University of Strathclyde

Faculty of Science

Department of Computer and Information Sciences

Diane Cochrane

MPhil
2018

Understanding the motivators and barriers for adolescents using digital diabetes technology to manage glycaemia in type 1 diabetes

Supervisors :	**Dr Marilyn Lennon,**
	Dr Alison Kirk
Date of presentation :	**September 2018**

Declaration

This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree. The copyright of this thesis belongs to the author under the terms of the United Kingdom Copyright Acts as qualified by University of Strathclyde Regulation 3.50. Due acknowledgement must always be made of the use of any material contained in, or derived from, this thesis.

Signed:

Date:

Acknowledgements

I would like to extend great thanks to my supervisor’s Dr Marilyn Lennon and Dr Alison Kirk for their continued support, encouragement and assistance. In addition, great thanks go to the families and children who participated in my data collection interviews, and activities, and who shared their experiences with me so candidly and warmly.

Additionally, I would like to thank the Digital Health and Wellness Research group (University of Strathclyde) and the Digital Health and Care Institute (DHI) Scotland for their insight, inspiration and enthusiasm in an industry, which is taking leaps forward to support those living with chronic illness. Along with Diabetes UK and Diabetes Scotland for their continued support through local support groups and opportunities to meet new friends.

My loving partner, family and friends who have supported me throughout my research also have my heartfelt thanks and admiration for their love and patience.

Finally, I want to thank my children. To Katie, John’s sister for always supporting her brother with love and care, and to my son John - diagnosed with type 1 diabetes at age 4 and then coeliac disease at age 8, his immune system truly went rogue. For all the days he had no sleep, no patience, no motivation and felt completely exhausted living with type 1 diabetes – in the words of Bob Dylan for “keep on, keeping on”. He is my inspiration, he is my reason for this research and I wish for him a long, happy life with lots of love and support.

Love mum.

Abstract

Type 1 diabetes, a life threatening autoimmune medical condition, affects over 370,000 people in the UK at present. It costs the NHS budget over £1bn annually. Of this population, the adolescent age group are at increased risk of morbidity and mortality issues. The focus of support from parents/caregivers is to achieve stable glycaemia. This support also involves daily interaction with technology to monitor glucose and prevent serious side effects of insulin replacement treatment.

This thesis qualitatively explored the lived experience of adolescents who live with type 1 diabetes, and the impact it can have on their families. Data was collected from interviews (n=7), an online survey (n=26) and a live opinion poll (n=19). The benefits and barriers of current diabetes technology for managing glycaemia in type 1 diabetes, were discussed. Four global themes were identified a priori based on the literature and a total of 34 emerging themes were revealed which contribute to a deeper understanding of the complexities of the use and acceptance of technology for managing glycaemia.

Throughout this research study, it frequently emerged that participant's experiences of technology were related to improvement of glycaemia, in addition to greater control over lifestyle and dietary choices. However, many barriers were also uncovered as participants spoke of the effects of inaccuracy of the current technology, which often led to severe episodes of hypoglycaemia/hyperglycaemia and diabetic ketoacidosis. Furthermore, visibility of wearing diabetes related devices, often left the adolescent feeling self-conscious and embarrassed. The adhesion of some current devices caused severe skin reaction, leading to reduced usage. Adolescents living with type 1 diabetes, and their families highlighted the need for technology to be predictive with warnings and alerts to prevent hypoglycaemia/hyperglycaemia.

In conclusion, this research study unveiled the complexities of living with type 1 diabetes for the adolescent, which they and their families experience. These complexities are strongly associated with widespread barriers found when using current diabetes technologies. Moreover, these barriers can lead to a withdrawal from use. Improvements in accuracy and application, and reduced visibility of technologies for managing glycaemia are needed to maximise user engagement and benefit.

Contents

List of Tables

List of Figures

Chapter 1 Thesis outline & Introduction

Type 1 diabetes is a chronic life-long, life-threatening medical condition. It is brought about by the autoimmune destruction of pancreatic β cells, which secrete insulin in vivo, as discussed by Nokoff and Rewers (2013). This metabolic impairment requires to be treated with insulin to sustain life - either by multiple daily injections (MDI) or continual subcutaneous insulin infusion (CSII - insulin pump). If undiagnosed, untreated or maladjusted, glucose in the blood can rise to life threatening levels due to insulin deficiency. The outcome of this can be coma and/or death (Chiasson et al., 2003).

At present, the economic burden on the NHS in the UK for treating type 1 diabetes, and associated complications, accounts for £1bn annually. Estimations show that these figures will rise dramatically by 2035 (Hex, Bartlett, Wright, Taylor, & Varley, 2012). Therefore, helping people cope with managing type 1 diabetes is a priority for future generations in the fight against preventing serious complications. There is much interest globally in developing technology which manages blood glucose for those with diabetes and those who manage their condition using insulin. Much of the population with type 1 diabetes will therefore be engaging with technology of some form or other - be it a glucometer or an insulin pump (this is discussed further in Chapter 2). According to Iyengar, Wolf, Brown, & Close (2016) digital health in diabetes is considered the “convergence” of health and technology. The presumption is that the connection of diabetes devices improves lives and brings useful data to aid care and improve health outcomes.

The World Health Organisation classify adolescence as between the ages of 10 years old and 19 years old. For this study, ages 12-17 years old were considered as adolescent, based on the educational, Secondary school age. The problem with the adolescent population living with type 1 diabetes is that of learning to engage with managing the condition; accepting the continual and relentless demands it takes to monitor glucose and normalising their lives alongside the role of technology in the management of glycaemia. All these factors affect glucose control (Hoey et al., 2001; Ziegler, Freckmann, & Heinemann, 2016). Added importance comes from the need for diabetes technology (including insulin pumps and glucose sensing devices) to be accurate and supportive in an appropriate manner (Francescato, Geat, Stel, & Cauci, 2012). Otherwise, there is increased risk of not only long-term ill health, and complications of the condition, but that also of survival.

Adolescents find it difficult to assume full control of the related tasks and very often require support from others as well as technology (Gray, Dolan, & Hood, 2013). However, as Dashiff, Vance, Abdullatif, and Wallander (2009) and colleagues reported, parental support and care can sometimes be seen in a negative light. This study highlights that “nagging” and “frustration” is often experienced in relation to managing glycaemia. Difficulties experienced by families, are deep and complex and can lie within health beliefs and behaviours toward coping (Seiffge-Krenke, Laursen, Dickson, & Hartl, 2013).

There are many different technologies available to assist management of type 1 diabetes. These include different types of insulin pumps, continuous glucose monitoring devices and supporting technologies such as SmartPhone Apps and social networking, which all play a part in helping the adolescent to understand and effectively manage the condition. More and more technologies become available to the patient each year, with different features and functionalities.

Exploring the adolescents’ experiences of current technological treatments has had little attention from the academic community. Previous research regarding diabetes technology have often focused on measuring improvements of glucose control with few addressing the need to understand the lived experience, and what impact this has on uptake and successful use.

The **overall aim** of this thesis is therefore to explore the barriers and motivators the adolescent (and their parents/caregivers) encounter when managing glycaemia in type 1 diabetes, using diabetes health technologies.

The specific **objectives** for the thesis are:

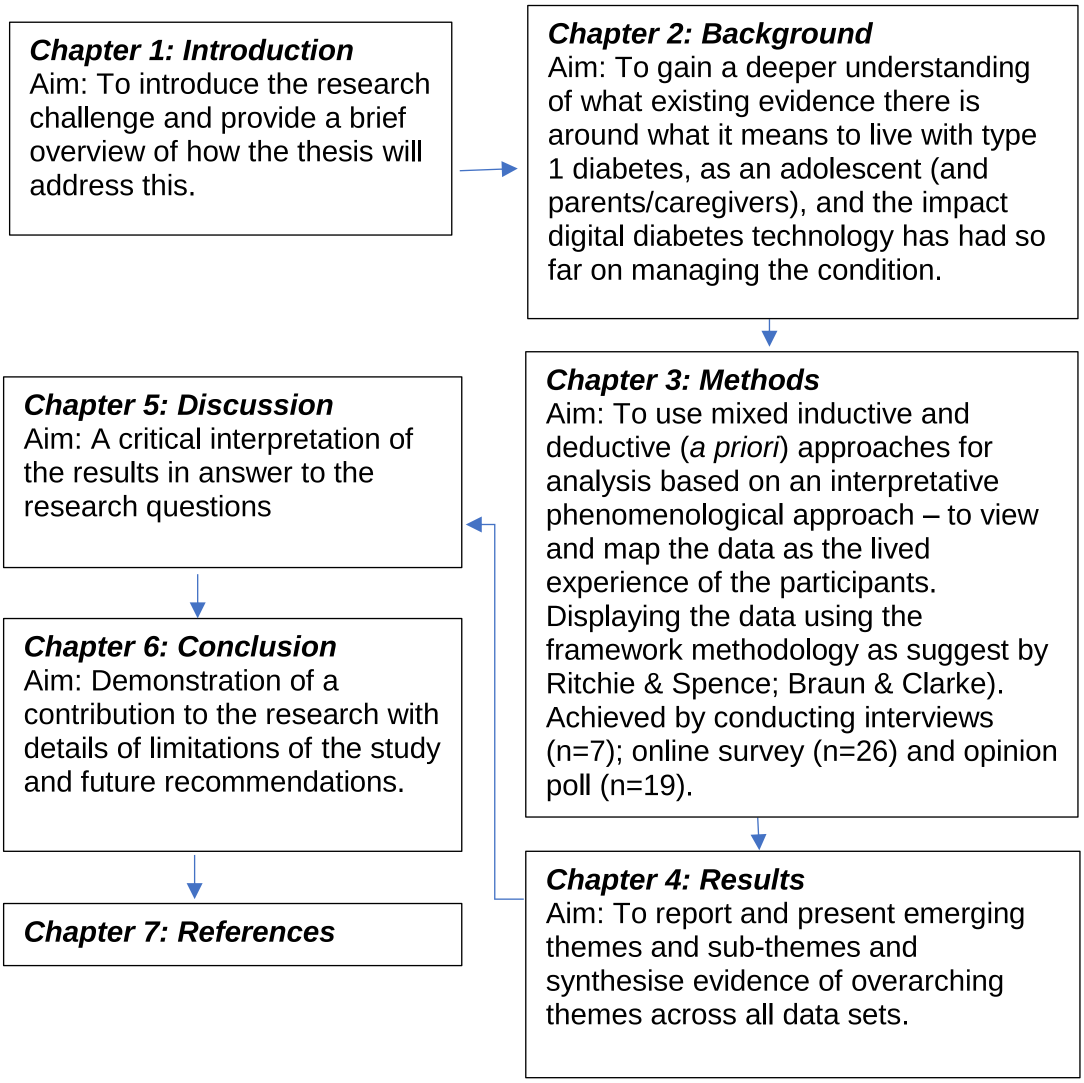
1. To understand the complexities of type 1 diabetes from the adolescent and parents/caregivers perspective.
2. To understand what technology is currently available for managing glycaemia in type 1 diabetes and what adolescents are currently using.
3. To explore current barriers and motivations the adolescent is experiencing towards managing glycaemia in type 1 diabetes.
4. To explore and map the views of the adolescent and their parents/caregivers with regards to future improvements of technology for managing glycaemia in type 1 diabetes.

Research Approach

This thesis was written from the perspective of a parent who raises an adolescent with type 1 diabetes and coeliac disease, and as a researcher with previous biomedical science experience. The wider scope of this research would be to look at the role that digital health technology will play in preventative medicine - meeting improved health goals within current care settings at home and within the NHS, to improve the health and wellbeing of adolescents living with type 1 diabetes. However, this thesis specifically aims to first understand the complex motivations, and barriers that the adolescent (and their parents/caregivers) experience in managing their diabetes and integrating technology into their self-management routine. Figure 1 illustrates the chapters included in this thesis.

With an a priori understanding of the themes associated with managing type 1 diabetes, an untangling of the data produced complex emergent sub-themes using inductive analysis. Methods used in this study involved interviews with adolescents between the ages of 12 and 17 years, using semi-structured questions relating to their current experiences of treating type 1 diabetes with technology.

Secondly, the research objectives were further tested by collecting data from an online survey, aimed at both adolescents and their parents/caregivers. Thirdly, opinion poll data was gathered at a registered charity event for families and children with type 1 diabetes. Each method adds additional layers of data to understand what the adolescent and their families' like/dislike/hope for the future surrounding diabetes glucose management technology. These methods will be described in more detail in chapter three.



Chapter 1: Introduction
Aim: To introduce the research challenge and provide a brief overview of how the thesis will address this.

Chapter 2: Background
Aim: To gain a deeper understanding of what existing evidence there is around what it means to live with type 1 diabetes, as an adolescent (and parents/caregivers), and the impact digital diabetes technology has had so far on managing the condition.

Chapter 3: Methods
Aim: To use mixed inductive and deductive (*a priori*) approaches for analysis based on an interpretative phenomenological approach – to view and map the data as the lived experience of the participants. Displaying the data using the framework methodology as suggest by Ritchie & Spence; Braun & Clarke). Achieved by conducting interviews (n=7); online survey (n=26) and opinion poll (n=19).

Chapter 4: Results
Aim: To report and present emerging themes and sub-themes and synthesise evidence of overarching themes across all data sets.

Chapter 5: Discussion
Aim: A critical interpretation of the results in answer to the research questions

Chapter 6: Conclusion
Aim: Demonstration of a contribution to the research with details of limitations of the study and future recommendations.

Chapter 7: References

Figure 1. Chapter outline.

Chapter 2 Type 1 diabetes

This chapter will discuss the elements of living with such a complex condition, and the implications surrounding decision making and task management, required daily for the adolescent with type 1 diabetes. It is essential to understand the management of the condition with regards to treatment, adolescence, maturity and associated barriers and motivations with technology which are addressed in Chapter 3 as part of a scoping review.

2.1 Type 1 diabetes - diagnosis and glucose metabolism

To understand the complexities of type 1 diabetes for the adolescent and their families, it is important to understand the tasks they require to perform to stay well and alive – compared to the healthy state. In this section, aspects of managing the condition will be discussed to highlight the change from the healthy state and the new responsibilities the adolescent finds themselves with every day.

Firstly, the beginning stages of diagnosis of type 1 diabetes are characterised by a blood or urine test showing signs of hyperglycaemia as described by Diabetes UK (Diabetes UK, 2017). The following stages of education on insulin replacement can be a steep learning curve as discussed by Murphy, Rayman, and Skinner (2006) . Awareness and understanding of the fully functioning pancreatic control of glucose metabolism, and the action of insulin, is the foundation of what families and the adolescent are educated to try to achieve daily, with different diabetes treatment types – such as insulin pumps and continuous glucose monitoring devices (explained further in this chapter). For example, a person who has a fully functioning pancreas can metabolise dietary and background (hepatic) glucose through the secretion of insulin from the pancreatic β cells. Insulin release is inhibited by the secretion of glucagon from fully functioning pancreatic α cells. Figure 2 gives background detail into the fully functioning scenario of glucose metabolism.

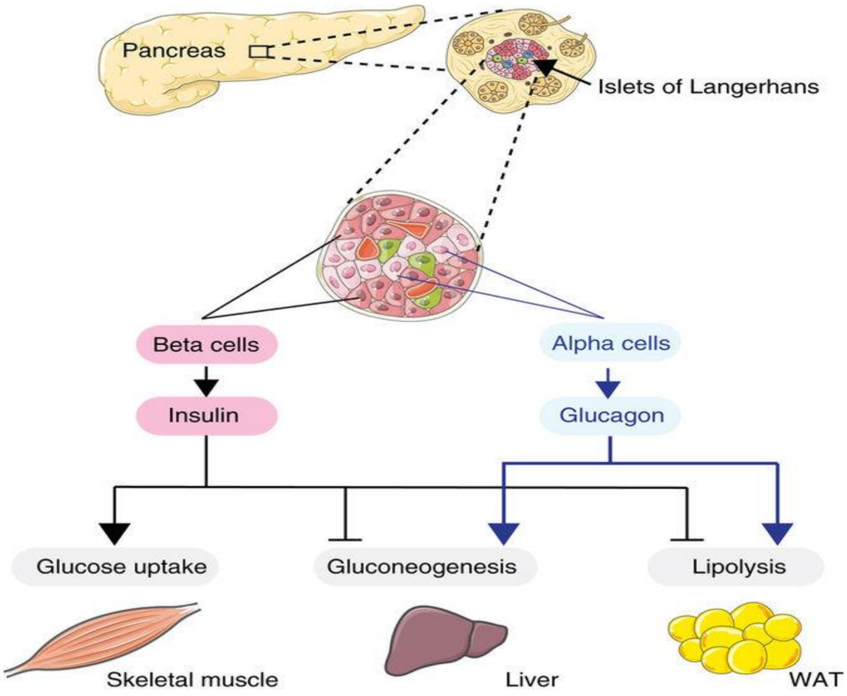


Figure 2. Regulation of glucose by insulin and glucagon from the healthy pancreas. Showing insulin allowing uptake of glucose to muscle tissue and glucagon action on white adipose tissue (WAT) and liver to raise glucose levels by lipolysis and gluconeogenesis. Image sourced from Ruud, Steculorum, and Brüning (2017).

An important message to take from this image is that the counter regulation of insulin secretion (glucagon delivery from the α cells) – acts to bring about balance and homeostasis. Vitally, in a person with type 1 diabetes, this counter balance mechanism diminishes over time, thus the hope is there for technology to help with the complexities of managing the condition.

Additionally, it is essential to understand that insulin has a very narrow therapeutic range – meaning that even the smallest amount of dose increase can bring about a severe reaction. Although it is necessary for life, it also must be managed meticulously at several points in the day to ameliorate side effects. Therefore, constant monitoring, every day is needed for safety and wellbeing. The adolescent now lives with the responsibility of monitoring glucose and replacing a lifesaving hormone – without reprieve, amidst navigating technologies.

As the incidence of this condition is known to be on the rise, discussed by Patterson, Dahlquist, Gyürüs, Green, and Soltész (2009), the future implications of the need for digital technology diabetes tools to support patients is paramount. Not only in managing to cope with changing blood glucose levels but providing people with a lifestyle in which they relied upon before diagnosis.

In order to manage insulin replacement, as to mimic a fully functioning pancreas, the person with diabetes must adapt to a way of life whereby they continually monitor blood glucose levels with technology and make decisions as to how to give suitable dosages of insulin. This is to enable the person with diabetes to achieve normal glycaemia (normoglycaemia) – and spend less time in hypoglycaemia (low blood glucose) or hyperglycaemia (high blood glucose).

Many variables can cause the administered dose of insulin to cause dysglycaemia – abnormal high blood glucose (hyperglycaemia) and abnormal low blood glucose (hypoglycaemia). Hypoglycaemia can be described as a state in which the brain (which relies on a constant state of glucose to function) becomes starved and neuroglycopenic effects cause impairment in cognition and function. The ability to maintain normal motor and sensory functions become depleted - to the extreme scale of severe seizure, or in fact death, if not treated with fast acting glucose replacement (Seaquist et al., 2013).

