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# HOW YOUNG ADULTS WITH TYPE 1 DIABETES INTERACT WITH TECHNOLOGY AND HOW THEIR VIEWS AND EXPERIENCES CAN INFORM THE DEVELOPMENT OF A PATIENT-CENTRIC MOBILE HEALTH APP

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## **Abstract**

**Background:** Views of young adults with type 1 diabetes are vital in developing quality support services and improving their lives, yet research on their lifestyle and use of technology to support their condition is sparse.

### **Aim:**

- (1) Develop an insight into use of Internet and web/mobile technology and its impact on the lives of young adults, by understanding their experiences from qualitative interviewing, exploring how they made use of technology concerning their lives and condition.
- (2) Utilise sociotechnical design principles and develop a mobile app, seeking participant opinions on design and usefulness during the development cycle.

**Design:** Data collected through semi-structured, qualitative interviews ( $n=9$ ) of young adults aged 18-21 with type 1 diabetes. Data analysis undertaken during initial interviews ( $n=4$ ) to locate ideas for development. Later interviews assisted in the iterative design process ( $n=5$ ). Pre-launch feedback also obtained from clinical staff ( $n=5$ ). Evaluation data collected from different young adults from a wider range of demographic backgrounds post launch ( $n=11$ ) on app usability, usage and usefulness.

**Findings:** Six themes were identified providing an understanding of participant experiences with their condition and their use of technology. From suggestions prototyped, a clinically approved mobile alcohol guide app was developed. Post launch data analysis identified six different themes relating to app usability, usage and usefulness.

**Conclusion:** The study contributes to new knowledge regarding:

- (1) The lives of young adults with type 1 diabetes, by providing examples of how their lives could be improved based on use of the Internet and web/mobile technology.
- (2) The technical development process, by documenting best practice procedures and principles involved in creating a patient-centric educational health app (downloaded globally 2,639 times as of July 2015).
- (3) Policy, by highlighting areas where care and support were lacking in the target group and where there were gaps in knowledge and understanding.

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# 1 Introduction

*Type 1 diabetes* is a long-term condition (LTC) which occurs when the body produces no insulin (NHS Choices 2013) and can occur at any age, but usually develops before the age of 40, often during teenage years. A young adult with type 1 diabetes will need to take insulin injections for life and in order to reduce their risk of developing complications they must ensure good control of blood glucose levels by balancing their insulin doses, diet and activity; in addition to carrying out regular blood testing. In 2012, both the National Audit Office (NAO) and Diabetes UK published critical studies on diabetes care. Introducing their report, the NAO head (NAO 2012a) stated that the DoH had failed to deliver diabetes care to the standards it had set out as far back as 2001. Their report (2012b) found that despite some improvements since 2006-07, there was poor performance against expected levels of care, low achievement of treatment standards and high numbers of avoidable deaths, concluding that diabetes services in England were not delivering value for money. The Diabetes UK report (2012) found that although there had been some demonstrable improvements in services since the start of the delivery plan in 2003, with some good practice and effective interventions in place in some parts of the country, services geographically were variable and there were significant numbers of people with diabetes who did not have access to the agreed essential standards of care. A 2010 Office for National Statistics (ONS) survey of UK households found that only 1% of 16 to 24 year olds had never used the Internet and by 2012, for those aged 16 to 24, social networking had replaced sending or receiving emails as the most popular Internet activity (ONS 2012). Two-thirds of the world's population now has access to a mobile phone (Naughton 2012), with the adoption of mobile phone technology being led by young adults - 60% of 16 to 24 year-olds now use a mobile phone to access the Internet every day (ONS 2012). Apps harness the power of the Internet with the simplicity of multi-touch technology on a smaller screen and can be run on computers, smartphones or tablets. Health apps offer tremendous potential as they can be specifically geared towards particular conditions and purposes or focus on providing support for specific users. In the case of type 1 diabetes, Lamb (2012) believed that adolescence effectively conflicted with the management of chronic conditions and that technological interventions utilised previously - telephones, mobile phones and text messaging - might seem to empower individuals but had little to no effect on metabolic control in young adults so far. Even with these cautions, Lamb (2012)

still considered that technology might offer new ways of engaging with adolescents and this view is also backed by other practitioners who have continued to research, experiment and hypothesise on the integration of new technology with diabetes education and support (Dovey-Pearce et al. 2005; Mulvaney et al. 2010; Liang et al. 2011). However, crucially Mulvaney et al. (2012) highlighted that little is still known about how young adults use mobile phones for diabetes and to date only a small proportion of apps had been the subject of any research (Holtz and Lauckner 2012). Although Chomutare et al. (2011) suggested that research had consistently shown that diabetes management was one area where mobile devices could enhance health-related quality of life for people living with LTC, actual research evidence was hard to locate (Holtz and Lauckner 2012). Similarly, personal views on policy and key personal issues for this age group in terms of falling ill and maintaining and managing their health were also lacking in literature searches undertaken. I therefore identified a need to investigate young adults aged between 18 and 21 with type 1 diabetes and their use of web and mobile technology, as published research considering their views in the use of technology to support their condition was sparse. The aim of my research was to develop an insight into young adult use of web and mobile technology and its impact on their life. I wanted to explore what they felt about their use of technology and whether it might enable them to engage in an improved way with the NHS and their own health in the future. This would be achieved by forming an in-depth picture of their day-to-day experiences and challenges from extensive qualitative interviewing, exploring how they made use of technology in their lives and in relation to their condition and treatment. Then, building something which could help them and seeking their opinions on the design and usefulness of the final product; utilising sociotechnical design principles.

*Research Question:*

*How do young adults with type 1 diabetes interact with technology in their lives and in relation to their condition and how can their views and experiences inform the development of a patient-centric mobile health app?*

*Contribution to new knowledge:*

My research hoped to create a new framework influenced by lifeworld understanding, which humanised healthcare by creating technology using sociotechnical design principles. By including young adults with type 1 diabetes in the process of generating ideas and asking them to use and feedback on a number of developed iterations (pre and post launch), I was intending to provide a humanly sensitive approach to their healthcare. An approach giving them a chance to contribute to the development, something that a number of previous studies had not allowed for. In addition to involving clinic staff so that their feedback could also be considered. Sensitised by these theoretical perspectives, I was aiming to contribute to lifeworld-led development and approaches to care by the creation of a patient-centric educational app.

### **1. Contribution to Young Adult Lives**

There was a need to explore how young adults with type 1 diabetes related to their condition, how they used and interacted with technology and the Internet in health and non-health situations, and what they thought would be of use to them in terms of new health based technological innovations, by talking to them and asking for their suggestions and feedback.

### **2. Contribution to Technical Development Process**

I felt this present research would help to contribute to the creation of a structurally, technologically sound pathway to follow for the design, development, testing and implementation of a patient focused educational health app. One which responded to insightful suggestions from those with the condition, by designing tools using sociotechnical design principles, which enabled young adults to more effectively engage with health services and allowed them to support their condition in their own preferred manner.

### **3. Contribution to Policy.**

This present research also aimed to give young adults with type 1 diabetes a chance to air their own opinions during qualitative interviewing. This could help to influence future policy on their actual requirements and the problems that they experienced, by serving to highlight areas where their care and support had been lacking or where there were gaps in knowledge and understanding.



## **2 Literature Review**

### ***2.1 Introduction***

A series of literature reviews were conducted with the primary objective of identifying and clarifying the overall scope and direction of research within the fields of health and technology and how they integrated. In all cases, publications were selected which were written in the English language. The initial database searches were conducted between October 2008 and September 2009 in preparation for submitting my original research proposal to the School of Health & Social Care (HSC) Research Committee. A second search was conducted between October 2009 and April 2010 in preparation for my first two applications to NHS Ethics. A third search was conducted between December 2010 and May 2011 in order to rewrite my proposal and submit a third NHS Ethics application. A fourth search took place between January and April 2012 in preparation for my Transfer Viva and for qualitative interviewing, app design and data analysis. A fifth search was undertaken between May and October 2012 in preparation for refining the methodology chapter. A sixth search was conducted to contribute to the discussion and conclusion chapters and also to ensure that any new or updated references of relevance were included in the final thesis. The designated end date for searches that contributed to this review was the 31st May 2013, prior to thesis submission in June 2013. Two separate reviews were carried out post-viva to ensure that any additional relevant articles were included. The designated end date for the first review was the 31st December 2013 and the end date for the second review was 31st May 2015.

The databases included within these searches were Science Direct, SpringerLink, Web of Science, PubMed, Medline, CINAHL and Cochrane. A variety of different search terms were used to ensure that a high volume of background research material was collected. Use was also made of Google Scholar to ensure that other sources of information were uncovered. The Google search engine was also utilised to uncover resources not highlighted by Google Scholar searches, which could then be investigated for relevance and interest. Another search strategy employed consisted of following the reference trail within relevant articles located. This strategy allowed resources to be identified which had not appeared elsewhere and where they appeared again, provided a methodical way of cross-checking validity. A variety of search terms were used to ensure that a high

volume of background research was located. In the initial search these included: long-term conditions (LTC), quality of life (QOL) and health-related quality of life (HRQOL); the National Health Service (NHS) and how it historically and currently used and integrated Information Technology (IT) - including the *National Programme for IT in the NHS* (NPfIT); the use of the Internet and social networking tools by individuals including the terms web 1.0 and web 2.0; and investigating the use of these tools for searching for health information and seeking support online. For the second search these included: the rising emergence of mobile phone technology (as this had started to become noted in literature); the lack of a patient-centric approach to integrating health with technology and the need to design such a framework; and revisiting the evolving use in health contexts of the Internet and social networking tools. The third search used terms associated with the following areas. Focusing on young adults with type 1 diabetes (the LTC now being considered for researching); the growing use of apps and smartphone technology and their potential use within healthcare (an emerging technology trend); revisiting again Internet and social networking applications and their possible uses within healthcare; continuing to explore and expand on my ideas concerning the lack of a patient-centric approach to IT solutions in healthcare; and generic young adult use of the Internet for both social and health communication and support. The fourth search included terms looking at how type 1 diabetes and technology were being integrated and how effective this was; the disadvantages and advantages of using technology within healthcare - including how the NHS were progressing with IT issues post-NPfIT; refining my patient-centric model so that it could be used within a type 1 diabetes setting; online identity and associated health problems; and qualitative research approaches and interview and data analysis techniques - as I was conducting interviews and performing analysis on the data collected. The fifth search used terms associated with the following areas. Sociotechnical design; the lifeworld and qualitative healthcare research; humanising healthcare and empathetic understanding; theoretical positioning and reflexivity; generic qualitative approaches; strategies to establish rigour; ontology, epistemology and the analytic lens; and mobile app design and implementation in relation to health and type 1 diabetes. The last three searches included a range of previous search terms to ensure that a detailed review of the literature was achieved.

The review is divided into five parts. The first section defines long-term conditions (LTC), quality of life and assesses how the NHS has used and integrated IT within healthcare

generally and more specifically relating to LTC. The second section provides an overview of type 1 diabetes, NHS policy towards this condition and issues and ideas surrounding its care and management. The third section concerns the Internet, social media and their possible use within health contexts. It clarifies the differences between web 1.0 and web 2.0 technology, critiques and analyses use of the term health 2.0 and provides detailed descriptions and examples of a range of web 2.0 technologies and their possible uses within health for seeking information and support online. It then focuses on how this technology might be used for the support and management of type 1 diabetes and specifically young adults with the condition. The fourth section concentrates on the growing usage of mobile technology and how new mobile technologies and software could be applied within a health context including smartphones and the use of apps. It then describes the possibilities and problems of using this technology relating to type 1 diabetes support and management. The fifth and final section brings these threads together to provide a rationale for this present research. It highlights the gap in the literature to be addressed and how it contributes to the generation of new knowledge in the three areas of young adult lives; the technical development process and policy.

## ***2.2 Long-term Conditions, Quality of Life and NHS Policy***

### **2.2.1 Long-term Conditions and Health-related Quality of Life**

A long-term condition (LTC) is a condition that cannot at present be cured, but can be controlled by medication and other therapies (Department of Health 2008). In England, 15.4 million people have a LTC (Department of Health 2008). The life of a person with a LTC is altered forever and there is no return to normal, with the impact on the individual being both physical and psychological. The NHS currently spends 70% of its budget on people who have one or more LTC and with an ageing population, patient numbers are expected to grow by 23% over the next twenty years (Cruickshank 2010). Fallowfield (2009) defined quality of life (QOL) as a ubiquitous concept, with different philosophical, political and health-related definitions. She felt that as illness and its treatment affected psychological, social and economic well-being, as well as the biological integrity of individuals, any definition of QOL should be all encompassing whilst allowing individual components to be delineated. Testa and Nackly (1994) described health-related quality

of life (HRQOL) as involving five broad dimensions of opportunity, health perceptions, functional status, morbidity or impairment and mortality. Walker (1992) defined HRQOL as the level of well-being and satisfaction associated with an individual's life and how this was affected by disease, accidents and treatment. Carr et al. (2001, p.1240) suggested that QOL was purely a matter of subjectively experienced health-related discrepancies:

*Quality of life...is those aspects of an individual's subjective experience that relate both directly and indirectly to health, disease, disability and impairment...health related quality of life is the gap between our expectations of health and our experience of it.*

However, Cummins (1997) felt that the key problem with these definitions was confusion as to what constituted a reasonable set of variables to measure medical outcome and QOL. He also considered the idea that people who were medically or physically compromised could enjoy a QOL equal to or greater than the non-disabled population was not included. Rapley (2003) summarised these viewpoints, suggesting that a valid definition of HRQOL came together around an operational definition similar to that of Cummins (1997) where HRQOL was considered as a universal construct. For the purposes of this present research it is instructive to reflect on how QOL and HRQOL are defined, but as this is a qualitative study there were no attempts to measure them in relation to participants within the study.

### **2.2.2 The NHS and Information Technology: Uneasy Bedfellows**

Governmental policy towards investment in IT within the NHS to provide high quality services to patients was acknowledged by the creation of the *National Programme for IT in the NHS* (NPfIT) in 2002. It constituted the largest single IT investment in the UK at that point in time (HM Government 2007a) and was viewed as possibly revolutionising the way in which the NHS in England used information, and being able to make significant improvements to the quality of patient care (HM Government 2007b). More recently, the NHS Operating Framework for 2008/09 (Department of Health 2007) identified the need for a sustained focus on Information Management and Technology (IM&T) in the NHS to deliver better, safer care. The *Guidance on Preparation of Local IM&T Plans for 2008/09* (Department of Health 2007) stated that local health community

IM&T planning was an explicit requirement, with the emphasis on local ownership and leadership driving a local IM&T agenda which also met a defined set of national expectations and exploited NPfIT. The coalition government formally announced the scrapping of NPfIT in September 2011, dubbing it the biggest IT disaster of the last administration (Simons 2011). The move came after a series of damning reports from the Public Accounts Committee (PAC) and more muted criticism from the National Audit Office (NAO). The final indignity was the publication of the new government's Major Projects Authority (MPA) study of the project, which stated that it was not fit to provide services to the NHS and recommended that the government dismantle and reconstitute it with new management and organisational arrangements (Simons 2011). Thus NPfIT joined the long list of historical projects within the NHS where attempts to integrate IT and healthcare had wasted huge tranches of funding, which could have been better spent on directly improving patient care. Another notable local example of this approach being the Wessex IT scandal that cost the NHS over £10 million (Klein 1994).

### **2.2.3 Integration of Information Technology and Long-term Conditions within the NHS**

In 2005, the *NHS and Social Care Model* - a blueprint to support organisations in improving local services for people with LTC - was published (Department of Health 2005). By 2008, it was acknowledged that people wanted services that would support them to remain independent and healthy and have increased choice (Department of Health 2008). These views were considered when drawing up five high-level outcomes for people with LTC. For the delivery framework, four areas of support - Case Management, Disease Management, Supported Self Care and Promoting Better Health - were identified to help create empowered and informed patients (Department of Health 2008). It was also noted (Department of Health 2008) that some of the options health and social care communities could use to support people with LTC might include technological tools which:

- Supported personalised care and choice.
- Helped people remain independent.
- Monitored them remotely and sped up processes - promoting independence, detecting early changes and preventing deterioration.
- Provided resources and support for patients to self-care and self-manage.

In 2010, *Equity and excellence: liberating the NHS* (Department of Health 2010) set out the coalition government's long-term vision for the future of the NHS. The vision built on the core values and principles of the NHS - a comprehensive service, available to all, free at the point of use, based on need, not ability to pay. It set out how the NHS would:

- Put patients at the heart of everything the NHS did.
- Focus on continuously improving those things that really mattered to patients - the outcome of their healthcare.
- Empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services.

For people with LTC, this meant being at the centre of decisions about their care and support (Department of Health 2010, p. 3):

*No decision about me without me.*

Whilst the generic LTC model placed the emphasis on engaging the individual in making shared decisions about their care (Department of Health 2010). The controversial *Health and Social Care Bill* (HM Government 2011) was a crucial part of the government's vision to modernise the NHS so that it was built around patients, led by health professionals and focused on delivering world-class healthcare outcomes. Following Royal Assent in March 2012, the Bill became the *Health and Social Care Act*. At the same time as this bill was being implemented, the Whole System Demonstrator (WSD) programme (Department of Health 2009) was concluding. The programme was a two-year project to find out how technology could help people manage their own health whilst maintaining independence. It was believed to be the largest randomised control trial (RCT) of telecare and telehealth in the world to date and ran at three UK sites with over 6,000 people involved. The hope was that WSD results would assist both the Department of Health (DoH) and NHS in understanding to what extent the integration between health and social care when supported by telecare and telehealth technologies could (Department of Health 2009):

- Promote people's long-term health and independence.

- Improve QOL for people and their carers.
- Improve the working lives of health and social care professionals.
- Provide an evidence base for more cost and clinically effective ways of managing LTCs.

Major findings from the study (Department of Health 2011) highlighted that if delivered properly, telehealth could substantially reduce mortality, reduce the need for admissions to hospital, lower the number of bed days spent in hospital and reduce time spent in accident and emergency (A&E). The findings also suggested that at least three million people with LTCs and/or social care needs could benefit from telehealth and telecare. To achieve this level of change, the DoH launched the *Three Million Lives* (3ML) campaign in 2012, aimed at alleviating the pressure on long term NHS costs and improving people's QOL through better self-care in a home setting (2013).

## **2.3 Diabetes: Policy and Self-Management**

### **2.3.1 Diabetes**

*Diabetes* is a LTC characterised by too much glucose, a type of sugar, in the blood (NHS Choices 2013). The World Health Organisation (WHO) has identified the treatment and care of diabetes as major challenges for healthcare systems worldwide (Gunn et al. 2012). There are 24,000 diabetes-related deaths every year and many more people with diabetes develop complications, such as blindness and kidney disease. The NHS spends at least £3.9 billion a year on diabetes services and around 80% goes on treating avoidable complications. The number of people with diabetes is set to rise to 3.8 million between 2012 and 2020 and unless care improves significantly the NHS faces ever-increasing costs (Commons Select Committee 2012). For example, the number of prescriptions for treating diabetes in England has increased to over 40 million - a 50% rise in six years (BBC News Online 2012). In the UK, around 5-10% of total UK NHS resources (including hospital expenditures) are used for the care of people with diabetes, although if there were improvements in the management of the disease, it is estimated that treatment costs could be reduced by 25% (World Health Organisation 2003).

### 2.3.2 Types of Diabetes

There are two types of diabetes: *Type 1* and *Type 2*. Usually, the amount of sugar in the blood is controlled by the hormone insulin, which is produced by the pancreas. When food is digested and enters the bloodstream, insulin moves any glucose out of the blood and into cells, where it is broken down to produce energy. However, in people with diabetes, the body is unable to break down glucose into energy, either because there is not enough insulin to move the glucose, or because the insulin that is there does not work properly. *Type 1 diabetes* occurs when the body produces no insulin because of autoimmune destruction of the pancreatic cells that produce it (NHS Choices 2013). It can occur at any age, but usually develops before the age of 40, often during teenage years. Someone who has type 1 diabetes will need to take insulin injections for life. In order to reduce their risk of developing complications they must ensure that their blood glucose levels are as good as possible by balancing insulin doses, diet and activity, as well as carrying out regular blood testing. The primary diabetes outcome is glycaemic control, as measured by a blood test (glycosylated haemoglobin or *HbA1c*) that indicates average plasma glucose for the previous 2-3 months (Mulvaney et al. 2012). Poor glycaemic control has been related to short-term consequences such as *Hypoglycaemia* and *Diabetic Ketoacidosis*, as well as serious health consequences later in life such as limb amputation, retinopathy, and renal failure (Mulvaney et al. 2012). Completion of recommended self-care tasks is considered critical to glycaemic control, with the primary tasks which help to maintain glycaemic control, such as monitoring blood glucose levels, injecting insulin, and dosing insulin according to meter results or other factors, needing to be carried out several times per day, often around mealtimes in varied contexts and locations (Mulvaney et al. 2012). Type 1 diabetes is far less common than type 2 diabetes, accounting for 10% of all people in the UK with diabetes, but notably 90% of young adults with diabetes (Diabetes.co.uk 2013).

### 2.3.3 Diabetes Care in Crisis

In 2012, both the NAO and Diabetes UK published critical studies on diabetes care. Introducing their report, the NAO head (NAO 2012a) stated that the DoH had failed to deliver diabetes care to the standards it had set out as far back as 2001. Their report (2012b) found that, despite some improvements since 2006-07, there was poor performance against expected levels of care, low achievement of treatment standards and high numbers of avoidable deaths, concluding that diabetes services in England



were not delivering value for money. The Diabetes UK report (2012) found that although there had been some demonstrable improvements in services since the start of the delivery plan in 2003, with some good practice and effective interventions in place in some parts of the country, services geographically were variable and there were significant numbers of people with diabetes who did not have access to the agreed essential standards of care. In her introduction to the report (2012, p.3), the Chief Executive of Diabetes UK stated:

*We are in a state of crisis. Ministers and the NHS need to recognise this, to prioritise prevention of diabetes and its complications.*

In November 2012, following on from these two critical reports a PAC published their report on the management of adult diabetes services in the NHS, stating that the standard of care for diabetes in England was depressingly poor, causing unnecessary deaths and disabilities. The PAC Chair noted (Commons Select Committee 2012) that although the DoH had set out clear minimum standards for diabetes care - including nine basic checks for the early signs of avoidable complications - fewer than half of people with diabetes were receiving all nine tests. The PAC report also highlighted that the DoH had given local NHS organisations the freedom to decide how to deliver diabetes services and did not introduce mandatory performance targets as it had for cancer, stroke and heart disease. Consequently, there was no strong national leadership and no effective accountability arrangements for commissioners. Variations in the level of progress across the NHS meant there was an unacceptable “postcode lottery” of care, where the quality of care varied dramatically around the country. The report stated that the PAC had seen no evidence that the DoH would ensure these issues were addressed effectively under the new NHS structure. It suggested that it must set out how improvements in diabetes care would be delivered under the new arrangements and what steps it would take, alongside Public Health England, to improve public awareness of the risk factors for diabetes. In November 2012, members of the House of Lords debated the management of diabetes services in the NHS following the PAC report. Lord Harrison who had lived with type 1 diabetes for 43 years stated that his biggest concern was that the onus of care and of making important decisions was becoming the sole burden of the individual with the condition (Lords Hansard 2012).

### **2.3.4 Age and Self-Management**

It is thought that education about long-term complications via access to information could help patients with diabetes empower themselves to manage their condition more effectively, thereby reducing complications. Van Dam et al. (2005) acknowledged that better knowledge of the ways in which social support operated was vital for enhancing diabetes patient self-care, ensuring adherence to advice, encouraging lifestyle changes and helping to improve outcomes of care and increase personal freedom. Lamb's (2012) article on integrating technology into adolescent type 1 diabetes care highlighted how metabolic control - defined by HbA1c - varied with age. Results from his study showed a progressive rise in HbA1c values throughout adolescence, peaking through the ages of 18 and 22, before falling again in early adulthood. He considered a number of factors at work which could affect this inability to control HbA1c during late adolescence, including puberty and the physiological changes taking place during it; changes in the adolescent brain; changes affecting personal identity and young adult roles in society; needing to seek a degree of emotional and economic independence from parental control; and irritation and anger with others advising them of what they should be doing. For these reasons he suggested it was not surprising that metabolic control deteriorated whilst the incidence of acute complications such as diabetic ketoacidosis increased during adolescence (Lamb 2012).

## ***2.4 The Internet, Social Networking and Health Possibilities***

### **2.4.1 The Rise of the Internet, Web 1.0 and Web 2.0**

The Internet has revolutionised the world, allowing information to be disseminated and collaboration and interaction between individuals to take place irrespective of location or time (Leiner et al. 1997). As Searls and Weinberger (2003) argued, the Internet's value is founded in its technical architecture. The growth in its use is often attributed to the lack of a central administration, allowing organic network growth, as well as the non-proprietary nature of Internet protocols, which encourage interoperability and prevent anyone from exerting overall control. Berners-Lee (1999) described his original vision for the Internet as encompassing the decentralised organic growth of ideas, technology, and society made possible by this structure. His vision was of a collaborative workspace

where everything was linked in a single, global information space - a web of information (Berners-Lee 1999). An early development during his career led to the creation of a web browser, which allowed users to browse and edit documents simultaneously. However, as development continued, no newer browsers included edit functionality due to the complexities of programming this feature. Crucially, this left people regarding the web as a medium where few individuals could publish information whilst most browsed. This version of the Internet can be defined as *Web 1.0*. In 1999, DiNucci coined the term *Web 2.0*, using it to describe mainly web design and aesthetics. But it is important to note, that her original definition was not used to capture the essence of an identified group of technologies, but something far more amorphous. Anderson's (2007) definition of web 2.0 technology reflected this enhanced generation of web-based communities and services, which aimed to facilitate creativity, collaboration, and sharing between people. Web 2.0 could be viewed as connecting people and facilitating new kinds of collaboration whereas web 1.0 focused solely on connecting computers and making information available to people. From this perspective, web 2.0 should not be viewed as competing with web 1.0, but as aligning more closely to the original vision of Berners-Lee. Anderson (2007) saw this distinction as being the key to understanding where the boundaries were between the Internet as a set of technologies, and web 2.0, which he saw as an attempt to conceptualise the significance of a set of outcomes enabled by those technologies. In a 2010 survey of UK households and individuals, the Office for National Statistics (ONS) found that only 1% of 16 to 24 year olds had never used the Internet, whilst 82% accessed it daily, or every other day. Social networking activities proved to be the most popular amongst this age group in a more recent ONS survey (2012), with 87% using social networking as a form of Internet communication. For those aged 16 to 24, social networking had replaced sending or receiving emails (83%) as the most popular Internet activity. The immediate ability of the web to provide increased access to diverse peoples and the nature of text-based relationships removes much of the influence of status, age and gender and can also give new pathways of access to peers who might be experiencing disorders and conditions that do not have face-to-face (F2F) discussion groups.

## **2.4.2 Blogs and Microblogs**

A Blog is a method of publishing information online, similar to keeping a journal and

writing entries (Pulman 2009a). A Micro blog is a shortened version of a blog post and is a more recent web 2.0 technology. Its attraction is increasing when compared to blogs due to its ability to encourage shorter posts, which lowers users' requirement of time and thought investment for content generation (Java et al. 2007). The other important difference is the frequency of update. On average, a blogger updates their blog every few days, whilst a micro blogger might post more than several updates per day. Twitter (2013) is an online micro blogging application, which provides users with the ability to communicate through the exchange of quick, frequent 140 character messages called *Tweets*. Originally messages were in answer to the question "What are you doing?" the question upon which Twitter was founded. Today, tweets could be responses to other enquiries, links to online resources the user finds interesting, musings, or questions. Unless tweets are protected, they appear on a public timeline, which serves as an electronic pinboard showcasing a constant stream of user postings (Codel 2006). Users can also send private messages to friends (*Followers* in Twitter terminology) or reply privately to another tweet by sending a *Direct Message*. Twitter is now fully integrated with mobile technology and messaging clients, making it an easy way for mobile users to stay in touch wherever they are. Twitter is also integrated with blogs and provides Really Simple Syndication (RSS) which allows news aggregators to subscribe to individual feeds of interest. In many cases a Twitter user might not be an individual but rather a group of people, part of an organisation, or an event. It has now evolved beyond its basic functionality to offer a variety of alternate uses, some of which could be health-related (Baumann 2009; Kerr 2011a; Kerr 2011b; Kar 2013). Writing in 2009, I considered that Twitter might be a sound candidate for providing an innovative solution to the problem of delivering improved HRQOL, as it had the potential to increase social capital by cultivating and inspiring private, focused group conversations between people with LTC and also offering an effective targeted channel for sharing news and information between practitioners and patients (Pulman 2009b).

### **2.4.3 Podcasts and Multimedia**

The popularity of multimedia web sites - which enable the sharing of digital content on web applications like Flickr (2013) for photos, YouTube (2013a) for video and Instagram (2015) for both - has seen significant growth over recent years. Over 800 million unique users visit YouTube each month, over 4 billion hours of video are watched monthly and 72 hours of video are uploaded every minute (YouTube 2013b). Multimedia-sharing

software allows for the capturing of activities and the sharing and repurposing of digital content – the term *Lifecasting* being used to define the continual broadcasting of events in a person's life through digital media. A *Podcast* is an audio file that can be streamed or downloaded from a web source onto an MP3 player or mobile phone whilst a *Vodcast* (video podcast) integrates visuals with audio. Since 2007, NHS Choices has been providing a dedicated YouTube channel (2013c) aiming to help viewers make choices about their health; from lifestyle decisions about subjects like smoking, drinking and exercise, through to the practical aspects of finding and using NHS services in England.

#### **2.4.4 Really Simple Syndication**

*Really Simple Syndication* (RSS) provides a method of aggregating and distributing changes to websites, blogs and podcasts that keeps users informed of news and updates. News feeds allow a user to see when websites have added new content to them, so that they can be notified immediately and obtain the latest health-related information in one place as soon as it is published (NHS Choices 2011c).

#### **2.4.5 Wikis**

A wiki is a group of web pages that allows users to add content but which also permits others, sometimes without restriction, to edit that content. The best known wiki is Wikipedia (2013), a free encyclopedia collaboratively written by unpaid users who are continuously making changes, all of which are recorded historically. Wikis offer the potential of working collaboratively to compile and edit health-related web pages without the need for advanced technical knowledge. However, as Archambault et al. (2012) highlighted, even though wikis might provide an easy way of allowing multiple users to create new online content that anyone can edit or supplement, tough questions remained about their safety, reliability, lack of traditional authorship and the legal implications for decision making surrounding them. Seeman (2008) suggested that customised wikis could advise local patients as to which agencies to visit for education, nutrition, counselling or rehabilitation services; or how to access telehealth or culturally specific services. Archambault et al. (2012) explored the depth and breadth of evidence for the use of collaborative writing applications in health care and documented examples of patients using wikis to share their experiences of conditions like diabetes (Wikia 2013) and to find health related information from sites like WikiProject Medicine (Heilman et al. 2011). This wiki coordinates and discusses the English-language Wikipedia's medical

content, with the goal of providing people with free access to reliable, understandable, and most importantly up-to-date health information.

#### **2.4.6 Facebook and Social Networks**

Facebook (2013) is an example of a social networking site. It is free to use and generates revenues through advertising. Over 845 million users log into Facebook each month with 483 million users logging in daily. By the end of 2011, Facebook announced there had been 100 billion friend connections, and in recent months users had registered 2.7 billion *Likes* - a way of letting Facebook users register their approval of a post, business, group or web page - and *Comments* per day (CrunchBase 2013). Facebook supports online meetings, conversations and collaborations with Ahmed et al. (2013) noting that it now had hundreds of health-related groups that connected individuals and allowed interactive communication in lieu of static information. Many of these groups being condition-specific, such as support groups for breast cancer (Bender et al. 2011), diabetes (Greene et al. 2011) and attention deficit hyperactivity disorder (ADHD) (Gajaria et al. 2011). Away from Facebook, targeted communal diabetes sites include TuDiabetes (2013), a social network for people with diabetes. TuDiabetes allows members to connect and help each other by exchanging information and tips on living a healthy lifestyle whilst having the condition, sharing videos, photos and blogs and actively participating in forum discussions.

#### **2.4.7 Health 2.0 and Medicine 2.0**

Research and policy concerning the integration of health information and support with technology do not effectively consider the viewpoint of the patient. *Health 2.0* is still being defined but Landro (2006) provided one of the earliest descriptions of web 2.0 coming to healthcare. Shreeve's definition of health 2.0 (2010) considered that while this view ascribed it as the merging of the web 2.0 phenomenon within healthcare, others believed that it was much more - going beyond social networking technology to include a complete renaissance in the way in which healthcare was delivered. Holt's definition (2010) rightly criticised Shreeve's viewpoint as being overly ambitious in what was defined as health 2.0, believing it to be just a term that grouped together the healthcare use of web 2.0. He felt that the tools and techniques were going to be used regardless of outcomes, quality, or health reform and that nobody had a proper feel for how they would adopt health 2.0 tools and techniques. O'Grady (2010) preferred the term *e-Health*

2.0 and thought Shreeve's viewpoint referred to issues beyond health and technology, with his perspective being centred around the US, relating to managed care issues and for profit medicine and tended to agree with Holt. O'Grady (2010) suggested the main point of the web 2.0 movement in health care was the use of social software and its ability to promote collaboration between patients, caregivers, and practitioners. She felt that using the web to exchange information with others, especially for experiential or anecdotal information had a lot to do with learning - about an illness, what treatment options were available, how to make decisions, and for support - and thought the next steps in the e-Health movement would include finding ways to ensure these collaborative efforts were supported. Eysenbach's (2008) definition of *Medicine 2.0* had a broader view, which focused on a global perspective with biomedical researchers being considered as a part of the scope. In 2010, Van De Belt et al. undertook a systematic review to identify unique definitions of health 2.0 and medicine 2.0 and recurrent topics within previous definitions. They concluded that both terms were still evolving concepts and as yet there was no general consensus of definition. However, what could be noted from discussions around these terms concerned the integration of health with web and mobile technology, which were primarily concerned with using concepts and technology from a healthcare or medical perspective. Consequently, the thought of refining and using new technology alongside a new or pre-existing model of healthcare overshadowed and did not effectively consider how this might work from the perspective of the patient at the centre. They also failed to effectively consider how patients might already be using this technology themselves, or might want to adapt it in the future for their own personal use.

#### **2.4.8 Social Networking Tools and Type 1 Diabetes Possibilities**

There have been numerous suggestions that the development of user-friendly web sites, newsletters, and social networking links for young adults with diabetes might enhance education and awareness of community resources (Weissberg-Benchell et al. 2007). Bowen et al. (2010) feeling that web-based discussion forums and social networking sites (see **2.4.6**) could enhance peer interaction amongst adolescents with diabetes (Scott 2005) and might also help to alleviate feelings of abandonment by a health care team during transition and transfer of care. Scott's study (2005) concluded that the emphasis placed on social and peer support pointed to the need for diabetes clinics to foster and encourage young adults to receive, from a community of other young adults

with type 1 diabetes, the validation and sense of normalcy that was currently missing in their own experiences. Participants recommended that services of the ideal centre included a social component and most expressed it was important for an ideal centre to offer opportunities for them to come together and share and learn; which could possibly be done through a peer social group. Dovey-Pearce et al. (2005) listed participants' suggestions for providing age-appropriate diabetes services as including access to regular newsletters, reviews of diabetes websites and email and Short Message Service (SMS) text message contact with staff, in order to improve informational care; features that could be provided by connecting elements of technology with different social networking tools currently available. Some of the hypotheses detailed by Dovey-Pearce et al. (2005) were also highlighted in suggestions for future development within a study by Mulvaney et al. (2010); concerning an Internet-based problem-solving tool for adolescents with type 1 diabetes. Their study concluding that an Internet-based intervention was a feasible and accessible means of improving diabetes care. Finally, in 2011, Whittemore et al. noted that whilst an Internet coping skills training program developed by their research team did not demonstrate differential improvements in metabolic control and diabetes-related outcomes compared to an Internet diabetes education program, youths in both groups reported significantly increased self-care autonomy, higher diabetes self-efficacy, and improved overall QOL over time.

#### **2.4.9 Seeking Health Information and Support Online**

Debate has intensified around whether the increasing use of the Internet and the impact of technology in the areas of seeking health information online and giving and receiving health support online might have a positive or negative impact on the people using it – whether they are patients, caregivers, or practitioners.

Ahmed et al. (2010) described reasons cited for the use of the Internet for seeking health information online as including convenience of access, concerns about confidentiality from F2F interactions, and the ability of those in isolated areas to access information more easily. Telemedicine is commonly used as a means of accessing specialist health care in remote areas (Giansanti et al. 2008) and this phenomenon has important consequences for medicine, with personal health care information accessed by this method potentially being used for decision-making (Shuyler and Knight 2003). Feldman (2000) suggested that health care professionals needed to be aware of the range of



different medical information and communication formats available on the Internet, since they might influence the questions being asked and the decisions being made by patients. These issues expanding in importance as patients increasingly used the Internet to seek advice from physicians and others whom they had not met. A 2011 report on use of the Internet in Britain by Oxford Internet Surveys (OxIS) noted that searching for health information had risen to an estimated 71% of the population (compared to 68% in 2007 and 37% in 2005). The report also found that 48% of *Next Generation Users* – someone accessing the Internet from multiple locations and devices – had found information online that had helped to improve their health. In the US, a recent Pew survey on online health (Fox and Duggan 2013) found that 59% of US adults had looked online for health information in the last year and 35% had at one time or another gone online specifically to try to find out what medical condition they or someone else might have (known as *Online Diagnosticians*). White and Horvitz (2009) stressed that of the medical information available online, some was unreliable in general (Jadad and Gagliardi 1998) and specifically (Biermann et al. 1999), which could mislead users with health concerns. A study by Fox (2006) showed that of the 8 in 10 American adults who had searched for healthcare information online, three quarters did not check key quality indicators like the validity of the source and the creation date of medical information. Although Berland et al. (2001) suggested that medical information present on the Internet was generally valid; they also suggested it was likely to be incomplete. Eysenbach et al. (2002) systematically reviewed studies of health website evaluations and noted that in 70% of the studies examined, the quality of health-related web content was found to be low - according to the authors of the reviewed studies. Additionally, Benigeri and Pluye (2003) highlighted that exposing people with no medical training to complex terminology and descriptions of medical conditions on the Internet might put them at risk of harm from incorrect self-diagnosis and self-treatment. These factors combining to make the Internet a potentially dangerous place to look for medical advice. Indeed, Adams (2010) suggested that more recent studies pointed to the fact that health websites still do not adhere to established guidelines, that more patient-oriented tools must be developed, and that a universal method for depicting credibility in health websites must be developed. Cyberchondria has been defined by White and Horvitz (2009, p.3) as:

*The unfounded escalation of concerns about common symptomatology, based on the review of search results and literature on the web.*

White and Horvitz (2008) suggested that the information obtained from healthcare-related searches could affect peoples' decisions about when to engage a physician for assistance with diagnosis or therapy; how to treat an acute illness or cope with a chronic condition; and their overall approach to maintaining their health or the health of someone in their care with regard to diet, exercise, and preventative, proactive health activities. The Internet may also play a major role in the development and spread of beliefs, which are unsupported by scientific evidence. For example, the spread of information about Morgellons disease on the Internet has led to several cases of delusional parasitosis (Lustig et al. 2009). In response, Vila-Rodriguez and MacEwan (2008) recommended that an awareness of the capacity of the Internet to enable and spread shared delusional ideation was essential to current medical practice. It should also be noted that not all health information found online is freely available. A recent Pew survey (Fox and Duggan 2013) found that one in four people seeking health information online had hit a pay wall, with only 2% of those asked to pay acquiescing - enabling them to then access the desired information.

Putnam (2000) defined Social Capital and theorised that its possession held great significance in terms of human well-being. He noted that it had been demonstrated to operate through psychological and biological processes to improve people's lives, with mounting evidence suggesting that people whose lives were rich in social capital coped better with traumas and fought illness more effectively. More recently, Seeman (2008) posited that the emerging application of web 2.0 to chronic illness might be considered proof of Putnam's hypothesis that improved physical and mental health could result from generating social capital through increased networks of trust. This view was mirrored in research by Russell et al. (2008), who acknowledged that available evidence supported a positive view of the capacity for Internet communication to enhance social capital in ways which did not undermine and might in some cases strengthen local connections. Online support groups are available for nearly every illness or disability; ranging from those that are communication-related (such as autism and hearing-impairment) to relatively common illnesses (such as asthma and diabetes). They have been suggested as being beneficial for patients with a wide range of health conditions (Ahmed et al.

2010; Pulman 2010a; Ahmed and Pulman 2013) and are also becoming an increasing feature of health care for those with LTC (Griffiths and Caelear 2009). Fox (2011) found that 23% of social network site users (11% of US adults) had followed their friends' personal health experiences or updates; 17% (8%) had used social networking sites to remember or memorialise others who had a health condition and 15% (7%) had obtained health information from these sites. In the UK, over 20,000 people had signed up as fans of the Diabetes UK social networking page on Facebook (Diabetes UK 2011a). This group was established in 2008 to provide support, advice and a safe online space for people with diabetes and their families to share experiences of the condition. Ziebland and Wyke (2012) suggested that accessing people's experiences online might help users make better health care choices and alert them to health issues; improve health literacy and understanding of susceptibility to illness; compare their situation with others; improve their own illness narration; access more appropriate services; and develop better relationships. However, they also cautioned against assuming that the effects of this exposure would always be benign. The disadvantages of online communication include issues around the technology used to communicate. Membership in online communities is limited to people with access to devices with an Internet connection and the ability to type. Learning how to access and participate in a desired online group may be more complicated for some than attending a F2F meeting (King and Moreggi 2007). There can be a high ratio of false or irrelevant data compared to useful information in online self-help groups, as there is an absence of group rules and guidelines and few controls to prevent people from posting erroneous or off-topic information. Joinson (2003) noted that the format of a childcare email list, which seemingly encouraged venting and the name calling of parents and children amidst the unconditional support of other caregivers, created an environment leading to the acceptance of practices that were not child-centered and were potentially damaging to children. Internet health support groups can also face problems when targeted by individuals with factitious disorder. In *Munchausen by Internet* (MBI) (Pulman and Taylor 2012), an individual seeks attention by playing out a series of dramatic near-fatal illnesses, alternating with recoveries that increasingly strain credulity. In-fighting in the wake of such deceptive postings has destroyed many support groups. Finally, the online 'pro-anorexia' movement (Maloney 2013) supports those with anorexia but adopts an anti-recovery perspective with some websites discussing the need for recovery, yet providing tips on how to fast and deceive medical professionals. There are similar

movements in other diseases such as chronic fatigue syndrome supporters who advise abundant rest and avoidance of activity for sufferers, in direct opposition to medical thinking (Wright et al. 2000) and people with diabetes can learn from forums about non-prescribed ways to use (misuse) their insulin for weight loss (Ziebland and Wyke 2012).

#### **2.4.10 Young Adult Use of Internet for Accessing Health Information and Support Online**

Increasingly, younger patients have been seeking medical information outside of conventional medical sources. A Pew survey (Lenhart et al. 2010) found that 31% of online teenagers aged 12 to 17 had used the Internet to look for health, dieting or physical fitness information - a finding which had increased since 2000, when only 26% gathered health information online. Teenagers also used the Internet to look for information on health topics that were hard to talk about. More than one in six (17%) had looked online for information about sensitive health topics like drug use, sexual health and depression. In Fox and Duggan's Pew Survey (2013), online diagnosers (see **2.4.9**) aged between 18 and 29 were noted as the highest age group, with 47% having looked online to diagnose a condition. Meanwhile, in the UK, 27% of 16 to 24 year-olds had used the Internet to look for health-related information according to ONS (2010).

### ***2.5 Mobile Technology and Health Possibilities***

#### **2.5.1 Mobile Growth: from Phones to Smartphones**

Two-thirds of the world's population now has access to a mobile phone (Naughton 2012) and a 2005 survey noted that 82% of respondents in the UK used mobile phones, with use of SMS text messaging for 15 to 24 year olds highest at 89% (Vodafone Group 2006). Users of mobile phones and smartphones have gradually become more interested in searching the Internet via their devices, due to the increasing take-up of third and fourth generation mobile phones, the increasing availability of optimised mobile specific content and home broadband and new mobile devices which are more flexible and capable of handling an increased range of functionality. Recent surveys predict that mobile Internet usage will soon exceed desktop usage (Anderson & Rainie 2008; Richmond 2011). This drive toward mobile Internet access is due in part to the *Mobile*

*Difference* identified by Pew (Fox 2010). This considers that once someone has a wireless device, they are more likely to use the Internet to gather and share information and create new content. In the 2012 ONS survey, the mobile phone was found to be the most popular device used to access the Internet wirelessly, away from the home or workplace. The adoption of mobile phone technology is again led by young adults, with 60% of 16 to 24 year-olds using a mobile phone to access the Internet every day (ONS 2012). Mobile also plays an increasingly important role in social networking. Mobile users now make up half of Facebook's user base, with 425 million monthly active users (CrunchBase 2013) and 23% of UK mobile web users have visited a social network through their handset - 4% greater than the US (Nielsen Online 2009).

### **2.5.2 Mobile Technology and Healthcare**

Mobile difference patterns are also beginning to emerge in Americans' pursuit of health information on mobile devices. A Pew survey (Fox 2010) found that 78% of wireless Internet users had looked online for health information, compared to 70% of Internet users with desktop access. Previous research by Pew had shown that wireless connections were associated with deeper engagement in health-related social media, with mobile Internet users more likely than those with tethered access to post comments and reviews online about health and health care (Fox and Jones 2009). From a health perspective, the Vodafone Group report (2006) highlighted NHS Direct increasing access to NHS services amongst users aged between 16 and 44. This age bracket had traditionally been low users of services, but was now most likely to use NHS Direct and to use a mobile phone whilst doing so. The analysis also showed that those accessing NHS Direct most frequently from mobile phones were predominantly in younger age groups. In aggregate, over 59% of all mobile calls made to NHS Direct were by people aged between 15 and 34. The enhanced privacy offered by a mobile phone was deemed to be very important to some groups - with teenage girls notable in their much greater reliance on using mobile phones to contact NHS Direct. In the US, a Pew mobile health survey documented that 85% of adults used a mobile phone and of those, 31% had used it to look up health or medical information with 42% of mobile owners aged 18 to 29 having done such searches (Fox and Duggan 2012).

