man with Type 2 diabetes, talked about his past attitude saying *'I was burying my head in the sands a little bit and thinking it was only a minor thing'*, and suggested that during the study his attitude had changed. Poppymist, a 60 year-old woman with Type 2 diabetes, expressed an ambivalent approach that indicated some acceptance and some avoidance, saying *'I am conscious I am a diabetic'* but also *'I just hate being ill, I just try and forget'*. Berrybank, who was 21, was so reluctant to engage with diabetes it affected his self-management routines. He explained:

I don't do my readings ... I can't be bothered half the time; I try to forget about it as much as I can. I feel like it's just reminding me of it, if I have to check myself four times a day.

Hatfork, a recently-diagnosed 46 year-old man with Type 2 diabetes, said his approach had been *'just shut your eyes and if I ignore it, it will go away'*. Participants who repeatedly talked about avoiding thinking about diabetes generally did not use the system very much, and in some cases, such as Berrybank, could not bring themselves to use it at all.

Many participants talked about how their focus came and went over time and how it was difficult to maintain. Lionmoor, a 41 year-old man with insulin-controlled Type 2 diabetes, said *'if you don't do your readings you tend to forget you have got diabetes'*. Brightwater, a 37 year-old

with Type 1 diabetes, said *'without focus I can drift off'* and talked about a period of time during which *'I lost touch with the diabetic clinic'*. Sandstar also said *'it's difficult to concentrate on it'*. However, participants also talked about the importance of getting the right balance and not focussing too much. Meadowsong, a 52 year-old man with Type 2 diabetes, said while he wanted *'to be more focussed'* he also acknowledged *'I don't want my life to revolve around it.'* Owlrose explained that a combination of the chronicity of the condition and her reluctance to focus on it, made it hard:

I think the problem with me is, because I have had it for so long now, I just sort of, it's not me, it's sort of it's a bit of baggage that I don't really look at, it should be at the forefront of my mind and I don't want it to be ...

And later in the same interview she added

I don't want to focus on it, that's the problem I don't want to focus on it. I want it to be alright, and I want to keep control of it, but I don't want it to be the be-all and end-all.

This was mirrored by many participants' use of the system during the study. Although some participants settled into a routine with using the system and used it regularly, many found it difficult to keep up regular use and used it sporadically, focussing on it at certain times and then simply not using it at all for a while. Some participants talked about forgetting to use the system at times.

Participants described emotional responses they had to particular diabetes-related events. Anxiety and fear were most commonly mentioned. These responses often coloured participants' approach to diabetes either in the short or the long term. Greenfish said it was *'frightening'* when his blood glucose readings inexplicably went high. Shoepen, a 33 year-old woman with Type 1 diabetes, said that having a fit as a result of low blood glucose *'was a bit scary ... it has taken quite a long time to get over that'*. Roundocean, a 51 year-old man with Type 2 diabetes, said he was *'very apprehensive'* as the doctor had suggested he may need to start taking insulin, and he considered it to be a major step. Chairtree, a 57 year old man with Type 2 diabetes that had only been diagnosed after he had developed foot ulcers and who also had severe neuropathy, said he felt *'angry'* at what diabetes had *'taken away from me'*. He spoke about how difficult it was to deal with bad news after a consultation saying:

It has increased your knowledge, but it hasn't altered anything. You have still got the day to day living things to do, and looking at your feet rather than casting your eyes up to the hills, the horizon, because the horizon is scary.

5.3.4 Diabetes Management Aims

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
	Diabetes Management Outcomes

This sub-category describes participants' diabetes management aims. Participants' aims tended to fall into four distinct categories, aims to improve their lifestyle

(diet, activity, smoking and drinking), aims to improve their blood glucose control (metering, adjusting food intake and activity to readings, taking medication), aims to learn more about diabetes (medical knowledge and awareness of personal symptoms), and aims to improve their approach to diabetes (awareness, focus). Aims varied in their intensity: sometimes participants talked about their aims using clear and specific language, at other times they talked about their aims in vague terms or talked about having private aims that they did not want to express to others. Some participants did not have clear aims at all. Often when participants talked about their diabetes management aims they were referring to aims they wanted to achieve during the six months of the research project. However, sometimes they were also talking more generally about long-term aims. Although the research project took place over six months, this was just a drop in the ocean when put in the context of having a chronic disease for a lifetime. There was an indistinct boundary between participants' aims for the project and their wider aims.

Many participants talked about aiming to maintain or improve their health-related lifestyle in some way. This involved aims such as losing weight, eating more healthily and being more active. For example Shoepen said she would like to '*lose some weight*', as did Owlrose. Forestcircle said he aimed to have '*a healthier lifestyle*', and his specific goal was '*to lose one stone*'. Sandstar's aims were '*to cut down on what I drink, obviously exercise more, eat more healthily*'. Poppymist said '*I am determined I am going to get more exercise*'. Having cut back salt, sugar and alcohol, Meadowsong said the issue was '*maintaining it*'. He also talked about his longer term ambitions to lose weight, explaining:

My daughter is getting married not next year the year after, so I am kind of building up, I have got a target to get my weight, in my own mind I haven't even mentioned it to my wife where I want to be with it, but I am getting there you know, and whereas I am a stone and a half lighter than what I was 6 months ago, so I am doing it just absolutely steady.

Orangenote, a 49 year-old man with Type 2 diabetes talked about his life-style related aims and how they related to each other and together formed a longer term plan:

I certainly want to have a better dietary regime; I certainly want to do that. And I am finding it difficult because of my obesity, I am finding it difficult to take strenuous exercise, and but I think I can lose significant weight at the moment without taking excessive exercise, because I have so much to lose and I am thinking if I can, my idea is if I can get that initial bulk off, I would be better able then to take on other more physical exercise.

Participants also talked about wanting to control their blood glucose levels. Frogbook was very clear about her aims saying:

I want to get my diabetes a bit more under control; I don't want to go on medication'.

Shoepen, who had Type 1 diabetes, talked about wanting to have her diabetes 'more under control', explaining that it was something she had to do 'every so often'. Gardenpen also said he wanted to 'control my blood better' and get his blood glucose levels 'down into single figures'. Owlrose said she wanted 'a lot more tighter control over my blood sugars'. Berrybank, a 21 year-old man with Type 1 diabetes said that he never took his blood glucose readings, he stated in the first interview:

Yes I am going to try and do my blood more. That is the only thing I want to do.

Some participants talked about aiming to improve their approach towards diabetes. Participants with this aim talked about trying to increase their awareness and focus on diabetes, or attempting to be more positive. Smilecup talked about wanting to 'be more aware of me'. Papercat, a 53 year-old man who had had Type 1 diabetes for 30 years, also said he wanted to 'be more aware' of his diabetes, and Lionmoor said he wanted to 'keep it in my mind'.

Brightwater said he wanted ‘*to focus a bit better*’. Catlily said she intended ‘*staying on task*’, and Clearlake said he wanted to ‘*be regimented again*’.

Many participants talked about aims to learn more about diabetes. Rosecandle said he wanted more ‘*knowledge*’, and Breezelane, a 43 year-old man with Type 2 diabetes, said he wanted to ‘*keep more up to date*’. Greenmouse said she wanted ‘*a better understanding of it really*’. Palmstone, a 42 year-old man with Type 2 diabetes, said he wanted

A better understanding of my condition to be honest ... why do I lose my temper at certain times, is it because my blood sugar is down, or, is it because it's too high? I don't know.

Many participants said that despite having made some changes there was still more to do. Palmstone said ‘*I should do even more*’, Shopbeach, a 31 year-old man with Type 1 diabetes, said ‘*I should do more*’. Greenmouse said ‘*I'm sure there could be room for more improvement*’. Forestcircle said although he had made ‘*some substantial changes*’, they were ‘*not enough*’. Sandstar, who said he felt he had made enough changes, acknowledged that he still had to put effort into maintaining them, he said

I realise now, yes, the changes and things I do, I have got to keep going forever. There is no alternative really. There is no cure.

5.3.5 Barriers to Diabetes Management

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
	Diabetes Management Outcomes

This sub-category describes factors that participants highlighted as hindering their management efforts. Participants talked about a variety of barriers, such as lack of motivation, lack of self-discipline, health problems, and not having enough time. Logically it seems that there should have been some facilitators as well, however participants did not mention any. This is possibly because when aims were achieved, participants focussed on their success rather than trying to identify factors that had contributed to the success. In contrast, when aims were not achieved, frustration and disappointment meant that the barriers came to the fore and were therefore highlighted and talked about.

Several participants talked about finding it hard to motivate themselves to maintain a healthy lifestyle consistently. Hollybrook, a 33 year-old man with Type 2 diabetes, explained ‘*I will*

have 6 months or a year of going to the gym and then I will drop off for 6 months. Waterlight said that when he got back from work *'all I want to do is have a nap'*, even though he knew he should exercise *'I don't want to'*. Frogbook explained:

I start off and I go right I have to do that, and I get like half way through the week and I go oh I can't be bothered with this, so it goes.

Health issues were barriers to making lifestyle improvements. For instance three participants had longstanding mobility problems that limited their ability to be active – Rosecandle, Bluepurse and Meadowsong. Shoepen said it was a *'struggle'* for her to exercise because *'I hypo very quickly'*. Owlrose said she had not been to the gym because she recently *'had an inflammation of the knee'*, and similarly Friendsky had *'two bad knees'* that stopped him from using the gym. Fieldshine, a 39 year-old man who had been newly diagnosed with 'Type 2 diabetes, said he wanted to play football but he was not *'physically up to any level of fitness'* where he could contemplate starting.

Some participants talked about facing multiple health barriers. For example Chairtree had neuropathy with 16 electrodes in his spine to help with pain control and also had a heart condition, both of which were a result of diabetes. He often felt tired and had to use a mobility scooter when he went out because he could not walk far. He had very little feeling in his hands and feet because of nerve damage. He had been forced to give up his job as a teacher after his diagnosis because of the damage diabetes had caused, and this left him with a deep resentment of diabetes. Because of these problems Chairtree could only use medication and dietary control to manage his condition.

Participants also talked about external barriers to achieving aims that focussed on work, and lack of time. Some external barriers were not within the control of participants. Shopbeach said he had started swimming but then *'the swimming pool shut down for refurbishment'*. Lilyrose said she wanted to go to the gym but *'it's the cost you know... we only have one salary coming in'*. Several participants talked about working long hours, like Smilecup who said it was hard to exercise because she felt *'so tired when I get home'*. Poppymist talked about being busy at work saying:

I have been so busy I mean that's, I think it's a vicious circle. I am stressed because I haven't got time to do what I want to make my diabetes levels go down.

Social occasions were mentioned by several participants as presenting barriers, because it was difficult to resist the temptation to eat and drink too much. Meadowsong said his wife ‘is a great cook’ and socialising revolved around ‘having meals’. Forestcircle found it difficult to maintain discipline at social occasions saying:

I am very weak-willed. I am alright through the week, I find I have problems on a Saturday and a Sunday where there is a lot more options open to me to go out and do things that I want to do. And if I am going out I do tend to, I do go out once a week with my father and my brother and we just go and have a couple of drinks but I have got to watch that because it can lead to excess.

5.3.6 Self-management Approach

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
	Diabetes Management Outcomes

This sub-category covers the approach participants have towards daily self-management. It is closely linked to the subcategory ‘Approach to Diabetes’,

discussed above. Routine and self-discipline were mentioned as important factors for self-management. Participants also talked about elements of self-management that they struggled with, such as fear of needles or not managing to take their medication regularly.

Participants talked about the importance of having a routine for managing diabetes, although participants varied in how successful they were at this. Rosecandle described his daily routine which revolved around eating and metering:

I take one [meter reading] first thing in the morning before I have anything to eat at all and then I have my breakfast at about 10 [or], 20 past 10, and then I will wait until about 4 o'clock in the afternoon and take another one, and then I have my evening meal.

Friendsky described himself as ‘quite regimented’, and Lilyrose talked about the importance of ‘getting into the routine’. Gardenpen said, ‘it all comes down to routine,’ he said of his evening

activities *'by the time I get in, my tea is on the table, so it's blood, inject, tea'*. Berrybank described his insulin regime saying *'I take it near enough right on the same time every day.'* Papercat, who also had Type 1 diabetes, emphasized regular metering saying *'you have got to monitor yourself regularly'*. Shopbeach talked about the importance of planning ahead as part of his routine saying *'you are always thinking like 2 steps ahead'*, going on to explain:

It's not easy you have got 3 meals to fit in during the day. What time [will] I have my breakfast? What time my dinner? What am I going to have for my dinner? Where I am going to have my dinner and when am I going to have my tea?

Some participants talked about how they struggled with routines. Boatapple, who had had uncontrolled diabetes for some time considered that what he lacked was a good routine, *'I don't think it's even motivation, its habit more than anything else'*. Hatfork likewise did not control his diabetes well but was aiming to *'create a habit by watching what I am doing.'*

Participants said self-discipline was important for managing a healthy lifestyle but varied in their success at being self-disciplined. Lionmoor said *'I think it's all down to will power'*. Papercat said *'I am very strict with myself, very, very strict'*. Lilyrose also said she felt what she needed was a combination of *'self-discipline and being kind of motivated'*. Waterlight talked about trying to go to the gym regularly but added it was not always possible saying *'the spaces in between get longer, its discipline'*.

Some participants talked about forgetting aspects of their diabetes management activities. Several participants talked about forgetting medication. Catlily said in the second interview *'I don't think I've been taking my tablets regular[y]'*, and Gardenpen said a recent change in routine made him forget to take some of his tablets. Boatapple talked about how he would put his insulin out and then *'go off and do something else and forget about it'*. Forestcircle also he had recently been *'missing some injections'*. Lionmoor linked regular metering with remembering saying that at times when he did not meter *'you tend to forget you've got diabetes.'*

Some participants talked about self-management fears, particularly fear of having to inject themselves and prick their fingers. Bluepurse said that going onto insulin was *'the only thing that worries me'* because *'I hate needles, terrible fear of needles'*. Hatfork had discussed injections as a treatment option and said *'I had a cold sweat as soon as someone mentioned that'*. Gardenpen had to

inject insulin even though he was frightened of needles and said when he started ‘*I could feel it all welling up inside, you know the fear of it?*’. In contrast, Berrybank was fine about injecting himself with insulin but said ‘*I don’t want to prick my fingers?*’, explaining further ‘*I hate it?*’ which was one of the reasons he stopped using his meter.

5.3.7 Diabetes Symptoms and Experiences

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
	Diabetes Management Outcomes

This sub-category covers the everyday symptoms participants experience with diabetes. They affected the way that participants managed their diabetes from

day to day and were strongly linked with issues such as focus and approach. Two contrasting features were either not experiencing any symptoms at all, or experiencing difficult symptoms. Additionally, many participants talked about experienced symptoms of diabetes that they had to manage but could not control. Tiredness, hypos and fluctuating blood glucose were mentioned in this context.

Some participants talked about how not experiencing any health problems affected their focus on diabetes. Brightwater, a 37 year old man with Type 1 diabetes, said he did not focus much on diabetes ‘*because I feel fit, healthy, and it doesn’t seem to like give me any adverse effects?*’ Similarly Friendsky, a 51 year old man with Type 2 diabetes, said because he felt well most of the time ‘*I forget I have even got it to be honest?*’ Also Sandstar, a 54 year old man with Type 2 diabetes, explained in the first interview

I think because I have got no outward signs, or even inward signs of having something wrong with me, you tend to forget all about it and it’s only when I need to replace tablets or things like that, that I go yes.

He went on to say in the second interview how not having any symptoms made it difficult for him to know whether he was doing the right thing:

It’s strange; like I say to him [the doctor] I don’t feel unwell. You know, it’s difficult, if I had a pain in my back or something like that I could say ok my pain has gone now so I know I am doing something right but I don’t know what ...

In contrast, many participants recounted experiencing symptoms of diabetes that they had to manage but could not control. Tiredness, hypos and fluctuating blood glucose were mentioned in this context. Half the participants mentioned tiredness as a symptom of diabetes. Greenfish said that having diabetes made him feel *'tired and listless'*. Grasslake also said he generally felt *'tired, lethargic, quite slow'*, and Applehand said she would often *'sleep in the daytime'*. Several participants associated high blood glucose with tiredness, such as Clearlake and Gardenpen who said *'if the sugars levels are high the tendency is to feel tired'*.

Participants talked about experiencing hypos. Bluepurse, a 58 year-old man with insulin-controlled Type 2 diabetes said *'I know when I'm getting a hypo because I get all shaky'*, and Treeswan, a 38 year-old woman with Type 1 diabetes, said *'I know my own tell-tale signs'*. Shoepen said it was difficult to be spontaneous because *'if I go for a walk I will then hypo because I didn't plan for the exercise'*. Shopbeach said he had to be aware of the possibility of hypos saying *'if I go out ... I have to carry sugar with me'*.

Another experience that participants mentioned was fluctuating blood glucose. Gardenpen said some days *'I get up in the morning and my sugar might be 12'* but he explained that he could not adjust his insulin at that time because if he was active at work it *'just plummets'*. Shopbeach talked about experiencing times when *'my sugar levels go up and I can't bring them down.'* Boatapple said at the second interview *'it was off the scale yesterday ... for no apparent reason'*, he later explained *'it just come up 'high', so 'high' means its past 30 odd'*. Participants who did not take insulin also experienced fluctuating blood glucose. Poppymist said in the second interview her blood glucose had *'gone out of control'* and Fairstream said she phoned the nurse once because her monitor once *'was flashing 'high' at me'*. Other examples of intrusive symptoms mentioned by participants were pain from neuropathy mentioned by Chairtree and Applehand and excessive sweating mentioned by Chairtree, Gardenpen and Fieldshine.

5.3.8 Self-management Aids and Tools

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
	Diabetes Management Outcomes

This sub-category covers the self-management tools that participants used to help them manage their diabetes. The electronic aid most commonly used by participants was the blood glucose meter. One participant (Shoepen), used an insulin pump.

Participants' use of blood glucose meters varied. Some participants used their meter daily, such as Rosecandle who metered three times a day, Greenfish who said he metered '*twice a day*' and Eastwind who said '*I normally do a morning one and a night one*'. Most participants who injected insulin used a meter; even Boatapple, who barely managed a routine, said '*I am managing the metering and the insulin, and all that lark; I am still getting bloody high readings, though*'.

Many participants used their meter sporadically. For some participants this was because there was not much change in their readings. For instance Friendsky explained '*I might take them, twice a day for a week, and say they are alright, I might go 4 or 5 days and not do them*'. Waterlight explained why he had stopped using his meter in the past, linking non-use to a lack of variation in the readings in addition to a lack of interest from the doctors:

I used to test and keep a diary, and basically it was just for me own records, because the surgery weren't interested, the Doctor wasn't interested so after a few months you go, well it's always under the 10, it always varies round there, and I was doing it 4 times a day ... and then it dropped to a couple of times a day and then I just say well there is no point ... that's why I stopped.

Sometimes sporadic use of a meter was linked to lack of motivation. Hollybrook said of his meter use '*I have a little go and put it down and pick it up again, it's hard to get into a routine*'. Applehand also explained that she found it hard to sustain regular metering saying:

I started doing it and then it's like I will do it tomorrow, I will do it tomorrow, I will give it a week's break and then see how things are and then I hadn't realised quite how long it had been.

Sometimes sporadic use was linked to health issues. Poppymist said she did not use it for a period because '*I was ill and I was taking antibiotics, and I thought there is no point in doing this because I know your levels go through the roof when you are not well*'. Palmstone said that when '*I was feeling fit and active I was doing them every other day*', but that '*at the moment I haven't bothered*' because he was not feeling well and '*the last thing I want to do is go bang and see what it is*'. In contrast, Friendsky said '*when I feel a bit iffy you know, I will check it then*' and so did Smilecup who said '*if I don't feel well I will use it then*'.

Sporadic use was also mentioned in relation to other events. Eastwind said she did not use her meter while *'I was on holidays ... but I have been using it every day since I come back'*. Hollybrook said he did not take his meter to work and only metered *'on my days off'*.

Three participants did not use a meter at all during the duration of the research, Meadowsong and Sandstar who said *'I spoke to Dr **** last time I came in and he didn't seem to think as though I needed to go onto the daily Accutest'*. Also Berrybank, a 21 year-old man with Type 1 diabetes said he did it *'4 times a day, every day'* for the first 2 months after his diagnosis but then said *'I just thought, I hate this'* so he stopped.

Some participants used paper diaries to keep meter readings or other health and diet notes. Papercat said he tried to keep a paper diary of his readings saying *'I have always kept a little paper diary'*, but also said *'sometimes I forget to fill it in'*. Shopbeach kept a paper diary of readings to show to his consultant, but would let it lapse and then have to fill it in retrospectively saying *'it's a bit of a pain when you have got like 3 months worth of readings to write out'*. Breezelane said he used to keep *'a diary'* of his readings *'but then I used to think, well what happened 3 weeks ago, does it matter? ... that information is really irrelevant to me'*, so he stopped using it.

Rosecandle said he made *'notes of things I feel'* because he did not like *'bothering the doctors'*. Poppymist said when she had time she would like *'to keep a food diary as well, so I can track exactly what is happening and why'* and Lilyrose also said in the last interview *'a food diary might have been a good idea'* and that when she had used one before she found *'it does make you a little more strict I think when you write it down.'*

5.3.9 Diabetes Management Outcomes

DIABETES SELF-MANAGEMENT EXPERIENCE	
Health Context	Self-management approach
Diabetes Knowledge	Diabetes Symptoms and Experiences
Approach to Diabetes	Self-management Aids and Tools
Diabetes Management Aims	
Barriers to Diabetes Management	
Diabetes Management Outcomes	

This sub-category describes the outcomes participants reported as a result of their management activities.

These outcomes were affected by a) participants' self-management experiences, b) their support experiences and c) their use of the eHealth system. Participants mainly talked about changes they had made during the period of the study but they also sometimes talked about previous attainments. Many of the outcomes participants mentioned were achieved as a result of using the eHealth system, but not all. A notable feature of the project was that it was not always possible to disentangle what had caused a participant to change some aspect of their diabetes management

behaviour. Only a few participants indicated that they had not made any changes during the project, apart from Bluepurse, these were participants who hardly used the system at all. A table of participant-reported changes is provided in Appendix #9.

Changes in health-related lifestyle

Most participants talked about making some change to their lifestyle during the course of the study such as improving diet, losing weight, increasing exercise, cutting down on alcohol or giving up smoking, although they had varied success in maintaining changes. Most of the changes participants talked about were made during the project but these changes almost always fitted in with longer term plans for changes.

For example Greenfish said *'I have changed some of the foods I eat and when I eat'*, Grasslake said *'it's I suppose spurred me on to lose a little bit of weight, I have lost about half a stone'*. Greenmouse increased her activity saying *'I haven't accepted lifts I have made myself walk, so 20 minutes exercise every day'*. Shopbeach talked about his attempts *'I am trying to change yes, I am trying to do some changeover, from a slob to an active person'* saying that he had *'starting going to the gym, walking more'*.

Many participants reported varied success in making changes, even during the six months they were involved in the project. For example at the second interview Smilecup said *'I am losing weight, so I have lost a stone, so I am really pleased'*, but in the third interview she said *'I put the weight back on since July'*. Forestcircle said in the second interview he felt *'a lot better in myself, a lot healthier, eating a lot better, cutting all the fatty food out'* however in the last interview he said *'[the] problem is the weight loss, and I haven't been able to do that'*.

Changes in blood glucose control

Some participants made changes to their blood glucose control during the project.

One aspect of improving blood glucose control was increasing meter usage, which several participants mentioned. For example Boatapple, who did not use any other aspect of the system during the project, said *'I am using my meter more, so that's you know, I'm having a go'*. Similarly Eastwind, a 65 year-old woman with Type 2 diabetes, did not use any other part of the system but said *'I'm doing it once a day now, I never used to do it once a day'*.

Some participants said they had improved their blood glucose control for periods during the project. For example Gardenpen explained *'my morning ones have dropped a lot more ... they are*

down rather than, like they were always in double figures, but now the majority of them, are in single figures. Brightwater explained that since using the system he was looking at his readings 'for the whole week' instead of going 'from needle to needle' as he was before, he said:

[I] noticed the difference that it makes if I do manage to have even a slice or two of toast or something, and by using, over the last week or whatever, it does make a difference. It makes controlling it a bit further down the line, the teatime one easier to control.

However, there was not a general improvement in participants' HbA_{1c} readings over the course of the project either for the whole cohort, or for those who used the system more regularly. HbA_{1c} results are provided in Appendix #9.

Changes in approach to diabetes

Many participants reported success in changing their approach to diabetes. Almost all reported improvements in their awareness and about two-thirds improvements in attitude.

Many participants said at the end of the project that they had experienced increased awareness of diabetes. For instance Gardenpen said that using the system 'makes me more aware of my control' and Palmstone said 'it's made me more aware of my condition and how it changes'. Even some participants who had described themselves as generally avoiding or ignoring their diabetes reported experiencing a change in attitude. For instance Hatfork said 'awareness is the main thing ... even though I have not been able to use the system as it should be used' and Applehand that it had 'made you more aware and makes you think about it more instead of just trundling along each day and not sort of taking it into account at all'.

Participants mentioned a variety of other changes in approach. Forestcircle said 'I feel more motivated', Hatfork said he had gained a 'realisation that I am going to have to keep control of this forever', and Greenfish said 'since I have been using these charts, it's in your face like, you come to accept it more'. Berrybank, who did not use any part of the system and who tried to forget about diabetes as much as possible, talked about a change in the last interview

I keep going on the Diabetes website and things, looking up information. I never used to do that, when I first got it [diabetes], I just, didn't use to talk about it to anyone, but I am alright with it now.

Some participants said their approach had not changed during the course of the project. Catlily said *'I always had an attitude that I needed to control it'* and Lilyrose said *'it's stayed the same'*.

Changes in knowledge and understanding of diabetes

Participants had varied success in improving their knowledge of diabetes. Several participants talked about improving knowledge of their own diabetes through looking at their own readings, for example Waterlight said *'I can see the patterns'* and Greenmouse said that she had learnt *'that it's spiking'*. Participants reported learning more about diabetes through reading articles. For example Brightwater said he had learnt *'little things... even after like 20 years I thought, oh that's interesting'*, and Palmstone said he had learnt from *'reading the websites'*. Hatfork explained how what he had learned had changed his view:

I have learnt things, it's hard to say that it's specific, and it's those little bits and pieces, I think it's more coming to awareness of how it affects you, just the way you live your life. It's just an awareness of how much I am going to have to keep down to certain levels, every time I see the thing where it says the possibilities, not possibilities the repercussions of not controlling it, loss of limbs, heart, stroke, and you go through the list and it's like, oh, the fact that it's going to be a long term, keeping to set plans, keeping control and keeping an eye on it, keeping it monitored.

No changes

Participants had varied success in improving their knowledge of diabetes. Several participants reported no changes during the study.

5.3.10 Category One Summary

The *Diabetes Self Management Experience* is a category that covers the experiences of participants as they self-manage their diabetes. This includes three broad sections: contextualising factors, self-management factors and management outcomes. First, participants talked about factors that affected the context of their diabetes management – these were their health context, diabetes knowledge and approach to diabetes as well as their aims and intentions and the barriers they experienced when trying to manage their diabetes. Second, participants talked about factors related to their diabetes self-management. This included their symptoms and experiences of diabetes, the approach they took to self-management, and the aids and tools

that they used. The self-management experiences participants described are deeply embedded into their daily lives. Finally, they talked about the outcomes that had resulted from the changes they had made.

5.4 Category Two: Diabetes Support Experience

This category covers participants' outward facing experiences of seeking and receiving support for their diabetes. These experiences are about receiving support from the external world in relation to diabetes. This includes receiving medical care by visiting the GP, the diabetes clinic and other healthcare practitioners (such as chiropractors, dieticians etc.), receiving support from others such as friends or family and learning more about diabetes by reading or talking to others. Participants' experiences in this category were influenced by contextual elements identified in the first category. As with participants' self-management experiences there was evidence of a cycle through which participants' support-seeking approach affected their support experiences and the support aids they used which in turn affected their diabetes outcomes. However, as supported activities were more sporadic than daily self-management activities the cycle was not as tightly drawn as it was for self-management. The three sub-categories in this category are shown in Table #9 below:

<p>DIABETES SUPPORT EXPERIENCE</p> <p>5.4.1 Support-seeking Approach</p> <p>5.4.2 Support Experiences</p> <p>5.4.3 Support Aids and Tools</p>

Table 9: Category Two Overview

5.4.1 Support-seeking Approach

<p>DIABETES SUPPORT EXPERIENCE</p> <p>Support-seeking Approach</p> <p>Support Experiences</p> <p>Support Aids and Tools</p>

This sub-category is about the approach to support-seeking reported by participants. There were two elements to support-seeking, reading information about diabetes and communicating with others. Almost all participants talked about seeking support sometimes, but needs varied. When seeking written information about diabetes the two major themes that emerged were being able to find trusted sources and being put off by reading frightening information. When seeking to communicate with others the two major themes that emerged

were first, wanting personal exchange with others, and second, learning from the experiences of others.

Some participants said they actively sought information about diabetes, for instance Meadowsong, a 52 year man with Type 2 diabetes, said *'I cut out newspaper articles, things like that'* and Berrybank a 21 year old man with Type 1 diabetes, said he regularly used Google to *'trawl through everything'* he could find about diabetes. In contrast, several participants only looked for information at certain times, like Waterlight, who sought information *'when I was originally diagnosed'*. Others said they did not seek information, like Palmstone, a 42 year old man with Type 2 diabetes, who said *'I don't actively look'* and Fieldshine, a 35 year old man with Type 2 diabetes, who said *'I don't feel it is necessary'*. Some participants reported difficulties with finding the information they wanted when they looked, such as Frogbook who could not find much about diet-controlled diabetes, saying:

Insulin based you have got loads of information, right, Type 1, Type 2 doesn't make any difference but you have got an option right, there is different things. There is my type of diabetes which is diet controlled, zilch. There really isn't that information there, except to say you know, well yes, you can control it by doing this and doing that, and not doing that. I needed that bit more info to do, instead of just saying don't eat these, you know, make a balanced diet.

Participants talked about the importance of having trusted information sources, particularly when they were using the Internet. Of the 26 participants who said that they used the Internet to look for information about diabetes, 12 stated that they generally trusted information they found on the Internet but 14 stated that they were wary of some or all of the sites they found. In response to these concerns many participants explained that they only used known web sites when they were looking for information online. Diabetes UK and NHS Direct were the two most frequently mentioned. Eight participants said they found it hard to trust American web sites and they avoided them. For instance Gardenpen, a 59 year old man with Type 2 diabetes, said *'they have different ideas in America'* and Hatfork, a 46 year old man with Type 2 diabetes, said soon after diagnosis he had found American sites that suggested *'if you follow certain things you will immediately become cured'* which he eventually realised was *'a bit of wishful thinking'*. However, participants acknowledged that there were more

American sites about diabetes than UK ones. Frogbook suggested that UK sites were *'very limited'*, and considered that this was a problem.

Trust was a wider issue than the country of origin of information. Shoepen, a 33 year old woman with Type 1 diabetes, said she was wary about information she read on websites because she had *'been told differently by the hospital'* so she always checked information with a doctor before following it. Participants also mentioned that many media stories tended to oversimplify issues, not distinguish between Type 1 and Type 2 diabetes and, as Steelsky a 35 year old man with Type 1 diabetes said, be *'a bit doom-laden'*. Greenmouse, a 37 year old woman with insulin-controlled Type 2 diabetes, talked about conflicting information saying of the Balance magazine (published by Diabetes UK):

I wouldn't read it and think that everything I read in there was 100% true, you know, and

I could follow it to the letter. I think a lot of their information is open for discussion.

Participants talked about wanting to find specific bits of information that they thought they could usefully pick up from a health professional outside the consulting room or by sharing tips with others. This was a reason given by some participants for their interest in the discussion board on the eHealth system. However, the need to trust sources of information was raised even for small queries. Greenmouse expressed this when she said:

Well, I think that there are just things that happen to you whilst you have diabetes where you think 'Why does that happen?' But obviously you don't want to make an appointment to go and see the Dr, so you could use the discussion group, but the problem is you don't know who is feeding back to you, as to whether that is a medical person, or just someone who has perhaps experienced something like it.

Another factor that influenced information-seeking was the emotional response that participants often experienced when reading about diabetes. This was particularly the case when learning about the long-term problems associated with diabetes. Hatfork said reading about amputations *'came as a bit of a shock'*. Some participants explained that fear and anxiety made them avoid reading or learning more. For example Sandstar, a 54 year man with Type 2 diabetes, said *'if I don't like what it says I don't read it! I frighten myself'*, and Berrybank, a 21 year-

old man with Type 1 diabetes, said *'I can't bear to read about your eyes going, it kind of kills me'*. Friendsky was very clear about not wanting to read some information saying:

I don't want to know my feet are going to drop off and I am going to have to have that amputated and this amputated. I know that things like that are possibilities but I don't want to be reading into it. I am afraid.

Clearlake, who had Type 2 diabetes and schizophrenia, said he did not read information about diabetes because *'with me having a mental health condition, you know you can start worrying too much.'* No-one directly mentioned not wanting to read any of the information on the eHealth system because of anxiety. However, by talking about how fear dissuaded them from reading certain types of information, participants were signalling that focussing on and learning about diabetes was a problem for them despite their recognition of its value.

Some participants expressed an interest in communicating with others who had diabetes or practitioners as a way of getting support for diabetes. An important factor driving this seemed to be the desire to communicate with someone who 'understands'. Boatapple said he wanted to *'get in touch with other diabetics'* to *'find out how they sorted out some of their problems'*. Frogbook said she would like it *'if there is just a forum where people can discuss'* because she said

I get more from a one-to-one with somebody that understands what you have got and is going through it themselves, than listening to the experts I am afraid.

Treeswan said she would like to *'exchange information with people'*. Papercat said he wanted to *'relate to people who were in the same situation to myself'*. Steelsky, a 35 year-old man with Type 1 diabetes, said *'I don't really have nobody'* to share experiences with, adding *'normal people don't know what you have.'* Palmstone said he noticed *'silly little cuts on my legs or whatever, they take longer to heal'* and wanted to be able to discuss such issues with others.

However, although many participants said they were happy for others to know they had diabetes, some participants explained that they were cautious about revealing their diabetes to others. For instance Berrybank said he often did not tell others, because he did not like talking or thinking about diabetes:

Berrybank: I hate thinking about it because you have people questioning you all the time and people asking whether you are ok, I just prefer no one to know. It's easier for me, except my friends and that, that's the only people I really tell.

Interviewer: Right, so you tell your friends?

Berrybank: Yes my friends know like but other people, no I don't tell anyone in work.

Meadowsong also said he did not tell people at work explaining that '*without telling any fibs, I kind of keep it private*'

5.4.2 Support Experiences

DIABETES SUPPORT EXPERIENCE
Support-seeking Approach
Support Experiences
Support Aids and Tools

This sub-category describes participants' support experiences – both medical and personal. Family and friends and healthcare practitioners were the two main groups providing support. On the whole participants were positive about receiving support for their diabetes, both from healthcare practitioners and from family members. However, some negative experiences were reported, such as being nagged, not getting enough support, and feeling alone.