One main variable that can bring about hypoglycaemia in the person with diabetes can be a slight increase in insulin dosage (Zaykov, Mayer, & DiMarchi, 2016). Additionally, a lack of changing insulin dose by decrease/compensation for exercise (effects of aerobic respiration) is known to cause hypoglycaemia, during and after the period of activity. Other illness is also a vitally important factor in causing changes in glycaemia. Therefore, to safely achieve normoglycaemia, the person with diabetes has to be thinking of a reduction or change in dose on an hourly basis, i.e. before physical activity, in order to try to prevent this side effect of treatment (Cryer, Davis, & Shamoon, 2003).

2.2 Complications

Complications of uncontrolled glycaemia over time are well documented in research. The Diabetes Control and Complications Trial group (DCCT) conducted a large population trial of over 1400 people living with type 1 diabetes from 1983-1993. This involved a long-term clinical trial to evaluate and compare intensive insulin treatments to improve glycaemia and prevent complications. The complications associated with changes to eye health (retinopathy); kidney disease (nephropathy) and peripheral nerve damage (neuropathy) were measured over the duration. From this trial, intensive insulin treatment by pump or multiple injections showed that complications were decreased in the population. However, as a side effect of this hypoglycaemia risk was increased.

Overall the published results of the DCCT changed the future of diabetes treatment and is looked upon as a benchmark for comparative studies and implementation of policy to support the need for intensive monitoring of glucose. It is worth noting that the DCCT trial mainly focused on measuring biochemistry to publish results correlating to improved glycaemia and prevention of complications or progression. No other factors such as quality of life or psychosocial elements were reported (DCCT, 1993).

Quality of life measures in adolescents differ greatly from young children. With regards to younger children, the condition is managed by caregivers. However as children progress through their lives, the self-management role inevitably will ensue as pointed out by Doe (2016). Since the incidence rate rises more noticeably in children, this growing global concern, brings about demand for improved methods of management; preventative medicine and greater support (Imkampe & Gulliford, 2011). Moreover, in a population where the adolescent age group experience increased morbidities, effective diabetes management is imperative to improve the quality of life and reduce their health burden (Lansing, Berg, Butner, & Wiebe, 2016).

2.3 Influences on glycaemic metabolism

Factors affecting glycaemic control are not always connected with behaviours (Ingerski, Laffel, Drotar, Repaske, & Hood, 2010). Puberty itself can demand greater involvement in glucose management and dose adjustment each day. Forward planning to incorporate life choices, such as exercise, and perhaps illness, means that the adolescent must constantly think ahead, plan and adjust dosage. The rigidity of the regime in managing glucose can signify for a teenager a lack of control ironically. This in turn affects glycaemic control and the loop of negative moods and depression may quickly affect coping mechanisms (Davidson, Penney, Muller, & Grey, 2004). Furthermore, studies have shown that the age, sex and duration of living with the condition affects overall quality of life perceptions, which score lower as the length of time living with type 1 diabetes increases.

There are many studies pointing towards developing a better understanding of the psychosocial impact of managing blood glucose, indicated by the HbA1C result (described in section 2). The correlation between perceived autonomy and parental/caregiver support has a direct effect on overall glucose control (Pelicand, Maes, Charlier, & Aujoulat, 2012; Wysocki & Greco, 2006). However, as mentioned, adolescence comes with challenges linked to puberty such as; physical maturity; emotional development; developing neural pathways to problem solving and planning - aside from having a chronic medical condition to manage and cope with. Differing models of understanding of how the adolescent perceives their lives, support and interacts with others is discussed by Scholte, van Lieshout, and van Aken (2001).

2.3.1 Dietary control

This expansive area of treatment technique - counting dietary carbohydrates and matching these with appropriate insulin doses (**bolus**), requires ongoing education and training pertaining to reading dietary labels on food packaging. For those who use this method to manage insulin dosing an understanding of glycaemic indices; weighing contents of food using scales and using visual cues to guess carbohydrate content of meals is required (Finner, Quinn, Donovan, O'Leary, & O'Gorman, 2015).

From this education, the basis of treating type 1 diabetes with insulin, when it comes to food, is calculated on a carb: insulin ratio (CIR). That is, if someone eats a certain amount of carbohydrates, the insulin required to cope with the glucose load (as the carbohydrates break down into smaller molecules of glucose) is measure by how many parts insulin to carbohydrates eaten – for the blood glucose range to return to a normal range. This may look like:

1u:6cho

Therefore, the person requires 1 unit of insulin per 6 grams of carbohydrates eaten. This is often calculated by performing paired glucose readings. Paired readings involve the person with diabetes checking blood glucose before eating, and then two hours after eating. If the blood glucose is out with the desired range, then incremental increases of insulin are taken, to establish a safe ratio for that person. An adolescent with diabetes may have many ratios at separate times of the day, i.e. at breakfast a 1:3cho ratio and at dinner in the evening have a 1:6cho ratio. These important calculations are safeguarding techniques to calculate safe insulin dosages (Schmidt, Schelde, & Norgaard, 2014).

As discussed by Ziegler et al. (2016), making decisions on bolus insulin (the amount taken at mealtimes or to correct a high blood glucose reading) must be calculated with precision and accuracy. This can be difficult to achieve when the carbohydrate content of the meal is not known, and a certain amount of estimation must be performed. Additionally, the knowledge of how the action of the bolused fast acting insulin behaves, in relation to the glycaemic index of the meal, is regarded as intensive insulin management.

During puberty our growth hormone inhibits the action of insulin. If we become ill, our immune system can inhibit the action of insulin through many immune cell activators. These are known as counter regulatory hormones to the action of insulin. Therefore, the internal dialogue becomes very complex between this molecule and others. Taking this on board, we can now see that most of the time – counting carbohydrates and taking the appropriate insulin dose for said meal, is just one thing that an adolescent can try to control if they have the condition.

Therefore, knowing and understanding how to dose insulin for meals, and how it will affect blood glucose levels is only part of the picture. Importantly, it is difficult and can cause lack of glycaemic control, regardless of how hard the teenager and their parents/caregivers works towards the goal target range set by NICE guidelines (Borus & Laffel, 2010). This is a major important contributory factor in bringing about lack of motivation. Maximum energy and thought to try and control a condition, which has many underlying, unseen and uncontrollable factors other than dietary control. Although glucose metabolism is a vital metabolic microenvironment, that is managed so tightly with a healthy pancreas, trying to mimic this same task can seem like the work of magic or an art form, for those treating themselves with insulin replacement therapy (Jain, 2014; Sherwin & Sacca, 1984). In summary, one of the limiting factors in maintaining blood glucose control is to look at dietary glucose management. Taking a brief snapshot of one meal, one data set of carbohydrate amount, and dose given does not mean that the same rules will apply tomorrow, which gives an appearance that the person does not have "*stability*". However, as adolescents try to learn methods of self-management, education is highly focused on helping to count dietary carbohydrates. The variation in result from guessing carbohydrate count; delivery of insulin bolus; injection site issues or delivery style; glycaemic index; illness and prior or existing exercise regimes will all influence the outcome.

Therefore, the goal of not only using technology to count carbohydrates but the development of the mind-set; autonomy and level of maturity needs to be supplementary for the tool to be effective. Sometimes, education is not what is required – rather coming to a place of acceptance, insight and self-awareness (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Ingerski et al., 2010).

2.3.2 Exercise

Another important lifestyle choice in considering the assistance of technology, to help with blood glucose management, is the expansive field of maintaining a healthy life through exercise. For adolescents with type 1 diabetes, the measurement of how exercise will affect their blood glucose is one of trial and error. The approaches taken are considered by type, intensity and duration of exercise, in addition to current health status. Pushing endurance levels with insulin on board has to be taken with extreme vigilance, not only for the duration of the pursuit, but also for the short term future as exercise can cause remarkable hypoglycaemia for a prolonged period of time following extreme exercise (Riddell & Iscoe, 2006).

The profile of the internal glycolysis and needs of soft tissue, muscle and liver cellular functions is one of a complex environment that the body regulates tightly. In terms of management with on board infused or injected insulin – the counter regulatory environment may be lost in some and be unable to prevent side effects such as hypoglycaemia – as mentioned in section 2.1, when discussing the secretion of glucagon by the α cells to raise blood glucose (Riddell et al., 2017).

Considering this, the complex nature of prevention of hypoglycaemia/hyperglycaemia becomes again in the hands of the patient/parent/caregiver/healthcare provider to solve. As with dietary control, there are no set patterns, which are effective for the same sporting activities, for the same duration, and for all patients. Therefore, the degree of flexibility and snap decision making are called for again. It is widely known that fear of hypoglycaemia can be a barrier to exercise (Mitchell, Wilkie, Robertson, Reilly, and Kirk 2018).

2.3.3 Sleep

If the waking conscious day is filled with important decisions on maintaining glycaemic control for the adolescent, then also the sleeping, unconscious part of the day must be also. There is no miraculous cure at night time with such a complex condition - things can still go bump in the night, and very often do. Lack of sleep and quality sleep in those living with type 1 diabetes, and their night time caregivers' is very often overlooked in research (Monaghan, Hilliard, Cogen, & Streisand, 2009).

After interviewing over 70 parents, results showed that parents feel the strain of lack of sleep by very often testing their child's blood glucose levels once they have fallen asleep. This is often overlooked in research and requires more investigation from a clinical viewpoint also. The stress of lack of sleep and worrying about nocturnal hypoglycaemia in parents of children and adolescents is a huge burden for a family – one which technological advancements try to ameliorate / ease by developing alarm functionality.

The importance of quality of sleep is widely known to reduce stress, cardiovascular disease and anxiety (Hoevenaar-Blom, Spijkerman, Kromhout, van den Berg, & Verschuren, 2011). However, with type 1 diabetes this is not achievable. Adolescents very rarely would wish for a parent to enter their personal space in the waking day, never mind at night time when asleep, but the monitoring aspect of this condition requires vigilance whilst a child is asleep. Nocturnal hypoglycaemia can be greatly feared with patients who use insulin pump technology, the threat of quickly developing ketoacidosis during the small hours is the flip side of this fear - due to failure of delivery of insulin – i.e. blockages or technology failing with no alarm to warn that the patient isn't receiving any insulin. The careful balancing act of the adolescent receiving enough insulin to prevent either one of these severe side-effects with an insulin pump that is only as good as the user who programmes it, and the technological aspects related to its functioning (Gonder-Frederick, Nyer, Shepard, Vajda, & Clarke, 2011). Conversely, there is evidence to suggest that some patients and their parents feel comforted by reduced occurrences of hypoglycaemia when choosing CSII therapy as written by Pickup, Freeman, and Sutton (2011).

Additionally, having awareness of being in the hypoglycaemic state during sleep is essential for patients to wake and treat this life threatening side effect, and very often requires some sort of alarm system if there is no parent/caregiver to monitor this (Victor, Nejhdeh, Stanislav, Nirubasini, & Timothy, 2010). In current climates of technological changes, very often the algorithms and calculations for these predictive systems are tested rigorously (Eren-Oruklu, Cinar, & Quinn, 2010). Even in those who treat their condition using technology which alarms, the questions of the rate of false positives due to accuracy failures, and whether or not the patient can ignore the alarms, or sleep through them still occurs as a factor which limits effectiveness of the function of this technology (Shivers, Mackowiak, Anhalt, & Zisser, 2013).

2.4 National guidelines for health

Since the DCCT – mentioned earlier in this chapter, there has been greater understanding of the need to control glucose metabolism to sustain a longer, healthier life. Presently, there are guidelines in place by governmental sponsored health organisations such as NICE (National Institute for Health and Care Excellence) and in SIGN (Scottish Intercollegiate Guidelines Network) as part of the NHS health improvement programmes. These guidelines are formed from public health improvement, evidence-based research and current clinical practices.

Based on all this research, the evidence has proven that the risk of complications for a person with type 1 diabetes can be lessened if their control is closely monitored and targeted as close to normoglycaemia as possible.

The standard measurement for reviewing how well the blood glucose is being managed is taken from averaging the lifespan of a red blood cell, with glucose bound to the extracellular receptors. Giving rise to a representation of the blood glucose over the past 2-3 months of the individual living with type 1diabetes (Sikaris, 2009). NICE guidelines publish that “an HbA1c target level of 48mmol/mol (6.5%) or lower is ideal” in the battle to prevent complications further in life, for the child or young person with type 1 diabetes (NICE, 2015). In view of managing glycaemia everyday with insulin replacement, the pinnacle of treatment is to achieve as near to the target mentioned above, for as long as possible. This in turn, is hoped to prevent or delay further complications from living with the condition – in practice (Ziegler et al., 2011).

Importantly in research, there is evidence to prove that adolescents, (who do not adhere to current monitoring practices) have reduced overall glycaemic health, and a higher risk of morbidity and mortality issues - associated with the seriousness of type 1 diabetes (Anderson, 1997; Borus & Laffel 2016, Guo, Whittemore, & He, 2011). Therefore, this research aims to report a much deeper understanding of the place of current diabetes technology. Addressing the usage behaviours and expectations – in the prevention, support and assistance to ameliorate these complications.

Chapter 3 Digital health technology in management of type 1 diabetes: A scoping review of evidence

This chapter will be divided into two main sections of influence: (1) types of technology associated with treating type 1 diabetes, for example insulin pumps; CGMs and mobile App technology and, (2) psychological evidence surrounding the adolescent's experience – which affects interaction with diabetes technology and self-care patterns (see section 3.4). The second section will address evidence supporting adolescent issues relating to engaging with technology and experiences to this age group such as puberty and relationship changes.

The focus of this scoping review was to examine the use of digital health technology to assist with the management of type 1 diabetes. Although this study is related to adolescents, there are references relating to the general population in relation to diabetes management, which were included in the evidence - due to their relevance for providing background information. Despite the fact this is not a systematic review, Figure 3 illustrates the scoping review process undertaken.

The year 2003 saw the advent of global insulin pump usage and trends began to increase as the NICE guidelines were published in the UK (Hill, 2008). Therefore, search results from this year were incorporated. Keywords used in searching literature included: *type 1 diabetes; adolescent; quality of life; adherence; psychosocial; blood glucose; insulin pump; continuous glucose monitor*; and diabetes technology.* Studies were excluded if they were not related to the focus of the scoping review. Databases shown in the identification phase were consulted to obtain records between 2003 -2017 shown in Figure 3.

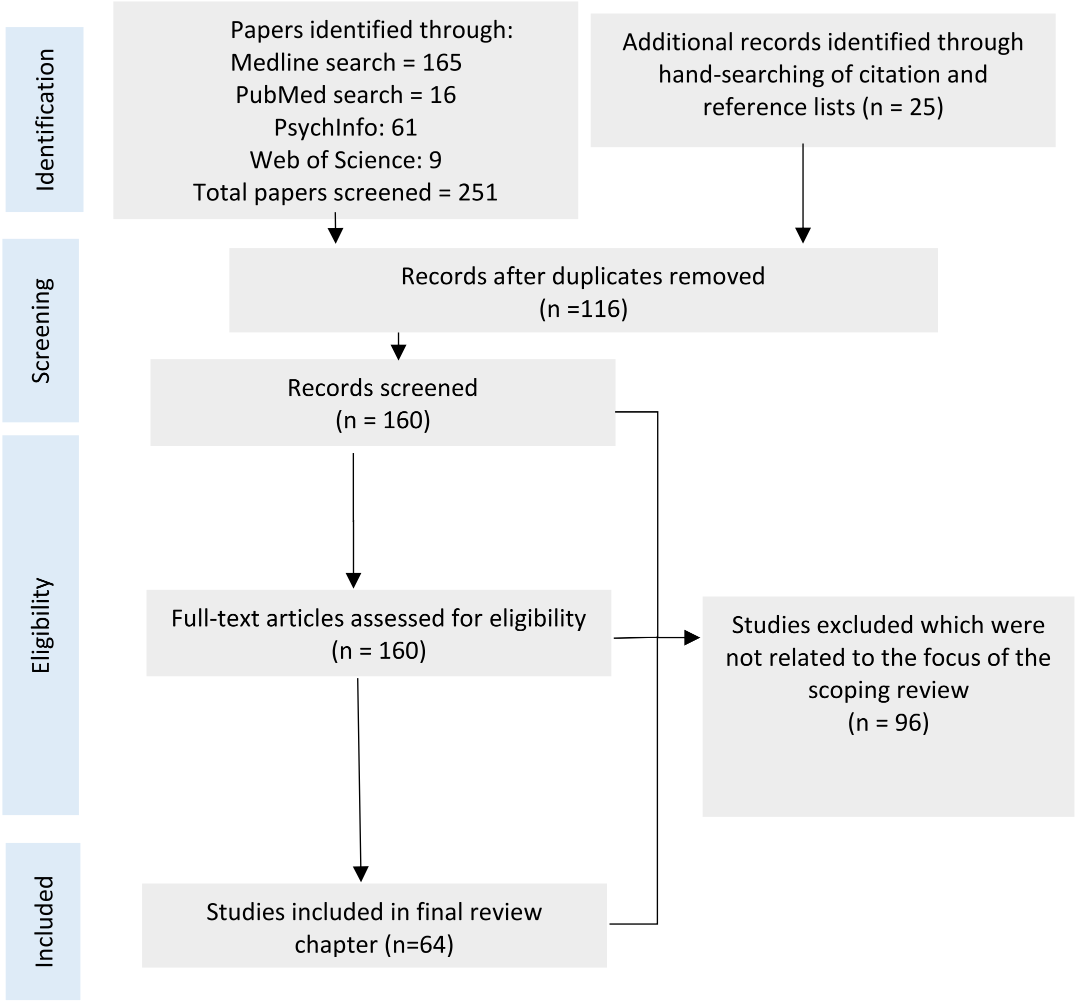


Figure 3. Scoping review process detailed.

3.1 Insulin replacement

As stated, the need for survival and replacement of the hormone Insulin is essential for those diagnosed with type 1 diabetes. The mode of delivery of this hormone is currently either by pen injection or continuous subcutaneous insulin infusion using an insulin pump (CSII). Pen delivery of insulin is injected subcutaneously, with frequent rotation of site needed to prevent hyperlipotrophy (Chowdhury & Escudier, 2003), bruising and pain. People can use different methods of delivery by either injecting a different type of insulin for basal (background) e. g. Levemir and another type of fast acting, insulin analogue for bolus (mealtime) insulin dose e.g. Novorapid. This dual method is known as Multiple Dose Insulin (MDI).

In order to reduce hypoglycaemia and to ameliorate or delay micro/macro vascular complications such as nephropathy (damage to kidney tissue) or neuropathy (damage to nerve tissue) in patients with type 1 diabetes, progression from mixed daily injections (MDI) to pump therapy (CSII) moved rapidly forward from the early 2000’s (UK) (DCCT, 1993). The aim of this was to give patients a choice to alter insulin delivery methods over the space of 24 hours, with features such as temporary basal rates; dual wave bolus – extended bolus delivery functions; insulin delivery suspend features and alarms and reminders as shown in Table 1 (Kordonouri, Hartmann, & Danne, 2011).

Introduction of insulin pumps allowed for the later emergence of connectivity with blood glucometers and continuous glucose monitoring systems (CGMs), which are discussed further in the chapter. Insulin pumps deliver insulin by infusion through a cannula under the skin, in situ. They are designed to decrease the need for daily injections and make delivery of doses interactive and flexible. For insulin pump treatment, no basal insulin analogue is used, only fast acting insulin (REPOSE, 2017). The pump is programmed to act a range of basal insulin dose from very minimal to larger amounts i.e. 0.05 units per hour can be infused – suitable for many, including small children. This constant drip-fed amount is mimicking the basal delivery. In pen injection therapy, this would be injected normally as a full dose either at breakfast, bedtime or split in half between both. In effect, by introducing insulin pump therapy, there are different skills needed to live with type 1 diabetes – one of which is to be aware of the flexibility of changing basal dose patterns ahead of scheduled activity – on an hourly basis, which cannot be achieved with pen injection therapy (Pickup & Keen, 2002).