The small screen size of mobile devices has been proposed as a potential barrier to usability (Pulman 2010b). The size issue and lack of keyboard can occasionally be seen

as an obstacle for individuals seeking mobile health information or support via a social network (Haddon 2008) - especially for those whose condition affected their dexterity or eyesight. Pinnock et al. (2007) also raised important concerns about the risk of engendering dependence on mobile technology and suggested this warranted further investigation, in order to understand how systems could best be used to enhance self-management. Other negatives might include the possibility of having privacy violated by another group member who, whilst not being intentionally harmful, did not understand the nuances of online self-help participation. Waldron et al. (2000) documented how a member's real life address was made available to the whole group when the sender had intended to send it to only one group member. Hitting the wrong key and sending a reply to a group instead of an individual, or posting an instant ill-conceived global public tweet instead of a more considered, personalised direct message is a common occurrence online (Bates 2013). The small size of mobile keypads coupled with the more immediate manner of communication that they encourage, make this more likely to occur on a mobile platform. Although these findings point to compromised usability, the newer versions of many smartphones now have improved larger touch screen layouts with more innovative, user-friendly interfaces. These are helping to offset concerns and increase popularity (Sherwood 2010), alongside the increasing use of mobile tablets which have larger screens.

### **2.5.3 Mobile Apps and Healthcare**

Apps harness the power of the Internet with the simplicity of multi-touch technology on a smaller screen and can be run on computers, smartphones or tablets. In 2007, Steve Jobs launched Apple's App Store with only 500 applications (Ricker 2008). As of May 2013, users had downloaded over 50 billion apps (including a variety of health based ones) from Apple's App Store - downloading at a rate of more than 800 apps per second and over two billion apps per month (Apple 2013). Owned and operated by Google, the growth of Android has been just as fast (Barra 2011). Health apps offer tremendous potential as they can be geared towards particular conditions and purposes or focus on providing support for specific users. Pew's 2012 mobile health study found that 19% of US mobile owners had apps installed that helped them track or manage their health, with 24% of those aged 18 to 29 owning such apps. These users were also more likely than older owners to use mobile health apps (Fox and Duggan 2012). An app requires careful design to suit a mobile platform and to ensure that it is clinically accurate and fully

considers the individual needs of its user, and at the time of writing, there is little research relating to the design process, development, and use of health-related apps by individuals or groups, although this will certainly change as they become more widely distributed and used in the next few years. One specific area of concern with health apps is the current lack of any medical regulation for those released. In 2013, the US Food and Drug Administration (FDA) released its policy on which mobile medical apps it would oversee. Appositely, in Europe and the UK, there are currently no official guidelines for the regulation of apps to be used in health settings. The Medicines and Healthcare products Regulatory Agency (MHRA) is currently tasked with responsibility for regulating medical devices within the UK. Registered medical devices are required to carry the *CE* mark and to date only one publically available health app has been registered as a medical device (D4 Research 2012). The *Mersey Burns* app (2012) being a clinical tool for estimating burn area percentages, prescribing fluids using the Parkland formula and recording patients' details. However, there are some signs of things changing in the UK with the NHS Commissioning Board (2013) launching their Health App Library project in March 2013. The library was intended to assist the public and health care professionals in deciding which apps could best assist them to inform, monitor, and improve health and care. It aimed to provide patient ratings, kite mark the source of information and also provide a flexible certification process, although this was not an official regulatory body for UK health apps and participation in the scheme was entirely voluntary.

#### **2.5.4 Mobile Technology and Diabetes – Possibilities and Problems**

A Vodafone Group report (2006) saw mobile technology as one way of improving communication between health care professionals and patients, which could help alleviate the disease burden of young adults with diabetes and reduce costs through the reduction of admissions and long-term complications. However, to date, the sole use of phone functionality for clinical interventions concerning type 1 diabetes has shown little actual impact. A recent study showed traditional cognitive behaviour interventions like educational sessions through phone calls having little value in changing negative health behaviours in children with type 1 diabetes (Salamon et al. 2010). However, in the same year, Bowen et al. (2010) had noted that young adults with diabetes had expressed an interest in email and SMS text messaging in previous studies to enhance disease management and that SMS in particular had been proven to be beneficial as a possible motivational tool (Franklin et al. 2003). However, Lamb (2012) cautioned that although in

this research, SMS text messaging was used to support an insulin intensification trial that led to improved HbA1c results, the specific role of texting in the improvement was unclear. He also posited that although adolescents loved their phones, this was principally for use as a means of improving and sustaining peer group contact, rather than communicating with parents and a diabetes team - with additional clinic contact possibly seen as an extension of the nagging which they hated. In the case of type 1 diabetes, Lamb (2012) believed that adolescence effectively conflicted with the management of chronic conditions and that interventions utilised previously - telephones, mobile phones and text messaging - might seem to empower individuals but had little to no effect on metabolic control in young adults to date. At younger ages, there might also be other barriers that restricted the use of mobile phones to support diabetes self-care such as limitations of phone functionality, and/or strict school mobile phone policies (Mulvaney et al. 2012). Even with these cautions, Lamb (2012) still considered technology might offer new ways of engaging with adolescents and this view is also backed by other practitioners who have continued to research, experiment and hypothesise on the integration of new technology with diabetes education and support (Dovey-Pearce et al. 2005; Mulvaney et al. 2010; Liang et al. 2011). Williamson (2010) notably suggesting that new technology should be explored as a possible means of communicating with patients - highlighting a pilot study of a virtual diabetes clinic (Jennings et al. 2009), which was well received with young adults showing positive attitudes to this type of innovation (Lowe et al. 2005). This approach could be applied to a diabetes app on a mobile phone which was always near to them - joining the growing number of existing apps available (Chomutare et al. 2011; Cafazzo et al. 2012; Tran et al. 2012; Diabetes UK 2013) or as a part of a mobile friendly assistive device related to their condition (Rao et al. 2010; Dolan 2011; Sanofi 2011; Tran et al. 2012). For patients, Schwimmer (2007) felt that using a mobile device like Apple's iPhone could be useful for medical education. He suggested utilising its integrated YouTube player with client specific medical education videos, which could be identified, bookmarked and played back at an appropriate time. As an example, a young person with type 1 diabetes who had just been diagnosed might be given access to a mobile device or app which played an introductory guide to the condition in a friendly non-threatening manner, directly after their appointment as a post-diagnosis supportive aid. Other examples might include an app as an alternative approach which helped to counter the high rates of non-attendance at clinics by young adults after transferring to adult services - associated with poorer



glycaemic control when compared to those who attended the diabetes clinic (Masding et al. 2010). For self-monitoring of blood glucose, it could also enable patients to act on their blood glucose results, transfer and manage blood glucose data, assist with interpretation and support behavioural changes (Kerr et al. 2011). Diabetes apps could also be used in collaboration with healthcare professionals to improve glycaemic control and self-management in poorly controlled younger patients – a study of adults with type 1 diabetes recently showing some positive findings (Tran et al. 2012). In this study, the objective was to examine the effectiveness of a free diabetes self-management app – Diabetes Buddy (2012) - combined with support from an accredited diabetes educator to improve self-management, glycaemic control and QOL in poorly controlled patients with type 1 diabetes (Kirwan et al. 2012). The outcome was that in adjunct with usual care, use of the Glucose Buddy app combined with weekly text-message feedback from the educator led to a significant decrease in HbA1c in comparison to the control group receiving only usual care. However, there are a number of caveats for this study. The specific role of using the Glucose Buddy app when set alongside the other method of assisting participants – text messaging between the educator and participants - in the improvement is not clear. There were differences in glycaemic control and gender between groups at baseline and the mean age of patients participating was 35.20 (Tran et al. 2012), which does not necessarily mean this intervention is suitable for young adults with type 1 diabetes – who might not be keen on regularly filling in online data submissions via their mobile phones. Finally, as with a number of the other key studies reviewed, the participants seemingly had no say in choosing the intervention to be tested with them, so was this app really what they wanted to use?

## **2.6 Research Rationale**

### **2.6.1 Research Question**

The literature review process (see 2.1) led me to ask the following research question:

*How do young adults with type 1 diabetes interact with technology in their lives and in relation to their condition and how can their views and experiences inform the development of a patient-centric mobile health app?*

Prior to this present research, as Mulvaney et al. noted (2012), little was known about how young adults used mobile phones for their diabetes and only a small proportion of apps available had been the subject of any concerted research effort (Holtz and Lauckner 2012). This research aimed to contribute to new knowledge in three areas:

- Contribution to young adult lives.
- Contribution to technical development process.
- Contribution to policy.

### **2.6.2 Contribution to Young Adult Lives**

There is little to analyse concerning how young adults with type 1 diabetes make use of web and mobile technology and its value/usefulness in everyday life. Franklin et al.'s (2003) study was the first RCT that explored the impact of SMS text message enabled behavioural support, with intensive therapy in a young age group. However, the study made no mention of engaging with the targeted audience to discuss what they would like to use on which to influence the hypothesis at the heart of the study. Similarly, Pena et al.'s (2009) cross-sectional web-based survey of parents with children who had diabetes focused on the adults, once again lacking interaction with the concerns of the young adults which were neither addressed nor included. Reporting on an Internet-based self-management intervention, Mulvaney et al. (2010) stated that this was the first trial of an Internet program to improve problem solving in adolescents with type 1 diabetes. However the study made no reference as to whether any young adults were asked their opinions during the design of the intervention. In 2012, Mulvaney et al. highlighted that little was currently known about how young adults used mobile phones for diabetes and as yet only a small proportion of apps available had been the subject of any research (Holtz and Lauckner 2012). This view was most recently reaffirmed by Whittemore et al. (2013) who noted that there was limited literature available on strategies to promote greater engagement of youth in behavioural interventions for type 1 diabetes, with even less information on the use of the Internet and mobile technologies for minority and low-income youth. I felt that there was a need to explore how young adults with type 1 diabetes related to their condition, how they used and interacted with technology and the Internet in health and non-health related situations, and what they thought would actually be of use to them in terms of new health based technological innovations, by talking to them in-depth and asking for their suggestions and feedback.

### **2.6.3 Contribution to Technical Development Process**

Although Chomutare et al. (2011) suggested that research had consistently shown that diabetes management was one area where mobile devices could enhance HRQOL for people living with LTC, actual research evidence was hard to locate (Holtz and Lauckner 2012). However, one of the only reviews of features of mobile diabetes apps carried out by Chomutare et al. in 2011 surprisingly uncovered that a critical feature strongly recommended by clinical guidelines - personalised education, an area my research was interested in - was not included in any current application. As I have argued, definitions concerning the integration of health with web and mobile technology are primarily concerned with taking and using concepts and technology from a healthcare or medical perspective (see **2.4.7**). There was a need to design a framework encompassing the use of web and mobile technology for the benefit of patients with type 1 diabetes (and other LTCs) originating from their perspective, which encapsulated and humanised the use of web and mobile technology for patients who might want to support, mitigate or improve their own HRQOL (Pulman 2010c). Young adult views are vitally important as they have a radically different view of technology and how they make use of it than either their parents or practitioners (see **2.4.1** and **2.4.10**). Due to their mostly commercial nature, there is little research available relating to the design, development, implementation, use and regulatory procedures for approving and monitoring health-related diabetes apps in the UK (D4 Research 2012). I felt this study would help to contribute to the creation of a structurally and technologically sound pathway to follow for the design, development, testing and implementation of a patient focused educational health app. One which specifically responded to insightful suggestions from interviewees, by designing tools using sociotechnical design principles, which enabled young adults to more effectively engage with health services and allowed them to support their condition in their own preferred manner.

### **2.6.4 Contribution to Policy**

Giddens (1995, p.54) described power as:

*The ability of individuals or groups to make their own concerns count, even when others resist. Power sometimes involves the direct use of force, but is almost always accompanied by the development of ideas (ideologies) which justify the actions of the powerful.*

So power could be viewed as not just being about force, but also the creation of knowledge. Morse (2012) suggested that qualitative health research is conducted to see what is going on from the perspective of the patient. My research aimed to give young adults with type 1 diabetes a chance to air their own opinions during qualitative interviewing, which could then be used to create technological innovations which might benefit them in some way by the interpretation of their personal ideas and experiences (see **2.6.2**). Additionally, it could help to influence future policy on their actual needs and shine a light on any problems they had personally experienced. Highlighting areas where care and support had been lacking, or where there were gaps in knowledge and understanding.

## 3 Methodology

### 3.1 Research Aims and Objectives

#### 3.1.1 Introduction

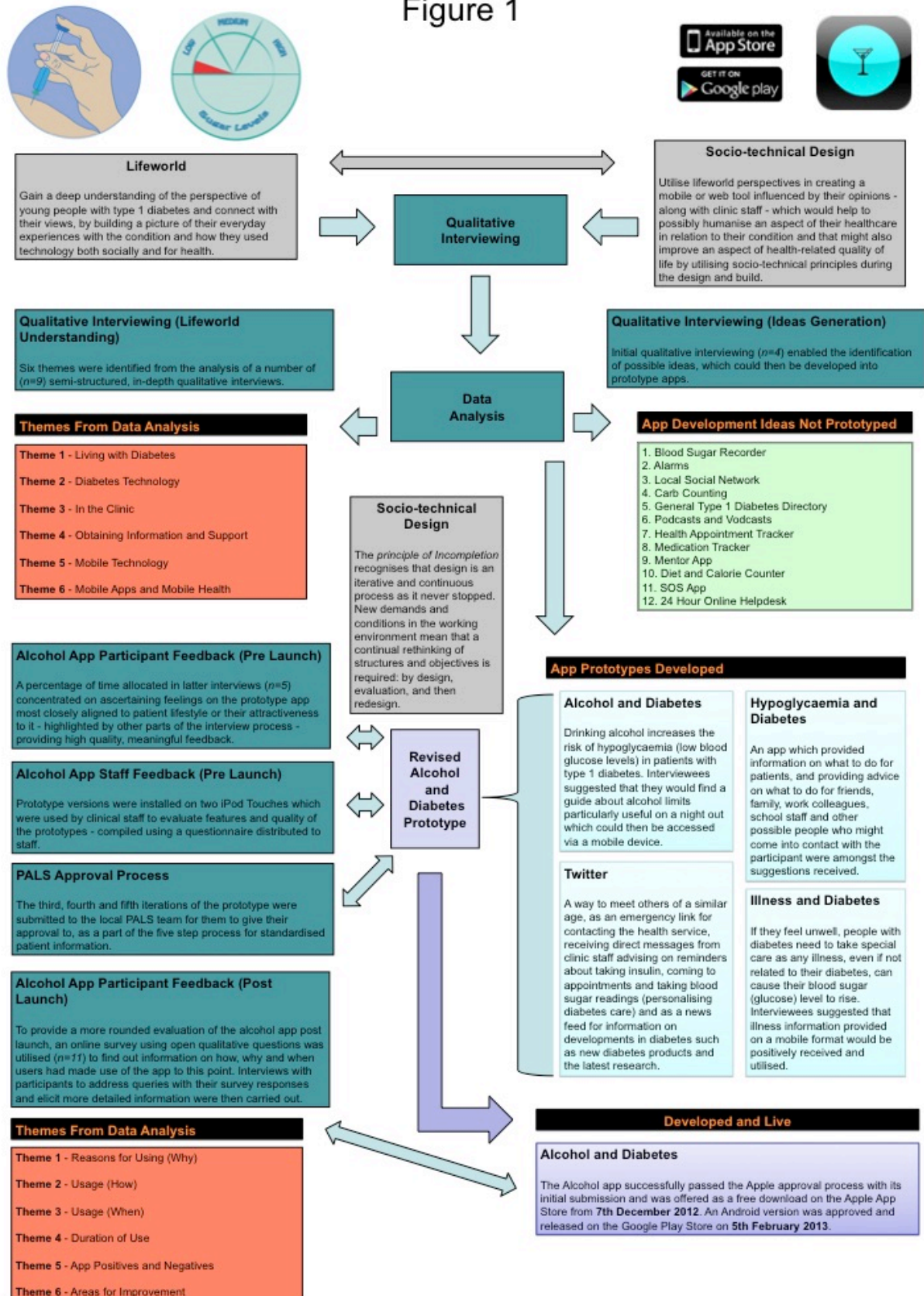
In this chapter I will outline my methodological approach. This used sociotechnical design principles as a way of developing an app for healthcare that was also informed by humanising healthcare and lifeworld influences. This approach is shown in diagrammatic form on page 33 (see **Figure 1**).

##### *Research Aim:*

I undertook a series of literature reviews and participated in a number of discussions with staff at a diabetes centre located within a district hospital in the South West (SWDC). I identified a need to investigate young adults aged between 18 and 21 with type 1 diabetes and their use of web and mobile technology, as published research considering their views in the use of technology to support their condition was sparse (see **2.6**). The aim of my research was to develop an insight into current young adult use of web and mobile technology and its impact on their life. I wanted to explore what they felt about their use of technology and whether it might enable them to engage in an improved way with the NHS and their own health in the future. I would achieve this by forming an in-depth picture of their day-to-day experiences from qualitative interviewing, exploring how they made use of technology in their lives and in relation to their condition and treatment. Then, building something which might help them, using my technical expertise and seeking their opinions on the design and usefulness of the final product – utilising sociotechnical design principles. The research aimed to contribute to new knowledge in three areas:

- Contribution to young adult lives (see **2.6.2**).
- Contribution to technical development process (see **2.6.3**).
- Contribution to policy (see **2.6.4**).

Figure 1



### *Research Objectives:*

- *To explore young adults with type 1 diabetes perspectives of their day-to-day lives and how they made use of web and mobile technology.*
- *To identify from these views and experiences, how young adults used web and mobile technology (if at all) in relation to their condition and treatment for:*
  - a) *Finding knowledge.*
  - b) *Exchanging relevant experience.*
  - c) *Creating biographical accounts.*
  - d) *Recording, transmitting and receiving information.*
- *To build a number of prototype mobile phone apps based on ideas suggested during phase 1 qualitative interviewing (in collaboration with the SWDC).*
- *To gather and evaluate feedback from participants and healthcare professionals on prototype apps developed during phase 2 qualitative interviewing.*
- *To develop the most popular and useful app suggested by interviewees and release it for free on an App Store (in collaboration with the SWDC).*
- *To gather and evaluate post launch feedback from non SWDC external users on the published app during phase 3 qualitative interviewing.*

## **3.2 Assumptions Underlying Qualitative Research**

A paradigm is a way of viewing reality, informed by a particular theoretical perspective, belief or set of assumptions (Gerrish and Lacey 2010). There are two main paradigms in research, the *Quantitative* (Holloway and Wheeler 2002) and *Qualitative* paradigms (Holloway 2008). A third paradigm - the *Pragmatic* paradigm - involves combining both perspectives within one research study (Creswell 2003). Rather than looking for objective facts, qualitative research is a field of inquiry used to gain insight into people's

beliefs, attitudes, behaviours, culture or lifestyles (Morse and Field 1995). It is an approach emphasising words and meaning rather than quantification in the collection and analysis of data. This approach tends to be *Inductive*, stressing the generation of qualitative knowledge (*Discovery*) rather than testing for a hypothesis (*Verification*). Morse (2012) suggested that whereas quantitative researchers provided proof and evidence of distributions, correlations and causation, the qualitative researcher provided a different kind of evidence that illustrated, emotionally aroused and provided instant comprehension. Qualitative research often employs the logic of *Inductive Reasoning* - going from the specific to the general - starting with the observation of a number of individual cases and then examining the data in detail for descriptions, patterns and the hypothesised relationships which connect them (Morse and Field 1995). Researchers collect data without making prior assumptions, analyse and then generate theories from it. They must also distinguish between representative and anecdotal cases and take into account negative cases – important, because they help to clarify additional causal properties that influence the phenomena being studied (Denzin 1978). Most qualitative research starts with inductive strategies, although they become *Deductive* in approach when researchers start to produce working propositions. Holloway (2008) describes sampling in qualitative research as being the selection of a subset of a particular population, of an element of time, or, a number of similar events to be studied in the inquiry. Qualitative studies are not powered to detect statistical significance, but rather generate hypotheses that can then be studied more fully within a representative sample. The logic of qualitative sampling rests not on *Generalisability* but on the notion of *Saturation* - the point at which no new information is obtained (Morse and Field 1995). Therefore, sample size is not a criterion for evaluating the rigour of qualitative sampling, but for evaluating the adequacy and comprehensiveness of the findings. Qualitative studies use small, typically purposive samples, thus their findings might not generalise to larger more diverse populations, unlike quantitative studies (Holloway 2008).

### **3.3 Qualitative Approach to my Study**

#### **3.3.1 Why a Qualitative Approach Was Taken**

Morse (2012, p.21) defined *Qualitative Health Research* as:



*A research approach to exploring health and illness as they are perceived by the people themselves, rather than from the researcher's perspective.*

Researchers use qualitative research methods to elicit emotions and perspectives, beliefs and values, and actions and behaviours, and to understand the participant's responses to health and illness and the meanings that they compose about their experiences. Qualitative research has long been suggested as a valid means of enabling patients and clinicians to be able to say in their own words what mattered to them and why (Patton 1990). Qualitative research methodology has become more recognised and valued in diabetes behavioural research in recent years. Ritholz et al. (2011) suggesting that qualitative methods could help clinicians answer questions that quantitative research might not answer; by exploring patient motivations, preceptions and expectations. Johansson et al. (2008) noted that pre-2001 studies described the experience of being a person living with diabetes (Ternuf-Nyhlin et al. 1987; Hernandez 1995), but none concerned knowledge of the experience of falling ill with diabetes, which was their focus. Other studies described how caregivers and patients had different goals and criteria for reaching the goal of treatment of the disease, but shared a common standpoint that the illness could be controlled, even if it could not be cured (Hunt et al. 1998); the importance of participation and respect for the understanding and knowledge of the person with diabetes (Thorne et al. 1999); and the care and importance of a global approach (Romeo 2000). Johansson et al. (2008) noted that previous research outcomes placed further focus on the importance of the caregiver being attentive to the needs and wishes of the patient, with educators needing to become reflective practitioners. To practice empathy as a way of knowing each of their clients and to follow their lead in building and maintaining collaborative alliance relationships (Hernandez 1995). Post 2000, Ritholz et al. (2011) noted that the number of qualitative health studies focusing on diabetes appearing in research literature had nearly doubled. In 2001, Malterud suggested that qualitative research had a great deal to contribute to clinician's improved understanding of diabetes care, whilst in 2002, Hornsten et al. described the importance of knowledge, ability and a wish on the part of the patient to make necessary changes. Later studies have explored interpersonal relationships in diabetes care, including patients and health care providers and patients and families informing on communication difficulties in the doctor-patient relationship; anxious interactions

between parents and children; and the need for family partnerships in the management of diabetes (Carroll and Marrero 2006; Beverly et al. 2008; Smaldone and Ritzholz 2011; Lowes et al. 2015). Meanwhile, qualitative behavioural diabetes studies of first-hand patient experiences have allowed for the identification of factors that supported and interfered with effective diabetes care (Eborall et al. 2007; Troughton et al. 2008; Chlebowy et al. 2010). However, there is very little to analyse concerning how young adults with type 1 diabetes have historically made use of web and mobile technology and its impact on their lives (see **2.6.2**). In 2012, Mulvaney et al. highlighted that little was currently known about how young adults used mobile phones for diabetes and at that point in time only a small proportion of apps had been the subject of any research (Holtz and Lauckner 2012). Although Chomutare et al. (2011) suggested that research had consistently shown that diabetes management was one area where mobile devices could enhance HRQOL for people living with LTC, actual research evidence was hard to locate (see **2.6.3**). Similarly, personal views on policy and key personal issues for this age group in terms of falling ill and maintaining and managing their health were also lacking in literature searches undertaken (see **2.6.4**). There was, therefore, an overwhelming body of evidence to support taking a qualitative research in healthcare approach to this present research, which would help to collect new data on the perceptions and experiences of young adults with type 1 diabetes post diagnosis and discovering how they used web and mobile technology for health and non-health reasons.

### **3.3.2 Why a Generic Qualitative Approach Was Taken**

Caelli et al. (2003) defined *Generic Qualitative Research* as an approach that was not guided by an explicit set of philosophic assumptions in one of the known qualitative methodologies. In qualitative research literature, many different terms have been used to define qualitative research that does not fit within an established approach. In recent efforts to clarify generic approaches, Thorne et al. (1997) described *Interpretive Description* as a non-categorical qualitative research approach whilst Sandelowski (2000) suggested *Basic or Fundamental Qualitative Description*. Merriam (1998) referred to this genre of research as *Basic or Generic Qualitative Research*, whereas Brink and Wood (2001) referred to all descriptive qualitative research as *Exploratory Research*. Merriam (1998, p.11) took the view that generic qualitative research studies were those

which epitomised the characteristics of qualitative research, but rather than focusing on culture - like *Ethnography* - or building a theory - like *Grounded Theory* – they:

*Simply seek to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved.*

I wanted to gain a deep understanding of the perspective of young adults with type 1 diabetes and connect with their opinions, views and reflections, by building a picture of their everyday experiences with the condition and how they used technology both socially and for health. This understanding being influenced by approaches from qualitative research in healthcare such as the lifeworld. Then, integrating this perspective into a newly created technological tool which utilised humanising sociotechnical principles during the design, build and post launch evaluation of its use (see **Figure 1**). In order to effectively approach my research question and for sound methodological reasons, I decided to adopt a generic qualitative approach. This would allow for the development of a breadth – allowing participants maximum freedom in expressing the range, scope and boundaries of the complex experience (Todres and Galvin 2005) - and depth – further exploration of specific events and experiences in participant lives (Holloway 2008) - of understanding regarding the nature of the studied experience. Caelli et al. (2003) argued for an epistemologically and methodologically congruent standard, rather than an incoherent amalgamation of methods in any generic qualitative approach and suggested four key issues that needed to be successfully articulated:

- Declaration of position (see **3.4**).
- Congruence between methodology and method (see **3.5 – 3.8**).
- Clear articulation of approach to rigour (**3.9**).
- Explanation of analytic lens (see **3.10**).

### **3.4 Theoretical Positioning and Critical Reflexivity**

#### **3.4.1 Introduction**

Malterud (2001) noted that a researcher's background and position affected what they chose to investigate, the angle of investigation, the methods judged most adequate, the findings considered most appropriate, and the framing and communication of conclusions. She defined *Reflexivity* (2001, p.484) as:

*An attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process.*

Malterud (2001) noted that reflexivity started by identifying any preconceptions brought to the project by a researcher; representing previous personal and professional experiences, pre-study beliefs about how things are and what will be investigated, motivation and qualifications for exploration of the field and perspectives and theoretical foundations related to education and interests. Decisions made about the methods to be applied at the beginning of a study are influenced by the ideas and theories held by the researcher and must be made explicit when describing the research process. *Theoretical Positioning* refers to a researcher's motives, presuppositions, and personal history which has led them toward and subsequently shaped an inquiry (Caelli et al. 2003). *Critical Reflexivity* means adopting a critical stance to oneself as a researcher (Holloway 2008). Personal response and thoughts about the research and research participants are taken into account and researchers are aware and reflect on their own social location and how this might affect a study. I will now provide an overview of how my own theoretical position was reached, reflecting on my personal and professional background and the different influences I have absorbed whilst engaging in an explicit, self-aware analysis of my own role (Finlay 2002).

#### **3.4.2 Personal Journey from Technological to Health and Social Care Perspectives**

In 2005, my final MA Interactive Media project (Pulman 2005) originated from conversations with a Lecturer Practitioner in Diabetic Care who also worked at a local hospital. She felt there would be real benefit in providing interactive information on type 2 diabetes to practitioners and patients. When a patient was diagnosed, they were given

a range of resources that might include videos, web links and leaflets. After patients had received an initial diagnosis, in her experience they would seek out as much information as possible about the condition, but were sometimes unsure of where to look. Frequently this resulted in them browsing the Internet for information, which could be inaccurate or provided a different cultural approach to treatment. Subsequently, many patients revisiting her arrived with mixed messages concerning treatment, symptoms and diet. I developed a patient focused tool - *Type 2 Diabetes Interactive (T2Di)* - including the best information that patients received, conveyed in a clear, concise manner. Background research provided sound practical advice on accessibility and usability issues, whilst viewing historical multimedia designs enlightened and informed the screen designs and layouts. Most importantly, working alongside patients greatly enhanced the final product, as they provided many useful and thought provoking comments that informed the design and functionality of T2Di. It was satisfying for me to know that potential users had been closely involved in the design and creation of a visually compelling, educational and informational resource which provided reassuring, friendly and clinically proven advice.

During 2006, I was investigating ways of making a simulated online community used for e-learning more innovative (Pulman et al. 2009). One approach concerned integrating the methods and themes of lifeworld with *Hypertext Narrative* into an interactive educational resource. This project had begun as an adaptation of an article (Todres and Galvin 2006) that aimed to contribute to a deeper understanding of caring for a partner with advancing memory loss, by interviewing a service user about his experience of caring for his loved one. This used a descriptive phenomenological research design to achieve descriptions of six related phenomena within the intimate carer's journey. The initial project idea aimed to generate a deeper understanding of these phenomena and the carer featured in the article granted permission to use personal photos, diary extracts and video clips from *A Sweeter Pill to Swallow: Beryl's Story* (2002) within the project. *The Carer's World* (Pulman et al. 2010) was designed to give users greater knowledge about, and insight into, the challenges of caring for people with Alzheimer's. The package was based on the idea that learning required not only knowledge about the condition and its treatment, but also *what it was like* (Todres 2008) to be with a person with the condition. The aim was to offer users opportunities to engage not only with technical knowledge about the condition, but more importantly with understandings of the world of the carer. Working closely with the carer and seeing how they had been

affected by their experience of caring and dealing with the political injustices concerning how Alzheimer's drugs were distributed, strongly affected my personal feelings about both the NHS and how patients and carers were sometimes treated by practitioners and in their day-to-day lives, just prior to beginning this present research. It also brought back feelings of how positive and negative experiences of the NHS had affected me in 1999 and 2000 whilst my own father was being treated for skin cancer. Similarly, attending an Economic and Social Research Council (ESRC) event in 2008 and speaking to carers highlighted to me how the richness of their experiences could enhance understanding and provide important evidence to influence future policy, as well as by being applied in a technical format for potential education and support. Reflecting on these experiences, I noted (Pulman et al. 2010) there were exciting possibilities in working with healthcare professionals in their education and using new media techniques to focus on the experiences of people, in ways which could help them understand and learn from issues and personal views - therefore becoming more effective and empathetic in supporting people. The use of interactive media to convey lifeworld stories around diseases and their effects also offered a uniquely potent way to harness public awareness and engage policy makers, practitioners, students and carers in important health and social care issues.

In 2010, I began assisting with the development of a collaborative lifeworld-led transprofessional curriculum for health and social work disciplines - Exploring Evidence to Guide Practice (EE2GP). At the heart of the philosophy underpinning this work was an opportunity for students to integrate understandings about a person's or service user's experience with their own insights which came from imagining *what it was like* (Todres 2008) for the person experiencing a condition or situation and encountering human services (Galvin 2010; Galvin and Todres 2011). Central to EE2GP was the creation of a number of web-based case studies including the human experience of the impact of specific illnesses and more general experiences such as social isolation and homelessness. I was the main author of nineteen case studies and undertook extensive research on the visual clips to be used for each case. I thus developed a close, immersive relationship with the source materials including *The Sea Inside* (2004), *The Diving Bell and the Butterfly* (2007) and *Here's Johnny* (2008). These resonated deeply with me, as they covered a range of differing visual perspectives on conditions and illnesses and how they affected the people themselves, their families and the

practitioners who they came into contact with. As a technical developer I had not worked in a professional capacity within healthcare (although as a member of a local hospital radio charity I had regularly met and chatted with patients during the 1980s and 1990s), and so I experienced similar reactions to some of the effects noted by students within group blog postings undertaken as part of EE2GP. These highlighted the powerful effect that case studies could leave on viewer perceptions (Pulman et al. 2012).

During 2011, in my spare time I had started to experiment with building mobile apps in a bid to increase my technical skills. In March 2011, I released my first app - *The Social Media Friend* (2011) - created with the intention of helping users navigate the world of social media. In May 2011, I released a second app - *The Thomas Hardy Trail* (2011) – which allowed users to discover Hardy’s birthplace and inspiration. In September 2011, my third app co-created with a friend - *The Cult Movie Directory* (2012) - was launched providing cult movie recommendations and reviews. The developmental process and feedback generated from apps released in a commercial environment provided many valuable lessons. The most important of which was as a successful proof of concept for a viable platform for the production of potential health apps which could look good, were user friendly, worked quickly with or without an Internet connection and that could reach a large number of people through a mobile format that was always near to them.

### **3.4.3 My Theoretical Position**

Reflecting on my personal journey, I had been following a pathway towards thinking of ways in which a humanising healthcare agenda could be incorporated into a technological package for use by people with health issues. This approach was a strong thread running through my recent working life, my educational development from my Master’s course onwards and also in aspects of my personal life - how I had been experimenting technically - so that it had become the central influence on my theoretical positioning for this present research. Working on T2Di and the Carer’s World provided me with evidence of the need for strong patient involvement in designing products they might want to use, describing their own experiences of healthcare which could then influence the design and also highlighting issues which could help to educate and impact on future health policy. Working on EE2GP and the Carer’s World gave me an enhanced understanding of the need to provide health students and practitioners with a way to deeply connect with the lives and experiences of their patients. To understand what it

might feel like to have a particular condition. An approach which could also be used in the development of mechanisms for providing technological engagement with patients (such as education or support) by understanding their requirements in more detail. Building a variety of different mobile phone apps provided me with a stable, proven mechanism for producing materials in a format that could be appealing to and usable by many audiences. Finally, the opportunity to study at PhD level offered me a unique opportunity to merge my love of technical development with my urge to create something of benefit to people experiencing health issues.

Underpinning this present research were lifeworld perspectives, with the central tenet of my research being to follow a qualitative health research agenda, as the goal was to implement change through a new approach to care – one which put the patient at the heart of deciding what technological solutions could be of use to them (see **Figure 1**). I saw myself as being a conduit for the views and reflections of the participants, providing them with an opportunity to contribute to the development and use of technological tools which could provide innovative approaches to their own and others education and support. But which also described the *State of Things* (Morse 2012), helping to influence future health policy. I wanted to:

- Gain a deep understanding of the perspective of young adults with type 1 diabetes and connect with their views, opinions and reflections, by building a picture of their everyday experiences with the condition and how they used technology both socially and for health issues.
- Integrate this perspective within a newly created technological tool, influenced by their opinions and also informed by clinical staff, which would help to possibly humanise an aspect of their healthcare in relation to their condition, by utilising sociotechnical principles during the design, build and post launch evaluation of its use.



### **3.5 Key Influences Underpinning Methodology**

#### **3.5.1 Congruence between Methodology and Methods**

When engaging in qualitative research, Caelli et al. (2003) suggested that methodology must be clearly distinguished from method. Methodology reflects beliefs about knowledge and existence that arise from the values in the philosophic framework being employed (Van Manen 1998). It also represents theoretical frameworks that guide how research should be carried out (King 1995; Rawnsley 1998) and implies a concern for building a particular type of knowledge (Morrow and Brown 1994). Although all research is value driven, few approaches accord such significance to clear recognition of the values and assumptions inherent in the theoretical framework as the qualitative domain (Caelli et al. 2003). Methods refer to the tools, techniques, or procedures that are used to gather research evidence (Harding 1987). I will now clarify how my methodology is distinguished from my methods and show congruence between them.

#### **3.5.2 A Need to Understand the Lifeworld**

One perspective to consider when thinking about the development of technology to help young adults with type 1 diabetes is the need to understand their everyday experiences and how they cope and live with their condition on a daily basis – gaining an insight into their thoughts, feelings and beliefs and an understanding of what it is like to live with an illness (Holloway 2008). Husserl (1970) was seen as the founder of the phenomenological movement and tried to make the nature of human-world intimacy more explicit. He named this the *Lifeworld* - the world of lived experience, or (Todres et al. 2007, p.55):

*The beginning place-flow from which we divide up our experiences into more abstract categories and names.*

In their article on the concept of lifeworld-led healthcare, Todres et al. (2007) revisited the potential of Husserl's notion of the lifeworld and theorised how lifeworld-led care might provide important ideas and values which were central to the humanisation of healthcare practice (Dahlberg et al. 2009). These included phenomenological and narrative studies which could deepen insights into a variety of lifeworld phenomena (Seymour and Clark 1998; Johansson et al. 2003; Nyström et al. 2003). They also noted

ways of disseminating qualitative research findings to make them valuable to users and to help deepen professionals' lifeworld understanding (Ziebland 2004). Todres et al. (2007) also highlighted the central foundations of lifeworld-led care: its humanising value, the holistic contextuality of lifeworld experience, and its benefits of experiential credibility and citizen empowerment. They asked what relationships should be referred to when attempting to describe a world that was humanly lived and felt that lifeworld theory was helpful as it attempted to indicate the *What* of relationships - these *What's* referring to the constituents of the lifeworld. Mostly, in everyday life the lifeworld is *Transparent* in the sense that day-to-day life *Just Happens*, grounded in spatial temporal parameters which are more or less regular (Seamon 1979). However, an integral part of lived transparency is good health, which is "*lived as a kind of tacit attunement normally not given direct attention*" (Seamon 2012, p.202), whilst illness or disability activate a resistance to the lifeworld as they "*transform its transparency into awkwardness, unease or discomfort*" (Seamon 2012, p.202). The concept of daily life materialises as a continual event to be faced because of pain, inconvenience or the inability to perform as usual (Seamon 2012).

Öhman et al. (2003) suggested that it was important to gain a deeper understanding of how chronically ill people experienced illness and life in order to understand the illness from the perspective of the individual and their relationships with family, friends, carers and health professionals. By considering the nature of people's needs who lived with chronic illness and reflecting on how they coped and adapted to their situation, it enables people to obtain a better foundation for understanding systems which might have a rationale basis for helping them. It has been suggested that practitioners might like to consider how best to meet the needs of young adults with diabetes by seeking to understand their experiences and the social networks in which they are embedded, alongside how self-management might be supported by healthcare (Allen and Gregory 2009). Lamb (2012) recommended that clinicians involved in the care of young adults with type 1 diabetes should explore online examples of adolescent experiences contributed to forums as they made for sobering reading. In the case of type 1 diabetes, he suggested two key ideas; that adolescence tended to conflict with the management of chronic conditions - particularly diabetes - and that new technical interventions utilised previously might seem to empower individuals but had little or no effect on metabolic control in young adults (see 2.5.4). Research considering the views of young adults with

diabetes in their use of new technology to support their condition is sparse (see **2.6.2**). Hindmarsh (Vodafone Group 2006) felt practitioners needed to think hard about what methods of communication a young adult in a rapidly advancing technological environment would be most likely to use and incorporate self management into the daily routine, so that it became a normal activity rather than an inconvenience. This could be achieved by exploring what the preferred methods of communication were and then designing tools which enabled young adults to engage with the health service and their own health in their own preferred manner - putting the individual firmly in charge. Hindmarsh (Vodafone Group 2006) viewed communication as important because management does not just require motivating individuals and getting them to change their behaviour, but also requires sustaining and monitoring that behaviour over many years. This is all the more important as it is acknowledged that today's young adults have a radically different view of technology than either their parents or practitioners (see **2.4.1** and **2.4.10**). For example, in countries like Japan, young adults equipped with mobile devices now see no reason to also own a personal computer (Johnson et al. 2009).

My research aimed to form a vivid picture of the diagnosis, post diagnosis and day-to-day lived experience and technology use of young adults aged between 18 and 21 with type 1 diabetes by using in-depth qualitative interviewing. Physicians and caregivers as well as young adults with diabetes often experience frustration and powerlessness when adolescents repeatedly return to their clinics with poor metabolic control (Frøisland et al. 2012). By talking to young adults and imagining *what it was like* (Todres 2008) to be diagnosed with type 1 diabetes and to have to continually examine food labels, looking for hidden sugars which could affect control from a young age and remembering to take insulin injections at set times, every single day for the rest of my life, I would be able to gain a deep personal insight of the young adult experiencing the condition and how they encountered human services at home, at school and work, in healthcare settings and in other social contexts. Why their blood glucose control might be poorest between 18 and 21 (Lamb 2012) and how there might be new, innovative ways that could help them improve this, or other aspects of their lifestyle and others diagnosed with type 1 diabetes in the future (see **2.6.2**). An influential perspective on this work has been lifeworld methodology. The following section summarises key features of the lifeworld perspective and whilst I am not undertaking a lifeworld study – rather taking a generic qualitative

approach (see 3.3.2) - it is important to detail the key influences on my thinking (see 3.4) and why I wanted to adhere closely to a qualitative approach (see 3.3.1).

### 3.5.3 The Lifeworld of Type 1 Diabetes

At the point of diagnosis with type 1 diabetes, the transparency of good health dematerialises (see 3.5.2). Johansson et al. (2008) performed a phenomenological lifeworld study where post-diagnosed participants with insulin-treated diabetes were asked to write a narrative about the process of falling ill. This study suggested that the essential meaning of falling ill with diabetes was a fight not to become one's illness, that everything was to remain as usual and that the new situation would become the natural one. When the bodily imbalance was verified as diabetes, it could be acknowledged and eventually accepted, but the acceptance was possibly an illusory reconciliation to be able to go on. In any case, there was no choice. If the diagnosed person wanted to feel well then they had to be adaptable to their illness, which made demands that must be reconciled, but which must also not be allowed to govern their lives. Despite being diagnosed, they still wanted to continue the same life and be the same person as they were before - although they now carried diabetes within them (Johansson et al. 2008). In 2010, a lifeworld approach was utilised by Todres et al. to provide in-depth insight into the changes experienced by people with type 1 diabetes who embarked on continuous subcutaneous insulin infusion - *what it was like* to live with an insulin pump. This research was able to highlight that switching from multiple injection therapy to an insulin pump presented challenges in the short term, but over a longer period, use of the technology was associated with a significant improvement in QOL for the users and also changed the relationship between them and their healthcare provider. More recently, a lifeworld approach was used by Kneck et al. (2012) who interviewed people who had been diagnosed with diabetes three years earlier (five of whom had type 1 diabetes). This study showed that the duration of illness was not important for the understanding of living with diabetes. Living with the condition post-diagnosis meant experiencing an overall balance in their existence and a daily struggle. Managing interaction with others to share experiences, so important to a healthy transition when living with diabetes, was crucially dependent on the ability to interact in such situations. For interaction to occur, participants had to understand their body as a unique subject and the circumstances for their lives as unique. When diabetes was integrated into the lived body, living was in

general experienced as simple, since decisions made always involved having diabetes. Kneck et al. (2012) also concluded that patient education in a group setting - with the goal of sharing experiences in a learning process - would only be meaningful if the person could interact with others.

In summary, I was setting my study in the context of a lifeworld-led perspective but intended to use generic qualitative methods (see 3.3.2), as the aim of my research was to develop an insight into young adults with type 1 diabetes use of web and mobile technology and its potential impact on their life. I wanted to explore what they felt about their use of technology and whether it might enable them to engage in an improved way with the NHS and their own health. I would achieve this by forming an in-depth picture of their day-to-day experiences and challenges from qualitative interviewing. Exploring how they made use of technology in their lives and in relation to their condition and treatment. Then, building something which might help them, using my technical expertise and the broad picture of perspectives developed – whilst remaining sensitive to their feelings and experiences of living with a LTC. This process would enable me to engage with and make more effective use of sociotechnical design principles.

#### **3.5.4 Sociotechnical Design and Healthcare**

Charon (2006, p.193) spoke of the vexing failures of medicine and its:

*Wholesale refusal to take into account the human dimensions of illness and healing.*

Todres et al. (2009) proposed that humanising health care was the consideration of the human dimensions in illness and caring. They identified eight different *Touchstones of Awareness* for the prevention of dehumanising practices in health care. When these dimensions were not considered, Morse (2012, p.53) noted that:

*Patients and people are treated as objects; they do not comply with “orders”; recovery is impeded; and, while trying to balance the forces of technology and pharmaceutical advances, healthcare professionals depersonalize, demoralize and dehumanize patients.*

Morse (2012) suggested that a humanising health care agenda included identifying methods of evaluating humanising care at all levels of application and analysis, so that the research focus included individual's experiences and conceptualisations of well-being and QOL. Galvin and Todres (2013) suggest that where technology is involved with systems of care, it should be balanced with humanising forces. An interesting idea from Lamb's article on integrating technology into adolescent diabetes care (2012) theorised that technology could not yet remove the largely behavioural barriers to good diabetes control, but might offer an alternate option to engage individuals more closely. This is especially prescient as the relationship between a young person and their mobile phone now begins from an increasingly young age (see **2.5.1**).

The aim of a design is to create something that fits, but creating something which fits comfortably and naturally is not always easy. *Sociotechnical Design* is a response to the desire to create systems that are useful and apt (Faulkner 2000). Mumford (2006) noted that sociotechnical design theory began with the desire of a group of therapists, researchers and consultants to more widely use the techniques they had developed to help war-damaged soldiers regain psychological health and successfully return to civilian life. The group believed that their therapeutic tools and techniques could be usefully applied to the organisation of work in industry, which they saw as restricting and degrading many low rank employees forced to spend their days carrying out simple, routine tasks with no possibility of personal development or job satisfaction. The nine key principles of sociotechnical design (Cherns 1976; Faulkner 2000; Mumford 2006) are:

- The *principle of Compatibility* where the process of design must be compatible with its objectives. This means that if the aim is to create democratic work structures then democratic processes must be used to create them; and therefore the end-user must be involved in this process, as they will be clear on what the objectives are.
- The *principle of Minimal Critical Specification* where no more should be specified than is absolutely essential. However, the essential must be specified - often interpreted as giving employee groups clear objectives, but leaving them to decide how to achieve them. This principle also helps to make a system faster and simpler to use as redundant functionality can overcomplicate and make

something more difficult to use from the perspective of the user.

- *The principle of Sociotechnical Criterion* states that a problem should be controlled as closely as possible to the site of origin. If variances - defined as deviations from expected norms and standards - cannot be eliminated they must be controlled as close to their point of origin as possible, to avoid them being passed on and increasing in size; and also as the best understanding of the problem is likely to exist where it occurs. This also empowers individuals concerned with the problem with feelings of responsibility and control.
- *The principle of Multifunctionality* aimed to increase job satisfaction by ensuring that employees had suitable tasks that would give them a sense of seeing a task through to the end.
- *The principle of Boundary Location* suggested boundaries should facilitate the sharing of knowledge and experience and should occur where there was a natural discontinuity in the work process - such as time or technology change.
- *The principle of Information Flow* is concerned where information should go. In the first instance, to the place where it is needed for action. Ideally, it should not include others, as this might overcomplicate processes and lead to errors.
- *The principle of Support Congruence* suggested systems of social support must be designed to reinforce the desired social behaviour. The nature of the organisation should dictate the structure of the system, not the other way around.
- *The principle of Design and Human Values* suggested that human computer systems should concentrate on providing a high quality of working life; if an individual was content, it followed the quality of work produced would be higher.
- *The principle of Incompletion* recognised that design was an iterative and continuous process. New demands and conditions in the working environment meant that a continual rethinking of structures and objectives was required: by design, evaluation, and then redesign.