Many participants said that family support was important to them, and that it was positive. Participants generally mentioned close family (spouses, children, parents, siblings), particularly those with whom the participant lived and shared meals. Much of the useful support was about eating healthily and remembering medication. Greenfish said '*my wife, she keeps me on the straight and narrow*'. Friendsky, whose wife was a nurse, said '*my wife has got a good knowledge of diabetes and so she keeps an eye on it*', and in addition he said '*I will have my daughter saying have you took your tablets today, so everyone is involved*'. Orangenote, a 45 year-old man with Type 2 diabetes, who was trying to lose weight said in the second interview:

Orangenote: I have managed to lose 7 kilos before Christmas, which was, I am probably down to about 4.5 now with Christmas puds, but I used the children, I use the children to weigh me which is a really good motivator for me.

Researcher: Your children?

Orangenote: My children weigh me and so I have to answer to them. So they are putting a little bit of pressure on me.

Berrybank, who had Type 1 diabetes acknowledged the importance of family and friends to help him remember his insulin saying

Berrybank: I can't do it on my own it's a struggle. I wouldn't take insulin on my own unless someone told me to.

Interviewer: Does your mother encourage you?

Berrybank: Yes, and work mates and stuff.

In contrast, some participants said they had little or no family support. When asked about family support Smilecup said *'I don't think they really understand, although my brother lives with me and he is diabetic'*. Rosecandle said *'my wife is just not interested you know'*, and Boatapple said *'I'm sure they think I am pretending'*. Owlrose said *'I live on my own'*, but added later that she did not involve her boyfriend in discussions about her health because *'he is a total hypochondriac himself and he would drive me berserk'*.

The importance of support from health practitioners was acknowledged by participants. For instance Hatfork said practitioner support was important *'to make sure I don't go extremely wrong'* and Grasslake said *'I obviously need input from a professional like Dr ****... without medicines I wouldn't be around now'*. Smilecup said:

I need a shoulder to lean on, I need a crutch and the practice here are really good ... I couldn't do it on my own, I would lose track on my own.

When asked about their relationship with the GP or specialist, about half of participants said the relationship was collaborative, and half said the relationship was either led by the professional or formal. Owlrose described her consultations with the specialist:

There isn't really much of a discussion there. He will look at my file, look at my bloods, erm, look at my weight, the nurses will already have done my blood pressure and stuff and that is all he does. He just sees if I am still on the right road or tells me off if my bloods are too high, that's about it.

Apart from one participant who stated that he led the discussion, all the other participants stated that consultations at the hospital were formal or were led by the consultant. Most of the conversational consultations with doctors seemed to occur at the GP surgery rather than the hospital. Breezelane said he had '*really good conversations*' with his GP and '*he makes sure that you understand*'. Participants also talked about being aware that doctors were busy, and that they did not want to waste their time. Greenfish, who had Type 2 diabetes, said there were some things he would not ask the GP saying:

You don't want to come to the surgery with little problems... like I have been having a problem over the last week where, I can't understand why my sugar levels have gone up over the last week, and it would have been nice just to be able to say, any suggestions for this you know. Because sometimes when you come in over little thing like that into the surgery, you think you are taking up other people's precious time.

A few participants expressed an ambivalent relationship with their doctors. Orangenote talked about '*dodging the doctor*', feeling because he was overweight he received '*a lower degree of empathy from my doctor than perhaps you need at that particular time*'. Applehand also said of the doctor '*I try to dodge him to be honest with you because he shouts*' and later she said '*he knows me too well, he reads me like a book*'.

Some participants talked about being 'nagged' or 'told off' about how they were managing their diabetes, generally by family members. It became clear through discussions that there was often a fine line for participants between being supported and feeling intruded upon. Sometimes nagging was a prompt for participants to take action. Orangenote acknowledged '*I get a lot of telling off by the kids if they see me doing things I shouldn't be doing*'. Hatfork said '*I have got family members who will nag ferociously because I do have a habit of ignoring things*', and accepted that '*I leave things so it's when Drs insist and when family insist it tends to chase out issues*'.

However, participants also described feeling very negative about being nagged. Shopbeach used language that indicated how hard it was for him to be nagged saying *'my mum, she grabs me and pulls me apart'*. Fairstream said about her family *'oh they watch me like a hawk'* going on to say *'my mum is terrible; she looks in the cupboard, should you be drinking that?'* Applehand said her family *'have a go at me'* and added *'it can be counterproductive'*.

In contrast, many participants talked about feeling alone with diabetes. About a third of participants mentioned feeling alone with diabetes in some way. Some participants directly said that they felt isolated. Shopbeach said he felt *'on my own, isolated'*. Poppymist said she felt *'out on a limb'*, and Eastwind said she felt *'a bit isolated'*. Hatfork particularly mentioned the lack of others to talk to saying *'you don't speak to anyone with diabetes'* adding *'I don't really know anyone with diabetes except me'*.

Some participants also talked about feeling isolated from practitioners. Brightwater said that only going to the clinic twice a year meant feeling *'like you were on your own'* the rest of the time. Eastwind said *'all you are doing is coming back for your repeat prescription ... so you are sort of on your own'*. Hatfork said his experience was that *'surgeries have been such a remote thing'*, and talked about the *'difficulty of just getting in'* to see a doctor when he wanted to ask a question. Several participants talked about the problem of making appointments with the doctor when they worked full time.

5.4.3 Support Aids and Tools

DIABETES SUPPORT EXPERIENCE
Support-seeking Approach
Support Experiences
Support Aids and Tools

This sub-category concerns the support aids and tools that participants reported using. Consultations with health practitioners were the main form of regular, formal support participants received. Other support aids and tools that participants mentioned were diabetes information sources, formal education programmes and informal support groups.

Twenty-seven of the participants were either entirely looked after by the GP surgery or largely looked after by the GP surgery, with just an annual check up at the diabetic clinic in the local hospital. Eight of the participants were jointly looked after by a specialist at the hospital and the GP and three were mainly looked after at the hospital. There was a division between participants with Type 1 and those with Type 2 diabetes. All the participants with Type 1 diabetes, apart from one, were either jointly looked after by a specialist at the hospital

and the GP or were only looked after by a specialist. All the participants with Type 2 diabetes were looked after only by the GP or mainly by the GP with regular visits to the hospital.

Apart from regular consultations, the other main form of support aid that participants used was reading information about diabetes. Sources of information that participants mentioned were the Internet, the GP, the Practice nurse, information leaflets given out at the GP surgery and hospital, books, magazines (most commonly Balance – the magazine published by Diabetes UK), newspapers and sharing information with other diabetics. The Internet was the most frequently mentioned source of diabetes information, mentioned by two-thirds of participants.

Fieldshine talked about the Expert Patient Programme that he had been on saying he *'came away from there a little bit disappointed'* because he *'felt it was aimed at someone different to me'*, adding *'I felt as though they were telling me things that I had learnt in primary school'*. No-one else mentioned going on the programme although Smilecup said she would like to be an expert patient so that she could *'have more knowledge and pass it on'*.

Eastwind talked about an informal support group that had started up at her workplace. As a result of this she said *'I seem to be more open about it'*, adding *'we discuss our scores, what was yours this morning, and things like that'*.

5.4.4 Category Two Summary

The *Diabetes Support Experience* is a category that covers the outward-facing experiences of participants as they seek both professional and non-professional support for their diabetes. Participants talked about their support experiences, their support-seeking approach and support aids and tools. This is the external realm of diabetes health support in which participants reach out and seek support and help from others.

5.5 Category Three: Diabetes eHealth System Experience

The category the *Diabetes eHealth System Experience* is concerned with participants' experiences of using the eHealth system. This category is the focus of the research study. Preliminary findings from this part of the study have been published elsewhere (Gregory and Flynn, 2008). It became clear during the study that participants' use of the eHealth system could not be understood separately from their diabetes management. This was because participants' focus was on how to manage their diabetes and they used the eHealth system as a tool within

that broad aim. As a tool the eHealth system provided support for participants’ self-management and their support experience. Normally these two spheres are separated in participants’ lives – however through the eHealth system both are co-located and supported in a novel way.

The seven sub-categories in this category are shown in Table #10 below:

DIABETES eHEALTH SYSTEM EXPERIENCE	
5.5.1 System Aims	5.5.5 System Use
5.5.2 Experience of Technology	5.5.6 Response to System
5.5.3 Barriers and Facilitators to System Use	5.5.7 Unmet Expectations
5.5.4 System View	

Table 10: Category Three Overview

5.5.1 System Aims

DIABETES eHEALTH SYSTEM EXPERIENCE	
System Aims	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

Participants expressed both general and specific aims for what they wanted to gain from using the system. Participants’

aims for using the system overlapped with their diabetes management aims (discussed in section 5.3.4). Participants’ aims for using the system were generally a short-term version of their long-term diabetes management aims. There were four broad categories of aims – these were to improve 1) healthy lifestyle, 2) diabetic control, 3) awareness/focus on diabetes, and 4) knowledge about diabetes. Participants also mentioned specific aims linked to the system. These were increased communication with others, better motivation, and wanting to be checked. A summary of aims is provided in Table #11 below.

When talking about their aims many participants gave a list of several aims, for example Poppymist wanted:

More information and I like the idea that I can, my GP can look to see what is going on without me taking the time, his time, more than mine, to come and ask questions really. I think it’s a good idea and it will be nice to look at the discussion page to see what other people are doing.

Aims	#
Improve control/metering	14
Learn more	14
Improve awareness/focus	9
Improve lifestyle (i.e. lose weight)	8
Contact/communication	7
Unsure	6
Better motivation	5
Being checked by the doctor	3

Table 11: Participants' aims for using the system

Some participants expressed very general aims, such as Smilecup who wanted to *'tune into reality a bit more, you can't lie to yourself'*, and Eastwind who wanted *'just to keep it under control'*. In contrast, some participants expressed very particular aims. Berrybank said *'I am going to try and do my blood more. That's all I want to do'*, Hollybrook said she wanted *'to keep an eye on my blood readings'* and Rosecandle said he wanted more *'knowledge'*. A few participants were unsure what they wanted to achieve by using the system such as Bluepurse who said *'I don't really know'* and later *'I'm doing it as a favour to him [the doctor]'*.

5.5.2 Experience of Technology

DIABETES eHEALTH SYSTEM EXPERIENCE	
System Aims	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

This sub-category describes participants' access to computing facilities at home, their confidence with using computers

and the technical problems they encountered. Participants' experience with technology in the home emerged as a major factor in the use of the eHealth system. It was found that participants who had less access to their computers and less confidence in technology used the system less. Participants' comments helped to identify issues with technology use at home but did not help to explain why some participants were not prepared to use their home computers more for this study.

Computer access and use

Five participants did not have access to a computer at all throughout the project. Papercat, Fairstream and Smilecup reported that their computers broke down soon after the start of the project. Papercat and Fairstream eventually decided they could not afford to replace them. Smilecup said that she did not want to replace her computer, and decided that she would access the system from work. She asked her manager, but was not allowed to access the system from work. Steelsky gave his computer away soon after starting the project, saying

'my sister is doing like a writers course and I just give it to her and then I never thought nothing of it'. Hollybrook was waiting to be given a computer by a family member throughout the project, but never received it. Papercat and Steelsky dropped out of the study after the second interview but the others completed all three interviews as they had anticipated they would get access to a computer before the end of the study although in the event they did not.

Thirteen participants said they only had one family computer in the home and that they had to negotiate access to it with other members of the household. Often the main computer users were children, who were either using the computer for school work or to play games. Waterlight said *'I have to chase the kids off'*. Forestcircle explained that his daughter was doing 'A' levels and *'she is preparing coursework already, so my biggest problem is actually finding the time to access the system at home'*. But it was not always children with whom participants had to share. Bluepurse said in the last interview *'now I don't get a look in on the computer because my Missus is always on it, she is doing her family tree'*.

Seven participants said the family computer was in a young person's bedroom, and therefore difficult to access. For instance Lilyrose's son had their computer, *'it's in his space, so you have actually got to kind of wait until he is not around or, not on it to go on'*. Meadowsong explained:

We used to have the computer downstairs and so you could just go in anytime you liked, and now as I say my son just started Uni, so he has kind of, it's in his bedroom now.

Participants' interest in and use of their home computers varied widely. Frequency of participants' home computer use is shown in Table #12.

Use of computer/Internet	# participants
Daily	14
Regularly	10
Variably	5
Occasionally	6
Not at all	3

Table 12: Frequency of Computer Use

Some participants were very keen computer users. Frogbook was interested in technology and used her computer *'24/7 really'*. Age was not a strong indicator; Rosecandle for example, who was 79, said he used his computer *'every day'*. However, his primary motivation was to

access reading material from the Open University, not an intrinsic interest in technology. Berrybank, a 21 year-old man, said he used his computer ‘*every day*’ for a range of purposes such as ‘*looking for holidays, playing games, talking to people*’. Shopbeach explained how his computer use was integrated into his life saying:

*I tend to jump on the internet anyway because we have broadband it’s just something to do,
I bought a laptop, put it on your lap and you can watch TV or whatever.*

In contrast, a number of participants said they used computers a lot at work and did not want to use them at home. Palmstone for instance explained that ‘*I use the computer in work and it just drives me wild, so I use it for work and then I come home and then switch off basically*’. Smilecup expressed a similar sentiment saying at work:

Everything is having to go on to computer so by the time I come away from that at work, I really don’t even want to speak to anybody let alone look at a computer again.

Forestcircle explained ‘*I work with the Internet and Intranet all day long*’ and ‘*when I get home I try to put it to one side*’.

Some participants said they rarely used their computers at home, even though they had access to them. Breezelane said ‘*you know they are a fantastic invention but if I don’t have to use them, I don’t want to*’. When asked how often he used his computer at home, Waterlight replied ‘*not a great deal*’. Applehand said in the second interview, ‘*I go upstairs maybe once a month to use the computer*’, but in the final interview she adjusted her estimation saying, ‘*I have used it about twice in two or three years*’.

Computer confidence

Table #13 below shows participants’ self-assessment of their confidence with technology.

Confidence with Information Technology	# participants
Expert	7
Very confident	14
Can cope	6
Unconfident	8
Very unconfident	3

Table 13: Confidence with Information Technology

The majority of participants said they felt either fairly or very confident using technology, however a significant minority were lacking in confidence.

Catilly was very confident with technology and used it extensively. She said *'I much prefer people e-mailing me I don't like using the phone at all. I'd much sooner go online'*. Frogbook was also a technophile; she built computers at home and used her computer on a daily basis.

Many participants described themselves as confident. Hatfork said *'I've passed my ECDL'* and added *'there is not much I can't do if needed'*. Treeswan also mentioned she had done *'a CLAIT course ... and ECDL'*. Gardenpen was measured, saying *'I'm not too bad, not brilliant'*.

Others felt they could cope, but often mentioned they had ways of getting help if necessary. Greenfish said about his confidence with technology *'I will have a go. If I can't I will call my mate who is an expert.'* Rosecandle described his confidence as *'very, very low'*, but he had a weekly helper who helped him with any technology problems.

Some participants had very little confidence such as Papercat who said *'I am not computer literate'*. Grasslake described himself as a *'luddite'* as did Smilecup, although they both used computers at work. Boatapple described his confidence as *'terrible'*.

Computer problems

Twenty participants reported problems with their home computers or Internet connections during the project. Problems ranged in their severity from home Internet connections not working temporarily to the whole machine crashing and needing to be replaced. In between these two extremes participants reported a variety of problems for example virus problems, set up problems, not having legal copies of software, and routers not working. Many participants who experienced problems with their computer at home were not confident or knowledgeable enough to mend their computers themselves. Consequently they had to wait for a friend or member of the family to help, take the machine to a shop, or save up to buy a new machine. This meant that home computers were often out of action for weeks or months while they were waiting to be mended. Details of technical problems experienced and support given are listed in Appendix #6.

A number of participants had major computer problems during the study. For instance Chairtree reported at the second interview that his *'computer packed in'* and he had to *'wait until*

I got the money to pay for a new mother board and all that sort of stuff. Frogbook said in the second interview *'my machine went bang in a very loud way'*. She went on to explain in more detail

I did fix it and got it going but it wouldn't recognise half of the attachments that was with it, and one of them was the meter, just wouldn't recognise it at all. Nearly drove me mad. So, I toyed with the idea of oh do I build a new one, and I thought blow it I will go and get a laptop its easier, so I have not long got that, and am still putting stuff on.

She continued to report technical problems throughout the project. Eastwind reported in the second interview that her computer was not working. In the final interview she said she had waited for her son-in-law to help them and *'we only got it back the other day'*, so they effectively had no working computer for the whole period.

Some disruptions were severe but short-lived. Owlrose reported *'I have had mega problems with my computer, even getting emails ... but I am back up and running again now'*. Sandstar said

My computer went down and my son had to wipe the hard drive for me and its only as I realised I need different programmes that I am putting them back on.

Palmstone reported in the last interview *'I had problems with my computer, the hard disk crashed. I had to put it all back'*.

A range of low level computer disruptions were also reported. For example Hatfork had problems accessing the Internet saying *'it takes forever and a day ... just to get onto the Internet'*. He said this was because a friend had loaded his machine with an unauthorised copy of Microsoft's operating system. Grasslake reported his problems saying:

I bought a laptop, specifically to use, well not specifically but mainly to use on this, and I thought well I will start to get my head around this technology thing and I got it set up and I had somebody install the router for me and within 2 days I had got a virus on it, and so it was out of action for quite a while. Then the router for some reason packed up as well, well it's up and running again now, but I am scared to death of using it to be honest apart from things like bringing up photos and that sort of thing.

Lilyrose was also uncertain about using her computer ‘*I am a bit kind of cautious about loading that disk ... because I know we have had problems with the computer*’. Clearlake reported in the final interview that he had ‘*been off the Internet for quite some time*’.

To conclude, an interesting insight into domestic computer use emerged from the study. Although there were some keen computer users among participants, access to technology was often partial and patchy and having an up-to-date, working computer was not a priority in many homes. A few participants were frequent and keen computer users, and some even suggested that the technology had been a motivator for them to get involved in the study. However in contrast, several people said they used their computers a lot at work and therefore did not want to spend much time on them at home. Some participants did not use their computers at all during the course of the study either because their computers did not work or because they had low confidence in their ability to use them.

5.5.3 Barriers and Facilitators to System Use

DIABETES eHEALTH SYSTEM EXPERIENCE	
System Aims	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

This sub-category covers barriers and facilitators to system use. These were personal, motivational and technical.

Participants talked more about barriers than facilitators. This was probably because participants who had used the system talked about *how* they had used it rather than what had influenced them to use it.

Participants cited various personal reasons for not using the system as much as they had hoped. Illness was one reason given. Poppymist said in the second interview

It's just that there has been so much going on, and I have not been well and busy in work and I think I told you my mother died in the middle of refurbishing the house, so I didn't get that on the market, and I just felt there was so much going on and I just couldn't be bothered with anything else.

Palmstone also said he had been unwell and just wanted to ‘*get through the week*’. Clearlake, who had mental health problems said he did not use it because ‘*I was going through personal problems and I wasn't able to use it*’. Boatapple had cataracts and said in the last interview ‘*I just*

can't read it, and then ... as I am taking my eyes off it to look at the keyboard its taking 5 minutes to adjust like'.

Some participants said that they had not engaged enough with using the system. Hatfork said *I have been a bit lazy about it, to be honest'*. Sandstar, who had Type 2 diabetes and did not use a meter used the system, but indicated he did not feel very engaged:

It's like it doesn't involve me. It's like you know, like I said it is really strange that if I felt unwell I could relate and I could think ok, yes, and I look at other people, what are they doing, should I be doing the same.

In the final interview Poppymist admitted that she had not really engaged with it saying:

I am glad it's there as a back-up. And, but I am conscious that I should have been using it more. I think it's down to this thing in my mind that's trying to tell me I am not ill and I don't need it.

For some participants time, working patterns, or computer access (discussed in section 5.5.2) were barriers. Brightwater said:

I probably could use it a lot more, or having said that because of the way I work, there is 4 nights that ... I work nights ... that I basically get up out of bed, go to work and come home and go to bed again, so it's the other 3 nights or 3 days of the week, and then I am fighting with my youngest son to get on the computer.

Some participants talked about their reluctance to use technology at home and additionally some participants explained they were not very confident or expert computer users (these issues were discussed in the previous section 5.5.2 *Experience of Technology*). Both these factors acted as barriers to using the system. For example Grasslake said he considered himself to be *'idle or phobic'* about using the computer, and said that was one of the reasons he had not used the system as much as he had intended. Boatapple, who did not use the system at all, lacked confidence with using technology. He said in the first interview *'I do get really frustrated when it*

don't do what I want it to do like', and in the middle interview he explained how he was waiting for a friend to help him use the system (he also had poor eyesight).

Participants talked about a range of technical factors that acted as barriers to system use. Those participants who did not have access to a computer during the project could not use the system at all. Those who experienced computer problems during the project also had limited access to the system (these issues were discussed in the previous section 5.5.2 *Experience of Technology*). In addition, some participants experienced problems with using the system (these issues are discussed in the next section 5.5.4 *System Use*).

Participants also explained that after experiencing problems they were more reluctant to spend time on the system. Hatfork had persistent problems with slow Internet access, and when asked what put him off said *'just the computer to be honest, I have not spent a great deal of time on it at all'*. Breezelane said *'I haven't really explored it properly'*, explaining further that *'at first I was thinking oh I can't get on this so, it's like I backed off a little bit'*. Owlrose also experienced a series of technical problems and summarised her experiences:

No, well putting the readings on I just didn't manage, and I did try, I connected it all up but I just couldn't grasp that and I think I loaded everything on, then I lost my computer, everything went down and then loading it all on again I just couldn't do it, and then couldn't find anything that I wanted to find, but it was probably because I hadn't loaded it again properly. So it was a bit frustrating really. But I was lazy as well, it wasn't just the system it was me.

Participants did not mention many facilitators to system use, however the use of technology and the encouragement of others were mentioned. For some participants the technology was a facilitator. Frogbook stated that her motivation to join the study was *'the technology involved in it'*, saying *'if it's like computer related I don't get bored'* and *'this is the incentive that I need'*. Catlily also mentioned technology as a facilitator particularly for using the Alive system saying

I do everything by e-mail, so it's like twice a day I will check my e-mails so I am always right on top of that and it, it sort of fits in with work as well, so that was just yes, so easy.

Several participants talked about members of the family encouraging them to use the system. Friendsky for example said of the system set up *'it went on ok; I got my daughter to do it for me'*. Applehand said her son encouraged her to use the system saying *'my son is quite pleased in the sense that I am starting to take it serious ... last night he was like mom I will do it for you'*. Greenfish said his wife *'likes to know what the readings are and all that'* and that she had looked at the system with him. Brightwater also said his wife *'has been over my shoulder'*, and was interested in the Alive emails saying *'she wants to take part in that with me'*. Berrybank did not use the system but said, *'my mum is always encouraging me to set it up and that.'*

5.5.4 System View

DIABETES eHEALTH SYSTEM EXPERIENCE	
System Aims	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

Participants expressed a range of views of the system as a whole. Some viewed it as a tool for helping them manage specific problems, others saw it as providing general background support, others a help with focus and motivation, others saw it as a self-management and information tool, and one saw it as a tool for the doctor.

Some participants viewed it as a tool to help a particular time of trouble. For example Roundocean thought *'the benefits of the system are really for people who have problems with their diabetes'*, adding that he had thought he was *'going onto Type 1'* in which case it would have been useful but *'there is nothing there for me, because I am in control, I don't have a problem'*, however he still viewed it as *'a tool that is in my health cabinet'*. Sandstar had a similar view saying, *'in a strange way it doesn't involve me'*, but added that it would be useful if he was having problems, *'if I felt unwell I could relate [to it]'*. Friendsky said *'if you needed some help and support, then you could come onto the system and probably get it you know'*.

Several participants saw it as a general support tool. Poppymist said *'I'm so glad it's there as a backup, but I don't use it as a bible'*, and Brightwater said *'knowing it's there is quite handy ... you know where you can go to find something'*. Orangenote said *'this is probably the least invasive support process I have seen'* and added *'I dallied on it for a long, long time and ... once I read it more I felt that it wasn't a medical intervention'*, indicating that he had been looking for non-invasive support rather than medical help. Grasslake said he *'would look on it as on-going support'*.

Some participants saw it as a motivator, and a help with focus and remembering. For instance Brightwater said it helped him to *'focus on my diabetes'*. Fairstream said it *'helps to focus*

you’ and Forestcircle said he felt *‘more motivated’*. Meadowsong said it was *‘about focussing on yourself’* and commented about Alive *‘the reminders have been good’*. Frogbook had been ignoring her diabetes but found that it was a reminder saying *‘it’s here and it’s in my mind’*.

Some participants saw it largely as an information tool. Shopbeach said it was a way to *‘get a bit more information’*, most particularly about his blood glucose readings. Treeswan said the most useful part was *‘putting your information on’*. Catlily said it was useful to find information *‘without having to trawl round the Internet and round the diabetes sites’*, and Hatfork emphasised it was a place for trusted information saying it was *‘useful to know what the correct information is’*.

Bluepurse saw it as a tool to help the doctor. He said in the last interview

I hope it’s given the Dr a lot more insight into what is going on, so he can manage my treatment better, than he would have done before. You know it’s alright coming in saying I feel terrible Doc, this has happened, that has happening, he can go to that screen and see if it is anything to do with diabetes, and rule that out.

Bluepurse had also said in the first interview that his motivation for taking part in the study was to *‘help the doctor’*.

5.5.5 System Use

DIABETES eHEALTH SYSTEM EXPERIENCE	
System Aims	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

This sub-category details how the system was used by participants. First, a categorisation of participants’ frequency

of system use is provided, followed by a detailed view of how each part of the system was used, and a discussion of participants’ experiences of using each system element. Finally, there is a discussion of problems with system use.

Frequency of system use

Participants varied in the frequency with which they used the system. In Table #14 below a summary is given of patterns of system use at three and six months. This is a categorisation based on how frequently participants used the system. The four parts of the system of interest for this categorisation were 1) upload to Compass, 2) upload to website, 3) use of website (news, discussion, diary, targets) and 4) use of the Alive email system. Data about use

of the different parts of the system was collected in the following ways: meter and Compass software use were self-reported during interviews; web site and Alive system use were self-reported and were also quantified by electronic login records. Participants' use characteristics were ascertained by considering how frequently they used any part of the system. Consequently some participants were categorised as frequent users even though they only used certain elements of the system. Meter use was not considered a factor in this categorisation as it was already a part of most participants' self-care routine before the study commenced. Five categories of use characteristics were identified 'Frequent', 'Regular', 'Occasional', 'Minimal' and 'Non-users'.

Frequency of use	# at 3 months	# at 6 months
Frequent users	3	3
Regular users	9	11
Occasional users	8	7
Minimal users	6	5
Non-users	12	6

Table 14: Frequency of System Use

'Frequent' users were those who used parts of the system more than once a week. In practice the 'frequent' users were those who logged on at least twice a week, although such users did not necessarily use all parts of the system. 'Regular' users were identified as those who used parts of the system on a regular (usually weekly, but sometimes fortnightly) basis. Some of the 'regular' users did not use the website very much but used the Alive system regularly (which involved responding to a weekly email). 'Occasional' users were those who used parts of the system occasionally, usually sporadically, and who had not got into a routine with use. Some of the 'occasional' users logged on to the web site very infrequently but used the meter and Compass software more than the 'minimal' users. 'Minimal' users were classed as such because they had made very little use of any parts of the system. For some of these users this involved some use of the Compass software, for some it involved regular metering when they had not previously been metering. 'Non-users' were those who did not use the system at all, apart from maybe very sporadic use of the meter. These users had not attempted to log on to the website or used the Alive email system, and they had not loaded the Compass software.

Frequent and regular users were those who had settled into a habitual pattern of use. Greenmouse for instance described her routine:

Sunday evening I will go up and do it, and then when I am in work, if I have got some free time and I think, oh I wonder if anybody has replied to whatever, I can go in and have a look.

Shopbeach said *'I usually download every Wednesday and every Sunday'*. Almost all the frequent and regular users were also the set of users who uploaded their blood glucose readings onto the website, apart from three who were regular users because they used the Alive emails regularly. However, apart from these observations it was difficult to find any patterns that indicated why certain participants became frequent or regular users.

In contrast, other participants used the system in more patchy ways. Sandstar explained in the second interview *'I would say in the first month I used it ok, and then I must have just forgotten about it and then my computer died'*. Meadowsong explained about his use of the web site, *'initially I tried to use it every you know once a week at least and since then kind of I haven't really gone into it much'*.

However, he used the Alive emails more regularly saying, *'I have tried to respond to that every week'*. Other participants took a while to get going, such as Waterlight who only uploaded readings to his PC and used the Alive emails during the first three months, but then started uploading to and using the website during the second three months.

Participants who uploaded to their PCs and the website often waited until they had a batch of readings before uploading. Waterlight said in the second interview *'I have only done it twice, I have left it for like 2 or 3 weeks, 4 weeks, then I would upload'*. Roundocean said *'what I do is collect some data and then going on it I would say every 2 to 3 weeks at the moment'*.

Non-use was an interesting phenomenon that emerged in the project. It was unexpected as all the participants had volunteered to take part and had originally expressed an interest in using the system. I did not get requests for help from non-users in between interviews. Of the 12 who were non-users in the first three months, eight stated that they did not use the system because their computers broke down or their internet connections stopped working or they did not have a computer in the house. In one case a participant gave his computer away, and in another a promised computer did not materialise. Two of the other non-users reported being very reluctant to use their computers at home and found that the person they normally relied on for help was not available. The other two participants appear to have not

used the system largely because they were not engaged with their diabetes. For example Berrybank said ‘*I haven’t been using nothing, just put my insulin in that’s the only thing I do. I am not checking nothing*’. By the end of the study six participants who had attended all three interviews were non-users. Three of these did not have working computers, one was reluctant to use his computer at home and two were not engaged with their diabetes. Fieldshine, for example, was newly diagnosed with Type 2 diabetes when he started the study. He had a working computer but chose not to use the system, saying ‘*to be honest I didn’t. I had a look at it, a quick look at it but I haven’t been on. To be honest I haven’t got that many questions.*’

Looking at the web site log in statistics for each user, two different use patterns emerge. Some users looked at the system fairly early on and then either slowed down or even stopped after a series of log-ins. Other users took several weeks or even months to get going. Of the ‘frequent’ users, one started logging in regularly from week one, the other two took more time (four and eight weeks) before they logged on to the web site at all. Only the ‘frequent’ users logged on to the website regularly, the other types of users appear to have used the system in a more sporadic fashion. Those who used the email system reported that they looked at the emails regularly, although with that system the initiative for use did not lie with the user, but with the system.

Elements of system used

Table #15 below shows how many participants used each element of the system. The blood glucose meter was used by most participants. The discussion board, news and information pages, all of which were available through the website, were the most widely used elements of the system, followed by the uploading and viewing of blood glucose readings. The Alive email system and the diary and targets pages on the website were minimally used.

Elements of System Used	No. of participants
Blood glucose meter	31
Logged onto website	26
Read/posted to website discussion board	22
Read news/information on website	22
Uploaded blood glucose readings to computer	18
Uploaded blood glucose readings to website	15
Received a website message from the practice	14
Used Alive email system	10
Sent a website message to the practice	8
Used diary/targets on website	7

Table 15: Elements of the system used

Most participants used selected parts of the system rather than all of it. When asked, most participants talked about particular aspects of the site that had caught their interest. For instance, although Gardenpen looked at many areas of the system, he explained his focus of interest was looking at his blood glucose readings and using the discussion board, saying *'basically I use the uploads, the meters, the pies, the, you know, the graphs, and the discussion board'*. In contrast, Poppymist mainly used the *'American programme [Alive emails]'*, and used the website *'not very often at all'*. Lilyrose only used *'the website and the discussion board'*, and also started the Alive programme towards the end of the project period. Rosecandle only uploaded his meter readings and used the message service with the GP, but was not interested in the rest of the site saying only *'I've had a quick look through it'*.

A few participants used the most elements of the site. These tended to be the more regular users. Greenmouse, a frequent user, was the only participant to try all elements of the system. She commented that she had:

Downloaded the graph information, so uploaded my stats, had a look at the graphs, went into the news section, went into the message service, I had a couple of feedbacks from the surgery, from the message service which were quite, well quite good to see that my readings were ok, and asked some questions and answers some of my questions as well, so that was quite good side of it. I did the discussion group, went in that a few times.

In contrast, Rosecandle, who was 77 and a frequent user, only uploaded his blood glucose readings and looked for messages from the surgery. He saw his needs as limited, explaining:

Not at my age no. For young people I would say yes ... or people in their 30s or 40s, I mean people can do an awful lot to help themselves. See I am limited to what I can do.

Table #16 below shows individual use of each of the system elements.

Participant	Meter	Web site	Discussion	News/info	Upload to PC	Upload to web	Alive	Messages	Diary/targets	System Use
Frogbook	Y	Y	Y	Y	Y	Y	-	-	-	Minimal
Greenfish	Y	-	-	-	Y	-	-	-	-	Occasional
Bluepurse	Y	Y	Y	Y	Y	Y	-	-	-	Regular
Rosecandle	Y	Y	-	-	Y	Y	-	Y	-	Frequent
Papercat	Y	-	-	-	-	-	-	-	-	Non
Hatfork	Y	Y	Y	Y	Y	-	-	-	-	Occasional
Treeswan	Y	Y	Y	Y	Y	Y	-	-	-	Regular
Boatapple	Y	-	-	-	-	-	-	-	-	Non
Catlily	Y	Y	Y	Y	Y	Y	Y	-	Y	Regular
Smilecup	-	-	-	-	-	-	-	-	-	Non
Shoepen	Y	Y	Y	Y	Y	Y	-	Y	Y	Frequent
Chairtree	-	-	-	-	-	-	-	-	-	Non
Gardenpen	Y	Y	Y	Y	Y	Y	-	Y	-	Regular
Grasslake	Y	Y	Y	-	-	-	-	-	Y	Occasional
Owrose	Y	Y	Y	Y	-	-	-	-	-	Minimal
Greenmouse	Y	Y	Y	Y	Y	Y	Y	Y	Y	Frequent
Shopbeach	Y	Y	Y	Y	Y	Y	-	Y	Y	Frequent
Poppymist	Y	Y	-	Y	-	-	Y	-	-	Regular
Steelsky	-	-	-	-	-	-	-	-	-	Non
Breezelane	Y	Y	Y	Y	-	-	Y	Y	-	Regular
Forestcircle	Y	Y	Y	-	Y	Y	Y	-	-	Regular
Sandstar	-	Y	Y	Y	-	-	-	-	Y	Occasional
Brightwater	Y	Y	Y	Y	Y	Y	Y	-	-	Regular
Berrybank	-	-	-	-	-	-	-	-	-	Non
Clearlake	Y	Y	-	Y	-	-	-	-	-	Minimal
Roundocean	Y	Y	Y	-	Y	Y	-	Y	-	Occasional
Hollybrook	Y	-	-	-	-	-	-	-	-	Non
Eastwind	Y	-	-	-	-	-	-	-	-	Non
Fairstream	Y	Y	-	Y	-	-	-	-	-	Minimal
Palmstone	Y	Y	Y	Y	Y	Y	-	-	Y	Occasional
Lilyrose	Y	Y	Y	Y	-	-	Y	-	-	Occasional
Lionmoor	Y	Y	Y	Y	-	-	-	-	-	Minimal
Friendsky	Y	Y	Y	Y	Y	Y	-	-	-	Regular
Fieldshine	Y	-	-	-	-	-	-	-	-	Non
Meadowsong	-	Y	Y	Y	-	-	Y	Y	-	Regular
Waterlight	Y	Y	Y	Y	Y	Y	Y	-	-	Regular
Orangenote	-	-	-	-	-	-	Y	-	-	Minimal
Applehand	Y	-	-	-	Y	-	-	-	-	Minimal

Table 16: Participants' use of system elements

The meter

Thirty-one participants chose to use the Aviva meter provided by Roche for the project, only seven participants did not. Of these, two participants never used a meter, three preferred to

use their own meters, one already had an AccuChek meter so did not change to the new one, and one did not use a meter at all during the study although he was meant to.