Adolescents who live with type 1 diabetes very frequently need to change infusion sets (cannulas) or treatment patterns quickly and within short timescales. This need is often brought about by rapid rate of change of glucose and the fear of severe hypo/hyperglycaemia. Additionally, in adolescents, puberty; illness and growth are the main drivers for the frequent increase of basal insulin patterns and can often be linked to causing nocturnal hypoglycaemia when dose adjustment is not actively considered to compensate for these changes (King & Armstrong, 2007; Woodward, Weston, Casson, & Gill, 2009).

When an adolescent suffers hypoglycaemia during sleep, it is hoped that they will awake and be able to treat or call for help. Otherwise, caregivers set alarms to test blood glucose during the night through fear of the basal insulin causing a severe hypoglycaemia from which the teenager may not ever wake. This causes great concern as nocturnal hypoglycaemia can be linked with mortality issues (Clarke, Jones, Rewers, Dunger, & Klingensmith, 2009). One method that caregivers and adolescents now try to prevent these episodes is by connecting an insulin pump with associated continuous glucose monitor to provide alarm functions when glucose is dropping (Buckingham et al., 2010). An example of a widely used insulin pump in the UK is the Medtronic brand of pumps, as shown in Figure 4.

Figure 4. Medtronic 640g insulin pump as detailed by UCLH patient information leaflet (www.uclh.nhs.uk).

Different insulin pumps have different features, Table 1 lists these functions and a brief description of how this function could improve treatment (www.medtronic-diabetes.co.uk).

Table 1

Examples of functions provided in a Medtronic insulin pump (www.medtronic-diabetes.co.uk; Cochrane, D. 2018).

Insulin Pump Function	**Improvement of treatment**
Reduced basal unit increments e.g. 0.000	Helpful for people reducing basal amounts due to age, exercise or basal requirements as advised by clinicians for example.
Integration with smart meters	Blood Glucose meters which allow Bluetooth or Near Infra-red technology interaction with the pumps.
Warning alarms	If the pump malfunctions, this alerts the patient to address troubleshooting pathways immediately. Alarms connected to CGM technology alert blood glucose levels which are dangerous.
Temporary Basal Rates	The interaction of the patient with the pump to change dosage or basal insulin in preparation for exercise, or to treat illness
Bolus delivery options	When the patient boluses insulin for example when eating dietary carbohydrates – a patient will tell the pump the amount. (O'Connell, Gilbertson, Donath, & Cameron, 2008)

3.2 Blood glucose levels and technology

Across the literature, managing blood glucose levels and dietary carbohydrate counting are closely connected. Frequency of injection, or infusion of insulin, and frequency of monitoring of blood glucose are also important factors mentioned widely. Moreover, with puberty (the continual growth and development) means that this is an ever-changing goal post, with intensive monitoring during both sleep and awake time (Chowdhury, 2015).

However, as research suggests, there can be a proportion of adolescents who feel they would rather not test their blood glucose. In a study with 89 adolescents, Anderson et al (1997) explored parental involvement for the adolescent's age group. The study reported a decline in self-management in terms of blood glucose testing as adolescent's mature. It was also reported that this age group can benefit from increased parental involvement to improve self-care and overall HbA1c result.

Furthermore, it is globally recognised that the adolescent population, with type 1 diabetes, are at risk of morbidities due to lack of adherence to self-monitoring with management of such a complex condition (Guo, Whittemore, & He, 2011). In a study by Dashiff, McCaleb, and Cull (2006) with over 150 participants, between the ages of 11 -15 years, it was found that as the participants aged they were at risk of a decline in self-care behaviours, suggesting that an intervention would be best placed within the early adolescent years to prevent this happening at a later age.

Suchy et al. (2016) address the thought processes needed to perform such tasks and highlight the need for higher brain function in execution of planning - seeing through decisions and problem solving. All of which can be tiresome, especially when blood glucose variability causes physiological symptoms such as mood swings, headaches, shaking and other motor skill symptoms (Weinger, Jacobson, Draelos, Finkelstein, & Simonson, 1995).

3.2.1 Smart meters

In terms of glucose meters which connect to insulin pumps, these allow the person with diabetes to quickly engage with the insulin pump, as the blood glucose reading is sent to the pump via radio frequency or Bluetooth™ connections. This then allows the pump to calculate the dose based on the settings programmed in which is known on the pump as a bolus wizard (www.medtronic-diabetes.co.uk). This assistance very often takes away the need to constantly calculate dose – but can be overridden if the person feels they may be ill or about to take part in rigorous exercise for example. For those with pen injections, there are meters which allow the adolescent to enter carb: insulin ratio's (CIR) into their meter – giving them a quick calculated idea of how much to bolus (https://www.accu-chek.co.uk/which-meter).

3.2.2 Glucose monitoring - Continuous Glucose Monitors (CGM)

This device, as depicted in Figure. 5, determines the glucose levels under the skin in the interstitial fluid, by a cannula attached to the device. A transmitted numerical glucose result is delivered to the insulin pump – bringing integration and less need for the person with diabetes to manually input data from one device into another. Once the CGM device measures glucose, it can suggest to the insulin pump several steps that the person with diabetes can follow. The CGM can alarm; suggest suspending delivery of insulin and contacting emergency help; and allow the user to engage with dosage changes. Thus, treating glycaemic ranges which are either too low or too high (www.medtronic-diabetes.co.uk).

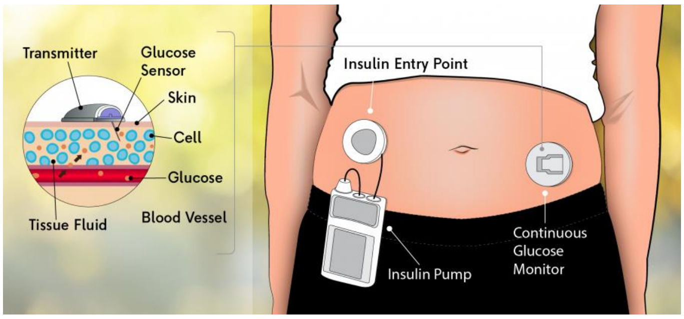


Figure 5. A visual model of a CGM in situ, showing cannulation and sensing of interstitial glucose, as it travels from the blood to the interstitial fluid. Transmitting of glucose reading to the insulin pump (www.ontrackdiabetes.com/newly-diagnosed/what-continuous-glucose-monitor-cgm).

There are many publications reporting the vital aspect of measuring finger capillary blood for accurate glucose readings. Similarly, there is evidence that self-management of blood glucose (SMBG) can be improved upon, when the patient choses to wear a continuous glucose monitor (CGM), as discussed in depth by the meta-analysis study performed by Pickup et al. (2011). However, this review focused on adult age groups, with very little data about blood glucose variations. Out of all reviews considered, over 440 participants in RCTs using CGM systems were compared to the same amount of people using self-management of blood glucose techniques. The findings did show that the duration of wearing a CGM decreased HbA1c significantly in the group who started with a baseline high HbA1c reading. This shows that the technology can positively reduce overall glucose – if the participant is willing to wear the device for the long term.

Boland et al. (2001) also discuss that CGM technology can give valuable data on trends between finger pricks. By comparing the CGM with SMBG technique, lessons are learned from using real time data to control post meal spikes in blood glucose, and potentially harmful episodes of nocturnal hypoglycaemia. It was noted that error margins are greater as blood glucose levels become hypoglycaemic with accuracy of sensory data, which still requires calibration or verification with blood capillary finger prick testing.

However, the market for accuracy in CGM technology has greatly improved since 2002, highlighted with a study conducted by Glowinska-Olszewska, Tobiaszewska, Luczynski, and Bossowski (2013). This study examined the use of CGM technology for short term improved glycaemic control in adolescents – proving that CGM usage lowers HbA1c measurement in a cohort of n=40 with average age of 14.9yrs in collaboration with a therapeutic team with specific clinical support. However, the study does not explore why CGMs technology did not help teenagers with very poorly controlled glycaemia (HbA1c>10%). This could mean that a great part of the population of adolescents are underrepresented and needs further research.

Detailed manufacturer CGM systems and glucose monitoring with software and smart device connectivity is shown by Rodbard (2016). Highlighting

Dexcom G6™ CGM as the newest most interactive version with iOS and android mobile app connectivity. This system is the most expensive option available to those who self-fund, as it is not funded by NHS services as discussed by INPUT, a UK charity ran by users of insulin pump technology and their families (www.inputdiabetes.org.uk).

3.2.3 Flash glucose systems - Abbott Diabetes Care - Freestyle Libre® monitoring system

This new system is designed to read interstitial glucose levels under the skin of the upper arm, by a small, circular cannulated device. The glucose is read by "Flashing" a reader device, or co-designed smartphone App to produce graphic displays of trends over time – as per the programmable algorithm developed by the manufacturer (www.freestylediabetes.co.uk/freestyle-libre). As this reads glucose in a different fluid from blood, the correlation between a finger prick/capillary blood result and the "Flash" reader are not always aligned. Lag time is a known difference when all systems are measuring and being compared from blood to interstitial fluid as with CGMs also, as discussed by Basu et al. (2013) who found by measuring fasting adults, overnight the mean time for lag between vascular and interstitial glucose accuracy was calculate at 5-6mins. This lag time is vitally important for education when adolescents with type 1 diabetes rely on a data value to administer insulin – as accuracy is paramount to safety (Leelarathna & Wilmot, 2018).

From a marketing angle, Abbott present this device to reduce burden of finger pricking from their slogan "*why prick when you can scan?*" https://www.freestylelibre.co.uk/libre/. The intention here is to reduce pain and burden of having to measure finger, capillary blood at inconvenient times. The comparison drawn is that the glucometer comes in a small bag with test strips, a finger pricking device and a meter. Instead of one device – a Flash reader which scans the device on the upper arm (Bolinder, Antuna, Geelhoed-Duijvestijn, Kroger, & Weitgasser, 2016). In the UK, Abbott Diabetes Care (Alameda, CA) licensed their Freestyle Libre® to allow children from age 4 -17 years to read real time interstitial glucose levels with a reader. This reader is used as a device to scan a wearable sensor (worn in the upper arm for increased accuracy) and can report graphical information based on stored data over a 14-day period. As of September 2017 NHS, boards have vowed to begin funding procedures for certain patients meeting certain criteria. This is cutting edge news and the progress for accessibility, and treatment options have yet to be documented (Abbott, 2017).

There is very little reported data on the accuracy and efficacy of FGM for children and adolescents with type 1 diabetes. Bonora, Maran, Ciciliot, Avogaro, and Fadini (2016) conducted a study but only focused on a small cohort of patients to test FGM, and children and adolescents were not included in the study. There is concern that flash glucose monitoring is not as accurate as continuous glucose monitoring however the cost of the product is competitively priced compared to other CGM systems (Heinemann & Freckmann, 2015). Heinemann and Freckmann highlight the dangers using FGM to determine insulin dosages as the regulation for such has not yet been approved, especially during times of rapid blood glucose (BG) changes.

Rodbard (2016) describes the Freestyle Libre® flash glucose monitoring system as an alternative to finger pricking (SMBG) - giving advantages to those who are averse to managing glycaemia using this manual and somewhat painful method. Limitations have been discussed of the FGM system in relation to no functionality with insulin pump connectivity yet, and lack of cross platform application support with iPhone products. Interestingly Rodbard (2016) also mentions that they presume the FGM to be aimed at patients who have type 2 diabetes, due to this lack of functionality. This is based on the gold standard CGM platforms are providing a patient with type 1 diabetes with alarm functions; low suspend functions and real time data connectivity - visualizing the change of glucose on the insulin pump screen. However, research funded by Abbott Diabetes Care (Bolinder et al., 2016), shows that the FGM system is successful in reducing hypoglycaemic episodes by 38% in adults with type

1 diabetes. Further research is required to explore the optimal use of the Freestyle Libre® flash glucose monitoring system within management of diabetes.

3.2.4 Sensor augmented therapy in research – closed loop systems

CGM technology is usually used alongside insulin pump therapy for best results, this is known as sensor-augmented pump therapy. Abraham (2015) found that the CGM capabilities when used to predict hypoglycaemia were most useful following an insulin bolus or increased temporary basal rates overnight. These findings highlight that the patient did not always need to treat hypoglycaemia due to the suspend function following algorithmic control via CGM and insulin pump connectivity. This relies on a clever measurement of pattern of rate of change in glucose levels and has been found to be successful in a small trial of 40 patients conducted by Choudhary et al. (2016).

The basis of this technological race is to prevent long term side effects and complications, such as severe hypoglycaemia, using technology. To take the responsibility out of trying to control so many variables in one’s life, not only exercise but food; bolus amounts; diet and wellbeing. The term being coined for this is the artificial pancreas, a closed loop system which allows the insulin pump, and CGM technology, to be able to use predictive patterns to adjust insulin infusion (Thabit & Hovorka, 2016). Expectations of the CGM to be artificially intelligent have been explored in this study by Thabit and Hovorka.

Current devices promise low glucose suspend functionality in order to prevent hypoglycaemia (Abraham, 2015). This claim can attract caregivers who worry about impaired hypoglycaemic awareness and nocturnal hypoglycaemia, as researched by Gonder-Frederick et al. (2011). As the main function of the CGMs system is to monitor interstitial glucose levels at intervals close to every 3-5 minutes, the data collection for insulin dosing is frequent. However, the frequency of use and determination of HbA1c at baseline prior to studies seem to influence outcome as reviewed by Rodbard (2016). These include loss of signal or signal disruption between the CGM device and the insulin pump. Critically, false alarms and notifications could inevitably lead to fear and lack of trust in the device (Shivers et al., 2013). Additionally, there are issues with skin irritation from the adhesives of the devices, alarm settings causing intrusion and frustration; signal disruption; calibration of settings and many other functions that bring about questions pointing towards usability of the CGM devices (Englert et al., 2014).

Another important element raised in research so far is the visible aspect of wearing a CGM and the uninvited questioning from others as to the nature of the device. Adolescent groups may not wish to openly discuss living with type 1 diabetes, and sharing this information with someone can be seen as very private and personal issue (Borges & Kubiak, 2016). Therefore, the size and visibility of devices are important to this population. Brazeau et al. (2018) highlights the stigma related to the visible aspect of living with type 1 diabetes in that people fear judgement *"*Stigma related to chronic disease is a negative social judgement that leads to unwarranted rejection or exclusion. It is related to visible features of the disease or its management" (p.3).

3.3 Current climate and challenges for success

As this research takes place, new developments are on the horizon with manufacturers of CGM systems and Flash glucose monitoring to enable users to integrate their mobile phone usage with the devices. Currently, the user can download a connected App on a SmartPhone to view glucose trends and data – to share this data with clinicians. This allows the person with diabetes to view real-time data on their glycaemia and possibly allow for dosage/treatment changes (www.dexcom.com/apps; https://www.freestylelibre.co.uk/libre).

Interestingly, there are a group of parents/caregivers of children with type 1 diabetes known as "NightScout", who are engaging in developing their own glucose management systems for remote viewing of live glucose data (http://www.nightscout.info). Their project relies on using current glucose sensing devices such as Dexcom G5 (http://www.dexcom.com/en-GB), Medtronic or Freestyle Libre® to transmit the glucose data to a receiving device which then can be analysed by web programs to then allow the user to view the data using software. Devices used for viewing the data include watches and smartphones. There is a growing community of parents/caregivers using cloud data now to interact with their child's glucose ranges using real-time data to intervene when glucose ranges become spurious and out of control. The underpinning motivation for this technology is again to prevent threat of hypoglycaemia/hyperglycaemia in vulnerable age groups.

As these devices are all operating via a cannula in situ, cannulation errors or lack of programming of long acting insulin for overnight basal insulin requirements are likely to cause rising blood glucose levels, alongside ketone bodies requiring emergency medical intervention (Guilhem, Leguerrier, Lecordier, Poirier, & Maugendre, 2006). Thus, the care of the adolescent overnight, can be as vital and lifesaving as dealing with a young baby or child.

In essence, with future development of technology in glucose management, the need for an understanding of the burden of the condition and how it will be best used by the adolescent is a challenge for researchers. The aim of this thesis is to address some of these issues as approached by Kumah-Crystal et al. (2015) - *"Better understanding of the nature of technology use for self-management over time is needed to guide the development of technology-mediated problem solving tools for youth with type 1 diabetes"* (p.449).

Treating type 1 diabetes with insulin replacement can be such a complex daily task, that there can be errors in accurate dosing, or failure of delivery - leading to insulin deficiency and impaired counter-regulation bringing about hypoglycaemia. Not only does the technology have to deliver insulin, but also monitor glucose levels.

Insulin replacement can be affected by poor absorption; injection site issues; failures of technology and insulin pump cannula failures; drugs; alcohol; illness or injury all leading to serious metabolic states such as hyperglycaemia. Hyperglycaemia can become life threatening if it leads to the development of diabetic ketoacidosis (DKA). A state whereby the pH of the blood becomes acidic due to the breakdown of fats for energy and resulting ketone bodies in the blood, the patient is at risk of coma or death (Laffel et al., 2006).

In summary there is a need for improvements to accuracy of functions, and design of appropriate usability studies, to help drive future developments in diabetes technology and to improve uptake by adolescent patients.

3.4 Psychological elements

Currently there are over 31,500 people under the age of 19 years living with type 1 diabetes in the UK. In Scotland and the adolescent population living with type 1 diabetes account for 1.18% of the population. Incidence rate is rising in pre-school children, and these statistics are set to increase in the future (Diabetes uk, 2016).

Therefore, the issues relating to understanding adolescent behaviours - choices and beliefs centred around managing blood glucose levels with technology, will continue to emerge in the family and healthcare settings (Diabetes uk, 2016). This section of the thesis highlights evidence of the set of skills that have been identified that the adolescent needs to develop and learn as they mature with type 1 diabetes.

There are variables within the person with diabetes’ control and those which are not – for example counter-regulatory hormones such as growth hormone during puberty – affecting efficacy of dose treatment plans (Diabetes Research in Children Network Study, 2007). Adherence and coping skills of the adolescent could be viewed as something that needs a different type of intervention (with intention to treat trials showing psychosocial and peer issues). The way in which both these metabolic states are managed – by the assistance and support of others and the available technology is the cornerstone in aiming to achieve health and living well with type 1 diabetes (Borus & Laffel, 2010).

Adolescents have a behaviourally challenging time ahead with puberty and growth, with the added complexity of managing a chronic condition. Relationship changes with parents/caregivers and peers influence their daily lives whilst learning self-management and autonomy (Anderson, 1997). Related to managing such a complex condition, is the level of mood or anxiety and there have been many researchers pointing towards the detrimental effect this has on blood glucose management and overall control of the condition (Christie et al., 2016; Herzer & Hood, 2010).