When health professionals began to focus on sociotechnical perspectives in the late 1990s they were confronted by a complex, multi-disciplinary field (Whetton and Georgiou 2010). Building upon previous research, Berg (1999) noted that the specificity of the sociotechnical approach to technology applications in health care could be characterised in three points:

### **1. Health Care Practices Seen As Heterogeneous Networks**

Berg (1999) considered that a technical application in a health care practice should be seen as forming a seamless web, rather than a technology in an organisation. In addressing, managing and studying the network, he felt that project managers should not attempt to separate it into separate social and technical systems - a point also reiterated by Mumford (2006). Technology and organisation did not occupy separate domains or operate according to separate logics and neither did their relationship develop in a non-linear way - one causing change in the other or vice versa. The inter-related elements constituted an assembly, which should be dealt with as a whole, rather than as a technical piece for technicians and a social piece for social scientists.

### **2. Nature of Health Care Work**

Berg (1999) considered that the sociotechnical view of work was at odds with traditional health-related views of work prevalent within traditional technical development. Firstly, it emphasised the need to address co-operative work processes, rather than discrete individual tasks. Most discussions in healthcare informatics focused on the individual doctor or nurse and modelled their decision-making process accordingly, as if that could be depicted as a sequence of logically distinguishable steps. Secondly, the sociotechnical view of work fundamentally undermined the idea that the essence of work practices could be caught in pre-fixed workflows, clinical pathways, formal task descriptions or other models.

### **3. Empirical Orientation, Emphasising Qualitative Methods**

Berg (1999) suggested that the required empirical knowledge could be made available in two ways, both of which should be utilised. Firstly, end-users should be involved and secondly, that qualitative research methods should be employed. He felt that the use of interviews was generally inadequate for the level of insight required and that participant



observation ideally formed the starting point for any sociotechnical development or evaluation. He suggested that it was difficult to acquire a feeling for the intricate inter-relations between healthcare professionals and paper or electronic documentation techniques, without having viewed the work patterns. He also considered that to understand the flows and forms of information that a healthcare professional handled in a specific patient care scenario, the designer should not limit themselves to interviews or surveys. Without detailed on-site insight, an adequate grasp of what technical functionalities should be available, in what form, was practically impossible.

Berg et al. (2003) later posited that user ownership and engagement were critical to sociotechnical design success and that just implementing a technical solution would never work effectively. As awareness of sociotechnical approaches in various healthcare settings increased (Aarts et al. 1998; Berg 1999; Kuhn and Giuse 2001), Berg et al. (2003) considered that these uniquely different settings had brought forward their own interests. This was an important point, as the various ways in which the inter-relation of social and technical aspects was presented in healthcare could not be adequately captured in one model or theory. In 2004, Coiera suggested four rules for sociotechnical informatics, which could help guide the active design of health services:

### **1. Technical Systems Have Social Consequences**

Coiera (2004) suggested that introducing a technology into a setting affected not only the users it was intended for, but also the people surrounding them.

### **2. Social Systems Have Technical Consequences**

Coiera (2004) posited that the utility of technology was socially shaped. Humans related to the world with social rules and values and used these same rules to judge and interact with technology.

### **3. We Do Not Design Technology, We Design Sociotechnical Systems**

Coiera (2004) felt that if the social and the technical were inseparable then the design of systems needed to change. He thought we should no longer accept designs restricted to technological systems alone, but should broaden the scope of design to include social structures.

#### **4. Understanding How People and Technologies Interacted**

Coiera (2004) believed there was a sizeable gap in the science of informatics, relating to the understanding of health systems. For example, designers of busy clinical services needed to factor in human cognitive limits and the workloads generated by other services over which they had no control.

In 2009, UK health and social care delegates participated in a sociotechnical think-tank. The creation of a manifesto was an action from this meeting. In the manifesto, Clegg et al. (2010) argued that various sociotechnical principles were of direct relevance to current NHS IT management, design, implementation and use (Peltu et al. 2008). They discussed how their manifesto was based on the premise that through learning from past successes and problems in the health and social care sector and by applying sociotechnical principles to future IT projects, better health and care and value for money could be delivered. As an example, they highlighted how the implementation and roll-out of the Integrated Children's System (ICS) in 2007 had not included users in the development process, engendering alienation and causing signs of practitioner disquiet in pilot studies. Other lessons learned from this failure included the:

- Need for engaged senior management.
- Importance of putting work organisation first.
- Recognition that simple solutions were often best.
- Need to be innovative in the use of technology.
- Imperative to examine all stakeholder positions in a multi-perspective approach.
- Need to be vigilant for unintended consequences and perverse incentives.

#### **3.5.5 Lifeworld Understanding and Sociotechnical Design in this Study**

The last twenty years of diabetes education reflect an increased emphasis on integrated educational strategies and patient collaboration (Frøisland et al. 2012). Clegg et al. (2010) theorised that a key characteristic of sociotechnical thinking lay in highlighting the importance of developing new ways of working which significantly met the needs of both clients (patients) and users (service providers). Sociotechnical approaches have recently started to appear in diabetes research literature as a valid means of collecting data for designing systems to be used by staff (Adaji et al. 2011) and patients (Ma et al. 2009).

Many writers have discussed the potentially dehumanising implications of technology (Galvin and Todres 2013). This present research hoped to address this problem in the creation of a new framework (see **2.6.3**) influenced by lifeworld understanding, which humanised healthcare by creating and evaluating technology using sociotechnical design principles (see **Figure 1**). By including young adults with type 1 diabetes in the process of generating ideas and asking them to use and feedback on a number of developed iterations (pre and post launch) of any tools developed, I was intending to provide a humanly sensitive approach to their healthcare, which also gave them active participation in development - something which most previous studies had not allowed for (see **2.6.2**) - in addition to involving clinic staff so that their feedback could also be considered. Sensitised by these theoretical perspectives - and whilst acknowledging that this was a generic qualitative approach (see **3.3.2**) - I was aiming to contribute to lifeworld-led development and approaches to care (Todres et al. 2007), by the development of a patient-centric mobile phone app.

## **3.6 Sampling**

### **3.6.1 Strategy**

Prior to producing my sampling strategy I considered information collected during my literature review; feedback from supervisors; and my own independent discussions with clinical staff working within the health service who specialised in treating different LTCs. The sampling strategy focused on young adults with type 1 diabetes aged between 18 and 21. Although clinics like the SWDC had children under 18 attending it was decided to focus on older clinic members as this alleviated the need for parental consent, which the NHS currently requires until the age of 16 (NHS Choices 2015). The upper limit of 21 was set as this was the age at which participants no longer regularly attended clinics. The sampling strategy utilised a non-random *Convenience Sample*, as selection was from participants who had type 1 diabetes within the population definition. The sampling strategy would be *Purposive* (non randomised) - the selection of participants who had knowledge or experience of the area being investigated.

For lifeworld understanding, ideas generation and pre launch feedback recruitment was conducted at the SWDC and also at a Local University (LU). Participants were

considered eligible if they had type 1 diabetes, were six months post diagnosis, were within the age range at time of recruitment and were fluent in English. To ensure a wider range of potential participants, no exclusions to eligibility were made for either a lack of technical competence or for participants with learning difficulties. The author acknowledges that including a small number of qualitative respondents from the same SWDC and LU means results could not be generalised and that interviewing at a different diabetes centre may have provided different localised data responses based on that location. To address the limitations of the initial recruitment strategy, post launch an additional number of respondents from the existing user base of the app were externally recruited away from the SWDC and LU. This provided a wider perspective on how they had been using the app since downloading. As the alcohol app had been downloaded 1,164 times worldwide at the time this recruitment took place it is acknowledged that obtaining a small percentage of qualitative feedback post launch from 0.94% of this user base is another limitation of the study. Participants for post launch feedback were considered eligible if they had type 1 diabetes; were six months post diagnosis; had been using the app for at least one month; were prepared to complete a questionnaire and take part in a interview; were within the age range at time of recruitment; and were fluent in English. Again, no exclusions to eligibility were made for either a lack of technical competence or for participants with learning difficulties

Initial recruitment began after research governance was completed. I initially attended a meeting at the SWDC to discuss recruitment practicalities. My invitational flier was checked and approved by SWDC staff (see **Appendix A**). Tear off details allowing participants to make direct contact with myself were originally available on the bottom of the flier, however staff felt this might not catch the attention of young adults attending the clinic and so invited me to attend in person. The Young Person's Clinic (YPC) is held monthly. However, the way in which the appointment process works - with different appointments and tests taking place in different rooms - meant that an initial recruitment attempt approaching possible interviewees during the evening was unsuccessful. Due to the layout of the clinic and appointment timings, I was only able to meet with one of four possible participants. The recruitment approach was subsequently amended to produce an invitational letter (see **Appendix B**) and mail out to possible interviewees. The first mailshot was conducted in November 2011, with participants identified from a list of young adults with type 1 diabetes in the specified age range supplied by SWDC ( $n=110$ ).

I compiled the letters at the clinic as names and addresses were required to be kept on site. Enclosures with this letter included a stamped addressed envelope (SAE), a tear off slip (see **Appendix B**) and the Participant Information Sheet (PIS) (see **Appendix C**). The letter asked participants to return the tear off slip to myself, indicating whether or not they wished to participate and return it in the SAE. If participants had any questions regarding the research they were invited to contact me for clarification. When a positive acceptance was confirmed, participants were contacted to confirm interview arrangements. SWDC administration was then contacted, to confirm the room booking and to ascertain that a member of staff would also be available at the time of the interview if required. Once the room booking was confirmed, participants were contacted to confirm attendance. A member of the clinic staff also suggested a student contact at the LU who had approached them about starting a local type 1 diabetes support group as a potential interviewee to approach. The process of recruitment for the interview held at the LU followed a similar procedure with the invitation letter and PIS being emailed to them through the internal LU email system. Room booking procedures at the LU followed those of the clinic. Externally from the SWDC, I also emailed out to all health and computing students at the LU using an online version of the flier (see **Appendix D**), but this yielded no new responses. In light of this, SWDC staff suggested a second mailshot to previous and new attendees, in addition to a new letter stating that I was looking for further interviewees to add to those already completed (see **Appendix E**). This mailshot was conducted in April 2012 to previously identified possible recruits ( $n=15$ ) and to new potential recruits ( $n=5$ ). In an attempt to improve the gender balance of the study, a further mailshot targeting potential new male recruits was undertaken in July 2012 ( $n=5$ ).

Recruitment of participants for providing feedback after launch was through a variety of different approaches, which included requests initiated through the app itself ( $n=1,164$ ); Twitter; and other social media networks (see **Appendix F**). These approaches were subsequently deleted from the social networks utilised to maintain confidentiality after recruitment was completed. Organisations including Diabetes UK and TuDiabetes were also approached via email (see **Appendix G**) to utilise their own community networks to assist in the recruitment process. An amended version of the PIS was made available during post launch recruitment to explain the study in more detail if required (see **Appendix H**). When a positive acceptance was received from participants - after

completing an online questionnaire (see **3.8.12**) - they were contacted to confirm possible interview arrangements via email. This approach was undertaken to cover a wide geographical area and to ensure the research was independent from SWDC, enabling me to reach a more demographically representative sample than from one single clinic. The use of social media for recruitment of participants has increased in popularity in recent years (Nowson and Madden 2015; Yonker et al. 2015), but also involves a number of new ethical issues, which needed consideration to ensure proper protection of potential interviewees (Martinez et al. 2014; Yonker et al. 2015). This method of recruitment also brings with it limitations which should be acknowledged, particularly the risk of bias due to the self-selection of more motivated and technologically literate participants who may not have been representative of all users of the app (Nowson and Madden 2015). Prior to post launch recruitment, I discussed the recruitment process and method with health professionals specialising in diabetes care at Southampton and Portsmouth hospitals who had successfully utilised this approach before in research recruitment (Barnard et al. 2014) to outline appropriate strategies to protect confidentiality, how to minimise the risk of bias and to discuss the proper way to approach potential participants (Martinez et al. 2014).

### **3.6.2 Sample Size**

Sample size aims to achieve effective engagement of the sample recruited. To secure robust data with stable themes emerging - that a *Saturation Point* is reached. Saturation occurs when further sampling does not uncover new ideas - an exhaustive analysis of the phenomenon being studied has been undertaken and a complete picture of theoretical ideas has emerged (Holloway 2008). The overall sample size ( $n=20$ ) consisted of nine participants – seven females and two males - recruited within the SWDC and LU for ideas generation and pre-launch feedback and eleven participants – nine females and two males - recruited externally for post launch feedback. Given the difficulties of recruiting and maintaining an effective research dialogue with young adults involved in health studies (Lee et al. 2009; Whittemore et al. 2013; Barnard et al. 2014), the sample size was selected according to the availability and willingness of participants that met the inclusion criteria. It was also selected on the grounds that it would be a more than adequate number to provide rich, qualitative data. The sampling size is relatively small in qualitative research, with an in-depth examination of *Information-Rich* cases and the group. Detailed interviews and immersion in the culture make a large

sample size unnecessary. In purposive sampling, generalisability is less important than the collection of rich data and an understanding of the ideas of the people chosen for the sample (Holloway 2008).

After reviewing and analysing interview responses and discussing the analytical process with both my supervisors and clinical staff for external ratification, I considered that a satisfactory saturation point had been reached in forming a clear picture and understanding of the experiences of a young person with type 1 diabetes and in relation to what kinds of information and apps would be helpful to them ( $n=9$ ) (see 4.1). Following a similar process of review, analysis and discussion in addition to referencing participant observation memos, I considered that a satisfactory saturation point had been reached in terms of initial ideas generation for prototyping app developments ( $n=4$ ) (see 4.2 - 4.4) and compiling feedback on the prototype apps developed pre-launch from participants ( $n=5$ ) (see 4.4.4) and from SWDC staff ( $n=5$ ) (see 4.4.5). After reviewing and analysing the post launch feedback data collected and discussing the analytical process with my supervisors and clinical staff for external ratification, I considered that a satisfactory saturation point had been reached for collating this feedback ( $n=11$ ) (see 4.4.11 - 4.4.17).

### **3.7 Methods (Lifeworld Understanding)**

#### **3.7.1 Qualitative Interviewing Overview**

An interview is a conversation, but one where the *Interviewer* is seeking responses for a particular purpose from the *Interviewee*. The main difference is the extent to which the interview is structured and the degree to which the interviewee is allowed to lead the content of the interview (Gillham 2000). Morse (2012) noted that qualitative health research is defined by two parameters; *Focus* - on the health-illness continuum – and *Method* – primarily inductive and designed to gain information about personal or group perspectives and behaviours. King and Horrocks (2010) believed that the success of a qualitative research interview was not only based on how well the interviewer asked questions and analysed data, but also on all decisions made from the beginning of the research, which would have an impact on the outcome. When designing an interview the importance of questions is clear, but they felt that how they were presented would have

an effect on the answer. Therefore, many aspects should be taken into account during interview design. My design utilised in-depth, one hour, semi-structured interviews. These are used when the researcher knows what questions they want to ask, but does not know what answers to expect (Morse 2012). Question stems are usually asked in the same order during each interview and responses to open-ended questions can then be probed, so that the interviewee has the freedom to respond as they wish (Morse 2012). In-depth interviews are typically used when seeking information on individual, personal experiences from people about a specific issue, by capturing their own voices and stories (Hennink et al. 2011). It was decided to progress with individual interviews rather than use focus groups, as SWDC staff indicated that a young age group with a mix of male and females would not produce good quality results. They had noticed in previous focus groups that young males had a tendency to show off, in attempts to impress females present. It was also noted that this age group had a preference for talking individually and that some interviewees might find talking about particular aspects of their condition and lifestyle embarrassing or stressful within a group environment. Finally, as Morse (2012) notes, focus group opinions are offered publically, so they might not always reflect the interviewee's true response. A semi-structured interview guide (Mason 2002) was developed (see **Appendix I**). Some broad questions and areas of interest were prepared beforehand, but I recognised there was also a need for improvisation during each interview, based on anticipated and unanticipated responses. The general purpose of each interview was to explore, in detail, specific topics relevant to the interviewee's knowledge and it's relevance to the research question and objectives (Silveman 2004).

### **3.7.2 Pre Interview Phase**

Each interview was conducted at a time most convenient and suitable for the interviewees. The location was an appropriate local venue - the SWDC - which was convenient for travel arrangements and the most suitable setting for meeting research governance and ethical guidelines. Where possible, interviews were arranged to coincide with an interviewee's regular clinic visit (rather than asking them to attend at another time) to minimise inconvenience. Each interview was recorded in an open meeting room. The SWDC education centre was a light, airy room, which had a central set of configurable, rectangular tables. This enabled an open and relaxing atmosphere to be generated. For the first interview, it was not possible to book this room and so the



office of one of the SWDC healthcare professionals was used as a replacement setting. This interview took place on comfortable chairs facing each other and was in a more intimate setting than other interviews. In all cases, a member of the clinic was available near the interview room to ensure that any distress or disclosures could be dealt with immediately. The interview at the LU was recorded in an open meeting room in a building located on the main campus. This environment allowed for chairs to be arranged either side of a large table, in an informal layout, to make the interview seem more casual. For this interview, a member of the supervisory team was in attendance in their office to again ensure that any distress or disclosures could be dealt with immediately.

*Self-presentation* is defined as what the interviewer is wearing, their use of non-verbal communication and the type of vocabulary used (King and Horrocks 2010). As an example, Ross (2005) described a student who thought they had dressed too formally in initial focus group interviews. For later interviews, she dressed more casually and emphasised her student status, which seemed to contribute toward a more trusting, open atmosphere in later groups. During the interview process, I made a conscious attempt to dress as casually as possible to differentiate myself from clinic staff. This was to ensure that I was seen to be from a different environment, which would help me to build rapport. *Rapport* is essentially about trust, enabling the interviewee to feel comfortable in opening up (King and Horrocks 2010). To help build rapport, I made a conscious effort to ask questions in a relaxed style which did not patronise interviewees - appreciating that my age might have a negative effect on their answers if I tried to come over as being from a similar generation. This concerned the issue of *Status* and a consideration of situations where the interviewer is perceived to be of higher status than the interviewee. This is often in the context of discussions about power in an interview and the desire to equalise this (Briggs 2002; Mckie 2002). In a further attempt to improve rapport, in three instances participants were offered the choice of bringing their partner or relation into the interview to watch it take place and chip in if they felt the need to offer their own opinions or comments, rather than waiting outside the interview room. This added a further dimension to these interviews, as it allowed for additional discussion and ideas to be generated around some topics. This helped to focus on some additional perspectives of the experience of living with type 1 diabetes, which might not otherwise have been considered or mentioned by the interviewees themselves.

### 3.7.3 Qualitative Interviewing Process

The interview would commence with the first question being:

*So can you tell me a little bit about the first mobile phone that you had?*

I felt that by starting the interview by talking about technology and then moving onto how this related to their condition and their life as someone with type 1 diabetes it would put the interviewees at ease, as a non-threatening starting point. The core focus of the interview moved from the interviewee's first mobile phone and the historical timeline of different phones they had owned, to talk about the history of other technology they had used. This usually led into a discussion concerning their usage of Internet software (such as email and Google) and social media tools (such as Facebook and Twitter). I would then introduce a question about their diagnosis date at a convenient and appropriate point, which might lead into them talking about their diagnosis and how they had utilised technology (if at all), since then. This could then lead into a discussion of different aspects of their day-to-day life with type 1 diabetes; their experiences of the clinic, GP surgeries and other health services they encountered; experiences socially, at school, at home and at work; how they coped with and used technology related to their condition, such as Capillary Blood Glucose Monitors (CBGM) and Pen Mates; and if they had used any health-related apps. When we were discussing any problems that they had experienced, we would then explore ideas they had for something which could improve that aspect of their lifestyle or others and whether a technical solution might be of any help. King and Horrocks (2010) noted that pre-conceived notions are dangerous in research interviews. *Leading Questions* occur when wording is used which suggests to the interviewee the kind of response the interviewer anticipates. *Over Complex* and *Multiple Questions* can be avoided by wording questions as simply and clearly as possible. I tried to avoid responding to what the interviewee said in a way that suggested I was making a judgement about their position (King and Horrocks 2010), as this might signify the kind of answer that would be deemed appropriate and might make them defensive. I was also aware of always trying to listen to the interviewee - as a failure to listen could lead to inappropriate questioning (King and Horrocks 2010). This might potentially leave them feeling frustrated or irritated - very important at a young age where tolerance levels might be lower. I was also aware of managing interviewees who might be either under or over communicative (King and Horrocks 2010), although fortunately

there was no need to tackle either of these issues. I was also sensitive to the feelings of interviewees and occasionally avoided asking overtly direct questions; instead, moving on when I felt they were uncomfortable on being probed further on a particular subject (such as potentially embarrassing revelations about something which had previously happened to them). I was also prepared to deal carefully with any sensitive topics discussed (King and Horrocks 2010), but this issue did not arise during any interviews.

Chenail (2011) suggested that sometimes piloting is not always practicable because researchers do not wish to lose limited research participants and their information to a pilot study database. Secondly, some researchers might not favour wasting interviewee's time with under-developed questions. Both of these issues were valid concerns for my study; the pool of participants willing to be interviewed in the target age range was deemed to be low by clinic staff. This group being particularly time poor with busy lifestyles; juggling a combination of jobs and living and studying away from the area, which made making additional visits to SWDC in addition to their biannual scheduled appointments difficult. Given these concerns, I therefore wanted to ensure that any willing interviewee was granted a full qualitative interview. Dahlberg et al. (2001) suggested that although a total bracketing of one's pre-understanding of a phenomenon is not possible, self-reflection done with the idea of restraining one's pre-understanding is an important help in separating one's experiences from the interviewees. With this in mind, I wanted to begin interviewing from a completely neutral perspective, with no pre-conceptions. I considered that if I used pilot approaches during the first few interviews I would be subtly altering my perspective on them, feeling less focused by considering them as being dummy runs, which would also lead to a slightly different approach being taken in subsequent interviews. For these reasons I decided against using pilot interviews, although I provided my supervisors with an audio recording and transcription of the first interview and sought feedback on how I could improve my technique. As each interview took place, I obtained a greater understanding of where each interview could flow in relation to the growing structure of the picture of young adults with type 1 diabetes and this helped to inform my own abilities as an interviewer - in pursuing relevant and interesting question paths as new information was discovered. Gillham (2000) reflected that it takes confidence to be a listener, to decentre from oneself and focus on the person being interviewed and this process is always iterative. After each interview, I spent time reflecting on the interview's progression and as I transcribed, read

through transcripts and listened to audio recordings, I searched for instances where I could improve. This highlighted additional alterations to my technique, such as letting longer natural pauses occur, which might be filled by further discussion from interviewees; and of where I might have probed more deeply, rather than moving on immediately to ask other questions.

Interviews were brought to a close by asking one final question:

*Now the last thing that I want to ask you about is...*

After this response, I would then summarise the main points to ensure that we had covered everything. This sometimes led the interviewee to elucidate further on a particular subject that we had already covered, or alternatively offering a new comment. Interviews were then closed:

*You've given me a lot of useful material there - I'm very grateful. Thanks for your time and I'll stop the interview at this point.*

Post interview, participants were advised that written feedback on study findings could be sent to them upon request. It was also explained that they could contact me at a later date for discussion about the research project, or to request removal of their data from the study if required.

### **3.7.4 Ethical Considerations**

Ethically, my research aimed to be for the benefit of others - *Beneficence* - and to do no harm - *Non-Maleficence*. A research proposal was submitted alongside my submission to the NRES Committee South Central (Portsmouth) in May 2011. The panel were content to give a favourable ethical opinion, subject to a response to six issues where clarification was required (see **Appendix J**). After clarification (see **Appendix K**), formal approval was granted (see **Appendix L**). NHS research governance was granted for the study to take place at SWDC in September 2011 (see **Appendix M**). Informed consent was sought from all interviewees through a form attached to an introductory letter (see **Appendix B**), supported by a PIS (see **Appendix C**), containing information on the

project. Those participating were also informed that by not participating in or withdrawing from the study at any time; they would not prejudice current or future care. Where there could be concerns about confidentiality and/or anonymity, I reiterated what I would do with the collected data and how interviewee's identity was protected. King and Horrocks (2010) suggested that it is dangerous to assume that just because participants had been given an information sheet and signed a consent form, that they shared the interviewers understanding of the research purpose and nature of the interview. As Warren (2002, p.89) states there are many indications in research literature that participant understanding:

*May not match the interviewer's from the start, may shift over time, or may be 'confused'.*

For this reason, each interview began with clarifying the purpose of the study and a reiteration of expectations, in addition to providing information on why the interview was being recorded and what to do if they felt uncomfortable before the consent form was signed.

Possible risks from interview participation were assessed and considered to be no greater than any other normal activity the interviewee might undertake. It was not anticipated that they would suffer discomfort from being involved with the study, although I had an awareness of the symptoms of hypoglycaemia and if interviewees exhibited symptoms during an interview, I was prepared to arrange for immediate support from a member of the clinical team. If any disclosure during the interview revealed an illegal action, I was prepared to stop the interview immediately and seek expert professional advice. No requests to withdraw from the study were received; no interviews were stopped for ethical reasons; and no issues of note were recorded which required further action.

Discussions between the researcher and clinic staff identified one health and safety concern. In the case of interviewing lone females, we decided that the education centre room should always be used, rather than the SWDC office used for the initial interview (see 3.7.2). This was to ensure that nothing untoward might be incorrectly reported - due to my being an older male researcher interviewing a younger female patient alone. The

identified risks associated with prolonged computer use and incorrect posture during my study were addressed by carrying out a Display Screen Equipment (DSE) assessment of the equipment to be used during writing and programming and ensuring that regular screen breaks were taken.

### 3.7.5 Methods Timeline (Lifeworld Understanding)

Date	Description (Collection)	Description (Analysis)
June 2011 – Nov 2011	<i>Qualitative Approach Phase 1</i> Developing qualitative interview approach and semi-structured questions.	
Dec 2011 – Feb 2012	<i>Qualitative Approach Phase 1</i> In-depth interviews: T1-QOL-01 to T1-QOL-04	Data Analysis and Theme Identification
Mar 2012 – Jun 2012	<i>Qualitative Approach Phase 1</i> In-depth interviews: T1-QOL-05 to T1-QOL-09	Data Analysis and Theme Identification
Jun 2012 – Apr 2013		Data Analysis and Theme Identification

**Table 1. Methods Timeline (Lifeworld Understanding)**

## 3.8 Methods (Sociotechnical Design of App)

### 3.8.1 Ideas Generation - Participant Interviews

Initial qualitative interviewing ( $n=4$ ) enabled the identification of possible ideas, which could then be developed into prototype apps. By February 2012 the prototype apps were considered to have been developed to a point where testing within the clinic could begin - having successfully passed the testing criteria (*principle of Minimal Critical*

*Specification*). The prototypes were installed on two iPod Touches and these were then used within the clinic to show to latter interviewees and SWDC staff.

### **3.8.2 App Feedback Pre Launch - Participant Interviews**

For latter qualitative interviews ( $n=5$ ) the emphasis on the prototype apps being developed required part of the interview to be allocated for feedback on them. A percentage of time allocated in these interviews concentrated on ascertaining from the participants their feelings on the prototype app most closely aligned to their particular areas of interest - highlighted during previous parts of each interview - to provide deep, meaningful feedback (*principle of Compatibility*). This was important, as in terms of usability engineering, unstructured interviews are able to provide a wealth of information that the interviewer might not anticipate (Faulkner 2000). For these interviews, it was possible to highlight, record and segregate differing positive and negative comments on the prototype apps described by interviewees and to subsequently feed this back into the design process (*principle of Compatibility*, *principle of Sociotechnical Criterion*, *principle of Minimal Critical Specification* and *principle of Incompletion*). This was both for my benefit as the developer – for look and feel and navigational purposes - and for clinic staff – the actual text content and the quality of the information provided. The most popular app of the prototypes developed was the alcohol education guide (see 4.4).

### **3.8.3 App Feedback Pre Launch - Participant Observation**

Alongside the section of the qualitative interview that focused on obtaining feedback, I was also able to observe the interviewees using the prototype apps for a short, concerted period of time. This assisted in demonstrating how they were using them and highlighted any problems participants experienced in understanding how to use the apps and navigate them. This would not have been apparent from listening to an audio recording or reading an interview transcription (*principle of Sociotechnical Criterion*). This method followed the sociotechnical design principles recommended by Berg (1999).

### **3.8.4 App Feedback Pre Launch - Staff Questionnaire**

A questionnaire is a method used for collecting data and involves a set of written questions, which calls for responses on the part of the research participant. They are designed through the careful composition of questions to identify facts and opinions from specific groups of respondents (Bowling 2014). They are also a good source of

subjective responses - a measure of user attitude - and are one of the ways in which usability engineers can gather information about current work practices or opinions on systems under development (Faulkner 2000). Questionnaires are also convenient to access and allow respondents to communicate from a more distant perspective than the closeness of an interview, so that they may feel more inclined to give negative feedback (Yin 2009). So that I could ensure that from a clinical perspective anything developed met the goals of the SWDC, a questionnaire (see **Appendix N**) was distributed to all relevant clinic staff. These were staff who dealt with the care of young adults with type 1 diabetes ( $n=5$ ) and who had first had a chance to use one of the prototype apps (see **3.8.1**). The questionnaire consisted of a number of Likert scale statements about the user themselves; their opinions on the design, usability and information quality of the prototype app being examined; and an open question for suggesting improvements. Likert-type scales use fixed choice response formats and are designed to effectively collect data concerning participant attitudes or opinions (Bowling 2014). They therefore offer an excellent means of collecting quality feedback on prototype technical applications (*principle of Incompletion*) and provided another important feedback loop on what was being developed.

### **3.8.5 NHS Regulation / Approval Process**

The principal purpose of regulation of any health related profession is to protect the public from unqualified or inadequately trained practitioners (Smith 2010) and it might be thought logical to apply these same principles when regulating the use of health and medical apps. At a 2012 conference, Wyatt presented systematic research on healthcare apps (Yap 2012) and discussed the need for assessing their quality through various evaluation theories. He suggested the majority of popular apps for health promotion were those that were eye-catching and looked aesthetically attractive - but there was no real evidence that they could improve patient health. Besides the need for qualitative and quantitative methods of evaluation, he also emphasised that stakeholders and evaluators played roles that were as important as developers in relation to asking, prioritising and formalising relevant questions for health apps. Within the NHS, it is currently unclear as to how apps are regulated and who is responsible for this process (see **2.5.3**). Because of the wide variety of apps available, it would be an immense task to review every new health and medical app released and not all require regulation (Karnerow 2013). However, an app that changes a smartphone into a medical device, or



is used to control existing medical devices needs stricter regulation and critical appraisal. In terms of regulation, in the USA the FDA released its policy on which mobile medical apps it would oversee in 2013 (see **2.5.3**), but in the UK things are less clear. To date, only one publically available health app has been registered as a medical device (see **2.5.3**) and there is a distinct lack of guidance and policy coming from the NHS nationally on this issue with possibly alarming consequences. This regulatory vacuum has resulted in current policy decisions concerning apps developed for patient information and their approval processes being unofficially delegated to a local Trust level. However, this only occurs when they are approached for assistance, as this is not a mandatory requirement and no guidelines suggest that this is the correct pathway to take.

### **3.8.6 PALS Regulation / Approval Process**

At a local Trust level, it is not always clear who should be involved in the app approval process, as this is still seen as a relatively new way of passing information to patients. In 2002, the Department of Health (DoH) announced a scheme to ensure that in each hospital there would be a Patient Advice and Liaison Service (PALS) to provide on the spot help and information about Independent Complaints Advocacy (ICAS) and where people could get help to pursue formal complaints or resolve concerns informally. Patients' forums would be set up to influence the day-to-day management of health services by the Trust and would also monitor the effectiveness of the PALS and ICAS in their area. The Commission for Patient and Public Involvement in Health would then support and co-ordinate patients' forums through local networks (Department of Health 2002). Due to the current lack of national NHS regulation (see **3.8.5**), to ensure that the app selected for development met the standards required at the local hospital - in terms of clinical governance and the quality of the information provided - after chatting with clinic staff a decision was made to formally approach the local PALS team who were based at the hospital where SWDC was sited. The aim was to discuss how to arrange for the information contained within the app to be checked and approved. PALS contacted the local hospital IT department and also the Royal Society of Public Health for their advice, as this was the first time that the subject had been officially raised with them. Surprisingly, the IT team left the final decision up to PALS - i.e. they sat on the fence - but this policy is subject for review in 2015. However, PALS representatives felt that given the rate at which technology was advancing and that they had received a number of other informal enquiries about app strategy, regulation and approval during

2012, that it would be a good time to formulate a draft local strategy on this matter. The results of this discussion led to a local decision that the alcohol education app should be considered as the first app to go through the local PALS approval process - necessitating special consideration to be made during the process. As a part of this process, the third, fourth and fifth iterations of the app were submitted to the PALS team for them to give their approval to - utilising their five step process for standardised patient information. This process acted as a detailed proof read on all aspects of the developed app and highlighted several additional changes, which needed to be made. The patient information production process consisted of five steps:

### **Step 1 – Before Submission**

As with all patient information, PALS were required to ensure that the content and presentation of any app met their quality standards. To achieve this, they requested that three members of their Readership Panel (RP) reviewed the app information, in the same way as leaflets or posters would be reviewed. *Step 1* includes the production of informational materials and as the alcohol education guide had already been prototyped, this step was already complete by the time of our initial approach.

### **Step 2 - Submission**

In *Step 2*, once information is ready for submission, the Patient Information Coordinator (PIC) sends a submission template together with copies of accompanying materials to the Patient Information Team (PIT). A different version of the template needed to be supplied than usual. This included the app information provided in written format, in addition to screenshots taken from the app - to show how it was designed - and also a link allowing access to the audio file used for the alcohol podcast - so it could be listened to and approved. The form for the fifth iteration app submission to PALS is included in the appendices (see **Appendix O**).

### **Step 3 – The Readership Panel and Feedback**

In *Step 3*, the PIT sends patient information to the RP for review by a minimum of three independent reviewers - at least one of whom must be a patient or user. The panel reviews the format and clarity of information and might make suggestions to improve it. Once this review is complete, feedback is prepared incorporating suggestions from RP members. For the app, this process was the same as for the standard information

approval process, but PALS specifically needed to locate RP members who had a particular interest in this technology who might be interested in reviewing it.

#### **Step 4 - Agreement**

In *Step 4*, once the patient information has been approved by the RP, it has the Information Standard logo applied to it by PALS. This shows that it has successfully passed the patient information process. The process for the app was identical.

#### **Step 5 - Approval and Distribution.**

In *Step 5*, once complete, the product is ready for use and can be given to patients. This would usually result in it being uploaded onto the local hospital Intranet, in addition to being physically printed as a leaflet, but in the case of an app this was not a required part of the review process.

### **3.8.7 Apple and Google Regulation / Approval Process**

The Apple Developer App Review Guidelines (2015) provide rules and examples across a range of topics, including user interface design, functionality, content, and the use of specific technologies. Unfortunately, they are only accessible if you have purchased a developer account. Surprisingly the developer guidelines contain no specific information relating to developing health and medical apps. Developers submitting apps to Apple must ensure that they comply with these guidelines before submitting them for review. If a review is met with rejection this can be for a number of reasons, but the process must be successfully completed before an app can be downloaded on the Apple App Store. Like Apple, Google's developer guidelines contain no specific information on the design of health and medical apps and their approval process is basic in comparison with Apple. There are only a small number of technical checks made on either the quality or purpose of the app being offered for download. This has ramifications on wrongful information being made available and subsequently used by someone within a health context (White and Horvitz 2009; Visvanathan et al. 2012).

### 3.8.8 Methods Timeline (Sociotechnical Design of App - Pre Launch)

Date	Description	App Build Version
Dec 2011 – Feb 2012	<i>Qualitative Approach Phase 1</i>  Ideas Generation from interviews: T1-QOL-01 to T1-QOL-04	
Feb 2012 – Mar 2012		Prototype Apps Development (Alcohol/Hypoglycaemia/Illness)  App v1.2 (First Iteration)
Mar 2012 – Jun 2012	<i>Qualitative Approach Phase 2</i>  Additional Ideas Generation from interviews: T1-QOL-05 to T1-QOL-09 <i>[N.B. any additional ideas generated from these interviews were not used for prototyping]</i>  App Feedback Pre Launch from interviews: T1-QOL-05 to T1-QOL-09  Participant Observation of: T1-QOL-05 to T1-QOL-09  App Feedback Pre Launch from staff questionnaire data: QR01 – QR05	Prototype Apps Development (Alcohol/Hypoglycaemia/Illness)  App v1.6 (Second Iterations)  <i>[N.B. the Hypoglycaemia and Illness prototype apps were not developed beyond their v1.6 versions]</i>
Aug 2012 - Nov 2012	PALS Regulation / Approval Process	Alcohol App Development  App v 1.8 (Third Iteration) App v 1.11a (Fourth Iteration) App v 1.11b (Fifth Iteration) <i>[Approved by PALS]</i>
Dec 2012 - Mar 2013	Apple and Google Regulation / Approval Process	Approved by Apple - 07/12/12  Approved by Google - 05/03/13

**Table 2. Methods Timeline (Sociotechnical Design of App - Pre Launch)**

### **3.8.9 App Feedback Post Launch - Participant Questionnaire**

An online questionnaire (see **Appendix P**) was designed with a number of open-ended qualitative questions and a small number of closed questions (for collecting demographic information). The questionnaire was created using Bristol Online Surveys (BOS) (2013). The use of an online survey tool allowed for a much wider group of external participants to be sampled (see **3.6.1**). This questionnaire was designed to collect reflective accounts of how useful the app had been to participants, which could be expanded upon during later interviewing if required. It collected more detailed information on (i) when and why they had decided to download it; (ii) how, why, where and when they had used it so far, and (iii) whether they had any suggestions for improvement or negative feedback on their use of it. Online questionnaires were convenient to access for the target group (see **3.6.1**) and would allow them to initially communicate from a more distant perspective than the closeness of an interview, so that they would feel more inclined to offer negative feedback (Yin 2009), an area of particular interest post launch. Prior to making the online questionnaire live, it was checked for usability and relevance by my supervisors. It was also circulated to health professionals specialising in diabetes care at Southampton and Portsmouth hospitals who had utilised this approach before in their research recruitment (Barnard et al. 2014) for additional feedback and refinement. Minor modifications to the wording of certain questions were made to improve their clarity for the target audience and the order in which questions were asked was updated to provide a clearer path through the areas being investigated.

### **3.8.10 App Feedback Post Launch - Participant Interviews**

During the collection of data for post launch feedback, participants ( $n=11$ ) contributed their experiences, reflections and suggestions based on their use of the alcohol app since downloading. A semi-structured interview guide (Mason 2002) was developed for post launch interviews (see **Appendix Q**). The emphasis was on clarifying queries with questionnaire responses and elaborating on certain responses in addition to ascertaining feelings on the developed app to provide deep, meaningful feedback (*principle of Compatibility*) on both its practical use and how the participants had engaged with it since downloading. This was important, as in terms of usability engineering, unstructured interviews are able to provide a wealth of information that the interviewer may not anticipate (Faulkner 2000). Due to the sampling strategy employed for post launch feedback (see **3.6.1**) Skype was used to conduct any post launch interviews undertaken.

Interviews aimed to be of a similar duration (15 minutes) as to when collecting pre launch feedback (see **3.8.2**). Interviews would usually begin with the first question being:

*How did you come across the alcohol app?*

followed by a number of additional questions from the interview guide (see **Appendix Q**), which helped to build up a picture around three specific areas of interest. These were why participants had used the app; how participants had used the app; and when participants had used the app (if at all). For the section of the interview which covered why participants had used the app, discussion might include their reasons for originally downloading it; what they wanted to use it for initially; how long ago they had downloaded it; and on which devices they had used it. For the section of the interview that involved how participants had used it, discussion might include talking about examples of how they had made use of the app since downloading and whether it had been of use to them in specific situations. Whether they had used all of the apps functionality - such as the podcast - and whether they had any suggestions for improvement or glitches to report which prevented functionality from being used correctly. This part of the interview would also cover the features that they liked most and least about the app; highlighting both positive and negative comments which could be incorporated into future iterations of the continual design process post doctorate (*principle of Compatibility, principle of Sociotechnical Criterion, principle of Minimal Critical Specification and principle of Incompletion*). For the section of the interview concerning when they had used the alcohol app, discussion would focus on where, when and at what times they had used it; how often they had used it to date; and if they hadn't used it very much since downloading why they thought that might be. This part of the interview would also cover whether they thought that they would continue to use it in the future. Interviews were brought to a close by asking one final question:

*Now the last thing that I want to ask you about is...*

After their response, I would then summarise the main points to ensure that we had covered everything. This might sometimes lead interviewees to elaborate further on a particular point or subject already covered, or alternatively offering additional comments. Interviews were then closed:

*You've given me a lot of useful material there - I'm very grateful. Thanks for your time and I'll stop the interview at this point.*

Post interview, participants were advised that written feedback on study findings could be sent to them upon request. It was also explained that they could contact me at a later date for discussion about the research project, or to request removal of their data from the study if required.

### **3.8.11 Methods Timeline (Sociotechnical Design of App - Post Launch)**

<b>Date</b>	<b>Description (Collection)</b>	<b>Description (Analysis)</b>
Oct 2013	<i>Qualitative Approach Phase 3</i>  Development and modification of post launch questionnaire.  Developing qualitative interview approach and semi-structured questions.	
Nov 2013 – Jan 2014	<i>Qualitative Approach Phase 3</i>  App Feedback Post Launch from participant questionnaire responses and interviews: T1-QOL-10 to T1-QOL-20	Data Analysis and Theme Identification
Feb 2013 – Mar 2014		Data Analysis and Theme Identification
Oct 2014 – Dec 2014		Data Analysis and Theme Identification (Revision and Refinement)

**Table 3. Methods Timeline (Sociotechnical Design of App - Post Launch)**

### 3.8.12 Ethical Considerations

The challenge to be relevant after some time has passed is the case for all research that aims to provide a new technologically based support resource and throughout the study I continued to be mindful of how potential changes could have a bearing on the study. As a technical developer of many years of experience, it was sensible to acknowledge that as a technology based study being undertaken on a part-time basis over many years, there was a real risk of using a technology that might be rendered obsolete by the time of the study concluding. I remain confident that the final product developed is sufficiently future proof in terms of the current design and delivery mechanism, as the PhoneGap architecture utilised (2013) continues to work with all major mobile phone manufacturer operating systems and having been taken over by Adobe - a major software company – in 2011, continues to provide a proven, reliable and continuously updated architecture for future development and support issues. Also, as an open source product, it is more likely to continue to gain traction as a popular development tool utilised by large number of developers. I was also encouraged by the continued growth of the mobile smartphone market and the increasing popularity and sales of mobile apps. Ethical considerations for interviews undertaken during the sociotechnical design of the app and for pre launch feedback were deemed to be the same as for lifeworld understanding (see **3.7.4**). However, for post launch feedback, informed consent was obtained at the beginning of the online questionnaire before completion (see **Appendix P**) and also before interviews were undertaken (see **Appendix R**), supported by a revised PIS (see **Appendix H**). When considering the use of Skype for obtaining post launch feedback, ethical issues were considered to be similar to those of face-to-face (Janghorban et al. 2014). For example, the principles of obtaining consent, recording the interview and obtaining permission to do so and ensuring protocols were in place in case a participant became uncomfortable and wished to withdraw from the study were similar to those performed during the face-to-face pre launch interviews (see **3.7.4**). There have been some concerns expressed regarding the use of Skype and other similar online methods to obtain qualitative data. These include whether it is a sufficiently secure platform and whether the transmission quality is adequate for some studies where visual and nonverbal cues are important (Baker and Bufka 2011; Sullivan 2012). However, given the logistics of the sampling strategy employed (see **3.6.1**), there was no compelling



reason not to consider its use as it was going to be used appropriately (Sullivan 2012), alongside good qualitative interview practice (see 3.7).

### **3.9 Strategies to Establish Rigour**

Caelli et al. (2003) argued that qualitative approaches needed to be rigorous to judge the soundness of the methodology, with the notion of what constituted a rigorous qualitative study being the subject of debate - often intertwined with discussions about what constituted quality criteria. Lincoln and Guba (1985) described four criteria for the validity of qualitative research:

- Credibility (*Internal Validity*).
- Transferability (*External Validity*).
- Dependability (*Reliability*).
- Confirmability (*Objectivity*).

#### **3.9.1 Credibility**

Credibility refers to the accuracy of information obtained during a study and is maintained via triangulation of data sources, methods and investigators (Lincoln and Guba 1985). One way in which credibility was achieved in this present research was by prolonged exposure to the subject being investigated. By spending a prolonged period of time (from September 2011 - June 2012) regularly visiting the SWDC and observing the day-to-day activities and routines, it was possible to become immersed in the world of the clinic. During my visits I was able to build rapport with practitioners, dietitians and receptionists. During the pre and post interview process and during interviews, I was able to build rapport with the participants of the study. The process of peer debriefing is described by Lincoln and Guba (1985, p.308) as:

*Exposing oneself to a disinterested peer in a manner paralleling an analytical session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind.*

This process was used as a further method of establishing credibility. The purposes of debriefing are that through analytical probing a debriefer can help uncover taken for granted biases, perspectives and assumptions on my part; through this process I could become aware of my position towards the data and the process of analysis; and that there was an opportunity for *Catharsis*. A further method of establishing credibility was by publishing my ongoing research concepts and ideas, methodology and findings during the study. By continually submitting my work to the peer-review process and successfully presenting and defending it at conferences and responding to feedback and critiques during the peer-review process prior to publication, I was able to ascertain that my ideas held weight and were acceptable to a variety of different reviewers from academic, technical and health disciplines. A list of publications and presentations is listed in the appendices (see **Appendix S**).

### **3.9.2 Transferability**

Transferability refers to the extent to which study findings are transferable, rather than generalisable, to other contexts (Lincoln and Guba 1985). Transferability can be shown by thoroughly describing the research context. The context of this research study included the lifeworld of young adults with type 1 diabetes; understanding how they felt and interacted with different aspects of technology; providing participants with a chance to air their views on subjects which might impact future policy; and also allow them to contribute to the production of something which helped to humanise one aspect of their healthcare. Transferability can also be shown by making this present research explicit; describing clearly any assumptions and limitations inherent within it. This provides future researchers, practitioners and developers with a clear pathway through which they could transfer the results to a different context or other LTC. However, the onus would be on those individuals to decide how sensible the transfer strategy was in the context of their own particular work, culture and environment.

### **3.9.3 Dependability**

Dependability refers to the consistency of the data and can be achieved with an audit trail, which tracks data collection and analysis (Lincoln and Guba 1985). This study made use of a technique for achieving dependability known as the *Inquiry Audit* (Lincoln and Guba 1985). This involved positioning myself as the designated *Auditor*, whose job was to produce a valid, thorough audit trail and examine the research documentation to

determine acceptability and attest to the dependability of inquiry. This role also involved examining the final product in terms of data, findings, interpretations and future recommendations; in order to confirm that they were accurately supported by the data. This latter process can be shown to be assisting in establishing the confirmability of the inquiry.