On the whole participants liked the new meter. Brightwater, responded positively, saying:

Brightwater: I have found the new meter really good, so much better than my last one.

Researcher: That's good.

Brightwater: One it takes a fraction of the blood, the other one I would end up squeezing and squeezing, my old Advantage one, it's a lot quicker as well than my old Advantage one, and also and probably my old Advantage one had the facility for it, but I didn't, I have been able to use to recall like previous ones, and I didn't realise, or I found out with this one, I don't think my old one did, it can actually give you an average over like the last 7 days or whatever, and month, which has really been quite good as well.

Several other participants mentioned that the scroll back feature was beneficial. Some did not like the meter. Smilecup said *'I thought it was out of date, it was cumbersome, it wasn't a good meter at all'* and Shopbeach said *'it's pretty hopeless, the meter, to be honest'*. Some participants continued to use their old meters as well as the new meter such as Breezelane who said *'I am reading the one that they originally gave me more than your one'*. He intended to use the new meter for uploading, and therefore to use two meters concurrently.

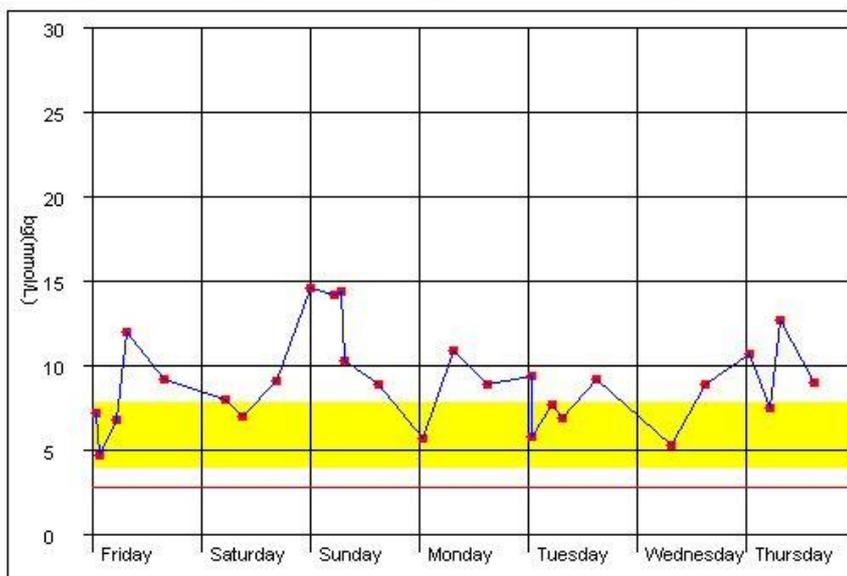
Participants had different routines with meter use. Some participants used their meters regularly, but others used them more sporadically, such as Catlily who said *'I use it for a few days quite frequently and then I suddenly realise I haven't looked for a week maybe'*. A number of participants said they did not use their meter when they were feeling ill for instance Palmstone who said *'When I am feeling rubbish then the last thing I want to do is go bang and see what it is'* and Waterlight who said *'I have stopped testing because I am taking like cough medicine syrupy stuff and it just went [up], it was 13, and I thought, all my others were like around 6 or 7 even the top ones are under 10'*. In contrast, some participants said they liked to check their blood glucose when they were not feeling well. Friendsky said *'sometimes when I feel a bit iffy you know, I will check it then as well'*.

Blood glucose reading upload and viewing

Blood glucose readings were first uploaded from the participants' meter to their PC (using the Compass software), and then to the website. After upload, participants could view their readings in graph and table view both through Compass and the website.

Twenty-five participants installed the Compass software onto their home computer and 18 went on to upload their readings to their home PCs. Fifteen of those who uploaded their readings to Compass also uploaded their readings to the website. The primary reason that participants with readings on Compass did not go on to upload their readings to the website was because of some sort of technical problem. Uploading data was a fast process. Greenmouse said *'it's very quick. I mean it takes seconds to download the data'*. Figure #6 below shows an example of a graph view of Greenmouse's readings from the website, and Figure#7 shows an example of a table view of the same set of readings.

Graph View [View as greenmouse]



From: 23/11/2007 To: 29/11/2007



Figure 6: Graph view of a participant's blood glucose readings

Most participants who uploaded blood glucose data found that the graph view was particularly useful. Rosecandle said ‘Yes, I can keep my eye on what’s going on. I think it’s great’, Gardenpen said ‘When I upload, I always run through the graphs, and you get a pie [chart] as well don’t you’ and Palmstone said ‘the chart, when it comes up you know, you can see your highest peaks and whatever, and you know that reminds you that they are not too good’. However, if participants were not using their meters often, they found their readings were scattered and the viewing facilities in the system were less useful. For instance Hatfork said:

Hatfork: I have had a look at the graphs, again but I need to put all the information in basically to, I mean I can put an average of what I am but I need more, well more careful monitoring, regular monitoring.

Researcher: Those graphs probably look a bit weird if you have big gaps.

Hatfork: Yes, that’s half the problem you can’t gain an average if they are not regular enough.

Table View [View as greenmouse]

BG mmol/L	Date Time
7.2	23 Nov 2007 01:09
4.7	23 Nov 2007 02:17
6.8	23 Nov 2007 07:49
12.0	23 Nov 2007 10:54
9.2	23 Nov 2007 21:51
8.0	24 Nov 2007 07:12
7.0	24 Nov 2007 12:27
9.1	24 Nov 2007 22:25
14.6	25 Nov 2007 00:54
14.2	25 Nov 2007 07:13
1 2 3	

Filter Readings

< Step By Week >

Figure 7: Table view of a participant’s blood glucose readings

Other participants who used their meters very frequently suggested that they would have liked a wider range of views. For example Shoepen suggested:

It would have been good to try and view your readings at the same time, say over a period of a week... instead of them being listed ... possibly in a table format, so that I could sort of see what my bloods are at 9 o'clock [every morning for a week].

The Compass software had more facilities than the website, which meant that users could add extra information (for instance about mealtimes and insulin dosages) if they wanted. However, some participants found these extra features were not necessary. For instance Greenmouse found that the automatic settings for mealtimes in the Compass software were not useful for her data:

Greenmouse: One of the things I have noticed, when I download the data, it assumes timings either before or after meals, depending upon and it puts them in the table,

Researcher: In the Compass software?

Greenmouse: Yes, and I would have thought that that would have been quite important, but I don't know how you can tell, for example for me, Monday to Friday there is a certain timetable in terms of getting up, but at the weekend I have a lie-in, so my readings in the morning would be taken later, and I think the system is assuming I have had my breakfast, and so it puts those in as after meals, rather than pre [before].

The website

Twenty participants accessed the website during their first three month period in the study; by the end of the study the number rose to 26. The website went live in September 2006 and continued in use until March 2008. Early on in the study, at the end of February 2007, the most frequently accessed part of the web site was the discussion board, followed by the targets page, the news page and the information page (all with very nearly the same number of hits), with the upload page being accessed the least number of times. By the end of the study the discussion board was still the most frequently accessed part of the site with 361

participant hits, followed by the information page (281 hits), the news page (249 hits) and the uploads (107 hits). The targets and diary pages were the least used part of the website.

A few comments were made about the website as a whole, rather than particular facilities on it. Frogbook was positive about the website saying

It's good. It is easy to use. Ok I have knowledge, even for those, I got my partner who is zilch on anything computers and I just said go through that, easy enough, easy enough, so the feedback on that was good.

Various other participants made similar comments, for instance Hatfork said *'it's straight forward, I don't like things that sing and flash and dance'*. However, some participants felt that it was too plain, for instance Clearlake said he thought *'it looks bland'* and Greenmouse said *'if you go onto other websites, they are all so busy with lots of things on them, it just seems very plain'*.

The discussion board

The discussion board was the part of the website most frequently accessed. Altogether 13 patient participants posted to the site, as well as the GP, Trish, and I. Greenmouse, Shopbeach, Treeswan and Roundocean were the most frequent posters. However, altogether 22 participants accessed the discussion board, so nearly half those who viewed the discussion board either did not feel comfortable enough to post to it or did not have anything to say. It contained eight discussion topics that participants could post to. The most popular topics were 'Healthy eating' and 'Ask Trish' (see Table #17 below). Most of the posts contained personal experiences of managing diabetes, with a mix of questions, answers and comments.

Discussion Board Topics	Posts
Healthy Eating	6
Exercise	19
Monitoring	5
Drugs	3
Heart, feet, eyes etc.	3
Website	12
General	5
Ask Trish	19

Table 17: Discussion board posts by topic

Because the discussion board allowed participants to share experiences and ideas with each other, it generated quite a lot of interest. For instance Treeswan said

It's like tips isn't it, somebody having one condition and it's about exchanging, you exchange that information and then you can take it away and do nothing with it but you can also apply it into your life can't you, so that's the beauty of it really. It's, you know you can do what you want with it basically.

Others made similar comments, such as Shoepen who said *'if people have the same problem then obviously you can sort of get ideas from it'*. Lilyrose said *'you can learn things from it'*. Greenmouse said that it was the part of the system that she was most interested in but she felt there was not enough activity on it.

It's the discussion group I think that interests me more than anything, I just want to see what other people are doing and thinking about. But that seems very slow to sort of get off the ground and I don't want to be regarded as the mad person that is always on there every 5 minutes.

This was noted by a number of participants. It is speculated that there was not a big enough cohort of participants using the system at any one time for the discussion board to really get going. Meadowsong said he had posted a comment but *'it didn't really go that far because no one responded to me'*. Also Treeswan said *'I didn't get any replies when I got on and I put a bit of information on'*.

Some participants felt that because they did not know anything about the participants who were posting it was difficult to know how to interpret what people were saying. Greenmouse commented *'the problem is you don't know who is feeding back to you'* and Breezelane said:

These people have got diabetes; they are answering questions and asking questions. I don't know what, you don't really know what stage sometimes, what they are up to, whether they have had it for five or six years, more or less.

Waterlight said he felt that many of the posts were not relevant to him saying *'they are all on medication. I haven't found anyone that's controlling the diabetes just by diet'*.

Some participants felt reticent about posting. Meadowsong, who made a couple of posts said *'I am not one for chit chat'*, Bluepurse said he had read the board but not posted to it because *'I am a sort of private person really'*. Waterlight said *'I haven't got a specific question I want to ask'*. Catlily made some posts but was reticent because of the permanence of posts saying

Once you put pen to paper it's on the discussion [board], it's there, where as if you decide later on, that no that wasn't right...

She also commented that discussion boards were more distant than face-to-face communication, saying *'on a discussion board it's almost like being in the next room listening'*.

News and Information

The news and information pages were the second most frequently visited part of the website after the discussion board. It is speculated that this was because participants tended to browse these pages when they were logged in to the website for other purposes. Several participants said the links were useful for instance Frogbook said they were *'very good'* and Brightwater that they were *'interesting to read'*. Interest in this section can be linked to the problem of finding trusted sources of information. Catlily said:

It's difficult sometimes finding things; I found that really useful just being able to pick up the articles listed in there.

Some participants liked the fact that the links had been checked by a GP. Hatfork said:

I am more likely to gain information by this ... rather than just going onto general sites because I am not really into that sort of thing.

However, the links had to catch the interest of participants if they were going to go ahead and read them. Greenmouse said:

I have looked at the headings in the news, I haven't actually found anything there that I thought, oh I will have a look at that. I think it might be more of a time issue, that than anything else.

Although later she also said that one of the articles she read was too technical saying:

It went into too much detail ... I didn't understand a lot and then I thought this is not helping, this is causing more confusion than actually helping.

Messages to the surgery

Eight participants sent messages to the surgery, and 14 received messages from the surgery. The messages from patient participants were either specific questions asking about issues such as medication, test results and for letters from the doctor or responses to messages from the surgery. The messages sent from the surgery were either in answer to specific questions from participants or comments on participants' blood glucose readings. A few participants engaged in a messaging 'conversation' with the GP/nurse about aspects of their diabetes management.

Participants who sent and received messages said they found them useful. The messages that Greenmouse had received helped her to understand her reading better:

*I got one from the Dr, Dr **** that just actually said that keep sending in your readings, your readings are fine in themselves, however maybe you are suffering from spikes after eating, perhaps you should test an hour after eating, and then the 2nd week I did that, you look at the graph and you just think, yes, you can just see them after an hour, so I found that was very good.*

Also the messages that Forestcircle received from the doctor helped him to realise that he was getting high readings because he was missing insulin injections:

*I have had feedback from Dr ****, he was worried about the, I can't remember the title, what they are called, something like the control, he was worried about me missing injections which I found out I was doing. Because I found out half way through I had exceptionally high readings and when I am thinking back the only thing I can think of was I had missed a reading, I had missed an injection somewhere along the line and that's normally where the problems had occurred.*

Several participants felt that the messaging service was useful as it helped them to ask small questions. Greenmouse said '*it's a time saving tool*' and Frogbook said

It's ideal. Instead of this like an appointment once every so often, there is a way of communicating if you have a problem ... it doesn't matter how little or how big it is, so long as there would be somebody there to answer your question.

Targets and diary

The targets and diary pages were the least used part of the website. Four participants entered targets in the target section and four used the diary. There were considerable more page hits on these pages than entries made in them. This indicated that participants had looked at the page but then clicked away without making an entry.

Participants talked about the dissonance between managing their targets over time and using the target facility. Catlily said she had set her targets, but then found she would slip:

I have used the targets, set the targets thing but then I found, I would set the targets and get through them but then you leave a few months and then when you go back you realise you have slipped off them again, so it's like setting the same targets up again.

Greenmouse explained that as she hoped to achieve her targets over time it was difficult to set an end date for them, consequently the targets facility did not quite meet her needs. She said in the second interview:

I have to say when I set my targets I don't sort of like rush and go back in and say I have achieved that sort of thing, I just put them in, I haven't actually marked them off as having achieved any of them.

She went on to say in the third interview:

I don't think it actually gave me anything back, so I put in a couple of targets like that I was going to walk to the train station, and not accept any lifts, but I do that every day, and I have stopped accepting lifts, I have made myself walk, but there was nothing, nothing else to sort of add to that really.

Shopbeach, like Greenmouse, explained that he had internalised his targets:

Yes it was to get something out that was the main target to be honest. It was all in m head anyway, trying to get a bit more exercise and that's resulted, it has.

Other participants who did not use the targets facility mentioned that they did not need to write them down, such as Sandstar, who said *'I have set myself targets, but I didn't need to remind myself*

The diary facility was not used frequently. Shopbeach said *'You have got to remember you put things in it'*. Sandstar explained he did not have much information to put in it:

I have used it a couple of times but all I was doing but basically just saying what I was doing. I couldn't give any information other than you know, like personal information, like I change shift patterns on 1 January, and I thought that might make a difference because I am, I have got into a regular routine now where I know what shifts I am working regularly, but they are longer shifts so whether that will make any difference, I don't know.

Most participants just stated that they had not used the diary without giving much explanation why. Lilyrose said *'I didn't know what benefit I would have from it'*.

The Alive emails

The Alive email system was used by ten participants. Six participants used it in the first three months of the study and by the end of the study an extra four used it. Eight out of the ten participants who used the email system found it beneficial, two did not like it.

Once participants had joined the Alive email system, it sent out 12 weekly emails and also weekly reminders. Participants found the regular emails kept them involved. Meadowsong said ‘*I like the way it sends you a reminder, so you know you are compelled really*’, and Poppymist said:

Even though it was, they couldn't see and they weren't watching me, I felt as though because I sort of said yes I will do this, and this, felt I had to do it.

Catlily said the reminders were useful, saying:

I think the feeling that you almost if you didn't, if I missed, if I went a bit later in a week and hadn't, then you get an e-mail to say you know you haven't made your targets for this week, that sort of, a check-up on it, I found quite good. Because you do, a week will go by and you just don't realise it's gone.

Breezelane used the ‘Move more, sit less’ programme and commented that the targets suggested in the emails were simple but effective:

They are very simple rules than they give you to do... walking instead of taking the stairs and stuff like that, just all them simple things that you can fit in quite easily, yes, I just feel as if you think sometimes they are that small, you are not going to benefit, it's not even worth doing it... but once you start getting used to doing it, I see it as a challenge and I keep thinking the more I do it, the easier it will be.

Orangenote used the ‘Eat more fruits and vegetables’ programme and found the information helped him improve his eating habits saying:

I have just been picking aspects out and there has been some suggestions you know on vegetable usage and some dietary suggestions and things like that ... I don't know whether there is any link to it at all but ... my appetite has halved to what it used to be. And it might be because I have reduced my intake, but subsequently I have had some positive health issues, as a response to that.

Meadowsong used the 'Choose Good Carbs and Fats' programme saying:

Just the last couple of weeks they have given you a detailed, they have given you the consequences if you like of what, of not eating ... saturated fats and cheese and that, so that's quite useful.

Meadowsong also said that the Alive system had prompted more communication between him and his wife about their diet at home as one of the emails had raised the issue:

And just talking about the cooking and that, and just I don't know, because she works as well so it's kind of a bit unfair criticising you know some of the meals, so I kind of had to be diplomatic, but nevertheless she is still aware and there is always a bowl of fruit now you know, there wasn't always a bowl of fruit [before].

In contrast, Greenmouse said she 'got so cross with it' because the system was American and seemed to be repetitive. Although other participants said they noticed that the programme was American they did not consider it a problem. Catlily for instance said 'I do a lot of IT and a lot of things are from America ... they just do things better don't they. Usually they are further ahead'. Waterlight commented that he would have preferred to be able to input his own targets, as that he found the targets were not suitable for him. Poppymist also said she would have liked it to be 'more interactive' and there were times when she wanted to ask questions, explaining:

There were one or two things that I thought I wanted to ask questions and you couldn't ask questions, because at the time they were talking about saying I needed to do more strenuous exercise, and at the time I was being investigated for angina, and I wanted something where I could say I can't do this at the moment.

Problems with using the system

Participants experienced various technical and access problems with using the system. A few participants reported problems with their meter. Three participants had faulty meters and were given replacements. The batteries ran out of Fieldshine's meter who reported '*it won't even switch on*'. Gardenpen said at the final interview '*I dropped my meter today ... I have lost everything on it*'.

The most problematic part of the system was uploading blood glucose readings meter to the home computer. Several participants experienced problems with this and had to ring the Roche helpline in order to get help. For example Shopbeach explained Roche provided phone help and '*set it up for me, told me, they were dead helpful, they are very good*'. Other participants however gave up when they found they could not upload, for instance Lionmoor said he '*became frustrated with the erm, the blood counter not connecting to the computer*' and then he '*lost interest*' without phoning the help line. Owlrose said '*I have tried and I haven't figured out how to do it*'. In addition some participants experienced problems uploading from Compass to the website. For instance Hatfork reported '*I tried to upload it to the site but it wouldn't upload, tried a couple of times, you sent through new details to me, so I need to try again*'.

A few participants reported problems accessing the website. Grasslake struggled to input the correct web address saying '*I tried several different combinations of lower case, upper case and couldn't get through and I said sod it*'. Greenfish said '*I can't get on the website, it keeps saying it won't let me in, it's a secure site*', however it appeared he was trying to access the wrong URL.

A couple of participants had problems with the Alive emails. Meadowsong said when he was submitting his choices '*sometimes I'm not sure whether it's been sent or not*' and Shopbeach said he did not get a response from it saying he '*filled it all in, submitted it and nothing*'.

5.5.6 Response to System

DIABETES eHEALTH SYSTEM EXPERIENCE	
System Aims	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

This sub-category describes participants' responses to the system. These are: being watched, being comforted, not feeling

alone, the automated system. It also describes the benefits and drawbacks that participants experienced of using the system.

Being watched

Participants described positive and negative responses to being watched through the system. During the first interview Sandstar speculated '*perhaps it will give me the push to do what I know I need to do, because I am writing it down and other people are looking at it*', and Orangenote considered '*I am viewing this as a big brother*'. Brightwater expressed a similar view in the first interview:

Obviously you know you don't want other people to see that you are not performing well, so because it is something which is, it's not me hidden away with my little results type thing, it might spur me on to look at it, and make me focus a bit better.

Poppymist talked about the Alive email system saying she liked '*the discipline*' of it, and:

It was really silly, I felt as though they were watching me, and if I didn't go into it, I would get my knuckles rapped, so it's quite good.

Shoepen said knowing someone was looking at her blood glucose readings motivated her, saying '*I do think you try harder if you know someone is looking at them*'. Palmstone explained it made him more careful with his diet, thinking '*I won't have that because that will make that go higher*'. Shopbeach said that being watched made him feel that the surgery '*actually do care*', adding '*at least someone is watching you, I feel a bit more better for that*'.

Some participants expressed unease about their readings being seen. Poppymist said:

If I put my readings up there and they see all these 13s they are going to think, what is she doing, and they won't believe me that I have not been stuffing myself with sweets and chocolates.

Brightwater also wondered what people would think:

I thought to myself it's quite embarrassing to actually send these readings, but that is one thing when I started I thought I did want to try and be honest about it, rather than just say well, I will use my other meter and if it looks good, then I will record that one, I didn't want to do that type of thing.

Breezelane had also planned to use two meters, one for his normal readings and one for readings he intended to upload. Palmstone admitted that he had at times avoided taking meter readings when he had eaten something that would affect them, thinking 'I will have that and then I won't take a reading'.

Being comforted

Some participants said the system was a comfort and helped to alleviate their anxiety. Greenfish said it 'helps you not to panic so much when your sugars are fluctuating' because he could see the reason for a fluctuation 'oh yes we went for a meal that night you know'.

Roundocean had thought he was going to have to start injecting insulin and said in the final interview 'it relieved my anxiety of going onto Type 1'. Breezelane said he felt 'reassurance' from the system. Brightwater reflected 'knowing it's there is a bit of comfort ...even if you only need to use it... once a month' and also 'just having that backup is like a peace of mind thing'.

Even participants who hardly used the system talked about gaining comfort. Poppymist said 'it makes me feel a little more secure that the Drs can see what is going on'. Eastwind, who also did not use the system at all said 'it's taken the fear away ... I was ... really worried about it up until speaking to you and having a look at that'.

Not feeling alone

Some participants spoke about how the system made them feel that they were not alone. Brightwater said that sharing his blood glucose readings with the surgery 'makes you feel as though you are still part, well you are part of a group type thing, and quite a close group', and Palmstone said that taking part in the discussion group 'makes you feel like you are not alone'. Breezelane said he felt that 'even though you are on the computer, you have got the communication'.

Eastwind did not use the system, but said what attracted her to it was ‘*a feeling of not being on your own doing it*’. Similarly Boatapple speculated about finding someone to share exercise ideas with ‘*if I was to meet someone on there, in the same predicament, and do it together then, it’s easier like*’.

The automated system

Two participants talked about the Alive email system being automated. Meadowsong described it as a ‘*number cruncher*’ and said he liked the automated reminders:

It’s a reminder because it comes through and then when you don’t respond, I like the way it sends you a reminder, so you know you are compelled really.

In contrast, Greenmouse found the automation off-putting:

I just felt this is just automated, I felt as if, no thought, it was just ... some brain box had come up with this concoction of bringing all these things together and then I started doubting you know, how, the information I have given them, how do they, how have they come back with this?

She went on to say she started doubting ‘*the authenticity of it*’ and ‘*it’s a bit like reading your stars in the paper, you know, ‘how does that fit with me?’ sort of thing.*’

System benefits

Participants talked about specific benefits they had gained from using the system, including some participants who said they did not get any benefits from using the system.

General benefits were mentioned by a number of participants. Frogbook said she took her diabetes ‘*more seriously ... I wouldn’t say I don’t stick my head in the sand totally, but I am more aware that I have diabetes*’. Greenfish said it had made him ‘*more aware*’ of his diabetes, as did many other participants. Shopbeach, along with several others said a benefit of using the system was that it ‘*motivated me*’, and Friendsky said ‘*it’s kept me on my toes*’. Forestcircle talked about the benefits as a whole saying ‘*by giving the machine and the graphs so I can look at them and see how I am doing against a set regime, I feel a lot better. I have got targets to aim for; I feel I was achieving the targets*’.

Some participants said they used their meter more frequently than previously as a result of taking part in the study. Owlrose said she used her meter *'more, not as often as I should or I wanted to, but more than I was'*.

Participants who uploaded readings and looked at the graphs mentioned several benefits: that it helped them to make connections between their actions and their blood glucose readings, to see patterns, to adjust their behaviour, and to change their attitude. Several participants mentioned the speed of uploading; Shopbeach said *'it takes seconds'*. Greenfish compared looking at graphs with using a notebook saying *'when you are using the book you turn over the page and forget what is on the previous page'*, but with the system found that *'you can see the ups and downs'*. Rosecandle said *'I can keep my eye on what's going on. I think it's great'*. Waterlight talked about noticing particular effects, he said *'what I have noticed [is that] alcohol affects me'*. Shopbeach said looking at the graphs helped him to *'change my insulin'*, but also it affected his attitude saying *'it's motivated me'* and *'it's like a wake-up call'*. Forestcircle said he felt *'a lot more confident'* and that looking at the graphs helped him to realise *'I can actually keep myself in control'*. Greenmouse found the graphs *'helped me focus on what I need to do on certain days to prevent things happening'*. For instance she noticed,

A night where I would have a very low sugar, that I would have a hypo and have to get up in the middle of the night, and it was happening on the same night each week and it's my ironing night. Now without that, I wouldn't have known, and although ironing isn't very strenuous it's obviously something that I have not taken into account.

Participants said benefits gained from using the discussion board to communicate with others were exchanging information and feeling more motivated. Gardenpen said he found the discussions *'like a motivation as well, you know to see other people, what they are saying and what they are doing'*.

Participants said that benefits from communicating with the surgery were that it was quick and time-saving, they could ask small questions they may have forgotten during an appointment, and the healthcare practitioners could make useful comments about their readings. Greenmouse said sending messages to the doctor was beneficial because:

If you had a question you could just drop them a message and then when they had the time, they would respond to you and it was done rather than having to ring up or try and make an appointment to see someone just for a chat.

Hatfork found a benefit of the website was *'to know what the correct information is'*. Brightwater reading the website made him realize that he still had things to learn about diabetes, saying *'I suppose after 20 years I got a bit blasé about it'* and *'one thing that this has shown me is that you don't [know everything]'*. Grasslake said he found he learnt from the website about the importance of *'greater self care, because of the long term complications, which I suppose I knew about ... but I didn't know about them in the depth that I do now'*.

A few participants mentioned finding the targets useful. For instance Palmstone said *'you put your target in, it would remind you when you go back to it ... you ... successful or not successful. That was good'*.

Benefits mentioned about the Alive system were that the targets were manageable and the reminders were motivating. Breezelane said the targets were *'simple things that you can fit in quite easily'*. Catlily amongst others said it was good *'to have someone reminding you'*. Poppymist said she felt *'somebody sort of pushing me, motivating me'*. Meadowsong, for instance, used it to change his eating habits and Brightwater used it to increase his exercise.

A few participants said they did not get any benefits from using the system, for instance Roundocean who said *'I got no benefits'* but he qualified this by adding *'but if you said well give us the equipment back then because you didn't get any benefits, I would say no'*.

System drawbacks

Some participants wanted to be able to input more detail into Compass and the website than simply blood glucose readings. For example, Greenmouse wanted to be able to set mealtime details herself, and Shopbeach wanted to be able to add information such as *'units of insulin'*. Treeswan said that when using the computer she missed seeing her readings accumulate over the week as she did when she wrote them down *'it's usually there in black and white and it's only up until you get on the computer that you go, that's how my BMs have been all week'*.

Several drawbacks were mentioned about the discussion board. It was not made clear on the discussion board whether posts came from 'lay' participants or medical practitioners, so some

participants were uncertain about the believability of the posts. Greenmouse said *'you are not the expert so you don't know whether what you say is a load of rubbish or if there is any sense in it'*. Some participants found the discussion board format difficult to engage with. For instance Fairstream said she did not post to the discussion board because she felt *'too shy'*. Catlily found the permanence of the discussion board off-putting because you could not retract statements once you had posted them. Waterlight wanted to communicate with someone managing their diabetes by diet as he was.

The comprehensibility of the information provided on the information page was a potential drawback. Greenmouse, for instance, mentioned that one of the news articles on the website was too technical.

Drawbacks with the targets were forgetting them and finding it hard to be motivated by them. Greenmouse, for instance, thought *'I don't think it actually gave me anything back.'*

5.5.7 Unmet Expectations

DIABETES eHEALTH SYSTEM EXPERIENCE	
System Aims	System Use
Experience of Technology	Response to System
Barriers and Facilitators to System Use	Unmet Expectations
System View	

This sub-category covers expectations that participants had of the system that had not been met, or extra facilities that

they thought would enhance the system.

Several participants said they had hoped there would be more communication through the system, particularly on the discussion board. Greenmouse said she was *'disappointed there are not so many people on it'* adding *'there is no sort of two way communication'*. Meadowsong said *'I was a little bit disappointed, you know, no one kind of responded to a couple of things that I put on'*, and Forestcircle expressed a similar view saying *'I put a question but there was no response'*. Roundocean commented *'I log on just to see what is going on ... if there had been something stimulating there it would have drawn me in'*. Also Rosecandle said he was *'disappointed'* that he did not get more regular feedback from the doctor or nurse about his readings, saying *'I have been more or less left to my own devices'*.

Participants made comments about extra facilities they would have liked on the system. Poppymist said she would have liked the Alive email system to have been more *'interactive'*. Berrybank thought *'a chat room would be great'*. Three participants thought alerts would be useful both for the blood glucose readings and the diary. Roundocean suggested flagging

blood glucose readings, suggesting *'red flagged ... needs to be looked at or, and then you can have an orange flag where it goes to the diabetic nurse, who monitors it more intensively'*. Other proposals were Lilyrose's suggestion to have an electronic *'food diary'* and Meadowsong's to have *'your weight being monitored'*. Meadowsong also suggested it would be useful to *'submit your repeat prescriptions'* through the system.

Palmstone suggested it would be good to have an integrated device *'that will take your blood sugar, upload it and whatever, all in one thing'*. Only a third of participants, when asked, said they would like to use the system on a dedicated handheld device. Hatfork said it would be easier *'to access and use specifically because you can use it while you are travelling and in work'*. However, many participants thought that a handheld device would be hard to see and manipulate, and said they would prefer to use their home computers. Palmstone said *'it's harder to read a small screen, I like a big screen'*, and Chairtree said the problem with handheld devices was *'they are too small for my fingers ... I have got no feelings in my hands you see'*.

5.5.8 Category Three Summary

The *Diabetes eHealth System Experience* is a category that covers participants' experiences of using the eHealth system. Participants talked about their aims for using the system, their experience of technology and the barriers and facilitators that helped and hindered them in using the system. They talked about how they used the system, how they viewed the system and what benefits they had gained from the system. Finally, they talked about expectations they had for the system that had not been met.

5.6 Summary

In this chapter the main findings of the study have been presented in three core categories: the Diabetes Self Management Experience, the Diabetes Support Experience and the Diabetes eHealth System Experience. Subcategories have been identified within each category and within the subcategories codes have been identified and explained. Detailed interview data has been provided for each code to illustrate the range of views expressed by participants. In the next chapter the conceptual framework that was developed through the analysis of the data is presented and the themes emerging from the study will be discussed.

6. CROSSING BOUNDARIES: THE CONCEPTUAL FRAMEWORK

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We have first raised a dust and then complain we cannot see.

Bishop George Berkeley 1685-1753: *A Treatise Concerning the Principles of Human Knowledge* (1710)

6.1 Introduction

Following on from the previous chapter in which the categories and subcategories identified from participants' interviews were presented along with detailed evidence from the interview data, this chapter presents a conceptual framework of how the categories and subcategories relate to each other and an interpretation of how that framework can be understood.

This chapter contains six sections. The first section introduces the content and the structure of the chapter. The second section introduces the conceptual framework developed during the data analysis and explains how the framework interprets the results presented in the previous chapter. The third section discusses some of the qualities of the eHealth system that emerge from the study. The fourth section introduces the idea of the eHealth system as an artefact that crosses boundaries and explores how participants' experiences of the system reflect that interpretation. The fifth section discusses the concept of boundary objects and introduces the idea of the eHealth system as a boundary structure. The sixth section summarises the main points made in the chapter.

6.2 Conceptual Framework

The conceptual framework was developed to illustrate the relationship between the three categories the *Diabetes Self-Management Experience*, the *Diabetes Support Experience* and the *Diabetes eHealth System Experience*. The whole framework represents a dynamic process of interacting elements. In the diagrams presented in this section, categories are represented by

ovals, sub-categories by boxes, groups of sub-categories by clouds, and directions of influence by arrows.