Gaining knowledge and understanding of the condition from date of diagnosis to navigating through different treatment regimens becomes a family issue and learning to support the adolescent in learning to develop self-management tools can be a vast psychological undertaking (Anderson, 1997). For example, in a study by Barnard et al. (2014) whereby they were looking at an overnight trial of a new technology to manage glycaemia, there were results showing improved glycaemia overnight with peace of mind for the parent to have improved sleep, and less worry. Although the device showed signs of inaccuracy and caused disruption during the night, overall, most participants found the benefits of the system and felt this new technology could be improved upon. Interestingly, this mixed method study is one of very few in literature to date, to explore acceptability of technology to support diabetes care (Barnard et al., 2014; Gray et al., 2013; Murphy et al., 2012).

In their series of phased modelling to understand how the adolescent “figure’s it out”, Babler and Strickland (2016) importantly raise the issue that normalising diabetes is a vital step for the person with type 1 diabetes to take in making self-management decisions, that not everything should be centred around achieving a perfect HbA1c result. Education and interventions have also been reviewed. A review by Borus (2010) highlighted an important aspect that some educational interventions do not influence the overall glycaemic control-the HbA1C, as this biochemical measure has been correlated against how well a person is managing with the condition. Interestingly, they highlight factors that can affect glycaemia – bringing to the table a discussion on the wider elements necessary to achieve a “good” HbA1c (as shown in Figure. 6.). Borus also addresses the need for the adolescent to feel less burden by technology by stating “as evidenced by the adolescents' reluctance to use CGM consistently in the JDRF CGM trial, strategies to increase treatment adherence for teens must require minimal distraction from the teen's routine tasks of daily living*…”* (Borus, Laffel 2016, P.409).

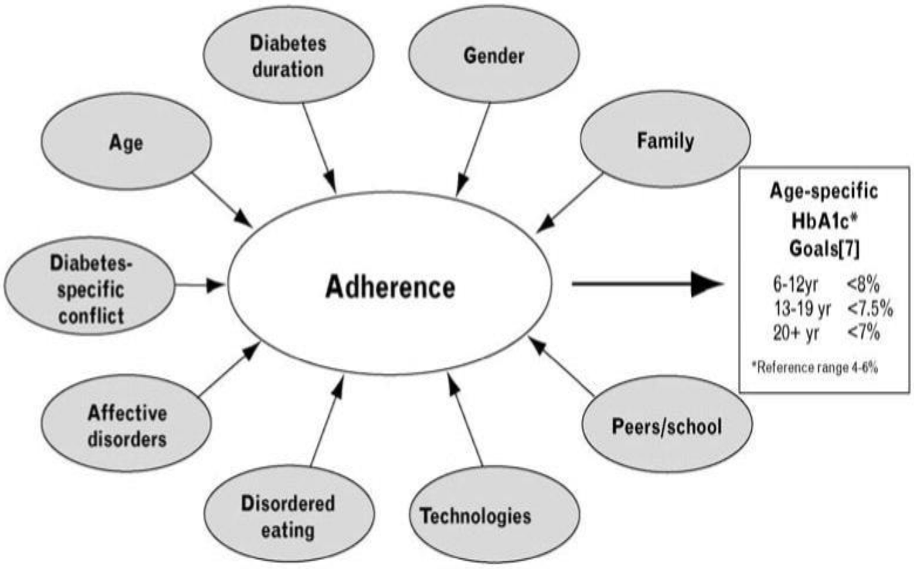


Figure 6. – Taken from Borus, Laffell (2016) showing involvement of wider issues in the quest for improved glycaemia and HbA1c results. Implying that technology can be looked upon as one issue amongst many.

These findings highlight that Type 1 diabetes may be the same physiological condition, but experienced by people in many different ways, at different times of their lives (Borus & Laffel, 2010). Murphy et al. (2012) points to the fact that educational programmes are often not person centred and do not always yield success. In their study, over 300 families were recruited to take part in an educational programme to support their quality of life; education and support. The study found lack of participation with less than half participants attending the planned sessions. There was no change to overall HbA1c result after 18 months. More research is required to understand how to engage and deliver support for families of children with Type 1 diabetes - "Despite widespread adaptation of intensive insulin therapy and technological advances in the management of Type 1 diabetes, a characteristic deterioration in glycaemic control persists during adolescence" (Murphy et al., 2012, p.e249).

Importantly, Palladino and Helgeson (2012) raised a fundamental issue with adolescent's ability to focus and manage such a complicated condition with a view to support mechanisms, and decision making. Dashiff et al. (2009) also give evidence of peer and parental support being central to development of behavioural choices towards self-care and the desire to choose healthy options. In this study, the maternal anxiety of allowing self-care of the adolescent to prevail was measured with key findings focusing on cognitive autonomy. Maternal influences and parental support can affect self-care – not only that of involvement with technology.

Contrastingly, as highlighted by Giani, Snelgrove, Volkening, and Laffel (2016), poor glycaemic control could be alleviated by the effective use of diabetes technology such as continuous glucose monitoring devices. Steineck, Ranjan, Nørgaard, and Schmidt (2016) cleverly indicating that the new age of technology on the horizon is the prediction of glucose trends, (rate of change) and the augmented dosing changes via a pump and sensor system. They point to this panacea alleviating the current complex dose adjustment decisions.

However, there are many variants in the life of an adolescent, which are dependent on dose adjustment – not just glucose levels. One of which is fear which is widely studied across the research – shown by Gonder-Frederick et al. (2011) .For an adolescent to trust insulin-dosing technology, it would need to be accurate enough as to not build any more feelings of fear (Laffel, 2016). As addressed further in this chapter, fear surrounding severe hypoglycaemia for children and parents (a side effect of insulin replacement) is already a huge element of insulin avoidance and poor control (Johnson, Cooper, Davis, & Jones, 2013). Adding to this, Barnard et al, (2014) led a study looking at the psychosocial impact of wearing a closed loop system, which involves an insulin pump cannulated in situ and a continuous blood glucose monitor cannulated in situ. Parents/caregivers as well as adolescents were interviewed, and these results were both measured - showing the acknowledgement in research, that managing this condition by oneself is in fact, not what adolescents and their family's practice. Barnard et al. (2014) also found that most families felt positive outcomes due to reduced fear of nocturnal hypoglycaemia. More research is needed to encompass feelings, mood and fear of the side effects of treatment with technology.

In summary, in understanding daily tasks associated with managing type 1 diabetes for adolescents, it becomes apparent that this condition requires layers of complex behaviour skills which are needed to ameliorate deterioration of health. This burden is often shared with parents/caregivers who often change their lives to become full time carers, perhaps giving up work to look after the child or teen with type 1 diabetes. The transition from parental care to collaborative, self-management roles highlights this phasic, and developing journey as shown in Figure 7. The image depicts responsibilities of the person with diabetes, their family and the community. Showing the integration of adherence to treatment, outcomes affected by a lifelong condition and how systems cope financially to deliver health care. The significance of the image, for this study, shows that type 1 diabetes demands high input of monitoring and care from the adolescent; their family; community and healthcare professionals.

Many children and adolescents who wear diabetes technology, can present with dilemmas related to this much specialised technology in the wider environment outside of the home. Therefore, understanding that people need support, not only from technology, but from family, caregivers and community is essential in allowing the growing arena of digital health technologies to integrate into our world and lives.

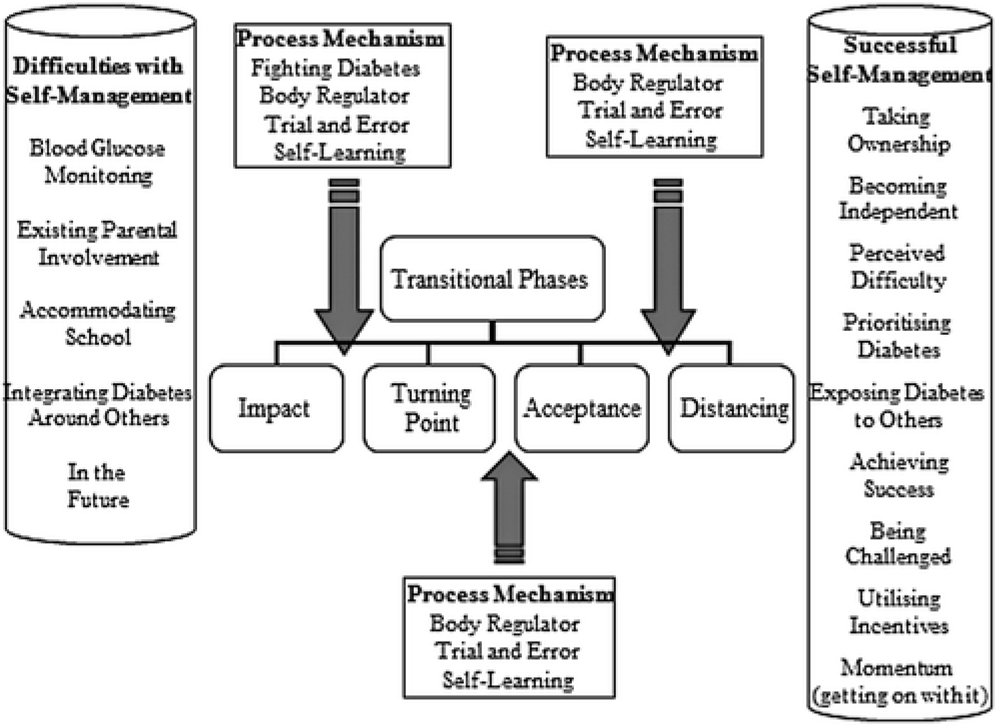


Figure 7. An adolescent model of self care and self management as discussed by Chilton and Pires-Yfantouda (2015). This represents the decisions and moments of development in living with type 1 diabetes showing parental, school and wider community exposure of their condition.

Overall, in current literature, the research focus has been on controlling glucose levels to improve glycaemia with technology. Studies vary in focus looking at quality of life; interventions on education and family support and treatment advances. However, little attention has been given to understanding the lived experience for the adolescent with current diabetes technology. As this industry is adapting and changing, the research in this study is at the forefront of new technologies, which are emerging, and being used by a global community. The desire for new technology is prevalent within the type 1 diabetes population, as the demand for improved quality of life drives this.

Chapter 4 Methods

In this chapter, the research philosophy and methods used are described and justified. The purpose of this research was to explore and understand motivations and barriers for adolescents towards using digital diabetes technology to manage glycaemia in type 1 diabetes. To gather valuable, rich data the three methods chosen to collect participant data were in-depth semi structured interviews (with adolescents and parents/caregivers present); an online survey (adolescents and their parents/caregivers); and opinion poll data from a family charity event organised by the charity Juvenile Diabetes Research Foundation (JDRF®). Each step of the methods is briefly outlined below and Figure 8 provides a diagrammatic representation of the data collection and analysis to build a conceptual framework. Each section of this chapter will explain the methods in more detail. As discussed in Chapter 1, an a priori understanding of the themes associated with managing type 1 diabetes allowed for untangling of the data gathered to report complex, sub-themes using inductive analysis.

Ethical consideration when approaching participants was conducted with sensitivity and the emotive subject was explained prior to participation. It was made clear that participants could volunteer to take part or withhold/withdraw for the study if they so wished. Adolescent participants gave agreement for parents to be present and involved during interviews and if they also wished their parents to share opinions during discussions. All but one of the interviews were mainly answered by the adolescents with parents stating their agreement on occasion , apart from the interview conducted over Skype - whereby the participant was not outspoken, and the parent answered extensively (male, age 17). However, during analysis – only the adolescent perspective data was taken as evidence - this was communicated to the participants during interviews. All ethics were approved by the University Ethics Committee.

Bracketing and taking a reflexive tone to the methods of analysis was also performed due to dual position of researcher and parent. It is understood that the perspective of the researcher will inevitably impact on any research undertaken. Tufford and Newman (2010) discuss bracketing in qualitative research as:

> Bracketing has the potential to greatly enrich data collection, research findings and interpretation – to the extent the researcher as instrument, maintains self-awareness as part of an ongoing process. Alternately, emotional reactions and past experiences or cognitive biases of the researcher have the potential to obfuscate, distort or truncate data collection and analysis (Tufford & Newman, 2010, p. 85).

Therefore, in understanding the position of the researcher, as a parent of a child with type 1 diabetes - being aligned with some experiences within the data and literature – it was important to maintain a reflexive view to ensure objectivity, by minimising opinion whilst focusing on the inductive process. Removing preconceived ideas; designing general research question with emotion removed; listening carefully to the participants and becoming an open and passive interviewer allowed the data to become a rich, reflective process of the participants, in relation to the research questions. This allowed for awareness of elements of researcher bias. Limitations of the study are discussed in section 6.7 which explains bias further.

4.1 Qualitative Methodology

Qualitative methods were used to gain a deeper understanding of the lived experiences of adolescents' living with type 1 diabetes - giving the individuals a voice. Due to personal and extensive knowledge of the topic, challenging existing assumptions was necessary throughout using an Interpretivist lens. Viewing the individuals' as making their own choices in life and experiencing society by their own conscious thoughts was applied when analysing and treating the data.

This approach is known as interpretative phenomenological analysis and it aims to provide detailed examinations of personal lived experiences, as described by Smith and Osborn (2015). Understanding the condition from the participant's perspective underpins this approach, also shown by Creswell (2007), a phenomenological study "describes the meaning for several individuals of their lived experiences of a concept or a phenomenon" (p. 57). Therefore, the Interpretative Phenomenological Aanalysis (IPA) approach was taken.

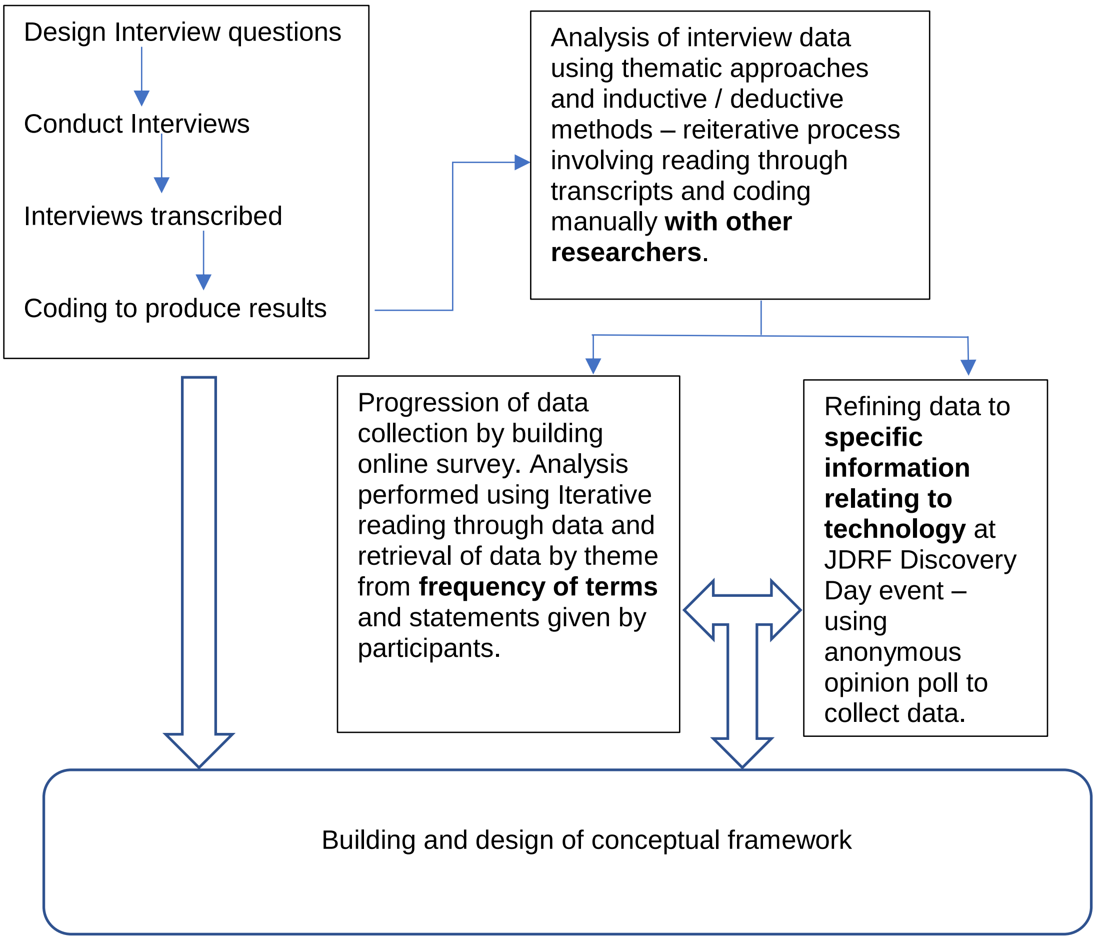
The interview questions were designed to engage participants in open discussion about their life experiences with type 1 diabetes and health technology to manage glucose. Awareness of the lived experience of everyone was researched in an idiographic sense, taking each participant's opinions from their own viewpoint (Barnard, 2014). Steps 1 – 3 outline each step in the process, with a brief overview of the timeline of data collection:

Step 1 – In-depth Interviewing with adolescents and their parents/caregivers: to gather initial data and participant's opinions and feelings surrounding living with type 1 diabetes and diabetes technology used. Designed using semi-structured interview questions. Sampled from local participants enlisted from Diabetes UK support groups. **Outcome**: Gathered in-depth, qualitative data to help refine data collection using the next stage of gathering of wider views via a Survey. Possible parental influence may have shaped the data; therefore, survey was designed for adolescent participants to complete alone without this influence.

Step 2 – Online Survey: Survey approach was to identify and collect anonymous data to produce more non-biased data, aside from the effects of interviewer-interviewee interactions. Sampling parents/caregivers and adolescents from the diabetes online community by posting in FaceBook and Twitter private groups - requesting families with teenagers to complete the designed questions as shown in Appendix. **Outcome**: out of 107 people who opened the survey, 26 fully completed results were analysed. Of the remaining 81 records, 78 were completely blank and 3 others had insufficient data for analysis. Gathering of data was specific to not only the adolescent, but to the family Parents/caregivers & adolescents n=16, adolescents n=10.

Step 3 – Anonymous opinion poll data gathered from families living with type 1 diabetes - questions shown in Section 3.3. **Outcome**: Data was collected to focus solely on the technological aspect of managing glycaemia. This was a natural progression, as no new themes were collected from Step 1 & 2, from the viewpoint of living with type 1 diabetes. This step gathered data specific to the interactions with technologies relating to managing glycaemia. It was presented to the families that the researcher was collecting anonymous data relating to adolescent experiences with technology, therefore it was assumed that those who took part in the exercise were aware of the study focus.

4.2 Methods



Analysis of interview data using thematic approaches and inductive / deductive methods – reiterative process involving reading through transcripts and coding manually **with other researchers**.

Progression of data collection by building online survey. Analysis performed using Iterative reading through data and retrieval of data by theme from **frequency of terms** and statements given by participants.

Refining data to **specific information relating to technology** at JDRF Discovery Day event – using anonymous opinion poll to collect data.

Figure 8. Diagrammatic representation of the evolution of data collection and analysis to build a conceptual framework (Cochrane, D. 2018).