### **3.9.4 Confirmability**

Trustworthiness is an essential component of qualitative research and therefore any data collected reflects the reality of the experience. Confirmability refers to the objectivity, or the degree to which the findings can be confirmed or corroborated by others. Lincoln and Guba (1985) noted that Halpern (1983) had suggested different classes of raw record data:

- Raw data in the form of videotapes, written field notes, documents and survey results.
- Data reduction and analysis products like field note write-ups, condensed notes and summaries, theoretical notes and concepts.
- Data reconstruction and synthesis products - themes developed, findings and conclusions.
- Process notes that could be methodological, trustworthiness and audit trail notes.
- Material relating to intentions and dispositions, inquiry proposal, personal notes and expectations.
- Instrument development information like pilots, forms and preliminary schedules, observation formats and surveys.

By keeping an accurate record of this information during my study, it was possible to build a detailed audit trail that would enable any auditor to determine whether the study findings could be supported, therefore asserting confirmability within the study.

### **3.10 Foundations for my Research Approach**

#### **3.10.1 My Analytic Lens**

I have been very much influenced by lifeworld research approaches (see 3.5.5), having worked on a number of different blended learning and technical projects with qualitative researchers (see 3.4.2 and 3.4.3). However, my *Analytic Lens* comes from Caelli et al. (2003), who used the term to refer to the methodological and interpretive pre-suppositions that a researcher brings to bear on their data. Whilst theoretical positioning is about the researcher and their motives for pursuing a particular inquiry (see 3.4), the analytic lens concerns how the researcher engages with their data. All research approaches have underlying pre-suppositions about the nature of knowledge (Epistemology). Qualitative approaches also carry with them implicit assumptions about what it means to be human (Ontology). The underlying assumptions of the approach should then implicitly guide every aspect of the study (Caelli et al. 2003). Whilst I was not undertaking a lifeworld study – rather taking a generic qualitative approach (see 3.3.2) - my ontological viewpoint was based around interpreting the day-to-day experiences of young adults with type 1 diabetes, by drawing and reflecting on my empathetic understanding. Then, utilising this perspective in the creation of a technological tool influenced by their opinions (and those of clinic staff), which could help to humanise an aspect of their healthcare in relation to their condition. This meant drawing out innovative ideas for creating a technical solution from their suggestions and the descriptions of their lives (*Words*) reported descriptively, forming a part of their day-to-day life. Then, utilising sociotechnical design principles to create a user centred final product, which helped to support compassion in practice. For example, this might be by creating something that could have a positive effect on their ability to control their blood sugar levels more effectively, based on examples suggested during qualitative interviewing (see 3.8.1).

### **3.11 Data Analysis**

#### **3.11.1 Introduction**

Creswell (2007) noted that the core elements of qualitative data analysis were coding the data (reducing it into meaningful segments and assigning names to those

segments), combining codes into broader categories or themes and then displaying and making data comparisons. Being relatively new to qualitative work and coming to academic research from a technological background, I found the systematic approach of Creswell to be very helpful and therefore followed it to help me manage and analyse the data obtained. My data analysis approach followed Creswell's *Data Analysis Spiral* (2007), where the first loop in the spiral starts with data collection and includes the data management process. The second loop consists of getting a sense of the whole database of organised materials, whilst the third loop is the describing, classifying and interpreting loop. In this loop, code or category formation represents the heart of qualitative data analysis. In the final phase of the spiral, data is presented in some form, such as a table, figure, or text. I will now describe this approach in the context of this present research.

### **3.11.2 Data Management (Loop 1)**

#### **1. Data Management (Interviews)**

Interview data for lifeworld understanding (see 3.7), ideas generation (see 3.8.1), app feedback pre launch (see 3.8.2 - 3.8.3) and app feedback post launch (see 3.8.10) was recorded onto a digital recorder, which produced individual MP3 files - a digital audio file which can be played on a computer. The files were imported into iTunes (an audio player) and synced (copied) to an iPod (an MP3 player). Listening to the iPod through speakers beside a computer allowed for each audio recording to be carefully transcribed verbatim. Each recording was transcribed slowly and methodically to allow me to become more familiar with the data. A sample transcription extract can be viewed in the appendices (see **Appendix T**). Each recording was listened to in full and further notes were made. The purpose of listening to the whole recording was to highlight areas for investigation in subsequent interviews, critique the interview process to improve technique and most importantly, identify potential themes and categories of data for coding. Transcriptions were initially recorded onto individual Microsoft Word files and then loaded onto an NVivo 9 database. NVivo is a software analysis package (QSR International 2012), which helps to ensure that the analytical process is systematic, sequential and verifiable. It is the leading commercial package for qualitative data analysis - also known as a computer-assisted qualitative data analysis (CAQDAS) tool - which can enhance the research process; quickly processing queries and expanding

analytical avenues (Auld et al. 2007). As Welsh notes (2002), NVivo is simple to use and it is easy to import individual documents directly from Microsoft tools, ready for coding.

## **2. Data Management (Questionnaires)**

Open question questionnaire data for app feedback pre launch from staff (see **3.8.4**) was transcribed from questionnaire responses onto Microsoft Word and was then imported into NVivo for analysis using the same database as for interview data. Questionnaire data for app feedback post launch from users (see **3.8.9**) was recorded directly onto the online survey tool. Survey data were then exported directly to a Microsoft Excel file where, after formatting, it was imported into NVivo for analysis using the same database as for interview data.

## **3. Data Management (Security)**

In accordance with Bournemouth University ethical procedures, during data analysis all information was kept secure. It is intended that all paper transcripts will continue to be kept in a locked filing cabinet and held digitally on a secure private network drive, accessible only by myself, for a period of five years after final thesis submission.

### **3.11.3 Reading/Memoing (Loop 2)**

Agar (1980, p.103) suggested that researchers should read through transcripts several times:

*Immerse yourself in the details, trying to get a sense of the interview as a whole before breaking it into parts.*

During this loop I carefully read through the data collected and recorded interesting memos (short phrases, ideas and key concepts) which occurred to me as I read onto rough paper, and then transferred these initially to a Microsoft Word file which became a living document of the initial interviews (see **Appendix U**) prior to NVivo installation. This produced a list of possible topics and sub-topics, which could be used to assist with cross-checking the initial coding process. Once NVivo was installed, further reading and memoing was completed using the software package.

## **1. Reading/Memoing (Lifeworld Understanding)**

As has been previously discussed (see 3.5.2), a perspective to consider when thinking about developing technology to help young adults with type 1 diabetes is the need to understand their everyday experiences and how they cope and live with their condition on a daily basis. Gaining an insight into their thoughts, feelings and beliefs and an understanding of what it is like to live with an illness (Holloway 2008). By immersing myself in the data and recording interesting memos that occurred to me as I read, I was able to make a conceptual bridge from the raw textual data to preliminary abstractions which could be used to explain and clarify this perspective (Birks et al. 2008).

## **2. Reading/Memoing (Sociotechnical Design of App)**

After the initial qualitative interviews had been undertaken ( $n=4$ ) and transcription was complete, skeletal baseline data analysis was conducted to locate potential ideas for app development. Ideas suggested were recorded in the living document. The living document was then used to create a list of ideas, which were taken into discussions with SWDC staff. Four were identified as being suitable for development as prototypes. These were based on suggestions that met clinic goals and which also followed statutory NHS Trust technical requirements - for example, patient data could not be recorded which ruled out certain ideas. The prototype ideas are discussed in Chapter 4, in addition to ideas that were not developed.

### **3.11.4 Describing/Classifying/Interpreting (Loop 3)**

It is possible to easily code documents on screen (Welsh 2002) and in NVivo data is coded at *Nodes*. Coding stripes can be made visible in the margins of documents, so that the researcher can see which codes have been used and where. Additionally, it is possible to write memos about particular aspects of documents and link these to relevant pieces of text in different documents. NVivo's search tools allow researchers to interrogate their data at a particular level (Welsh 2002). This can, in turn, improve the rigour of the analysis process (see 3.9) by validating (or not) some of their impressions of the data. However, NVivo is less useful in terms of addressing validity and reliability issues in the thematic ideas that emerge during data analysis. This is due to the fluid, creative way in which themes often emerge (Welsh 2002). Details can be checked on the content of particular nodes and this could affect the inter-relationships of thematic ideas, but in terms of searching through the ideas themselves in order to gain a deep

understanding of the data, NVivo is less useful because of the type of searching it can perform (Welsh 2002). To address this problem, personal and professional experience, a thorough knowledge of relevant literature (see 2.1) and interaction with and immersion in the data helped to contribute to *Theoretical Sensitivity*, so that I was sensitive to any important issues which emerged (Holloway 2008).

### **1. Describing/Classifying/Interpreting (Lifeworld Understanding)**

In terms of lifeworld understanding, NVivo was used to analyse and identify thematic data relating to how young adults with type 1 diabetes aged between 18 and 21 lived with and experienced their condition and how they made use of web and mobile technology and its impact on their life. An example of the developmental process for Theme 5 – Mobile Technology (see 4.1.6) is available in the appendices (see **Appendix V**).

### **2. Describing/Classifying/Interpreting (Sociotechnical Design of App)**

For potential app development ideas, NVivo was used to identify different ideas from suggestions, comments and observations made by participants. For participant feedback prior to launching, NVivo was used to highlight, record and segregate different comments on the prototype apps by interviewees and questionnaire respondents (open question only). This could then be fed back into the sociotechnical design process for the developer (look and feel and navigation) and for clinic staff (textual content and the quality of the information provided). For post launch feedback by participants, NVivo was used to analyse, highlight, record and segregate data relating to the developing themes around how, when and why the app was being used and its usefulness to participants.

## **3.11.5 Representing/Visualising (Loop 4)**

### **1. Representing/Visualising (Lifeworld Understanding)**

The lifeworld of a young person with type 1 diabetes is represented by six themes (see 4.1).

### **2. Representing/Visualising (Sociotechnical Design of App)**

Ideas generation is represented by the ideas suggested by those interviewed with type 1 diabetes which were identified as potential prototypes for development (see 4.3), those that were not able to be chosen (see 4.2) and the final product developed, approved and



launched (see 4.4). Screenshots of this app can be found in the submission documentation to PALS (see **Appendix O**). Experiences, reflections and suggestions based on participant use of the alcohol app since downloading is represented by their post launch feedback in six themes (see 4.4.11 - 4.4.17). It should be noted that these themes are separate from the six lifeworld themes which were identified (see 4.1).

### **3.11.6 Data Analysis: Risk / Health and Safety Issues**

Johnson and Clarke (2003) highlighted that accessing patient views and experiences presented difficulties not only for the participant, but also for the researcher, as the process of information gathering involved direct contact with people with whom sensitive and difficult topics were often raised - sometimes within difficult contexts. Morse (2012) noted that in considering the ethical conduct of qualitative health research, researchers must be aware of their own vulnerability. As by involving themselves with participants' stories they might forget that the stories were affecting them emotionally and to be aware of the line between feeling for and feeling with one's participants – in effect, becoming over-involved. Johnson and Clarke's (2003) research also suggested that researchers could feel isolated and unsupported, which might lead to feelings of hopelessness, impotence and fear of having the condition being investigated and also causing them to suffer from insomnia or nightmares. A researcher feeling isolated and unsupported might be experiencing this; as when they needed support, only their partners, family, or friends were available at a particularly difficult moment to help them reflect on their research work experiences. Some felt a strong need to separate work from their personal life, but did not know what to do with the information that they had gathered and virtually experienced - where to discuss it, or how to deal with processing it. Some felt isolated in dealing with their concerns, because they found it difficult to discuss these matters with either project directors or supervisors.

This point was reinforced when discussing the interview and transcription process with a Diabetes Nurse Specialist at SWDC, during our regular meetings during the development of the prototype apps. She talked about her observations on how I might feel after prolonged exposure to listening to and reflecting on the interviews, concerning the experiences of young adults with type 1 diabetes. She also suggested some possible techniques for dealing with this aspect of the study - such as taking time away from it and focusing on something enjoyable after interviewing or transcribing - rather than

dwelling on the issues raised in too much depth. In my case this involved playing with our rescue puppy, or winding down by playing computer games or watching DVD's. At that particular moment, this peer support was extremely valuable. It helped me discover why I was feeling emotionally tired after prolonged periods of transcribing and interviewing - an issue documented in research by Dickson-Swift et al. (2007). It also enabled me to focus more effectively on switching off and relaxing after prolonged periods of data collection and analysis.

### ***3.12 Addressing Qualitative Inquiry Criticisms***

Morse (2012) noted four major criticisms of qualitative inquiry, which will now be discussed.

#### **3.12.1 Qualitative research is not generalisable**

Because qualitative samples are not selected randomly and are usually small, quantitative researchers believe their findings are not generalisable. Morse (2012) suggested that qualitative researcher's generalised concepts and theoretical findings were removed from the original context and compared with the results of others. To generalise the findings, I was looking for a setting with similar problems or characteristics - the various experiences of a young adult with type 1 diabetes and their ideas for technological innovations, which were similar across different interviews - and recontextualising the results which were useful and insightful and that might provide programmatic guidance.

#### **3.12.2 Qualitative research is biased**

For suggestions that this research is reporting what I was looking for, this present research had checks and balances in the process of inquiry to check and recheck each finding during all research steps. I attended to the principles of sampling, saturation, negative cases, confirmation, and logical progression throughout, so that bias and any other errors identified were eradicated during the inquiry process. For suggestions concerning bias with the purposeful sampling (see 3.6) - where the belief is that qualitative research should be describing the medium or the norm - the point to underline is that new phenomena are being described, so I needed to purposively select the best

examples of what I was interested in. This gave me the clearest cases with the least *Noise* or extraneous errors and allowed for the identification of characteristics and boundaries (Morse 2012).

### **3.12.3 One investigator cannot code reliably**

Morse (2012) suggested that detractors might suggest that as a single coder, the researcher might be biased or careless, thereby causing results to be worthless as they demanded inter-rater reliability for coding. As the lone coder, but also as the lone interviewer and transcriber, a segment of text had much more meaning for me. I was able to understand its full meaning in context of the young adults (see 4.1 – 4.5) compared to another checker, who might see a phrase or paragraph and take it at face value, thereby invalidating the coding. Morse (2012) stated that inter-rater reliability is only useful if you have semi-structured interviews - where all participants have been asked the same questions in the same order; there is a large sample; and the purpose might be to transpose textual to numeric data.

### **3.12.4 Replicating studies previously performed**

In hard science, Morse noted (2012) that where results were incrementally derived, there was usually a definitive answer to a problem and so she suggested this might date research if it was examining behaviours and responses to new technology or procedures, but normally behaviours, concepts and theories remained pertinent. For example, although my innovation uses mobile phone technology (see 4.4), the principles of designing technological innovations using sociotechnical design which the patient contributes to and which understands their viewpoint would work equally as well with alternative technology. For example, the implementation and use of touchscreen technology in doctor's surgeries does not take into account how some elderly patients get confused and worried when using the system, as I have reflected whilst watching the use of this facility during surgery visits. This is an important factor, which by asking them to have contributed during the design and testing might have been uncovered prior to implementation and then subsequently redesigned. This problem can also be equally highlighted within a different context - such as the difficulties experienced by elderly users of self-scanning checkout functionality in department stores and supermarkets.

## 4 Results

### 4.1 Lifeworld Understanding

#### 4.1.1 Introduction - The Life of a Young Adult with Type 1 Diabetes

Although this was not a phenomenological study, my aim was to understand from the perspective of the interviewees what it was like to live with their condition; therefore this present research was lifeworld influenced (Todres et al. 2007). Data analysis was able to paint a broad, in-depth picture providing a detailed understanding of how young adults with type 1 diabetes aged between 18 and 21 lived with and experienced their condition and how they made use of web and mobile technology and its impact on their life. Six themes were identified from the analysis of nine semi-structured, in-depth qualitative interviews (T1-QOL-01 to T1-QOL-09). The timeline for this approach is shown in **Table**

1. The themes identified were:

- Theme 1 - Living with Diabetes.
- Theme 2 - Diabetes Technology.
- Theme 3 - In the Clinic.
- Theme 4 - Obtaining Information and Support.
- Theme 5 - Mobile Technology.
- Theme 6 - Mobile Apps and Mobile Health Apps.

#### 4.1.2 Theme 1 - Living with Diabetes

The first theme - *Living with Diabetes* - concerns how a young person with type 1 diabetes has coped with living with their condition from diagnosis onwards. This theme is important as it underpins how they manage with their condition and seeks to identify aspects of living with it where technology might be able to help (and where it might not), in addition to identifying areas that highlight possible future policy improvements.

The daily life of a young person with type 1 diabetes presents a number of practical problems after diagnosis. This includes the number of items which need to be close at hand at all times:

*P: I have to remember to take my sugar reader, my insulin, if spare needles, a sugary treat... [T1-QOL-04]*

For males this presents more of a problem, as they will usually only have their coat and trouser pockets available for storage:

*I: ...is that a problem for you, just sort of carrying it around?*

*P: No, normally I take the needle off 'cos I've had a few times now, where I've had it in my pocket with the needle on still...*

*I: Right*

*P: ...and the lid's come off the needle. So I've gone in and pricked myself (laughs) in the hand or something 'cos the pen's come off in me pocket... [T1-QOL-08]*

Or, alternatively have to rely on a helpful partner who is prepared to carry everything for them. There are also other practical problems that need to be considered with some diabetes equipment, such as remembering to carry spare batteries. They might also encounter friends or family who are frightened of needles, which needs to be considered when injecting and there may be occasions when having to inject is either impractical or impossible:

*P: ...Or again, when I'm at Uni, just whenever we get a break there and, when I'm at home, getting into the work, sometimes I can get so into it...*

*I: Yeah*

*P: ...that I'm eating as I'm going, and you just keep going and just do not go and do your injection... [T1-QOL-05]*

Injecting over a prolonged period of time can also cause problems if their body starts to resist the constant injection regime. There is also a need to consider if any change in activity or routine - like physical exercise - might impact on the body and to be continually aware of the amount of testing strips left in their possession – the lack of which could cause problems. This is also true of having to remember to take a set amount of both slow and fast acting insulin with them, wherever they go. Something due to their lifestyle and attitude that young adults are not always likely to consider or

remember:

*P: ...it was a last minute plan to go and we went to London, and I packed like, overnight stuff, just not my insulin. I er, it was really stupid, I had one, I had my background insulin, but I did not have my main insulin... [T1-QOL-08]*

The practicalities of dealing with the condition on a daily basis offer some opportunities for technical solutions that could improve this aspect of their life, such as providing alarms to remind them about what to take with them, having something to eat by a certain time, or when to inject.

As soon as a young person is diagnosed with type 1 diabetes they need to learn an understanding of controlling their blood sugar levels. This means testing at regular intervals. There is a *Honeymoon Period* (where the pancreas continues producing some insulin), which means initially they might have a small amount of leeway:

*I: ...have your readings always been on the high side from sort of like eleven?*

*P: Um, they were quite good for sort of like three years I think, after I was diagnosed, but I think you've got one and a half years, two years of the honeymoon period... [T1-QOL-09]*

However, the ability to take regular readings at a younger age - the lack of which inhibits successful control - was acknowledged as a problem by interviewees after diagnosis, but which ultimately got better over time:

*P: ...I'd had sugar levels sort of as high as twenties and even thirty for a little while because obviously, it took me a little while to get diagnosed, um, so then I was just working on getting them down, I mean, I guess my control got better with time, just getting used to it. [T1-QOL-06]*

Taking regular readings might not seem particularly difficult to an observer, but this is a requirement three to four times a day, every day for the rest of their life. There is no release from testing. Each time a test is necessary, it requires a pricked finger and a methodical routine to be undertaken. Again, this might not seem particularly onerous to

someone who does not have the condition, but the incessant nature of testing might become irritating and frustrating over time and occasionally prove difficult to achieve, depending on the location or activity being performed. Additional tests may also be required if physical activity takes place, or, if the individual becomes ill. Given the enormous changes in physiology and neurobiology prevalent during adolescence, it is hardly surprising that this is the time when metabolic control of their diabetes is at its worst (Lamb 2012). The age of 18 to 21 is therefore not an ideal time for sensible, regular measuring of blood sugar levels - something that interviewees acknowledged and which might be improved by an innovative technical approach to the problem. However, some interviewees were seemingly unable to explain why they sometimes did not test, even though they knew that they should - especially given it was so important for their own health:

*P: ...because I'm on a musical theatre course so it's very, it's very active. So I should really be testing my blood sugar levels sort of before I do a dance class sort of, um after I do a dance class or before I eat anything. I should just be constantly be testing my blood sugar levels really (laughs). Um, but I do not....*

**[T1-QOL-03]**

Some participants seemed to view the issue of taking regular readings as amusing rather than concerning:

*P: ...and then when I got to about sixteen, they started going up a bit high, and then when I was about seventeen, they were up really high, and they were so high that I'd fall asleep all over the place. I was so tired (giggles)...* **[T1-QOL-09]**

Whilst others viewed it as more of an adhoc requirement:

*P: ... I probably check my levels about o- sort of when I feel that I need to but then I try to do it once a day so, I'm not very good at doing it three times a day but...I like to do it either in the morning or the evening just so I know how I am...*

**[T1-QOL-06]**

The clinic role in helping to encourage regular readings was highlighted, but again, the urgency of providing readings to take to the clinic was not always paramount:

*P: Aah, I do not really do it anymore. I just found it a bit of a nuisance really.*

*I: Right.*

*P: And also I found like, writing in the book I do not, I know it helps them, but it did not really help me at all... [T1-QOL-07]*

This might be partly due to the majority of new Capillary Blood Glucose Monitors (CBGM) having the ability to record historical data in device memory, which can then be accessed by medical staff. Indeed, prior to this innovation, after diagnosis most participants had been encouraged to manually enter their readings into a paper logbook which could be laborious and frustrating, leading to the recording of a lower number of readings if the book was not near them:

*P: ...I just was not doing it because I was not carrying the book around with me...*

*[T1-QOL-05]*

This is another area where providing a technical add-on to existing CBGM functionality might help to improve QOL, by encouraging users to take more regular readings - possibly being reward based.

The process of injecting begins immediately a young person is diagnosed. It was rare in interviews to find participants who had not immediately been able to start injecting without a problem:

*P: I've kind of, well, kind of took to injecting straight off really er since I got, since I got into the children's er clinic when I was first diagnosed, they just gave me a pen and told me what to do with it. Said that they might just want to give me a hand and I just did it. And I've used the same type of pen pretty much... [T1-QOL-02]*

with only one interviewee mentioning this was an issue. Most were quite blasé about the process. They described it as being like an additional part of themselves and



interestingly wishing to supervise or control anyone else trying to inject them from that moment on:

*P: I cannot remember not having it really, so it's always been a part of me. I've always known how to inject myself blah blah blah, to the point where I do not like people (laughs) giving me injections or giving me sort of like a flu jab or something I'll be like "Can I do it myself?" (laughs). [T1-QOL-03]*

The continual exposure to the injection process also showed an unexpected side, in which their own bodily parts being injected were discussed quite coldly:

*P: Yeah, you just, you go for the fleshy or the fatty areas of your body. So...*

*I: Yeah.*

*P: Bottom, leg, top of your arms, stomach, you could probably do it in your chest or somewhere else as well... [T1-QOL-08]*

The toll of injecting constantly caused problems with some participants if the same injection sites were used due to their lifestyle or injection technique, leading to shortcuts that could be problematic:

*P: And I know someone that injected through their clothes and he's got blue smudge mark where he's always did it in jeans and the fibres have gone into the needle, and sort of tattooed him where he used to do the injections so much just through his clothes... [T1-QOL-08]*

For some, the process of injecting had become ingrained at certain times of the day, but others were more lackadaisical in their approach:

*P: It was not that I was forgetting, it was just like a bit of a hindrance, you know, like having to do an injection twenty minutes before you eat or something, have to eat the exact same time every day... [T1-QOL-07]*

This mirrors their behaviour with taking blood sugar readings and also in potential ways of perhaps addressing this problem technically. In addition to the issue of using the

same sites for injection over again, other problems described included injecting air into the bloodstream by accident - due to not performing an air shot properly - and injecting through lumps so that the insulin was not absorbed correctly:

*P: I had a problem with insulin lumps and I was injecting into the lumps so the insulin was not going through. So I was injecting two lots of insulin for one set of food...*

*I: Right...*

*P: I kept going low with that... [T1-QOL-08]*

Insulin is inextricably linked to injecting, but rather than being a straightforward process which is quickly performed and then forgotten until next time, it requires a more cerebral and calculated approach concerning what should be taken when:

*P: I'm good at remembering when I've taken my insulin and there's one, like the long acting twenty four hour one just, I'd sort of take it between the same time every night so then it's always just sort of topping itself up but the um, the short acting one you can sort of take it at any time when you eat so much food so um, but I'm good with that one... [T1-QOL-03]*

It is a delicate balancing act; working out what should be injected and when and also considering if what was injected was the right amount for their own body. If the insulin did not perform in the way that they had expected, it could cause them problems:

*P: So, she'd injected twice, whereas the food had just worked a bit faster than the insulin had that day. So, then she was going low, and she said 'Oh, what do I do'. I said 'just drink a bottle of lucozade and inject two units'. And she was like 'Oh no, I cannot do that'. And I was like 'No, seriously, if you just drink the lucozade and do not inject anything else you'll go high again'... [T1-QOL-08]*

This could be helped by use of the *Basal Bolus Regimen*, which involves taking a longer acting form of insulin to keep blood glucose levels stable through periods of fasting and separate injections of shorter acting insulin to prevent rises in blood glucose levels resulting from meals. However, this requires thought and careful consideration to be

effective – an important point, as it has been suggested that for many people with diabetes, learning about complex treatments and monitoring regimes is particularly difficult and stressful (Kerr 2011b). Insulin needs to be kept cold, so this requires a fridge to be available in all locations where the young person is, which could be a problem if they wanted to travel abroad, although not insurmountable. Practicalities concerning forgetting to travel with a relevant dose of both short and long acting insulin had caused issues for some, as had the changes to the amount of insulin required if they became ill. But as with blood sugar measurement, over time, interviewees had become more confident about their insulin use and how they should be administering it:

*P: ...I did use that as a reference to begin with and then as time went on I just dropped that and sort of, I guess I was a bit more guessing sort of things and I've become now used to what items and roughly about what, er, how much I should inject for them... [T1-QOL-06]*

Adaptation to a chronic illness in childhood is a complex process, which involves internal and external factors that influence the initial response and later adjustment to the illness (Grey et al. 1997). Research (Grey et al. 1997) has highlighted that children and adolescents with diabetes differed significantly, according to age, in the way that they coped with their condition. Younger subjects were more likely to cope by ventilating feelings through yelling and arguing, whereas older ones were more likely to cope with avoidance behaviours like drinking and smoking. Graue et al. (2004) suggested that in adolescents with diabetes, avoidance coping and venting emotions had been found to predict poor illness-specific self-care behaviour but were unrelated to metabolic control, whereas ways of coping with stress had also been identified as important factors in relation to metabolic control. Skinner and Hampson (2001) suggested that adolescent beliefs about their diabetes and its treatment should be considered as key factors that influenced self-care, emotional well-being and metabolic control. At the start of their relationship with type 1 diabetes and during its early stages, a young person has a relationship with their condition akin to having to deal with another person who requires constant attention. This 'person' might make them feel frustrated, sad and despairing:

*P: I feel like oh why the hell have I got diabetes you know like, why me all the time and then I always seem to be getting it wrong as well... [T1-QOL-03]*

Someone who they might wish to disengage from, even though they could not, or ignore and hide from outside of clinic visits:

*P: ...I think my general approach with diabetes generally is just deal with it when it, um, is generally stuff like, um most of the time is just like deal with it when it comes up so I need to eat so I'll do a blood test or an injection or I'm having a hypo so I deal with that. Beyond that I try and just to er, generally keep it out of the way.... [T1-QOL-02]*

Longer term, there seemed to be an acceptance of the condition in their lives:

*P: ...I've accepted it and it does not really bother me anymore. I just, I feel that, if I keep good control it does not really affect my life so I'm quite stable and happy in it... [T1-QOL-06]*

Once they'd established better control and as they came to the end of their regular visits to the Young Person's Clinic (YPC). There was also a strong feeling expressed that although the condition might be the same, the experience of living with it was completely different for each individual:

*P: ...no-one, no two people are the same with diabetes, everybody is different... [T1-QOL-08]*

which has important implications for providing innovations that might support them. In terms of allowing the innovation to be tailored to individual needs as with treatment, self-management issues and education.

Attitudes to initiating improvement highlighted how interviewees felt they could improve their condition and symptoms and whether they were able to maintain good techniques and principles of self-management. These aspects frequently conflict with other issues related to social, identity, cognitive, and physiological development and at the same time, the young person is learning to take over responsibility for the management of their

condition from their parents (Edgar and Skinner 2003). These demands were acknowledged in interviews, alongside reflections that they were not always acted upon:

*P: ...'cos I do tend to slack with my diabetes... [T1-QOL-05]*

What is interesting is that young adults acknowledge what they need to do to improve, but are unable to effectively explain exactly what it is that is stopping them from achieving this. This fact was not something they wanted to hide; they were open about not always doing the correct things - sometimes demonstrating immaturity and a certain level of bravado. Lifestyle demands were noted as a reason for not always being able to manage the best blood sugar control. This might be due to having a demanding job - like working in a school - where breaks could not always be taken at convenient times, or being on a university placement in a job where regular breaks were minimal:

*P: I am interested, I, I just do not think about it I guess, um, because I'm always rushing around, keeping myself busy, I just, you know, I do not know, I do not really think about it. But I should I think look up more things about it but I just do not... [T1-QOL-06]*

It also seemed there was a subtle perception lurking below the surface that at this age, they did not always appreciate being told what to do - even by friends, who might only have their best interests at heart. Some participants wanted a tougher approach in terms of the information tone pitched at them by clinic staff, to make them appreciate the risks more. The key problem seemed to be that despite their best endeavours of wanting to try to improve, this feeling gradually dissipated once they were away from the clinic:

*P: And then you'd get told while you were here like what to do and then you'd...I'd leave here...even now leave here and then think I'm going to do this and do that but then within two or three days when you're just back to your old routine or like back at Uni it's not, it's not always the same so it's like trying...I do not know trying to put the two things together... [T1-QOL-03]*

Something that could be improved upon by creating a portable mobile innovation, which might help to bridge the gap between the clinic and the patient. There was also a slightly

cavalier, almost immature attitude sometimes expressed to wanting to initiate improvement (which Lamb (2012) equated to the nature of the adolescent ego), leading them to believe that they were immune from harm - even when they knew particular actions might be risky:

*P: ...if I do not feel sort of dodgy with it, then I'll leave it, I do not feel the need to do it, what's the point in pricking yourself in the finger if you feel fine? [T1-QOL-08]*

This area is particularly difficult to address and has occupied much research discussion historically (see 2.3.4); but the unique relationship between a young person and their mobile phone (see 2.5) offers possible new directions to focus strategy on, which may help to improve this difficult aspect of the condition for a young adult.

Interviewees encountered a range of different emotional responses and fear was an emotion that was continually expressed and experienced in different ways. To begin with, there is fear that a test will result in a positive diagnosis and the wording of an emergency blood test seemed to heighten initial anxiety:

*P: ...I'd gone to the doctor and they said... "I think we need to do a diabetes test, can you fast overnight and come back and we'll do the emergency blood test tomorrow morning"...so of course that night there I was (laughs), sat researching it, erm, because I just wanted to know all about it... [T1-QOL-04]*

Depending on the age of diagnosis (which ranged between 3 and 17), the younger the age of the person, the worse the confusion and anxiety might be when they were in a hospital with no explanation about what was being done to them and why. This could result in fear that might manifest itself in longer-term problems lasting beyond youth – such as *Needle Phobia*. It is possible to visualise what it must be like to be cornered by a group of nurses in a clinical room to be given an injection and what the psychological damage could be to a young child:

*P: ...and it took six nurses to pin me down to give me my first injection because they sort of cornered me in a room... [T1-QOL-08]*

At a younger age, parents initially have to take the lead in looking after their children. However, parental concern of wanting to protect their child might have the unfortunate consequence of making things seem worse to them. Fear of the unknown might manifest itself when children are unable to look at certain books - prohibited due to parental worries of the effect they might have on the child:

*P: I was not allowed to look through that one [describing book] in case it scared me... [T1-QOL-02]*

Within the clinic, one of the most difficult issues discussed by staff is how to pitch the level of information given to young adults, initially visiting the clinic with their parents and subsequently on their own. Should it be a hard or soft approach? An unfortunate side-effect of trying to make a serious point about what might happen if a young adult had poor control over a longer time period might also cause heightened anxieties. This could cause them to imagine the worst in their own mind and then go and seek out more information on the areas that most concerned them – either via the Internet or in person:

*P: And when my HBA1's were high. And then I started getting shown like graphs and things and you know if you carry on going higher this can happen and if you do this, then that will happen. So it kind of put the fear of God into me a bit... [T1-QOL-03]*

Fear was also apparent in the daily struggle to stay on top of dietary requirements, by not eating too many sugary treats at the wrong time. In terms of deciding whether to use an insulin pump, one of the key issues was that it might be visible to others, causing anxiety concerning personal appearance that could also have a detrimental effect on QOL.

When discussing the stigma associated with having diabetes, people with the condition often describe the burden as not only affecting health issues but also social functioning and QOL (Barnard, Peyrot and Holt 2012). Negativity concerning their type 1 diabetes was something that lay beneath some comments - usually expressed later in interviews when they felt more at ease. There seemed to be a perception with some organisations

like Diabetes UK that these feelings were not able to be properly expressed and that it was almost taboo to put forward negative opinions and discuss why their control and measurement was not as good as it could be:

*P: ... you'd want to have a bit of a bitch with someone about it as opposed to "Yeah I'm a good diabetic, I do this, I do that..." [T1-QOL-03]*

These feelings sometimes being mixed with adolescent angst, making discussing important issues concerning control and measurement difficult for some parents:

*P: ...my parents would try and have talks about it and I'd just "Oh, no I'm not interested"... [T1-QOL-03]*

Part of this negativity was around why they had type 1 diabetes, but negative feelings might also be caused by an unhappy clinic visit - where criticism of blood glucose control and measurement or weight management might be taken to heart and subsequently dwelt on after an appointment had finished:

*P: I know that is my fault but they do not need to be so mean about it (laughs)... [T1-QOL-07]*

Similarly, being told what to do, rather than being given the same information in a more open and involving manner could also provoke negative thoughts and feelings. This could have the effect of causing blame to be apportioned to the individual by themselves and rather than feeling supported, they might feel picked on:

*P: No, no. It is my fault... [T1-QOL-08]*

Another interesting sub-theme, concerned how interviewees felt about their condition - viewing it as something they had to deal with on their own. Mirroring Scott's findings (2005), interviewees would have welcomed someone of the same age (but notably neither practitioners nor parents), in the same position as they were to talk to:



*P: ...it went through that stage and that's probably when I could've done with someone at the clinic or not my, even my parents, maybe someone saying you know there's a group of fifteen year olds who are all in the same boat... [T1-QOL-03]*

However, finding people of the same age with the same condition had proved difficult:

*P: ...because on a day-to-day basis, even if you are engaging with people with type 1 diabetes, you might not even know about it and so, it's quite a hard thing to meet other people who are living with the same condition as you... [T1-QOL-04]*

and most buddies had either been arranged through the clinic, or been found through a friend of a friend. What is most striking about this perceived isolation is that when they came in for clinic appointments, they shied away from initiating conversations or friendships with others of the same age that were visiting the clinic at the same time.

Resolving issues of fear, negativity and isolation can be partially addressed through technical solutions, but need to be considered in light of how each individual feels and is coping with their condition; as each experience is different. As they gradually grow older and more confident in coping with certain aspects of living with type 1 diabetes, so the technology needs to adapt with them. Mirroring the parental relationship, which starts with parents in control of the condition on behalf of their child and then is gradually relinquished over to the young adult as they become older.

Although in a lot of cases the injection and measurement routines of interviewees were discussed quite casually, there were a number of remarks relating to pain and discomfort as a part of their QOL. Injections might cause uncomfortable feelings to occur post-injection:

*P: I do have a rather um, primitive method for remembering if I've done my levemir is that a, sometimes, sometimes doing the injection it hurts and it stays hurting afterwards and so I know I've definitely done my levemir if my leg's hurting... [T1-QOL-02]*

Whilst the simple act of taking a blood sugar reading with some CBGM was also noted as being quite painful:

*P: ...I was finding it quite um, painful doing the erm...*

*I: Where it jabs into your...*

*P: Yeah, into my fingers... [T1-QOL-05]*

The insulin pump needle was also discussed as being uncomfortable, as was injecting through clothing. Most importantly, poor blood testing procedures in health settings could be painful:

*P: ...and she did it on the inside of my arm and through a week my arm was like painful, when I tried to move it...*

*I: Yeah*

*P: ...so I think that's what put me off, and then after that I just sort of...everytime it came to it, got nervous and it took sort of about an hour for them to even get near me with a needle... [T1-QOL-08]*

If not done carefully, this could stay in the mind of the interviewee after the appointment had taken place – an important policy issue to document.

Williams (2000) found that the majority of female adolescents incorporated diabetes into their social identities; openly telling people about their condition and willingly treating themselves in public settings. Male adolescents were noticeably not as open, refraining from telling others about their condition and keeping it separate from social identity, suggesting that they may be less overt in self-care management. A further area of interest that emerged was how social identity concerns affected the interviewees and their worries of being seen as different. As if having type 1 diabetes marked them out in their own minds as being different from their peers. At school they would need to find somewhere quiet to inject away from others:

*P: ...when I was injecting four times a day and I had to do it at lunchtime. It was a little bit awkward in upper school there was not anywhere I could really do it,*

*because obviously the other students did not realise what was going on, thought it was a bit weird that I was randomly stabbing myself... [T1-QOL-07]*

and at home, having to inject could cause changes in family relationships to occur:

*P: ...and that was a bit harder. Because she would not actually, when I was first came home from hospital she would not let me go in the same room as her anymore... [T1-QOL-07]*

Deciding to use an insulin pump brought additional concerns regarding the physical appearance of the device, which might affect how they lived their life. There was also a feeling that although interviewees wanted to take a pragmatic approach to passing on vital information such as what might happen if they had a hypoglycaemic attack, they sometimes wanted to downplay this when discussing the topic with friends. Partly wanting to minimise the effect of this information, to avoid seeming too different from others in their social group. This area notably arose as a key idea for a possible innovation, which could benefit interviewees in both cascading information on hypoglycaemia to their friends and also providing support that could help them (and others near to them) if they ever went into a hypoglycaemic coma.

### **4.1.3 Theme 2 – Diabetes Technology**

The second theme - *Diabetes Technology* - concerns how a young person with type 1 diabetes interacts with the various pieces of diabetes related technology that they are required to use. This theme is important as it highlights how they currently use technology directly related to their condition, how it is designed, problems they have experienced when using it and areas which its use does and does not currently address, which could then help to improve QOL.

Capillary Blood Glucose Monitors (CBGM) were an essential part of life for interviewees. There are many different types, but the basic functionality is designed to provide an almost instantaneous reading of blood sugar levels in the body, provided by supplying a blood sample. Newer meters are able to store historical readings, meaning that there is an instant record of readings over a period of time which allows clinic staff to see how a

users control has been at different times (see 4.1.2). Acquiring a CBGM depended on which ones the clinic had in stock at a particular time:

*P: ...most of the ones, I think the hospital just get a couple of companies in and the ones I had were just ones that my nurse would give me when I said “Oh, can I have a new tester?” she’d er, give me a new one... [T1-QOL-04]*

rather than on what was the most beneficial one for a particular individual to have and as with mobile phone contracts, the supply of newer meters tended to be restricted. Older units were more likely to be given away, whereas state of the art CBGM like the iBGStar (Sanofi 2011) had to be paid for outside of the clinic:

*P: We had to buy this one, and it’s really um, its actually really nice using it as well because it’s um in addition to, it tests the blood really fast and in addition to the, it’s got the labels and also it’s got a little countdown menu so you do not have to sit there waiting for like how close is it for testing? (smiles)... [T1-QOL-02]*

There was also a tendency for newer meters to be more ergonomically designed and compact than older models and to have features that improved QOL for participants such as the ability to test for ketones:

*P: I used to carry around a brick basically...a massive pack... [T1-QOL-03]*

However, although interviewees considered that newer models had enhanced functionality, they still lacked features that would make life simpler for them when used regularly. Interviewees were unimpressed with how CBGM could be currently integrated with their computers; allowing them to seamlessly transfer readings onto different systems where they could analyse, graph or interrogate readings. Problems working between different iterations of the Windows operating system tended to be the major culprit mentioned. Another problem identified was the pain experienced when using some CBGM on a regular basis (see 4.1.2). Also, the amount of blood required by some CBGM seemed to be high:

*P: My first one used a lot of blood... [T1-QOL-07]*

and there were difficulties mentioned with the process of obtaining an accurate reading (although recently introduced products had reduced these problems). Sound may seem trivial, but blood testing is a procedure that needs to be performed regularly each day:

*P: Because it's got like a motor in it 'cos it changes it's strip automatically, so it's not a quiet one. So I do not like that about it... [T1-QOL-01]*

There might also be instances where the user was not always able to find a discrete, private location to perform a required reading. Some of the features incorporated into newer CBGM providing supposedly helpful functionality had probably not been thought through properly in terms of design for the lifestyle needs of a younger user:

*P: ...the frequency of putting in the insulin amount, it was, it was, we did it, we tried doing it about once a week and I inject about four times a day...*

*I: Right*

*P: So that's 28 things to remember (smiles)... [T1-QOL-02]*

Other CBGM had complicated user interfaces, which made supposedly easy tasks difficult to complete:

*P: Yeah it did have time, they all have time and date settings but I've never worked out how to make them work.... [T1-QOL-04]*

and which this age range did not wish to spend time flicking through a manual to find out:

*P: I'm not a manual person... [T1-QOL-04].*

Insulin pumps have been shown to have a beneficial impact on QOL (Todres et al. 2010), as they tend to improve a young person's control. However, the onus seemed to be on the interviewee to investigate and research them, rather than information being provided by the clinic. Their basic functionality automatically issues insulin into the

bloodstream without the user needing to trigger or inject an amount - although they can be configured to different settings as required. This is especially useful if the user is asleep and hypoglycaemia unaware, or if different amounts need to be issued or released over the course of a particular day, with the ability to change levels as and when required:

*P: ...they programme it so that it's like, it does it automatically, and then it's just when I eat, then I do the other stuff...*

**[T1-QOL-07]**

One of the main problems highlighted by interviewees tended to focus on the cost of using some of the features of the insulin pump:

*P: ...but it's £ 30 a day to do that, I think...*

*I: Really?*

*P: You get a little microchip like, put underneath your skin and they leave it in for three days and it does a blood test every five minutes and it tells your insulin pump the reading and then it will respond to that... [T1-QOL-07]*

and also on the increased risk of having ketones, as opposed to injections. The dangers of a malfunctioning insulin pump were also discussed:

*P: ...I've had a few insulin pump malfunctions actually.*

*I: Right.*

*P: Which obviously is quite dangerous (nervous laughter)... [T1-QOL-07]*

Although, as was typical of this age group (see 4.1.2), the interviewee expressed a rather casual attitude to the dangers that this may cause. Anxiety from wearing the pump:

*P: ...I was worried like when I'd go to the beach and things it would be sort of there and I did not really like it... [T1-QOL-09]*

and discomfort from wearing the chip (see 4.1.2) were also mentioned by interviewees; both factors possibly impairing the QOL of the individual (depending on what they were doing).

Pen mates that hide the needle to avoid the problems associated with *Needle Phobia* (see 4.1.2) were also discussed as a technology used by interviewees. These devices allow a user to avoid touching or viewing the needle upon injection:

*P: Basically you put your insulin inside it, you screw the little*

*I: Right*

*P: ...dialing device in the bottom of it, and then you put the device on your leg, the needle sits in the top, but when you put it on it's flat...*

*I: You cannot see it...*

*P: You press a button and it puts the needle in for you, so you do not have to touch it... [T1-QOL-08]*

Problems reported with the use of these devices included issues (as with CBGM) of being able to obtain newer models and the inability of clinic staff to be able to advise on the newer pens that were going to be issued by manufacturers:

*P: They update them, but they do not seem to tell you they're updating them because I've had these pens since 2006 so I've just replaced them now... [T1-QOL-01]*

There were also problems with use in circumstances where clothing could not be removed - as it is not always possible to be somewhere convenient when the injection needs to be made, in addition to the results of using them incorrectly (see 4.1.2).

The main impact of diabetes technology is that unlike other forms of technology that they may have come across, interviewees have had to use some form of this technology and have not have a free choice in the matter. The main points to draw from this theme are that in terms of design from a user standpoint, the requirements of the product functionality and performance have sometimes been prioritised over the experience of using them from the perspective of the participants. This has ramifications for any new

technical innovation that could be created. There might also be a number of new ways in which integrating existing diabetes technology with mobile and web technology could possibly help to improve QOL. For example, on a basic level, the way in which information about new CBGM, pumps or pen mates is publicised and cascaded to users attending SWDC could definitely be improved upon - perhaps mirroring how information about new commercial mobile phones is distributed and promoted.

#### **4.1.4 Theme 3 – In the Clinic**

The third theme - *In The Clinic* - concerns how a young person with type 1 diabetes has interacted with healthcare services since their diagnosis – during clinic visits; in hospital; at doctor's surgeries; and when contacting NHS Direct. This theme is important as it serves to highlight both positive and negative experiences relating to practice, which can help to inform policy. This theme and the points of interest documented could also help to improve the lives of young adults with type 1 diabetes from diagnosis onwards and assist in pinpointing places where technology might be able to make a difference.