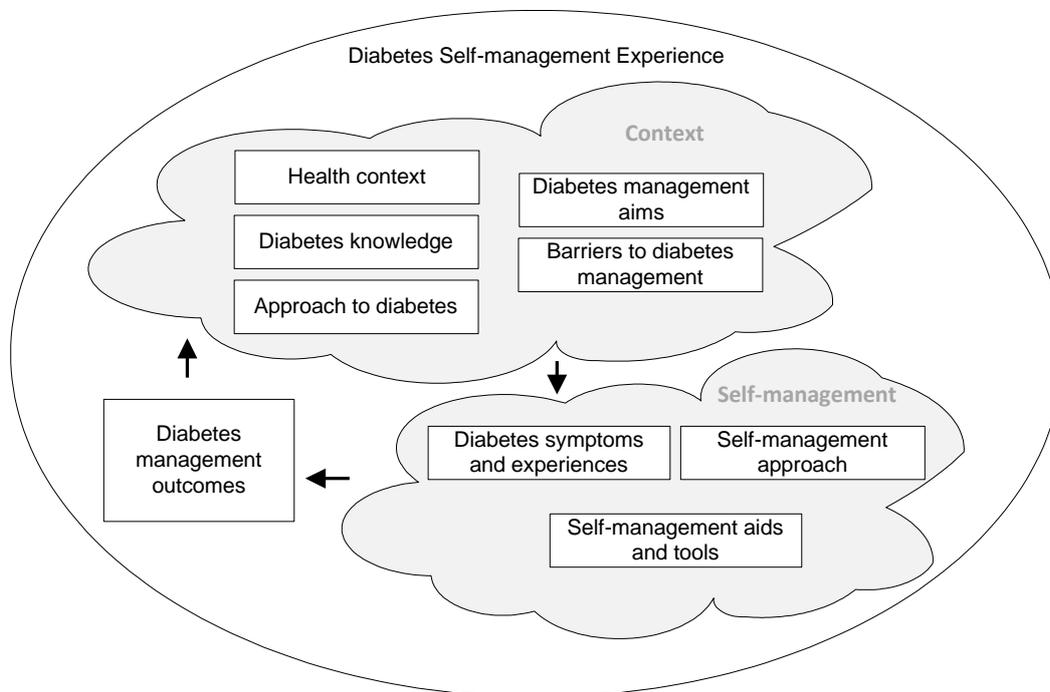


Figure 8: Diabetes Self-management Experience

The *Diabetes Self-Management Experience* is illustrated in Figure #8 above. It illustrates the private, personal sphere of disease management. This comprises three groupings: contextual factors, self-management activities and outcomes from those activities. The experience of self-management is modelled as a constant process in which factors influence each other – diabetes contextual factors influence self-management activities which influence outcomes. Five factors are identified as contextual factors that affect all diabetes management experience. The first three are ‘health context’, ‘diabetes knowledge’ and ‘diabetes approach’. These are core factors that both influence the way participants undertake their diabetes management and which change in response to activities undertaken. ‘Health context’ refers to both diabetes and non-diabetes related health; ‘diabetes knowledge’ to both medical and experiential knowledge of diabetes, and ‘diabetes approach’ to attitude and focus on diabetes. In addition, two other contextual factors were identified: ‘diabetes management aims’ (which includes short and long term aims as well as not having any clear aims at all) and ‘barriers to

diabetes management'. Self-management itself is seen as a grouping of related elements which consist of 'self-management approach', 'diabetes symptoms and experiences', and 'self-management aids and tools'. 'Self-management approach' covers the way in which participants approach self-management activities such as taking medication, taking blood glucose readings, and maintaining a healthy lifestyle. Examples of 'self-management aids and tools' are using blood glucose meters and blood glucose diaries, as well as other tools that individuals use to support healthy lifestyles such as calorie calculators and food diaries. 'Diabetes symptoms and experiences' are the immediate day-to-day symptoms that individuals experience – such as feeling tired or experiencing a blood glucose dip after exercise. Self-management activities and decisions are wide-ranging and many are embedded in everyday life in ways that they are frequently habitual behaviours that are not always undertaken consciously. Various outcomes result from self-management activities, (for instance changes to symptoms, knowledge, and diabetes approach), which then feed back into the process and affect future self-management activities. This process continues over time as an individual's health changes and their focus intensifies, diminishes or disappears – but as diabetes is a chronic disease, the process is continuous.

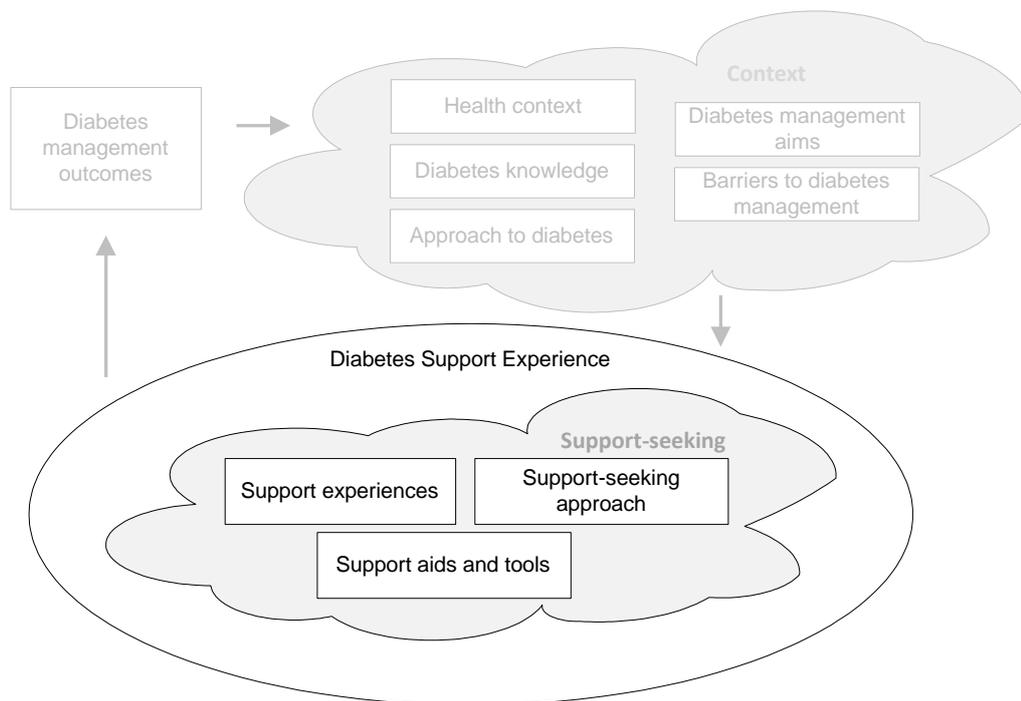


Figure 9: Diabetes Support Experience

The *Diabetes Support Experience* is illustrated in Figure #9 above. It consists of outward-looking, intermittent activities through which participants seek and receive support for their diabetes. In the external sphere are activities such as going to the GP or diabetic clinic, discussing medication regimes, going for a blood test, attending a diabetes education class, discussing experiences with a friend or looking up new information about diabetes. These are sporadic events that involve going to a particular place or making a special effort. They involve looking outwards, actively seeking help and communicating with others. In the conceptual framework participants' support experience is also modelled as a cyclical process linked to self-management as the need for support is an important part of self-management. In this process, contextual factors influence the support experience, which influences outcomes. The three elements identified in participants' support experience were 'support-seeking approach', 'support experiences' and 'support aids and tools'.

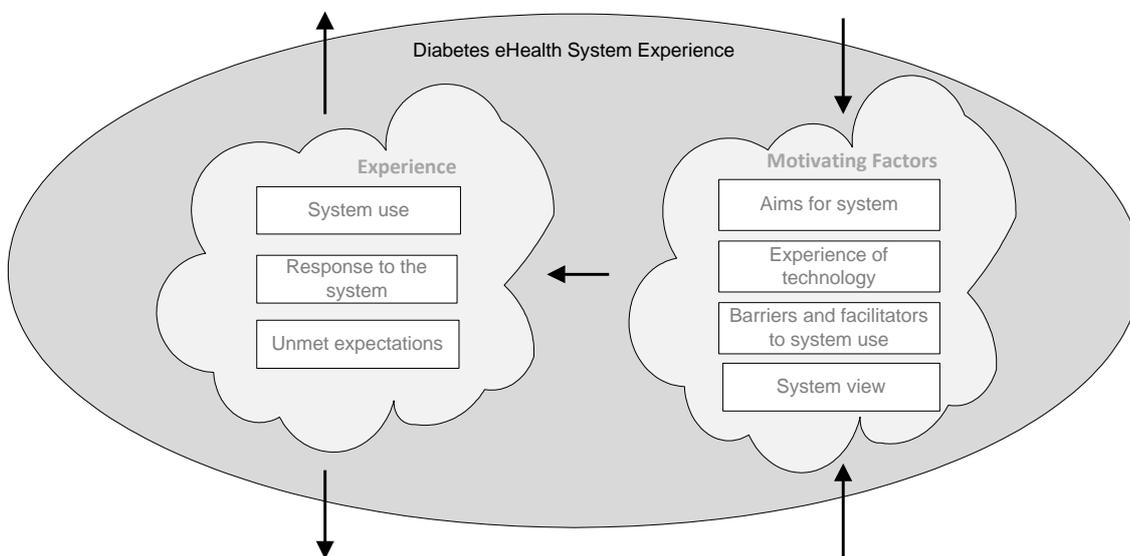


Figure 10: Diabetes eHealth System Experience

The *Diabetes eHealth System Experience* is illustrated in Figure #10 above. In the conceptual framework this sits between the *Diabetes Self-Management Experience* and the *Diabetes Support Experience*, and overlaps part of each area as a tool that supports both processes. Consequently it is affected in some way by all factors. The two broad groupings of factors within the eHealth system experience are motivating factors and experiences of system use. In the framework motivating factors are considered as important influences affecting use of the eHealth system. For instance patients who experienced technical problems with their home computers found they affected their use of the system. Motivating factors comprise

'aims for system use', 'experience of technology', 'barriers and facilitators to system use' and 'system view'. Experiences of system use comprise 'system use', 'unmet expectations' and 'response to the system'. Participants' experiences of the system feed back out and affect self-management practices and support experiences as well as diabetes management outcomes.

The full conceptual framework is illustrated below in Figure #11. This shows the dynamic links between the different sections of the model. In use the Diabetes eHealth system crosses the boundary between the two different spheres of a participant's experience of diabetes management – the personal sphere of self-management, and the external sphere of seeking and receiving support from medical experts, others with diabetes and friends and family. The eHealth system brings these activities together and co-locates them in a virtual system that is accessed from the participant's home environment. In this way the eHealth system shifts the geographical location of diabetes support. The personal world of self-management is strongly associated with the home environment, and external support-seeking activities are associated with places outside the home. By co-locating these two spheres the eHealth system brings external supported activities into the home environment and opens a window to the outside world through which personal self-management activities are exposed. Through co-locating activities in a virtual environment a new infrastructure for diabetes management is created.

There was not a single 'participant view' of the Diabetes eHealth system, but multiple views. Participants developed a view of the system before they used it, through the formation of their diabetes management aims and through their perception of what facilities the system could provide for them. This view affected whether they used the system at all, for what purposes they used it, and how they used it. Participants also changed their view of the system while they were using it, depending on how easy they found it to use, and whether they experienced benefits from using it. Participant views were therefore shaped before, during and after system use and were influenced significantly by the availability of technology in the home and their experience of and confidence in using the technology.

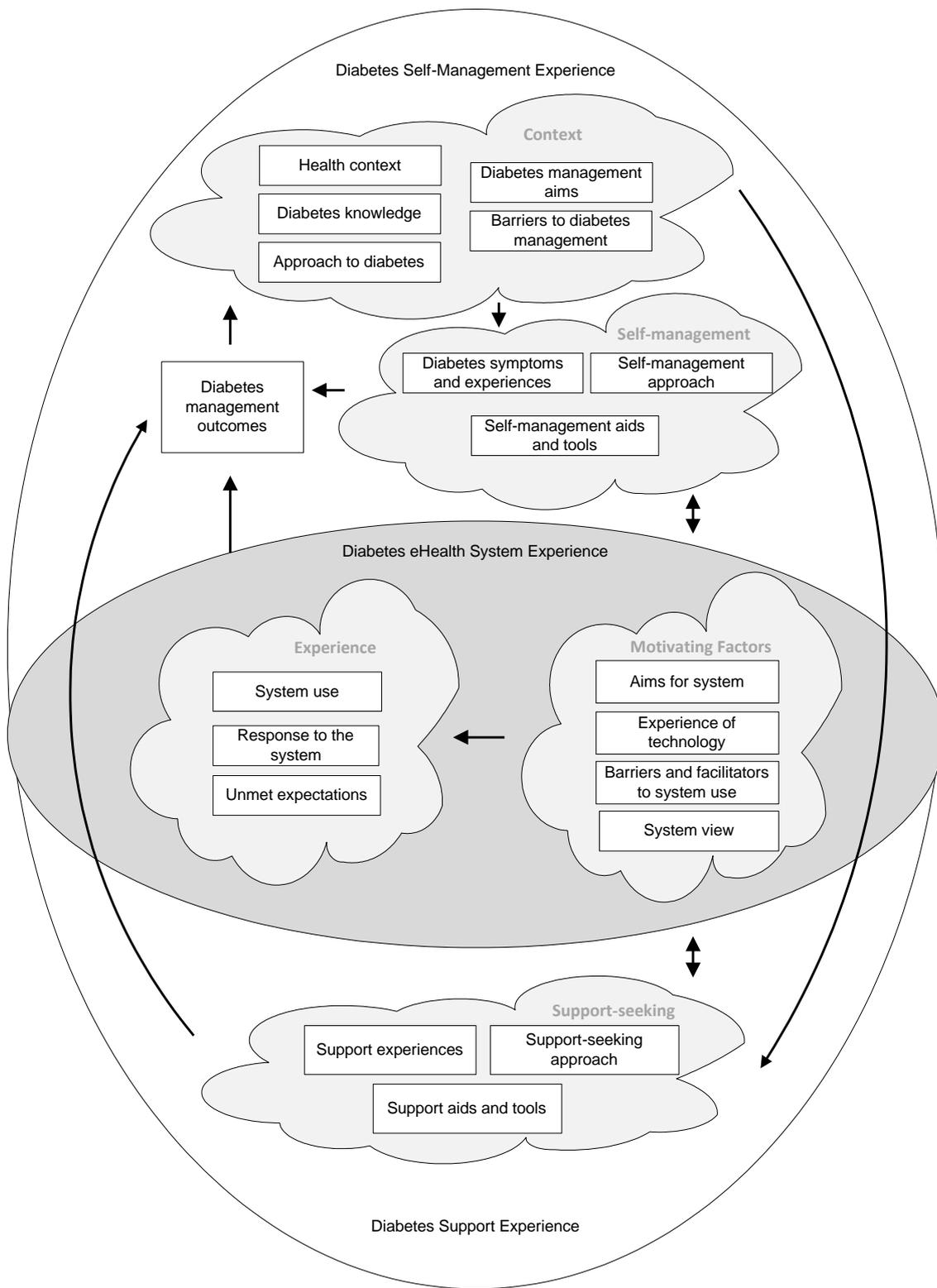


Figure 11: Conceptual Framework: The Diabetes eHealth System in Use

6.3 Crossing Boundaries

The key feature of the eHealth system was that it crossed the boundary between the personal sphere of diabetes self-management and the external sphere of diabetes support-seeking by co-locating support for both spheres in the same system. It also crossed the boundary between the home environment of the participant and their family, and the outside world of medical specialists and others with diabetes, through the co-location of aspects normally associated with each environment in the system.

Self-management belongs in the personal sphere. In this sphere individuals with diabetes are responsible for managing themselves, however well or badly. Self-management revolves around eating, being active, taking medication, taking blood glucose readings and possibly keeping a diary of readings. Many personal self-management activities are associated with the home environment as this is the base from which participants manage their diet, medication and plan recreational and social activities. This is the personal, private context of managing a chronic disease, most of which is undertaken alone. Consequently, many of the ups and downs of daily self-management are internalised as a narrative which constitutes the participants' personal diabetes story.

Participants only had fairly crude tools to support their self management activities before they used the eHealth system. Typically they used a blood glucose meter and sometimes a paper diary. They used those tools on their own and usually did not share self-management information with others. The only occasion on which they talked about sharing results with others was during an appointment when they may show a GP, nurse, or hospital consultant their paper diary of blood glucose readings. The eHealth system extended those self-management tools by allowing personal management information to be shared with the GP and practice nurse on a more regular basis. As a result of this, participants could feel supported in their personal self-management in a way that they did not normally experience. However, the problem of regularly sharing blood glucose readings with the GP is that it exposes participants' personal, daily self-management activities to scrutiny by health professionals. The health professional, who is normally only visited occasionally and shown a summary of participants' readings, is now able to have regular access to detailed self-management data.

Sharing self-management data elicited reactions of interest and disquiet from participants. Some participants talked about feeling reassured by being able to share data. Roundocean, who uploaded readings several times, said that having access to the system was '*comforting*'. At the beginning of the study he said he was about to switch from taking tablets to injecting insulin. He was anxious about this and planned to use the eHealth system as a support aid during this period of transition. However, he found during the course of the study that with careful management he was able to control his blood glucose levels sufficiently that he did not need to start injecting insulin. At the end of the study he explained that he had not used the system as much as he had thought he would because he had not started injecting insulin. However, he considered the system a comfort, as it was there if necessary. Several other participants also expressed the view that the system provided them with a feeling of comfort that was not directly related to how much they used it, but to the fact that it was there if they needed to use it. Others however, indicated that sharing readings exposed their self-management behaviour in a way that was not entirely comfortable. Palmstone, who uploaded fairly regularly, said that he was aware of being watched. When he ate sweets, or had a '*naughty*' day he would sometimes not take his readings, as he did not want to share high readings. Brightwater said at the beginning of the project he had considered using two meters so that he only recorded good readings on the system, but that he had decided not to do that. Breezelane also planned to use two meters. This indicates that there was some disquiet about the sharing of data. By crossing the boundary between the personal and the external sphere, the eHealth system provided comfort because health support was being extended into the personal sphere, but it also allowed intrusion as the personal sphere was laid open to scrutiny.

Participants' support-seeking activities belong in the external sphere. When participants look for support they are looking outwards, often for a particular purpose. Participants talked about seeking support from health practitioners, others with diabetes, friends and family. They talked about receiving medical advice, treatment, information about diabetes, as well as sharing stories with others and getting emotional support. This is the external-facing experience of diabetes much of it involving communicating with others and gathering information about diabetes. These activities are not the daily, regular activities of self-management, but are less frequent activities that punctuate and externally validate the ongoing narrative of diabetes. Many occur outside the home for instance in the doctors' surgery or the diabetic clinic, the chiropodist's practice, or the support group's meeting room.

Participants' stories of talking to others about diabetes and receiving support for diabetes indicated that it could be both a positive and a negative experience for them, particularly outside the confidential therapeutic relationship. On the positive side, participants acknowledged the importance of the medical support they received from the GP and the diabetic clinic as it provided them with medication and medical knowledge. Many participants also mentioned the importance of the support they received from family and friends. On the negative side several participants mentioned being '*nagged*', having their actions questioned, or feeling judged by others. When talking to others about diabetes, individuals became visible as having diabetes. Several said that they were selective about who they would talk to about their diabetes. Talking to others risked exposure, judgement and possible censure, so participants indicated that they were often keen to limit the level of that exposure to others.

When participants started using the eHealth system almost all were already familiar with using the Internet to seek information about diabetes. Although looking up health information on the Internet can be classed as a support-seeking activity, it is largely an impersonal activity. In contrast, the eHealth system provided access to more personal support-seeking activities of the type that usually took place outside the home, such as talking to the doctor or getting support from others with diabetes. Through the system these were made available in the home environment. The eHealth system made it possible for participants to send private messages to the GP or practice nurse, as well as being able to use the discussion board with other participants and the specialist diabetes nurse. These facilities enabled some aspects of the external, diabetes support world into participants' homes, and located them alongside self-management support tools.

Gaining access to the external world of diabetes support from home through the eHealth system elicited reactions of interest combined with reticence. Participants talked about not feeling so alone as a consequence of using the system, and of feeling part of a group. Shopbeach, who was the most frequent user of the system, described himself at the beginning of the project as feeling '*isolated*'. He said he often felt alone with diabetes as he worked full time and found it very difficult to make an appointment with the doctor if he was worried about something. He said that being in contact with the practice through the system made him feel better, as he felt more looked after. Brightwater, who used the system regularly, also talked about feeling on his own with diabetes and said using the system made him feel like he was part of a '*close group*'. Even some of those who did not use the system

talked about wanting to find ways to combat feelings of isolation. Berrybank, a 21 year old man who did not use the system, said that reading about the experiences of others in Internet chat rooms (that were not part of the system implemented in this study), stopped him feeling so alone.

In contrast, participants also talked about feeling exposed by talking to others through the eHealth system. A number of participants expressed an interest in the discussion board and looked at it regularly but did not contribute to it, preferring to 'lurk' instead. Fairstream said she was too shy to contribute to the discussion board. Catlily for instance explained her reluctance to take part in discussions on the board saying that when you posted something it was fixed and it could not be removed. She also said that online discussion groups were a bit like being in the next room listening – there was a sense of detachment and not really being involved. Several participants said they did not have anything interesting to say on the discussion board and that was why they did not contribute. However, in addition some participants commented that the discussion board was not very lively. Many participants indicated that they liked the idea of being able to communicate with the practice through the messaging service but they showed reticence in using it, several stating that they did not want to waste the doctor's time. Some participants took a passive approach to communication through the system. Rosecandle for instance said he would log on, upload his readings and check to see if there were any messages from the surgery and then log off again. Frogbook said that she thought the practice would contact her if there was a problem to say '*we need to speak to you about your diabetes*'. This passive approach indicates that there was some uneasiness about how to reach out through the system into the external world of support. The eHealth system introduced a new way of communicating with the outside world that participants expressed an interest in, but which they found hard to take advantage of.

To summarise the eHealth system crosses the boundary between the personal world of diabetes self-management and the external world of receiving support for diabetes. These two aspects of diabetes management, previously located in different environments, become co-located in the diabetes eHealth system, which is accessed using participants' home computers. Through this co-location the eHealth system creates a new structure for aspects of diabetes management. This structure can be challenging for participants as it opens up an area of conflict. It challenges them to integrate different aspects of their diabetes management and it challenges them to focus more on diabetes. While some were prepared to

rise to that challenge, others shied away from it and as a consequence used the system less fully than they had intended.

6.4 A Boundary Structure

By crossing the boundary between different spheres the eHealth system shares similarities with the concept of a boundary object (Star and Griesemer, 1989, Star, 1989). Star and Griesemer use the concept to explain how heterogeneity and cooperation is achieved when trying to manage objects that inhabit numerous social worlds. The issues of heterogeneity and cooperation also characterise the situation in which the eHealth system is used. Boundary objects are defined as follows (Star and Griesemer, 1989 p.393):

Boundary objects are objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site use. These objects may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds.

The concepts of boundary objects and social worlds have been found to be useful tools in this study for developing an understanding of why the diabetes eHealth system was used in anomalous ways. The three key user groups, patients with diabetes, GP's, and nurses, all inhabit different social worlds – particularly in relation to their view of diabetes. As a result they come to the system with different aims and different understandings of diabetes intellectually, emotionally and experientially. The system is endorsed by the expertise of health practitioners, most particularly by the GPs at the surgery, and it is legitimated through this endorsement. Nurses are the health practitioners who use the system most, by viewing patient data, sending messages and responding to discussion queries. However, patient participants are the main users of the system, and are the group intended to benefit most from its use. They learn from viewing their own data, reading about diabetes and communicating with others. Others, such as health researchers, journalists, and those who

produce charity websites (such as Diabetes UK) have some input into the content of the diabetes eHealth system but do not interact in the system. Their work is viewed through the system, and their views are interpreted and accommodated by those who use the system. All groups who use and communicate through the eHealth system have to create and maintain their own view of the system and create alliances with others using the system through the development of shared understandings. This many-to-many cooperation between ‘allies’ is necessary in order for the system to be viable.

Engagement with the eHealth system resembles Star and Griesemer’s observation of ‘many-to-many’ mappings between allies in their case study of Berkeley’s Museum of Vertebrate Zoology (Star and Griesemer, 1989). In their study they draw on and develop Callon, Latour and Law’s concepts of *enrolment*, *translation* and *interessement* in the building of alliances between actors (Latour, 1987, Callon, 1985, Law, 1992). Because this eHealth system was set up solely as a research study it was not possible to investigate the real-world processes of *enrolment* and *interessement* that might normally be observed during the set-up of such a system. The observations made in this study only focussed on how the system was used.

It is proposed that the eHealth system used for this study should be viewed as a boundary structure through which virtual objects are shared. ‘Virtual objects’ in the system are structured objects that only exist electronically; they do not exist as ‘real’ physical objects. Examples of virtual objects in the system are electronically formatted blood glucose readings, newspaper articles, discussion posts, messages, targets etc. Each facility in the eHealth system (the discussion board, the messaging facility etc.) provides a mechanism for the creation, viewing and sharing of virtual objects. Virtual objects are generated by actors who inhabit one social world and become boundary objects as they are shared across social worlds and take on different meanings. The whole eHealth system takes on the identity of a boundary structure as different users interact with it and use the facilities within it. This study has particularly focussed on the experiences of patient participants using the system and the meanings they have endowed these virtual objects with as they have created, used and shared them.

A digitally stored blood glucose reading residing in the eHealth system and viewed through its facilities can be seen as a boundary object. It is the digital formatting of the blood glucose readings that enables them to become boundary objects because through this formatting they

become sharable. These blood glucose readings will be interpreted differently by those who look at them. For the participant with diabetes a set of blood glucose readings will be a very personal set of data reflecting one aspect of their health. The set of readings may have a range of resonances for them. Looking at it may elicit feelings of guilt or satisfaction about how they had been eating, drinking and exercising during the period the readings were taken. Greenfish said when looking at his readings he may think *'oh hang on what happened there? Oh yes I went for a meal'*; whereas Treeswan was pleased to note *'the days that I exercise my sugars are a lot more balanced'*. Some individuals may look at a set of their own readings and feel bemused or anxious about what they mean, such as Applehand who said *'I don't understand what is a good reading, and what is a bad reading'*. In contrast, a health practitioner will interpret the readings in the light of their knowledge about diabetes and the health status and behaviour of the individual from whom they have come. They may look at the readings to look for indications of whether the patient's current medication is working, or to look for signs of spikes or dips at particular times. Some practitioners may not even be that interested in a particular set of readings except as a general indicator of the levels that are being recorded – they may be more interested in the HbA_{1c} that gives a long term indication of blood glucose control. Additionally, different types of health practitioner – the general practitioner, the practice nurse, and the diabetic specialist – may interpret the readings in slightly different ways because of a different focus or specialist knowledge. In contrast, to a patient's family the readings may look like a stream of random numbers that confirm that the illness is serious and needs careful monitoring.

Likewise a discussion post may also be seen as a boundary object. When a post is electronically created on the discussion board, the author of the post is creating a virtual object. The question or story that forms the content of the post is stored electronically on the server and becomes a permanent record of that action. This process of inscription makes the act of contributing to a discussion board different from that of having a conversation. The content of the post itself may have more than one meaning for the person who creates it as well as for those that read and comment on it. For example Greenmouse asked a question on the discussion board about having high blood glucose readings in the morning. She was surprised by the answer she got from Shoepen, who gave the experience a name (dawn phenomenon) and suggested that she take her readings in the middle of the night in order to ascertain at what time the increase in blood glucose was happening. Greenmouse thought that suggesting she wake up in the night to take readings was excessive. It made her question

whether she should believe the comment and made her aware that she did not know anything about other participants. Although both participants were struggling with their diabetic control, Shoepen had Type 1 diabetes and had recently started using an insulin pump, whereas Greenmouse had Type 2 diabetes for which she took insulin. In the first interview Shoepen had told a story about experiencing potentially life-threatening night-time hypoglycaemia when she was staying in a hotel, which had scared her. Because she had difficulties with managing her blood glucose levels she did not consider it unreasonable to take night-time readings for a short time period. However, Greenmouse's experience of blood glucose variation was not so extreme, although she still wanted to understand how to improve her blood glucose control. In contrast to a social discourse, where these contexts are likely to have been shared, these 'back stories' were absent from the electronic post. This led one of the participants to start doubting the content of the other's post. The anonymity of the contributors and the lack of shared information about their perspective on diabetes partly contributed to the misunderstanding. The role of discussion posts as boundary objects that must maintain some shared meaning as they cross social worlds is highlighted in this case. When the validity of the boundary object is doubted because the context is not shared, some allies may start to question the act of cooperation that they are engaged in.

Before using the eHealth system participants managed and stored their own self-management information for themselves and most of their supported activities took place as face-to-face meetings. The personal world of self-management and the external world of support-seeking were largely separated. When self-management and support activities move from the real world into the virtual world of the eHealth system some of the data and communications involved undergo a process of inscription through which they become virtual objects. What would have been part of a conversation is typed and stored electronically and so becomes a 'discussion post', a personal aim is stored as a 'target', and the result of checking one's blood glucose becomes an electronically stored 'blood glucose reading'. Once these data, discussions and decisions become virtual objects they can be shared more easily across social worlds. The objects take on new meanings and significances as they are shared across the boundary between the personal world of self-management and the external world of support-seeking. The process of inscription gives these objects a permanence and hence a new significance as well as mobility between worlds. Using the eHealth system requires participants to create virtual objects that reflect their own self-management activities and their supported activities.

6.5 System Qualities

The eHealth system exhibits qualities of interest that were highlighted during interviews with participants. These were surveillance, automation, endorsement and interaction.

Surveillance is an aspect of the system that several participants noted by mentioning they felt 'watched'. The system was not designed as a surveillance system for healthcare practitioners; it was designed as a system to facilitate sharing. However, there are elements in the system, particularly the sharing of blood glucose readings that exhibit the quality of surveillance. Surveillance starts with self-surveillance through the practice of watching one's own blood glucose and extends to external surveillance as a health practitioner looks at participants' blood glucose readings. Additionally, the system collected data about log-ins and page hits for research purposes, consequently I was also undertaking surveillance of system users. The surveillance implemented in this system, as with many other electronic systems, is covert – participants did not know how frequently their readings were being looked at or exactly who was looking at them. This aspect of the system seemed to encourage some participants but to discourage others. Those who were encouraged said that feeling watched made them improve their behaviour. However, others said that the potential for being watched meant they were reluctant to upload blood readings or write discussion posts when it meant they were exposing themselves as not being 'good'. This indicated that participants were happy to be watched when things were going well, but not when they were not. Although these views were only openly expressed by a few participants this tendency matches observations that participants who used the system most were those who were on an even keel with managing their diabetes. Those who were having problems or who were feeling unsure or negative about diabetes used the system less (see section 5.5.3 Barriers and Facilitators to System Use). No one openly objected to being watched, or expressed a desire to have control over how they were watched. However, this was an intrinsic part of the system and it is speculated that it was difficult for participants to discuss.

The automated nature of features such as the blood glucose upload facility and the Alive email system were noted by participants. Greenmouse mentioned that the automated features of the Alive system made her doubt their authenticity – as if an automated system was not as trustworthy as one in which interactions were initiated by an individual. Several participants talked about wanting more automation – and suggested they wanted elements such as alarms or food diaries with elements of automated support – all of which could easily be provided in

such a system. Roundocean liked the instantaneous nature of the messaging service, compared with his normal experience of waiting for an appointment with the doctor that took a couple of weeks. Arguably the system may have run more smoothly if it had incorporated more automation. Most particularly the process of uploading blood glucose readings from individual meters to the central server could have been more automated. However, although automation can increase speed and reliability, its covert nature means that, like surveillance, it is not entirely understood or controlled by the user. Both surveillance and automation are system qualities that may have both positive and negative effects on users.

Endorsement was another important system quality that was an intrinsic part of the system. The system had been endorsed by the surgery for use with participants, and this was important for participants. A number of participants mentioned the issue of needing 'trusted' sources of information about diabetes, particularly when using the Internet. Consultants, doctors, and nurses were cited as the most reliable sources of information, and one of the attractions of the system was that it enabled participants to have access to healthcare practitioners outside surgery hours. Additionally, all information and news items that were put up on the system were vetted first. Because of this, the eHealth system provided 'trusted' information. The eHealth system was also a place for safe communication with others. However, while communication between individuals and healthcare practitioners was not contentious, some participants queried the validity of comments that were made on the discussion board by other participants. Also some participants wanted to discuss issues with other participants who had the same type of problems as them, but as posts were anonymous this information was not available. The endorsed quality of the system was therefore specifically linked to healthcare practitioners. Participants responded to the legitimacy of the practitioners' position but were sometimes wary of other contributors.

Interaction was a quality that enabled participants to communicate with others through the system in different ways. The system enabled different types of interaction – there were one-to-one interactions, such as messages between individual participants and individual health practitioners, and also one-to-many interactions, such as the discussion board. Participants could communicate with the GP, the practice nurse, the specialist diabetes nurse and also other participants. Several participants talked about wanting to communicate more with others, even those who did not log onto the system or post to the discussion board. A

number of participants had talked about feeling ‘alone’ with diabetes and indicated that being able to communicate with others may help them. The potential for communicating through the system was a feature that participants were attracted to. However, participants’ intentions and expectations were not matched by real use. A number of participants looked at the discussion board but did not post messages to it. Some who posted to the discussion board mentioned feeling a little disappointed that others had not responded to them, and that the discussion board had not been livelier. The low numbers of participants taking part in the study possibly affected this. When talking about the discussion board at the end of the project, some mentioned that they felt shy about posting to it, and that the permanency of their comments made them reluctant to take part. The potential for interaction was therefore a desirable quality in the system, although communication facilities were not used as freely as had been anticipated.

As a boundary structure, the eHealth system exhibits some ambiguous properties that reflect the ambiguous views expressed by some participants about diabetes management and about the system; these cause the system to be both engaging and problematic. By its very existence the system reminds participants of their diabetes, and invites them to focus on it, when at times they want to forget about it. Participants are protected by their anonymity when they use the system, but they may find it hard to engage with other users if they do not know who they are. Participants can learn through the system as it stores their data and messages permanently and makes them visible to others, but at times they may want to engage in transactions that are ephemeral and transient. Finally the system watches them, but sometimes they do not want to be watched.

6.6 Summary

In this chapter the conceptual framework of the eHealth system has been presented. The framework describes how the three categories *Diabetes Self-management Experience*, *Diabetes eHealth System Experience* and *Diabetes Support Experience* and the sub-categories within them interact with each other. The cyclical process of diabetes self-management has been identified as it works through these categories. The key feature of the eHealth system was that it crossed the boundary between the personal sphere of diabetes self-management and the external sphere of diabetes support-seeking by co-locating both elements in one system. Furthermore the eHealth system was identified as a boundary structure that provides a virtual space through which boundary objects can be shared. System qualities of surveillance,

automation, endorsement and interaction were discussed. In the next chapter, the conceptual framework presented in this chapter will be discussed and evaluated.

7. EXPLORATION OF THE STUDY: DISCUSSION

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Errors, like straws, upon the surface flow;

He who would search for pearls must dive below.

John Dryden 1631-1700: *All for Love* (1678)

7.1 Introduction

This chapter discusses the results presented in the study and the theoretical view of the eHealth system developed in this thesis, drawing out the implications of the work and situating it in relation to other work. As the nature of this study is interdisciplinary, this discussion will draw on theory, concepts and research from a range of disciplines including social science, health, management science, information systems, and computing. Such diversity lends richness to the discussion and contextualises the research findings.

In this chapter there are six sections. The first section introduces the content and the structure of the chapter. The second section considers the conceptual framework developed in the study and explores how the eHealth system crosses boundaries. This includes a discussion of how the concept of boundary objects has been used in Information Systems and health literature as well as in this study, and a discussion of why the eHealth system has been viewed as a boundary structure. The third section revisits the broad research question and the three detailed research questions introduced in Chapter Three, discussing how the research results shed light on these. This section also looks back to the literature review in Chapter Two and discusses how the findings from this study compare to those of previous studies. The fourth section discusses how the experience of diabetes described by participants in this study compares with findings in other studies. The fifth section discusses

the technical nature of the system and the issues that arise as a result of this technical system being used in the home environment. The sixth section summarises the main points made in the chapter.