4.2.1 Overall Data Collection

By nature, type 1 diabetes is well known for being a complex condition to manage for families. Part of the phenomenological approach was informed by concepts raised by Laverty (2003) – pertaining to “illuminating detail” and giving participants a voice for issues which are taken for granted. Beginning the research with in-depth interviews to gain initial understanding of the lived experience from the participant’s perspective. In bringing the principles of IPA to this research – understanding human consciousness and experiences, allowed for exploration of the phenomena during collection and analysis of data. Furthermore, due to the extensive personal knowledge of the condition, empathy allowed for deeper exploration of feelings and perceptions associated with managing glycaemia with technology. It is acknowledged that showing a level of understanding during interviews comparative to the participants experiences, allowed for development of deeper conversation. Showing empathy and understanding at times allowed for unravelling of feelings and emotions from the participants and this built a tone of trust during interviewing. Whilst emotional detachment ensured a professional approach to conducting the interview was maintained. Explaining to the participants they could withdraw from answering anything they did not feel was appropriate or difficult to answer (Lerum, 2001).

Prior agreement between research members was obtained to ensure objectivity was applied during interview question design and research methods in deducing analytical meaning from the data. Recognizing subjectivity and emotion allowed for further reflecting during the process of writing results. Questions for the interview process were designed from prior reading from literature (see section 3.3.1,). For example: *“Can you tell me how long you have been living with type 1 diabetes?”* relates to the prior knowledge that the landscape of daily issues and feelings towards living with condition can change for an individual based on variables such as the duration of diagnosis (Sparring et al., 2013).

In order to triangulate data, methods were extended to include surveys and opinion polls. An opportunity to gather data at a specific family charity event meant that the data could further be triangulated, by collecting opinion poll results from people attending a juvenile diabetes research foundation event – held to discuss research and type 1 diabetes, – giving focus to the likes, dislikes and ideas for improvement of current technology. Opinion polls are more focused than surveys and take less time to complete. Surveys and Interviews are frequently used in social and health psychology research as discussed also by Braun and Clarke (2013).

4.2.2 Organising, Analysing and Classifying data

Data were collected and analysed using a thematic framework method as described by Ritchie (2003). This approach was chosen to allow flexibility between the inductive and deductive process. Finding meaning in the data by coding themes, using frequency of words/synonyms, and making critical judgement of important themes, alongside *a priori* themes (understanding barriers and motivators for the adolescent). The thematic analysis is depicted in Figure 9. Familiarisation with the data was experienced through transcription of the interview recordings by the researcher, and frequent reiterative reading, of the data. Establishing trust in the results was performed through coding clinics with two qualified researchers who were not present during data collection. This also helped to reduce researcher bias in the process. Comparing codes and establishing agreement in the results.

The action of coding was performed manually, by noting the nature and frequency of terms used by participants – throughout all data sets. Themes developed from these methods are shown in tabular format in Chapter 4 – Results and Findings. Higher levels of interpretation were performed during data analysis to categorise the data into four different areas to be considered for digital technologies and the management of type 1 diabetes. These categories were agreed upon during coding clinics with external researchers.

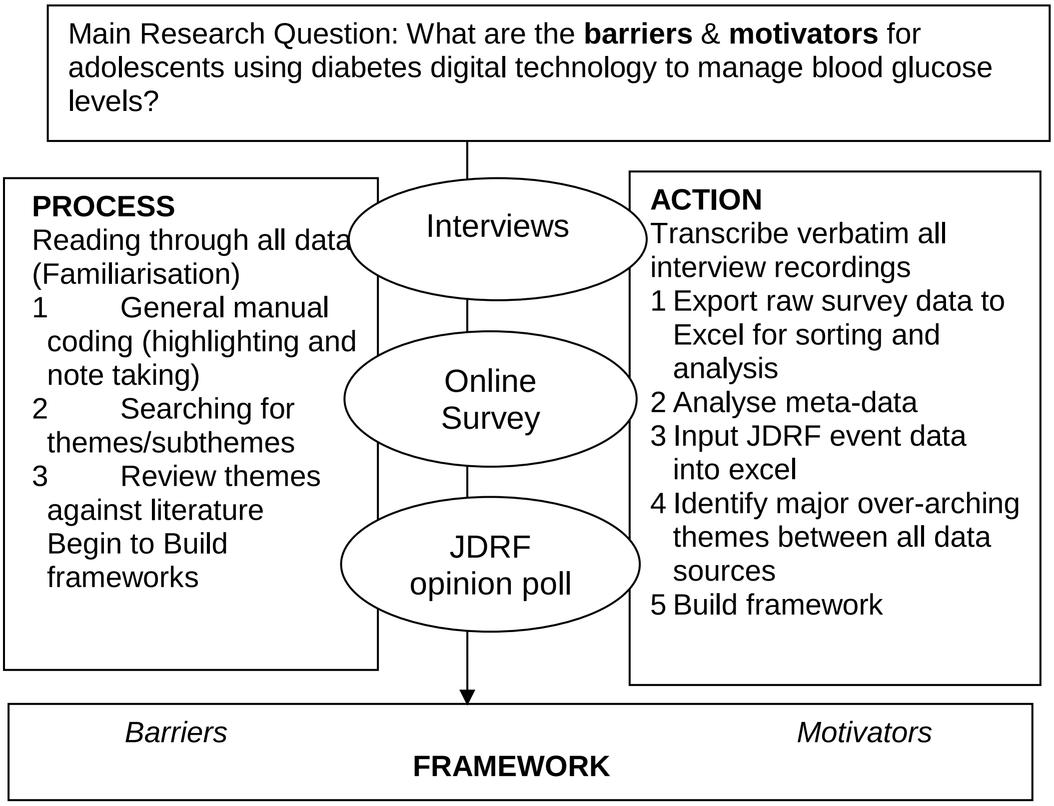


Figure 9. A diagrammatic representation of the thematic analysis process used to complete frameworks (Cochrane, D. 2018).

4.3 In-depth Interviews

During interviewing, it became apparent that bracketing one's own experiences as a parent of a child with type 1 diabetes, was necessary. This helped to create a professional approach, but also to allow for greater empathy with the participants own experiences, aside from feeling of relating to the participant and their parent.

4.3.1 Participants

Adolescents with type 1 diabetes were recruited for face to face interviewing with parents/caregiver's present. They were recruited from local Diabetes UK Support groups. In one interview, the participant was recruited via Twitter as a non-UK national citizen and interviewed over Skype. In total 7 adolescents were recruited, 4 boys and 3 girls with mean age of 15.5yrs (range 13-17 years) and mean diabetes duration 6.5 years (range 2-12 years) as shown below (Table 2). The average length of interview was 27.40 minutes. To minimise unnecessary discomfort or stress participants were invited to take part in interviews at the location and time of their choice.

Table 2

Details of interview participants by age and duration of type 1 diabetes.

Participant ID	**Age & Gender**	**Duration of Diabetes**
1	17 year old, male	7 years
2	17 year old, male	3 years
3	15 year old, male	9 years
4	15 year old, female	12 years
5	17 year old, female	7 years
6	16 year old, female	6 years
7	13 year old, male	2 years

In designing interview questions, *a priori* themes, prior existing knowledge and a review of questionnaires which evaluate quality of life and adherence to treatment, were consulted such as (Hannah, 2014; Barnard, 2014).

4.3.2 Research Questions for interviews and survey:

1 Tell me about how you are currently feeling about having type 1 diabetes.

2 How does it impact your life?

3 Which treatment methods are you currently using? I.e. pens / pumps

4 How is that working out for you?

5 Can you tell me how long you have been living with type 1 diabetes?

6 In what ways do you feel you accomplish good self-care?

7 What is your idea of managing the condition in a positive way?

8 How often do you rely on the way you feel rather than testing blood glucose levels?

9 How often do you forget to treat your blood glucose results with a correction or a blood finger prick test in a day?

10 What people are involved with your care on a daily basis?

11 Do you have one main area that causes you an issue, perhaps that you could ask for training on? I.e. carb counting or dose adjustment

12 If there was a piece of technology that you could have to help you manage type 1 diabetes, what do you imagine it would be able to do? I.e. act as a reminder?

13 On a scale of 1-10, how painful is it to prick your finger for a blood glucose test? (1 being not painful at all, and 10 being excruciating).

14 Are you happy with your current HbA1C? Do you know what this represents?

15 Are you currently using the Freestyle Libre Flash Glucose monitoring system? Is there a reason for that?

16 Do you have an app on your mobile phone for managing type 1 diabetes?

17 Have you ever trialled a CGM, if so how was it?

4.4 Online Survey

Data was gathered from an online survey from 26 respondents and analysed using the same deductive methods during analysis of interview data, to build themes from recurring and frequent comments. For questions designed with open comment boxes – to elicit data based on feelings, the rich text was analysed and used to compile codes or sub-themes. In relation to questions designed as closed options, these were used to identify respondents and how long they have lived with the condition. Rank order questions were designed to assess perceptions within the respondents, of preferences of treatment. Finally, multiple choice questions gave the respondents options, with following comments boxes if they needed to explain why they chose a specific answer.

4.4.1 Participants

The first question in the survey was designed for disqualifying logic by asking who was completing the survey: (1) the participant to be of adolescent age group (12-17 year olds), or (2) a parent whom was helping their adolescent child to complete the survey. This survey was distributed throughout social media Facebook groups (which are closed, private groups) and Twitter requesting adolescents and parents/caregivers of teens with type 1 diabetes, to enrol a purposive sample group.

4.4.2 Survey Design & Analysis

After gaining knowledge from the interview participants, the survey questions were adapted with regards to creating open text boxes to elicit deeper understanding than that of the closed survey questions – as you would with a face to face experience. For example, some questions were developed with a text box to allow participants to comment further when asked an open question. Survey reports are given in the Appendix B. The survey was designed using Qualtrics (Qualtrics, Provo, UT). Data was imported to Microsoft Excel (2010) for analysis.

4.5 JDRF Discovery Day, Scotstoun Stadium, Glasgow, 2017.

Speaking at the parent and child open event, organised by a global charity for diabetes research – JDRF, Juvenile Diabetes Research Foundation™ allowed for the live collection of data from the audience (by anonymous feedback) to three opinion poll questions. This allowed for triangulation of the other two data sources, to ensure further understanding of the phenomenon in the data (Patton, 1999). Although participants were mixed, and replies were anonymous, the focus of technology and life with type 1 diabetes allowed for responses related to parent-adolescent interactions with technology. See Table 4 for an example.

4.5.1 Participants

The attendees of the event mostly consisted of families with children diagnosed with type 1 diabetes. During the event the children were taken on a tour of Scotstoun stadium, Glasgow by trained staff, whilst the parents/caregivers and other attendees with type 1 diabetes stayed to listen to each speaker.

4.5.2 Data collection

At the end of all the speaker presentations, event participants were invited to answer three opinion poll questions. Three boxes were numbered according to the three opinion poll questions which were presented to the audience alongside a brief description of this study. It was made clear this was an anonymous, voluntary exercise and that all data would be protected by the ethics obtained by the University of Strathclyde. Participants engaged at will, with the questions and wrote their replies on paper – which was then posted in the anonymous boxes for collection. The questions are shown below:

1. Can you tell me what you love/like about technology that you have seen/use/have had?

2. Can you tell me what you dislike/hate/worry about in the diabetes technology that you use/have seen/are familiar with?

3. For the future – what single aspect of technology would you like to see developed / improved upon?

Chapter 5 Results & Findings

This chapter will report results and findings beginning with an interpretation of the participant's experiences grouped by categories (Table 3). Figure 10 gives a diagram of grouping of the major and sub-themes (across all three data collection methods). Table 4 explains the sub-theme coding relative to data sets and explanatory, representative sub-theme excerpts, in response to the research questions, are given throughout the chapter. The reported themes give representation of the complexities which are perceived, and experienced, in terms of barriers and motivations for managing glycaemia with technology in type 1 diabetes. These reported themes were developed from a priori knowledge and understanding. Each section will be reported using excerpts related to themes collected by the three different methods, i.e. interview; survey and JDRF Event. Data from all these collection methods are available by request. (Interview transcripts; survey report and JDRF opinion poll entries as posted into anonymous boxes with labelled questions).

In the first instance, adolescent data from interview sources was rich and personal with great emphasis on feelings of impact of living with type 1 diabetes – recorded and analysed as a conversation. Secondly, survey data was gathered anonymously with different structured questions (multiple choice; Likert scale and drop-down boxes for comments) allowing for greater depth of experiences and representation of the participant group (parents/caregivers and adolescents). These are divided into two sample groups for analysis (1 – parents/caregivers & adolescents; 2 – adolescents only). Thirdly, at the JDRF event most children were not present during the presentation, therefore all answers were given solely from a parent/adult perspective.

Based on the extent of complex sub-themes shown in Figure 10, results were further interpreted. The 34 sub-themes were grouped into 11 sub-categories: feelings; time management; HbA1c; clinical guidance; food choices; clinical criteria; usability; usefulness; financial; device support; psychosocial. These were further collated into four overall categories: human factors; clinical practice; technological and educational - to provide further interpretation of the data. These categories were agreed upon during coding clinics which focused on interpreting data. Participants gave rich detail in response to the research questions, and coding structure was applied by the methods mentioned in section 4.2.2.

Table 3

Four categories: (1) human factors; (2) clinical practice; (3) Technological and (4) Educational.

Human Factors	Clinical Practice	Technological	Educational
Feelings: Frustration & Anger, low mood, mistrust & fear. Acceptance; embarrassment.	***HbA1c:*** Improving glycaemia.	***Usability:*** Easier treatment method, easier to monitor, improving alarm algorithm and design.	***Device Support:*** Lack of knowledge and understanding; Education to interpret data.
Time management: Remembering / Prioritizing tasks.	***Clinical guidance / education***: Difficulties related to using technologies, support to cope with malfunctions.	***Usefulness:*** Data interaction, Overnight monitoring, Connectivity with other devices –, Passive technology – pattern recognition, Less disruption, Smaller devices – less visible.	***Psychosocial:*** Support to deal with fear and mistrust – psychological support, School support to enable peer and educational support – “fitting in, normalizing and understanding of complexities.
Food choices: Dietary Freedom.	***Clinical criteria***: Reduced cost – clinical input.	***Financial:*** Reduced cost.	

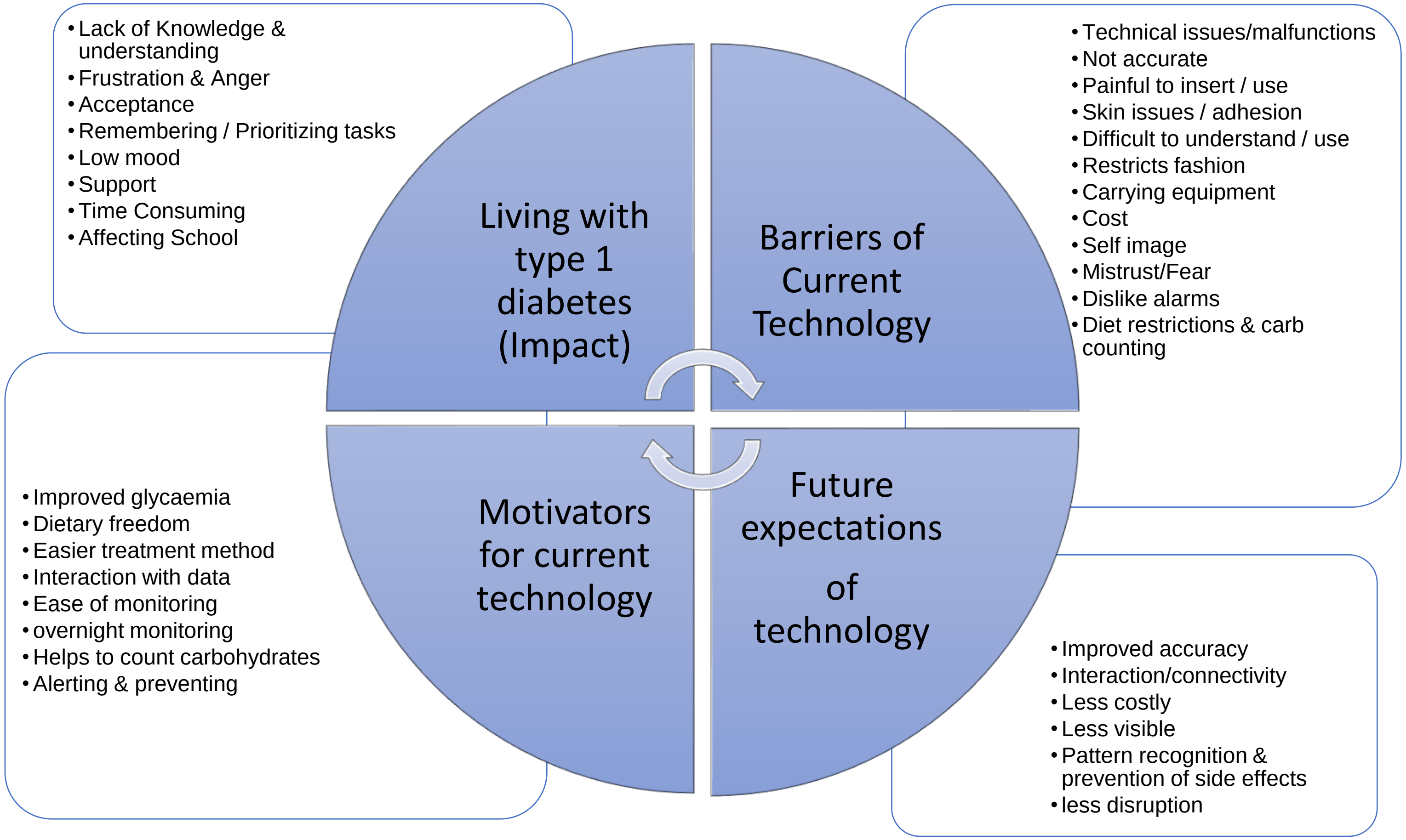


Figure 10. A diagram showing common themes across all data sets, showing 34 sub-themes grouped under the four global themes: (1) Living with type 1 diabetes - impact; (2) Barriers of current technology; (3) Motivators for current technology; (4) Future expectations for diabetes technology.

Table 4

Showing four global themes with sub-theme categorised by data set.

Global theme	sub-theme	Interview	Survey	JDRF
Living with type 1 diabetes – impact	lack of knowledge & understanding	✓	✓	
	frustration & anger	✓		
	acceptance	✓	✓	
	Remembering/prioritizing tasks	✓	✓	
	low mood	✓		
	support	✓		
	time consuming		✓	
	affecting school	✓	✓	
Barriers to current technology	not accurate	✓	✓	✓
	painful to insert/use	✓		
	skin issues/adhesion	✓		
	difficult to understand/use	✓		
	restrict fashion	✓		
	carrying equipment	✓	✓	
	cost	✓		
	self-image	✓	✓	✓
	mistrust/fear	✓		
	dislike alarms			✓
	diet restrictions & carb counting		✓	

Table 4 continued

Showing four global themes with sub-theme categorised by data set.

global theme	sub-theme	Interview	Survey	JDRF
motivators for current technology	improved glycaemia	✓		✓
	dietary freedom	✓	✓	
	easier treatment method	✓	✓	✓
	interaction with data	✓		✓
	ease of monitoring overnight		✓	✓
	helps to count carbs	✓		
	alerting & preventing		✓	
Future expectations for technology	improved accuracy	✓		
	Interaction with FitBit/Apple/Other	✓		
	Less costly			✓
	Less visible	✓	✓	✓
	Pattern recognition & prevention of side effects	✓		✓
	Less disruption	✓	✓	✓

Table 5 below shows one example of the process of conceptualising/naming themes, showing excerpts gathered across all data sets (representing parents/caregivers and adolescent's opinions and feelings).