There were many interesting reflections on the interviewee's relationship with their clinic. Appointment discussions might cover how to use a CBGM or the correct way to inject. At a younger age, this relationship tended to be more one-sided, but allowed for questions they might have to be answered (with leafleted information supplied in some instances). The half-yearly check-up at the clinic is a lengthy process, consisting of a number of separate checks interspersed with sitting for long periods of time in a sparse, bland waiting room:

*P: When you come in you sign in then you sit down. Sometimes it can take between five and ten minutes and then one of the nurses will come up and weigh you and check your blood pressure and height and you sit down, that can take up to forty minutes sometimes, it depends on how busy they are. See the doctor then you book another appointment and you can go home... [T1-QOL-01]*

CBGM are brought in by patients so that they can be checked. Historically, this would have happened by looking through a logbook that the patient maintained; as CBGM have not always held historical data (see 4.1.3). More regular meetings are arranged if



the control of the patient is deemed to be in need of more thorough monitoring, with decisions on the level of risk based upon average readings over a period of time (that are either flagged as good or bad control):

*P: So your blood sugar should read between four and seven all the time. Um, any higher is not very good and any lower and you need to do less insulin and have more food. So if you come in with an average reading and it's sort of twelve or something it means you're BM is running at nine or ten or ten or eleven or something like that. So they'll say well your blood sugar readings are too high at the moment. Likewise if you came in and your HBA1 was five or four they'd be like well you need to do less insulin and eat more... [T1-QOL-03]*

The schedule of appointments might also be controlled by external factors, such as the patient's location due to work or educational commitments. The gap between appointments can sometimes mean that information is not always supplied to the clinic as required (see 4.1.2). It might also be the case that the longer length of time between appointments helps to create a false sense of security in those young adults whose control is viewed as better - in that they might not take as much notice of their lifestyle as those coming in more regularly, who will be reminded of good and bad practice. In addition to regular appointments to talk about aspects of control and check if any additional information was required, separate letters are also sent out to young adults with type 1 diabetes for other appointments and checks which need to be regularly carried out on their behalf (such as monitoring the eyes and feet).

Isolation at the clinic was a particularly interesting area where each young adult visiting seemed to be in their own particular bubble:

*I: ...when you've been in to see Clinic, you have not really spoken to any of the other people that are...*

*P: No, I've never spoken to anyone... [T1-QOL-05]*

Never interacting with others present (see 4.1.2):

*I: ...you've never linked up with anyone else in the clinic here, as sort of like er, other people that are sort of waiting, you've not chatted?*

*P: No (agrees). Er, you know I think everyone in the clinic just sits there in silence with like the magazines staring into space or something... [T1-QOL-02]*

This might be considered strange, although perhaps not when considering the ways in which young adults with type 1 diabetes will keep their distance in certain situations (Williams 2000). Definitely, most interviewees knew few others with the same condition and expressed a wish to contact others for mentoring and general discussion about their condition (see 4.1.2) as Scott (2005) alluded to and here there was an opportunity to mix and chat with others, albeit not in a particularly pleasant environment.

The transition between the child clinic and the YPC is notable for having an effect on those diagnosed at a younger age. For a younger diagnosis, the onus is more on the parents to take the lead role in looking at all factors associated with the condition (see 4.1.2); looking for ways of obtaining information and support from a variety of sources including leaflets, books and magazines and providing additional information to other people when required:

*P: My mum, when I was younger, if I went to a sleepover or something she'd like print off this A4 sheet of what to do and hand it all over to the parents and stuff (giggles)... [T1-QOL-07]*

The move to the YPC from the child clinic heaps more expectation onto the shoulders of the young adult:

*P: ...I've been expected to do stuff rather than talking to mum. And mostly I have mum come in with me because she's better at remembering stuff and so on... [T1-QOL-02]*

Whilst effectively reducing and then gradually removing the role of parents from this relationship. But in some cases, there could be issues with information not being cascaded correctly; based on the gap between appointments and the understanding of participants about how this transition should be phased in and when:

*P (M): Because of the six months gap you do not...I think we might have missed some certain things or new services. Sometimes I think they might have been introduced without us knowing... [T1-QOL-02]*

However, by the end of their time at the YPC the hope was that the young adult would have a good grounding in all aspects of support and control for their condition. Although some interviewees seemed to be unsure as to what this actually meant; in terms of future support as they came to the end of their time at the YPC. Transition again offers pointers to improvements that could be made within policy (for example, by improving communication processes) and also for how technology might be able to ease the transitional process and improve QOL as a result.

The need for structured diabetes education (SDE) programmes in paediatric care has been flagged as a priority by both government bodies and diabetes organisations (Chaney et al. 2011). The U-CAIR course is run for people with diabetes at SWDC and is based around learning the principles of carbohydrate counting, in order to adjust insulin doses appropriately. It also covers other aspects of diabetes care in group sessions. This course met with mixed reviews from interviewees, with some who had been invited not feeling that they needed to attend, whilst others had gone to only one session as they thought they already knew the information. Others had found some of the course information to be useful, but had found there was quite a difference in the age range of attendees, making them feel uncomfortable when they attended:

*P: I was probably about sixteen.*

*I: Sixteen? So they were talking down to you? Maybe?*

*P: Yeah, I mean I get that they kind of have to do that, to make sure that everyone knows stuff...(giggles)... [T1-QOL-07]*

The feeling was that it was mainly for middle-aged people and that they would have preferred to attend a separate session comprised entirely of an age group similar to their own. The way in which the information was given to them - by PowerPoint slides - was, they felt, more suited to a mature audience as was the tone of presentation. There was also a preference for the course to be split into specific type 1 and type 2 diabetes

information and also be broken down into the different phases of experience for people with type 1 diabetes:

*P: Everyone is different. Everyone reacts differently to different foods, you're all on different ratios. Whereas the U-CAIR course, tried to sort of group you altogether... [T1-QOL-08]*

This was because some interviewees viewed the group approach as being difficult to make work within a course environment and had a preference for more personalised discussion - whilst appreciative of the fact that this might not always be possible. Especially, if they wanted to discuss sensitive subjects:

*I: ...if you, you had to go to the clinic for say a talk about alcohol um, and diabetes, would you prefer that on a one-to-one with a clinician or...*

*P: Yeah, probably...*

*I: ...say six of you...*

*P: No. Things like that are quite personal I think... [T1-QOL-04]*

Which might require different responses in terms of support (depending upon the individual):

*P: ...in a group there probably might be one person that does not even drink and there'll be another one who goes out five times a week, so, I think, in terms of that you need personalised information... [T1-QOL-04]*

This area is important for reflecting on how technological solutions could be approached. The style and content of presenting information to a young age group could be specifically tailored to them on a mobile platform and from their personal requirements, interviewees preferred a singular approach relevant to them rather than a group educational scenario.

Clinic appointments were deemed to be a good source of information on new CBGM which may have been launched - although this did not necessarily mean they would be

distributed (see 4.1.3); for obtaining new CBGM if old ones had broken; for addressing problems like needle phobia:

*P: ...the head of diabetes who was [name of person] at the time, she suggested for these (shows pen mate), so yeah, that was good... [T1-QOL-08]*

and for receiving advice on the possible use of innovative technological solutions (see 4.1.3). Staff might also suggest new useful tools - like diabetes apps - that they had come across. Positive comments were also received on the clinic support it was possible to obtain over the phone in case of queries; even if it meant someone returning their call at a later time:

*P: ...I remember the first time I was late with my insulin I phoned them up and asked them what to do and then I think there might have been another time when I was, maybe I was eighteen, I do not think I'd ever been that high before so then I phoned them up and asked them. So it's just really small little things that I can call them about... [T1-QOL-09]*

However, not all of the information received at the various appointments held at the clinic was positive. Negative views included contradictory information being received in different clinics surrounding topics like what to do when ill and being overly critical in the view of the interviewee regarding issues like weight - probably a more sensitive issue for a young female to receive than a young male:

*P: I mean like I know that I need to eat healthily and not, you know put on too much weight but I'm still at the kind of weight where I've got enough of, I've got, I've got plenty of leeway, I do not need to be told to keep watching it, it just causes me to get paranoid... [T1-QOL-02]*

Also, unsuccessfully relating to interviewees why the seriousness of the information being discussed needed to be shared with them - causing a lack of understanding and sometimes provoking fear (see 4.1.2) in the interviewee:

*P: ...or people would say "If your blood sugars are running at this amount for this amount of time then you know you could create this problem, that problem"...and to a fourteen year old I do not think it really like...it just sort of...I do not know what I'm supposed to do with that.... [T1-QOL-03]*

This could be a factor of the age of the young adult at the time the original information was given to them, causing a misunderstanding and then subsequently, at a later age, assumptions being made about what they might or might not know based on this:

*P: I think like sometimes they just do not just tell you enough, like I think, because I was quite young when I was diagnosed, I did not probably really understand what was going on that well...and I think, because I was so young that no one really explained it properly. And then later on, they just assumed that I already knew like, how it worked and stuff...*

**[T1-QOL-07]**

This being a particularly difficult issue for interviewees to address if they were shy and retiring during their appointments. It was noted by interviewees that different clinical team members had their own particular approach to communicating information, but unfortunately not all were seemingly good at chatting effectively to someone young. What was noticeable about this issue is that the best relationship one interviewee shared was with their doctor, who also had diabetes and who would therefore be more empathetic as they knew what it was like to live with the condition. Some interviewees did not appreciate a 'tough love' style of delivery when receiving information. This could cause resentment about the way in which information was given to them (see **4.1.2**) and at a younger age could have serious implications; as during teenage years, those who wanted to rebel against people who told them what to do were more likely to ignore this approach, even if it had their best health concerns at heart (Lamb 2012). Appositely, others reflecting retrospectively preferred this style of delivery to drum into them particularly important points to remember.

In general, the SWDC was praised for its friendly staff by interviewees (when talking about their attitudes to the clinic) and there was a preference for obtaining information and support from them as opposed to any other method:

*P: ...I'd much rather have the personal, I think that's the most important part of the personal interaction with another person on the other end...*

*I: Individual...*

*P: ...rather than having to read about it or decipher it for yourself, because you could read a certain bit of information and get four different opinions of what it means... [T1-QOL-08].*

Although there was an underlying feeling that they were not always asked for their opinion. Rather, it was mostly focused on telling them specific information and not always adapting or even attempting to second-guess what they might want to know:

*P: ...'cos they tell you how to improve and that's really it and then they ask you how you're doing. They listen to you in a sense what you're doing wrong and then tell you what you need to improve but they do not seem to listen to you about like what type of information. They'll give you the information if you ask for it but they do not seem to ask you if you need any information... [T1-QOL-01]*

The tone of information given to a young person could provoke negative reactions (see 4.1.2). Whilst recognising this as a problem that needed addressing, dwelling on the negative aspects most of the time was highlighted as an issue by participants and, during adolescence, this type of approach affected their attitudes to the clinic. However, a couple of participants felt that the clinic staff had gone too much the other way in their approach:

*P: ...for me I think sometimes they're a bit too nice. I think I need for me to be able to start to really do it all properly 24-7...*

*I: Right*

*P: ...I need that bit of a scare I think or for them to push me and say well you need to do this because of blah, blah, blah, complications... [T1-QOL-05]*

In part, this is a problem caused by the length of time between appointments and the fact that all the clinic can really do is preach a message which is not able to be effectively enforced by them (as they are not able to be with the individual at all times).

Another way in which the clinic possibly mirrored an interviewee's view of school was the way in which participants received and listened to the information being given to them:

*P: ...when someone's talking to me I tend to zone out a bit...(giggles)... [T1-QOL-07]*

Or, perhaps not fully understanding what was being discussed and not mentioning this at the time. On the part of the clinic, there might be an assumption that the patient already knew the information being given to them (so therefore not mentioning it), or unfortunately pitching the tone of discussion at a level that might be viewed as either patronising or repetitive:

*P: And they basically went through my diet with me, and they said "You're fine" (laughs)...and then they did like "How many, does this contain carbs?" like showing me loads of plastic foods and stuff...*

*I: Right.*

*P: ...so that was a bit like..."Really?" (Laughs) [T1-QOL-04]*

Interviewees tended to be quite open with the clinic about their lifestyle:

*P: And so I've never lied about what I do. I'm fairly open with the doctors and I say you know, I do not always test my bloods, sometimes I do eat sugary stuff... [T1-QOL-08]*

But they had tended to experience difficulties in the relationship if they behaved slightly differently from normal (where more time might need to be taken). This might be when obtaining blood tests (see 4.1.2), which might have grounds in the practicalities of having to run a clinic to time. Or, if someone did not conform to type - meaning that it was not matching the expectations of what most people were doing at that age. Such as continuing to bring parents along to clinical appointments:

*P: ...but then they kinda got annoyed and were like 'you should not bring your mum to these things' so then I started going on my own (laughs)...*

*I: But did they say a reason why?*



*P: Oh, they just said you're getting older now, you should do it yourself, was pretty much what they said... [T1-QOL-09]*

Very occasionally mention was made of issues that were not being addressed by the clinic, even though they had been raised more than once. However, in general these were one-offs, such as the lack of communication when trying to obtain an insulin pump through the clinic:

*P: And then they promised me a pump. And then they, I think they forgot about me or something and then I said 'Ooh, am I getting a pump sometime soon?' And then they said, 'Oh, you have to go on this waiting list and you have to go and do these courses'. And I said 'I've done these courses', and I've been on the waiting list'. And they're like 'Oh, right' (laughs). And then that was that, and I have not heard anything else since... [T1-QOL-09]*

Aspects of the negative and positive comments on the clinic and how they affected the attitudes of the young adults visiting offer many important lessons for future policy; relating to communicating personally and interacting differently with individuals of this age group. This is also instructive when trying to work out the level and tone to pitch information and support materials in an interactive format, which avoids some of the issues mentioned by interviewees such as being overly patronising or preachy.

As opposed to the generally more positive than negative perceptions of and experiences at the clinic, the interviewees experiences of other parts of the health service such as NHS Direct and visiting GPs left a lot to be desired. Perhaps the attentive, good quality service received at a local clinic level served to highlight this to an even greater extent. The trust factor between doctors and interviewees was highlighted as being brittle and at this age the desire for control was stronger than at a younger age:

*P: ... it was more of a trust issue because some of the things you have to do, do not make sense to you from what the doctors tell you but from personal experience they do... [T1-QOL-08]*

As was the acute awareness of a lack of listening to the patient's viewpoint; being patronising and arrogant:

*P: I find a lot of doctors quite, I do not know what the word is erm, they just, they think that they know your diabetes better than you do... [T1-QOL-04]*

Not being helpful:

*P: They were not particularly helpful, they were quite sort of, as if they had better things to be getting on with, you know, there was obviously people that were a lot worse off, but you still want a bit of peace of mind, to know either what your doing's right. It was when I was on um, a night out, and I did not have any insulin on me and I had no way of getting home. So I said, is there anything I can do to prolong the effects of the food...*

*I: Uh-huh.*

*P: ...and in the end I phoned my parents and got them to drive for a couple of hours to come and get me, because the information I had was so useless from the NHS... [T1-QOL-08]*

and being thought of as stubborn and not prepared to consider any other views:

*P: So if you're phoning an NHS doctor, they will, they do not, they get your date of birth and everything from the start but they do not ask how you've had diabetes, they do not...*

*I: Hmm.*

*P: ...they do not get the sort of full scope of what's going, so as much as you can try giving them the information, they'll be dead-set that judging by what their textbook has told them they will be right... [T1-QOL-08]*

With some doctors seeming to view the interviewees as a condition rather than an actual person. This had the serious issue of making some interviewees actively avoid certain aspects of possible support within the health service, due to these negative perceptions or previous bad service:

*I: ...we'd had someone who'd spoken to NHS Direct, got one of the NHS Direct doctors out...*

*P: I avoid them at all costs... [T1-QOL-08]*

This is an important point to note in future policy. This aspect of care was also reflected in hospital trips outside of the clinic environment, where patient comments were ignored without acknowledgement causing them additional pain and irritation which could have been avoided.

#### **4.1.5 Theme 4 – Obtaining Information and Support**

The fourth theme - *Obtaining Information and Support* - concerns how a young adult with type 1 diabetes obtains knowledge and help relating to their condition. This theme is important as it serves to highlight the shift away from traditional forms of support - such as personal F2F interaction with friends and family and utilising books, magazines and leaflets. Moving towards incorporating new technological methods of support like the use of online support groups and different social media and web tools to locate information and communicate advice and support. This has many implications concerning how the lives of young adults with type 1 diabetes could be improved; by integrating the best and most suitable methods from this theme with new technological innovations for self-management, education and support.

Both friends and family were able to offer help and support to interviewees. Friends of the same age with type 1 diabetes were typically more difficult to meet (see **4.1.2** and **4.1.4**), so either tended to be met in a specific health context, through family circumstances, via friends of friends or by word of mouth at school or university:

*P: ...I met him through school when because we had to medical intake and had to take our injections at the same time... [T1-QOL-01]*

Although for some interviewees when younger, they had found it particularly difficult to locate anyone in a similar situation to themselves, which would have been helpful at the time by providing an additional avenue of personal support:

*P: ...what would have been more helpful to me was to sort of contact other people that were in the same situation as me that had gone to secondary school or just...were absolutely hating having diabetes, who wanted to eat sweets all the time, eat chocolate, have McDonalds, anything. It would have been much more like beneficial I suppose than you know "Let's find a cure" and you know "We can work through this" and "It's a helpful thing" and "Look at this person, is not she a star"... [T1-QOL-03]*

This had occasionally led to the clinic attempting to initiate friendships at the time of diagnosis between different patients. This could prove difficult, as the initial offer of friendship had come via the clinic, rather than the individuals themselves. This method of linking up also extended to older members of related families and friends, which could occasionally prove serendipitous:

*P: ...one of my boyfriend's friends whose mother was diabetic was asking me about this meter, so I did manage to give him a quick explanation about it... [T1-QOL-02]*

Friends of a similar age who did not have type 1 diabetes were larger in number and tended to be very supportive - such as during a hypoglycaemic attack also known as a *Hypo*:

*P: ...I'm quite lucky, the only times I've had bad ones is when I've been round flat mates who have been like "Oh no! Get the sugar" (laughs)... [T1-QOL-04]*

Sharing an interest in the condition; wanting to initiate conversations about it; attempting to understand it from their own perspective; and being quite protective of the interviewee within their social group:

*P: They do not just sort of play it off, they're very, I guess supportive is the word. They, they do not shy away from it they do not sort of outcast me from it, they just sort of try to er, associate it with their lives as well, which is pretty cool... [T1-QOL-08]*

This had proved to be useful when trusting them to know what to do on nights out if the interviewee were to experience a hypo; but could also sometimes cause them to exhibit behaviours that were viewed by interviewees as being either too overbearing or overcautious. Occasionally, this issue was something that some participants found quite difficult to discuss with their friends.

Family members also provided a useful support mechanism. In one case, having a sister who was diagnosed with the same condition proved useful as a means of supporting each other and encouraging level monitoring:

*P: Yeah we do, we try and encourage each other to do our levels, and I think she struggles with it more than me, so my family and I sort of help her out or try to help her... [T1-QOL-06]*

Having a close relationship with a sibling (who also had or did not have type 1 diabetes) also allowed for the discussion of topics, which might not be possible with other family members:

*I: ...is there a difference between you talking about diabetes with her to maybe your friends and family?*

*P: Yeah it's a lot different, um (thinks), because with your parents you never want to worry them so you sort of sand over everything... [T1-QOL-03]*

This is of interest, as it was highlighted in discussions that when wanting to talk to someone, participants inevitably wanted to speak to someone close to their own age (see 4.1.2) rather than older people, even if they were related. Although the support of parents in certain situations (such as attending appointments) was still appreciated (see 4.1.4).

Out of hours phone and email support from the clinic had been utilised by some interviewees. They particularly appreciated the freedom of being able to get in touch at any time:

*P: ...normally, the verbals, I mean it's brilliant here. You can ring up whenever you want and they will guide you through whatever you, whatever problems you're having... [T1-QOL-08]*

and the responses they received were deemed to be more satisfactory than those experienced when contacting NHS direct - serving to highlight both how poor this service was in comparison (see 4.1.4) and the possible benefits of improving HRQOL through the use of instant synchronous support mechanisms like Twitter (see 2.4.2). Queries ranged from what to do when travelling abroad concerning time zones and how to store insulin effectively whilst travelling (see 4.1.2). In addition to providing a welcome confidence boost to them before travel:

*P: He's very supportive and um, he made me feel like, er he said it should not ruin you holiday and it should not, you know, control it, you, you should be able to do all normal things that everyone else does and so that was nice to have that sort of support and yeah I've ended up being fine with it... [T1-QOL-06]*

Through to more urgent problems such as what to do when they had injected air rather than insulin and insulin lumps and the problems associated with injecting through them (see 4.1.2). Part of the appeal of using this service was the fact that interviewees could talk to someone one-to-one and gain verbal confirmation, instead of having to research it themselves (see 4.1.4).

Leaflets might at first glance appear unfashionable to young adults in a digital age, but were still seen as a valid and useful means of obtaining information and support; although some interviewees had not been able to obtain much helpful leafleted information. Whilst others had seen it, given it a cursory read through once and then disposed of it:

*I: ...with the leaflets, what did you do with them?*

*P: (laughs)...Skim, skim, and bin! (laughs)... [T1-QOL-04]*

As soon as they felt they had gained control of their condition, some interviewees had not returned to looking at leaflets as a form of support. Occasionally, they would look at

information they had received immediately after diagnosis, but as time passed this seemed less likely to occur. In fact, some interviewees had not even looked at the leaflets when they were originally given to them – partly due to their parents taking the lead in the early stages of post-diagnosis (see 4.1.4), whilst others had only looked at the information a couple of times:

*P: I guess I did not really do that much background reading about it. I mean I'd learnt about it in school a little bit, I mean...I read all the leaflets that I was given explaining the condition and that was it really... [T1-QOL-06]*

Consequently, they could be relying on old, half-remembered information and might only wish to access certain relevant leafleted information at specific times or on specific occasions:

*P: ...'cos they got all the information here but when you're here you do not really look at it because you do not seem to think you need it... [T1-QOL-01]*

Something, which could be easily provided for immediate access on a mobile device.

Books were lower down the list of methods mentioned for obtaining information and support by interviewees. Most had come to buy books as a result of clinic recommendations. Carbs and Cals (Cheyette and Balolia 2013) was the most popular book discussed and utilised after diagnosis. Others mentioned included a general medical manual, although this was already at home prior to diagnosis taking place and the interviewee was not allowed to look at it in case the information scared them (see 4.1.2). Two interviewees also mentioned the Collins Gem pocket size book on Glycaemic Index (Collins 2005); although again in one case their parents had initially purchased this book for them. The disadvantages of having to carry around a bulky book were pointed out by many interviewees; especially difficult if they needed to use it during a restaurant meal:

*P: I have the books at home or in my flat but I would not carry it around in a bag like this or something to go out for a meal or I'd just try and guess work how much carbs I was eating... [T1-QOL-03]*

This made them more likely to leave it at home and often resulted in them relying on the packaging information supplied on the back of products, on menus or displayed in restaurants:

*P: I mostly do go off the back of um packaging and so it, it can, it has been useful but most of the times where it would be useful say eating out someplace that is not [fast food chain] – just saying that is not [fast food chain] because they actually include the nutritional information on the back – because that's actually quite good, is most of the places where it's not acceptable to whip out a large book at the table... [T1-QOL-02]*

This had also led some interviewees to seek out other means of carrying this information around with them such as apps, where large amounts of information could be easily accessed and carried via a mobile phone in preference to a book. Another disadvantage mentioned by interviewees was the lack of a useful index in some cases; which made it difficult to locate the information required quickly and easily. Something which an app on a mobile phone would be able to address, in both the design and layout of a well-designed search facility.

Interviewees had grown up in a world where the ability to access information immediately, via a computer, had always been available to them. This included the ability to access health information and specifically information and support on their condition. Although circumstances might preclude this from taking place initially, if family finances did not allow for a computer or Internet connection to be available at home. Interestingly, for some, the urge to look for information on their condition straight after their diagnosis had not been strong, whilst for others it had been a matter of urgency even before the diagnosis was confirmed (see 4.1.2):

*I: ...after you'd had your initial sort of chat, did you immediately go on to the Internet to look for information or ...*

*P: Yeah before I got even the diagnosis... [T1-QOL-04]*



Searching for information concerning their condition included looking for information about control; information on new CBGM:

*P: I guess you keep an eye on stuff like technological stuff if there was like an article that you did not have to pay for about something or like or just mention that there's been like a new type of meter like this come out... [T1-QOL-02]*

information on medical conditions related to their condition (see 4.1.2) (sometimes in preference to attending the surgery for an opinion):

*P: ...but yeah I did go, look on the Internet to see what that was rather than make an appointment at my local surgery and then come here... [T1-QOL-05]*

researching insulin pumps and investigating new advances in diabetes research and technological enhancements, which might be able to help them at some point in the future:

*P: ...I do look at stuff occasionally. I did see something about the other day about some people finding animal insulin better than human insulin. I do not tend to like look specifically for things anymore. I just like, I say occasionally come across something general... [T1-QOL-07].*

Google was the preferred search engine mentioned by interviewees, which could be accessed anywhere via their mobile phone - a portable search tool which was always available to them:

*P: ...when I go on my phone and when I go on my laptop, the first homepage that comes up on the Internet is Google, so that's the first thing I do if I want to find some information is just go into Google, unless it, I know specifically what it's about... [T1-QOL-05]*

Once a search had been performed, on the results pages users generally started at the top and worked their way down through the first couple of pages to access any sites of interest:

*P: ...I would just Google it and then quite often when you go on different pages it will say like this oh is three or four and blah blah blah and you know if I found it interesting enough I probably would click on it... [T1-QOL-03]*

One interviewee remembered looking on their iPod Touch for information on their diagnosis, prior to receiving confirmation that they had type 1 diabetes:

*P: ...and that had Wi-Fi on it, so I remember just sitting in bed and Googling it on that yeah... [T1-QOL-04]*

Another described the ability - a key feature of this computer literate generation - to be able to think and tailor search strings to pick out the correct information, when looking for diabetes specific information online:

*P: ...Google, is really useful, it, normally you would type in things, although you have to go the long way to find it, it's just a case of figuring out how to do it and how to word your search as well... [T1-QOL-08]*

This meant instead of keeping hold of leaflets they preferred to access something immediately via online methods, rather than looking elsewhere first. This might be information on particular aspects of their condition - such as complications arising from using an insulin pump, or, symptoms which had arisen as a result of having the condition. Analysing this generation's use of search strategies and how they filter and access the information they require - relevant to their condition at different times, but always immediately available to them - again suggests that the new generation of smartphones offer huge potential in providing this facility. If suitably tailored to the person and condition and offering quality approved clinical information in an easily searchable format.

Wikipedia was mentioned by a relatively small number of interviewees. Positively, the majority knew that the content supplied within it was able to be changed by anybody - so that the information on there must be treated with care (only one interviewee mentioned they had not realised this). Some had already experimented with editing Wikipedia at a

young age, which had helped to inform their opinions; others had been notified at university about why they should not be using it. Interviewees had tended to make use of the site as a place for obtaining background knowledge:

*P: ...Wikipedia I use more for my own personal interest rather than anything informative... [T1-QOL-08]*

but none had looked for specific type 1 diabetes information on there.

In terms of recognising the quality of information that they were looking at online (see 2.4.9) concerning their condition, interviewees were confident in their ability to source correct information. As Internet natives who had been using it from a young age:

*I: And I mean were you happy that the site that you looked at was telling you the right thing?*

*P: Yeah, I looked on about five or six different sites... [T1-QOL-05]*

Able to deduce what information was incorrect and recognising any inherent online information dangers:

*P: ...I've done things like that, found loads of things that are wrong, which can be quite annoying, because if you did not know and you thought it was right some of them are quite dangerously wrong... [T1-QOL-01]*

Just as they approached Wikipedia, they were happy about not taking everything that they read on the Internet at face value. They prioritised certain websites over others and made informed choices on what they found, double-checking certain information across different sites, rather than assimilating and using the information they found on the first site they came across:

*P: ...generally, if I was to like look up something on diabetes on the Internet I have enough basic knowledge to be able to sift out the crap... [T1-QOL-02].*

In terms of search strategies, interviewees were adept at refining their search terms to pick out the best results, accepting that Google would not just provide an immediate answer to any question that they had on their condition.

Websites specifically mentioned by interviewees included manufacturers of technical products that they used in relation to their diabetes - such as CBGM and insulin pumps; informational sites which might have fact sheets that could be printed off for use; and news sites like the BBC which might have features and stories on interesting diabetes related issues. A number of American sites about diabetes had been accessed historically, but the results from these were not always rated highly as good quality sources of information:

*P: I remember going on a really rubbish American site which had loads of videos of an American Nurse going on about it... [T1-QOL-04]*

However, accessing some websites could have satisfying outcomes as they might accidentally yield useful information, which had not yet reached interviewees from other sources (such as the prescription online service):

*P: And I found out recently that you could do your prescriptions online, which is quite cool (laughs)... [T1-QOL-07]*

It is this facility for accidental discovery, which makes the Internet such a powerful resource for obtaining new information and support for conditions like type 1 diabetes. One, which could be harnessed effectively in a beneficial technological innovation related to the condition.

The charity Diabetes UK has a strong presence in the UK (see 2.4.9), making it a popular website to go to in relation to certain queries some interviewees had - although this view was not fully endorsed:

*I: ...have you been there quite a lot and...*

*P: Not really, only....only every now and then if I wanted to know something or wanted to look into something in more detail... [T1-QOL-05]*

This feeling also concerned their Facebook presence. Interestingly, some interviewees had never visited the Diabetes UK Facebook page because they viewed it as a fund-raising presence, rather than as a useful source of information. Others may have *Liked* the page (see 2.4.6), but had not actively engaged with the content or looked at any information on the page:

*P: Yeah, it's like I did not, yeah I've liked the Facebook page but um, I do not really engage with its content... [T1-QOL-04]*

This highlights an oft discussed point concerning the perceived usefulness of the Facebook *Like* concept - namely what does liking a Facebook or website page actually mean in reality for the person liking something and the owner of the page being liked? In fact surprisingly the number of interviewees who had not engaged with Diabetes UK or actively sought to avoid it, outnumbered those that did. This could be because of negative perceptions toward the organisation and its profile - associating it with government and health services in the minds of some:

*P: It's a government and charity like thing, er, I do not think it's, well I do not actually know much about it, but my assumptions of it were, it was either doctors or the government making, trying to make good with the whole situation. I did not think it was very much patient submitted... [T1-QOL-08]*

Or, due to the feelings of the interviewees, concerning the picture of the condition that they were painting as opposed to the real views of themselves. Feelings towards Diabetes UK publications were also notably more negative than positive:

*I: ...the Diabetes UK, pulse magazine, did you ever...*

*P: Mum used to get one of the magazines every month or week or whatever it was, but I never really looked at them (laughs)... [T1-QOL-09]*

This was partly due to the appeal of the contents to interviewees and also consideration that the majority of articles were targeted at a much older age group - which in terms of enhancing QOL for a younger age group should be more specifically pitched toward

them. Additionally, in relation to the adverts that they carried - reinforcing the perceived age gap by featuring adverts for retirement homes as an example. There was also a perception that certain articles on the negative aspects of the condition were being ignored:

*P: ...and you know this person's gone blind because they abused their diabetes between the ages of thirteen and eighteen or something but why would you not print that in Balance magazine? [T1-QOL-03]*

Whilst other features over-accentuated positive perceptions of people with the condition doing incredible things:

*P: There's always like in the Balance magazine, the you know, this person had a struggle but now they're walking up Mount Everest and they have, they've done everything and you think "everyday life people do not have that kind of thing". They do not really live like that... [T1-QOL-03]*

which did not connect with the normal life of a young adult with type 1 diabetes. These messages perhaps reflecting a need to reconsider how to highlight and show a complete perspective of the condition to this particular age group, rather than unconsciously or consciously hiding some aspects from them.

The lack of adequate access to F2F friends or family with the same condition (see 4.1.2) meant that online support groups offered an effective alternative means of meeting like-minded people as opposed to medical practitioners:

*P: It, there, there are other people out there that are going through it and it's, although it's bad, it's not as bad as you think because you're just sort of, when you get bad news like that you tend to (inhales) ...brilliant (laughs)... [T1-QOL-08]*

Although the location of some of these groups was not always immediately apparent in terms of trying to locate them and some interviewees had shied away from using them - sometimes due in part to their own characteristics, such as a lack of confidence in

wanting to chat and share information online. Methods for searching for and finding online groups varied, depending upon what the interviewee was looking for. This had resulted in one interviewee finding a forum focusing specifically on diabetes support - TuDiabetes (see 2.4.6) - which they praised as being a particularly friendly communal environment. It had proved beneficial in terms of general awareness raising and providing other information related to their condition:

*P: ...it was just nice not hearing from doctors but from someone who actually experiences it... [T1-QOL-07]*

as well as for posting personal queries in the discussion forum. However, only 1 out of 9 interviewees mentioning the community suggests that it is still not particularly well known within the UK. TuDiabetes also allows for the sharing of personal information with others, but the most positive impact on QOL for the interviewee had been that use of the forum had convinced them to try out an insulin pump:

*P: Yeah, I have found it quite useful. Because it, yeah, in the main it convinced me to use the insulin pump in the first place, which I'm pretty glad I did... [T1-QOL-07]*

It had also allowed them to find out information on subjects which they had queries on quickly and easily. Away from TuDiabetes, other forums interviewees had come across either tended to be viewed as being too focused on the US or populated by the wrong age groups:

*P: ...'cos when I've been on there before I've found that the people on them are either quite older or they're parents of younger children...*

*I: Right*

*P: ...rather than people my age... [T1-QOL-05]*

This suggests there is a gap in the market for this particular age group concerning their online support requirements (see **Appendix W**).

Facebook was the most popular social media tool discussed by interviewees. It was used by a number of them to keep in touch with friends and group members. However, some interviewees still preferred to speak to their friends in person or by SMS text message:

*P: I talk to people quite a lot face-to-face. I also text people quite a lot. And use Facebook (laughs)...*

*I: Text (writing). So, out of that you'd probably say face-to-face first, then text, then Facebook...*

*P: Yep. [T1-QOL-07]*

So the commonly held view that Facebook is used by young adults at all times is a slightly incorrect, even if literature suggested that this might sometimes be the case (see 2.4.6). There were also other reasons given for wanting to avoid using it due to the nature of the interactions. Similarly, some interviewees also contradicted the belief that users of this age group were happy to share every aspect of their personal life on Facebook:

*P: I go on Facebook more, that's more private and...*

*I: Right*

*P: ...that I'll look into things more and talk to people more... [T1-QOL-05]*

The historical move to Facebook from other social networks like Bebo (2013) was also described, as peer pressure had caused many to switch allegiance from other similar sites used prior to Facebook launching in the UK; suggesting this situation could occur again if a Facebook beating technology ever appears. Privacy setting concerns were issues which had been noted by interviewees:

*P: ...there's certain information say like I've got my email address and my mobile number on there, I hide that phone, but only my friends can see that... [T1-QOL-01]*

but did not overly concern them. They were also aware of the nature of what was private and public on Facebook - impressive, given the number of times these privacy settings



had been altered by the company during the last few years. Finally, the problems of using Facebook had affected one user to the extent where they were actively considering stopping logging into their account (rather than actually closing it):

*P: What they do is show up pictures of like all your friends in your Facebook and say they'll miss you if you delete this account. It's like 'No I'm not going to be able to handle doing that'. So I just you know...*

*P (M): Cos that worked on you...*

*P: So I what I decided to do was like logout forever and go over to Twitter... [T1-QOL-02]*

Surprisingly, Facebook proved an unpopular choice as a place to look for type 1 diabetes information online. Only one interviewee had used it for looking for people and groups to connect with, whilst other interviewees suggested that they preferred not to find new connections in this way. Interviewees also mentioned that changes of functionality within Facebook or within groups they subscribed to had precluded it from being used as a useful way of obtaining interesting news on the condition anymore. Or, failing to get beyond pressing the *Like* button, subsequently failing to engage any further with a particular group. Lack of using the social network to link up with others was partly due to not being able to find anyone suitable to connect with, or, due to problems with email spamming - caused by joining a particular group - which had made them want to leave it again shortly after. There was also a commonly expressed view that Facebook was not somewhere that interviewees felt comfortable discussing their diabetes, in contrast to talking about anything else on there – which again alludes to issues concerning social identity (see 4.1.2):

*P: ...I do not tend to use, to talk about Facebook on or diabetes on Facebook. So there's not anything to talk about really... [T1-QOL-07]*

Another negative factor was the way in which some Facebook groups like Diabetes UK expressed their opinions about diabetes - overly positive - which had the effect of turning some interviewees away:

*P: ...but again it always uh (laughs)...I'm not a pessimistic person but it's just very, very positive and you know, like obviously it would be but, it's not like, a very truthful response... [T1-QOL-03]*

Some Facebook groups consisted of an age range outside of their preferred one - like other online support groups - or just scared them away with the number of people they could potentially link up with. In the one case where an interviewee had connected with someone else, it seemed to have been more by luck than any concerted search strategy - the initial attraction to the group having been because of its name:

*P: I typed in Diabetes on the search bit and there were hundreds of pages that came up but I found the one with the most subscribers, that was not Diabetes UK (laughs)...and went on that and it was actually called 'I Hate Diabetes' which I thought was quite a comical sort of page to join... [T1-QOL-08]*

However, the person the interviewee had come across had ultimately proved to be very supportive and reassuring, reducing their sense of isolation (see 4.1.2) and counteracting their worries of their future life, whilst also providing valuable reassurance:

*P: ... I just went on one of the diabetes pages on Facebook and spoke to the um, administrator of the page. And she's thirty-five, and been through...*

*I: Hmm.*

*P: ...quite a few problems because of diabetes and she's still going and so it was quite inspirational talking to someone else who'd had it, and made me think well actually it, yeah it's a severe thing that's happening but y- it can be overcome. It was more of the reassurance that, yeah actually, I'm not actually doing it alone...*

**[T1-QOL-08]**

This group had proved attractive to the interviewee, as it was people sharing opinions in a non-medical environment – seen as a refreshing change to the norm, as opposed to some practitioners and their way of telling them what to do (see 4.1.2). Other attractions to responding to information within Facebook groups from this interviewee were quirky requests from other members, such as asking about different people's blood levels - although cultural and international differences made the terminology confusing

depending on which country users were based in. For another interviewee, Facebook had been used in an attempt to set up an online version of a local support group, but it had not been utilised as the follow-up F2F meeting had not been arranged. This suggests that some groups need additional regular F2F impetus to make them useful and attractive to visit and interact with online over a longer period. For the majority of interviewees, Facebook seemingly had not proved to be an attractive place to visit to either discuss their condition, or, engage with others in a similar position. This suggests that more private focused communities (see **Appendix W**) might be a better place to begin in terms of providing online support for this age group. This mirrors to a degree, the concerns of interviewees regarding education (see **4.1.4**), where they preferred a more private approach to talking about the issues affecting them, rather than in a wider group environment.

Blogs were not very often referred to as a potential source of information and support by interviewees. This might be due to the style of blog writing, which can be very self-centred and could therefore be deemed uninteresting or too personal for some to want to continue reading at a younger age:

*P: ... if it does not make me want to carry on reading it I will not. If, it's the same as a book, if it's not a good book I will not read it deliberately because someone else has said it's good... [T1-QOL-08]*

Only one of the interviewees - notably the LU interviewee taking a media related course - had set up their own temporary blog, but they had found it to be a very useful source of contact and support, enhancing their own QOL. The blog was initially set up to talk about their condition with the functionality enabling them to categorise posts for a reader to peruse, including the use of video diaries. This had enabled them to distribute interesting diabetes related news stories and also link up with others to share experiences and tips and also help their own learning and understanding of the condition:

*P: ...so through doing that, I think you can learn a lot from other people, erm, and I think putting it online kind of helps you understand as well... [T1-QOL-04]*

Surprisingly, the blog had proved to be a more popular method of connecting and staying in touch with people than a F2F support group set up locally. It had also proved useful in supporting others with the condition:

*P: ...'cos I had a really nice post from a guy who erm, was quite older but has been diagnosed with type 1 diabetes and he's really struggled with it, erm, and through reading my blog he's found it easier to manage his Diabetes and just knowing that, if you've just helped one person... [T1-QOL-04]*

encouraging the interviewee to subscribe to other blogs in addition to promoting a positive feeling in them, from being able to share feelings about the condition more widely across the Internet. The other blogs providing a number of different views and reflections on the condition that could be used for obtaining both support and information. In fact, it is a strange aspect of this present research that not more interviewees mentioned accessing or writing blogs, considering how confident and adept they were at searching for and engaging with information and support about their condition on the Internet. This is also surprising given the amount of people now blogging about the condition online. Although factors such as a reluctance to publicly share personal feelings and emotions online with others (similar to their feelings about Facebook); the very personal nature of blog posts; and the subjects and opinions that they were writing about – social identity issues again possibly influencing this area - seemed to be enough of a deterrent to limit the majority of interviewees from either accessing or creating them. This might also be due to the fact that once written blogs tend to become static pieces of text with no interactivity possible except through the comments section at the bottom of a post, unlike other social networks like Twitter which offer more immediate, real-time discussion possibilities. However, based on these findings it was hard to see value in progressing with ideas focusing on the utilisation of blogs in a new innovation for this age group.

Twitter proved less popular than Facebook in terms of use and interest. It had some supporters amongst interviewees, although others were more interested in the celebrity aspect of its use rather than using it to keep in touch with their friends. Some interviewees were not interested in using it due to this very perception:

*P: I think that's more of a stalking the stars website than er socialising with your friends... [T1-QOL-08]*

Some were not even sure of what it could be used for and expressed no interest in finding out:

*P: ...I'm not really a very up-to-date person so er (laughs), I do not, I do not really know what Twitter does except people follow people around I think, that's as far as I've got... [T1-QOL-09]*

Indeed, it seemed as if the amount of discussion in the media about Twitter was in some cases harming its ability to attract this age group toward making use of it:

*P: ...like Radio 1 are always going on about it, 'Oh we've got so many followers'. I'm not really bothered about what Radio 1 are doing in their spare time... [T1-QOL-08]*

although one interviewee had decided to leave Facebook and use Twitter instead. In terms of usage, some were using Twitter as a news source, whilst others used it as a tool to alleviate boredom:

*P: ...whereas Twitter's just, just have a quick flick through if I'm, just if I'm bored or something...*

*I: And you're not tweeting yourself, you do not...*

*P: Every now and then, but hardly... [T1-QOL-05]*

Significantly, none seemed particularly keen on tweeting about themselves and some mentioned the problem of having too much information being tweeted at them by too many people. This was similar to the Facebook phenomenon of too many people being available on the site to link up with, causing them to exert tight controls on what they looked at and who they followed:

*P: ...when I use Twitter, I've got so much going through there I blank half of it... [T1-QOL-01]*

Even with these caveats, Twitter proved to be a popular suggestion for integrating with support for their condition in preference to Facebook, when the functionality and possibilities were discussed.

Podcasts were a less popular form of social media, utilised by a few interviewees. Some were not interested in them due to their lack of appeal, or, sometimes this might be due to another factor - such as a pre-existing condition like Asperger's - which made them difficult to use:

*P: ...I kind of just feel sort of really awkward listening to people talking on radio's sometimes...that's probably the Asperger's... [T1-QOL-02]*

Where participants mentioned using them, the flexibility of accessing podcasts at particular moments (like during a gym session or whilst travelling to a location via public transport) was discussed as a benefit:

*P: Even like a podcast, 'cos erm, often I download a lot of podcasts and listen to them like, on the way to Uni or in the gym and stuff so even something like that, um, and 'cos you're doing something whilst listening to it, it does not feel like you're taking the time out... [T1-QOL-04]*

As was the attraction of listening to something that could be either informative or entertaining:

*P: I normally listen to comedies (laughs)... [T1-QOL-03]*

This was mentioned as a positive reason for accessing them that might be able to enhance QOL. Their low production costs in comparison to videos made sense as a cost-effective and useful means of providing information in an attractive, alternative format to text based materials.

Perhaps surprisingly, YouTube did not feature quite as widely as might have been expected in terms of usage within this age group (both for viewing and lifecasting) as

suggested by the literature (see **2.4.3**). Where it was used, the preference of some interviewees for looking at step-by-step instructions was mentioned as a benefit, but none had looked at injection videos as they all felt comfortable with this procedure (see **4.1.2**). Like podcasts, some users had pre-existing conditions, which made viewing online videos difficult, whilst others were only interested in viewing entertainment media like music videos or viral crazes rather than health videos. The ubiquity of YouTube and the ability of anyone to be able to post up their own videos acted as a negative aspect for some:

*P: When you watch YouTube, you see the ridiculous videos of people on there, because they've got a really good base idea but they've just gone too flamboyant or too over the top with it to try and make it more than what it actually is, and I would not want some sort of half-witted American on there telling me about it because it would just irritate me more than grab my attention if you see what I mean... [T1-QOL-08]*

But the ability to view video content from YouTube on a number of different mobile devices had proved to be popular and useful for some interviewees:

*P: You can have it on YouTube as well, 'cos it had YouTube on the iPod Touch and view YouTube videos about it...*

*I: Were they sort of just talking heads?*

*P: Yeah, pretty much... [T1-QOL-04]*

25% of global YouTube views now come from mobile devices with viewing traffic from mobile devices tripling in 2011 (YouTube 2013b) - although maybe not offering the same low cost flexibility as podcasts do for potential new innovations. The other factor to note concerned interviewees expressing no great preference for watching video information instead of listening to just audio information. This suggests the extra costs of visual production would not offer many additional benefits to this age group.

The general theory concerning web 2.0 and social media (see **2.4.1**) suggests that it facilitates and encourages use and collaboration. For example, a study by Greene et al. (2011) identified the fifteen largest Facebook groups focused on diabetes management,

with their findings suggesting that diabetes communities in Facebook contained a plurality of participants with divergent interests and modes of communication. These groups simultaneously acted as promotional spaces, support communities and venues for the solicitation and provision of forms of disease management-knowledge - not necessarily available through more formal channels of professional consultation. So, it is in stark contrast to find that there are a variety of reasons why this age group do not always feel inclined to use every form of social media as a mechanism for obtaining information and support for their condition. It might be that certain character aspects - personal feelings and traits - limit them from interacting in some online environments with people they do not know:

*P: ...I'm kind of very shy and I do not really like going onto Internet things... [T1-QOL-02]*

Or, they might have conditions precluding certain areas of online activity. Some interviewees preferred to be interacting with professionals rather than individuals who might not have the medical training to assist with their enquiry. Effectively, not wishing to engage with people from an empathetic or helpful viewpoint, but making sure they received the correct information from health professionals:

*P: I mean, it's more people's opinions is not it? And, rather than, I do not know, if I'm going on there to look for something that I want help with, I suppose I'd rather a more professional view... [T1-QOL-05]*

Regarding their use of Facebook, some interviewees only wanted to use its forums for talking to friends about their life outside of type 1 diabetes, rather than using it for diabetes related searches and group discussions. This is the technological equivalent of Williams (2000) findings on how diabetes is sometimes kept separate from social identity. Given the literature review (see 2.4.6), which suggests that younger age groups are more likely to engage with new social networking products, it is instructive to note that not all interviewees were drawn to engage with new products and tools if they did not directly appeal to them:



*I: And is there a reason why you're not sort of really paid much attention to Twitter.*

*P: Um, I'm just not a, I just do not really find it that um, interesting. I think it's....I think the whole notion of it's a little bit strange to be honest. Like, I just never really felt the need to get an account done... [T1-QOL-06]*

This means that careful consideration must be given to the method and means of providing or developing new technological tools for support, education, or self-management.