7.2 The Conceptual Framework

The conceptual framework presented in Chapter Six was developed through my thematic analysis of participant interviews. In this framework participants' diabetes management experience is conceptualised as a cyclical process in which contextual factors influence aims and approach, which then influence management experiences, resulting in certain outcomes. These outcomes feed back into the cyclical process. This process was observed being enacted in two spheres, the personal sphere of self-management activities and the external sphere of support activities. The eHealth system sits between these two spheres as a tool that supports both aspects of diabetes management. Participants' use of the eHealth system was part of their diabetes management process and therefore reflected both positive and negative aspects of that process. Consequently, participants who appeared to have a weak grasp of their diabetes management found it hard to start using the system whereas those who had a strong grasp were more likely to use the system.

The process described in the conceptual framework is neither envisaged as a learning process, nor is it a normative or 'ideal' process. It is not a learning model (Price, 1993), a chronic care model (Wagner, 1998), or a phase model (Fennell, 2003) and it is not intended in any way to be a 'complete' model of patient's experience of diabetes or diabetes management. The process is an explanatory framework of the role of the diabetes eHealth system in participants' diabetes management activities. The elements identified in the process describe aspects of diabetes management that in practice were experienced in a variety of ways by participants (including not at all), and that generally changed over time. It was built from participants' descriptions of their experiences, some of which were controlled and organised and others that were chaotic. In interviews participants generally talked about their current experience of diabetes, however they also talked about past experiences and how their experiences, behaviour, and focus changed over time.

The concepts of boundaries, boundary objects and social worlds were used as exploratory constructs to aid the interpretation of the study. I found that the eHealth system crossed the boundary between the private sphere of personal self-management and the external world of

receiving support. The eHealth system is also viewed as a boundary structure that enables the creation, viewing and sharing of virtual objects such as blood glucose readings, online newspaper articles, discussion posts etc. These objects are 'virtual' in that they only exist as electronic traces in the eHealth system. If the server were to crash or the hard disk to be corrupted or reformatted, they would cease to exist (except where backups are stored on other devices such as participants' computer hard drives or blood glucose meters, although they may also be deleted on these devices). These objects are generated in one social world and become boundary objects as they are shared across social worlds and take on different meanings. Alliances are formed as the objects are shared and translated into the concerns of others (Star and Griesemer, 1989, Star, 1989). As the eHealth system was run as a pilot, it was intrinsically short-lived, however it was observed that it was made stronger through the alliances formed when it was used, and weakened when facilities were weakly used. Participation was therefore essential to the strength of the system.

Originally Star and Griesemer (1989) introduce the concept of boundary objects as a way of explaining how cooperation was ensured across the heterogeneous concerns of divergent social worlds in the development of Berkeley's museum of Vertebrate Zoology. The concept was further developed in a study about classification (Bowker and Star, 2000). In this analysis the focus is on the role of boundary objects in aiding the translation of concerns between different worlds in the process of building the museum. This translation is differentiated from Latour and Callon's notion of *interessement* (Latour, 1987, Callon, 1985) in that it is not just a one-way translation of the concerns of the non-scientist into those of the scientist but an n-way translation in which each set of players maintains the integrity of their own interests and uses the objects for their own purposes as well as for the purpose of cooperation. Boundary objects are therefore objects that are recognised and of interest to different groups. Star and Griesemer identify four different types of boundary objects, repositories, ideal types (such as diagrams, atlases), coincident boundaries (such as maps), and standardised forms. In comparison with people who inhabit more than one group (marginal people), whose response is often to face a crisis of identity and membership, objects that exist at boundaries do not reflexively change themselves or have to manage membership problems. However, boundaries are demanding places to inhabit and in particular problems of adequate representation, integrity and comprehension arise.

The concept of boundary objects has been used in the Information Systems literature in a number of different ways. It has been used to understand the modelling of organisational knowledge (Karsten et al., 2001, Carlile, 2002), to investigate the politics and processes involved in the development of new software (Garrety and Badham, 2000), to explore the strengths and limitations of new software (Henderson, 1991, Henderson, 1998, Gal et al., 2004) and the design of new software (Christiansen, 2005). These studies uncover a rich variety of boundary objects being used in work settings of which Information Technology artefacts are one type. As Information Technology systems take an increasingly central role in organisations and supersede other methods of working, the concept of boundary objects has proved useful for investigating how technology and technical artefacts are involved in the processes of cooperation, negotiation and inscription that occur in work situations.

Information Technology artefacts particularly lend themselves to being seen as boundary objects because of their standardised interfaces, ubiquitous use, storage capacity and the complex functionality that they embed. In contemporary working environments Information Technology systems are the primary means by which information is captured, stored and shared between different groups of workers. They therefore frequently act as boundary objects that standardise and store information for use by different groups, alongside other artefacts such as written documents, schedules, diagrams, diaries. The idea has been taken up extensively by researchers in the field of Computer Supported Cooperative Work (CSCW) (Bannon and Bødker, 1997, Lutters and Ackerman, 2007, Lee, 2007, Phelps and Reddy, 2009) along with the idea of ‘communities of practice’ (Lave and Wenger, 1991). In this field, the creation and management of shared work through the use of technology is of particular interest. Bannon and Bødker for instance write about constructing common information spaces which need “openness and malleability of information on the one hand, and, on the other, the need for some form of closure, to allow for forms of translation and portability between communities” (Bannon and Bødker, 1997). They argue that when common information spaces create closures or punctuations, they can be seen as boundary objects, border resources (Brown and Duguid, 1994) or ‘immutable mobiles’ (Latour, 1987) .

Similar work has been undertaken in the field of health information systems, although there is considerably less of it, and the concept of boundary objects is often only used tangentially as part of a wider enquiry. The work tends to focus on medical and clinical records, their creation and use by the diverse groups of practitioners who use them. Some early influential

sociological work was undertaken by Berg and Bowker (1997). Drawing on Foucault's work on the clinic (Foucault, 1963), they argue that the medical record does not only represent the patient's body but in a medical setting it plays a role in the body's production. Likewise they argue that the medical record is involved in the production of a multiplicity of organisations. The medical record serves as an organisational infrastructure to the hospital and the other organisations that have interests in it and because of this it needs to be interoperable. As the different organisations that have an interest in the medical record have different and sometimes conflicting needs, the process of standardisation is not a single event but a result of a continuing process of negotiation and alignment. The medical record is used by different groups and has different meanings to them, but it also serves to coordinate and communicate across the different groups. In this sense it acts as a boundary object.

The concept of boundary objects has been used in some studies that explore information in clinical settings. However, generally the focus has been on collaborative work between health professionals. In their study of medical work in an intensive care unit, Reddy et al. (2001) reference the concept of boundary objects through their focus on the information needs of the different groups working in the unit. They argue that although the medical practitioners are physically co-located, their work is opaque to each other, and consequently information plays an important role in coordinating their activities. In this situation, the ability of computer systems to decouple information from its representation enables coordination to be smoothed. Bossen (2002) takes up these ideas and through an ethnographic study of a hospital ward produces a framework for common information spaces. Kimble et al. (2010) investigate strategies used when brokers choose boundary objects, investigating a network of healthcare professionals. Paterson applies the concept of boundary objects to communication with patients as well as between health professionals. She uses the concept in her work on making quality improvements to clinical discharge summaries (Paterson, 2005) and for the development of a knowledge repository for case-based teaching (Paterson et al., 2005). In her thesis she proposes the development of a 'boundary infostructure' to improve communication between different communities of practice (clinicians, health informatics specialists, administrators, medical educators and patients) in the context of chronic disease (Paterson, 2007). In this work the term 'boundary object' is used as a descriptive term for designed elements in a computerised information system. The work is information-centred, focussing on the automated integration of data from various sources using controlled vocabularies and topic maps most of which are structured documents described in XML

(Extendable Markup Language). In contrast, Kristoffersen (2008, 2009) discusses the development of an interactive learning system for adolescents with diabetes using mobile phone technology. The aim is to use simulation software to help young people with diabetes to improve their understanding of the relationship between activity, food and medication by getting information based on their own blood glucose readings. Kristoffersen describes the system as a boundary object between the social worlds of doctors and children with diabetes, although the tool itself is designed to be used solely by young people. The focus of this work is on the development of an accurate algorithm for simulating different scenarios given patients' blood glucose readings and insulin doses and an effective interface that communicates information in a meaningful way to young people.

Much of the work discussed above focuses on the design of information artefacts for the needs of medical administration where the focus is on the needs of health professionals. Even when systems that involve patients' needs are considered (Paterson, 2005, Paterson, 2007) a patient-centric view has not been taken. Only Kristoffersen (2008, 2009) applies the concept to patient-centred eHealth systems. However, his focus is on the design of the artefact (a prototype that has not been used by patients), rather than the experiences of those who use it. In this study I have applied the concept of boundary objects as a theoretical device that helps to make sense of participants' responses to using the eHealth system, not as a purely descriptive concept that explains a software system with a practitioner view and a patient view, as in the case of Kristoffersen's study.

Little criticism has been levelled at the concept of boundary objects in the literature. Some authors have critiqued the ways in which the concept has been used by others (Christiansen, 2005), or have proposed developments to the concept (Lee, 2007, Lutters and Ackerman, 2007). A number of authors use the term in a descriptive rather than an interpretive way (Kindberg et al., 1999). In its origins, it is used in studies that owe their interpretive stance to Actor-Network Theory (Callon, 1985, Latour, 1987). A number of criticisms have been levelled at studies using Actor-Network Theory: that they focus on local structures at the expense of investigating broader social structures, take an amoral stance, ascribe agency to non-human actors, and have a tendency to be very descriptive (Walsham, 1997). It could be argued that by focussing on the boundary between the private sphere and the public sphere this study is merely describing a distinction that can be made about illness in general. However, I consider that taking this view provides a useful way of conceptualising the

eHealth system and interactions that occur through it. My position is that viewing the diabetes eHealth system as a boundary structure through which boundary objects are created and shared helps us to explore its use in a way that goes beyond purely individual descriptions of experiences. Some of the ambiguities inherent in the system and in participants' views of the system have been drawn out and highlighted by this interpretation. By using these concepts we can build a more generalised understanding of why such systems may be both beneficial and problematic for participants.

The diabetes eHealth system has not been viewed as a single boundary object because it contains such heterogeneous facilities, each of which has a different structure and fulfils a different role. This reflects the way participants talked about the system during interviews, at the level of specific facilities, such as the discussion board or the Alive emails. The system is therefore viewed as a structure that enables the creation and sharing of different types of boundary objects through facilities that contain standardising structures. Each facility in the system (for instance the discussion board, the blood glucose facility, the Alive email system) provides a means by which a particular type of virtual boundary object can be created and shared. The facilities in the system each provide a standardised structure or template. The virtual objects that are created by these facilities are boundary objects that are used to communicate over boundaries. For instance, the discussion board is a repository of messages with a standard structure that are ordered hierarchically (by subject and threads) and by time. Also, the blood glucose viewing facility is a repository of blood glucose readings that supports different models (graph view, table view) to enable the readings to be viewed in different ways. Other facilities are also repositories into which data is entered using standardised forms. The structuring capability of the system facilities is '*a shared syntax or language for individuals to represent their knowledge*' (Carlile, 2002). Some of these objects, such as the blood glucose readings, already exist in electronic format and are imported electronically into the system where the blood glucose facility enables them to be viewed in different formats (graph or table) and shared with healthcare practitioners at the practice. Other boundary objects, such as the discussion posts in the discussion board are created in the software by participants as they type text in and click the post button.

From a patient perspective, many activities undertaken through the eHealth system are concerned with sharing across the boundary between the personal sphere and the external sphere. The virtual space created by the system is used in two ways by patient participants,

first to strengthen self-management practice, and second to communicate with and learn from those from other social worlds, doctors, practice nurses, specialist nurses, health researchers and other with diabetes. These activities are related to each other, but the focus of self-management is reflexive whereas the focus of communicating with others is outward-looking. Some of the virtual objects, created in order to support self-management practice, are therefore not shared with others, although their creation in the system still constitutes an act of inscription. For instance, diary entries were not viewed by others and were therefore only used for self-management. Patient interactions with the system started from their own personal view and were dependent on their own self-management practice – this was found to strongly influence use of the system. When the system was being used to support self-management, the emphasis was on the ‘drawing inward’ of knowledge. When the system was being used to seek support, the emphasis was on ‘reaching outward’. However, as well as being part of an individual’s own diabetes management process, the system was part of other participants’ processes. The doctor and the practice nurse looked at the blood glucose readings and sent out messages. Other participants used the system and as a part of that posted messages to the discussion board. I added new information, news items, posted to the discussion board and viewed the usage data. The objects being created in the system represented the output from these processes. The eHealth system was strengthened primarily when alliances were being built as boundary objects were created and viewed. The strength of the alliances made through the system was affected by the efficacy of these boundary objects to satisfactorily translate the concerns and engage the interest of users.

In this system, on the face of it, the active users of the eHealth system inhabit two social worlds, patients with diabetes and healthcare practitioners. However, in the interactionist view, social worlds do not always coincide with fixed social groupings (Johnson, 2008, Strauss, 1993). In the eHealth system there is also input from other social worlds such as health researchers, diabetes specialists and diabetes charities, although they themselves do not take part in the interactions of the system. These worlds are only represented by virtual objects (news articles, research articles, web sites) that are placed into the system without the knowledge of their creators. These objects represent the views of those social worlds but members of those worlds cannot actively enter into the dialogue that takes place inside the space of the system and they do not become actively involved in the alliances built within the system. This study did not focus sufficiently on the healthcare practitioners who had input to the system to be able to make comments about their interactions. This decision was made

because only a few healthcare practitioners took part in the study, and it was not practical to broaden the study sufficiently to involve and gather interview data from more practitioners. However, patient participants' interactions were analysed in some depth. For the most part when participants used the system they knew which group they were interacting with, for example when using the messaging service they knew they were interacting with the GP or the practice nurse. However, when interactions were anonymous, such as in the discussion board or with the Alive email system, uncertainty was caused. Issues of trust were raised here as well as the need to know more contextual information. Greenmouse expressed uncertainty about some of the discussion board messages because she did not know how knowledgeable the senders were, she also expressed uncertainty about the Alive email system because it was automated. Breezelane was uncertain because there was no contextual information about a message sender's diabetes background. Waterlight thought that everyone posting on the discussion board was on medication and therefore different from him, as he had diet-controlled diabetes. These issues indicate that even within this small group, establishing shared meanings in the discussion board was not always easy. It is possible that it would have been better to set up sub-groups on the discussion board rather than having one general board. For instance, patient participants could be split into groups – distinguished by whether they had Type 1 or Type 2 diabetes, or three groups – distinguished by whether they injected insulin, took medication or were on diet-only control. The indications from the study are that trust and the need for contextual knowledge are factors in establishing shared meanings between participants. While trust is established for interactions between patients and healthcare professionals, where there are automated interactions (such as with the Alive email system) or anonymised interactions across groupings (such as on the discussion board), trust is not established and this can result in uncertainty.

7.3 Experiences of the eHealth System

The research question for the study was 'How do patient participants experience using a diabetes eHealth system?' The broad answer to that question is that participants experienced the eHealth system as a part of their diabetes management process. Also, the eHealth system co-located some diabetes management activities in ways that brought both reassurance and exposure. The effect was to challenge and change the way in which participants carried out some diabetes management activities. There were considerable individual variations in the way participants used the eHealth system. Using the system did not cause radical changes, but it facilitated change for those who became engaged in using it. Benefits reported were:

changes in diabetes approach, better focus on diabetes, improvements to diabetes management activities, increased learning. However, the system did not help when participants were facing problems and it was more likely to be ignored in these circumstances.

The research question was divided into three sub-questions: How and why do patient participants use the diabetes eHealth system? How do patient participants change in response to using the diabetes eHealth system? And how do patient participants view the diabetes eHealth system? Each of these will be discussed in turn.

The first sub-question was - how and why do participants use a diabetes eHealth system? First, looking at how participants used the system, use patterns were very varied. Five categories were identified that characterised participants' use of the system. These were 'frequent users' (accessing several times a week), 'regular users' (accessing weekly or regularly), 'occasional users' (accessing in an occasional or sporadic pattern), 'minimal users' (accessing infrequently) and 'non users'. The use pattern itself took on a shape close to a normal curve, which is similar to the adoption curve of Rogers' diffusion model (Rogers, 1995). In this study most users were either 'regular' or 'occasional' with fewer 'frequent' and 'minimal' users. Consistent reasons explaining use patterns were difficult to find, but those in the 'minimal' or 'non user' groups were more likely to experience one of the following: difficulty accepting their diabetes, technical problems that could not be solved or health and personal problems that made participation difficult. Those who fell into the 'frequent' or 'regular' user groups were more likely to have a positive approach to their diabetes and to use their computers regularly at home for reasons other than just the diabetes system.

Many previous studies of diabetes eHealth systems, such as those discussed in the literature review, do not discuss issues such as system use, domestic technical problems, or participants saying they had no time or did not want to focus too much on their diabetes. However, Ferrer-Roca (2004b) reports problems with low use by doctors and patients as well as problems with poor technical skills, Cavan (2003) reports problems with data entry, and Keshavjee reports a technical failure (Keshavjee et al., 2003). In general there seems to be a tendency for studies to focus on positive outcomes and to either ignore or avoid reporting problems. Gary et al. (2003) suggest that this is a result of a publication bias through which positive results are more likely to be published than negative ones. Also, it is possible that

socio-economic status and health literacy had an impact on how the system was used in this study, but it is a limitation of the study that socio-economic data were not collected. Although the terms ‘health literacy’ and ‘eHealth literacy’ are not uniformly defined in the literature (Berkman et al., 2010, Norman and Skinner, 2006), some studies have found that patients with low health literacy are less likely to access and navigate around Internet-based health information with confidence (Sarkar et al., 2010, Knapp et al., 2011).

Looking at why participants wanted to use the eHealth system, a variety of aims were expressed. The six broad reasons given for wanting to use the system were: to improve health behaviour, to improve blood glucose control, to learn, to communicate, to change approach and to help. These findings indicate that from a patient perspective interest in using the eHealth system was not solely driven by a desire to improve glycaemic control. In contrast, many of the evaluative studies discussed in the literature review used very narrow health outcomes (usually improvements in HbA_{1c} readings) to measure the success of diabetes eHealth systems. Such measures reflect a practitioner-focused view of benefits rather than a patient-centred view.

The second sub-question was – how do patient participants change in response to the diabetes eHealth system? This was an important question in terms of understanding what changes participants perceived they had experienced during the course of the study. As this was primarily a qualitative study, the principal means for ascertaining what changes were made was to ask participants during interviews. In addition, participants’ HbA_{1c} readings from tests closest to the beginning and end the project were also noted. The limitation of this approach was that, apart from collecting HbA_{1c} readings, changes were not measured with standard instruments, and therefore before and after comparisons could not be made. Additionally, as it was not possible to closely control the dates on which HbA_{1c} readings were taken, not all HbA_{1c} data were closely aligned to the beginning and end of the project (as shown in Appendix 9). Evidence from interviews showed that most participants perceived that they had benefited from using the system regardless of how frequently they had used it. The benefits participants talked about were in line with the aims they had articulated during the earlier interviews: to improve health behaviour, to improve blood glucose control, to learn more about diabetes, to communicate with others, to change approach and to help others. Only a small number of participants indicated that they had not made any changes

while using the system. Participants also reported fluctuating success at making changes, and many said that they felt they had not done enough, and there was always more to do.

Mean HbA_{1c} readings across the whole group of participants showed no evidence of improvement even for those who used the system. As the dates on which readings were taken were in many cases not closely aligned to the beginning and end of the project, this evidence does not clearly link to the period of system use. However, it does indicate that use of the system did not influence health behaviours sufficiently for participants HbA_{1c} readings to show improvements within six months of use. However, individual results varied, with some participants' readings improving and others getting worse. Some previous studies similarly found that patients' HbA_{1c} readings did not improve after system use (Barrera et al., 2002, McKay et al., 2002), whereas others report improvements (Kwon et al., 2004b, McMahon et al., 2005, Bond et al., 2007, Ralston et al., 2009). However, as discussed previously, it is difficult to adequately compare studies of such systems. A distinction needs to be made between the technical 'software system' that is built and the 'intervention' that is used with the system. This study did not replicate any other study and it appears that no other replication work has been attempted in this research field, except same site replication in which a pilot study is run followed by a larger study (for instance Kwon et al., 2004b, Cho et al., 2006). This is partly because there is no off-the-shelf software available, and partly because health provision and services for patients with diabetes varies in different locations. Hence there is no common ground from which to make comparisons. There were in any case a number of differences between this study and previous studies. This study was not a randomised controlled trial, did not have a large sample size and focussed on gathering qualitative data. Also the trajectory of participants' illness was not accounted for, and the process for taking HbA_{1c} readings was not linked to the interviews so in some cases there was a gap between the project period and the readings being taken. Additionally, the intervention in this study did not offer patient participants a specialist service that provided more access to their healthcare practitioners through the system than they would normally have, as was the case with a number of other study interventions (McKay et al., 2002, Kwon et al., 2004a, McMahon et al., 2005, Gerber et al., 2007, Ladyzynski and Wojcicki, 2007).

To summarise, participants reported changes to health behaviours, diabetes approach, and diabetes knowledge while using the system. Many of the health behaviour changes mentioned were small incremental changes that were not sufficient to change HbA_{1c} levels. Attitude and

knowledge changes were not quantified, but were talked about. Participants particularly mentioned that using the system resulted in increased awareness of diabetes or a more positive attitude towards diabetes. Results reported by other studies (Cooper et al., 2008) have also found that patients may experience positive improvements from an intervention without glycaemic improvements. In this study the improvements that were particularly mentioned by participants were increased awareness, a feeling of not being alone, and increased knowledge about diabetes. The use of a health change model during the research study, such as the transtheoretical model (or one of the models discussed in section 2.3.4), would have been beneficial.

The third sub-question was - how do participants view the diabetes eHealth system? Participants expressed a range of views of the system. These included views that: it was a tool for managing specific problems, that it provided general background support, that it helped with focus and motivation, that it was a communication tool, a self-management and information tool, or it was a tool for the doctor. These multi-faceted views reflect participants' personal use of the system, and indicate that there were a number of different models of use. The toolbox view was expressed by several participants who felt that the system could be used to 'help' them with particular problems. A number of participants saw the system as general background support, saying that even though they may not have used the system very much, they liked the fact that it was there. Some saw the system as something that was there to motivate them and keep them on track. Some saw it as a tool for the doctor, so they could 'keep an eye' on them.

Only two other qualitative studies of diabetes eHealth systems of relevance to this study were found in the literature. The Ralston (2004) study was a small qualitative study of a web-based diabetes eHealth system, run in a Washington University general medical clinic. The Gammon (2005) study, run in Norway, investigated a mobile system for transferring blood glucose readings from teenagers with Type 1 diabetes to their parents' mobile phones. A summary of the studies' findings are given in Table #18 below. Themes identified in both studies show similarities to those found in this study: a sense of security and reassurance, surveillance, and focus upon illness. However, the study I report here involved more data collection, and a more in-depth analysis focussing on a holistic view of participants' diabetes management experiences than the Ralston and Gammon studies.

Study	Themes
(Ralston et al., 2004) 10 adults with Type 2 diabetes in primary care use a web-based system for 6 months. (Bg upload & view, diary, information, view medical record, communicate with doctor)	Feeling non-acute concerns are uniquely valued Enhanced sense of security about health & healthcare Frustration with unmet expectations Feeling more able to manage Valuing feedback Difficulty fitting the programme into daily life
(Gammon et al., 2005) 15 young people with Type 1 diabetes use a mobile system for 4 months. (Mobile system communicates blood glucose readings to parents).	Sense of security and reassurance Nagging and scolding Control, responsibility, independence Surveillance and opposition Learning and age-phased appropriateness Focus on illness If it's not automatic, forget it System type and functionality It depends how you use it

Table 18: Qualitative diabetes eHealth studies

Findings from this study touch on the issues of health surveillance, trust, virtual presence and anonymity. Although these issues have been investigated in studies of Internet use, their effect on patients' use of eHealth systems for chronic disease has only been touched on in some studies (Gammon et al., 2005, Whitten et al., 2009), and has not been investigated in much depth. There is a need for more understanding of these areas. Of these topics, trust is the only area that has been commonly investigated in relation to health applications (Hesse et al., 2005, Lemire et al., 2008, Sillence et al., 2007). The social and ethical dilemmas engendered by increasing reliance on various forms of technological surveillance have been well documented (Lyon, 2001, Ball and Webster, 2003, Lyon, 2003), and there is a considerable body of literature on the topic. Many of these discussions have their roots in the work of recent sociological and philosophical thinkers, particularly Michel Foucault and Erving Goffman, who have both written compellingly about surveillance and its covert effects on human behaviour. Goffman (1961) writes about institutionalisation and its effect on patients in a mental asylum. He discusses how the lack of privacy and constant surveillance in the asylum form part of a regime that results in a loss of identity. Foucault (1979) borrows Bentham's concept of the panopticon to talk about the self-regulating effect of constant, invisible surveillance. In the study presented here, the surveillance in question is

what may be called a ‘caring’ surveillance rather than a ‘punishing’ surveillance. The fact that so few participants talked about being watched suggests that in some ways it was either invisible to them or completely accepted by them. The behaviour observed in this study suggests that when system use is optional (as it was in this case) one way of dealing with the problems caused by surveillance is to avoid it. Using the system but not engaging with it as a catalyst for change could be interpreted as either a failure, or a refusal to internalise the message of self-surveillance implicit in the system. Lyon (2001) notes that few studies have looked at this type of surveillance. Vaz and Bruno’s study of self-surveillance and being medically ‘at risk’ (2003) suggests that a reason for this may be that it is difficult to separate power and care in such circumstances. They suggest those who care for themselves may take the view that others should be watched because they are careless with themselves. There are clear links here between self-surveillance, self-management of diabetes and the discourse of individual responsibility for health.

7.4 Experiences of Diabetes

Although the primary aim of this study was to investigate the use of the eHealth system, it was found that this was so bound up with participants’ experience of diabetes it was difficult to disentangle. Many of the experiences participants recounted during interviews, both of diabetes and of using the eHealth system, resonate with those found in other qualitative studies of patients living with diabetes. Paterson et al. (1998), in a meta-analysis of 43 qualitative interpretive research reports on the lived experience of diabetes and found that ‘balance’ was a key metaphor used. In addition, they found that learning from the body, learning how to manage diabetes and fostering supportive, collaborative relationships were important. These all resonate with the core aims and concerns discussed by participants in this study, and corroborate these findings.

Ingadottir and Halldorsdottir (2008) found that trying to stay focused was a feature of the lives of patients with diabetes, as was living with fear, managing conflicting desires and the dual role of both medical and experiential knowledge. They also found that patients talked about wanting to find a balance in life between managing diabetes and not letting it take over their lives. For some this led them to neglect or ignore diabetes. They also highlight the apparent conflict between autonomy and compliance that can make effective management difficult for some individuals. Similarly experiences of conflicting needs were expressed during interviews for this study. These were found to be influential in the use of the eHealth

system. Conflicting experiences noted in this study were: being supported versus being independent, knowing versus not knowing, focussing versus not focussing, being observed versus being left alone. Each position conflicted with the other – and each had disadvantages as well as advantages.

Charmaz has written extensively about patients' experiences of living with chronic diseases. She has particularly charted the effects of chronic illness on the self (Charmaz, 1983), identity (Charmaz, 2005) and constructing meaning (Charmaz, 2006b). She identifies feelings of isolation as a problem for those with chronic illness. Feeling alone with diabetes was a theme noted during the coding of the interview data in the study as it was mentioned by a number of participants. In the context of this study, a number of participants talked about wanting to make contact with others who had diabetes, as a way of helping them to feel less alone and also because they felt that sharing experiences with others was a useful way to learn more and to share strategies for coping. The discussion board was the most used part of the web site alongside the news and information pages, and was an area that elicited interest and comment during interviews.

7.5 The Technical Nature of the System

The diabetes eHealth system was designed as a technical system to be used on participants' home computers. The rationale for the technical design of the system was that it used technologies that were currently available and hence it was both practical and low-cost. However, a number of participants reported technical problems during the research, these were two-fold – first there were problems with home computer equipment and second problems with using the system.

Two thirds of participants reported problems with using their home computer at some point during the course of the research. The nature of the problems reported was not surprising, but the frequency of problems was. Two observations may be made from these findings: first that many participants did not prioritise having a working computer in the home, and second that many participants did not have the skills to look after and make full use of their computers at home. What emerged was a picture suggesting that there are problems with using home computers as a platform on which to launch this sort of technically intense system. Even if some elements of a system could be made extremely easy to use, some of these fundamental problems would remain.

Previous studies into home computing have concentrated on aspects such as the decision to buy home computers (Haddon and Skinner, 1991, Goolsbee and Klenow, 2001), working from home (Venkatesh and Vitalari, 1992, Haddon and Lewis, 1994), and social issues such as privacy and social control (Gandy, 1989, Beniger, 1989) and the effect on children (Orleans and Laney, 2000, Hughes and Hans, 2001). There are considerably fewer studies focussing on how people use their computers at home (Habib, 2000, Brush and Inkpen, 2007, Beauvisage, 2009). Statistics for home computer use in the UK indicate steady increases over the last decade, with home computer ownership reaching 75% in 2009, and households with Internet connections reaching 71% in 2009 (Office for National Statistics, 2010). However, statistics do not tell the whole story. As different members of a household become reliant on computers for a wide range of activities, there is often competition between family members for access to the computer. Additionally, considerable skill is required to set up, manage and maintain technology in the home so that it is in good working order (Kiesler et al., 2000, Grinter et al., 2005). It is possible that socio-economic status may have been a factor influencing technology use in this study, as there is evidence from other studies that it has an impact on technology use in the home (Po-An Hsieh et al., 2008), however socio-economic data were not collected.

The second technical issue raised was that participants reported problems with using the system itself. Many of the problems experienced were about transferring blood glucose data, either from meters to the home computer, or from the home computer to the website. There were too many points in this part of the system at which hardware and software configurations could conflict and cause problems. These problems were soluble but only if participants had the confidence to believe they could solve them. There were help lines available but participants seemed reluctant to use them. These problems could have been avoided if all data transfer had been built into the meter - however such devices are not available to buy and it was beyond the remit of this project to build such a device.

It appears that for some participants there was not enough 'ease of use' in parts of the system, particularly the blood glucose upload facility, and that this might have affected system use. The Technology Acceptance Model (TAM) (Bagozzi et al., 1992, Davis, 1989) and extended versions such as TAM2 (Venkatesh and Davis, 2000), TAM3 (Venkatesh and Bala, 2008) and the Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al., 2003) are often used to give some insight into the phenomenon of technology use and

acceptance, and were discussed previously in Chapter 2.4.1. In the TAM model, which is based on the theory of reasoned action (Fishbein and Ajzen, 1975), perceived ease of use and perceived usefulness influence intentions and actual use of technology. Extensions have added concepts such as performance expectancy, effort expectancy, social influence and facilitating conditions as well as concepts such as 'perceptions of external control' and 'voluntariness' that link to the concept of 'behavioural control' used by the Theory of Planned Behaviour (Ajzen, 1985). The TAM model and its variants have been used widely in Information Systems research to investigate the uptake of technology such as email systems (Szajna, 1996, Gefen and Straub, 1997), ecommerce (Pavlou, 2003, Koufaris, 2002), online banking (Pikkarainen et al., 2004) and wireless networks (Lu et al., 2003) amongst others. They have also been used to investigate the acceptance of health technology by practitioners (Hu et al., 1999) and patients (Wilson and Lankton, 2004). Although most of these studies report that the model is useful, many propose extensions to its constructs. Criticisms of the model and its variants have been that it is too simplistic (Salovaara and Tamminen, 2009), that it measures system use with self-reported data and in voluntary situations, that the intention-actual use link is weak, and that its determinism precludes the effects of individual reflection and decision-making (Chutter, 2009). In this study, questions were not asked about 'perceived ease of use' or 'perceived usefulness' although it can be inferred from the interview data that both influenced system use. However, indications from this study cast doubt on the strength of the link between intention to use and actual use. This problem has been noted by others such as Bagozzi (2007), who suggests that 'actual use' might be influenced by factors in addition to 'intention to use', as well as other studies of health technology (Flynn et al., 2009). My view is that the constructs in the Technology Acceptance Model, although useful as a starting point, do not reflect the range of issues that arise for those who use technology in the context of a complex health intervention such as the one presented in this study. This is because system use involves both using a new technical system and making changes to health behaviour. The gap that was noted in this study between 'intention to use' and 'actual use' is partially addressed in the Theory of Planned Behaviour by the construct 'perceived behavioural control' which influences 'behaviour' as well as 'intention' (Ajzen, 1991). However, in my view further studies are needed to unpick some of the issues that arise when technology use is linked to health education, health self-management and chronic illness. Results from this study indicate that 'use' issues are connected both to the technology and to the health aspects of the system. In this context other theories such as Activity Theory (Engestrom, 1987) and experiential learning may

prove to be useful theoretical lenses. Activity Theory addresses contextual issues such as ‘community’, ‘meaning’ and ‘sense-making’ (Nardi, 1996), all of which were found to be important factors in this study. Theories of experiential learning (Itin, 1999) and constructivism (Vygotsky, 1962), which view knowledge and meaning as being generated through the interaction of active experience and ideas, may also serve to throw light on how people use health technologies.

The technical issues uncovered in this study were complex. Some aspects of the eHealth system developed for this study could have been easier to use, but other aspects were very easy to use. The nature and patterns of home computer use varied widely and indicated that regular use of home computers was patchy and often not prioritised. Participants were asked whether they would have preferred to use a standalone handheld device (such as a Personal Digital Assistant) but the majority said they would not be interested in using one, often because it was perceived that the small size would cause difficulties with manipulating the device and viewing the display.

7.6 The Researcher’s Role in the Study

It is important to consider the role of the researcher in the research process particularly in qualitative work (Silverman, 2005, Charmaz, 2006a). With a study such as this it is inevitable that a relationship develops between the researcher and the participant. As the researcher running the study I recruited and interviewed participants and spoke to them on the phone between interviews, and therefore my contact with them formed part of the intervention. This personal contact with an outside researcher would not have occurred if the system was being run by health-practitioners and administrators at the practice. It is difficult to assess the precise impact of this contact; however it undoubtedly had some effect. For instance, when talking about the benefits of taking part in the study in the final interview Smilecup said that one of the benefits for her was *‘I’ve had these nice chats with you’*. As the interviews consisted of participants talking about their experiences of managing diabetes and using the system, the interviews themselves were a way for participants to reflect on their experience of the disease and its management with an outsider. This in itself was a form of intervention.