Table 5

An example of the overarching theme "self-image" with excerpts from all data sets.

Sub-theme	Interviews	Survey	JDRF
Self-Image	"The more like an outcast you kinda feel" (01)	"I can check my blood sugars on my Pebble watch which is easier and less embarrassing at school"	"My teenage daughter is most concerned or anxious about technology making her stand out, e.g. self-conscious about her alarm going off in a busy classroom"
	"if they could like a pump, that was a lot smaller, so a bit less noticeable I guess" (02)	"…When I feel embarrassed"	"I'm self-conscious about it, don't like when it beeps e.g. when with other people in class. Have to carry a lot of stuff with you. Have pump, but still need back up stuff. Find Pod gets in the way, depending on what I'm wearing."
	"How does it impact your life? Feeling different really" (04)	"Letting other people known I have diabetes, I don't like talking about it or telling others, as I find it embarrassing"	"Concern about others seeing it"
	"it does make you a bit more self-conscious." (06)	"Makes me feel self-conscious monitoring it out in public or socialising with new friends"	"The treatment methods are visible / uncomfortable" "CGM, Libre are on display. This can be a huge care for self-conscious adults and children."

5.1 Results from Interview Data

As type 1 diabetes is a family issue, the adolescent participants were interviewed with parents/caregiver’s present. Themes were extracted and grouped from the interview responses using thematic analysis. Four global themes were established a priori, with an uncovering of sub-themes from the data: (1) living with type 1 diabetes – impact; (2) barriers of current technology; (3) motivators for current technology (4) future expectations to technologies (Refer to table 3.0 for sub-themes developed during interview phase).

To present these complex issues in more detail, each emerging sub-theme, from the interview data only, will be explained with narrative interpretation and exemplar excerpts in this section:

5.1.1 Understanding the complexities of type 1 diabetes from the adolescent and family perspective [Research Objective 1].

The majority of interviewee’s felt living with type 1 diabetes had a negative impact on their lives, that they “*hated it*” or it felt like a “*struggle*” in terms of sub-themes related to frustration and anger (n=4).

Of the seven participants interviewed, three people felt they just had to get “*used to it*” bringing a sub-theme of acceptance of the condition. However, one of these participants also then went on to say a contradicting statement that they felt like they were “*in a trap*”. These findings strongly highlight barriers – in alignment with coping with diagnosis.

At interview stage, a range of sub-themes gathered focused on planning tasks and the amount of effort taken to deal with the condition. From prioritising tasks, the participants felt that it was “*hard work*” and that there are “*so many different factors*” involved in causing impact, which can also lead to gaps in knowledge:n

Lack of Knowledge and Understanding

Insulin pump technology was discussed by participants within the context of feeling uncertain or unsure of how to change basal rates/dose adjustment and making changes.

Excerpt 1:

> *“05: Erm I just let my mum and my nurse do all my adjustments on my pump,*
>
> *Right, basal rates?*
>
> *05: yeah, I don’t like or adjust, I don’t deal with that. Erm, so I couldn’t even tell you any of the numbers that are on my pump at the moment, the ratios or anything”* (interview participant 05, female age 17)

Frustration & Anger

As known in literature, technology can be complex. However, dealing with type 1 diabetes can also be frustrating and complex - leading to low mood and feelings of anger. Strong feelings can be associated with the frustrations of type 1 diabetes and the diagnosis as highlighted by participants. However, participants also reported a feeling of acceptance by stating they “*just get on with it*” and that they are “*used to it*”. This contrast is shown by Excerpt 2 below:

Excerpt 2:

> *“… I hate it a lot to be honest, because it’s all, it feels like you can’t have fun a lot. I know it sounds stupid, but it’s all “watch what your bloods are”* (interview participant 05, female age 17).

The same participant then eludes that there are so many tasks to remember when discussing living with type 1 diabetes:

> *"…"do this" , "do that", "make sure you remember this", "remember that" for instance like going to Craig Tara (*holiday)*, took my pump off and then the whole night I was ill"*

Low Mood

Low mood and feelings of struggling with the demands of managing the condition was highlighted by interview participants, which aligns with many previous studies:

Excerpt 3:

> *"well sometimes it makes me feel like I can't be bothered, like low on energy and stuff like that, and it's just, if, like sometimes I think, like what's the point in doing it all if it's just gonna like, nothing works, it's just the same all the time, it's just gonna keep goin up and down and up and down"* (Interview participant 03, male age 15).

Support

Interview data indicated that support from others is essential in coping with the complexities of the condition. In terms of discussing support, all participants identified that their parents/caregivers supported them, alongside peers and trained professionals. Vitally, in terms of support during the night, one participant and his mum (see excerpt 4) mention their collaborative efforts of dealing with impact of changes to glycaemia during sleep, and the need to set alarms to awaken from sleep.

Excerpt 4:

> *Mum: so, he'll set two alarms at three in the morning to wake himself up and check, and then just at the moment, while he's getting into that*

> *routine, then one of us will get up at 3:15am and just double check that he hasn't slept through the alarms, but that's actually been working well hasn't it?*
>
> *02: yeah*
>
> *Mum: that's been a big step for him to do that, and really great.*
>
> *Does that impact you on a tiredness level during the day at school, or are you only awake for five minutes?*
>
> *02: yeah, not even that just awake 30 seconds half the time … say it's low I have a poppa and do what I need to do and then let mum and dad know.* (Interview participant 02, male age 17).

Affecting school

Aside from the participants feeling impact in terms of low mood and frustration, it was evident from the interviews that participants make attempts to avoid feeling embarrassed and at times, experience a certain level of ignorance and judgement from others around them especially in school (as shown in excerpts 5 and 6). In a school setting, Participant 01 (excerpt 5 below) felt that barriers for him treating type 1 diabetes and seeking help from others existed due to fear of bullying. Linked to this, the practice of going to a private, designated medical room, to use equipment was discussed by Participant 07 in excerpt 6 below.

Excerpt 5:

> *"Whereas in High school it's a bigger school with not a lot of people who knew me because a lot of them are reluctant to go about showing they are diabetic because they would get singled out or bullied."* (Interview participant 01, male age 17).

Excerpt 6:

> *“07: erm well I always test in the medical room, so I do it before I leave*
>
> *Oh right, so you’re going out of the class and checking when you’re down there?*

07: Yeah” (interview participant 07, male age 13.).

Continuing from this, non-verbal cues at this point in the interview showed signs of embarrassment, as mum joined the discussion:

Excerpt 6 continued:

> *“Mum: well, I’ve got a wee issue with that because 07 has to check wherever he is if he needs to, but he doesn’t, he waits til break time*
>
> *Right*
> *Mum: whereas he shouldn’t be waiting*
> *07: If I’m low, I’ll go down*
>
> *Mum: so, you can come out of class to go down?*
>
> *07: no*
>
> *Not yet, the school will be fine with that*
>
> *Mum: it’s the hang up on 07’s part, just doing it in the class*
>
> *Not wanting to get your test kit out in the class, and do a test, when your mates are all sitting there all quiet?*
>
> *07: uhu”*

5.1.2 Understand what technology is currently available (and used) for managing glycaemia in type 1 diabetes [Research Objective 2].

Three participants were currently using insulin pump therapy and four were treating with pen injections. However, of the four participants using pen injection therapy – three were previous insulin pump patients, shown in Table 6.

Table 6

Interview participant current use of technology.

Participant ID	**Insulin replacement technology**	**Freestyle Libre® / CGM**
01	Currently pen injections, previous insulin pump patient.	No
02	Pen injection	Short trial of CGM
03	Insulin pump	Freestyle Libre®
04	Currently pen injections, previous insulin pump patient.	Short trial of CGM
05	Insulin pump	Freestyle Libre®™
06	Currently pen injections, previous insulin pump patient.	Freestyle Libre®
07	Insulin pump	No

When asked if participants had experience of CGMs, participants mentioned they had been involved in short term trials and found the insertion of the device painful. Participant 03 mentioned that they had never been offered a trial of a CGMs device but were happy to talk about their Freestyle Libre® device during the interview.

This was the case with participants 05 and 06. Participant 07 felt that a CGMs device would be welcomed if it was offered *“07: I don’t mind, if I got offered one, I’d take it, but I don’t mind. But I wouldn’t go out my way to get one because I’m fine with my pump”.*

5.1.3 Exploring the current barriers and motivations the adolescent is experiencing (and using) to manage glycaemia in type 1 diabetes [Research Objective 3].

Excerpts are divided in this section by sub-section A - barriers and sub-section B- motivators, in relation to the third research objective:

A Barriers

Technical issues / malfunctions

One participant spoke of a serious of malfunctions with an insulin pump, and discussed this was the main determinant for reverting to pen injection therapy:

Excerpt 7:

> *“01: Water seal cracked, I had it completely error out and I had a section where all my data was wiped from it multiple times. To fix it again and for it to break again is a bit, excuse me (coughed), a bit erm…*
>
> *Worrying?*
>
> *01: unreliable and worrying. Especially if I’m sleeping and it errors, and I sleep through it.”* (Interview participant 01, male age 17).

Not accurate – fear & mistrust

This theme was recorded to highlight participant’s experiences with technology which malfunctioned or produced erroneous results – causing fear and concern as shown here in Excerpt 8*:*

Excerpt 8:

> *"05: Yeah I do because on the thing it said my blood sugars were 13 but, on my meter, it said they were 8 or something like that*
>
> *Which is quite a big discrepancy isn't it? A big change?*
>
> *05: so, I coulda put insulin to correct that and it would have been too much*" (interview participant 05, female age 17)

Painful to insert

Regarding the actual physical insertion of cannulas and devices, participants mention experiencing pain, details of an example of this is given here in Excerpt 9:

Excerpt 9:

> *"(CGMs) erm, it was sore to get it in" (*Interview participant 04, female age 14)

Skin issues / adhesion

As the devices adhere to the skin, participant's state they find skin rashes, reactions and the devices falling off, shown in Excerpt 10:

Excerpt 10:

> *"(Libre) it started at like, maybe at the 12th day, it started getting, like itchy, and really irritating and I think it must have been like the sticky stuff and not being able to wash it away"* (Interview participant 03, male age 15).

Difficult to understand

In this example, during interviews, a recurring pattern of reporting difficulties associated with the technology was found, as highlighted by Excerpt 11:

Excerpt 11:

> *“01: erm, I was on a pump, but I’ve been took back off into pens because I wasn’t looking after it. But it’s not so much that I don’t erm want to take care of myself, it’s more that the pump has a lot of sub headings like, individual titles for like my blood glucose and my history and things that I will never use. Just seems impractical, it’s not as sufficient as it should be. It’s not specific for example temp basals – cut back, I don’t use that. Because I feel that it’s too complicated to understand and set up and I’m relying on it.”* (Interview participant 01, male age 17).

Restricts fashion choices

A barrier described by a participant relates to the reason why the decision to revert back to pen injections was made Excerpt 12:

Excerpt 12:

> *“06: yeah exactly, if you’ve got a dress on you have to attach it to something*
>
> *So, did you feel restricted because of your clothing with the pump*
>
> *06: yeah, you have to buy extra like things to put it on, like I had to buy a strap round my leg to hold my pump on my*
>
> *When you’re wearing a dress or something? Keeping it hidden?*

> *06: not even that, it's not hidden and it's not that comfortable (* Interview participant 06, female age 16).

Carrying equipment

Additionally, participant 06 raised the issues of leaving the house and being organised enough to remember diabetes related technology. This participant talked about this in context as to why the decision was taken to move away from technology, and that it was felt to cause more of a barrier other than fashion choices, as shown below in Excerpt 13:

Excerpt 13:

> *"But sometimes you don't know, all the different ratios, you've always got to think on your feet, like you've got to think ahead so much about like if you're goin out with your friends your like "have I got my pump, have I got insulin, have I got my injections, have I got everything with me" so you're prepared".* (Interview participant 06, female age 16).

Cost implications

This theme was developed from the participant who lives in a country other than the UK and felt a major barrier to technology was that of cost as shown below in Excerpt 14. However, UK participants mentioned self-funding Freestyle Libre® technology and feeling that it was expensive also:

Excerpt 14:

> *"it's not licensed here for under 18's yet. So, I think that the new funding that is hopefully going to be released on the 1st of April is hopefully gonna be CGM's for under 18s and for under 21's the Freestyle Libre. But then when you're 21 you're cast out into the wilderness as if your*

> *diabetes has stopped or else you have to be able to afford it yourself. Cause it's a huge cost isn't it?"* (Interview participant 02, male age 16)

Self-image

Aside from cost issues, participant 02 also mentioned the element of disliking a visual aspect to technology - Excerpt 15:

Excerpt 15:

> *"aww, everything really, like the pump's good, but I don't really want to have something, like that big. So, if they could make like a pump that was like a lot smaller, so a bit less noticeable…"* (Interview participant 02, male age 16).

Mistrust/Fear

Interview data from participants reported inaccuracies using technology as shown in the example given in Excerpt 16:

Excerpt 16:

> *04: yeah because I didn't really feel safe to go back on it, cause I was scared it was gonna happen again*
>
> *Right, so you were scared?*
>
> *04: yeah*
>
> *And that's understandable, as DKA is life threatening so I totally understand why you felt that way, and are you feeling with the pens, what's your kind a view long term?*

> *04: I do want to try going back on the pump but there's still that thought that it will happen again"* (Interview participant 04, female age 15).

In terms of motivators for current technology which were discussed at interview stage, sub-themes are displayed in the same format as barriers, to keep results linear.

B Motivators

Improved glycaemia

With motivation to using technology linked to glycaemic changes, participant 05 mentions the importance of using an insulin pump - *Excerpt 17:*

Excerpt 17:

> *"Brilliant! I love the pump", Yeah it's great, like when I was on the pens, my blood sugars were never below like 13mmols, and it was so hard to try and keep remembering to do it, and everything. But with the pump, my blood sugars are, not always in target, but round about in target"* (Interview participant 05, female age 17).

Dietary freedom

A key theme mentioned across all interview data is dietary control, whether carbohydrate counting or feeling able to eat without set times, as described by Excerpt 18:

Excerpt 18:

> *"yeah, it's gives me more freedom. Like I can eat when I feel like eating, I don't have set meal times and I don't need to be in by a certain time to*

> *do my Levemir and stuff like that, it's a lot easier than the pens because I had a lot more like set times when I was on the pens"* (Interview participant 03, male age 15).

Easier treatment method

Participants who continue to use insulin pump therapy find the motivation can be linked towards having ease of delivery of insulin as described by the data in excerpt 19:

Excerpt 19:

> *"So that's easier for you to bolus in that way, than having your pen?*
>
> *05: yeah*
>
> *And do you feel it gives you a bit more flexibility then?*
>
> *05: yeah"* (Interview participant 05, female age 17).

Interaction with data

Interview data also indicated that an element of being motivated to use technology is related to viewing glycaemic data from insulin pump uploads as shown below in excerpt 20:

Excerpt 20:

> *"03: regularly we're just uploading, like maybe a few times a month and*
>
> *Right*
>
> *03: erm. Looking at all of that and sending it into the hospital*

> *Right, and is it your mum that looks at that data normally, or do you sit with your mum? Or what?*
>
> *03: erm, it's normally mum, but I will sit with her and look at it as well"* (Interview participant 03, male age 15).

Ease of monitoring

As a contrast to barriers, in excerpt 21, one participant mentions the motivation for using the Freestyle Libre® system as compared to frequent finger prick testing of capillary blood.

Excerpt 21:

> *"06: yeah I just test it, like it's easier, I just have it in my pocket as well when I'm sleeping, I'll just go like that (imitates scanning the arm with Libre scanner)*
>
> *Yeah, scan the libre?*
>
> *06: Yeah it's easier than finding your test kit in the dark, you have to find your meter"* (Interview participant 06, female age 16).

Helps to count carbohydrates

Additionally, from a SmartPhone App perspective, participants were asked if they use any apps to help them. From this, participants answered that they have used Apps on their smartphones for counting carbohydrates – mainly "Carbs N Cals" as shown in excerpt 22. These participants also mentioned the use of Facebook / Social Media groups in relation to using Apps to network with others for support in relation to managing type 1 diabetes. This was reported as a motivator to help manage glycaemia – as counting carbohydrates is a cornerstone of treatment adherence patterns for type 1 diabetes as mentioned in Chapter 2.

Excerpt 22:

> “*03: I had another one that’s just the “Carbs and Cals” one, it helps sometimes with looking at portions and*
>
> *Uhu, carbs and cals, that’s still good*
>
> *03: looking at carbs – it’s good as well*
>
> *Yeah, I know counting the carbs?*
>
> *03: yeah”* (Interview participant 03, male age 15).

5.1.4 Explore and map the views of the adolescent and their care givers with regards to future improvements of technology for managing glycaemia in type 1 diabetes [Research Objective 4].

As interview participants experienced failures with technology and current methods of treatment, assessing perceived expectations for future developments was gathered and reported below.

An overall theme of improved integration with systems connecting to Smartphones and trackers was reported as an expectation by all participants. A predictive capability, to prevent changes in blood glucose was mentioned alongside improved accuracy and reliability of glucose sensors:

Improved accuracy

Participants reported difficulties associated with this theme - having experiences whereby technology failed to give accurate glucose data or hardware errors were experienced. Excerpt 23 gives an example of the need for technology to improve.

Excerpt 23:

> *"Well I think the sensors a really good idea, it's just if it can be a bit more reliable like I think that's really handy…"* (Interview participant 06, female age 16).

Interaction/connectivity

When asked what changes they would like to see developed, participants discussed connecting diabetes devices with smartphones, with one participant mentioning interaction with a wearable device, as shown in Excerpt 24:

Excerpt 24:

> *"Something on your phone would be amazing, like do you know like the wee FitBits, having like a wee FitBit on your wrist that sends when you're low"* (Interview participant 05, female age 17).

Less visible

However, for one participant in particular – the changes reported were mostly related to the size of the device, as shown here in Excerpt 25:

Excerpt 25:

> *"Aww, everything really, like the pump's good, but I don't really want to have something, like that big. So, if they could make like a pump, that was like a lot smaller, so a bit less noticeable, I guess"* (Interview participant 02, male age 16).

Pattern recognition / prevention of side effects

Interview data from participants gave results linked to imagining a piece of technology which predicts and prevents hypoglycaemia or hyperglycaemia –

thus alerting the person with type 1 diabetes to impending risk, as shown by the example below in Excerpt 26:

Excerpt 26:

> *"probably pick up if you're high or low, like if it can pick up that before you start feeling high or low maybe"* (Interview participant 04, female age 15).

5.2 Survey Data

The data gathered and reported in the survey, widens and extends the findings of the interview data by accessing participants online. Anonymous participants reported on their lived experiences of type 1 diabetes, with regards to the research questions mentioned in Chapter 3 (table 7.0). In this section, major themes and sub-themes will be divided by the sample sets - defined in Figure 11. This is further explained from section 4.3.1. Example quotations will be identified using the row and column of the MS Excel sheet from which raw data was extracted.