#### **4.1.6 Theme 5 – Mobile Technology**

The fifth theme - *Mobile Technology* - concerns how a young adult with type 1 diabetes interacts with the various pieces of mobile technology that they own - such as mobile phones, tablets and mp3 players. This theme is important as it serves to highlight the immense impact this technology is having on their daily lifestyle; how it is changing their use of other technologies; and how these new patterns of usage might be integrated with innovations which could help to improve their QOL from diagnosis onwards.

The age when most interviewees obtained their first mobile phone was quite young in comparison to previous generations:

*P: Be about 12, 10... [T1-QOL-01]*

On average, around the beginning of their teenage years, although some interviewees had obtained them even earlier - sometimes from as young as nine:

*P: I think I was about nine or ten, when I got mine... [T1-QOL-05].*

Reasons given for obtaining phones at a young age included security concerns from a parental viewpoint and that during adolescence this was likely to be the most popular gift suggestion for celebratory presents. The age that interviewees received their first phone is interesting as it shows that from an increasingly young age interviewees were cognescent of and were happy to use this technology regularly within their daily lives, as with the Internet (see 4.1.5).

As most interviewees had grown up with a mobile phone (accumulating nearly ten years cumulative use by the time that they reached eighteen), it is unsurprising that it had become so closely integrated with them. Becoming almost like an extended part of the body to many users of this generation:

*P: ...because I was not carrying the book around with me whereas with my phone...it's always with me wherever I go... [T1-QOL-05]*

From a young age it had been their constant companion; accompanying them in their younger days at play through to school, university and work use. Consequently they were less likely to forget to take it with them in comparison to anything related to their condition - such as insulin. They were also more likely to be using it when travelling - either on public transport or whilst driving by plugging it into the radio; at home and work; and as a social tool:

*I: And you said you always remember your insulin. How about your phone. Do you always remember your phone? Do you forget your phone?*

*P: Yeah, I've always got my phone with me... [T1-QOL-03]*

The mobile phone is thus proving to be an ever more attractive option for thinking of, in terms of utilisation for diabetes related functionality. In some cases, its closeness to the interviewee had already led to it being used innovatively in relation to their condition - such as utilising the alarm functionality to remind them to take their medication:

*P: I put alarms on to remind me to do my insulin... [T1-QOL-09]*

This unique closeness and relationship with the interviewees, makes it an ideal tool for utilising in terms of innovative type 1 diabetes education, self-management and support provision.

Patterns of mobile phone ownership displayed by interviewees mirrored the historical sales trends of the phone manufacturers quite closely. Most had started with a Nokia as their first mobile phone, as Nokia was the market leader during the nineties prior to

smartphones being launched. The functionality available at this stage was usually just SMS text messaging and the ability to make calls. These early phones brought back fond memories, particularly concerning their ruggedness and design, which had not been carried over into newer smartphone design:

***P:** ...it was a Nokia, it was, it still had a black and white screen, was, and had an outer shell that was made out of rubber, so you could just basically throw it against the wall and it would survive... [T1-QOL-02].*

Most interviewees had persisted with Nokia through their first few mobile handsets into the early stages of the smartphone revolution, when their market share had started to erode and when Internet functionality had started to become more widespread - but notably before the introduction of apps in 2007. Only a couple of interviewees were still using Nokia mobile phones now, whilst most had moved to other brands - a trend also mirrored in the current marketplace.

As Nokia was to the nineties, in the eyes of interviewees the Apple iPhone was now deemed to be the phone of choice and on the wish list of most of those who did not currently own one. This might be due to parental factors or the perception that it was currently the best phone on the market. Unfortunately, for some, the cost of ownership was too prohibitive:

***P:** Well I did want an iPhone (laughs) but I could not afford it... [T1-QOL-03]*

But in some cases the cost was deemed to be acceptable in preference to issues experienced with their current phone. RIM, the makers of Blackberry and their phone problems being highlighted on numerous occasions. Use of an iPhone by their friends and partners had also proved to be a factor in wanting to obtain one:

***P:** ...my friend had an iPhone and I'd sort of used um, his a lot and I really liked it. Like I liked the way it text and things... [T1-QOL-09]*

Allowing them to see at close hand how good it would be as a replacement phone. Apps – the perceived quality of and the numbers available to buy - were also mentioned as a factor for wanting to switch to an iPhone from other manufacturers:

*P: ...well [name] (her partner) had an iPhone and then I could go onto iTunes and they've got better apps on there... [T1-QOL-05]*

Generally, problems reported with the iPhone tended to be minimal, but focused on the fragile nature of newer models - contrasting with the more durable nature of mobile phones of the past. Interestingly, interviewees who owned the iPhone also noted that it had gradually started to replace other electronic devices that they owned - like mp3 players, laptops, cameras and paper based media like diaries:

*P: Although now I've got my phone, that's replaced my laptop... [T1-QOL-08].*

Most interviewees said that they also owned mp3 players - in most cases purchased before owning a smartphone - with the Apple iPod in its various models proving to be the most popular. The iPod classic is a straightforward music player, which does not allow apps to be used on it, whilst the iPod Nano is a smaller and cheaper version of the iPod classic with a tiny screen. Again, this just allows music and video to be played, but also offers a lower cost entry point to the world of Apple products. The iPod Touch in its latest design offers the same functionality as an iPhone, except for the lack of phone functionality. This device allows Internet access through an integrated web browser and music and apps to also be used, as it employs similar touchscreen technology to an iPhone. This allowed it be used by some interviewees as a replacement for quick, casual Internet access through a PC or laptop:

*P: ... my Touch is mostly used as like a, er, back up Internet...*

*I: Right...*

*P: Say if I'm, like if my Internet's not working if I'm playing a game on my computer that like takes up the whole screen and it's hard to stay in touch with everyone or it's, or it's used as an alarm clock and sometimes used as an oven timer as well... [T1-QOL-02]*

Consequently, it is possible to view the iPod Touch as a low cost way of accessing the Internet on the move or at home. One interviewee had actually used this on the night before their diagnosis with type 1 (see 4.1.5). However, another interviewee had not used the Internet functionality on their device and there were also issues mentioned concerning the difficulty of charging it and the problem of the battery draining down too quickly - depending on which functions were being used. Summarising, it seems that the historical use of iPod's in their various guises (including the iPod Touch) might in some cases have helped to increase the attractiveness of the iPhone to this generation, based on the functionality and technology on display:

*P: Yeah, but my iPod Touch it's always, um, its always been like, really like works with my fingers and so on... [T1-QOL-02]*

Although interestingly, most wanted to own both devices rather than making do with one or the other.

As a relatively new device (launched in the UK during 2010), Apple's iPad was only mentioned in two interviews; but in both cases interviewees also owned a laptop and a smartphone. This caused some interesting reflections on how they made use of each device during the day in different circumstances and locations:

*P: ...it depends what I want to do. If I just want to say if I want to check my Facebook status and my laptops off then I'll use my iPad but if I want to search something on the Internet then I'll probably go on the computer If I get a document up then I'll do it on the computer because its quicker and easier... [T1-QOL-01]*

As the iPad continues to be upgraded with additional free software updates and features, its preference over the laptop as a way of consuming and accessing social media, music and games seems to be increasing. It also seems that the iPad's popularity - as opposed to using a laptop - is continuing to grow. From a practical point of view the size of the iPad precluded its use in as many situations as a mobile phone, but made it more popular than using a laptop:

*I: ...do you bring it to Uni much?*

*P: Yeah (laughs), I've got like a keyboard for it...*

*I: Right.*

*P: ...so I'll use it for lectures because it's just really easy to carry around than the laptop... [T1-QOL-04]*

However, in terms of using an iPhone and iPad regularly together, this could cause problems when accessing apps where information was situated separately on both devices.

Although other mobile devices were discussed, Amazon's Kindle Fire (launched in the UK during 2012) is notable:

*I: ...have you been tempted to get a tablet at all?*

*P: Erm, I'd like to get a Kindle actually, I'm just waiting for the particular one to get released that I wanted.*

*I: Is that a Kindle Fire?*

*P: Yeah. [T1-QOL-06]*

This shows that there are alternatives to the iPad in the tablet market, which might become more popular over time and win a larger percentage of market share.

It is very instructive to historically analyse the pattern of mobile phone and other mobile device usage from the data and look at the trends, which might be able to point to the best way of implementing successful new innovations for this age group. Ensuring that any technological solutions are relatively future proof in terms of mobile devices by adopting cross-platform solutions. The continual launch of new products like the Kindle Fire serve as a timely reminder that the popularity of different mobile devices will continue to rise and fall and that successful present performance in the marketplace might not always carry forward into the future. Also, not every user in this age group will own similar mobile technology and some might want to access tools on multiple mobile devices, depending on their needs, location and activity. As a result, any new mobile intervention should ideally be implemented across multiple platforms and different mobile

devices, to be able to reach the largest target audience of young adult users - whose technology desires it must be remembered will continue to wax and wane in the future.

The length of time each mobile phone is kept for has tended to fluctuate downwards recently as handsets have become increasingly cheaper and have come to be viewed by interviewees as interchangeable - fashion items that could be regularly replaced by something newer:

*P: I'd say I got a new phone once every year... [T1-QOL-05]*

Peer pressure to keep up with friends as they grew older seemed to be an issue, which had forced some to change their phones - rather than from their own needs or an awareness of beneficial technological enhancements to themselves and their condition:

*P: I'd probably still be on my Nokia 3310 if other people had not like, made me change... [T1-QOL-09]*

In one case, a friend had provided their old cast-off phones to help an interviewee keep updated. This had allowed them to avoid ever having to purchase a mobile phone. Cost was acknowledged as a factor, but occasionally even though there was an acceptance that something was expensive, this did not always preclude the purchase of the smartphone in question. Similarly, the cost of buying themselves out of a contract, or, forfeiting money once a phone had been lost but was not insured, did not stop interviewees from changing providers or upgrading to a newer model ahead of the end of their contract period. However, some interviewees had a more pragmatic view on when they would upgrade, based on price sensitivity:

*P: I would not see the point in spending the extra money unnecessarily, because at the end of the day they all pretty much work the same, I mean, they'll have a slight change in software... [T1-QOL-08]*

Perhaps surprisingly, the majority of interviewees had come late to the smartphone revolution, being slower to take up Internet use on their phone and to start making use of apps:

*P: Internet and Apps is only really recently started in the last couple of years...  
[T1-QOL-06]*

Reasons given for this included the length of time taken to move to a phone which had this functionality on it and contract vagaries, which also played a part in limiting usage:

*I: So you were paying every, every time you accessed the Internet. You were paying for...*

*P: I was paying for it. Yeah... [T1-QOL-08]*

Basic plans consisted of SMS text message and calling packages, whilst the extra cost of adding an Internet package had initially proved financially unfeasible for most interviewees, unless they were working:

*P: I think my current phone technically has Internet connectivity but I do not have a package to pay for it at the moment. [T1-QOL-02]*

Some of these issues were still being mentioned as current barriers to use by some of the interviewees. It would be easy to conclude that all young adults will have access to the latest smartphone technology for accessing the Internet and apps, but this might not always be the case. This is an important factor to consider when deciding if a mobile solution is the best format for this age group and whether providing alternate methods of access to the same information might also need to be considered - as contingency for those without access to the latest technology.

#### **4.1.7 Theme 6 – Mobile Apps and Health Apps**

The sixth theme - *Mobile Apps and Health Apps* - concerns how a young adult with type 1 diabetes interacts with mobile app technology that they use in relation to social, work and educational use and also for potential health uses linked to their condition. This theme is important as it serves to highlight how this relatively nascent technology is already being utilised in some cases in relation to type 1 diabetes. It also highlights how it could be used in the future to support a range of self-management, educational and



supportive tools, which could be integrated within specific lifestyles, locations and moments to help to improve aspects of living with the condition from diagnosis onwards.

Generic apps downloaded by interviewees included those that made one-to-one communication easier, such as chat clients. Notable downloads also included popular utilities like eBay - for buying and selling items - apps related to specific mobile phone providers and shopping apps like the Trainline for buying cheap rail tickets. Games and voucher code apps also proved popular, whilst good quality educational apps had proven more difficult to find. What is noticeable about the majority of these apps is that when initially discussing them, interviewees tended to concentrate on the apps they used for entertainment and pleasurable lifestyle functions rather than focusing on more serious subjects like business, finance or most importantly for this present research, health and fitness. For the majority of interviewees, apps were a recent development even though they had initially launched in 2007 (see **2.5.3**). Some interviewees had not made much use of them:

*P: I've only just started using apps, I was not really, I'd never used them before, er, about a year ago... [T1-QOL-06]*

One of the reasons for this was financial and a reluctance on their part to download them, because they were concerned about the implications of initiating an account. Or, because there was a reluctance to pay for an Internet connection as a part of a mobile phone contract (see **4.1.6**). If cost was not an issue, it is important to note that for some users this would have made them more likely to engage with using apps relating to their condition:

*I: ... if cost was no option do you think you'd prefer to do that on a phone or, or do, could you see it might be handy to do that or...*

*P: Yeah, it could be actually, 'cos then like you could do it on the go...rather than having to wait until you got home... [T1-QOL-07]*

Another reluctance to download was based on the frivolous time wasting nature of some apps. Interestingly, there was a keen awareness by interviewees that some apps could only be used effectively within the range of an Internet or wireless signal. Finally, across

different mobile devices (such as a phone and a tablet), app use followed similar patterns with the same apps being predominantly accessed on both.

Different app stores provoked a wide range of responses amongst interviewees with Apple's App Store garnering the most positive comments, whilst mirroring current commercial woes (see 4.1.6), RIM's Blackberry App Store was particularly criticised:

*I: ...Blackberry App World did you make much use of that?*

*P: No, it was rubbish... [T1-QOL-04]*

This included problems with the App Store app on the mobile phone - which kept deleting itself - and also included problems with speed, the poor interface of the search facility and difficulties when attempting to select and download apps. With Windows phone, the low number of available apps in comparison to other stores was mentioned as an issue, although in this case the interviewee had still gone ahead with the purchase of a Windows phone, even though they had highlighted this as an issue of concern.

When the cost of apps was discussed, the general feeling was that although some interviewees would pay whatever an app cost if they really wanted it, a ceiling of £ 3.99p was their preferred upper limit. The system that a company like Apple applies where gift vouchers can be loaded onto an account - in effect, a form of store credit - is key here:

*I: ...that did not put you off, price?*

*P: No, not necessary, no. Because I got some iTunes vouchers as gifts anyway... [T1-QOL-05]*

This system allows specific amounts of money to float on a personal account, which can then be used to purchase items on a whim. This is almost akin to making the account holder forget that it is real money they are using for purchases. In addition to the fully functioning paid version, a number of apps are also provided in *Lite* (free) versions. This allows users to try them out before they buy them - although usually with less features present than in the paid equivalent:

*P: Because if there's like a free app and a paid app I would not just go for the fr – I'd download the free app straight away but then I'd see how good it is, because if it's bad I'll go and look at the paid app...*

*I: Yeah*

*P: And normally the paid apps are slightly better and I probably would go for the paid app... [T1-QOL-01]*

This system was a feature which several interviewees had made use of. For example, the Carbs & Cals Lite app (2013) allowed users to try out a sample version with a limited selection of food items included to see if it was useful to them, before they paid for the full version:

*P: I downloaded the Lite one first and had a look through... [T1-QOL-05]*

Using the Apple Store as an example, new apps are highlighted for a short time on the home page when they are approved for release, but then gradually drop further down into the deeper recesses of the store as time passes. Recognition at this point is only possible by directly searching for a particular term or name, or by accessing a particular topic. This makes it difficult for apps to remain on display and it seems that as a result, app purchases for this age group tended to be guided more by word of mouth than through the use of the store search facility:

*I: ...and then that's when she said that you can get an app for it on the iPhone, um, and I just took mental note of it because I obviously still had the Blackberry at the time... [T1-QOL-05]*

Apps can also be found via advertising on websites, which then link the user directly to the store, or encourage them to access it through the search facility. The immediacy of the direct store link and the fact that interviewees were always in close proximity to their phone (see 4.1.6), meant that if an app was mentioned or referenced by someone else it could be immediately downloaded. Occasionally this might be due to a stray thought, reflection, or even boredom. In each case, the proximity of the mobile phone made idle enquiries easy to perform, sometimes with successful results:

*P: ...it was just spur of the moment I think, it just came up and I just thought, 'Oh right' and just had a look at what it, what it offered, what types of restaurants and foods were on there... [T1-QOL-06]*

In terms of searching for health-related apps, one of the main problems mentioned with stores other than the Apple Store - where the majority of developers tended to focus their apps initially - was the lack of availability. Although even on the Apple Store, the perceived lack of availability of good quality diabetes apps - at least during exploratory searches - was highlighted:

*P: I do remember having a poke around the medical apps section when I first got it, could not actually find anything... [T1-QOL-02]*

But this had not stopped interviewees from occasionally searching again at a later date, to see if anything new had been released - with later success, as more new apps had gradually been launched over time. Boredom had in some cases proved to be the catalyst for initiating new searches specifically related to health apps:

*P: ...I think just, you know, when you're bored, you're like, oh I wonder what diabetes apps are out there... [T1-QOL-04]*

Again, the proximity of the mobile phone to the user played a part in allowing this to occur, as did remembering previous recommendations from friends once a new phone had been obtained, which had also led them to investigate further. Or in some cases, even by accidental means. Some participants had found it difficult to locate anything that they thought might be of use to them, whilst a minority had no inclination to go searching to see if they could find anything which could be useful to them. These interviewees seemed reasonably non-committal on investigating further, but the majority were more enthusiastic and keen on further exploration. These various patterns of searching through App Stores highlighted several interesting usage trends; most importantly interviewees looked for new apps first by visiting the top 25 list of free apps in the Apple Store, rather than searching specifically by subject. Other times and types of searches suggested that sporadic searches would be carried out on particular areas of interest, which implies that a targeted awareness campaign should be run alongside any mobile

innovation launched with this age group in mind. Whilst the *Metadata* – descriptions and keywords describing the app and its functionality used by store search engines - associated with any app should aim at focusing on the search terms most likely to be used by this age group to help them locate useful products once released.

Carbs & Cals is an easy-to-understand visual guide to carbohydrate and calorie counting in diabetes management. In its book version (Cheyette and Balolia 2013) it contains photos of popular food and drink items, with the carbohydrate and calorific values clearly displayed above each photo. The app version for the iPhone (2013) was released in March 2011, and was the most popular diabetes health-related app mentioned by interviewees. Awareness of this app in comparison to the book was smaller, but it appeared that some interviewees had looked at purchasing the app based on previous use or knowledge of the book (see 4.1.5). Awareness of the book had sometimes been raised by clinic staff, who had also mentioned the availability of the app (see 4.1.4). In some instances the app had proved to be more useful than the book and as with attitudes to other apps, there was a tendency to try out the Lite version prior to purchasing the full version. This allowed interviewees to work out if it would be of any use to them. Replicating the format of the book in a digital format was positively received and usability on a mobile device did not seem to have been compromised with the design:

*I: ...and in terms of that app is it actually just replicating what's in the book?*

*P: Pretty much yeah, but it's a digital and because I've always got my iPad with me in most places, it's a lot easier... [T1-QOL-01]*

The lack of availability of a version for Blackberry was mentioned as a problem at the time of the first interview although a version was subsequently released in July 2012. This had caused the interviewee to download and use the iPhone version instead, as using the website version on their Blackberry had been too slow and time-consuming. This highlights a need for health apps to ideally be made available simultaneously on multiple platforms and, if possible, without requiring a constant mobile connection to the Internet for use. The amount of data provided by Carbs & Cals was positively regarded:

*P: That's been really good because not only does it have things that you'd eat at home, it has um, like takeaways as well, so if you...*

*I: Right*

*P: ...do go out with your friends, and things likes that, you can have a look at the portion sizes, that's really good... [T1-QOL-05]*

and reliability was deemed to be good. But in terms of the data itself, the US focused nature of a lot of the information was negatively perceived. The limited variety of some foods listed in categories like treats was specifically mentioned as lacking much UK specific information and the non-appearance of UK brands was noted:

*P: ...they do not have anything like the normal chocolate bars that we have... [T1-QOL-05]*

There were also problems mentioned with getting the app to work on differing mobile phones and tablets of the same manufacturer - specifically Apple devices.

The Diabetes UK app - the Diabetes UK Tracker (2013) - is designed to be quick and simple to use, taking the chore out of logging daily levels to help users effectively manage their diabetes. Awareness of this app was lower than Carbs & Cals and had only been accessed and used by two interviewees. The app allows a user to track insulin, blood glucose, ketones, carbohydrates, calories, weight and how they feel. For enhancing QOL, this app was favourably compared to some other methods of recording information, but most usage tended to focus on blood glucose tracking rather than on ketones - sometimes because the interviewee was struggling with control. Ease of use was one factor mentioned as to why this particular app was downloaded, with again the proximity of the mobile phone making it an easier way of logging and tracking levels, replacing written logbooks:

*I: Yeah. And I mean are you still keeping your, your erm written diary of readings as well?*

*P: No.*

*I: So did that sort of stop when you, you found the Diabetes App?*

*P: Yeah. [T1-QOL-04]*

However, due to advances in the capabilities of CBGM (see 4.1.3) which had gradually filtered through to interviewees since this app had been launched, a conflict of technological solutions was apparent. This had negatively impacted on the interviewee's use of this app:

*P: And then because they were logged in my testing kit anyway, you can just go back and look through that, so I stopped using that app and just kept it in, in the machine... [T1-QOL-05]*

as the functionality was now duplicated on both the app and their CBGM, causing one interviewee to stop using it. The other major problem discussed by interviewees was the inability to link up their iPhone and iPad versions of the app so that data entered on one was not simultaneously viewable on the other device.

There are a number of different apps available which focus on diet and weight management. *Target Weight* (2012) allows users to track their weight on their iPhone in less than six seconds according to manufacturer claims. One interviewee had downloaded the app, which opens up a personal weight dashboard containing inputs for height and weight, Body Mass Index (BMI) and the target weight, along with the date the target should be achieved by. Ultimately, the incentive to enter information was discretionary, making it difficult for interviewees if they did not have the willpower or inclination to continue to enter data regularly as time passed:

*I: So would you say that had been a sort of a successful app in terms of what you were using it for or ...*

*P: Yeah, if I was to stick to the diet more strictly, then definitely, but...*

*I: Right*

*P: ...I tend to go off track a bit (laughs)... [T1-QOL-05]*

On the plus side, it was deemed to be very easy to use with good instructions, but with limitations on how it could be used effectively.

*My Diet Diary* (2013) was another lifestyle app, which had been downloaded. It featured four main trackers for weight loss and featured similar functionality to *Target Weight*, although highlighting similar problems. The onus was always on the individual to continuously enter data on their lifestyle to get the most out of using it - not always convenient or attractive to do for a less patient younger user:

*P: You'd just be constantly, there's not enough time in the day just to sit there and calculate everything... [T1-QOL-05]*

The convenience of a mobile phone seemed to make it a popular choice for using as a tracking mechanism. But as with any other tracking system, the data needs to be continuously recorded - which for this age group is not a particularly attractive option after the first few days of enthusiasm have waned. One other app (not mentioned by name) was able to provide amounts of carbohydrate in particular foods. It was positively regarded, although it is interesting to note that the interviewee refrained from downloading it again once it had been deleted from their smartphone by accident. This implies that although it was well made, it was not something that was going to be used regularly by the interviewee.

The main benefits mentioned by interviewees of using diabetes apps tended to focus on the possibility of them replacing paper based materials and information – like logbooks (see 4.1.2) and books (see 4.1.5) - which they had previously had to carry around in addition to their diabetes equipment (see 4.1.2). However, current apps, although helpful, were not being used by some:

*P: There is apps on here but I've never used them because they do not seem that good. Just seems like someone in the back shed's made them... [T1-QOL-01]*

This could be due to the cost; the design, flexibility and usefulness of the apps themselves; the lack of a cohesive guiding framework for using them – whether instigated by the clinic or not; or conflicting technological solutions reducing their effectiveness. For example, if a CBGM logged historical blood glucose, what was the point of additionally entering it onto a separate app? Indeed, the lack of a good quality



app for blood glucose monitoring was mentioned by one interviewee specifically. Another mentioned the dearth of many UK specific apps so that the dietary values on those available was slightly different, making them difficult to use effectively. A comment also directed at some of the data held within the Carbs & Cals app. These findings suggest that any mobile app innovation developed should contain up-to-date, country specific, clinically valid information; be free to download; be able to run as a self contained app with only an occasional requirement to link out to the Internet; be integrated with a clinic for promotion, use, impact and quality purposes; should not duplicate existing functionality on existing diabetes technology; be easily visible from within stores; and be made available across multiple stores and operating systems simultaneously for parity of care and ease of access. It should also focus on providing an interface which is simple to use, but contains relevant re-usable information that will be useful over the long-term to this particular user base.

## ***4.2 Sociotechnical Design of App – Undeveloped Ideas***

### **4.2.1 Introduction**

A variety of innovative ideas suggested during qualitative interviewing (T1-QOL-01 to T1-QOL-09) were not able to be taken forward for development as prototypes - the timeline for ideas generation is shown in **Table 2**. In light of my research objectives, in addition to discussing the prototype ideas selected for development in the results (see **4.3** and **4.4**), it is also pertinent to include and reflect on the other ideas and suggestions interviewees had for improving their lifestyle and making a difference in areas of their lives affected by their condition. These ideas are therefore included as an appendix to the main thesis (see **Appendix W**).

## ***4.3 Sociotechnical Design of App – Prototyped Ideas***

### **4.3.1 Introduction**

By seeking suggestions for app development ideas during phase 1 of the qualitative interviewing process (T1-QOL-01 to T1-QOL-04), in collaboration with SWDC staff we

were able to select four ideas for development into prototype apps; from the list of innovative ideas suggested but not currently available in a satisfactory format to interviewees. The timeline for ideas generation is shown in **Table 2**. The four suggestions taken forward were required to meet clinic goals, closely reflect interviewee requirements and comments and also follow local and national NHS guidelines. As an example, patient data could not be recorded by the local hospital where SWDC was located. One of the prototype ideas was not able to be developed beyond the initial pilot stage:

- Twitter and diabetes.

This left three ideas which could be developed into prototype apps. Development of prototypes began in February 2012 (see **Table 2**), with two ideas not progressing beyond the prototype phase:

- Illness and diabetes.
- Hypoglycaemia and diabetes.

The ideas chosen for prototyping but not developed are now discussed.

### **4.3.2 Twitter and Diabetes**

Educause (2007) noted that as with social networking sites, Twitter (see **2.4.2**) lets users create formal friendships, which collectively establish numerous and interconnected networks of users, leading to useful professional or personal connections taking place. Mischaud (2007) felt that in its pure functionality Twitter addressed an innate human desire to converse and be heard. So, it was unsurprising that people had appropriated it to reflect whatever use or style of communication they wanted. Twitter has thus begun to have an interesting impact within novel domains, such as helping during a large-scale fire emergency, providing updates during rioting in Kenya, and supplying live traffic updates to track commuting delays (Krishnamurthy et al. 2008). For people who did not live in the same area Thompson (2007) felt that Twitter created a new channel of communication, as it facilitated a new way of seeing and understanding people. He viewed the real appeal of Twitter as being *Collectivist* - with users creating a shared understanding larger than one person. He saw Twitter and other similar constant-contact

media creating *Social Proprioception* - giving a group of people a sense of itself, making possible co-ordination. Educause (2007) noted that the most common criticism of Twitter was that it enabled inane interaction - tweets which said nothing of importance or relevance. Moreover, as an asynchronous broadcast service, there was no guarantee that any individual tweet would either be read or responded to by somebody. Twitter could also be seen as a distraction for committed users and viewed as an extremely time-consuming past time, with the sheer number of updates - particularly if a user followed a large number of accounts - seen as unwieldy (see 4.1.5). Others have raised concerns over privacy (Financial Times 2007) and its attack on powers of concentration (Pontin 2007). Lavallee (2007) noted that multiple user intentions had led to some users feeling overwhelmed by micro blogging services (see 4.1.5). Java et al. (2007) believed that the ability to categorise friends into different groups would greatly benefit the adoption of micro blogging platforms and that features which could help facilitate conversations and news sharing would be beneficial. Some of this functionality already exists in emerging products like TweetDeck (2013). This is an application which aims to help manage the existing functionality of Twitter, by allowing different customisable sets of users to be grouped together or filtered according to user taste.

In the health domain, Kerr (2011a) suggested that as with other social media there were concerns around confidentiality and security when using Twitter. However, he viewed the concept of a secure micro blogging system for a hospital and surrounding primary care network as having value. It could be used for sending patients reminders, recording the effects of introducing new medicines, following up after discharge from hospital and providing patient to patient support. It could also allow complaints to be dealt with and provide an opportunity for the dissemination of praise - replicating how some larger private companies were using it to interface directly with their customers. At a public health level Kerr (2011a) believed rapid communication with large numbers of people could be quite straightforward for health promotion and during major incidents. In terms of chronic conditions, Hernandez (2008) believed that the biggest value of Twitter was the ability to write short posts about topics that users would not usually feel compelled to blog about (see 4.1.5). In 2007, Scott Hanselman, a prominent technologist, spent time twittering information about his diabetes (2008). He felt the experiment was designed to generate empathy and turn that empathy into action by spreading understanding. Since this event had taken place Hernandez (2008) documented that lots of new users had

found value in Twitter as a logbook-meets-decentralised diabetes community. He believed the platform became more useful as users grew the list of people they followed; since they could learn from what they did to better manage their diabetes. For example, seeing an entry about random blood values every time a user ate potatoes - due to the starch content - could be a tweet which a user could read and learn from. Kerr (2011b) theorised that for the many people living with diabetes, learning about complex treatments and monitoring regimes was particularly daunting. Therefore, limited literacy and numeracy was likely to be an important issue preventing many patients from benefitting from using complex medical technology. Especially if a high numeracy skill level was required, as is the case with the basal bolus regimen (see 4.1.2) or with insulin pump therapy (see 4.1.3). He questioned whether Twitter (or an equivalent technology) could be used to support patient education. Kerr (2011b) also viewed Twitter as having the advantage that information could be shared on two levels: providing a two-way conversation between the group being taught and the wider audience outside; and also as a means of improving the communication processes between health providers and those patients who suffered from low literacy or numeracy levels.

Twitter was suggested as a tool which might provide many benefits to a young adult with type 1 diabetes; either used directly or through integration with other apps. Linking up with others was viewed positively in light of how isolated they sometimes felt (see 4.1.2 and 4.1.4). Linking up to a clinic via Twitter also appealed to participants as a way of keeping in touch; being able to ask general questions; or receiving information on how to cope in more serious circumstances:

*I: ...would you be interested in if you could sort of put a twitter message in to a nurse to say help I do not know do you think you'd need that at all? Can you think of times when you've actually thought oh it'd be great to speak to someone from the clinic?*

*P: Sometimes yeah, especially working out certain foods because even with the app it's quite difficult with some foods... [T1-QOL-01]*

Also, finding out new information on CBGM which had just been released; other technology innovations as they became available; or scientific advances:

*P: I suppose a general Twitter feed could also have stuff like, um I do not know like say, links to I guess if...you keep an eye on stuff like technological stuff if there was like an article that you did not have to pay for about something or like or just mention that there's been like a new type of meter like this come out...*

**[T1-QOL-02]**

Twitter was also suggested as an innovative way of providing generic encouragement to perform daily tasks, such as taking blood sugar readings or by more targeted direct messaging to individuals:

*I: How about if they actually did a direct message to you?*

*P: Yeah, definitely, that could be quite good.*

*I: You'd, you'd be...*

*P: Making it a bit more personal... [T1-QOL-05]*

These could be personally tailored; depending on their preference for receiving information positively or more critically, either within a specific Twitter focused app or as an integrated part of a different app. However, some interviewees were not enamoured of Twitter (see 4.1.5) and did not think that they would make use of a clinic Twitter feed (even though they liked the concept). Whilst others had not consciously connected the two areas together, until it was suggested to them as a possible technical aid for communication and support:

*P: To be honest, I have not ever thought of Twitter and Diabetes linked...*

*I: Right.*

*P: ...I've kind of just never thought of it like that... [T1-QOL-05]*

Without some form of prompting or discussion around the subject, this suggests that not all young adults immediately see each new form of social media as a potential way of being able to improve their QOL (see 4.1.5):

*I: ...is there a reason why you're not sort of really paid much attention to Twitter...*

*P: Um, I'm just not a, I just do not really find it that um, interesting. I think it's....I think the whole notion of it's a little bit strange to be honest. Like, I just never really felt the need to get an account done... [T1-QOL-06]*

So there seemed to be largely great enthusiasm from interviewees concerning making use of Twitter in some way to assist in the management, care and support of their diabetes. However, this idea was not able to progress beyond the initial pilot stage, due to NHS policy requirements at a local level making this particularly difficult to implement effectively.

### **4.3.3 Illness and Diabetes**

If they feel unwell, people with diabetes need to take special care as any illness, even if not specifically related to their diabetes (like the flu) can cause their blood sugar (glucose) level to rise:

*P: ...if [name of family relation] were to get the flu, she'll get the flu for three or four days, flu, a cold or something, be ill for three or four days whereas I'd be ill for, for eight or nine days instead...you know it's a bit of a longer...and my BM6 would be really, really high so I now know that I need to do more insulin, um, drink a lot of water you know, to keep sort of flushing it through kind of thing... [T1-QOL-03]*

The body's natural response to illness is to raise the circulating blood sugar level, but often this means that people with diabetes need to take a higher dose of insulin than usual, rather than reducing the dose or not taking any. Reducing an insulin dose or stopping it altogether can lead to serious problems and often causes *Diabetic Ketoacidosis* (DKA), which requires hospital admission. DKA is a dangerous complication that is caused by a lack of insulin in the body. It occurs when the body is unable to break down glucose, because there is not enough insulin. Instead, it breaks down fat as an alternative source of fuel. This causes a build-up of a by-product known as *Ketones*, which disrupts the metabolism. The more ketones produced, the more ill a person with DKA becomes and left untreated potentially fatal complications can occur (NHS Choices 2011a). Parents and carers of people with type 1 diabetes must therefore

be aware of the general principles of sick-day rules and local arrangements for seeking help and support (Dromgoole 2005).

Interviewees suggested that illness information provided on a mobile format would be positively received and utilised. The reasons given included changes in guidance for what precautions to take when ill not being passed to them:

*P: So that when I feel ill, what to do. Cos like the guidance has changed like I was ill not long ago and I was told when I'm ill and I'm not in do not take one of my injections now I've been told that I've got to take it. The guidance like that was changed somewhere and basically it's been like that for all the time but we were told something completely different... [T1-QOL-01]*

This would also help to minimise the problems of receiving differing - seemingly contradictory - advice from different parts of the health service over time (see 4.1.4). Covering what to do if a user was sick - including changes to the injection regime they undertook, or, giving details on specific minor illness related issues:

*P: ...the sort of things I guess people could do with knowing is when you're ill, like if you get athlete's foot or something someone's like oh you know that's 'cos of your diabetes. Well I've never been told that so I would not of known that, you know, and it does not just come up on Google like oh you know what you can expect from being diabetic or why that headache is because you've got diabetes. Like everything is always..."oh that's because of your diabetes" and you think well I would not have known that until this happened... [T1-QOL-03]*

Through to more serious issues associated with illness like DKA:

*P: ...if you get er ketonic acidosis or something and you're in hospital with it like how do you deal with that? [T1-QOL-03]*

In fact, some interviewees considered that how they accessed an app would vary depending on the illness or condition they were experiencing at the time; making it more personalised, which they could then tailor to their particular informational needs at the

time of access. It was felt by some interviewees that this information would have been very useful to have been given at a younger age after diagnosis, when they were unsure as to what they needed to do. Rather than at an older age, where they were more confident and practised with managing their condition when ill:

*P: ...but then I suppose once you have got ill, after a couple of times you know, you're more aware of your own body... [T1-QOL-05]*

#### **4.3.4 Hypoglycaemia and Diabetes**

Hypoglycaemia means having an abnormally low level of sugar (glucose) in the blood. When a person with type 1 diabetes has a glucose level that is too low, their body does not have enough energy to carry out its activities - known more commonly as a *Hypo*. Most people will have some warning that their blood glucose levels are too low or are going low, which will give them time to correct them. Symptoms usually occur when blood sugar levels drop under 4 millimoles per litre (mmol). Typical early warning signs are feeling hungry, trembling or shakiness and sweating (NHS Choices 2011b). In more severe cases there can also be confusion and difficulty concentrating:

*P: And I was hypo-ing, not in best control of my emotions anyway, plus panicking, plus not just thinking properly... [T1-QOL-02]*

It is also possible for hypoglycaemia to occur during sleep, which can cause excessive sweating, disturbed sleep and the patient feeling tired and confused upon waking (NHS Choices 2011b).

An app which provided information on what to do for interviewees and advice on what friends, family, work colleagues, school staff and other people who might come into contact with the young adult should do, were amongst the suggestions received on this subject:

*P: ... if you've got like a friend and you're not really in a state, a friend who would, even if they know what to do but they've kind of gone out of what they need to do like not having any juice on hand... [T1-QOL-02]*



The main concern expressed was the ability to pass on information on what to do (if someone went into a hypo) to a friend or colleague, that they could then use if required and, if the interviewee was not in a position to tell them:

*P: ...I'm quite happy to talk but if there was something on an app that made it clearer. I think it would be quite useful to, to show them, or tell them that they can read it themselves... [T1-QOL-06]*

Something which could be quickly consulted at the time of the hypo; advising the reader on what they could give to the person to alleviate their symptoms. Or beforehand, which had all of the relevant information contained within it, in a clear and concise manner; including the stages which could lead to a hypo. Many troubling experiences were documented by interviewees regarding instances in their life when people with them had not known what to do, or who had exhibited extremely poor knowledge on the differences between type 1 and type 2 diabetes:

*P(S): The teachers, all the teachers in different lessons do assume. They tell people that people get diabetes because they're fat. And that's only the other type of diabetes you know, but it's not even causes that either... [T1-QOL-03]*

In some cases this had resulted in a worsening of symptoms for an individual, which could have been prevented without the need for calling for an ambulance:

*P(S): Because there was a child in my year who was diabetic. He had a ...went low and went completely unconscious. They did not. He stopped fitting. He was past the point of fitting and went completely out, unconscious, out cold and they did not know what to do at all so they got an ambulance out and everything but they could have prevented that... [T1-QOL-03]*

In another incident, this had nearly had fatal consequences:

*P: When I was ten I was on a school trip and erm (laughs) and we were not allowed our lunch like on a normal time so obviously I was going a bit low and I tried to say I need some food I need some food but I was not allowed any. I do*

*not think the teacher was being harsh or anything I just think it was just you know let's walk through the museum and then we can have it. And then I obviously went into quite a bad hypo and I walked in front of a car, like completely out of my own control, um, and it was only that one of the helpers, her sister was diabetic and she said "oh flippin eck" you know "like this is not, you'll have to give her some food now"... [T1-QOL-03]*

This app could quickly highlight that the individual had type 1 diabetes as this information might be available but in a difficult to access location, or not be visible at all - as young adults no longer tend to wear bracelets advising of this fact (see **Appendix W**). It might also help to resolve the confusion that might occur due to some of the symptoms of hypoglycaemia, which can be confused with other conditions like drunkenness:

*P: Because quite often you can confuse someone who's having a hypo with someone who's really drunk because you're so, um, you know you would think what the hell is wrong with that person... [T1-QOL-03]*

It might contain information on the correct procedures to follow in the case of minor and more major hypoglycaemic episodes and what not to do. It could also mention some of the particular problems which might occur concerning the person having the hypo. These include changes to their behaviour (like resisting help or becoming aggressive), which the person helping might not be expecting or used to experiencing. Especially, if the hypo occurred suddenly and without warning to a close friend in situations where they might not have come across this happening before (like on a night out). Or, who might not have absorbed the initial information from their friend on what to do when it actually happened:

*P: I think sometimes it's quite hard to like explain to people about hypo's and stuff and also they do not always take it in. 'Cos if they have not done and it happens then (laughs)... [T1-QOL-07]*

However, some interviewees were less comfortable with this approach to giving information out. They felt that discussing the situation via a discreet, personal chat would be preferable:

*P: ...I mean I'm quite comfortable with, I'm quite happy with what I know and how to deal with, when I get an illness or have a hypo, so... [T1-QOL-05]*

and that giving someone an app to read which told them what to do would be almost socially inappropriate:

*P: I think...you cannot just go to someone...“Here, read this, this is what you have to do to look after me if something happens”, it's not their responsibility to look after you, I mean, if it came to it then, obviously they'd have to act but... [T1-QOL-04]*

This is surprising, given that this is exactly the same as the interviewee telling them what to do in person; but reflected their confidence in their friends' abilities to know what to do at the time if required. Although it could also possibly reflect their belief (see 4.1.2) that they were invulnerable from harm, due to the nature of their ego (Lamb 2012). However, most interviewees regarded this app idea very positively; as something which could be a really useful back-up mechanism for support for themselves and their friends and family and other non-health professionals they might meet.

## **4.4 Sociotechnical Design of App – Developed Idea**

### **4.4.1 Introduction**

One of the prototype ideas – an alcohol education guide - was subsequently selected by interviewees during phase 2 of the qualitative interviewing process (T1-QOL-05 to T1-QOL-09), to be taken forward for development and then released. Phase 2 interviewing of these participants (T1-QOL-05 to T1-QOL-09) and SWDC staff (QR01 to QR05) also enabled the collection of user feedback before launch. Phase 3 of the qualitative interviewing process (T1-QOL-10 to T1-QOL-20) obtained different, external user feedback post launch. The timeline for development, collecting feedback prior to implementation and launching is shown in **Table 2**. The timeline for collecting post launch feedback is shown in **Table 3**. In all of the phase 2 interviews ( $n=5$ ), this

prototype was chosen as the app most closely aligned with participant lifestyles; the one which they wanted to explore in more depth; and the one which interviewees viewed as being the most useful to them. They could also envisage using this app immediately - and some would have made use of it in the past if it had been available to them (*principle of Compatibility*). The developed idea and feedback obtained about it during and after the developmental process will now be discussed.

#### **4.4.2 Alcohol and Diabetes**

It is recommended that general advice about safe alcohol intake be applied to people with diabetes (Diabetes UK 2011b). Whilst people with the condition tend to drink less than others (Martínez-Aguayo et al. 2007), approximately 26% of adolescents with type 1 diabetes reported ongoing or sustained alcohol use (Glasgow et al. 1991). The potential and severity of harm associated with alcohol use is higher in people with diabetes. In addition to the range of physical, psychological and social harms experienced by all, there are specific effects of alcohol on diabetes and glycaemic control (Barnard et al. 2012). Alcohol may have a directly adverse effect on diabetes control; lowering levels of self-management (forgetting to inject insulin or monitor blood glucose levels), or, engaging in risky behaviours (Ramchandani et al. 2000). Which, in turn, may have a negative impact on diabetes control, QOL and risk of depression (Hislop et al. 2008). Acute alcohol ingestion can induce an altered state of consciousness, resulting in reduced diabetes self-care (Barnard et al. 2012). Other diabetes-related health risks associated with alcohol include increased *Glucose Lability* (Hislop et al. 2008), Hypoglycaemia (Nilsson et al. 1988; Turner et al. 2001) and DKA (Scaramuzza et al. 2010). In their study of trends in mortality amongst people with type 1 diabetes, an alarming finding by Harjutsalo et al. (2011) was that short and long term trends showed an increase in the standardised mortality ratios in people diagnosed between 15 and 29 years of age. The increase in mortality was due to an increase in alcohol and drug related mortality and acute complications; highlighting the importance of permanent, long lasting patient-doctor-nurse relationships, close supervision, and guidance on the short and long term effects of alcohol in young adults with type 1 diabetes, especially within alcohol permissive cultures.

Some interviewees were only occasional drinkers, which allowed them to avoid the negative symptoms usually associated with drinking heavily:

*P: I've only been hung-over once. I did not really notice a difference... [T1-QOL-07]*

However, others had experienced problems:

*I: There's been times?*

*P: ... (laughs)... Yeah. I did end up in hospital, um, 'cos of alcohol and ketones... [T1-QOL-04]*

In part, caused by the lifestyle choices available to them. For example, the university culture which might encourage some to continuously go on nights out and drink to excess during their initial years of study:

*I: I suppose it must be really difficult to be a student, erm, and actually have to manage this as well...*

*P: Yeah (laughs)...*

*I: ...because they do not, those lifestyles do not always...*

*P: No, they do not always mix very well at all. No... [T1-QOL-04]*

Interviewees suggested that they would find a guide about alcohol limits to be particularly useful on a night out - where it could be accessed via a mobile device; whether they were an occasional drinker or more of a more seasoned or adventurous one. This information was deemed to be very handy to have to hand by interviewees, for general information on alcohol and how that impacted on what they were doing on a night out (such as dancing in a club). The amount of different drinks available coupled with the now restrictive approach required once a positive diagnosis had been made (especially if at a later age), could lead to confusion surrounding what could be drunk and in what quantities. This led to some interviewees guessing at the time that they were drinking the amount of alcohol in particular drinks and how that might subsequently affect them:

*P: ...an app that explained what the each alcohol would do to you maybe. Because some alcohols have sugar in therefore they'd raise your sugar levels,*

*some alcohols er, have nothing in and can, can quite drastically reduce it if you're, especially if you're dancing as well, so I mean, something that linked maybe like a clubbing, I guess like a clubbing app would be quite useful... [T1-QOL-06]*

Different drinks needed to be approached with caution, such as cocktails and Alco-pops, due to the difficulty of finding out how much alcohol was in them during a night out:

*P: Yeah, that could be quite useful because, like I've found like Alco-pops and stuff, you just like have no idea, like how much is in it or anything... [T1-QOL-07]*

To some interviewees, there was a feeling that certain drinks were now off limits; leading to restrictive feelings as some preferred to avoid having to inject whilst they were out enjoying themselves. Remembering information from the clinic (see 4.1.3) seemed to be a problem which was highlighted at a young age:

*I: ...have they actually said at the clinic what you're, what they give, give you some ideas about what you should and should not be drinking if you are drinking, in terms of different types of drinks or...*

*P: Erm (thinking), they probably have, perhaps I did not listen... (Laughs)... [T1-QOL-07]*

Whether about the drinks themselves, or how they might impact on other potential activities during a night out. This might include dancing or other parts of the clubbing experience such as the consequences of drinking promotional drinks and shots, which might not have been highlighted beforehand:

*P: ...it's quite difficult when you've been diagnosed, especially if you've been drinking before, like what what...what each one will do, you know cider, beer, there's loads, and it would be nice to know what has, what has sugar in, what does not and something like that... [T1-QOL-06]*

Through to what they should ideally be eating at the end of a night out. This information not being available to hand at the time they needed it on a night out:

*I: ...did you know with Martini, what um, what you should do with Martini? Or did you just have a, a guess initially when you drink it...*

*P: Yeah. I just, just guessed. [T1-QOL-09]*

In terms of alcohol education, they would prefer to hear about the information individually rather than in groups. This is due to the personal nature of the subject being discussed and the likelihood that different young adult lifestyle choices (in terms of how much and how regularly they drunk), would impact on the response in terms of support (see 4.1.4). This being more likely to occur between eighteen (or even younger) and into their early twenties, as their ideas about control and general good practice concerning alcohol intake evolved to become more mature and measured (Lamb 2012). Personalised information could then be accessed at a time convenient to themselves:

*I: Right. Do you think you'd listen to that before you went out for a night?*

*P: No! (laughs)...I'd probably listen to it the next day (laughs)... [T1-QOL-04]*

With the information being provided as either text or audio depending on their personal preference for information distribution:

*P: I would not go out of my way to make sure I had it on my phone. But if, if I needed it then, yeah I would use something like this... [T1-QOL-08]*

#### **4.4.3 Prototype Apps - v1.2 (First Iterations)**

Sociotechnical theory has been continually developed and tested since its inception, but throughout its history, its supporters have always attempted to achieve what Mumford (2006) felt were its two most important values: the need to humanise work through the redesign of jobs and democracy at work. In order to realise these goals, the objective of sociotechnical design (see 3.5.4) has always been the joint optimisation of social and technical systems. Mumford (2006) believed that human needs should never be forgotten when technical systems were introduced and that the social and the technical should wherever possible be given an equal weighting. Over the years, this objective has been interpreted in many different ways, but it is still an important design

consideration. Mumford (2006) also suggested that the definition of human needs should come from the employees associated with, and thus affected by, the technology. This meant that democratic and participative communication and decision-making must always be available to give those people a voice. This was why the first stage of my design process was to seek out ideas generated by those who would be using the technological solutions and making use of them in relation to their own condition (*principle of Compatibility*). I needed to ensure that anything developed was actually required by this particular user group and that they would be likely to use anything that was subsequently developed; rather than ignoring or discarding it. This ensured that their human needs affected by the technology would be met, depending upon the base functionality contained within the app developed (*principle of Minimal Critical Specification*). The continual redesign of the app over several iterations with feedback provided by interviewees and SWDC staff during development and by users of the app post launch (*principle of Incompletion*) aimed to create an iteratively valid product for use; whilst acknowledging the continuous process of informational and technological change.