When conducting the interviews I was careful not to express any opinions and to let participants talk for as long as they wanted to about the issues raised. Also, I made it clear to participants that I was interested in what they had to say even if they had not used the system

much. With some participants this resulted in long interviews that went off the topic several times. In these cases I had to gently bring the interviewee back to the matter in hand. However, this style of interviewing was an important part of the methodological approach chosen, and was followed so that rich descriptions of experiences could be gathered. I believe that as participants became familiar with me and the presence of the tape recorder they became more open. I noticed that several participants made interesting observations during the final interview, and I considered that these may have occurred at this point because participants felt more at ease. For instance, Rosecandle admitted that he had had some uncertainties about his diagnosis which he had not mentioned before, and Lilyrose talked about how her religious beliefs affected her approach to diabetes. There were therefore advantages as well as disadvantages to being an active participant in the research process.

As the sole researcher I both collected and analysed the data on my own, with support from my supervisory team. This approach was used largely for practical reasons, as my supervisory team had changed during the project and the new team did not have time to analyse large quantities of data. Their role was therefore to guide me by scrutinising my work and interrogating my findings. This was useful as I gained experience of working as an independent researcher. During the study I was grappling with a large amount of data and using qualitative methods for the first time. The analysis process therefore took time, during which I became more confident about my decision-making and judgements. I spent a considerable amount of time during this period thinking about alternative ways of expressing the themes that arose in the work, and considering the relative importance of aspects of the research. For example, I questioned whether to include the embedding health context or focus entirely on experiences of the technical system. Whilst this approach afforded me an ideal opportunity to gain analysis experience, it meant that I did not get experience of working in a team. It also resulted in a lack of investigator triangulation, which is used to ensure confidence in and credibility of a study's findings. The limitations of using this approach are discussed further in the limitations section (8.4).

7.7 Summary

This chapter has discussed the results from the study in the light of other research in the field. To summarise, the conceptual framework developed for this study showed that the diabetes eHealth system was used as part of participants' diabetes management process. The system is viewed as a boundary structure through which boundary objects are created and

shared between participants from different social worlds. From a patient perspective many activities undertaken through the eHealth system involve the sharing of boundary objects across the boundary between the private, individual sphere of the self-management and the public sphere of communicating with others. The strength of the alliances made through the system was affected by the efficacy of the boundary objects shared through the system to satisfactorily translate the concerns and engage the interest of users.

The research question and sub-questions asked at the beginning of the study were reviewed and discussed in this section. This discussion covered frequency of system use, reasons for system use, participant self-reported changes, HbA_{1c} readings, and views of the system. Although using the system did not result in measureable HbA_{1c} changes the findings suggest that patients valued a wide range of outcomes additional to health benefits.

Other topics discussed in this chapter were issues raised such as health surveillance, trust, and anonymity. Findings from the study were discussed in relation to other qualitative studies of diabetes. Themes that emerged during this study such as ‘finding a balance’ and ‘feeling alone with diabetes’ were discussed in the light of other studies. These themes show how individuals’ use of the system was closely linked to their experience of diabetes. Finally, the technical nature of the system was discussed. The two main technical issues that arose – problems with home computer equipment and problems with using the system – were discussed in the light of the literature. The study was discussed in the light of the Technology Acceptance model, but it was found that while this casts useful light on some issues, it is too generalised to provide useful insights into a complex health intervention such as this one. Finally, the role of the researcher was discussed, particularly the impact of the frequent personal contact I had with participants on the study.

This discussion has highlighted that a rich diversity of issues converge when the diabetes eHealth system is used. In the following chapter the main contributions from the study are presented and conclusions are drawn.

8. REFLECTIONS ON THE RESEARCH: CONCLUSIONS

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What we call the beginning is often the end
And to make an end is to make a beginning.
The end is where we start from.

T. S. Eliot 1888-1965: *Four Quartets 'Little Gidding'* (1942)

8.1 Introduction

Following on from the previous chapter which discussed the results and implications of the work presented in this thesis, this chapter concludes the thesis by drawing out the key findings. It will do this by providing an overview of the key points made so far, summarising the contributions made, discussing the limitations of the research and making suggestions for further study.

8.2 Overview

The research undertaken for this study was a qualitative investigation of the use of a diabetes eHealth system in a primary care setting. The focus of the enquiry was patient experiences of using the system. The aim of the study was to further our understanding of how and why patients engage with diabetes eHealth systems. The underlying view I take in this study is that effecting change for patients through complex eHealth interventions requires an understanding of many aspects of the experience of the intervention, not just one simple outcome measure. Such an understanding can only be gained by uncovering and exploring the wide and rich range of experiences patients have of the eHealth intervention and looking at all the contextual features that feed into those experiences.

In Chapter One, I contextualised my research by discussing how technology use in healthcare is changing with the widespread use of Information Technology systems. These changes are occurring in the context of a general diffusion of Information Technology into all aspects of life at work and at home. As part of these changes and our increasing familiarity with Information Technology systems, a technological determinism pervades the discourse about Information Technology use.

In Chapter Two, I reviewed the literature specifically relevant to this study. I started by considering the growing global incidence of chronic diseases, particularly diabetes, and resulting concerns about the ability of public health systems to manage the increasing demands put upon them. I then summarised the literature on self-management in diabetes, particularly focussing on the work of Kate Lorig, who emphasises the importance of building patient confidence and self-efficacy (Lorig, 1982, Lorig, 2001). I then outlined the introduction and development of Information Technology systems in the NHS. Most of these systems have been developed for healthcare practitioners, but some patient-focussed systems such as NHS Direct have been developed. At the same time there is evidence that many individuals are using the Internet to search for health information. In the rest of the review I focused on technology for supporting patients with diabetes. The introduction of blood glucose meters that patients can use at home was the first big step towards a usable technology to support the healthcare needs of patients with diabetes. This was followed by the development of systems that connect patients to healthcare practitioners and endorsed learning materials. I concluded with a review of empirical studies of such technologies. I categorised these into educational systems, communication and social support systems, mobile systems and personalised Internet-based systems, with the focus on the final category. The conclusions I drew from this review were that many of these systems are prototypes or trial systems and few qualitative investigations into their use have been undertaken – so an understanding of how this technology is used by patients with diabetes is still in its early stages.

In Chapter Three I introduced and explained the methodological approach taken in the study. I started with a statement of the broad research question for the study ‘How do patients experience using a diabetes eHealth system?’ In addition I added three sub-questions. ‘How and why do patients use a diabetes eHealth system?’, ‘How do patients change in response to using a diabetes eHealth system?’ ‘How do patients view a diabetes eHealth

system?' I gave a rationale of how these research questions were developed from the original research questions while the study was underway, as a result of observations that participants were using the system in ways that had not been anticipated. I went on to outline and discuss the different methodological and epistemological positions that are commonly taken in Information Systems research in particular the increasing number of studies that reject the positivist paradigm. I then presented and discussed the approach I chose for this study. In summary, the epistemological approach was social constructionism and the theoretical perspective was interpretive using a symbolic interactionist approach. This approach was taken because I was particularly interested in investigating the interplay between the constructed meanings and actions of participants as they used the system. The methodology I used was a qualitative enquiry with elements of grounded theory, and the data collection methods I chose were interview, document collection and web page monitoring. Next, I outlined the research design, and provided a rationale for each element of the study. The study was designed so that each participant used the system for six months, and I interviewed them at the beginning, middle and end of the six month period. I also gave details of patient sampling and recruitment. Following this I discussed my approaches to qualitative semi-structured interviewing, and data analysis. I chose to broadly follow the grounded theory approach, as it provided a set of structured techniques that aided analysis and because of its close alliance with symbolic interactionism. Finally, I discussed the approach I took to ethics, research governance, and procedures for ensuring patient consent, confidentiality and anonymity, security and freedom from harm.

In Chapter Four, I discussed the set up and running of the study. First, I explored the two guiding factors for the design rationale – these were the design of similar systems investigated by previous studies and the needs of the primary care environment in which the system was to be used. I described the two views of the functionality of similar systems that were developed: the user/functionality view and the data management view. I discussed the features found in previously reported Internet-based diabetes eHealth systems and I described the features implemented in the system developed for this study. Following this, I discussed the research setting and the recruitment process. Finally, I gave an overview of the participants and healthcare practitioners recruited to the study.

In Chapter Five I presented the results of the study for each of the three categories I had identified. The content of each category was broken down into sub-categories. I explained

the content of each sub-category and presented a range of stories and quotations from participants to illustrate each category. The first category was the *Diabetes Self Management Experience* that covered the personal self-management experiences of participants. Participants talked about their diabetes symptoms and experiences, the approach they took to self-management and the aids and tools that they used to help them self-manage their diabetes. The second category was the *Diabetes Support Experience* that covered the outward-facing support-seeking experiences of participants. Participants talked about their support experiences, their support-seeking approach support aids and tools. The third category was the *Diabetes eHealth System Experience* that covered participants' experiences of using the eHealth system. Participants talked about their aims for using the system, their experiences of technology and the barriers and facilitators that helped and hindered them in using the system. They talked about how they used the system, how they viewed the system and what benefits they had gained from the system. Finally, they talked about expectations they had for the system that had not been met.

In Chapter Six, I presented and discussed my conceptual framework of the diabetes eHealth system. First, I presented a diagrammatic model of how the categories identified through the analysis related to each other. In this model participants' diabetes management experience is modelled as a cyclical process which consists of self-management and support-seeking. The eHealth system sits between these two aspects and provides support for both of them. I introduced the concept of the eHealth system as a boundary structure that enables the sharing of boundary objects between users who inhabit different social worlds. Finally, I discussed the system qualities of surveillance, automation, endorsement and interaction.

In Chapter Seven I discussed the main points made in the thesis. First, I reviewed the conceptual framework and discussed how the concept of boundary objects has been used in Information Systems literature, particularly in relation to health Information Systems. I discussed the eHealth system as a boundary structure that allows the sharing of boundary objects between those from different social worlds. Second, I revisited the research questions and outlined the insights gained from the study in relation to each research question. I discussed the issues of surveillance, trust and anonymity in relation to other literature, and contrasted the outcomes from this study with those of studies discussed in the Literature Review. I noted that the insights gained from this study shared similarities with those from other qualitative studies. Third, I discussed participants' experiences of diabetes. Two themes

emerging from this study that resonated with findings from other qualitative studies were: the need to find a balance when managing diabetes; and feeling alone. Next, I discussed the use of technology in the home. The two main observations from this study were that participants frequently reported problems with home computer equipment and secondly, they experienced a variety of problems with using the system. Finally, I considered the usefulness of applying the Technology Acceptance Model (Davis, 1989, Bagozzi et al., 1992) and its variants to this research, concluding that although the issues of 'perceived ease of use' and 'perceived usefulness' were relevant to system use the entanglements that participants discussed during the interviews reached beyond these two simple concepts.

8.3 Summary of Contributions

This study contributes to Health Information Systems research as it is an in-depth qualitative research study of a patient-focussed eHealth system, of which there are only a few examples. This investigation is the only qualitative study of a patient-centred diabetes eHealth system run from an English GP practice that I am aware of.

8.3.1 Theoretical Contribution

The theoretical contributions made by this study are twofold. First, I found that participants used the system as part of their own personal diabetes management process and there were consequently considerable individual differences in the views they had of the system and the ways in which they used it. Participants' use of the system was also influenced by their use of technology in the home and other personal priorities for their time and focus. Using the system was therefore deeply embedded in participants' overall experience of diabetes. The system seemed more likely to encourage small changes than large changes, and hence the impact on health was not easily measurable (for instance by looking at changes in HbA_{1c}). This contribution indicates that in order to design effective technological interventions to support diabetes management and change, more qualitative studies need to be undertaken. There is clearly room for innovative work in this field, but the design of systems needs to take account of the concerns and tensions of the lived experiences of people with diabetes.

The second theoretical contribution of this study is my proposal that the diabetes eHealth system should be seen as a boundary structure that enables the creation and sharing of boundary objects. I adopted the concept of 'boundary objects' (Star and Griesemer, 1989) as a lens for interpreting the system in use. Additionally, I proposed the concept of a 'boundary

structure' as a way of describing how the diabetes eHealth system used in this study provided a framework of facilities for creating and sharing boundary objects. The benefit of using these concepts in the interpretation of the study is that they enable us to talk about eHealth systems at a higher level of abstraction and to begin to develop a language through which we can discuss their properties. The concepts used in this study help us to consider the general properties of the virtual objects that are created in the system and the meanings and consequences of the social interactions that occur as those objects are created and passed around the system. In particular this view of the diabetes eHealth system helps to explain some of the apparent contradictions in its use – particularly the tensions between wanting to focus on improving diabetes while not allowing the focus on diabetes to become too dominant; between wanting to be independent and needing support; between wanting to be looked after but not wanting to be the subject of surveillance or intrusion. This conceptualisation of the eHealth system also helps to shape the discussion about the issues of surveillance, trust and anonymity that are raised as boundary objects are shared among system users.

Walsham (1995) suggests that there are four types of output from qualitative research of information systems (1) development of theory, (2) generation of concepts, (3) drawing of specific implications, and (4) contribution of rich insights. Both Walsham and others (Klein, 1999b, Hirschheim and Klein, 2000, Sawyer, 2000) have criticised Information Systems research for producing outputs that are too focused on specific implications and rich insights rather than concepts and theory. Work undertaken in the early stages of this PhD (Flynn and Gregory, 2004) reviewing twenty years of IFIP 8.2¹² empirical research, found that although theory was being generated it would be more useful to the research community as a whole if it was made more explicit. This study has aimed to develop concepts and theory that will contribute to a greater understanding of patient-oriented eHealth systems.

8.3.2 Practical Contribution

As well as providing theoretical contributions, I have made a number of practical contributions. First, the study was a detailed qualitative study of the use of a diabetes eHealth system by patients and healthcare practitioners in a city-based primary care practice

¹² IFIP is a multinational organisation with an interest in Information Systems, www.ifip.org. IFIP is an acronym for Information Federation for Information Processing. It consists of a number of technical committees and working groups. IFIP Technical Committee 8 is on Information Systems, and Working Group 8.2 is on the Interaction of Information Systems and the Organization.

in the UK. As such it makes a contribution to the field of eHealth research by adding to the set of qualitative empirical studies of such technologies. Accumulating a set of real-world studies is particularly important in this field as this is the only way in which we can build an understanding of the real impact of systems.

Findings from the study show that use of the diabetes eHealth system developed for this study did not influence health behaviours sufficiently for participants Hb_{A1c} readings to show improvements within six months of use. In addition, the study found that confidence with technology and frequency of home computer use varied considerably, and both these factors influenced participants' use of the system and hence the benefits they experienced from using it. Finally, in this study participants reported benefits from using the systems that were not just related to glycaemic control. For instance, participants mentioned having a more positive attitude towards diabetes during the project, not feeling alone, learning more about why blood glucose readings changed by looking at graphs, and feeling that support was there if it was needed. Whilst these benefits do not necessarily directly lead to improved glycaemic control they were nevertheless valued by patient participants. This study has found that it is important to build eHealth systems that accommodate the needs of patients with diabetes.

These findings have several implications for practice. First, they suggest that sharing blood glucose data with healthcare practitioners may not always result in improvements to glycaemic control as some previous studies have suggested. Additionally, they suggest that future eHealth research should investigate systems that are designed to deliver a range of benefits to patients in addition to glycaemic control. Finally, further studies should look at a range of technologies, including novel technologies, in order to find out which ones are most appropriate for this group of patients.

8.3.3 Methodological Contribution

Results from this study have highlighted the importance of undertaking qualitative research in eHealth as well as quantitative studies. This is particularly important where interventions are complex and technological systems are not yet fully mature. My study contributes to the field as it is one of a small set of qualitative diabetes eHealth studies. It also contributes to the field of Information Systems evaluation, where much work is quantitative and short term, rather than qualitative. The methodology chosen ensured that this study particularly focused on patient experiences of eHealth technology, which again is an under-studied area. eHealth

studies typically focus either on the technology developed or the intended public health benefits of interventions. Patient participants are often viewed as the ‘objects’ of such interventions, and are measured as if they were the dependent variable in an experiment. In contrast, patients are put in the centre of this study and they are seen as actively creating meaning from their experiences of using the eHealth system. New encounters with technology are particularly interesting to investigate in this way as they provide a catalyst for revealing perceptions, behaviours and interactions which later on become embedded and unconscious and are hence difficult to untangle.

8.4 Limitations of the Study

There are a number of limitations to the research study undertaken.

The lack of triangulation in the study is a limitation. Denzin (1970) distinguishes four types of triangulation: data (using different sampling approaches to gather data), investigator (using more than one field investigator), theoretical (using more than one theoretical position in interpreting data) and methodological (using more than one method for gathering data). Generally in qualitative research the emphasis has been on using more than one investigator or data source (Bryman, 2001), in order to increase confidence in the findings and hence credibility of the research. Credibility is an important aspect of the trustworthiness of qualitative research (Lincoln and Guba, 1985) and hence it’s quality. Methodological triangulation was carried out in this study, through the collection of qualitative interview data and quantitative log-in statistics. However, while the log-in statistics confirm what participants said about their frequency of system use, they do not help to confirm the main findings which rely on an analysis of the content of the interview data. For this purpose, investigator triangulation would have been the most useful approach. However, as discussed previously in section 7.6, this was impractical for the purposes of this study for numerous reasons: it was not possible to fund extra researcher time, the supervisory team changed during the study, and as a PhD study, the aim was to undertake the work independently.

Conducting the study, interviews and analysis on my own was a limitation of the work. Working in a team would have provided more opportunities for sharing ideas and comparing interpretations. Although I was careful to follow a rigorous coding process when analysing the interviews, and from these to gradually develop sub-categories, categories and then a conceptual framework, there was nevertheless a subjective element to this process. From the

beginning of the coding process each decision I made represented a small act of interpretation. The codes and categories I chose each simplified and summarised the data. There was therefore an unavoidable subjective and interpretive aspect to the analysis. Working in a team with others may have provided a way to triangulate the analysis, although the value of triangulation and the need to seek reliability in qualitative research is disputed by some authors (Denzin and Lincoln, 2000, Lewis and Ritchie, 2003). The view taken in this study is that although the complexity of the phenomena being studied and the individuality of the context make it unique, the categories developed through the analysis should be broadly applicable to other similar situations. The concepts of boundaries, boundary structures, boundary objects and social worlds used to interpret the study have aided the interpretation and provide the basis for a theoretical understanding of the phenomena from a broader social perspective. Using a team approach to analysis may have been helpful but it was not viable as PhD work needs to be individual. However, I discussed each stage of the analysis process with my supervisors and made changes to the categories and the conceptual framework as a result of our discussions about their comments, so there was some element of team work in the analysis.

There were limitations to the study because it was undertaken in one GP practice with a small group of participants. A more varied group of patient participants may have been recruited if the work had been undertaken in more than one practice. However, although ethical approval was given to work in more than one practice, that had only been sought as a backup and it was not necessary to start work in the second practice because sufficient participants were recruited from the first. Additionally, it would have been useful if more GPs in the practice had been involved in the study so that a wider variety of practitioner views could have been investigated and a more complete view of the system could have been built. However, as the study focussed on patient participants I did not consider it essential to encourage more GPs to take part. Patient recruitment was adequate for the type of study undertaken, although because of the nature of the study a large amount of data was collected. I decided to slightly over-recruit to compensate for potential drop-outs, and the final number of 32 patients completing all three interviews was close to the original estimate of 30.

There were limitations to the study caused by the necessity of developing pilot software for the study. As described previously the software was built as simply as possible using currently available technology. There is no doubt that if more time had been available for software

development some improvements could have been made, particularly to the upload process. The primary limitation in the software design was that the Compass software and the web site were two separate systems, and participants had to learn how to use both of them. Ease of use would have been improved if blood glucose readings could have been uploaded directly from the meter to the website, thus bypassing the Compass software altogether. However, that would have involved a completely different type of technical development, which was not feasible in the scope of this study. Additionally, the decision not to employ a user-centred design approach to the system was a limitation as having end-users on the design team would have ensured their insights informed design decisions. Advantages of using a user-centred design approach are improvements in acceptance, accuracy, efficiency, user understanding and reduced errors and need for training (Kujala, 2003, Bevan, 1999). However, disadvantages are the potential of user-developer conflict (Howcroft and Wilson, 2003), and increased workload (Broadbeck, 1984). There are many tensions inherent in deciding how to develop and evaluate new technologies in a research project. If end-users are heavily involved and consulted while iteratively specifying and testing software it is difficult to find time to conduct a thorough evaluation. Engaging users in the development of software is a different process from that of engaging users in in-depth evaluation, and ethical approval would have had to have been requested twice, once for each part of the process. There has been a lot of research on users being involved in requirements gathering and software development but very little on in-depth evaluation as part of a systematic approach to systems development (Waraich and Brna, 2007, Muller, 2008, Farbey et al., 1999). The aim of this project was to evaluate how the facilities provided would be used to meet the long-term needs of patient participants with diabetes. This can be seen as a form of Information Systems development work, but one that requires a longer time-line than prototyping or post-development evaluation methods.

As much of the data were collected through interviews there is also a question about how fully participants disclosed their views when they were talking to me and to what extent they adapted their stories to fit in with their perceptions of me. This is always a problem when working with human research subjects (Silverman, 2005). While log-on counts and upload data can be captured electronically, interview data is verbal and there is no way of verifying its accuracy. This problem is therefore a general limitation of this type of research. There were a few occasions when I noticed that participants had said one thing in one interview and something apparently contradictory in another interview. By undertaking qualitative research

however, one is acknowledging that story telling is an important part of sense-making and the changes made to stories as they are told and retold needs to be seen as part of that process (Frank, 1995).

Finally, the role of the researcher in the research process can be viewed as a limitation of the qualitative research method used. The interviews themselves were a part of the intervention that would not normally have occurred and which may have affected the way in which participants viewed the system and the benefits they gained from taking part in the study. This personal contact with an outside researcher would not have occurred if the system was being run by healthcare practitioners and administrators at the practice. It is not possible to measure the effect that the interviews may have had but they were an important part of the study and their potential effect needs to be acknowledged.

8.5 Further Research

Results from this study indicate that patients may experience a variety of benefits as a result of using a diabetes eHealth system, but that further research and development is needed. This study did not support the finding of some other studies that such systems benefit patients by improving glycaemic control. However, it was found that patients sought and received a wide variety of health-related benefits through using the system such as increased knowledge, support to make improvements to lifestyle, blood glucose control and approach to diabetes, as well as feelings of comfort and not being alone. Participants' varied responses to the system suggest that a 'one size fits all' approach is not appropriate. Further research may be easier if different facilities in the system, such as blood glucose viewing, discussion boards, activity and exercise support and trusted information were investigated separately in order to ascertain exactly what benefits can be gained from their use and how they should be designed to maximise the benefits to as many participants as possible. Additionally, the finding from this study that participants with several health problems were generally less likely to use the eHealth system than those without, is worthy of further investigation. With rising levels of obesity and sedentary lifestyles, more patients are likely to present with co-morbidities (Hirani et al., 2007), hence further work is needed to explore how the design of eHealth systems can be improved to support the needs of those patients.

One of the core facilities in the system developed for this study was the sharing of blood glucose readings with healthcare practitioners. While this has been shown to be feasible, it

was not found to be significantly beneficial in the setting used for this study. However, participants found that viewing their own blood glucose readings was often beneficial even if they only did it for a short period of time, and that getting feedback from healthcare practitioners was useful. Other models of viewing and sharing blood glucose readings need to be investigated, particularly looking at the needs of different groups of patients and different levels of sharing and support. For instance, while a small number of patients with poorly controlled blood glucose readings may find sharing blood glucose readings useful, other patients may find that sharing readings is only necessary occasionally when they have a specific problem. Areas for further investigation are the impact and experience of health surveillance and conflicting views about sharing health data. Additionally, further studies should investigate the views and responses of healthcare practitioners when using diabetes eHealth systems in order to explore how they construct their communications with patients through them.

Evidence from this study indicates that participants often felt alone with diabetes and wanted to be able to share their experiences with others and to communicate with health practitioners in safe, trusted environments. Further studies of discussion boards, chat rooms, virtual support groups and systems for communicating electronically with health-care practitioners would be worth pursuing. Aspects of such systems that need investigating are anonymity, trust, virtual presence, and the impact of using eHealth systems in the home.

Finally, novel technologies such as ambient, tangible and embedded systems may provide helpful ways of supporting the health needs of those with chronic disease. These technologies may provide useful ways of supporting people in subtle ways by addressing some of the needs identified in this study.

8.6 Concluding Remarks

There were three main findings from this study. First, the diabetes eHealth system was used as part of participants' diabetes management process. There was evidence that its use enhanced and supported diabetes management practices particularly for patients who had a positive or disciplined approach, but barriers to use were also identified and for some they were insurmountable. Second, the study found that the system crossed the boundary between the personal sphere of self-management and the external sphere of seeking and receiving support. Through the co-location of these two spheres participants could create and share

boundary objects. While this provided possibilities for collaboration and learning it also exposed participants to scrutiny and criticism. Third, the study found that using the system did not result in general improvements to glycaemic control but that it resulted in a wide range of other benefits that participants valued. These results indicate that technical systems to support patients with diabetes are viable but need to be carefully designed.

This thesis has reported the experiences of patient participants using a diabetes eHealth system over a period of eighteen months. Patient-focused eHealth is an area of growth in a world in which technology use is ubiquitous and global health challenges are growing. Technological determinism, with its assumption that new technology will inevitably lead to improvements, is a dominant discourse and is often used as a rationale for new developments. However, if we are to build technical systems that work for people we need to understand how and why they are used, not simply presume that because something is technically feasible it will be beneficial. Results from this study indicate that there is a place for simple but carefully designed systems to support patients with diabetes. The development of such systems needs input from a wide range of stakeholders: healthcare practitioners, policy makers, administrators, researchers, and software developers, but most importantly from patients themselves.

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10. APPENDICES

Appendix 1: Summary of related studies

Author	Type 1/2	Number of participants	Study length	Equipment	IT Features	Results	People help	Comments
American								
Ralston et al. 2009 & Harris et al. 2010	2	83	12 m	None given, needed comp./Int.	Bg upload, diary, info., ecomm. with Dr./nurse	Sig Lower HbA1c	Started with care management meeting. Uploads reviewed by nurse daily	RCT
Bond et al. 2007	2	62	6 m	Equip. given if needed	Info., online counselling, weekly chat session, daily activity log	Sig lower HDL chol.	Online patient programme, with active nurse involvement	RCT. Patients >60yrs
McMahon 2005 & Fonda et al. 2009	1&2	104 (52)	12 m	Given comp., bg meter, Bp meter	Bg upload, info., messages to nurse	Sig Lower HbA1c and blood pressure	Education class at beginning, phoned after 2 w if not logging, queries answered within 1 day, expert review of bg readings	RCT – ½ did study, ½ normal care. Lots of extra support
Goldberg 2003 & Ralston et al. 2004	2	10	6 m	None given- needed comp./Int.	Bg upload, diary, info., ecomm. with Dr/nurse	Some impr.	Uploads reviewed by nurse once a w	6 patients used the system 'in meaningful way'
McKay et al 2002 Barrera et al 2002	2	160	3 m	Given a D-Net comp. & Int.	(PC) & (A) – bg upload, messages (PS) & (A) – ediscuss., All – info.	Sig. impr. in dietary control – little else. PC and PS gps better.	2-6 hours initial training, PC & A twice weekly contact with dietary specialist, PS group had peer support	Randomised – 4 options info(I), personal coach (PC), peer support (PS), all (A). Bg uploads not used much.
Selecky 2001	1&2	6469	12 m	Given bg & bp meters. Either paper, phone, fax or Int.	bg, bp, hr readings, weight recorded, Info.	Cost reduction	Nurses for personalised coaching (high risk – got regular 1-1 coaching)	Different interventions according to risk.
European								
Ferrer-Roca et al. 2004	1 & 2	12	9 m	Needed comp./Int. or mobile phone.	Bg readings weight	Users satisfied, but preferred mobile	Doctors looked at web pages	Low recruitment, tech probs with home equip. Drs used infrequently
Plougmann et al. 2001 & Cavan 2003	1	6	6 m	Needed comp./Int.	Bg readings, insulin & food data	Helpful, tech diff, non-use	Automated feedback given to patients	Interesting patterns of non-use

Asian								
Cho 2006	2	80	30 m	Needed comp./Int. at home	Bg, weight & bp readings, drug data, ecomm.	HbA1c sig lower	Started with education programme. Diabetes specialists checked web site daily – sent individualised recom. Patients emailed when didn't log on	RCT. ½ int, ½ control
Kwon 2004b	2	110	12 w	Needed comp./Int. at home	Bg, weight & bp readings, drug data, ecomm.	HbA1c sig lower in int group	Diabetes specialists checked web site daily – sent individualised recom. Patients emailed when didn't log on	RCT. ½ int, ½ control

Table 19: Summary of related studies

Glossary of abbreviations by column:

Study length: m = month/s, w = week/s

Equipment: bg = blood glucose, bp = blood pressure, comp. = computer, equip. = equipment, Int. = Internet

IT Features: bg = blood glucose, bp = blood pressure, ecomm. = electronic communication, ediscuss = electronic discussion board, hr = heart rate, info. = information,

Results: HDL chol = High-density lipoprotein cholesterol, impr = improvement, int. = intervention, recom. = recommendation/s, sig = statistically significant

People help: bg = blood glucose, w = week/s

Comments: bg = blood glucose, int. = intervention, RCT = randomised controlled trial

Appendix 2: Patient invitation letter and explanatory leaflet

Diabetes Co-management Pilot Project Letter of Invitation

You are being invited to take part in a research study. Before you decide whether to be involved, it is important for you to understand why the research is being done and what it involves. Please take the time to read the following information carefully and discuss with others, including your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Purpose of the Study:

The purpose of the study is to find out if you will benefit from using a computerised web-based system that allows you to receive and store information about your diabetes and your lifestyle, and to share that information with your GP and practice nurse. The purpose is also to find out what attitudes there are towards using web-based systems for health purposes and whether being given information to browse in your own time helps you to understand your health better and motivates you to change your lifestyle to improve your health.

Criteria for inclusion in the study:

Patients who are eligible to take part in this study have to have diabetes, either Type 1 or Type 2, be aged 18 or over and be a patient at the Aintree Park Group Practice. Additionally you will have to have regular access to a computer and be able to read and write in English. In order to take part in the study you will have to have access to the Internet. If you do not currently have Internet access but would like to take part, we will be able to fund Internet access for some patients, so please contact the researcher, whose details are shown below.

The pilot study requires 25-30 individuals to take part. The research is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw from the project at any time. If you decide not to take part this will not affect the standard of care that you receive.

Your part in the study...

The study will take 6 months and will involve you logging on to a password-protected website where you will be able to upload and view blood glucose levels, use a diary, input health data, read weekly emails about health and nutrition, read other information about diabetes, contact your GP and practice nurse, discuss issues with other diabetes patients.

As part of the study you will be given a blood glucose monitor and shown how to use it. You will be interviewed at the beginning of the project, after 3 months and after 6 months in order for the researcher to gather information about your views over the period of the trial. You will also be asked to have some basic health checks (such as HbA_{1c}, weight, blood pressure) at the beginning of the project, after 3 months and after 6 months.

If you would like more information about the project or to take part in the project then please speak to your GP or ask at reception or contact:

Peggy Gregory, Department of Computing
University of Central Lancashire, Preston, PR1 2HE
Tel: 01772 893284
E-mail: ajgregory@uclan.ac.uk

Diabetes Co-management Pilot Project Patient Information Sheet

You are being invited to take part in the diabetes co-management pilot project. We value your input to help us with this research. The information below is for your reference and for you to keep throughout the duration of the project. Please take the time to read the following information carefully and discuss it with others, including you GP if you wish. Take time to decide whether or not you wish to take part. Ask us if there is anything that is not clear or if you would like more information.

Purpose of the Study:

The purpose of the study is to find out if you will benefit from using a computerised web-based system that enables you to receive and store information about your diabetes and your lifestyle (exercise and nutrition), and to share that information with your GP and practice nurse. The purpose is also to find out what range of attitudes there are towards using web-based systems for health purposes and whether being given information to browse in your own time helps you to understand your health better and motivates you to change your lifestyle to improve your health.

Who is organising this project?

The research is being undertaken by a team at ***** in collaboration with researchers from the University of Central Lancashire and the University of Manchester. The study has been reviewed and has favourable approval from the ***** Local Research Ethics Committee processed by COREC.

Frequently asked questions:

What will I have to do?

At the start of the project you will be asked to visit your GP to discuss a plan of action. The practice nurse will take some readings (for example a blood test, blood pressure, weight). The practice nurse will also give you a blood glucose monitor and show you how to use it. You will also be given a user name and password to enable you to log on to the web site, and some software and a data cable so that you can transfer data from the blood glucose monitor onto your computer. You will be given help to set up the software on your computer if you need it.

During the project you will be asked to log onto the system as many times a week as you wish and load up your blood glucose data. You will be asked to use the features of the system as you wish – these are: viewing blood glucose readings, entering other health data, using a diary, reading emails about nutrition and exercise, reading information about diabetes care, communicating with the practice using the system and communicating with other diabetes patients using a discussion board.

After 3 months you will be asked to have a consultation with your GP and to have some readings taken by the practice nurse (as before). You will also be interviewed by the researcher about how useful you found the system. You will then be asked to continue using the system for another 3 months. After this you will have a final short consultation with your GP and final readings taken by the practice nurse. You will also be interviewed again to find out whether you have found the system useful in the long term.

So how long will I have to be involved?

The project is a 6 month long project. As well as the time you spend at home using the system, the initial consultation and interview will take about 1 hour, the data collection and interview after 3 months will take about 1 hour and the final data collection and interview at 6 months will take about ½ hour.

How many other people are involved?
25-30 people are participating in this project.

Who will know that I am taking part?
Whoever you wish to tell. Your GP will know you are participating in the project as will the practice nurse. We will not tell anybody else of your involvement in the research.

Where and when will the interviews take place?
The interviews will take place at the Aintree Park Group Practice. The interviews will take at a time that is convenient for both you the practice and the researcher. The interviews will be confidential, but the researcher will ask your permission to tape them for data collection purposes. All data kept about the project will be kept anonymously (so your name will not be linked with your interviews), and will be deleted after the project has finished and the results written up.

Where can I look at the web site?
You can look at the web site wherever you normally access the Internet.

Will the researcher have access to any of my medical records or speak to my GP about me in connection with this project?
No.

Will the data I store in the web system be secure and confidential?
Yes. The data you store in the web system will be secure, confidential and anonymous. Only your GP, the practice nurse and the researcher will be able to see the data.

Do I have to change my lifestyle in any way to be part of this project?
You don't have to change your lifestyle – but you may decide to make some lifestyle changes as a result of taking part in the project.

Do I get paid to be part of this research?
We will be able to reimburse for you for reasonable travel costs to and from interviews.

What happens if I decide I don't want to participate half way through the project?
Your participation is completely voluntary and you are free to withdraw from the project whenever you wish. This will not adversely affect the treatment that you receive in the future in any way.

What will happen to the results of the study?
They will be written into a report and we also plan to publish the results in an academic journal. When the results have been analysed and written up we will place a notice in the GP surgeries summarising the main findings, and we can send you a copy of the report at your request.