5.2.1 Participants

In total, 107 respondents opened and viewed the survey from an online link posted in social network groups (which were relevant to parents/caregivers of teenagers with type 1 diabetes). Figure 11. below also shows the breakdown of survey results which were used for analysis. Although 107 people opened the file, for the purposes of analysis and representativeness a total of 26 records were used in reporting the findings.

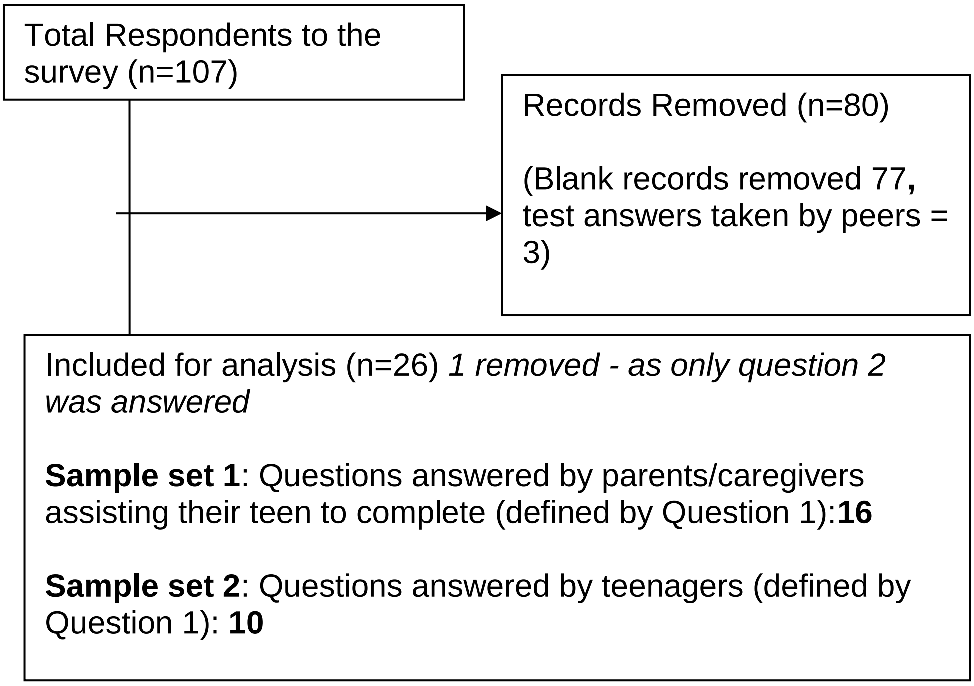


Figure 11. Flow diagram representing survey data analysis on complete respondents and rate of response – 30%.

5.2.2 Sample Sets

The survey first asked for the participant to identify if they were either a *“parent of an adolescent (12-17 year olds) assisting… to complete” (Sample set 1)*, or if the adolescent was completing it alone (sample set 2). In some instances, it was ambiguous throughout the first sample set if the parent or teenager answered the question directly, therefore all answers were treated as a collaborative effort between parent and child – an example of this is show below. This option in the survey was designed to allow parents/caregivers and adolescents to complete the questionnaire if they felt they would like to complete it together. Table 7 gives demographical information.

> *Question 1: How do you currently feel about having type 1 diabetes?*
> *Answer 1 - “I hate it”*
> *Answer 2 - “We are 10 years in and he doesn't let it beat him, he's a star athlete and determined it won't beat him, it's made him stronger.”*

In Answer 1 it is not clear if the parent answered the question, or if the child asked the parent to enter this data. In Answer 2, it is obvious that the data is descriptive of a collaborative effort. All data was treated as a collaborative effort – determined by the sample set as mentioned.

Table 7

Demographic Results from online survey (Questions 2; 24 – 27).

Sample set	**1 - Parent with Adolescent (n=16)**	**2 - Adolescent (n-10)**
Age	12-17 year olds (mean: 14.3years) *Parental ages were not considered*	12-15years (mean: 13.8years)
Gender	Female: 10 Male: 3 Unanswered: 3	Female: 5 Male: 3 Unanswered: 2
Location	UK	UK
Ethnicity	White: 12 Black or African American: 1 Unanswered: 3	White: 8 Unanswered: 2

As there were four global themes established from a prior knowledge and reading, the analysis of survey data was conducted to unravel complexities of sub-theme data. Categorising the data into sub-themes as shown below.

5.2.3 Global theme 1 – Living with type 1 diabetes – *impact* [Research Objective 1].

Time consuming

(Sample Set 1 – parent & adolescent)

In relation to feelings associated with living with type 1 diabetes, the respondents mention elements relating to how much time they spend treating the condition, *"Daily blood checking at academy is time consuming".* As shown in Appendix C, this sub-theme was prevalent throughout survey and interview discussions.

Affecting school

(Sample set 2 – adolescent)

As reported, the amount of effort not only takes time, but one respondent mentions missing school lessons as an element of living with type 1 diabetes: *“Constant monitoring my blood sugar, missing classes”.* Additionally, the cognitive effect is mentioned by a different respondent – *“When I have highs and lows it is a problem with my school, and I have trouble doing my schoolwork or taking tests”.* Strikingly, the element of fear in relation to attending school events is also mentioned *“Worry about dying at night. Scared to go abroad on school trips. Sometimes makes me feel unwell”.*

Remembering tasks

(Sample set 2 – adolescent)

Excerpt 1 shows a clear and concise statement by the following respondent highlights the effort required to remember diabetes related tasks, further providing evidence of the complexities of living with type 1 diabetes:

Excerpt1:

> *“It impacts your life tremendously!! You have to carb count everything you eat then mathematically work out for much insulin to take because one unit over can cause you to make a low and a unit or two over causes you go to high so it's a bit of a tightrope. You are I guess forced to do certain things that at first you think I can't do that but then you do, and you get into habit and routine. There is a lot of requirements you have to fulfil just to live life isn't as simple as it was you have to be prepared for any situations and always carry food and all your other medical supplies”.*

Acceptance

(Sample set 2 - adolescent)

Contrastingly, in terms of motivation for living with type 1 diabetes, and the complexities experienced - an exemplar quote, shown in excerpt 2, from a respondent who feels positive after living with the condition for 6 years is shown below:

Excerpt 2:

> *"I am a 6-year veteran of type on diabetes, so I think I have this whole thing figured out hopefully. I am feeling very good with where I am right now, my blood sugars are at a good level usually and my a1c is at a good level right now"*

Adding to the data collected regarding having a perception of good levels of blood glucose ranges, managing blood glucose was highlighted by 3 out of 9 participants as their idea of coping in a positive way *"Good blood control and staying on top of everything and being able to spot patterns".*

5.2.4 Global Themes 2 & 3: Barriers and motivators of current technology [Research Objective 2&3].

With regards to managing glycaemia and the use of technology, respondents were asked about their treatment method. Out of 26 fully completed survey results, the majority of respondents were currently opting for an insulin pump with finger prick technology and "other technology" (17 out of 26). When asked to give details of "other technology", 11 people stated they were using a CGM and 4 people stated they use the Freestyle Libre®. Progressing on from asking what technology they currently use; the participants expressed their feelings regarding current treatment as shown below:

Overnight monitoring

(Sample Set 1 – parent & adolescent)

To further explore the technological aspect further (Question 22), respondents were asked to describe *“how they felt about their CGM trial”*. Examples of the responses are shown below in excerpts 3 and 4.

Excerpt 3:

> *“I had the Libre but as I don't feel hypos and hypersensitivity my mum wanted me to have alarms, so she would feel safer with me going out with friends. Also, it helps overnight as it wakes my parents up. I like having cgm it makes it easier”*

Excerpt 4 gives further evidence to support choices made my adolescents and their families in the need to prevent hypoglycaemia during the night:

Excerpt 4:

> *“Self-funded Libre but needed alarms and low suspend due to no hypo awareness at night so put case to hospital for funding”*

Most respondents felt that the CGM trial was helpful, although some usability comments were raised such as them being *“bulky*”, or *“tape*” needed to stick it down *“I trialled it because I wanted to see how it would affect my blood sugar and it did help but I didn't like how bulky it was”.*

Easier treatment method

(Sample Set 1 – parent & adolescent)

Data representing opinions and feelings of the respondent with regards to making their lives easier is shown below in excerpt 5. Seven out of ten participants stated similar positive statements as shown below:

Excerpt 5:

> *"I love the insulin pump because it gives me so much freedom and as I said I love the Libre because of how easy and officiant (efficient) it is"* and the delivery method is felt to be better than pen injection - *"It's better than having to do pen injections 5 times every day".*

Excerpt 6:

> *"Much better than injections but cannula change painful. Tubing can be painful and gets tangled and stops me wearing some clothes. Libre can be a worry in case knocks off but much better than finger pricking."*

Ease of monitoring

(Sample Set 1 – parent & adolescent)

As monitoring glycaemia is the cornerstone of measuring how successful a treatment option can be, and the frequency of finger pricking can be extensive, sometimes adolescents will use a CGM device despite difficulties such as inaccuracy, as shown in excerpt 7:

Excerpt 7:

> *"I do not like to use the CGM. I like that it helps me monitor my BG, but, I often find it very inaccurate, alarming all the time and a distraction."*

Dietary freedom

(Sample Set 1 – parent & adolescent)

Additionally, motivators for choosing technology can be interconnected with barriers as shown in excerpt 8, whereby the respondent mentions issues relating to improved dietary freedom but also highlights ease of monitoring and cost implications:

Excerpt 8:

> *"I like the pump because it's easier. I can eat more of what I want when I want it! I like having the cgm because again it makes management easier - I hate doing finger pricker. It's a shame that the NHS won't fund the cgm for me, so my parents have to pay."*

Affecting school

(Sample Set 1 – parent & adolescent)

Issues relating to school have been prevalent throughout the survey with regards to the previous results showing time consumption; cognitive effects (see Pages 76 & 77) and embarrassment. This example gives details of a respondent feeling that technology can reduce issues relating to feeling "embarrassed" at school, by using software linked to a wearable watch device known as a Pebble, shown here in excerpt 9:

Excerpt 9:

> *"Nightscout is brilliant as I can check my blood sugars on my pebble watch which is easier and less embarrassing at school."*

Carrying equipment

(Sample Set 1 – parent & adolescent)

In reporting motivation for technology, and ease of monitoring – excerpt 10 shows from the data that this implies the adolescent will need to carry a lot of diabetes related technology around, a recurrent theme throughout all data sets:

Excerpt 10:

> *"I have to stay out of basketball for a while because I saw on my Dexcom or I felt that I was low"* and carrying supplies around – *"you*

> *have to be prepared for any situations and always carry food and all your other medical supplies".*

Self-image

(Sample set 2 - adolescent)

However, not all respondents felt favourably about technology and barriers associated with self-image were reported with regards to this in excerpt 11:

Excerpt 11:

> *"I can't go on a pump at the moment. But I often get self-conscious with injections in public and find it hard to do so. Also, still being a school sometimes I just think it would be so much easier to just eat and play rather prick my finger injection eat then play."*

Not accurate

(Sample set 2 – adolescent)

As discussed, respondents shared their feelings regarding their current treatment, sometimes with more than one theme throughout (as shown in excerpt 12) – due to the interconnectedness of usability and functionality of the technology. This respondent explains why they stopped using technology:

Excerpt 12:

> *"I don't like doing pump site changes. They hurt. And I had a cgm but stopped using it because the readings were always way off, and it alarmed a lot."*

Alerting & preventing

(Sample set 2 – adolescent)

Survey data shows the importance of technology in the prevention of severe side effects of hypoglycaemia, namely hypoglycaemic seizures with regards to the statement by the respondent shown in excerpt 13:

Excerpt 13:

> *“Grateful I have a pump and cgm I have seizures”.*

5.2.5 Global Theme 4: Future expectations for technology [Research Objective 4].

Progressing from current treatment, recorded data showing analysed results of mapped views for future improvements are as follows:

Less visible

Question 16 asked “*With regard to HbA1c measurements and blood glucose control, if technology could help you what statements would you choose?”* (shown in Figure 12):

With this Pre-Categorised response option, the data shows that participants choose the option *“If technology didn’t cause any disruption to your life i.e., alarms”* more frequently than all other options in the combined sample sets. These results relate to current experiences of intrusive alarms and disruption with insulin pumps connected to CGMs.

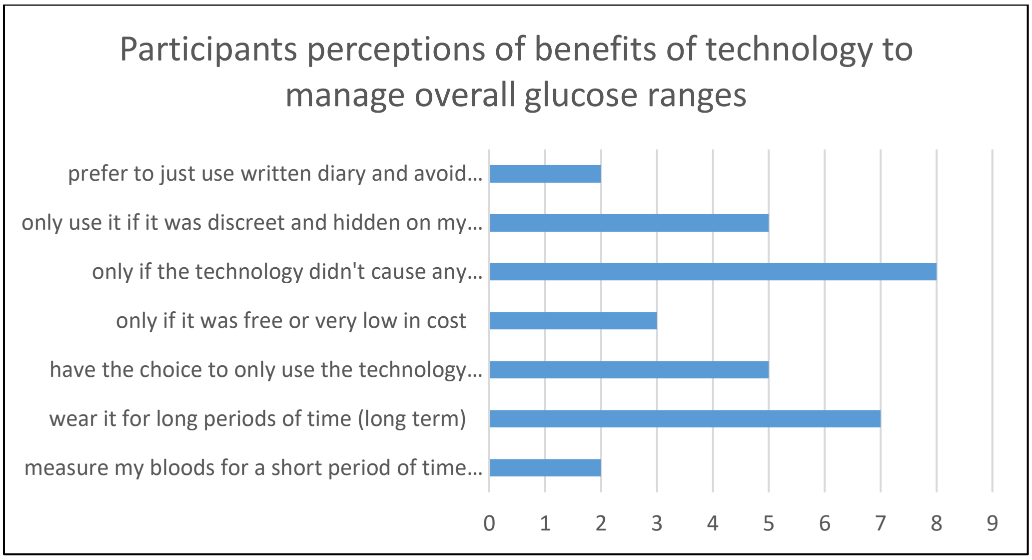


Figure 12. perceptions of benefits of using technology to improve HbA1C. Showing importance of reduced disruption to their lives – cross tabulates to data in the survey showing participants hating alarms.

Less disruption

The survey then asked participants to choose options which they felt would help them if they had technology to help with managing blood glucose and their HbA1C results: The options are shown in Table 8 with each sample set represented. The majority of participants to the survey chose the *“only if the technology didn’t cause any disruption to your life i.e. alarms”* option.

Table 8

Survey sample sets responses to choosing technology to affect blood glucose change.

(Question 16: With regard to HbA1C measurement and blood glucose control, if technology could help you what statements would you choose?)			
Survey option	**Sample set 1(Parents/caregivers & adolescents) n=17**	**Sample set 2 (adolescents only) n=10**	**Total chosen**
measure my bloods for a short period of time until blood glucose control was in range	0	1	1
wear it for long periods of time (long term)	6	1	7
have the choice to only use the technology when you recognize that you're not coping / feeling overwhelmed	2	1	3
only if it was free or very low in cost	1	1	2
only if the technology didn't cause any disruption to your life i.e. alarms	5	3	8
only use it if it was discreet and hidden on my body	3	2	5
prefer to just use written diary and avoid technology i.e. CGM	0	1	1

5.3 JDRF – Opinion poll data

This research was presented to an audience of families at a "Discovery Day" event held and organised by JDRF in Glasgow, UK. The event enables families of children with type 1 diabetes to learn about research and the fundraising community. At the event three opinion poll questions were presented related to technology used to manage glycaemia in type 1 diabetes.

In response to each question, hand written answers from 19 anonymous participants in the audience were gathered. Each answer was transferred to a Microsoft Excel spreadsheet, whereby each opinion was given a numerical identity to formulate a framework of themes shown in Tables 8.0 – 10.0. These identifiers are labelled beside each quotation, for cross referencing with Appendix D spreadsheet.

These themes where then analysed as overarching themes shown in table 4.0. Example excerpts from each question is given below, with explanation of sub-theme categorisation to provide indication of the application of the methods of thematic analysis.

This data relates to research objectives 3 & 4 – what views do the participants have on current and future technologies only.

5.3.1 Question 1: *Can you tell me what you love/like about technology that you have seen/use/have had?* [Research Objective 3].

Overnight monitoring

Data collected reported that parents/caregivers like being able to check their child's blood glucose during the night. Ease of reduced finger pricking, and injections was reported, alongside having alarm functions to monitor episode of hypoglycaemia throughout the night, *"As a parent, I love the continuous glucose monitoring. I can check through night, exercise without interruption" (B4).*

Interaction with data

Sharing the data; viewing the data from the technology and identifying areas for dosage changes was also given as a benefit/motivation for the technology used. From the types of technology mentioned there were: pumps; Freestyle Libre®; CGMs and smart devices, *"Libre - glucose level trend up or down, less finger pricks, download data, share with diabetes team for analysis to support diagnosis" (B9).*

Easier treatment method

Out of the nineteen participants, seven highlighted they love the ease of delivery of insulin or monitoring their adolescent child's glucose overnight by using technology through either the Freestyle Libre® system or CGMs/Insulin pumps, *"Pump is easier than injections, is less time consuming and more freedom especially when out - makes it easier to manage" (B6).* Table 9 gives an overview of themes collected and analysed from the question 1 of the opinion poll:

Table 9

Sub-themes recorded from participant's likes/dislikes regarding technology, taken from JDRF Opinion poll data.

Sub-theme	**Participant ID**	**Prevalence**
Ease of monitoring/delivery	1,3,4,5,6,10	6
Improved glycaemia	5	1
Data interaction	7,8,9,11,12,13,15	7
Freedom- lifestyle	6	1
Overnight monitoring	14,16	2
Visible	10	1

The ease and frequency of data interaction, the ability to view real-time data and change dosage was noted as most prevalent from this exercise, from gathering the opinions of families living with an adolescent with type 1 diabetes.

5.3.2 Question 2: *Can you tell me what you dislike/hate/worry about in the diabetes technology that you use/have seen/are familiar with?* [Research Objective 3].

Less visible

As this question prompted the participant for negative opinions, themes gathered here included feelings of being self-conscious when alarms go off in classrooms; gets in the way of clothing; uncomfortable to wear; financial burden of self-funding the Freestyle Libre®; Size of insulin pump too big and cannulation failures. Adding to the sub theme of size of device, the data was classified in the theme of being less visible, as shown in the examples given:

"Visibility to others during summer etc" (B33); "Concern about others seeing it" (B30) & "*Visible – it invites questions from people" (B39).*

Not accurate

Additionally, accuracy and calibrations of sensors were mentioned:

> *"Lag time of readings: tolerance and accuracy it's 10-15% out on readings" (B39); "Worry that the data is not accurate" (B42) &*
> *"Calibrations which appear to knock out sensor readings (Dexcom G5)" (B46).*

Table 10 below shows sub-themes collated from question 2 of the JDRF opinion poll. Showing frequency of themes related to disliking/hating current technology the family have used. Data was analysed to report the frequency of themes, in relation to the issues people dislike about current technology. Whether they may use or have seen it, the size, visibility and feelings of being self-conscious were noted.

Table 10

Prevalence of sub-themes relating to likes/dislikes of technology from JDRF Opinion poll data.