The U-CAIR course is run for people with type 1 diabetes at SWDC (see **4.1.4**). Information on type 1 diabetes and alcohol, illness and hypoglycaemia for the three prototype apps developed (see **4.3** and **4.4.2**) was initially extracted from the core U-CAIR materials. The extraction process took place only after the materials had been examined for consistency and currency by a dietitian at SWDC (*principle of Sociotechnical Criterion* and *principle of Support Congruence*). The information was then ported directly onto the app development platform for individual screen design. Development was initially undertaken on the Apple platform, as this was deemed to be the most popular, stable and structured platform for developing and approving apps at the time of development commencing. It was also viewed as having the most impact on the specified user group, based on discussions during interviews on which phones and other mobile devices the interviewees currently owned or were anticipating upgrading to in the future (*principle of Information Flow*) (see **4.1.6**). Development on Apple could be relatively easily transferred to other operating systems - like Google's Android platform or Windows Phone - as the prototype apps were developed using the PhoneGap architecture. PhoneGap (2013) - also known as *Cordova* - is an open source solution, which allows users to author native apps using web technologies and then deploy them



across multiple platforms via different App Stores. It is an open source implementation of open standards and is free to use, meaning developers can use it in the production of mobile applications that are free, commercial or open source in design.

In April 2012, I was successful in a bid for funding, which allowed for the purchase of two iPod Touches (see 4.1.6). These could be used by interviewees and SWDC staff to evaluate the features and quality of the prototype apps developed and also allowed for the provision of extensive feedback during the development process (*principle of Incompletion*). These devices could be configured so that a prototype app could be installed and piloted on a device without the need for it to be first published through the Apple App Store. This helped to alleviate the risk of a prototype app being published as a live resource, which might contain incorrect or incomplete health information. Also, not all interviewees would have access to the right mobile technology to enable them to test out the prototypes, without the developer being present during testing. The purchase of this equipment allowed richer and more truthful qualitative evaluative data to be collected (*principle of Compatibility*).

#### **4.4.4 Alcohol App Participant Feedback (Pre Launch)**

A percentage of time allocated in latter interviews ( $n=5$ ) concentrated on ascertaining participant feelings on the prototype app most closely aligned to their lifestyle or their attractiveness to it - highlighted by other parts of the interview process - providing high quality, meaningful feedback (see 3.8.2 and 3.8.3). Feedback on the early version of the alcohol app prototype was encouraging in terms of Human–Computer Interaction (HCI) and more specifically the principles of display design (Wickens et al. 2004). The look and feel was positively described in terms of the colours adopted and the balance between colour and monochrome was acceptable (*Avoid absolute judgment limits*):

*P: ...but, you know, the bright colours works well. The blue and white on black's very, you know, it er catches your eye, you do not wanna sort of look at it and think 'Great, this is boring'. It is, it's a good design. I do like that... [T1-QOL-08]*

With the caveat that some individual screens could be tweaked for improvement:

*I: So that's the menu screen...*

*P: Yeah. But then maybe...but if you go into, it just looks like quite a lot of writing. Maybe it needs to be broken up or a bit more colourful or...*

**[T1-QOL-05]**

Legibility of the text was satisfactory (*Make displays legible*) in terms of the colour scheme used and the size of the text. The navigation approach taken (*Top-down processing*) was deemed to be suitable for easy use; with mobile features such as the ability to scroll up and down being appreciated and quickly assimilated and utilised by interviewees during testing:

*I: ...and how about sort of navigating it? Is it alright or is it a bit fiddly?*

*P: Oh no, it's quite clear....* **[T1-QOL-07]**

The test images used in the prototype were thought to be appropriate and pitched at the right level for this age group (*Principle of pictorial realism*) and the speed and response of the prototype was well received (*Minimising information access cost*), compared to other apps interviewees had used:

*P: It's pretty straightforward and fast responding. I, it is...good...* **[T1-QOL-08]**

Layout wise, most interviewees were happy with how individual screen designs were assembled in terms of the content on display (*Replace memory with visual information: knowledge in the world*). Although it was considered by some that specific pieces of information could be further expanded and occasionally the pathway of navigation through different screens needed more clarification. This included some of the details on specific drinks mentioned (requiring additional information on what users should or should not ideally drink), to avoid confusion. Especially regarding potentially difficult drinks like Alco-pops, which were not highlighted as being drinks to avoid, but which seemed to be of particular importance for interviewees to know about:

*P: ...and on the back of some Alco-pops it says um, not suitable for diabetics, I've seen that before...whereas if I did not know that and I kind of come on this app, I think I would think that I could just go out and drink them...* **[T1-QOL-05]**

However, generally the level of information quality was considered to be good; mirroring advice that they had previously received at the clinic and covering most of the areas which they had described as being important on a night out. This included information on what to eat and when to inject:

*P: ...it mentions on here about you can drop low during the night, um, I mean it was actually the doctor here that suggested that I have a small snack before I go to bed to make sure that it sort of allows for you know an evening out so...yeah...I think...this looks like one of the sort of thing's I was saying actually, so it's quite good, hah (laughs)... [T1-QOL-06]*

and other useful advice, such as information on the different alcoholic drinks that they might come across (and might not have tried before) during a night out:

*P: And to be honest, I would not know what to inject for a sherry, I would not know what to do because as a, again, as I said the um, percentage of alcohol in it, affects it, obviously you can read it on the side of the bottle but that does not make any difference... [T1-QOL-08]*

Overall, many comments indicated that it was an app that they would make use of, although for some, more than others.

Additional functionality suggested by interviewees covered a variety of topics, not all of which could be included during the initial development cycles (*principle of Incompletion*). One of which was including information on the carbohydrate levels in certain drinks, in addition to the effects of sugar and other nutritional information. Another additional feature which would have been welcome was the addition of push technology, providing a regular reminder that they needed to take a blood sugar reading instead of relying on friends to remember to remind them at the time:

*P: I think maybe, for your alcohol one, you could like, make it so if you're saying you're going on a night out will like send you reminders to do a blood test every now and again for an hour or so... [T1-QOL-07]*

As was the addition of some audio features to the app. Although adding in podcasts around alcohol (and also illness and hypoglycaemia) had already been planned as an enhancement to be included in the second iteration of prototypes; once clinic staff had found time to record them. However, these podcasts needed to be specifically written for and tailored toward the particular age group likely to be using the app. Some interviewees required information on a wider selection of drinks than was originally listed, such as expanded information on different types of spirits and within this category of drinks, the different types which might be drunk - like different varieties of Schnapps:

*I: ...there's some shorts on there like um, down the bottom (looking at App)...*

*P: Yeah, I've got a couple here, have not I...Tia Maria, Baileys, I mean I guess with the spirits, because obviously something like vodka, and something like Archers, or I suppose it is, um, or like Rum, is there a difference? Like, it would be quite good to split that up... [T1-QOL-06]*

And for some drinks like wine, specifying the differences between particular glass sizes rather than having only one figure for a standard glass:

*P: ...it obviously would be different for different brands and different types of wine and all the different size glasses but it would give you a rough idea... [T1-QOL-09]*

Mirroring the different glass sizes on offer in pubs, clubs and restaurants; this would help to give the user a rough idea of what to expect and consequently what to do as a result.

#### **4.4.5 Alcohol App Staff Feedback (Pre Launch)**

So that I could ensure that from a clinical perspective anything developed met the goals of SWDC and the local hospital, a questionnaire (see **Appendix N**) was distributed to clinic staff ( $n=5$ ) that had first had a chance to try out the prototype apps (see **3.8.4**). This provided another useful feedback loop from questionnaire respondents (QR) on what was being developed (*principle of Incompletion* and *principle of Sociotechnical Criterion*). Feedback obtained from questionnaire responses and suggestions for improvement focused on the need for a better explanation of some of the terms listed within the app - like carbohydrate:

**QR04:** *Better explanation of what is meant by carbohydrate – e.g. give specific examples of what is meant by this...*

Also requiring the clarification of some text statements and rewording others to reduce the risk of information being viewed incorrectly (due to the wrong inference being taken when reading certain sentences):

**QR01:** *Clarify – alcohol contains sugars and will affect blood glucose - some patients will see this as need for insulin, add statement to clarify what's the problem...*

There was also a feeling that the information originally taken from the U-CAIR materials (see 4.4.3) needed to be more carefully adapted and displayed within the app environment. In terms of the different categories used and how they were displayed and split out:

**QR02:** *Interestingly, our written information does not come across as clear or appropriate on an app. The order of a lot of the categories - we should review...*

Also in terms of layout and the different links used:

**QR03:** *I like the idea of an app but felt that the layout/links could be made clearer and lots of the info was the same despite having to find it via many different sub-headings (esp. alcohol app)...*

Like qualitative interviewees (see 4.4.4), SWDC staff felt that the number of different drinks could be expanded upon and also suggested asking interviewees directly how the information on the app should be worded and ordered:

**QR02:** *Ask target audience how they would word information. Look at order, e.g. Alco-pops below port, martini and sherry!*

Something which had taken place in interviews undertaken (see 4.4.4). Overall, they felt the app was generally well designed; but in terms of more content and refinement might benefit from additional clinical team members contributing to the continued development (*principle of Incompletion* and *principle of Sociotechnical Criterion*):

**QR02:** *I think it would be good for us all to review the information...*

#### **4.4.6 Prototype Apps - v1.6 (Second Iterations)**

Adding in new functionality to second prototype iterations concerning podcasts had already been planned as an enhancement, once SWDC staff had written and recorded them. As discussed, feedback from qualitative interviewing also suggested this feature would be appreciated (see 4.4.4). A number of different versions of podcasts were subsequently recorded by the clinical team, with critical feedback being given by myself as an impartial observer - concerning the tone, content, length and quality. This resulted in latter recordings being of a much improved standard and targeted at the correct audience (*principle of Minimal Critical Specification*, *principle of Incompletion* and *principle of Sociotechnical Criterion*). Podcasts were subsequently incorporated into the second iterations of all three prototypes. Some text content was also amended, as it became apparent that once the information was displayed on a mobile screen it needed to be reformatted to make it easier to read and understand (see 4.4.4 and 4.4.5).

#### **4.4.7 Alcohol App - v1.8 (Third Iteration)**

Prior to the initial submission to PALS, a new home screen with revised content was added to focus on the '*Start Safe, Stay Safe*' message, which the clinical team wanted to convey each time a user opened the alcohol app. Links to NHS Choices Internet resources on alcohol were also added, to provide additional information if the user had access to the Internet. The first submission to PALS was completed at the end of September 2012 and was sent out for review in early October. As with all other reviews of paper based materials, the information was sent to three panel members (see 3.8.6).

#### **4.4.8 Alcohol App - v1.11a (Fourth Iteration)**

At the first review, PALS panel members picked up on the need for consistency between the menu screens in terms of what they were saying, in addition to the requirement for a

standardised approach to the use of capitals and bold text. Using block capitals removed the shape of a word, which could affect its legibility (particularly relevant when people have low health literacy or are in an emergency situation). They suggested avoiding capitalisation and considering the use of bold rather than capitals, where the app was required to stress an important message. However, they also considered that if after reflection it was decided that bold text could be missed on a small screen, then the app should make use of capitals instead. This caused a re-evaluation of the text on the first page users accessed, as it was at that point completely capitalised. PALS guidelines advise the avoidance of upper case; but in either case, suggest adopting a consistent approach. In this case, on the menu screen it was decided to use upper case with two key words (*Take* and *Eat*) and one key phrase (*Start Safe, Stay Safe*) with everything else provided in lower case. Other suggestions included certain terminology changes and rewording some sentences to improve legibility; expanding some text to make it more understandable; standardising bullet points across different screens; ensuring text was the right colour for certain pages (again for consistency); and most importantly, adding in two additional screens. Firstly, for contact information (for SWDC patients and an alternative message regarding locating support for those accessing the app from other locations) and secondly, providing further information on the term *Hypo*. Whilst the panel members acknowledged that the target age group would probably understand the term, they felt an additional screen featuring more information on this subject would be beneficial. Once these changes were made, the second submission to PALS was completed during mid-November 2012 and was sent out for review soon afterwards.

#### **4.4.9 Alcohol App - v1.11b (Fifth Iteration)**

After a second review, the third submission required only minor cosmetic changes. Mostly, these consisted of textual changes to certain phrases including whether long-acting should have a hyphen in it; ensuring certain words and phrases were correctly capitalised; reordering menu screens in line with feedback from earlier questionnaire responses (see 4.4.5); and also ensuring that drink names were correctly displayed. It was also decided to amend the contact information for local patients so that it included information on SWDC rather than containing information on the local PALS service. This ensured that they would not be overburdened by enquiries once the app was launched. The third submission to PALS was completed during late November 2012 and approval was granted by them at this point.

#### *How to View the Type 1 Diabetes Friend: Alcohol Guide:*

For viewing purposes, the *Type 1 Diabetes Friend: Alcohol Guide* can be downloaded from the Apple App Store if you own an iPhone, or, the Google Play App Store if you own a mobile phone which runs Android. Alternatively, full documentation from the third submission to PALS (which contains all text and screenshots from the app) can be viewed in the appendices (see **Appendix O**).

#### **4.4.10 Apple and Google Regulation / Approval Process**

The alcohol app successfully passed the Apple approval process (see **3.8.7**) with its initial submission (see **Appendix X**) and was then offered as a free download on the Apple App Store from 7th December 2012. A duplicate version of this app was then ported across to the Google Play Store as an Android App and was offered as a free download from 5th February 2013. Unlike Apple, the Google approval process does not provide an authorisation confirmation (see **3.8.7**).

#### **4.4.11 Alcohol App Participant Feedback (Post Launch)**

Recruitment for post launch feedback was dependent on a purposive sample (see **3.6.1**) and was carried out through a variety of different approaches, including requests initiated through Twitter and other social media networks (see **Appendix F**). This approach was taken to target and access a sample that had previously used the app and to cover a more demographically representative sample than from one single clinic. This ensured that the research was independent from SWDC (see **3.6.1**). Feedback was collected from ( $n=11$ ) participants who came forward using questionnaires (see **3.8.9**) and interviews (see **3.8.10**), to find out information on how, why and when users had made use of the app and whether it had been of any use to them. Geographically respondents were situated in the UK ( $n=7$ ), the US & Canada ( $n=2$ ), Europe ( $n=1$ ) and Africa ( $n=1$ ) demonstrating the global reach of this form of technology. Of this sample, one participant was under 1 year post diagnosis, two were 2 years post diagnosis, one was 3 years post diagnosis and seven were over 5 years post diagnosis. Six themes were identified from analysis of this data. It should be noted that these themes are separate from the six lifeworld themes which were identified (see **4.1**). The timeline for this approach is shown in **Table 3**. The themes identified were:



- Theme 1 - Reasons for Using (Why).
- Theme 2 - Usage (How).
- Theme 3 - Usage (When).
- Theme 4 - Duration of Usage.
- Theme 5 - Positives and Negatives of Usage.
- Theme 6 - Areas for Improvement.

#### 4.4.12 Theme 1 - Reasons for Using (Why)

Users had downloaded the app after coming across it through an iTunes Store search ( $n=2$ ), a Google Play Store search ( $n=1$ ), a generic Google search ( $n=1$ ), finding out about it via Twitter ( $n=3$ ), LinkedIn ( $n=1$ ), the blog associated with the app development ( $n=2$ ) and via word of mouth ( $n=1$ ). As the app was accessible only from within the App store, this illustrates the many pathways in which information on apps can be located external to the App Store search tool (see 4.1.7). Secondly that for this demographic group, the fragmented way in which they look for support (see 4.1.5) suggests that it is not advisable to limit the methods and ways in which an educational health app should be promoted. In their feedback, participants described their reasons for initially downloading the app. Reasons given were similar to pre launch findings (see 4.4.2), where information seeking about diabetes and the effect of alcohol is common in a younger audience with particular reference to glucose monitoring and management (Jones E et al. 2013). Such as, seeking out information to learn more on general correct practice:

*P: I do not know how to drink with diabetes so I thought I could learn how to stay safe through the app... [T1-QOL-12]*

Through to looking for specific areas, such as information on insulin reduction post drinking:

*P: I was interested to see what information was given about reducing basal and bolus doses post drinking and what to expect the next day... [T1-QOL-14]*

Concerns regarding safety in relation to diabetes (see 4.3.3 and 4.3.4) and the effect alcohol (see 4.4.2) had on diabetes control (Jones E et al. 2013) were also expressed as reasons for obtaining the app. Such as helping to better manage the prevention of hypos:

*P: On occasion I have had hypos the morning after drinking alcohol and was looking for advice on how to manage this and prevent it from happening in the future... [T1-QOL-18]*

Being relatively new to having type 1 diabetes (see 4.1.2) and wanting to know more about this aspect of living with the condition:

*P: I downloaded the app because I am barely two months into being type one... [T1-QOL-19]*

and an acknowledgment and concern that they drank heavily (see 4.4.2):

*P: I drink a lot... [T1-QOL-20]*

Therefore wanting more advice and help on what they should be doing before and after drinking.

#### **4.4.13 Theme 2 - Usage (How)**

Four participants had downloaded the Apple version of the app whilst six had downloaded the Android version. One participant owned a Windows phone and requested that a version of the app be produced for this format in the future:

*A version for the windows phone if possible...I believe that it would increase my knowledge and enable me to understanding the risks of drinking with diabetes better, when I can download the app in the future... [T1-QOL-13]*

Consequently, they had not been able to download the app onto their own phone, but had instead downloaded and used it on their boyfriend's apple phone. This data identifies the need for educational health apps to be produced cross-platform (for both

Android and Apple) to reach the widest audience (see 4.1.6). There is currently a much smaller market demand for Windows phone due to its lack of penetration at this time and no demand from Blackberry users mirroring recent mobile phone trends previously identified before prototyping (see 4.1.6). Nine users had downloaded the app to use on their phone; one had downloaded it to a partner's phone; whilst only one had downloaded it with the intention of using it on their tablet. This shows that the preference for usage of this type of app is still heavily weighted towards mobile phones rather than tablets at this moment in time. It mirrors earlier findings concerning the current use of tablets and phones by this age group (see 4.1.6) and also provides confirmation of the reasons given for focusing on developing an alcohol app initially (see 4.4.2). The use of mobiles could also highlight the nature of where they were likely to be making use of the information on this app (see 4.1.7 and 4.4.2). That is, participants used the app when it was needed and not just for information, such as when they were away from home on a night out where they would be less likely to have a tablet with them.

Participants described how they had been able to make use of the alcohol app since downloading it. This ranged from obtaining general information and advice on alcohol and diabetes:

*I've used the app for mainly reading all information regarding the influence of alcohol and diabetes. It was interesting to read a bit about the correlation between lows and highs.... [T1-QOL-17]*

Wanting to calculate the amount of units in a drink:

*I have used the app to calculate the amount of units in a drink and how many units I consume on a night out... [T1-QOL-18]*

and looking at different drinks depending on their blood glucose levels at a particular moment in time:

*Checked different alcohol depending on what my BG was... [T1-QOL-20]*

Participants had also used the app to pass on information about this subject to family members and friends:

*I have also used it to show some of my friends and family who I have seen over Christmas... [T1-QOL-16]*

This point had previously been made during pre launch suggestions as one of the benefits of information being provided on a mobile platform especially in relation to explaining hypos to others (see 4.3.4).

These findings again relate to pre launch findings (see 4.4.2) and a recent systematic review of data regarding safety concerns and information seeking (Jones E. et al. 2013). This points to a particular need being met by the app as suggested by users before (see 4.4.2) and during prototyping (see 4.4.4).

#### **4.4.14 Theme 3 - Usage (When)**

Participants had utilised the app in a variety of different social situations such as reflecting on what to do prior to going out:

*Before I go out... [T1-QOL-12]*

*...it was useful to be able to look up a rough guide as to how the amount of alcohol I was drinking was going to affect me and what precautions I should take (such as giving long acting insulin before I go out drinking - I usually do it when I get in)... [T1-QOL-16]*

*During the daytime before a planned night out... [T1-QOL-18]*

and during the actual night out itself:

*This app is always used when I'm out with friends... [T1-QOL-10]*

*I have used the app to calculate the amount of units in a drink and how many units I consume on a night out... [T1-QOL-18]*

Or when doing something different from normal:

*...on one occasion when I was going on a family meal and drinking wine, which I had not done before... [T1-QOL-18]*

It had also been of particular use at certain times of the year, especially during the Christmas and New Year period when some were more likely to drink higher amounts of alcohol:

*Used before NYE when having a few drinks... [T1-QOL-15]*

*I have used the app over the Christmas and New Year period as this is when I drink most alcohol... [T1-QOL-16]*

The type of usage described by participants highlights one of the advantages of the app over more conventional support resources (see 4.1.5 - 4.1.7) in that there is an ability to access this type of resource quickly, conveniently and less obtrusively in any place and at any time (Jones R. et al. 2013). For example, when out and about in a nightclub (see 4.1.7 and 4.4.2). Secondly, designing the app so that it was able to work without the need for a wireless connection at all times (see 4.1.7), meant that it was able to be used in a much wider variety of external locations (such as in a nightclub) than if a connection was required. This demonstrates the need for thoughtful design considerations (see 3.5.4) for the particular user group being targeted (see 4.1).

#### **4.4.15 Theme 4 - Duration of Usage**

One of the limitations of this study is that the app itself was not utilised as part of any strategic intervention (either at SWDC or elsewhere). So, the use of it alone should therefore be considered less likely to provide sufficient support to enable users to change their intentions; or, to continue to regularly use the app or remember the information on it post download (Lamb 2012). Usage of the app by participants varied once it had been downloaded; suggesting different levels of experience in the user base

and in individual requirements for making use of the app. Four users had used the app between 2 and 5 times and three had used it between five and ten times at the time of data collection. Of the four users who had only used the app once, three participants mentioned that this was due to their sound knowledge of drinking with diabetes:

*Although the app is useful, after having diabetes for 12 years I found that I knew the majority of the diabetes related information already. I think if I had been newly diagnosed or was reaching the legal age of consuming alcohol then I would have used it more... [T1-QOL-14]*

*...having diabetes for 10 years, I am well aware of what a hypo is... [T1-QOL-20]*

One of these users considered that everyone with type 1 diabetes would know what to do when drinking:

*I'm unsure how it can help as I thought it was basic knowledge that everyone knew not to inject for alcohol and to eat after drinking... [T1-QOL-11]*

This assumption was something that the majority of other respondents had not suggested during initial ideas generation (see **4.4.2**).

Longer term usage statistics taken from the Google Play Store highlighted a more negative trend in total installs on devices (away from data collected from the post launch feedback sample). Current Android device installs (at 81) - the number of unique active devices where the app is currently installed - versus total user installs (at 326) - the total number of unique users who have ever installed the app on a device - showed that at the time of feedback recruitment (see **Table 3**), 75% of installs were uninstalled. This suggests that the app was not being kept on a large number of installer's phones indefinitely - an area requiring wider investigation. Apple data is not currently available to provide information on usage trends once a user has downloaded an app (unless in-app purchases are made). This makes it more difficult to compare user groups and cross check this data across both device audiences for correlation.

#### 4.4.16 Theme 5 - Positives and Negatives of Usage

Negative opinions of the app included the speed of response in certain instances:

*It needs to be a little bit faster, it lagged a lot... [T1-QOL-19]*

Having to access external sites to obtain some of the information required:

*Include the information about alcohol units on the app itself rather than providing a link, however the links are still very useful... [T1-QOL-17]*

and some usability functions, such as when returning to the app from a different one and being returned again to the home page:

*If you close the app and later reopen it you are taken back to the 'before we begin' page. It may be easier if the app allowed you to stay on the page you were looking at so that you do not have to trawl through the app pages to find what you were previously looking at... [T1-QOL-17]*

Positive opinions of the app included the type of content included:

*It was interesting to read a bit about the correlation between lows and highs... [T1-QOL-17]*

and the quality of the information provided on the app:

*...it is very accurate, I follow what it says about hypos and how much to consume... [T1-QOL-10]*

Overall in response to the question of whether the app had made any difference to their life with type 1 diabetes there were five positive responses:

*Yes, I thought I could not drink at all but now I know how to while keeping safe... [T1-QOL-12]*

*I'm more aware of the consequences but as well the options you have to drink safe... [T1-QOL-17]*

*I have a better insight into the effects of alcohol and how it can affect my diabetes, particularly if I am consuming more than a couple of units on one occasion... [T1-QOL-18]*

One response was positive that the app would make a difference if they were able to download it onto their Windows phone in the future (see **4.4.13**); two did not express an opinion; three said not. These users considered themselves to be very knowledgeable on drinking and their diabetes (see **4.4.15**), so their use of the app was not as great as the other participants once they had initially downloaded it.

#### **4.4.17 Theme 6 - Areas for Improvement**

Alongside negative comments on the current iteration of the app (see **4.4.16**) which could be incorporated into a revised iteration, suggestions for improvements were made in a variety of areas. These included expanding the information on sugary drinks as per pre launch suggestions for enhancement (see **4.4.4**):

*What could be useful would be to have a catalogue of drinks (different brands, quantities etc) that tells you the sugar content of the drink, as if you are out and have the drink in a glass or a bottle with no information on then it is difficult to know how much sugar you are needing to give insulin for (if necessary)... [T1-QOL-16]*

and widening the information on coping with hypos, if experienced during a night out:

*Perhaps to include further information about the effects of sugary drinks like baileys, alco-pops and vodka and orange juice etc and how to combat Hypos... [T1-QOL-13]*

Also including separate advice for those with insulin pumps (depending on the individual, how much they drank and how their body reacted to alcohol consumption):



*I was particularly interested to see if any advice was given to those who use insulin pumps, but I could not see any. This is because there is an option on insulin pumps to use a reduced temporary basal rate for a certain amount of time to reduce the risk of hypos. I have been encouraged to use this by my diabetes consultant if I have been drinking... [T1-QOL-14]*

and more information was requested on the effects of alcohol and the ratio of carbohydrates to alcohol:

*Suggest a unit alcohol/carbs ratio, be more specific about the effects of alcohol, cater for people on insulin pumps as well as injections (e.g. Lowering basal rate as they aren't on long acting insulin)... [T1-QOL-20]*

This is an important area for inclusion in the next iteration of the app as more recently published literature in this area points to knowledge of alcohol and carbohydrate content of drinks being particularly poor for young adults with type 1 diabetes (Barnard et al. 2014).

## **4.5 Data Analysis Summary**

This analysis is able to provide a detailed understanding of the experiences of young adults with type 1 diabetes. It reflects how they have lived with their condition since diagnosis and how they have made use of the web and mobile technology and its impact on their life. This is an important area as prior to this present research, little was known about how young adults used mobile phones for their diabetes (Mulvaney et al. 2012) and only a small proportion of apps available had been the subject of any concerted research effort (Holtz and Lauckner 2012).

As a result of qualitative interviewing, I was also able to explore what the requirements of the interviewees were for new technological interventions (see **4.2** and **4.3**); investigating which suggestions could be useful to them (or perhaps enhance their HRQOL), but which had not yet been designed or suggested by either the health service or the private sector. What is perhaps the most surprising aspect of this study is that up until now, few

researchers or developers had wanted or thought to ask young adults for their opinions on these issues (see **2.6.2**). It is also this point which is the most important aspect of designing apps or any other technological innovations which might benefit this particular audience (see **3.5.4**). These interviewees were in the best position to advise both health professionals and technologists on where innovations might be implemented; how they could be integrated with current management techniques, support, education and existing diabetes technology; what sort of information they would regularly make use of; in what format they would prefer to receive it; on which devices; and in what situations they would be most likely to want to use them or not.

By including young adults with type 1 diabetes in the process of generating ideas and asking them to use and feedback on each iteration of the tool during its design, development and implementation (both pre and post launch), I was intending to provide a humanly sensitive approach to their healthcare. An approach which also gave them a chance to actively participate in the development and feedback process. This enabled a much greater and more well-rounded understanding to be achieved of how the tool should be developed prior to launch (see **4.4.2** and **4.4.4**) and how it would be located and utilised by the user base post launch (see **4.4.11 - 4.4.17**). Utilising sociotechnical design techniques allowed for post launch feedback to be directly fed back into the potential redesign process at a later date. Informing and focusing on important usage information and suggested enhancements for further iterations of the app. Post launch feedback also enabled greater reflection on the capability of the developed app to be used in a future intervention designed around its use. Future research could directly focus on a larger scale mixed methods approach, which would be able to specifically investigate and measure any HRQOL impact associated with usage of the app both locally and globally across the user base; and also investigate benefits or problems that have arisen from using it within a mobile environment.

## 5 Discussion

### 5.1 Contribution to New Knowledge

My research question was:

*How do young adults with type 1 diabetes interact with technology in their lives and in relation to their condition and how can their views and experiences inform the development of a patient-centric mobile health app?*

This present research took particular account of the agency-passivity dimension of humanising care (Todres et al. 2009), by enhancing young adult participation and therefore giving them some agency in their diabetes care and support. Analysing and immersing myself in the experiences of the interviewees and their suggestions for providing new innovative technological approaches to improving their life enabled me, as a developer, to more effectively and empathetically pause for reflection. Firstly considering the relationship with technology that young adults with type 1 diabetes had. Secondly, considering how this might make a difference and thirdly, when it might not be a suitable mechanism to use on some occasions. This sociotechnical approach is more likely to make anything subsequently developed more beneficial; user friendly; and reusable to the target audience than other system development approaches. My research aimed to contribute to new knowledge in three areas:

- Young adults with type 1 diabetes lives - providing examples of how their lives could be improved based on the use of web and mobile technology.
- Technical development process - documenting best practice procedures and principles involved in creating and releasing a patient-centric educational app.
- Policy - by highlighting areas where care and support had been lacking in the target group and where there were gaps in knowledge and understanding.

Each of these areas will now be discussed in the context of the data analysis and literature review. The discussion also includes a critical reflection on the limitations of the study.

## **5.2 Contribution to Young Adult Lives**

This research has identified a number of ways in which the lives of young adults with type 1 diabetes could be improved; through the design and implementation of new technological innovations which make use of web and mobile technology. However, as the data suggests, there is a need to consider three factors before anything is developed. Firstly, considering their unique individual relationship to technology. Then, reflecting on how this might be able to effectively make a difference to them, whilst at the same time considering when it might not be the best or most suitable mechanism to use.

### **5.2.1 Young adults relationship with technology**

The age when most interviewees obtained their first mobile phone was quite young in comparison to young adults growing up five years ago. Mostly at the start of early teenage years; although some interviewees obtained them even earlier - in some cases from nine or ten (see 4.1.6). Therefore, from a very young age this generation now viewed their phone as a constant companion, which they had always had constant access to during play, through school, university and then work use:

*P: ...because I was not carrying the book around with me whereas with my phone...it's always with me wherever I go... [T1-QOL-05]*

Newer smartphone devices have gradually started to replace other electronic devices that interviewees owned like mp3 players, laptops, cameras and paper based systems like diaries (see 4.1.6). As the capabilities of smartphones have increased, they can be viewed as ever more attractive options for utilising in relation to type 1 diabetes (see 2.5.4). Indeed, 60% of 16 to 24 year-olds in the UK use a mobile phone to access the Internet every day (ONS 2012); whilst in the US, 42% of mobile owners aged between 18 and 29 had looked for health and medical information (Fox and Duggan 2012). However, as this generation of users has become more attached to their mobile device there are important implications on how future education, awareness and management of type 1 diabetes could be altered or integrated with technology for these users. For example, in their study, Chaney et al. (2011) noted that the majority of adolescents only wished to communicate by SMS text message for follow-up post-education. This

highlights the need for health professionals to adapt to the lifestyle and mechanisms of communication adopted by today's adolescents. Literature suggests that there is a thirst for new technology to be applied in the care of their condition (see 2.5.4) and on the rare occasions when young adults have been asked - such as in this study and others (Bowen et al. 2010) - they are keen to try new solutions. Although there remain some doubts as to whether technology can effectively help them in all aspects of education and self-management (Lamb 2012).

### **5.2.2 How technology can make a difference**

In some cases the closeness of technology to the young person had already led to it being used innovatively in relation to their condition; such as using alarm functionality on a mobile phone (see 4.1.6). Whilst if cost was not an issue (see 4.1.7), it is important to note that some users would have been more likely to engage with using diabetes specific app related technology. The main benefits mentioned by interviewees of using diabetes apps tended to focus on the capability of them to replace paper based information – like logbooks (see 4.1.3) and books (see 4.1.5) - which they had previously had to carry with them, in addition to other diabetes equipment (see 4.1.2 and 4.1.3).

However, there was a feeling that the majority of currently available apps, although helpful, were not worth using (see 4.1.7). This could be due to the cost; the design, flexibility and usefulness of the apps themselves; or the lack of a cohesive guiding framework for using them which involved the clinic in some way. For example, if a Capillary Blood Glucose Monitor (CBGM) logged blood glucose, what was to be gained by interviewees having to additionally enter it for themselves onto their phone? (see 4.1.7). The lack of a decent quality app for blood glucose monitoring was mentioned by one participant (see 4.1.7), whilst another lamented the lack of many UK specific apps - so that the dietary values on those available were slightly different, making them difficult to use effectively. A comment also directed at some of the US-centric brand information held on the Carbs & Cals app (see 4.1.7), even though this app was generally well regarded.

Participants could see the value of accessing up-to-date information via a form of technology like Twitter (see 4.3.2), as a means of providing them with immediate support and information. This might include increasing awareness of information about new

CBGM being released and other technological innovations as they became available; highlighting news on scientific advances; and helping with support immediately after diagnosis (see 4.3.2). Technology could also be used to ease the transition between different clinics and prevent issues such as the lack of notification of changes in guidance from occurring (see 4.3.3). This could thus help to minimise the problems of receiving differing - seemingly contradictory - advice from different parts of the health service. Technological enhancements were suggested concerning the development of useful health apps that might be of use to them in the areas of Twitter (see 4.3.2); Illness and diabetes (see 4.3.3); Hypoglycaemia and diabetes (see 4.3.4) and Alcohol and diabetes (see 4.4.2). In addition to many other ideas and suggestions which they had for improving their lifestyle and making a difference in other areas of their lives affected by their condition, which were not able to be taken forward to development (see 4.2.1). These included possible technological enhancements in the areas of diet and calorie control; carbohydrate counting; local social networks (both private and public); mentorship of others; medication and health appointment tracking; blood sugar recording; enhanced alarm capabilities; additional supportive and entertaining video and audio information; a general type 1 diabetes directory; emergency information notification; and a continually open online helpdesk. As can be seen from these suggestions, there are a number of areas where new technological solutions might help to bridge a gap and possibly offer opportunities to improve the day-to-day lives of this age group and their condition. It is a surprising aspect of this present research that there were so many areas mentioned that have yet to be adequately addressed in light of the current poor performance of UK diabetes care (see 2.3.3) and the length of time these technologies have now been around for (see 2.4 and 2.5).

It is also instructive to note the positive feedback on the tool that was developed (see 4.4.11) and how it had been utilised since launching. For some, this was their first experience of using and benefiting from an app to help with their condition:

*I was diagnosed with type 1 diabetes in October 2008, when I was 16. I am now 21 and have never used any other apps for diabetes before... [T1-QOL-16]*

The app had been useful firstly as a way of providing both new insights into this aspect of living with diabetes:

*I have a better insight into the effects of alcohol and how it can affect my diabetes, particularly if I am consuming more than a couple of units on one occasion... [T1-QOL-18]*

and secondly, of raising awareness of the consequences of drinking:

*I'm more aware of the consequences but as well the options you have to drink safe... [T1-QOL-17]*

Users had been able to look for a variety of different drinks whilst using the app and in a variety of different social situations; some of which were new to them, or, where other forms of information had not been immediately to hand. This highlights the possible benefits of portable technology:

*During the daytime before a planned night out and on one occasion when I was going on a family meal and drinking wine, which I had not done before... [T1-QOL-18]*

It had also been of particular use at certain key times of the year such as Christmas and New Year:

*I have used the app over the Christmas and New Year period as this is when I drink most alcohol... [T1-QOL-16]*

In response to the question of whether the app had made any difference to their life with type 1 diabetes five out of eleven post feedback responses were generally positive, with a further positive response recorded if they were able to download the app to their Windows phone in the future (see 4.4.13). There were two non-committal responses, with three participants responding negatively. Of these, all were over 5 years post diagnosis and considered themselves to be very knowledgeable on drinking and their diabetes. This suggests usage would be higher in those recently diagnosed; who would have less knowledge and would therefore require more support. Post launch feedback (see 4.4.11 - 4.4.17) points to how effectively designed and considered mobile

technology solutions can be created; which might then be adapted and tailored for use within the particular lifestyle requirements of some young adults with type 1 diabetes with positively acknowledged benefits:

*I'm more aware of the consequences but as well the options you have to drink safe! [T1-QOL-17]*

### **5.2.3 Considering individual differences in use of technology**

Just as each person had their own unique perspective and a different personal experience of living and coping with type 1 diabetes (see 4.1.2), so they also required different customisable approaches based on their own personal preferences toward technology. This means not assuming that any new form of social media or technology will automatically be adopted by everybody in a particular age range (see 4.1.5). Given the research findings of the literature review (see 2.4.1), which suggested that younger age groups were more likely to engage with new social networking products, it is instructive to note that not all interviewees were drawn to engage with new products if they did not directly appeal to them (see 4.1.5). Similarly, the belief that users of this age group were happy to share every aspect of their personal life on Facebook - including health information - was also contradicted (see 4.1.5). Regarding their use of Facebook, some interviewees only wanted to use it for talking with friends about their life away from type 1 diabetes, rather than using it for diabetes related searches and communal group discussions. Considering how quickly popular opinion in this age range changes concerning different brands and products is also instructive (see 4.1.5 and 4.1.6). Indeed, it seemed as if the amount of discussion in the media about certain social media tools like Twitter was in some cases harming its ability to attract this age group toward using it. Some mentioned the problem of having too much information being constantly targeted at them by too many people - similar to the Facebook phenomenon of too many people being available to connect with (see 4.1.5), causing them to exert tight controls on what they looked at, who they engaged with and where they visited online.

For the majority of users (see 4.1.7) from a mobile perspective, apps were quite a new development even though launched in 2007 (see 2.5.3) and some interviewees had not made much use of them at time of interviewing. One of the reasons for this was financial and a reluctance to try them out because they were frightened about the implications of



creating an account; or, because there was a reluctance to pay for an Internet connection as a part of their mobile contract (see 4.1.6). The general theory concerning web 2.0 and social media (see 2.4.1) suggests that it facilitates and encourages use and collaboration. So, it is in stark contrast but important to note that there are a variety of reasons why this particular age group do not always feel inclined to use it as a mechanism for obtaining information and support for their LTC. It might be that aspects of their character or personal feelings (Livingstone 2008) limit them from interacting in some online environments with people they do not know (see 4.1.5). Or young adults might have conditions that preclude certain areas of online activity, like Asperger's, evidenced by one respondent in this present research (see 4.1.5). They might not wish to share information about their condition online (see 4.1.5) - the technological equivalent of Williams (2000) findings on how diabetes is sometimes kept separate from social identity (Ho et al. 2014). Some interviewees preferred to interact with professionals rather than individuals who might not have medical training to assist with their enquiry. Effectively not wishing to engage with people from an empathetic or helpful viewpoint, but rather ensuring that they received the correct information or advice.

There was a strong feeling expressed by participants that although the condition might be the same, the experience of living with it was completely different for each individual:

*P: ... no-one, no two people are the same with diabetes, everybody is different...*

**[T1-QOL-08]**

Their confidence and effectiveness in dealing with lifestyle elements like counting carbohydrates; injecting; and coping with illness, alcohol and the effects of hypos might vary. They might also have different equipment which impacted on their individual behaviour - such as wearing an insulin pump (see 4.1.3). Indeed, post-launch feedback (see 4.4.11 - 4.4.17) highlighted how the usefulness of the alcohol app varied depending on how confident the users were with this aspect of living with type 1 diabetes. More use of the app was made and more positive responses were recorded by those users who were adjusting to balancing type 1 diabetes and their alcohol use (see 5.2.2). Of the four users who had only used the app once; two mentioned this was due to their sound knowledge of drinking with diabetes and that they were both over 5 years post diagnosis:

*Although the app is useful, after having diabetes for 12 years I found that I knew the majority of the diabetes related information already. I think if I had been newly diagnosed or was reaching the legal age of consuming alcohol then I would have used it more... [T1-QOL-14]*

The advantage of producing a mobile app is that it can be easily downloaded by those who want to use it and then, stay accessible on their phone as they continue to make use of it. Or, alternatively be quickly discarded or used only sparingly by those who become more confident in a particular aspect of their life with the condition; but, who may at some point need a reminder - or in the case of alcohol, perhaps wish to try drinking something they had not come across before.

Aspects of technology use which might be diversive could negatively impact on any technological enhancement implemented. For example, using the wrong medium to spread a health message; trying to manipulate something entertaining into something educational without clear explanation, integration and support; or excluding through cost or software system used. These issues need to be given clear and careful consideration therefore, before any solution is developed and implemented during the continual iterative design process. The key to increasing uptake and usage will be to tailor these types of technological tools, once designed, into a more personal intervention where the app is perhaps one clearly defined, flexible and user friendly part of a larger and wider package. A package which also includes F2F interaction and education from trained health professionals, as Lamb (2012) and others have suggested. This would also help to reduce the risk of causing an incorrect behavioural change through improper use of technology (Maloney 2013).

### **5.3 Contribution to Technical Development Process**

As has been previously discussed (see 2.6.3), due to their mostly commercial nature, there is little research available relating to the design, development, implementation and use of health apps in the UK and of the regulatory procedures available for their approval and monitoring (D4 Research 2012). There is a need to contribute to this discussion; concerning the definition of a sensible, practical and methodical approach for

the design, development, testing and implementation of a patient focused educational health app. Such an approach needs to take into account the lack of regulatory processes and current gaps in the infrastructure of app-related health technology development. It should also reflect contemporary concerns inherent within the approach.

### **5.3.1 Concerns with Regulation / Approval Processes**

As health apps are increasingly used to support diagnosis and management of diseases (for example apps that allow users to input patient-specific information to diagnose a disease or condition), facilitating ethical use of technology is essential. Indeed, a number of authors (Visser and Bouman 2012; Buijink et al. 2013) have suggested that the DoH, the NHS, and individual hospitals and doctors should ensure that they clearly designate and peer review apps which were evidence based; confirm they were reliable and up-to-date for use in daily clinical care; decide when such use was appropriate; and also provide sufficient training to support this. However, as has been previously discussed (see 2.5.3, 3.8.5 and 3.8.6), policy and guidance on this area in the UK currently lags behind the US. The development of the alcohol app serving to highlight that in some cases guidance for submission and acceptance of patient information in this format is being made up 'on the fly' (see 3.8.6) and then, only if the developer voluntarily approaches the appropriate part of the health service. For example, during the local authentication process (see 3.8.6), the local Patient Advice and Liaison Service (PALS) initially struggled with identifying who might be able to review the materials in this new format. This necessitated sending out an email request for reviewers and potentially limiting the candidate list for peer review. In the absence of any proper regulation in the UK, what happens if there is a problem? In healthcare, companies recall medical devices regularly. A recall happens when something wrong happens to a device and it is the responsibility of the manufacturer to warn users if a product is defective. The advent and rapid growth of the health and medical app market has greatly increased the risk of using an app which is unreliable, not evidence based, or which could be dangerous. It is probably only a matter of time before medical errors caused by unreliable apps emerge (Visvanathan et al. 2012; Buijink et al. 2013). The Pfizer Rheumatology Calculator allowed physicians to measure the disease activity of patients with various inflammatory diseases. The app had been available for download since April 2011 but in October 2011 Pfizer had to issue a recall letter, as the application gave incorrect values for the DAS28 Calculation (Pfizer 2011).