Will you use my name or contact details in your project report?
No. The research team will have to take these details from you in order to contact you about the interviews. During the project this information will be kept secure and confidentiality will be protected. At the end of the project all data will be made anonymous. In the final report and in conference publications identities will not be disclosed, and any quotes from interviews will be anonymous.

What are the benefits of taking part?

We hope that the project will help to identify how you – the patient – would most benefit from using a web-based system to manage your diabetes. We wish to find out how using this system changes your attitude towards your health and the way you communicate with your GP and the practice nurse.

I'd like more information about the project or to rearrange an interview:

If you would like contact someone about the project for any reason please contact:

Peggy Gregory
Department of Computing
University of Central Lancashire
Preston
Lancashire
Tel: 01772 893284
E-mail: ajgregory@uclan.ac.uk

Appendix 3: Participant interview dates

User Name	Interview 1	Interview 2	Interview 3
Frogbook	28/09/2006	01/02/2007	23/05/2007
Greenfish	28/09/2006	25/01/2007	11/05/2007
Bluepurse	05/10/2006	25/01/2007	23/05/2007
Rosecandle	05/10/2006	25/01/2007	24/05/2007
Papercat	05/10/2006	14/03/2007	-
Hatfork	12/10/2006	21/02/2007	14/06/2007
Treeswan	19/10/2006	01/02/2007	19/06/2007
Boatapple	19/10/2006	08/02/2007	19/06/2007
Catlily	26/10/2006	16/03/2007	09/07/2007
Smilecup	26/10/2006	21/03/2007	26/10/2007
Shoepen	26/10/2006	1/03/2007	-
Chairtree	27/10/2006	15/02/2007	-
Gardenpen	27/10/2006	08/02/2007	26/06/2007
Grasslake	2/11/2006	15/02/2007	14/06/2007
Owlrose	2/11/2006	16/03/2007	09/08/2007
Greenmouse	3/11/2006	08/02/2007	19/06/2007
Shopbeach	30/11/2006	08/03/2007	09/07/2007
Poppymist	1/12/2006	16/03/2007	10/07/2007
Steelsky	7/12/2006	23/05/2007	-
Breezelane	8/12/2006	11/05/2007	16/08/2007
Forestcircle	14/12/2006	17/04/2007	24/08/2007
Sandstar	14/12/2006	03/04/2007	16/08/2007
Brightwater	15/12/2006	03/04/2007	10/07/2007
Berrybank	15/12/2006	02/07/2007	15/11/2007
Clearlake	21/12/2006	20/04/2007	7/09/2007
Roundocean	9/1/2007	2/05/2007	29/08/2007
Hollybrook	11/1/2007	26/04/2007	4/10/2007
Eastwind	23/08/2007	23/11/2007	11/03/2008
Fairstream	23/08/2007	15/11/2007	28/02/2008
Palmstone	24/08/2007	30/11/2007	04/03/2008
Lilyrose	29/08/2007	23/11/2007	28/03/2008
Lionmoor	30/08/2007	15/04/2008	-
Friendsky	30/08/2007	30/11/2007	11/03/2008
Fieldshine	30/08/2007	4/12/2007	13/03/2008
Meadowsong	03/09/2007	7/12/2007	07/03/2008
Waterlight	07/09/2007	4/12/2007	28/03/2008
Orangenote	20/09/2007	10/01/2008	-
Applehand	20/09/2007	7/12/2007	13/03/2008

Table 20: Summary of interview dates for participants

Appendix 4: Interview Topic Guides

First Interview – question guide

1. Explain and sign consent form
2. Demonstrate the web site and Compass software
3. Explain the purpose of the interview
4. Address terms of confidentiality
5. Tape recording?
6. Interview

Interview questions:

1. How healthy would you say you are at the moment?
2. What sort of diabetes healthcare do you get at the moment?
3. Where do you currently get diabetes information from? Web, Diabetes associations, leaflets, books/encyclopaedias, GP surgery, magazines, newspapers, friends, other
4. Do you trust the information that you get?
5. To what extent do you believe that you alone are responsible for managing your health condition?
6. Do you think you know enough about diabetes?
7. Do you feel you know enough about the risks of diabetes and how to manage your lifestyle effectively? (diet, exercise, alcohol, smoking, stress)
8. How confident are you that you can manage your health by yourself? For example can you keep the symptoms of your diabetes from interfering with the things you want to do?
9. Have you made any lifestyle changes to help manage your health? Have you done enough?
10. How good are you at sticking to the things (lifestyle, health management) you need to do?
11. To what extent do you participate when discussing your diabetes with your healthcare practitioner? Is the discussion GP-led, collaborative, patient-led?

12. Who would you say influences your decision-making concerning your health? (consultant, nurse, family member, friend, support group)
13. What are you hoping to gain from participating in this research project? (knowledge, increased collaboration, improved health, other)
14. What motivated you to join the study?
15. How experienced would you say you are with IT? How confident?
16. Use pre-printed form for demographics

Second interview – question guide

1. Have you been using the system or parts of the system? (Compass, Website, Email – check all 3)

If yes:

What parts of the system have you been using and what parts have you not been using?

What do you think the benefits of using the system have been for you?

Do you think anything has changed for you as a result of using the system?

What do you think of the design of the system?

Is there anything else you would like the system to do?

What do you think of the look of the system?

Do you think that the system was hard to set up or use?

Did someone else help you to set up the system? Was that ok?

How much time would you say you spend every week using the system?

Did you find it difficult to find enough time to use the system?

How frequently do you use your computer at home? What do you use it for?

Would you prefer it if this system used different technology such as a mobile phone, or a hand-held computer, or was built into the blood glucose monitor?

Which website would you say you use most often? What do you like about that website?

If no:

What put you off using the system?

Is there anything about the technology that you found hard or that put you off trying to use it?

Do you find it difficult to find enough time to start using the system?

How frequently do you use your computer at home? What do you use it for?

Which website would you say you use most often? What do you like about your favourite website?

Would you prefer it if this system used different technology such as a mobile phone, or a hand-held computer, or was built into the blood glucose monitor?

Which website would you say you use most often? What do you like about that website?

2. How has your health been over the past 3 months? Has anything happened to change your health?
3. What changes did you want to make as part of this project?
4. Have you been successful at making those changes?
5. If yes: what do you think contributed to that success?
If no: why do you think you were not successful?
6. Do you think that you have learnt anything more about diabetes over the last 3 months?
7. If yes: What have you learnt and what was the source of your information?
If no: Do you think you know everything you need to know about diabetes?
8. Do you think your attitude towards managing your diabetes has changed since you started the project? If yes, how?
9.
 - a. To what extent do you believe that you alone are responsible for managing your diabetes?
 - b. Do you think you know enough about diabetes?
 - c. How confident are you that you can manage your diabetes by yourself?
 - d. Have you made enough lifestyle changes to help manage your diabetes?
 - e. How good are you at sticking to the lifestyle changes you need to do?

10. Have you been to see your GP since you starting using the system?
 If yes:
 Have you looked at the system collaboratively with your GP?
 What was it like looking at the system?
 What sections did you look at?
11. Has participating in the project changed anything about your relationship with your GP/GP surgery?
12. Has using the system changed the way in which your family is involved in supporting your diabetes

Final Interview – question guide

1. Did you use the system as much as you thought you would when you started?
 What had you expected to get from the system?
2. What parts of the system did you use - meter, upload, diary, targets, news, info, discussion, email system?
 Why?
 How useful was it?
 How frequently did you logon/ use each part?
3. What benefits would you say you got from using the system?
 Was that what you had expected?
 Was there anything that you expected to get from the system that you didn't get?
 Or (for non-users)
 What part of the system would you have most liked to use... blood glucose upload and sharing, email system? What do you think the benefits of that would be?
4. What difficulties were there with using the system? (technology, time, health, work, other events). If you had difficulties – how many phone calls did you make, how much time did you spend trying to sort it out?
5. What would make the system more usable for you?

Would you prefer to have a portable system? (show PDA)

6. Have you been aware of any of these issues with the website – feeling you're being watched, focussing on illness instead of health, feeling you're being nagged to do something you don't want to do, feeling that logging into the website is a chore, or feeling it is a safe, secure place, feeling like it's your personal health space
7. Do you like the idea of being able to share your health information with the GP and practice nurse?

What benefits can you see from being able to share this information?

8. Are you more confident with computers/Internet than you were at the beginning of the project? /How confident would you say you are at using a computer? (Scale 1-10)
9. If the system was made permanent would you continue/start to use it?
10. Do you ever think about the security implications of storing health information on the web?
11. Do you think your attitude towards managing your diabetes has changed since you started the project? How?
12. To what extent do you feel you are in control of your diabetes?
13. Do you feel that having diabetes is part of your identity or do you feel it is completely separate?
14. Has taking part in the project changed your attitude towards the surgery?

Have you talked to your GP about the system?

Would you like to go through your data on the system with the GP/nurse?

Would you like there to be technical support for the system at the surgery?

15. Do you think you get enough support for your diabetes?

Where do you want to get support from?

Does it matter if the support involves personal contact or is done remotely?

Has taking part in the project changed the way your family supports your diabetes?

16. Do you use any other health systems on the web?
17. Would you like to have access to your electronic health notes at the GP surgery?
18. Would you like to have your own general health space on the web?

19. Do you think you know enough about diabetes?

What is the best way for you to learn more about diabetes?

What are the best sources for the information you want?

20. Did you achieve what you wanted to from taking part in the project?

Have you changed any of your health behaviour since starting the project?

How has your health been since you started the project?

Appendix 5: Participant Vignettes

Frogbook

A 50 year old woman with diet controlled Type 2 diabetes which had been diagnosed one year before the project started. Retired and living with a partner. This patient had a variety of health problems and the diagnosis of diabetes had been the 'last straw'. Her attitude towards diabetes was avoiding, 'head in the sand', but she acknowledged that it was her responsibility. She found diabetes intrusive in her life as it forced her to change some of her eating habits, which she found very hard. A technophile, she was technically able and used her computer on a daily basis. The use of technology was a primary motivator for her. Her aim was to improve her control and avoid having to go onto medication. She used the meter, uploaded to Compass and the web site, viewed the discussion board, news and information but did not use the diary, targets or the Alive system. She uploaded to the web site in the first couple of months but then she experienced persistent computer and internet problems which continued through most of the rest of the project. During the project she also suffered a long period of ill-health and depression.

Greenfish

A 60 year old man with a seven year history of Type 2 diabetes which was insulin- controlled. Married and working. His aim for the project was to improve his quality of life. He also had angina and for the first half of the project was off work with depression. He felt that depression was a greater problem for him than his diabetes. He considered himself to be fairly well in control of his diabetes, although sometimes he worried about fluctuating blood glucose readings. He needed to lose weight and found the temptation of eating, particularly sweet foods, was a problem. He often felt tired and listless. He felt relatively confident with a computer, mainly using it for shopping and finding holidays. He only used the meter and uploaded to Compass on his own machine. He reported no technical problems except he said he could not log into the website, but he never phoned up for advice. He did not try the Alive system.

Bluepurse

A 58 year old man who had had medication-controlled Type 2 diabetes for three years. Retired and married. He spent a lot of time on his computer, particularly playing simulated flight games. His motivation for joining the project was to help the doctor. He had a

pragmatic attitude towards his diabetes, he had not changed his lifestyle after diagnosis and just took his medicine and went about life as normal. The only thing that worried him was that he may have to go onto insulin. He found it hard to exercise because he had a very bad leg which made walking even short distances very difficult. He was reasonably confident about using a computer. He uploaded to Compass and the website, used the news and information and looked at the discussion board, but would not want to post to it because he was a 'private person'. He did not use the Alive system. His main interest was in uploading his blood glucose readings to the website so that the doctor could keep an eye on them.

Rosecandle

A 77 year old man with medication-controlled Type 2 diabetes, he had had for three and a half years. He was retired and lived with his housebound wife, their grown-up children lived away. He had a helper who came in twice a week, who was computer-savvy and who helped him with using the system. He used his computer daily and was primarily interested in science and used the Internet for study. He suffered from other health problems; he had had a stroke previously and suffered with dystonia. His attitude towards his health was that his 'biological clock was winding down' and there was nothing he or anyone else could do to wind it up again – he just had to look after himself as well as possible. His motivation for joining the study was to gain knowledge. He was a very regular user. He used the meter, uploaded to the website, looked at the graphs and sent messages to the surgery. He did not, and was not interested in, using any other parts of the system. He had had some doubts about whether he really had diabetes, but looking at the graphs convinced him he was.

Papercat

A 53 year-old man who had had Type 1 diabetes for 30 years. Physically fit and healthy, he worked as a plasterer and lived with wife and children. He was very careful with his diet and regularly went to the gym. His motivation for joining the study was to monitor his readings with an aim of improving them. He also wanted to learn a bit more about diabetes. He stated he was responsible for his diabetes but that he was aware that his readings were sometimes a bit high. He did not consider himself computer literate but was prepared to give it a go. He only used the meter because his computer broke down soon after the start of the project and he decided that it was not a financial priority to buy a new one. He dropped out of the project after the second interview.

Hatfork

A 46 year-old man with medication-controlled Type 2 diabetes - diagnosed six months previously. He worked full-time in a call centre, and found it difficult to take time off work to have GP or hospital visits. He considered himself unhealthy and overweight and although he'd made some lifestyle changes when he was first diagnosed he felt they had not done nearly enough. Early on he'd read web sites suggesting he could reverse his diabetes but now realised that was unrealistic. He had struggled with his weight for a long time and had a tendency to go on crash-diets and then put on weight again. His motivation for joining was to have better communication with the surgery. He was fairly confident with using a PC. He had a lot of problems with his computer throughout the study – which meant it was very difficult to get onto the Internet. He started used the meter fairly regularly and uploaded to Compass but that dropped off in the second half of the project. He logged onto the website occasionally, looking at the news and discussion board, he did not use Alive. He had some kidney problems during the project and problems with dizziness.

Treeswan

A 38-year woman with Type 1 diabetes – she had had all her life. She was a married housewife with a school-aged child. Her husband (Clearlake) also had diabetes and took part in the project. She was well-adapted to living with diabetes and tried to look after her health, she had recently given up smoking. Her aim was to improve her diabetes management. However, she had lots of caring responsibilities which often took priority in her life – her husband had Schizophrenia, her mother had Alzheimer's and there were other family problems and conflicts occurring during the timeframe of the project. For the first half of the project these other issues dominated her time. She had a number of other health issues including carpal tunnel syndrome and osteoporosis. She was confident with computing but did not use the computer much at home. She did not use the system at all in the first three months, but started using it in the second three months. She said she felt guilty that she had not used it more – at she felt she had not really achieved what she had wanted to. She used the meter and the web site, but did not use Alive.

Boatapple

A 55-year old man who had a 30 year history of insulin-dependent diabetes. He was retired at lived with his wife and teenaged children. He had poor diabetic control and was starting to feel the effects of not having looked after himself – experiencing eye-sight problems and

numbness in his hands and feet. He said he had never stuck to the right diet and he did not regularly check his blood. His aim was to learn a bit more about diabetes and to have some contact with others with diabetes. He was concerned about his deteriorating health and although he came along to all three interviews it never seemed likely that he would use the system. He had very little experience with computers and found them frustrating. He struggled to see the screen because of his eye-sight problems. He relied on a friend to set the system up for him and to show him how to use it, but his friend went away so he never set the system up. He did not use the system at all apart from sporadic use of the meter.

Catlily

A 54 year old woman with Type 2 diabetes which she had had for 12 years, she was married and a school teacher. Her motivation for joining the project was to focus on diabetes and 'stay on task'. Controlling her diet and consequently her weight was the biggest problem for her. She had had a series of health problems over the last few years; a hysterectomy, fibroids, bowel problems, severe migraines and menopausal problems, which meant that she had stopped exercising. During the project was told that she was not eligible for a gastric band operation because she was not heavy enough which she was very disappointed about. She was very confident with computers and used the Internet regularly at school and at home. She had some problems with her laptop during the project. She used all parts of the system including the Alive emails. Using the system made her more aware of her diabetes, she was metering more regularly and she did some more exercise but sporadically. At the end she still did not feel in control of her diabetes.

Smilecup

A 51 year old woman with medication-controlled Type 2 diabetes that she had had for seven years. She lived in an extended family home and had children who had left home but her granddaughter frequently stayed with her. Her aims were uncertain and she wanted to help the surgery, but she also wanted to lose weight. Just before starting the project she changed her job; she found her new job very stressful and it took up much of her time. As well as stress she had high blood pressure, asthma and gout and was ill and depressed for much of the project duration – some of which was a reaction to taking weight loss pills. She was considering having gastric band surgery. She tried using the meter but did not like it. She was a reasonably confident computer user – and liked surfing the Internet. She loaded the Compass software but her computer crashed and she decided not to buy another one at

home. She considered using the Alive system at work, but was told it was not appropriate to use the system at work. She therefore did not use any of the system. She felt that diabetes was not her main problem and she'd have been more interested in a system to help her lose weight.

Shoepen

A 33 year old woman with Type 1 diabetes she had had for seven years. She used an insulin pump and most of her care was undertaken by a consultant at the hospital. She worked full-time and lived with her partner. Her motivation for joining the study was to improve her control over her blood glucose readings and to lose some weight as she had put on a stone since going on the insulin pump. She installed the software immediately and regularly used the meter and uploaded her readings to the web site. She looked at all parts of the website but did not use the Alive system. Her main focus was looking at the graphs and monitoring her blood glucose levels, but she also used the discussion board. Her consultant requested that she stop the project after two months as he could not see her readings. She said that using the system made her more aware of her diabetes. She found it particularly useful to see her readings on a graph so that she could spot trends.

Chairtree

A 57 year old man with medication-controlled Type 2 diabetes that he had had for 17 years. A retired teacher he lived with his wife. He was active in his local church and motivated by helping people. His motivation in joining the project was to get a better overview of his blood glucose readings and to help the surgery. When he was diagnosed with diabetes he already had some neuropathy, by the time of the project the neuropathy was worse, and he had 16 electrodes in his spine and was in pain quite a lot of the time. He felt resentful that diabetes had damaged his health and forced him to retire from teaching. He did not use the meter or install the software because he had computer problems during the first three months of the project. He withdrew from the project after that first three months because he was ill.

Gardenpen

A 59-year man with insulin-controlled Type 2 diabetes that he had had for 12 years. He worked full-time and was married with grown-up children and young grandchildren living nearby. His aim in joining the study was to learn from others and to improve his blood

glucose control as his readings were fluctuating and he felt he needed to improve them. He felt he was ok with technology, not too bad but not brilliant either. He used his computer at home regularly. He felt he still had more to learn about diabetes, and could improve his lifestyle. He had really struggled when he first went onto insulin because he had a fear of needles and there were still some places where he could not inject himself. He used all parts of the system except for targets, the diary and the Alive emails. He had problems with uploading to the website in the first half of the project then in the second half he had problems uploading from the meter. He got frustrated with the technology problems but they did not put him off using the system or continuing to try connecting. He found the system useful and felt that he had learnt about how to improve his blood glucose control.

Grasslake

A 51-year old man with medication-controlled Type 2 diabetes he had had for 11 years. He was married with grown-up children one of whom still lived at home. His aim in joining the study was learn more about diabetes and how to manage it. His attitude towards diabetes for some time had been that he was burying his head in the sand about it, treating it like a 'minor ailment' and hoping that a cure would be found for it. He was very unconfident with technology and described himself as a luddite. He used the meter but did not use any other part of the system, although after the last interview he managed to log into the website and looked at it several times. He had various problems with his computer during the study but the main barrier was that he did not feel confident and he was waiting for his son to come and help him. He was ill during the study and had to change his diabetes medication. Despite hardly using the system at the end of the study he felt that his attitude towards diabetes had improved and he had learnt more about it.

Owlrose

A 40 year old woman with Type 1 diabetes she had had for 13 years. She worked full-time as a building society manager and lived alone; was in a relationship and did not have children. Her aim in joining the study was to have tighter control of her blood glucose readings and to lose some weight. She'd just started having a problem with one of her eyes which worried her. She managed her diabetes adequately but felt she was complacent and her control varied over time; she did not want to think about it too much because she wanted to live a normal life. She was not very confident with technology but was prepared to have a go. She did not want her boyfriend to help her because he worried too much. She used the meter and only

logged into the website once towards the end of the trial. She loaded everything up on her computer but then it crashed and it took a while for her to mend it. When it was mended she had problems uploading from the meter which she did not sort out. She said she would have used it if it had worked first time, but the technical hitches put her off. She liked the meter and said she was metering more because of it.

Greenmouse

A 37 year old woman with insulin-controlled Type 2 diabetes, she had had for eight years. She lived with her husband and worked full-time. She had grown-up children who lived away. She was fairly healthy and her aim in joining the study was to learn more about diabetes and to make it not so much an intrusion in her life. She was relatively healthy throughout the 6 month period of the project. She was relatively confident about using a computer and had help from her husband who was very confident. She regularly used her computer at home for shopping, banking and surfing. She had technical problems uploading from the meter to Compass at the beginning of the project took a while to sort out. She then used the system regularly. She tried all parts of the web site. She found looking at the graphs helped her to understand her blood glucose readings better. She wanted the discussion board to be livelier and her use of the system dropped a bit in the second half of the study although she consistently used it to look at her readings.

Shopbeach

A 31 year old man with a 7 year history of Type 1 diabetes. He lived with his wife and worked full-time. His aim in taking part was to get more organised about his diabetes. He was fairly healthy throughout the six month period of the project. He was relatively confident about controlling his diabetes but his readings were sometimes high. He was a confident computer user, using his home computer on a daily basis. He was a very frequent user of the system, and continued to log in to the system regularly until the site was taken down. He experienced a few technical problems but sorted them out. He focused on taking readings and uploading them to the site, looking at the news and information pages and using the discussion board. He did not use the diary or targets. He tried joining the Alive email system a couple of times but did not succeed in getting going with it. He was particularly interested in the discussion board. He found looking at the graphs very useful as it made him see how bad his readings were and said it was 'a wakeup call'. He said he felt alone with his diabetes and using the system made him feel less alone.

Poppymist

A 60 year old woman with medication controlled Type 2 diabetes, which she had had for 4 years. She lived on her own and was unmarried. She retired half way through her involvement in the project, she was a self-employed debt counsellor. Her health was not good in the first half of the project, she had suspected angina, a kidney infection, high blood pressure and high cholesterol. She felt that her ill health was partly caused by the fact that she had just emerged from a long period of caring for her elderly parents, first her father who died some years previously and then her mother who died shortly before she started the pilot. Her aim in taking part was to learn more about diabetes and to share her information with the GP. She was fairly confident with using computers but did not feel technically competent. She used the meter and the Alive email system but did not really use anything else except that she looked at the information on the website. She did not upload her readings. She found the Alive system useful to motivate her to increase exercising and went through it twice.

Steelsky

A 35 year old man with Type 1 diabetes he had had for seven years. He lived on his own and was self-employed. He considered himself healthy and able to manage his diabetes. His aim was to keep a better eye on his blood glucose readings. He felt he could muddle through with the Information Technology. He was also quite interested in sharing his experiences with others with diabetes because he felt that 'normal' people did not understand what it was like to have diabetes. He did not use the system at all. He had previously kept a manual log of his readings and he continued to do that. He gave his computer to his sister soon after the project started and did not buy another one. He dropped out of the project after the second interview.

Breezelane

A 43 year old man with Type 2 diabetes he had been diagnosed with 3 months before starting the project. He was married with children and worked very long hours. His aim in using the system was to learn more about diabetes and to contribute to the project. He was not very experienced at using computers although he used them a lot at work. He used the meter and looked at the website but he experienced problems uploading to Compass and did not have time to sort it out with Roche. In the second half of the project he started using the Alive email system which he found very useful. He was very busy at work during the time of

the project, and in the first interview he said he intended to increase his exercise sometime in the future when he had more time. When he found that he could not easily upload he backed off a bit, but he also found he did not need to monitor his blood very frequently. He used a computer a lot at work and did not really want to use it much at home.

Forestcircle

A 49 year old man with insulin-controlled Type 1 diabetes he had had for 15 years. He was married and worked full-time, with two children in their late teens, one of whom still lived at home while studying at University. He was trying to lose weight but his aim in joining the project was to generally improve his health. He had been experiencing problems with fluctuating blood glucose readings and frequent hypos and his medication was under review throughout the whole period of the project. The project therefore coincided with a period when he wanted keep a close eye on his blood glucose control. He used all parts of the system apart from the Alive email system. He was not very experienced with computing, but his son was studying Computing at University and gave him help when he needed it. He had problems with uploading to the Compass software at first, but phoned Roche who helped him out. Once the system was set up he found it easy to use and was a regular user. Over the six months he felt he had improved his blood glucose control, but he had not managed to lose any weight or increase his exercise.

Sandstar

A 54 year old man with medication-controlled Type 2 diabetes he had had for one and a half years. He did not use a meter. He was married and worked full-time. He had no particular health issues but he did not consider himself to be very healthy. His aim for the project was that it would give him the push to change his lifestyle. Although he had made some changes he felt he needed to do more. One of the problems for him was that he did not experience any symptoms so diabetes was not in the forefront of his mind. He felt fairly confident with technology. He used the news, information and discussion board part of the website. He had problems in the first half of the study when he tried to send a message. He did not use the Alive email system. He felt he did not get any benefit from the system, and did not feel drawn to using it – saying that he could not relate to it.

Brightwater

A 37 year old man with Type 1 diabetes he had had for 20 years. He was married with children and worked full-time. He considered himself fairly healthy and had no other problems apart from his diabetes. His aim in joining the project was to regain his focus on diabetes, which he felt he had lost. He felt that by being watched it may encourage him to take more notice. He was fairly confident with technology. He used all parts of the system apart from the diary and the targets. He had problems uploading to Compass in the first half of the project but he sorted that out and started uploading regularly in the second part of the project, although he did feel he could have used it more. He found that knowing it was there raised his awareness. He liked being able to see his readings on the graph. He found the Alive system useful and used it to increase his activity levels.

Berrybank

A 21 year old man with Type 1 diabetes he had had for two years. He was single and lived with his family and worked full-time as a plasterer. He was fit and played football regularly and had a healthy diet. He was in denial about his diabetes and did not like to think about it too much. He felt he was still just beginning with diabetes and he was still learning about it. He did not talk about diabetes with his friends. His mother had encouraged him to take part in the project and he was difficult to get hold of when it came to asking him for interview. He rarely did his bloods but he really just did his regular injections. He did not like taking his bloods because it involved him pricking his finger four times a day. His aim for the project was to start metering more regularly and to get better control of his blood glucose. He was a confident and regular computer user. He did not use the system at all and lost the meter. However, he felt that being on the project had made him more aware of his diabetes and helped him along in the process of coming to terms with it.

Clearlake

A 41 year old man with medication-controlled Type 2 diabetes, he had had for eight years. He lived with his wife (Treeswan) and school-aged son. He was studying at a local college as a mature student. He also was diagnosed with schizophrenia and did not consider diabetes to be his main health problem. He did not feel very healthy and considered that although in the past he had been regimented about his diabetes, he had let his control slip. His aim from the project was to get back into a better routine for managing his diabetes. He felt relatively confident with technology and used his computer at home quite a lot. He had personal

problems throughout the period of the pilot and did not log into the website at all. He used the meter sporadically, but then it stopped working and he did not contact the researcher to sort it out. He helped his wife to get onto and use the system. He found his mental health problems distracting through the project and did not consider that anything had changed about his attitude towards diabetes or his management of it as a result of being involved in the project.

Roundocean

A 51 year old man with medication controlled Type 2 diabetes he had had for seven years. He was married with grown up children and young grandchildren and worked full-time. He considered himself to be healthy but not fit. His aim in joining the study was to get support for managing his anticipated transition onto insulin which he considered to be a critical time. He planned to do more exercise during the project by using his gym membership. He was confident about technology and knew who to ask if there was something he did not know. He used the system occasionally, focussing on uploads and the discussion board. He did not use the other parts of the website or the Alive email. He considered the system to be useful primarily for those experiencing problems with their diabetes and said that he had not used it much because during the 6 month period because he had successfully controlled his diabetes during that time and did not need to go onto insulin as anticipated. He was also working particularly hard during the period of the project because there was overtime on offer at work which he felt he needed to take. He did not feel he had got any particular benefits from the system but he considered it a 'tool in my health cabinet' and that it was there as a backup if he needed it.

Hollybrook

A 33 year old man with medication-controlled Type 2 diabetes that had only recently been diagnosed. He was married with young children and worked full-time. He did not consider his diabetes to be a particular problem as it did not really affect him. His aim in joining the project was to keep a closer eye on his blood glucose and to see them plotted out on the graph. He planned to be more careful about his diet during the project. He was not very confident about using a computer and had not owned one before. When he joined the project he was about to get a computer, however over the 6 months of the project he did not have access to a computer. At the 3 month interview he said he was about to be given one but at the final interview he said that computer had been too old so he intended to use his

father's. However, when using his father's to download some football software he had downloaded a virus which had cost money to sort out, so his father had refused to let him touch his computer again. He only used the meter. At the end of the project he said his attitude towards diabetes had changed; he was taking it more seriously, he had given up smoking and was trying to improve his diet.

Eastwind

A 65 year-old woman with medication-controlled Type 2 diabetes she had had for two years. She was married with grown-up children and worked full-time in a supermarket. Her teenaged grandson lived with her. She did not feel particularly healthy, had high blood pressure and often felt tired. Her aim in joining the study was to become more knowledgeable about diabetes and to know that her blood glucose readings could be checked by the GP. She did not feel confident with technology but her grandson was so she would ask him to help – the computer was in his room. The computer was not working at all during the 6 months of the project. She only used the meter. The meter stopped working towards the end of the 6 months but she sorted that out with Roche. Despite not using the system at the end of the pilot she felt that her attitude towards diabetes was more positive and that she was not frightened of it any more.

Fairstream

A 32-year old woman with newly-diagnosed medication-controlled diabetes. She was single and currently unemployed, although she mentioned in one of the interviews that she had a PhD. She said she did not feel very healthy and during the first 3 months of the project she suffered from a number of health problems which resulted in hospital stays. Her aim in joining the project was to become more knowledgeable about diabetes and to get the motivation to make some lifestyle changes. She wanted to lose weight and do some more exercise. She was confident with technology. She installed the Compass software onto her machine but was having problems with uploading. Then her computer broke down soon after starting the project and she could not afford to get a new one. She used the meter. She only logged in once. She said being on the project had encouraged her to look up other diabetes websites, to meter more frequently, go to the gym and to be more aware.

Palmstone

A 42-year old man with medication-controlled Type 2 diabetes he had had for seven years. He worked full-time in a Further Education College teaching woodwork. He was married and had school-aged children. He was confident with technology and regularly used his computer at home. His aim for the project was to get a better understanding of diabetes and to share experiences with others. He found that he often lost his temper and wondered whether that was related to his diabetes and how. He tried all aspects of the system except for the Alive emails. He used it more in the first three months and only logged in once in the second 3 months of the project. In the second three months he had a hard drive crash which he had to sort out, and when he reinstalled everything he started having problems uploading to the website so he did not upload to the website in the second three months. He said he found the system easy to use, that it made him more aware of diabetes and that he had been metering more frequently. However, he did not feel drawn to using the system very frequently.

Lilyrose

A 42-year old woman with Type 2 diabetes she had had for seven years. She was married and on a career break with a young baby and a teenage son. When she had been pregnant she took insulin, but now this was not necessary. She was planning to get pregnant again so one of her aims from the project was to lose the weight she had gained with the previous pregnancy and to get into an optimum state for becoming pregnant again. She said she had always had issues with weight and had been dieting since she was young so food was an issue for her. She was also a committed Christian and believed that she could be healed of anything, so she felt that by having diabetes she was giving herself a label which she did not want. She was not confident with technology and the computer in the house was her son's, so he helped her. They moved house during the first 3 months of the project so she did not use the system at all during that time. Her son's computer used the Linux operating system so she could not install the Compass software and upload her readings. She used the website and the Alive system in the second half of the project. She thought using the system made her more aware of her diabetes but other than that nothing had changed.

Lionmoor

A 41 year-old man with insulin-controlled Type 2 diabetes that he had had for seven and a half years. He worked full time and was just married. His aim from the project was become

more regular at metering; he found he went for long periods of time without metering as if he did not have diabetes. He was confident with technology. He installed the Compass software onto his computer but could not successfully upload his readings from the meter. He found it very frustrating that he could not get the meter upload to work and he lost interest in it. He had logged onto the website to look at that but he considered the meter uploading to be the main feature he was interested in. He dropped out of the project after the second interview.

Friendsky

A 51 year-old man with medication control Type 2 diabetes that he had had for three years. He worked full-time and was married with grown-up children. He did not have a particular aim for the project except to see whether he was leading a healthy life and whether there was anything he could do to improve it. He was confident with Information Technology because 'I do that for a living'. He changed his job just as he started the project and was very busy throughout the period, finding it difficult to find time for it. In the first 3 months he loaded Compass up onto his daughter's laptop and got it working but then she went to university and he tried on his own machine but he could not get it working. In the second half of the project he succeeded in uploading and looked at the graphs, news, information and discussion on the website. He did not use the Alive emails. He felt that as a result of the project he was being stricter with his medication and more careful about his diet.

Fieldshine

A 39 year old man with newly-diagnosed medication-controlled Type 2 diabetes. He was married and worked full-time as a finance officer, he did not have children. For much of the time of the project he was struggling with his diabetic symptoms, getting very sweaty, finding it hard to exercise and feeling tired. He did not have any clear aims for the project but he wanted to lose weight. He was confident with Information Technology and used his computer at home regularly. At the second interview he had not used any part of the system because the meter was not working and he said he felt disillusioned because the symptoms were not under control. By the final interview he had used the meter but nothing else. He thought he had registered for Alive emails but had never received a reply possibly because of firewall problems. His readings were always about seven so he did not think there had been any point in uploading. He had been on an education programme which he thought was bit basic. However, he was starting to feel more positive, was using a Nintendo Wii at home and

felt his symptoms were under control. He did not think being part of the project had changed anything for him, as it had coincided with him being diagnosed with diabetes it had formed part of his experience of starting to deal with it.

Meadowsong

A 52 year old man with medication controlled Type 2 diabetes he had had for two years. He was married with grown up children and worked full time at the Post Office. He did not use a glucose meter. He was overweight and had recently put on two stone, so weight loss was an important issue for him. He had had polio as a young person and wore a calliper to help him walk – this limited the sort of exercise he could do. His aim in joining the study was to become more focussed and to help him to sustain some weight loss. He was fairly confident with Information Technology and used a computer every day at work. He used the Alive emails and the occasionally went onto the website but did not upload because he did not use a meter. He used the system on his work computer not at home. He found the Alive email system very helpful and went through twice. He felt he was more aware of his diabetes as a result of using the system. He had lost some weight initially but had not weighed himself recently.