This poses the question of how exactly a smartphone app can be recalled; effectively it cannot. Although a newer version with corrected information or enhanced functionality can be overwritten in App Stores where it is available for download, existing users still have to manually perform an update or deletion themselves; and it is their choice as to whether they do this or not. In more extreme circumstances, developers are able to remove an app completely from an App Store, but again this only prevents new downloads from taking place. Crucially, the developer is not able to remove apps directly from installed phones, so the users have to do it themselves. Although in worst case scenarios, both Apple and Google are able to remotely remove apps. Hence, there is a real risk that recalled apps might still be in use by doctors, medical students or patients which might pose risks to patient health. Currently, no protocols exist on how to recall a malfunctioning or dangerous medical app to stop its use (Visser and Bouman 2012). Because of the large number of apps and the lack of proper good quality indicators, specialised app markets have started to appear. Commercial companies are trying to solve this problem by creating their own medical app market and app certification programs like Happtique (2012). However, although in principle this seems a straightforward proposition, the process of curating and certifying large numbers of apps is not without difficulty as Happtique have discovered (Misra 2014). Additionally, as Misra notes (2014) simply labeling an app as certified is not nearly enough to help a patient or clinician judge whether a specific app is the right choice for them. This depends on the expectation and values of the user, as well as the specified clinical context. During March 2013, the NHS Commissioning Board launched a Health Apps Library (2013), which was intended to help the public and health professionals decide which apps could best assist them to inform, monitor, and improve health and care (see **2.5.3**). This poses questions surrounding whether apps designed in conjunction with parts of the NHS and locally approved by them are able to make use of NHS branding (even if a developer is not an official part of the organisation) and also whether any such branding exists. The NHS brand brings with it guaranteed authority and credibility (Wren 2012), which is beneficial in terms of promoting a high quality health app to patients and practitioners. A single corporate identity for the NHS was introduced in 1999, which replaced the many different logos used previously, all individually competing for public attention. This competition made it difficult for people to distinguish NHS services and communications from those of commercial companies or charities. The single NHS

identity was created to address these issues of identity and to improve recognition and accountability (Dyke 2012). There are guidelines for print, web and slide presentations, but surprisingly no definitive branding guidelines for apps. This is something which is viewed as slightly archaic (Wren 2012), given how much mobile technology has recently changed the technology landscape (see **2.5.3**).

### **5.3.2 Post Launch Concerns**

Post launch issues also need to be given consideration as a part of any technical design process concerning health apps, especially given the definition of the *principle of Incompletion* (see **3.5.4**). Where an app is designed which uses educational patient focused literature there is a need for procedures to be put in place to ensure that it is checked regularly after its launch and updated continuously from then on. This will ensure that future clinical changes in legislation or guidance are included. For example, information on the NHS Choices website (2011a; 2011b; 2011c; 2013) is scheduled to be reviewed in bi-annual cycles to avoid it becoming outdated. With the developed app, a part of the PALS process was to suggest a review date of three years from the time the information was first reviewed. However, the procedures for ensuring that this is carried out would seem to sit with the content owners and developers rather than the local PALS group or national or local health service departments. With patient focused apps this raises questions as to what happens to them to ensure that they continue to present the latest up-to-date information. For example, when national guidelines change (such as the rules for notifying the Driver and Vehicle Licensing Agency (DVLA) if someone with diabetes drives). The same questions also arise concerning how this information is cascaded out to users of an app, as there are no guarantees that they will update their phone with the latest version - a similar conundrum to the problems with withdrawing or recalling dangerous apps (see **5.3.1**). With these considerations in mind, a post implementation document in liaison with SWDC is currently in the process of being drawn up. This will include procedures for future updates; succession planning (if any partner involved in the creation of the app leaves their post); procedures for withdrawing the app; and the formalisation of the different intellectual property elements contained within the app.

### 5.3.3 Restraint of Use Concerns

Although there seemed to be mostly great enthusiasm from interviewees concerning making use of Twitter in some way to assist in the management, care and support of their condition (see 4.3.2), this idea was not able to progress beyond the suggestion phase. The idea for an app which either utilised Twitter or simply looked at setting up a local Twitter account for the SWDC was discarded early on during prototyping, due to current NHS policy requirements at the local level making this particularly difficult to achieve - something which Kerr (2011b) had alluded to. The reasons for being unable to utilise particular forms of social media within some health environments, whilst laudable, also has the effect of stifling potentially life-changing innovations concerning improving HRQOL for young adults in terms of managing their LTC (such as the use of Twitter). The DoH Informatics Directorate guidance (2012) listed potential risks and impact consequences, which they felt NHS organisations needed to be aware of including unauthorised disclosure of business information and potential confidentiality breach; reputational damage; malicious attack associated with identity theft; and legal liabilities from defamatory postings by staff. Whilst acknowledging that the use of blogging and other social networking tools by NHS staff could expose their organisation to unexpected informational risks or liabilities (even where these social media sites were not accessed directly from work), it is imperative that the NHS and DoH adopt a more proactive and flexible approach for utilising these forms of communication; rather than banning them indiscriminately (Kar 2013). Again, this issue currently seems to be managed at a local level rather than at a regional or national level, which makes each NHS Trust different in how they make use of these forms of technology (or not). This leads to a frustratingly unclear picture across the country of what exactly is possible from this aspect of technological innovation – especially when attempting to work across multiple sites.

Suggestions taken forward from the list of initial ideas for app development were required to meet clinic goals and also follow local and national guidelines. In the case of the local hospital where SWDC was located, this meant that patient data could not be recorded. This highlights an interesting problem, concerning what could be developed to improve lives, against what information is allowed to be recorded. One of the biggest concerns relating to the use of smartphones in clinical care is the potential breach of patient confidentiality (Nolan 2011). Visser and Bouman noted (2012) that the increasing usage of apps added a new aspect to patient information security, which would require

new security measures to be adopted. When patient data is stored electronically it risks becoming exposed to potential data breaches. The US government has already issued federal regulations that deal with how this information should be maintained and the steps to be taken to prevent data breaches (Federal Register 2009). Unfortunately, these regulations do not deal with issues related to the storage of protected health information in medical apps and once again, no definitive guidelines currently exist in the UK that indicate how these regulations apply to medical apps; or offer procedures to follow if a similar situation occurred in the UK. Moreover, different legal regulations apply in different countries, which make it complicated to create guidelines that are internationally applicable. Furthermore, it is easy to lose a smartphone, and would all patients and staff know what to do when it is lost or stolen and what the consequences might be in terms of their own data loss. Users can erase all data from a distance on certain smartphones like the iPhone if they are lost or stolen and most smartphones have some form of basic security feature installed on them. However, most do not have sufficient security measures - such as proper encryption of data - to ensure the effective safety of patient data. Besides this, even if a smartphone is protected by the use of a personal password this can be easily hacked, which could then compromise personal information as well as any saved patient information (Bommissetty 2012).

#### **5.3.4 Other Considerations**

Historically, the mobile medical apps sector has primarily focused on producing new apps and encouraging health professionals to use them (Visser and Bouman 2012). But before healthcare adopts health and medical apps, other issues such as interoperability and conflicts of interest should be considered. Initiatives focusing on the connectivity and data integration of mobile health apps have enormous potential for improving patient care. Many devices, such as apps, sensors, and monitoring devices can now be used by patients and health professionals, but as Wake and Cunningham (2013) point out, many diabetes technology tools and systems currently operate in silos. For example, patients might use CBGM and diabetes apps to manage their diabetes at home, but this information is never fully shared with their health care provider when they meet; missing out on an important opportunity for integration and intervention. Presently, they are not connected to each other, but in the future these devices might become interoperable. Davis (Todd 2012) believed that an ecosystem must be created where apps could work together and share data. This could act as an electronic medical record repository,

where data could be stored and others apps could access it. He acknowledged that information governance would always be an issue, but argued that the patient-facing component of apps could help to overcome these issues; as patients could be asked directly if they wanted to share their information and in what circumstances. Alongside the NHS Health Apps Library (see **2.5.3**), the NHS Commissioning Board also intend to provide a platform to encourage the development of online tools and applications that would be of future benefit to health and care. However, this is still in the early stages of development and will not by itself provide the solution without a much greater connection between all parts of the health service infrastructure (both social and technical). There is also the risk of duplication of functionality within the realms of diabetes equipment. For example, advances in the capabilities of CBGM (see **4.1.3**) that had filtered through to interviewees, had negatively impacted on their use of certain health related apps (see **4.1.7**). It is therefore imperative that there is awareness that this technology should ideally be synchronised or integrated with diabetes technological enhancements, to ensure that the same work is not duplicated (*principle of Compatibility*).

Issues relating to conflicts of interest include conscious and unconscious bias in prescribing habits, as well as the perception by patients and the public that health professionals do not always consider the best interests of their patients when making prescribing decisions (Visser and Bouman 2012). The drug industry is increasingly using medical apps for marketing (Digital Pharma Directory 2013) and it is often difficult to determine the origin of a particular medical or health app and whether it is funded privately or by a commercial company. Using apps developed by a drug company raise substantive ethical issues; these companies might be using apps as a subtle form of *Trojan Horse*, perhaps using them for marketing purposes to influence treatment options. Given the potential health implications and in light of the potential for biased clinical decision-making, Buijink et al. (2013) suggested that health professionals should be cautious about using apps made or sponsored by drug companies. Secondly, that given the potentially important consequences for clinical care of drug promotion in medical apps, regulators and manufacturers would have to share responsibility for any oversights (Greene and Kesselheim 2010; Husain 2011). Notably, again in the UK there seem to be no guidelines presently available or in the process of being written, which refer to the correct procedures to follow in these instances.



## **5.4 Contribution To Policy**

In 2012, the National Audit Office (2012a; 2012b) and Diabetes UK (2012) published critical studies on diabetes care (see 2.3.3). Following on from these reports, in the conclusions and recommendations to a Public Accounts Committee (PAC) report on the management of adult diabetes services in the NHS (Commons Select Committee 2012, p.6), it was noted that:

*Many people with diabetes develop avoidable complications because they are not effectively supported to manage their condition and do not always receive care from appropriately trained professionals across primary and secondary care.*

Within the Diabetes UK report (2012), support for young adults with type 1 diabetes was deemed to be poor. The UK was noted as being one of the worst performing countries in Europe, in terms of blood glucose levels for children with diabetes. It was suggested that self-management activities and education needed to be available and uptake encouraged; so that action could be taken to improve and manage the diabetes of children and young adults. One parent quoted in the report (2012, p.23) said:

*After having type 1 diabetes for 12 years and now being 16 years of age, it is time for my son to take more responsibility for his own condition. However, we still cannot access any structured education for him. This is an absolute disgrace.*

As has been discussed (see 2.6.3), the literature review revealed a need to design a more patient centred framework, which encompassed the use of web and mobile technology for the benefit of young adults with type 1 diabetes. A framework originating from their perspective, encapsulating and humanising the use of technology for the benefit of people who might want to support, mitigate or improve their own HRQOL (Pulman 2010c). In terms of type 1 diabetes young adult views are vitally important (see 2.6.4), as they have a radically different view to either their peers or practitioners. Before this present research began, their views of how they used current technology available to them were virtually undiscovered and unknown. These views are valuable and could

have an important impact on policy. Given the series of reports issued on poor current diabetes care across the UK, this is an appropriate time for these views to be expressed.

#### **5.4.1 Patient Experience – How their condition affected them**

Coping with type 1 diabetes is sometimes a lonely experience for a young person (see 4.1.2); something which they have to deal with on their own. Interviewees would have welcomed meeting and chatting to someone else of the same age (notably neither practitioners nor parents) in the same position as they were:

*P: ...because on a day to day basis, even if you are engaging with people with type 1 diabetes, you might not even know about it and so, it's quite a hard thing to meet other people who are living with the same condition as you... [T1-QOL-04]*

Finding people of the same age with the same condition had proved difficult. What is most striking about this perceived isolation is that when they came in for interviews at the clinic, they did not want to initiate conversations or friendships with others visiting at the same time (see 4.1.4). Isolation at the clinic is an interesting phenomenon, whereby each young person is in their own particular bubble (either alone or with parents), not seeking interaction with others present (see 4.1.2); perhaps due in part to the nature of the venue, the reason for visiting it and the social awkwardness that this might cause them (Lowes et al. 2015). Most interviewees knew few others with the same condition and would have liked to get in touch with others for mentoring and informal discussion about their condition (see 4.1.5). Here there was a real opportunity to mix and chat with others - albeit not in a very enticing environment - being missed.

Both friends and family were able to provide help and support to participants. Friends of the same age with type 1 were typically more difficult to meet (see 4.1.2 and 4.1.4). So they either tended to be met in health situations, through family circumstances, or via friends of friends, or word of mouth. Although for some interviewees, when younger, they had found it difficult to find anyone in the same situation, which would have been useful and supportive for them:

*P: ...what would have been more helpful to me was to sort of contact other people that were in the same situation as me that had gone to secondary school or just...were absolutely hating having diabetes, who wanted to eat sweets all the time, eat chocolate, have McDonalds, anything... [T1-QOL-03]*

Negativity concerning type 1 diabetes was something that came across regularly in participant comments. These feelings sometimes being mixed in with adolescent angst, making discussing important issues about control and measurement difficult for some parents (see 4.1.2). Part of this negativity, was around why they had type 1 diabetes:

*P: Not that you'd want to talk to me if you've just been diagnosed and I just tell you "unlucky!" you know (laughs)... [T1-QOL-03]*

Negative feelings might also be caused by an uncomfortable trip to the clinic where criticism of blood glucose control and measurement or weight management might be taken badly and brooded on. Similarly, being told what to do (see 4.1.2); rather than being given the same information in a more open, supportive manner. This could cause blame to be apportioned to the individual by themselves and rather than feeling supported they might feel picked on. During interviews, there were a number of remarks relating to pain and discomfort. Injections might cause painful feelings to occur post-injection. Whilst the simple act of taking a blood sugar reading with some machines was noted to be quite uncomfortable. As was the placement of the insulin pump needle and injecting through clothing (see 4.1.2). Most importantly, poor blood testing procedures in health settings could prove painful to the patient and if not done carefully, this could stay in the memory of the interviewee post appointment:

*P: ...and she did it on the inside of my arm and through a week my arm was like painful, when I tried to move it...*

*I: Yeah...*

*P: ...so I think that's what put me off, and then after that I just sort of...everytime it came to it, got nervous and it took sort of about an hour for them to even get near me with a needle... [T1-QOL-08]*

Fear was an emotion that was continually expressed and experienced in comments. To begin with, there was fear that a test would result in a positive diagnosis and the wording of an emergency blood test only served to heighten anxiety (see 4.1.2). Depending on the age of diagnosis, the younger the age of the person, the worse the confusion and anxiety might be when they were in a hospital with no explanation about what was being done to them and why. This could result in fear, which might manifest itself in longer-term problems lasting beyond youth - in one case becoming Needle Phobia (see 4.1.2). Within the clinic, an unfortunate side effect of trying to convey a serious point about what might happen in the future if a young person had poor control could also cause them to become worried or frightened. This might cause them to imagine the worst in their own mind and then go and look for more information on those areas, which were most concerning to them outside of their appointment:

*P: And when my HBA1's were high. And then I started getting shown like graphs and things and you know if you carry on going higher this can happen and if you do this, then that will happen. So it kind of put the fear of God into me a bit... [T1-QOL-03]*

Fear was also apparent in the daily struggle to stay on top of dietary requirements by not eating too many sugary treats at the wrong time. It might also occur concerning the issue of whether to use an insulin pump (see 4.1.3); and, if worn, whether it might be visible to others, causing anxiety concerning appearance. All of these concerns potentially causing a detrimental effect on quality of life.

Reflecting on the fear, negativity, discomfort, isolation and loneliness that young adults with type 1 diabetes sometimes experience in aspects of living with their condition should play a key role in helping to influence future policy. Concerning both improving HRQOL via treatment and support and also helping to assist in deciding how the role of technology might help to improve these issues.

#### **5.4.2 Patient Experience – Concerning their treatment**

Concerning their treatment, there was an awareness in interviews that young adult points of view were not being taken into account regarding all aspects of their care and that their opinions and suggestions were not always listened to (see 4.1.4). There was

also a feeling that they were never asked for their opinions; rather, discussions tended to focus on telling them specific information (see 4.1.4). NHS Direct in particular came in for scathing criticism (see 4.1.4), as opposed to interviewees slightly more positive than negative perceptions of the clinic itself (see 4.1.4). Comments included a lack of listening to the patient's point of view; being patronising and arrogant; not being of any help; and being seen as stubborn and not prepared to consider the views of the individual:

*P: I find a lot of doctors quite, I do not know what the word is erm, they just, they think that they know your diabetes better than you do... [T1-QOL-04]*

With some doctors viewing the interviewee as a condition, rather than as a person:

*P: But the NHS, as much as they mean well they, they're too textbook. They do not know you as a patient, they know you more as a sort of condition... [T1-QOL-08]*

This highlighted the serious issue of these actions causing some interviewees to avoid certain aspects of possible support within the health service, due to these negative perceptions or previous experiences of bad care or support.

Very occasionally, mention was made of issues, which were not being addressed at SWDC, even though they had been raised more than once. But in general these seemed to be exceptions rather than regular occurrences (see 4.1.4). Concerning their condition, there was a strong feeling expressed that although the condition might be the same, the experience of living with it was completely different for each person:

*P: ...no-one, no two people are the same with diabetes, everybody is different... [T1-QOL-08]*

Therefore, some viewed the group approach of education as being difficult to make work within a clinical course environment and had a preference for more personalised discussion. Especially if they wanted to discuss sensitive topics, or subjects that might require different responses in terms of support, depending upon the individual:

*P: ...in a group there probably might be one person that does not even drink and there'll be another one who goes out five times a week, so, I think, in terms of that you need personalised information... [T1-QOL-04]*

Negative opinions on the clinics interviewees encountered included contradictory information being received in different health settings concerning topics like guidance on what to do when ill (see 4.3.3). Also, being overly critical (in the view of the participant) regarding issues like weight (see 4.1.4):

*P: I mean like I know that I need to eat healthily and not, you know put on too much weight but I'm still at the kind of weight where I've got enough of, I've got, I've got plenty of leeway, I do not need to be told to keep watching it, it just causes me to get paranoid...[T1-QOL-02].*

The age of the patient at the time information was initially given to them sometimes caused misunderstandings or confusion at the time, which were not communicated and then subsequently, at a later age, incorrect assumptions were made about what they might or might not know:

*P: ...and I think, because I was so young that no-one really explained it properly. And then later on, they just assumed that I already knew like, how it worked and stuff... [T1-QOL-07]*

This being particularly difficult for the patient to address if they were shy and retiring during clinic appointments (see 4.1.4). In terms of the tone of clinic staff, some participants wanted a tougher approach to make them appreciate the risks of type 1 diabetes more fully (see 4.1.4). However, some participants felt that clinic staff had occasionally strayed too much the other way in their approach. Appositely, some interviewees did not enjoy the 'tough love' style of delivery when being passed information, as this could cause resentment about the way in which it was given to them (see 4.1.2). At a younger age this could have implications (Lamb 2012); as during teenage years, those who wanted to rebel against older people who told them what to do were more likely to ignore this approach, even if it had their best intentions at heart (see 4.1.2). Other issues noted included the problem of a gradually waning desire to improve

(see 4.1.2), as despite interviewee's best intentions of wanting to try and treat their condition with more care, this feeling gradually dissipated once they were away from the clinic:

*P: I'd leave here...even now leave here and then think I'm going to do this and do that but then within two or three days when you're just back to your old routine or like back at Uni it's not, it's not always the same so it's like trying...I do not know trying to put the two things together... [T1-QOL-03]*

There was also a slightly cavalier attitude sometimes expressed toward wanting to initiate improvement - which Lamb (2012) equated to the nature of the adolescent ego - leading them to believe that they were immune from harm - even when they knew particular actions might be risky:

*P: ...if I do not feel sort of dodgy with it, then I'll leave it, I do not feel the need to do it, what's the point in pricking yourself in the finger if you feel fine? [T1-QOL-08]*

Reflecting on instances of poor service from NHS Direct and highlighting the rudeness and arrogance experienced in some cases has a vital role to play in affecting future policy. As has the ability to re-examine clinical administrative procedures to ensure that any mistakes or procedural gaps are documented and addressed. Policy concerns should also investigate and address ways of recognising and personalising the individual information needs of each young adult; in terms of the approach for information giving and receiving. Paying particular attention to the age and profile of sensitive individuals who might be more vulnerable and realising that this character aspect might not always be apparent during appointments. What is most important from a policy point of view is that the best possible treatment is given to young adults whenever and wherever they are interacting with health services and considering where technology might have a role to play in assisting at both ends of this relationship.

### **5.4.3 Patient Experience - How others viewed diabetes**

Many troubling experiences were documented by interviewees (see 4.3.4), regarding instances in their life when people had not known what to do, or had exhibited extremely

poor knowledge of the differences between type 1 and type 2 diabetes:

*P(S): The teachers, all the teachers in different lessons do assume. They tell people that people get diabetes because they're fat. And that's only the other type of diabetes you know, but it's not even causes that either... [T1-QOL-03]*

In some cases this had resulted in a worsening of symptoms for an individual, which could have been prevented without the need for calling for an ambulance (see 4.3.4). In another incident, this had nearly had fatal consequences (see 4.3.4).

Reflecting on these experiences, it is important for future policy to include creating a much greater awareness of the differences between type 1 and type 2 diabetes and providing better education and training on the problems that might occur if someone has these conditions to certain key groups – like school staff. Improving public awareness of the risk factors for diabetes being something that the PAC report on the management of adult diabetes services in the NHS has also previously recommended (Commons Select Committee 2012).

#### **5.4.4 Patient Experience - Picture represented by others**

The way in which some groups expressed their opinions about diabetes was deemed to be overly positive by some interviewees (see 4.1.5):

*P: ...but again it always uh (laughs)...I'm not a pessimistic person but it's just very, very positive and you know, like obviously it would be but, it's not like, a very truthful response... [T1-QOL-03]*

This had the effect of turning them away from using services provided by these groups. There seemed to be a perception with some organisations (see 4.1.5) that these feelings were not able to be properly expressed. It was almost taboo to mention negative opinions and to be able to openly discuss why their control and measurement was not as good as it could be. Surprisingly, the number of interviewees who had not engaged with Diabetes UK (or who actively sought to avoid it) outnumbered those that did (see 4.1.5). This is perhaps because of negative perceptions toward the organisation and its profile - associating and grouping it together with government and health services - and also the



feelings of the interviewees, concerning the picture of the condition that they were painting (as opposed to their own individual views on what it was like to live with the condition):

*P: ...my assumptions of it were, it was either doctors or the government making, trying to make good with the whole situation. I did not think it was very much patient submitted... [T1-QOL-08]*

Interviewees considered that a number of the features highlighted by organisations accentuated or over-accentuated positive perceptions of people with the condition doing incredible things that did not connect with the typical lifestyle of a young adult with type 1 diabetes:

*P: There's always like in the Balance magazine, the you know, this person had a struggle but now they're walking up Mount Everest and they have, they've done everything and you think "everyday life people do not have that kind of thing". They do not really live like that... [T1-QOL-03]*

Reflecting on these comments, it might be prescient for some aspect of policy to refocus attention on making the point of stressing that is fine to be able to convey a negative view of living with type 1 diabetes, if that is what young adults want to do. Without being made to feel uncomfortable when talking openly about their problems, or, feeling unable to freely express their own views of living with the condition. Social media technology already allows individuals to freely express their opinions about anything, but could play an even more important role in allowing health related comments and opinion pieces to be made in a way which did not negatively impact on the individual (Williams 2000; Livingstone 2008; Ho et al. 2014). This would allow discussion and thoughts on these aspects of living with type 1 diabetes to be freely expressed rather than hiding them away, whether intentionally or unintentionally.

## **5.5 Limitations of this Research**

It is acknowledged that there are a number of limitations to this present research. Firstly, it only includes the lifeworld experiences and views of a very small number of qualitative respondents from the same SWDC, which therefore cannot be generalised. Similarly, a small number of individuals from the same centre provided ideas for development and initial feedback during the development of early iterations of the developed app; both young adults with type 1 diabetes and clinical staff were from the same centre. It is acknowledged that interviewing at another centre may well have provided different localised data responses based on that locale.

For post launch feedback, sampling through the use of online invitations and via patient support groups (see **3.6.1**) rather than through organised healthcare channels might have resulted in bias due to the self-selection of more motivated and technologically literate participants who may not have been representative of all users of the app (Nowson and Madden 2015). Furthermore, using online methods to recruit (see **3.6.1**), obtain survey responses from (see **3.8.9**) and interview (see **3.8.10**) participants did not allow for complete verification that those who responded had type 1 diabetes, were in the age group required, or had actually used the app. So there is a minor possibility that some post launch questionnaire responses might not have been from the intended population (Pulman and Taylor 2012). Although no responses suggested this was the case, this problem is also recognised.

At the time of recruiting for post launch feedback participants in October 2013 (see **3.8.11**), the alcohol app had been downloaded 1,164 times worldwide. It is acknowledged that obtaining such a small percentage of qualitative feedback post launch from 0.94% of this user base ( $n=11$ ) might give an inaccurate overall perspective of the potential for its use at this point. For example, current device installs versus total user installs on the Google Play Store have shown that 75% of downloads were deinstalled at a later date (see **4.4.15**). This negative download pattern requires further investigation to understand why this might be occurring.

It is also noted that the app was not used as a part of any strategic intervention (either at SWDC or elsewhere) and the use of it alone should therefore be considered less likely to provide sufficient support to enable users to change their intentions and behaviour.

Although it is instructive to reflect on how HRQOL could have been impacted positively in this group, as this was a qualitative study there was no attempt to quantitatively measure the impact in relation to participants within the study (see **2.2.1**). Therefore, future research could directly focus on a larger scale mixed methods approach, which would be able to specifically investigate and measure any HRQOL impact associated with usage of the app both locally and globally across the user base; and also investigate benefits or problems that have arisen from using it within a mobile environment.

These aspects are all acknowledged as limitations and the author does not wish to generalise the findings beyond the particular set of participants included within the present research.

## 6 Conclusion

### 6.1 Introduction

My research question was:

*How do young adults with type 1 diabetes interact with technology in their lives and in relation to their condition and how can their views and experiences inform the development of a patient-centric mobile health app?*

During this present research I undertook a series of literature reviews (see **2.1**) and participated in a number of discussions with clinical staff at a local diabetes clinic (SWDC). I identified a need to investigate young adults aged between 18 and 21 with type 1 diabetes and their use of web and mobile technology, as published research considering their views in the use of technology to support their condition was sparse (see **2.6.2**). The aim of my research was to develop an insight into their current use of technology and its potential impact on their life. I wanted to explore how they felt about using technology and whether it might enable them to engage in an improved way with the NHS and their own health in the future. This would be achieved by forming a detailed picture of their day-to-day experiences using qualitative interviewing; exploring how they made use of technology in their lives and in relation to their condition and treatment. Following this, I used sociotechnical design principles to build something which could be of use to them, whilst continuously seeking their opinions on the design and usefulness of the product during all stages of development (see **Figure 1**); thus contributing to methodological practice. Prior to this study, as Mulvaney et al. noted (2012) little was known about how young adults used mobile phones for their diabetes and only a small proportion of apps had at that point been the subject of any research (Holtz and Lauckner 2012). This research enabled a contribution to be made to new knowledge in three areas:

- Contribution to young adult lives (see **5.2**).
- Contribution to technical development process (see **5.3**).
- Contribution to policy (see **5.4**).

## **6.2 Methodological Contribution**

As specified in the aims and objectives (see 3.1), this present research hoped to counter the problem of the potentially dehumanising implications of technology (Galvin and Todres 2013). By creating a new framework (see 2.6.3) that was based upon understanding what it was like for young adults with type 1 diabetes, which had the potential to humanise by developing particular technology sensitive to their experiences. Sensitised (see **Figure 1**) by theoretical perspectives, I was aiming to contribute to lifeworld-led development and approaches to care (Todres et al. 2007) by developing a patient-centric mobile phone app for alcohol education. By including young adults with type 1 diabetes in the process of generating ideas and asking them to use and feedback on a number of developed iterations (both before and after launch), I was intending to provide a humanly sensitive approach to their healthcare, which also gave them an active part in iterative development - something which most previous studies had not allowed for (see 2.6.2). This technique used sociotechnical approaches as a valid means of collecting data for designing systems to be used by patients, but which also continually referred back to them throughout the whole design process (including before and after launch). This present research therefore provides a new contribution to an approach for effectively integrating qualitative research with sociotechnical design principles. Creating a technological solution where a more humanly sensitive approach to healthcare had been effected, in both the design and substance of the final product developed.

## **6.3 Contribution to Knowledge and Implication of Findings**

### **6.3.1 Contribution to Young Adult Lives**

The global rise in usage of mobile technology and the emergence of new devices offer many exciting opportunities for developing a variety of different diabetes resources aimed at practitioners, carers (their parents when young) and young adults with type 1 diabetes. However, care must be taken to ensure that any information provided through

such devices is accurate, and that any adapted forms of delivery (like apps) take fully into account the specific needs of the individual. An app requires careful design to suit the mobile platform and consideration also needs to be given to how effectively apps might be regulated, deployed and used across different healthcare settings and how they could be supported technically. We need to consider the relationship to technology that young adults with type 1 diabetes have (see **5.2.1**); then reflect on how this might be able to make a difference to them (see **5.2.2**); but also consider when it might not be a suitable mechanism to use, by thinking about the individual differences in the use of technology within this age group (see **5.2.3**). By reflecting on these areas, anything that is going to be created in technological terms is going to be a much more usable and suitable product for the people who will be accessing it. Effectively reflecting on the tenets of good sociotechnical design when related to the creation of new mobile health technology. That democratic and participative communication and decision-making must always be available to give those people a chance to contribute their views, opinions and ideas (Mumford 2006) - before, during and after development. Secondly, listening to, reflecting on and responding to these comments and experiences of use in a continual iterative cycle to maintain and ensure currency, practicality and usefulness. This approach being demonstrated by asking participants for ideas which would be of use to them during initial ideas generation (see **4.2 - 4.4**). Secondly, by listening to and considering their views and feedback on the prototypes (see **4.4.4**) and launched product (see **4.4.11 - 4.4.17**).

The general cultural impression of social media is that it encourages people to use it. So, it is interesting to note that there are many reasons why the target age group is not always inclined to use it as a mechanism for obtaining information and support for their condition. The belief that users of this age group were happy to share every aspect of their personal life on Facebook was also contradicted. Some interviewees only wanting to use forums for talking to friends about their life away from type 1 diabetes, rather than using it for diabetes related searches and communal group discussions. It seemed as if the amount of discussion in the media about certain social media tools like Twitter was in some cases harming its ability to attract this group towards using it. Notably, not all interviewees were desperate to engage with new social media tools if they did not appeal to them in some way. The age when most interviewees obtained their first mobile phone was noted to be increasingly younger than previously. From nine or ten onwards,

this generation viewed their phone as a constant companion, whether accompanying them at play, through school, to university and work. Newer smartphones had gradually replaced other electronic media that interviewees previously owned like MP3 players, laptops, cameras and paper based items like diaries. In some cases, the closeness of technology to the young adult had already led to it being used innovatively in relation to their condition (such as using alarm functionality as reminders to inject). Apps were quite a new development and for some they had not really made much use of them to date. One of the reasons for this was financial and because they were frightened about the implications of creating an account, or because there was a reluctance to pay for an Internet connection as a part of a mobile contract. If cost was not an issue, some would be more likely to engage with using diabetes app technology. The main benefits mentioned by interviewees of using diabetes apps tended to focus on the ability of them to replace existing paper based information - like logbooks and books - which they had previously carried around with them. However, there was a feeling that most current apps, although helpful, were not actually worth using. This could be due to the cost; the design, flexibility and usefulness of the apps themselves; or the lack of a cohesive guiding framework for using them, which lacked the involvement of a clinic.

The strength of this present research is that it provides much useful and new information on how a mobile educational tool might be effectively designed and used for young adults with type 1 diabetes and what some of the important issues are around its use and usefulness. It also helps to build an enhanced understanding of young adults with type 1 diabetes experiences and requirements. It provides readers with an idea of what this age group might make use of; what is not being provided to them in a format and design style that they require; and what they would like to benefit from in terms of future technological type 1 diabetes education and support, which could help to improve their lives and reduce the burden of healthcare. The need is there and has been highlighted - we just need to create the right and proper technological solutions that this user base is asking for. It is vital that proactive patients and practitioners start looking at the technology around them and reflecting on whether they could apply it within their own life or practice in innovative ways. Rather than waiting for technologists to take the lead, as they do not have the required medical knowledge that is central to improving the patient experience. Future developments concerning the use of mobile phones and health apps must reflect and focus on how this generation has become accustomed to making use of

them already (see 4.1.6 and 4.1.7) and where new developments might therefore fit best. Acknowledging that this will not naturally be successful in every circumstance; depending upon the personal circumstances and preferences of each individual. The approach taken allows a wide range of enhancements to be addressed, which could help to improve lives but that will also be used regularly (see 4.4.15) and perhaps help to make a difference for the people likely to be using them (see 4.4.16). As has been discussed, the sampling size is relatively small in qualitative research, with detailed interviews and immersion in the culture providing a deep understanding of the subject being researched; making a large sample size unnecessary (see 3.6.2). However, it should also be acknowledged that this study only includes the lifeworld experiences and ideas of a small number of qualitative respondents from the same diabetes centre during development and feedback before launch; and, a small number of external users feeding back on the usefulness and use of the app after launch. As such these aspects should be seen as a reminder of not generalising findings beyond this particular set of participants (see 5.5).

### **6.3.2 Contribution to Technical Development Process**

As has been discussed (see 2.6.3), due to their mostly commercial nature there is little research available relating to the design, development, implementation and use of health apps in the UK and of the regulatory procedures available for their approval and monitoring (see 5.3.1). This present research provides an excellent example of a clinically valid, patient-centric design pathway and structure to follow at a local trust level, working closely in conjunction with a health provider (the SWDC) on the design, development, testing and implementation of a patient focused educational health app. It has also been able to highlight and pinpoint some of the problems inherent in the current infrastructure, which might be potentially dangerous to patients and other health users (see 5.3). The sociotechnical approach utilised provides an excellent example of how patient education with an aim of improving lifestyles can be designed in a way, which meets the needs of a particular long-term condition. An innovative, humanising approach, which at its heart values and encourages the continual input of people with the condition to assist in the whole iterative creative process - before, during and after development. It is to be hoped that dissemination of this present research will assist in highlighting a more patient-centric approach to the development and production of high quality, health-based mobile apps which can be applied with appropriate consideration to



other LTC and health issues. This approach and these issues have also been highlighted in some of my presentations and publications to date (see **Appendix S**).

Albeit more slowly than the US Food and Drug Administration (see **2.5.3**), steps are now gradually starting to be taken to formulate policy concerning how the NHS and DoH address the issues of health and medical app approval, regulation and development. This has the potential to positively impact on both patients and practitioners. The NHS Commissioning Board Health App Library project (see **2.5.3**) provides the first UK trusted listing of online health tools, which could help improve health and care outcomes as well as enable the growth of an online health developer community. Whilst acknowledging that it is beyond the realms of the current NHS IT infrastructure to successfully create and develop all health apps that will be demanded by government policy; health initiatives; medical education demands; and patient requirements, it is at least a positive starting point that will help to address some of the more pressing issues documented. These include managing the regulatory infrastructure (see **5.3.1**); ensuring clinical information currency - such as future clinical changes in legislation or guidance being considered (see **5.3.2**); ensuring that health and safety requirements are being met (see **5.3.2**); restraint of use issues (see **5.3.3**); and interoperability and conflict of interest considerations (see **5.3.4**). However, there is still a long way to go and there are many areas which need to be considered, such as country-wide local regulation adherence; adequate recall procedures for medical apps; considering and resolving patient data storage and privacy issues; and re-evaluating how social media can be sensibly and sensitively used in the light of continuing growth in use of this technology by both patients and practitioners. Also investigating and issuing guidance on potential issues of interoperability and conflicts of interest (Nolan 2011; Husain 2011; Todd 2012; Wake and Cunningham 2013). The sheer scale of which will be too much for the NHS and DoH to handle independently and respond to effectively; particularly in light of the need for them to focus on providing first class health care as their top priority and reduce costs in all areas of their current service. Unfortunately, this might result in some potentially dangerous and ethically damaging consequences in the medium term (see **5.3**), whilst structures and policies are considered, planned and debated prior to being implemented.

### 6.3.3 Contribution to Policy

Morse (2012) believed that one of the most compelling reasons for conducting qualitative health research was a moral one. It is clear that current and past research has given little opportunity for the opinions of young adults with type 1 diabetes to be heard (see 2.6.2 and 2.6.4). However, given the poor current reputation of diabetes care across the UK (see 2.3.3); the potentially costly implications to future health services (see 2.3.1); the continuing lack of improvement of self-management at a young age (see 2.3.4); and participant attitudes and opinions in relation to their diabetes and illness (see 4.3.3), hypos (see 4.3.4) and alcohol (see 4.4.2), it is vital that their views are listened to and most importantly heard. Morse (2012) suggested that qualitative health research is conducted to see what is going on from the perspective of the patient - to provide rich, inductive description, and to interpret those descriptions. My research aimed to give young adults aged between 18 and 21 with type 1 diabetes a chance to air their views, opinions and ideas during qualitative interviewing (see 4.1). These could then be used to create technological innovations (see 4.2 - 4.4), which might benefit them in some way by the interpretation of their personal ideas and experiences (see 2.6.2). Then, secondly, help to influence future policy on their actual requirements and the problems that they had previously experienced. This could be achieved by highlighting areas where care and support was lacking, or where there may be gaps in knowledge and understanding (see 2.6.4).

Whilst interviewee's care at SWDC was deemed to be generally good, there were a number of areas referred to that could help to feed into the policy for improving services to this age group. Concerning their type 1 diabetes, there was a strong feeling expressed that although the condition might be the same, the experience of living with it was completely different for each person. Reflecting on the fear, negativity, discomfort, isolation and loneliness that young adults with type 1 diabetes sometimes feel - in the past, present and future - should form an important part of helping to influence future policy concerning improving their lives via treatment and support. It should also play a part in helping to decide how the role of technology might help to improve these areas. Policy could be informed on helping to make the day-to-day lives of young adults with type 1 diabetes more positive, starting from their diagnosis onwards through to daily management and control to help address some of the issues discussed (see 5.4.1). Technology can help to make a difference by connecting them with others who have the

same condition through social media to counter loneliness, negativity and isolation. It could provide helpful supportive information in new innovative ways to counteract fear and by improving on the existing design of diabetes equipment; it could help to make taking blood readings less painful. The people involved in the care and diagnosis of young adults also have an important role to play (see **5.4.2**). There was awareness in interviews that the young adult point of view was not being taken into account in all aspects of their care. There was also a feeling that they were very rarely asked for their opinions – rather discussions mostly focused on telling them specific information. Reflecting on the examples of poor service mentioned by participants regarding their use of NHS Direct is a policy issue that needs to be addressed urgently as it had caused a fracturing of the relationship between the interviewees and this aspect of the health service in some cases. Technology could help here, by highlighting aspects of care that were not up to standard in a similar way to the independent website Patient Opinion (2013). Whilst the services within local clinics were perceived as being a lot better (see **5.4.2**), there are still aspects of care which could be changed to improve this service. This could be achieved by revisiting current administrative processes, which might cause problems - such as communication on equipment issues like the insulin pump problem mentioned by one participant (see **4.1.4**). Also, by investigating how to improve the methods of personalising information given to each individual - especially important when addressing sensitive young adults. Interviewees discussed instances in their life (see **5.4.3**) where they had come across people who either had no idea about the differences between type 1 and type 2 diabetes (such as teachers), or had no awareness of the possible complications that might affect individuals who had type 1 diabetes. In some cases this lack of knowledge might have proved fatal and had occasionally caused the wasting of health service time. These circumstances could have been improved if the requisite knowledge was available at the time, so it is crucial for future policy to include building a much greater awareness of the differences between the two types of diabetes and providing more education and training to certain groups on the problems that may occur if someone has these conditions. An area that the PAC report (Commons Select Committee 2012, p.11) also alluded to. There is also a need to address the concerns of interviewees regarding their views on the overtly positive message being communicated about type 1 diabetes (see **5.4.4**). Participants felt that this was giving a falsely positive overall picture of living with type 1 diabetes and that it was difficult if they wanted to reflect their own personal views, which might have an

occasionally more negative slant during adolescence (Lamb 2012) - such as discussing why their control and measurement was not as good as it could be. This message needs to be fed back to charities like Diabetes UK, who might not realise that this has had the effect of preventing some of their potential young adult user base from making use of some of their services for help and support. Attention should be focused on explaining that is acceptable to sometimes convey a negative view of having type 1 diabetes (if that is what young adults want to do), without being made to feel uncomfortable when talking openly about their problems. Or worse, preventing them from being able to truly express their own personal views on living with the condition.

## **6.4 Future Research**

### **6.4.1 Diabetes Technology**

This present research has revealed a number of possible future research avenues, which are not yet addressed in literature. One of the most interesting concerns the launch of the innovative iBGStar (Sanofi 2011), the first Capillary Blood Glucose Monitor (CBGM) that could be used on its own or connected directly to an iPhone or iPod Touch to display, manage and communicate diabetes information. A device which also works in conjunction with a specifically written self-management app (Tran et al. 2012). This CBGM is only currently available to buy in the UK, rather than being issued for free through clinics. However, there is an interesting area of research concerning whether this CBGM, once purchased, benefits young adults with type 1 diabetes in association with the app technology provided for use alongside it. This project might help to build on some of the work that this present research has documented.

### **6.4.2 Mobile Technology - Existing Developments**

Limitations have been discussed fully. Whilst a number have been documented, one important limitation is that I was unable to formally test the impact of the innovative tool developed (see 5.5). However, future research projects can help to address this by formally measuring the impact of the app globally using a validated HRQOL measure which takes into account the post launch feedback received - which provides an initial understanding of how, where and when it is being used and its perceived effectiveness

in providing useful reusable educational materials to the target audience. This could then feed into a hypothesis around a more sustained and targeted intervention approach (Barnard et al. 2014), which could include some form of quantitative measurement. This might involve a specific goal such as using a new iteration of the app to help improve participant knowledge of alcohol and the carbohydrate content of drinks. This knowledge being particularly poor in young adults with type 1 diabetes according to recent research (Barnard et al. 2014). Future research might also consider investigating any longer term benefits or problems, which have come from using the app. As of July 19th 2015 - two and a half years on from initial release - the alcohol app has now been downloaded 2,639 times worldwide (with 2,574 Apple and 65 Android downloads - deinstalled app figures are not included). This means that the user base is now large enough to warrant further detailed research on app usage. The sizable negative download patterns identified by Google Play Store statistics on deinstallations of the app and acknowledged limitations with the small sample size of post launch feedback (see 5.5), both highlight a need for a wider and more detailed investigation of how the app is currently being used or abandoned after the initial download has been performed. Understanding usage trends over a longer period of time and evaluating whether closer integration with clinic visits or education, or, incorporating more interactive app features (such as push technology or additional content) impacted on this trend would also be a valuable research project to undertake. A further iteration of the app is also planned to address minor bug issues reported so far. It is also planned to continue development of the prototype app for hypoglycaemia (see 4.3.4) and progress it through the same approval process as the alcohol app (see 3.8.6). Research could also be undertaken on porting the existing app functionality over to be used on wearable technology like the Apple Watch (Apple 2015) or integrating it with the newly launched ResearchKit (Apple 2015), an open source software framework created specifically for medical research. Then, evaluating in more depth if this new form of technology might better interact with the target audience.

### **6.4.3 Mobile Technology - New Developments**

Future developments concerning the use of mobile phones and health apps should reflect and focus on how this generation has become accustomed to making use of them (see 4.1.6 and 4.1.7) and where they might fit best - acknowledging that this will not be successful in every circumstance. For example, tailoring a new CBGM app to include

personalised information about insulin, weight, food intake, height and other useful data; but which avoided replicating the functionality of existing machines, which already contained the ability to record some of this data. Perhaps stepping back and taking a more pragmatic, logistical approach to some of the problems they experienced, by providing a tip sheet written for other parents and friends which could be emailed over to them as a PDF file; viewable on a mobile device prior to a sleepover when young. Providing calorie and carbohydrate counting material as a specially tailored e-Book or readable PDF file instead of as an app, so that it could be accessed without the need for an Internet connection via a quick, simple indexed system. Harnessing existing mobile phone technology in new ways to create lifestyle improvements, such as using push technology for pop-up reminders about insulin injecting, blood sugar level checking and remembering to eat something. Or by reacting much more quickly to the latest research findings and trends concerning young adults and type 1 diabetes in a proactive manner and being innovative in the ways in which new technology can be utilised which both complements and integrates satisfactorily with their existing use of web and mobile technology in their day-to-day life. A further limitation acknowledged was that more of the additional suggestions made for apps which could possibly enhance young adult lives were not able to be taken forward for development (see **4.2**). A bid is planned concerning the development of a health related app design and research centre - the core of which aims to build on the work already undertaken to this point. Further apps based on this present research can then be designed, tested, built and implemented using the same approach and then be subsequently measured for any positive or negative impact on HRQOL (see **6.4.2**).

#### **6.4.4 Dissemination and Presentations**

Presenting at conferences and writing articles for journal publication have helped to spread awareness of both the policy issues discussed (see **5.4**) and also the outcomes of this present research (Pulman, Hill, et al. 2013; Pulman, Taylor, et al. 2013). To date, a number of articles from this study have already been accepted and published in high impact peer-reviewed journals including Practical Diabetes (see **Appendix S**). In March 2013, I attended the Diabetes UK Professional Conference in Manchester. Three posters about different aspects of this present research (Pulman et al. 2013a; Pulman et al. 2013b; Pulman et al. 2013c) created in collaboration with colleagues from SWDC were presented as posters (see **Appendix Y1**, **Appendix Y2** and **Appendix Y3**).

Attending the conference allowed me to investigate possible opportunities for future research and development in the area of mobile diabetes apps and also more importantly to discuss my study and the issues emerging from it (see **6.3.1** to **6.3.3**). I was also able to meet other technology developers to discuss shared areas of interest and distribute promotional mini cards which increased awareness in the app and the methods used to develop it. In addition to highlighting some of the papers written around the development (see **Appendix S**). I also ran a Café Scientifique event at the BU Festival of Learning in June 2013. In an informal environment, participants were able to chat with me about their own interests in this area and ask questions about aspects of the study and the methods employed. These events are the beginning of a process that aims to reach and influence people who might be able to take the messages from this work and integrate them within their own practice; or, alternatively affect the policy decision-making process. In this way it might help to make some further positive difference to the lives of young adults with type 1 diabetes.

## **6.5 In Conclusion**

Whilst recognising and acknowledging the limitations of this study, I present this thesis as a valid contribution to new knowledge, which adds to the existing body of literature and assists in the future improvement of young adult lives with type 1 diabetes by:

- Providing a detailed understanding of how young adults with type 1 diabetes live with and experience their condition and how they make use of web and mobile technology and the way it impacts on their lives both socially and for health.
- Detailing ideas partially developed as prototypes and ideas not developed within the study timeframe that offer new suggestions for potentially life enhancing technological solutions for young adults with type 1 diabetes.
- Discussing and reflecting on the development lifecycle and the procedures, processes and sociotechnical theories involved in the creation of a patient-centric educational alcohol app for young adults with type 1 diabetes. An approach that could also be utilised in relation to providing education and support to others with different LTC and health issues.

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