Waterlight

A 55 year old man with medication-controlled Type 2 diabetes he had had for two years. He was married and worked full-time on shift work. His aims for taking part in the project were to become more knowledgeable about diabetes and to keep himself on track so he did not need to go onto insulin. He felt his diet was ok, but he struggled to find time to do exercise. He said that his confidence with Information Technology was average. When he started the project he had not been metering for a while but he felt fairly confident about his diabetic control. He said he was uncertain whether his diagnosis of diabetes was correct or whether his body had reacted badly on the day they did the test. He used all parts of the system. He stopped using the Alive emails after a while because he felt the targets were not appropriate for him and he could not choose his own. He found that metering regularly and uploading his readings made him more aware of his diabetes and he succeeded in slightly increasing the amount of exercise he did, but he did not think that overall his attitude towards diabetes had changed.

Orangenote

A 49 year old man with medication-controlled Type 2 diabetes that he had had for four years. He was married with children and ran his own business; consequently he was often very busy and frequently spent time travelling away from home. His main concern was losing weight, and because of his obesity he found it hard to take exercise. He had a habit of dodging doctors and considered they often judged him negatively because of his weight. His aim for the project was that it would act as a motivator to get him to improve his lifestyle. He felt relatively confident with technology. During the project he used the Alive email system and said that he logged onto the website but there was no record of it. He got his children involved by getting them to weigh him, because he found that was a good motivator. At the second interview he said he had lost some weight, had learnt more about healthy eating and had become more aware of his diabetes. When contacted for his final interview he did not return calls or emails, so he effectively dropped out.

Applehand

A 51 year old woman who had had medication-controlled Type 2 diabetes for six years. She lived with her teenage son, and had another older son who had cystic fibrosis. She said that did not take her diabetes seriously because she did not really feel the effects, but in interviews she reported being frequently tired and thirsty. She also had arthritis which caused her pain. She did not feel confident with technology but the computer belonged to her son and he helped her. Her aim for the project was to take her diabetes more seriously and to learn more about it. She used the meter and uploaded to Compass during the first half of the project. In the second half of the project she had computer problems that stopped her from using the computer at all so she just used the meter. She said at the last interview that she still did not understand what a good reading was and what a bad reading was. At the end she did not think that her attitude towards diabetes had changed or improved; she was aware that she needed to control it more, but she was not really doing anything about it.

Appendix 6: Participant technical problems and support

User Name	Computer problems	Meter problems	Problems uploading to Compass	Phone support from Roche	Website access problems	Website upload problems	Email support from researcher	Phone support from researcher	Needed help at home from friend/family	Alive email problems
Frogbook	36									
Greenfish					36		36		Y	
Bluepurse					3	3				
Rosecandle			3			3		3	Y	
Papercat	Ø	3								
Hatfork	36				6	3	3			
Treeswan		3	6			6	6	6	Y	
Boatapple									Y	
Catlily	36		3		3					
Smilecup	0								Y	
Shoepen										
Chairtree	3									
Gardenpen			36			36	6	6		
Grasslake	36	6			6				Y	
Owlrose	3		36				6	6	Y	
Greenmouse			3	3			3		Y	
Shopbeach			36	3		36	6	6		
Poppymist					6					
Steelsky	Ø									
Breezelane			3	3			6			
Forestcircle	3		3	3			3		Y	
Sandstar	3				3				Y	
Brightwater			3	36						
Berrybank	3									
Clearlake										
Roundocean			3			6	6	6	Y	
Hollybrook	Ø									
Eastwind	36									
Fairstream	36		3	3			3			
Palmstone	6									
Lilyrose	3		6		6		6	6	Y	
Lionmoor			3	3			3			
Friendsky			3		3		6		Y	
Fieldshine		3								
Meadowsong							3			3
Waterlight										
Orangenote	3									
Applehand	36		3						Y	

Ø = no computer, 3 = during first 3 months, 6 during second 3 months, Y = yes

Table 21: Overview of technical support and problems

Appendix 7: Category and sub-category listing

Category One: Diabetes Management Context

Health Context

Diabetes-related health problems

Other health problems

No health problems

Diabetes Knowledge

Certainty about diabetes knowledge

Emotional responses to information about diabetes

Approach to Diabetes

Acceptance of diagnosis

Focus on diabetes

Emotional reaction to diabetes

Diabetes Management Aims

Aim to maintain and improve healthy lifestyle

Aim to control diabetes

Aim to improve approach to diabetes

Aim to learn more about diabetes

Always more to do

Barriers to Diabetes Management

Barriers to diabetes management: Personal factors

Barriers to diabetes management: External factors

Self-management Approach

Importance of routine

Self-discipline

Forgetting

Fear

Diabetes Symptoms and Experiences

Managing symptoms

Self-management Aids and Tools

Meter use

Paper aids

Diabetes Management Outcomes

Changes in health lifestyle

Changes in diabetes control

Changes in approach to diabetes

Changes in knowledge about diabetes

Category Two: Diabetes Support Experience

Support-seeking Approach

Seeking information about diabetes

Seeking to communicate with others

Support Experiences

Family support

Being nagged

Practitioner support

Feeling alone

Support Aids and Tools

Trusted information sources

Support aids

Category Three: Diabetes eHealth System Experience

System Aims

Aims

Experience of Technology

Computer access at home

Computer use and interest

Confidence with technology

Technical problems

Barriers and Facilitators to System Use

Barriers to system use: Personal factors

Barriers to system use: Lack of engagement

Barriers to system use: Approach to technology

Barriers to system use: Technology

Facilitators to system use

System View

System view

System Use

Elements of system used

Regularity of system use

Problems with system use

Response to System

Being watched

Comfort

Not feeling alone

Automated

System benefits

System drawbacks

Unmet Expectations

Unmet expectations

System requirements

Post-it note framework 6/11/2009

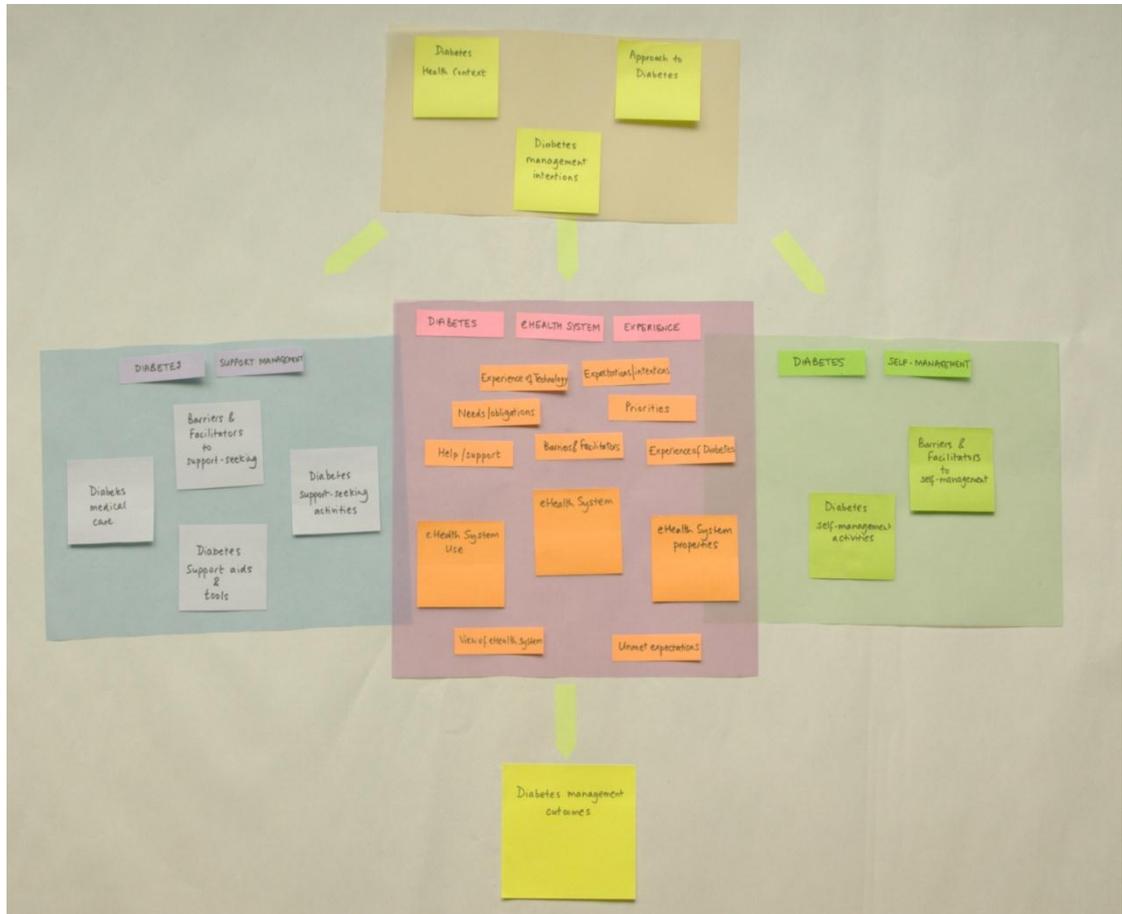


Figure 13: Post-it note framework November 2009

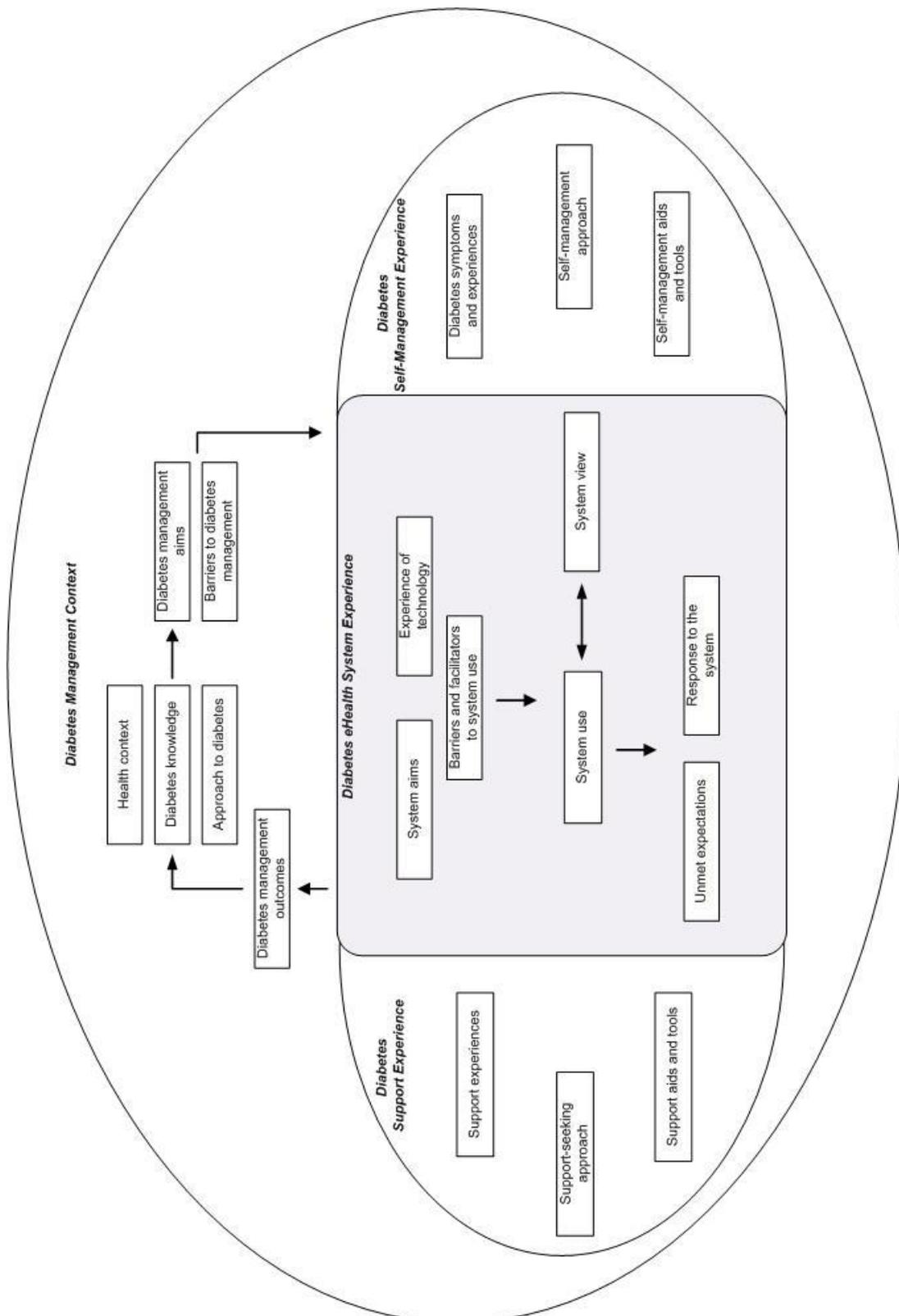


Figure 14: Conceptual framework August 2010

Appendix 9: Participant-reported changes

User Name	System Use *	Change in bg control & monitoring ^	Change of Change of lifestyle^	Change in knowledge^	Years with diabetes	Diabetes Type	Insulin User	Entry HbA _{1c} ~	Date of entry HbA _{1c}	Exit HbA _{1c} ~	Date of exit HbA _{1c}
Frogbook	R	N	Y Y	N	1	2	N	6.7	10/06	7.1	10/07
Greenfish	O	Y	Y Y	N	7	2	Y	-		-	
Bluepurse	R	N	N N	N	3	2	N	5.8	10/06	6.2	7/07
Rosecandle	F	Y	Y Y	Y	3.5	2	N	5.7	8/06	6.9	8/07
Papercat	N	-	- -	-	30	1	Y	-		-	
Hatfork	O	N	Y N	Y	0.5	2	N	6	11/06	5.9	10/07
Treeswan	R	N	Y Y	N	38	1	Y	9	12/06	8.9	8/07
Boatapple	N	Y	N N	N	30	1	Y	12.6	3/06	13.8	7/07
Catlily	R	Y	Y Y	N	12	2	N	6.9	10/06	6.8	9/07
Smilecup	N	N	N Y	N	7	2	N	6.8	8/06	6.5	11/07
Shoepen	F	-	- -	-	7	1	Y	7.2	6/06	-	
Chairtree	N	-	- -	-	17	2	Y	12.8	6/06	-	
Gardenpen	R	Y	Y Y	Y	12	2	Y	10.1	9/06	9.5	6/07
Grasslake	O	Y	Y Y	N	11	2	N	6.1	4/06	7.2	2/07
Owlrose	M	Y	Y Y	N	13	1	Y	-		8.3	7/07
Greenmouse	F	Y	N Y	Y	8	2	Y	7.5	1/07	8	8/07
Shopbeach	F	N	Y Y	Y	7	1	Y	9	11/06	9.9	11/07
Poppymist	R	Y	Y Y	N	4	2	N	10.3	10/06	6.8	7/07
Steelsky	N	-	- -	-	7	1	Y	7.7	11/06	-	
Breezelane	R	N	Y Y	N	0.3	2	N	8.2	10/06	6.5	12/07
Forestcircle	O	Y	Y Y	N	15	1	Y	9.2	12/06	11	8/07
Sandstar	M	N	N Y	N	1.5	2	N	7.2	8/06	6.4	2/07
Brightwater	R	Y	Y Y	Y	20	1	Y	8.9	1/07	8.5	11/07
Berrybank	N	Y	Y N	N	2	1	Y	10	2/07	9.6	11/07
Clearlake	M	Y	N N	N	8	2	N	10.2	11/06	8.8	12/07
Roundocean	M	N	N N	N	7	2	N	8.1	9/06	7.3	4/07
Hollybrook	N	N	Y Y	N	0.2	2	N	-		-	
Eastwind	N	Y	Y Y	N	2	2	N	6.6	5/07	7.4	5/08
Fairstream	M	Y	Y Y	Y	0.5	2	N	5.3	6/07	5.8	5/08
Palmstone	M	N	Y Y	Y	7	2	N	6.2	4/07	7	4/08
Lilyrose	O	N	Y N	N	7	2	N	5.8	10/06	6.5	12/07
Lionmoor	M	-	- -	-	7.5	2	N	9.4	6/07	-	
Friendsky	R	N	Y Y	N	3	2	N	7.5	2/07	6.6	4/08
Fieldshine	N	N	N N	N	1.5	2	N	6.5	10/07	6.3	6/08
Meadowsong	R	N	Y Y	Y	2	2	N	7.5	4/07	7.7	4/08
Waterlight	R	Y	N Y	Y	2	2	N	6.8	12/06	7	5/08
Orangenote	M	-	- Y	-	4	2	N	8.9	5/07	-	
Applehand	N	N	Y Y	N	6	2	N	8.2	1/07	7.6	3/08

Table 22: Participant-reported changes

*F = Frequent, R = Regular, O = Occasional, M = Minimal, N = Non-use, ^self-reported

~ Entry HbA_{1c} = closest reading to participant starting project; Exit HbA_{1c} = closest reading to participant ending project

Appendix 10: Diabetes eHealth Website Screen Shots

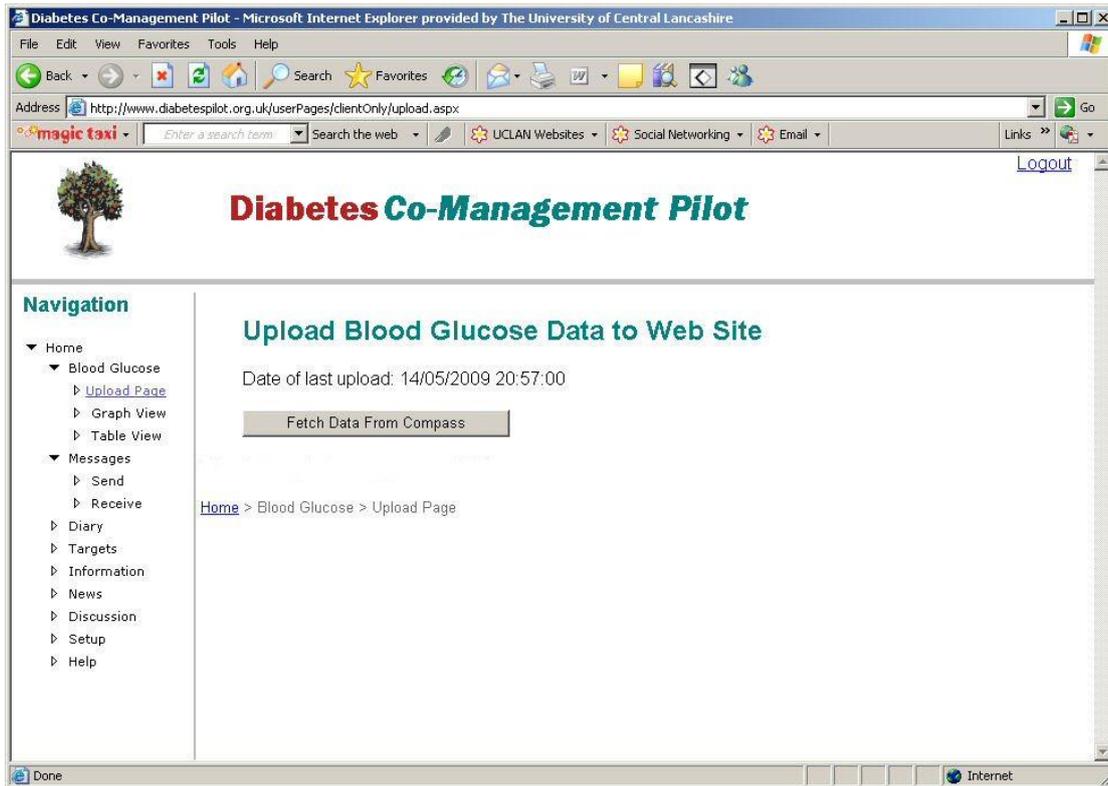


Figure 15: Website Blood Glucose Upload Page Screen Shot



Figure 16: Website Blood Glucose Table View Screen Shot

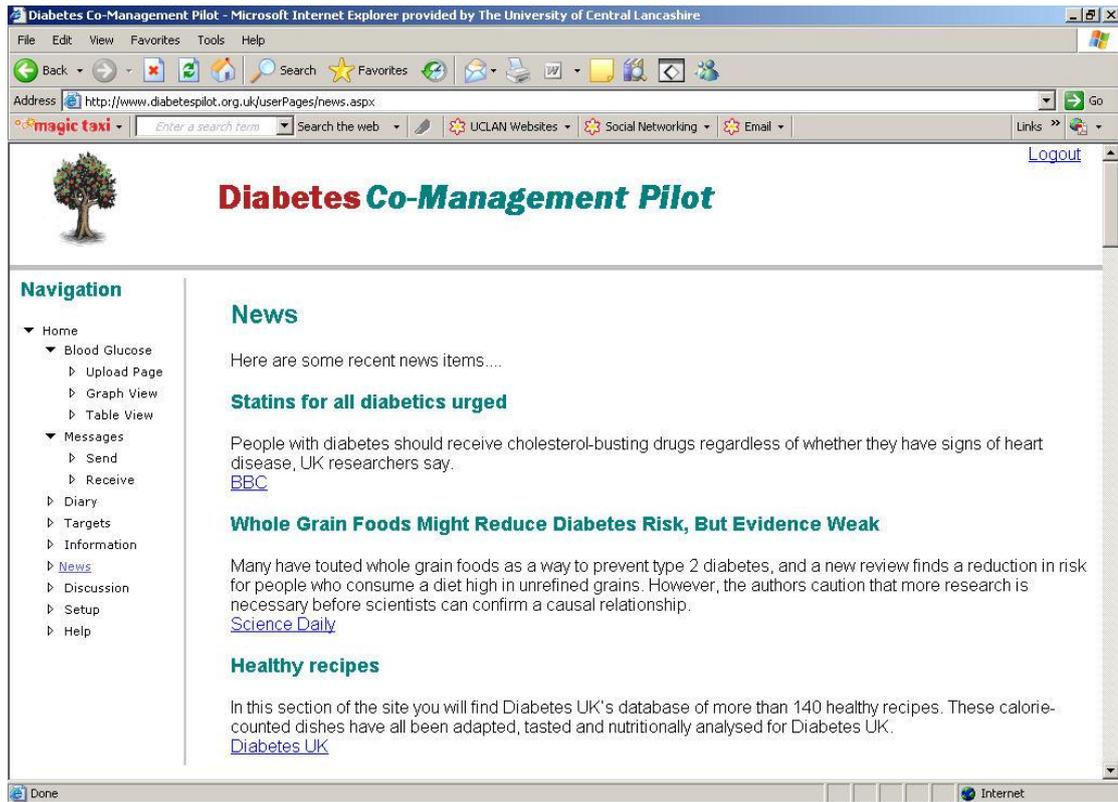


Figure 17: Website News Page Screen Shot

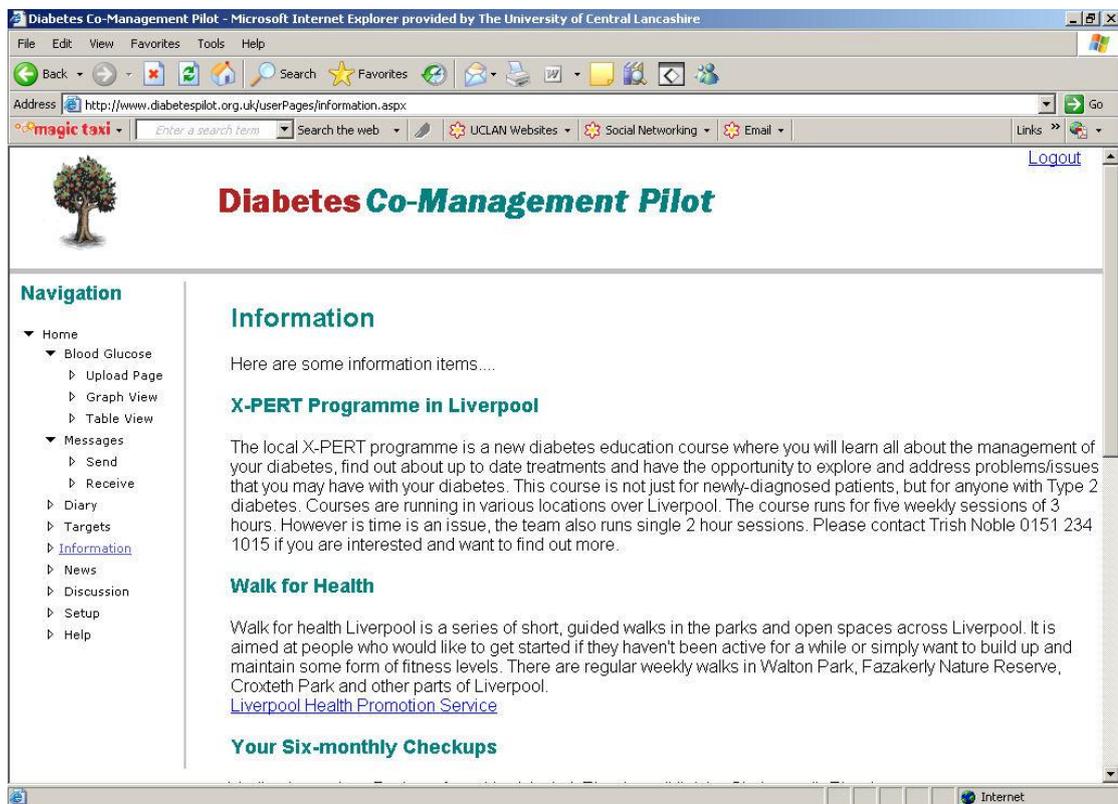


Figure 18: Website Information Page Screen Shot

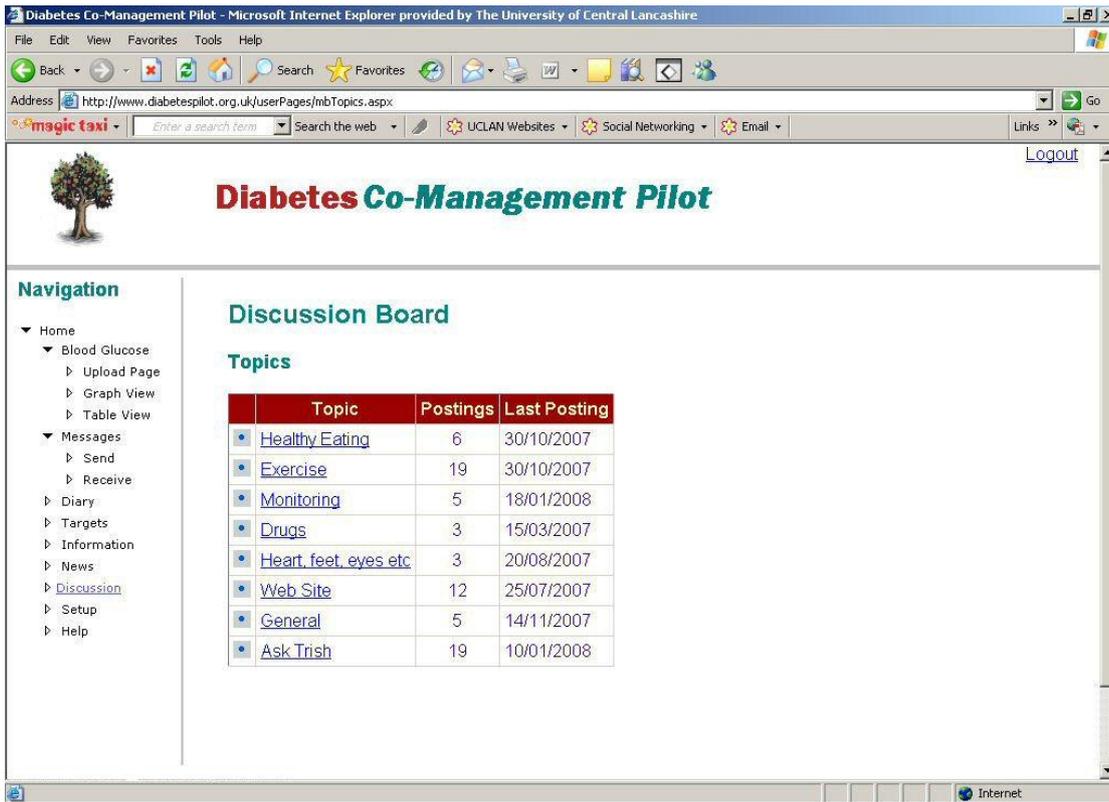


Figure 19: Website Discussion Board Screen Shot

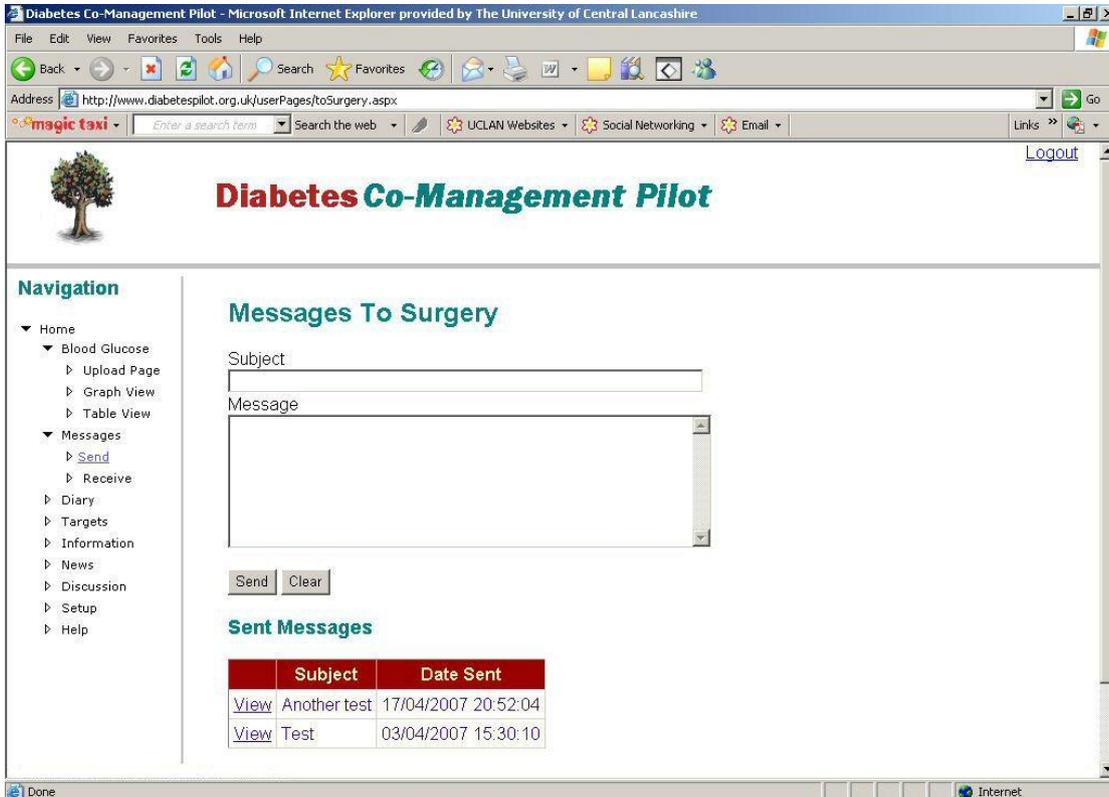


Figure 20: Website Messages to Surgery Screen Shot

The screenshot shows a web browser window titled "Diabetes Co-Management Pilot - Microsoft Internet Explorer provided by The University of Central Lancashire". The address bar shows the URL "http://www.diabetespilot.org.uk/userPages/targets.aspx". The page features a navigation menu on the left and a main content area titled "Targets".

Target	Date Set	Achieved?	When		
Eat a salad twice a week this month	24/08/2007	Yes	29/08/2007	Edit	Delete
Use the stairs instead of a lift	29/08/2007	Partly	30/08/2007	Edit	Delete
Eat less pastry this month	30/08/2007	Partly	07/09/2007	Edit	Delete
Go for a walk after work 3 times this week	30/08/2007	Yes	03/09/2007	Edit	Delete
Go to the swimming pool twice a week	30/08/2007	Yes	20/09/2007	Edit	Delete
Go for a lunchtime walk three times this week	03/09/2007	Yes	20/09/2007	Edit	Delete
This months target to go swimming more	07/09/2007	To Do		Edit	Delete
				Insert	

Home > Targets

Figure 21: Website Targets Screen Shot

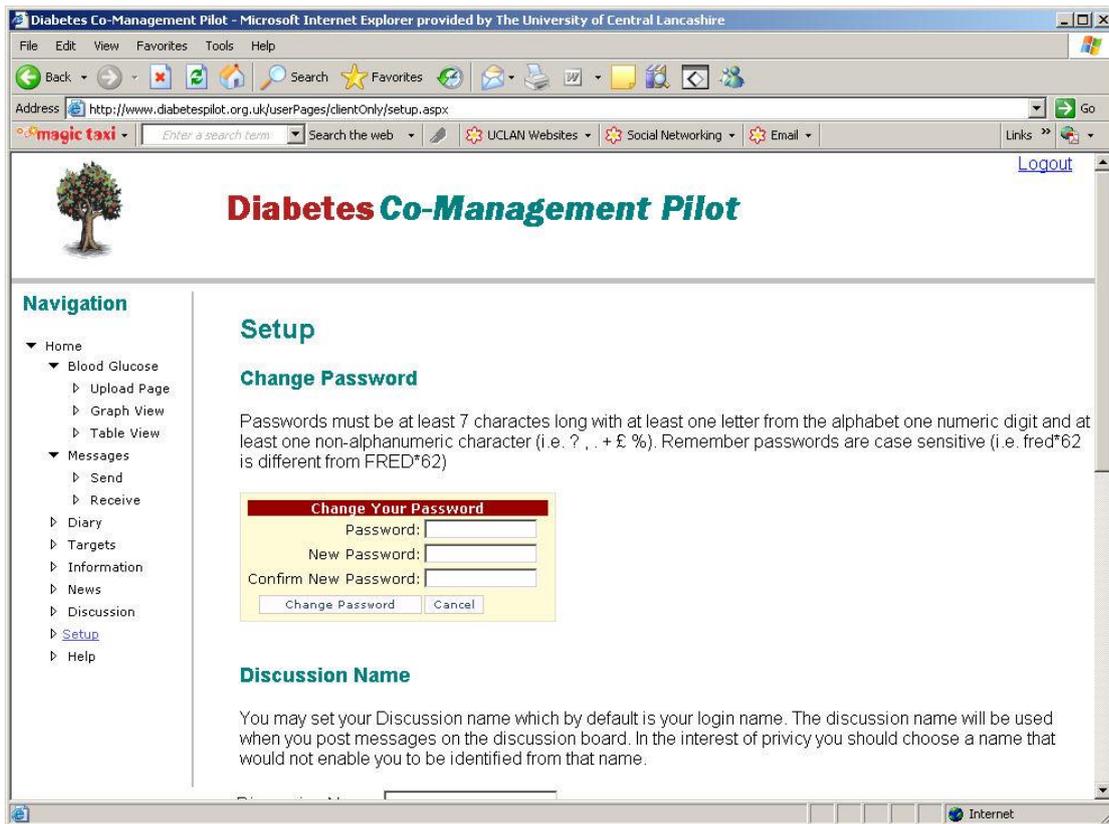


Figure 22: Website Setup Screen Shot