Sub-theme	**Participant ID**	**Prevalence**
Self-image	1,2,3,4,6,8,13	7
Cost	4,11,14	3
Inaccuracy	7,10,12,15,19	5
Connectivity	11	1
Pain (uncomfortable)	8,9,10,17,18	5

5.3.3 Question 3: *For the future – what single aspect of technology would you like to see developed / improved upon?* [Research Objective 4].

Pattern recognition / prevent side effects

The data shows that people would like the technology to "*prompt corrections*" with warnings and preventions of hypoglycaemia – "*ways of preventing lows when exercising*" were raised.

> "*Something that can responds to situations overnight and take care of potential sudden drops or rises in blood sugars. Something you can trust and test easy as a parent or a teenager going to sleep with diabetes" (B67).*

Interaction/connectivity

Lastly, the mention of connectivity with devices such as Apple™ & Android™ technology and the ability for the technology to take away some of the burden of responsibility away from the child *"who just doesn't want to deal with their condition" (B52).*

Table 11 below shows sub-themes collated from question 3 of the JDRF opinion poll. Showing frequency of themes related to future changes/expectations the family would like to see happen. The data shows that JDRF participants mentioned predictive capabilities more frequently than any other theme with regards to future changes to technological capabilities.

Table 11

Recorded sub-themes relating to future expectations of technology, from JDRF opinion poll data.

Sub-theme	**Participant ID**	**Prevalence**
reduced visibility	1,9,10,12	4
Predictive capabilities	4,13,16,18,19	5
Compatibility / connectivity	6,7,9	3
Reduced cost	7,15	2

Chapter 6 Discussion

The overall aim of my study was to explore the barriers and motivations the adolescent has when managing glycaemia in type 1 diabetes, using diabetes health technologies. Specific objectives were to:

1. To understand the complexities of type 1 diabetes from the adolescent and family perspective.
2. To understand what technology is currently available for managing glycaemia in type 1 diabetes and what adolescents are currently using.
3. To explore current barriers and motivations the adolescent is experiencing towards managing glycaemia in type 1 diabetes.
4. To explore and map the views of the adolescent and their care givers with regards to future improvements of technology for managing glycaemia in type 1 diabetes.

In this final chapter, I will discuss the data retrieved and analysed in this study alongside other related published work to address the overall aim and each study objective noted above.

6.1 Research objective 1: To understand the complexities of type 1 diabetes from the adolescent and family perspective.

As this study progressed, it became apparent from reading literature, that human factors researched previously into the complexities of type 1 diabetes have often been reported by separating statistical relevance of, HbA1c/treatment methods and psychosocial elements. However, this fast-moving industry is now allowing for more presentation of research with emergent focus on technology, showing interconnected psychological and social elements. Research shows a progression from the introduction of insulin pumps in the early 2000’s for the UK, toward these technological breakthroughs such as CGMs and Freestyle Libre®. Improvements to lives, health data and clinical care models have changed by the introduction and widespread use of connected pumps and CGMs systems. However, human factors related to understanding the complexity related to adolescence and behavioural motivations to the effects and user experience of diabetes technologies requires further investigation. Clinical guidelines highlight the necessity of education and improvement of HbA1c, however, developing diabetes treatment guidelines and support required to manage technological involvement for this population remains a work in progress. It is recommended that clinical research follows behavioural change theory and participatory design elements in attempting to deliver patient education and support – sympathetic with the maturity and developmental stage of the adolescent population.

From this study, the main area found was that adolescents find it a struggle to manage the complexities of the condition, whilst they mature and grow through life. They experience feelings of low mood and anxiety alongside coping with peer pressure and added difficulties with parental/family issues such as nagging and communication problems. This mirrors the study by Dashiff et al. (2009) in which family involvement and support was the main focus on building an environment which affects mood. As seen in this study, several interviewees mentioned seeking help and support from their mother’s at times and distancing themselves at other times. The phrase used in the study by Dashiff et al, to encompass this movement in self-care was represented by “cognitive autonomy”. Methods used mirrored elements of this study, in as much as recruitment of similar populations – mothers and adolescents. However, their data was collected using a structured survey. In this study, the questioning was developed from prior reading but with awareness and understanding - a priory knowledge. It was felt that this allowed for more qualitatively rich data.

Another layer of the complexities of the condition is their experience of education and knowledge – surrounding the condition. Their ability to learn how to manage with fluctuating glucose, let alone learning about technology which may or may not be accurate. To be able to interpret their glucose results, having background knowledge, education and expertise to question this inaccuracy may decrease the burden on the adolescent and their caregivers. However, some participants did not understand the full system functionalities, and that of principles underlying insulin treatment – i.e., a few participants stated that they did not understand the HbA1c result; they were not aware of why they have basal patterns set up on their pump, and how to adjust this. They very often rely on parents/caregivers, clinicians and diabetes educators to do this for them. Borus, Laffel (2016) addressed research which discusses the findings of interventions built to support the teen to cope with technology with family and taking on the burden of managing the condition progressively being identified as important areas.

When considering that diabetes technology is built to keep them free from harm and well each day, it is worrying that the adolescents in this research discussed a lack of knowledge and understanding. The expectation on the adolescent is to learn to self-manage. This could mean the health care service training needs improvement to keep adolescents frequently updated on how to grow and adapt, whilst attached to devices keeping them alive.

6.2 Research objective 2: To understand what technology is currently available for managing glycaemia in type 1 diabetes and what adolescents are currently using.

Adolescents who took part in the study identified with using insulin pumps; CGMs; Flash Glucose monitoring system – Freestyle Libre® and SmartPhone Apps such as “Carbs & Cals”, “X-Drip” and NightScout related systems to enable cloud-based storage and smartphone/wearable device interaction with live glucose data. Moreover, there was a mix of opinions and attitudes towards technology based on length of use of technology, malfunction and errors experienced and cost. It became apparent for those who experienced inaccuracies and malfunctions, the safest place was to retreat away from technology and resume pen injection delivery with multiple daily finger prick testing. However, a tone of reticence towards this was found as there were ultimate motivational aspects to making life easier with regards to mode of treatment; dietary freedom and lifestyle benefits. Making the choice to revert to pen injection therapy for some, was difficult but more about safeguarding from fear and mistrust and risk of DKA (see pages 66, 69 & 70).

In treating the condition using these technologies, the interconnection between feelings around diagnosis and coping with the complexities were highly associated – i.e., swings in glucose causing mood changes / difficult physiological symptoms can cause barriers to treatment. Therefore, throughout my data, it became evident that many adolescents feel their condition to be a struggle which in turn affected their ability and choices towards using technology, and/or avoiding it.

Three of the seven interview participants moved away from insulin pump technology and others felt they would rather not rely on the Freestyle Libre® until accuracy; adhesion and training and support were improved (See Table 5). In terms of support, all participants during interview and surveys related that seeking support from others was paramount. This is a widely researched area, focusing on the psychosocial aspects the adolescent with type 1 diabetes faces, alongside association of HbA1c results and parental input (Anderson et al., 1997; Barnard et al., 2014). Each of these studies draw on the association of glucose control with parental support. Whilst there are many factors for glucose variation in this age group, Anderson reports that although frequency of finger pricking and testing blood glucose correlates with improved HbA1c, it was also found that parental involvement had a direct correlation with these results – showing that the age group 13-15years had decreased parental input with higher HbA1c results – in direct contrast to the younger participants (10-12years) who received more parental input and had lower HbA1c results.

Barnard et al (2014) discussed the parental input whilst the participant's trialled a CGM trial overnight, and the input they needed to calibrate and stabilise the child overnight when glucose ranges required intervention.

Motivating factors in respect of living with type 1 diabetes were gathered to portray how the adolescent copes with the demands that the routine of treating glycaemia brings to their everyday life. Accomplishing self-care methods and coping techniques such as remembering to plan diabetes tasks – alongside carbohydrate counting was frequently mentioned. Statements gathered related to seeking support from family/others and using social media to seek peer support relates to findings published by Doe (2016) and Seiffge-Krenke et al. (2013). The latter study mentions the correlation between poor glucose control and reduced parental support (performed by measuring variables in their study such as family restrictiveness; perceived parental social support and physical maturity). Outcomes in this study were measured using questionnaires and ANOVA tests for analysis of variance. In essence, in this study, it was reported by the adolescents that they identify with their parents/caregivers and clinicians as people who help to care for them. This is in alignment with research shown by the findings of Seiffge-Krenke et al. (2013) when reduced glycaemic control as parental support is reduced.

During this aspect of the study, adolescents voluntarily selected to take part in the survey. At times the adolescent may have had input from parents/caregivers which could have influenced their responses.

6.3 Research objective three: To explore the barriers and motivations the adolescent is experiencing towards managing glycaemia in type 1 diabetes.

Many adolescents within the study reported that they preferred aspects related to ease of delivery or ease of monitoring rather than feeling pain from needle injections and finger prick capillary blood tests. However, for the adolescents and their families who experienced technological failings in this study – reverting to these methods came across as a reluctant, safe option for them at this time. Providing evidence to support that errors in insulin pump / cannulation or Freestyle Libre® technology, made the adolescent fearful and retreat to pen injection therapy. This was additionally supported by survey participants who noted they felt the Libre technology was not accurate and made them fearful. During the JDRF opinion poll exercise, it was further mentioned by parents/caregivers that they also found the technology to be inaccurate and lacked trust in the ability of it to keep their adolescent child safe. Therefore, the theme of inaccuracy became consistent throughout all data sets. This was discussed by Rodbard (2016) in his review of CGM accuracy in which he found 9 important themes including inaccuracy – the need for recalibration, which to this date is still an ongoing advancement for future developments in the manufacturing industry of these devices.

In their search for this stability of blood glucose, and prevention of hypoglycaemia/hyperglycaemia the teenager interacts, at times, with technology that alarms; monitors; prompts and reminds them of possible glucose results which require prompt attention. However, it was clearly remarked upon that these systems are often inaccurate, and the response could be an overdose of insulin, or indeed a reaction to a false positive reading (alerting the adolescent to a false hyperglycaemia/hypoglycaemia result), which would lead them into a situation of danger. Reported from this were feelings of mistrust and fear towards current technological treatment methods – shown as a subtheme across all data sets.

Additionally, it was reported that some adolescents disliked the alarm functions. This links with a study by Shivers et al. (2013) in which they discuss “alarm fatigue” and the link between hospital deaths due to alarm fatigue in general medical devices: “alarm fatigue in hospitals has been linked to over 200 patient deaths since January 2005 ” (p. 789). This area of research ties in with the ability of patients with devices (which constantly alarm) for them to feel it becomes more of a burden, an annoyance and something which can become excessive and a nuisance. In this study, they considered two main frameworks when considering this crucial element of diabetes technology. They looked at patients’ safety – “patient safety first” and then they looked at “human factors”:

> One scenario that demands particularly careful human factors design is nocturnal hypoglycaemia, which—if prolonged and severe—can be associated with seizures and even “dead-in-bed” syndrome. An individual must be woken up to act—a feat that standard alarms might not necessarily achieve (Shivers et al., 2013, p. 791).

This phenomenon describes when sometimes, a severe hypoglycaemic event reduces the likelihood to be “aroused” and wake up to treat with glucose – despite having and alarm. Correspondingly, in this thesis, the data showed (both survey and JDRF participants) that they disliked alarms and felt that the inaccuracy of sensor readings was a barrier to paying attention to alarms.

This barrier to engaging with alarm functions requires further research as it is becoming one popular aspect of diabetes technology which can be used to alert if there is a genuine risk to life, either during the conscious waking day, or during sleep. Although these findings are generally consistent with research discussed by Giani et al. (2016), findings in this thesis differ slightly, in that evidence shows up-to-date usability issues with not just one system of glucose management, but a range of technologies (as chosen by the person with diabetes; their families and clinicians).

Across different types of manufactured CGM devices, the same themes are mentioned: Lack of accuracy – problems arising from calibration and loss of signal. Although the research generally points towards CGMs bringing added burden (and therefore a barrier for intention to use), there was also correlating themes in this data, of system usability issues occurring presently across many different devices. For example, one participant who uses a continuous glucose monitor feels that the device alarms and calibration cause a discrepancy in results, and another participant who uses a glucose flash reader system also finds this same issue – despite the difference in device type.

Finally, cannulation issues with insulin pumps - lack of insulin delivery with associated DKA - and on the other extreme, risks of overdose of insulin due to false positives occurring with sensor related glucose results (see page 65).

In relation to previous research as discussed by Anderson, psychosocial elements of living with type 1 diabetes were mirrored in this study. Some participants did mention they felt self-conscious and worried about approaching (uninvited) questions from strangers relating to noise or visibility of their technology. Some adolescents delayed treatment until they felt they were in a private, non-judgemental place to avoid embarrassment. Adolescents within this study found they did not like the visible element of certain technological treatments and this is very much seen as a barrier in some cases i.e. Participant 02 from the interviews did not wish to start insulin pump therapy due to the size and visible nature of an insulin pump.

Many other participants referred to similar attitudes and feelings of the visible nature of not only insulin pumps, but that of Freestyle Libre® devices and CGMs also.

6.4 Research objective four: To explore and map the views of the adolescent and their caregivers with regards to future improvements of technology for managing glycaemia in type 1 diabetes.

Another major influence perceived by the participants was that of gaining peace of mind, a feeling of being safe and free from fear – especially during night-time.

Out of this, came awareness that, very often, the technological aspect of their treatment brought about that very feeling of fear due to inaccuracy and unreliability. These findings are consistent with previous research by Johnson et al, who reported that fear associated with hypoglycaemia can be linked to a reduced quality of life for the child with type 1 diabetes. In regards to the technology being inaccurate, these fears are experienced by families and adolescents as documented by Rodbard (2016) and Barnard et al. (2014). These studies found similarities in that when hypoglycaemia/hyperglycaemia (or swings in blood glucose) are occurring, the accuracy of the CGM device is compromised. However, the rate of accuracy from the year 2000 has steadily improved from 20%± error from the mean absolute relative difference (MARD) to 10% ±. This shows that progression of accuracy is a current driver for success and uptake of the technology.

A new emerging theme of being able to wear devices along with clothing and not feeling free to interact with the device – i.e., hidden under a dress, left the participants feeling associated restrictions.

Importantly, the participants in this study also gave some data related to skin reactions/allergies/irritations to the adhesion of sensors and readers for glucose monitoring. These devices are worn for several days at a time, leading to pain, bruising and marks on the skin. It was stated that a future desire would be to address these issues for improved retention and usability/usefulness parameters. The adoption of these changes could mean vast improvements to quality of life, and clinical care practices.

6.5 Synthesis of Data

Holistically, a person’s life with type 1 diabetes is not merely the management of glucose, but rather the lived experience and the daily task management that can become a burden – in terms of time, effort and thought.

From reading literature and synthesizing data gathered in this thesis, a development of understanding the place of technology alongside the plethora of factors which affect the lives of the adolescent with type 1 diabetes is shown in Figure 13. Using this model allows for areas of future research recommendations and clinical practice. Further interpretation also helped to draw conclusion as discussed in Chapter 7.

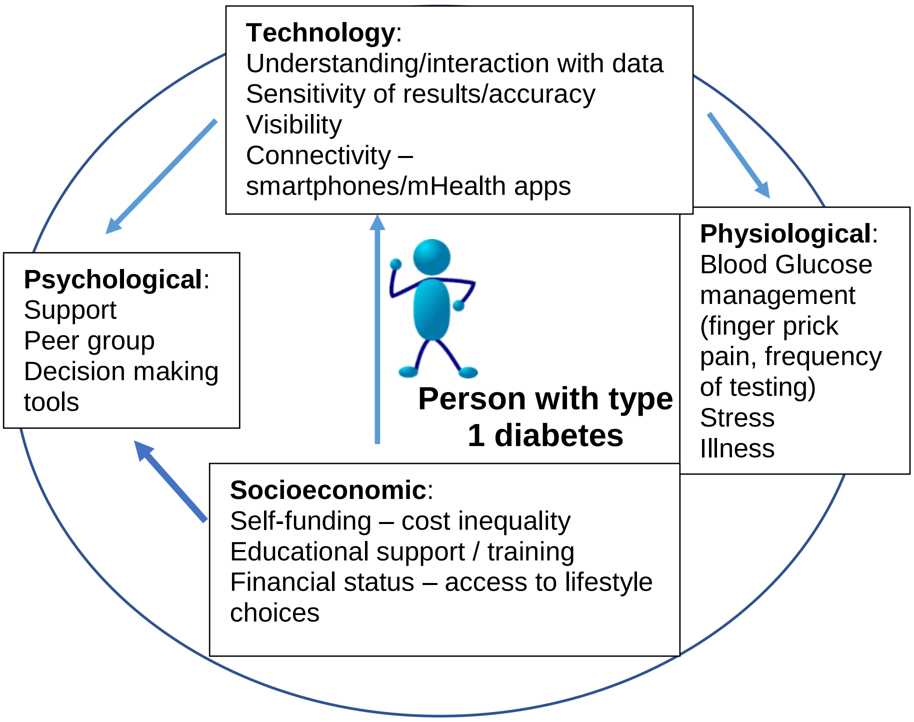


Figure 13. An abstract model of variables which impact the health of an adolescent with type 1 diabetes, and the role of technology in self-management techniques, developed from the data gathered from this research (Cochrane, D. 2018).

6.6 Conceptual Frameworks

Throughout this study, it became apparent that relevant models could be applied to “best-fit” the emergence of technology in treating and managing glycaemia for the adolescent with type 1 diabetes. The Health Belief Model and Technology Acceptance Models (Irwin, Victor, & Marshall, 1988) helped to synthesize data and build a conceptualised framework specific to managing glycaemia as an adolescent - shown in Figure 16.

As a guiding structure to base the data analysis around, (alongside reading literature) - the health belief model and technology acceptance model (Figures 14. & 15.) were consulted.

The health belief model has been developed by social psychologists to measure beliefs and attitudes associated with engagement and adherence of health service products and treatments, with emphasis on behavioural challenges and likelihood of change of behaviour (Strecher & Rosenstock, 1997).

The technology acceptance model represents a theoretical model for perceptions related to ease of use of any information system, and the likelihood of usage (Davis 1989). Much research has used these models in the healthcare and the clinical practice environment. Relatable concepts between both theories can be drawn when participants and their families are relying on interaction with glucose data and devices for type 1 diabetes management (Bond, 1992).

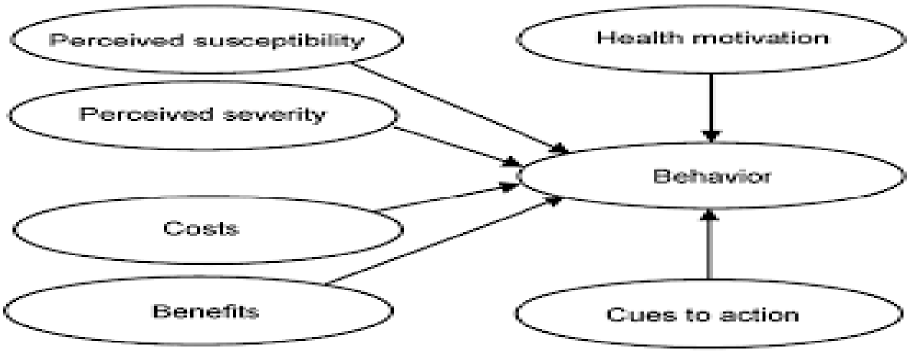


Figure 14. The Health Belief Model (Strecher & Rosenstock, 1997).

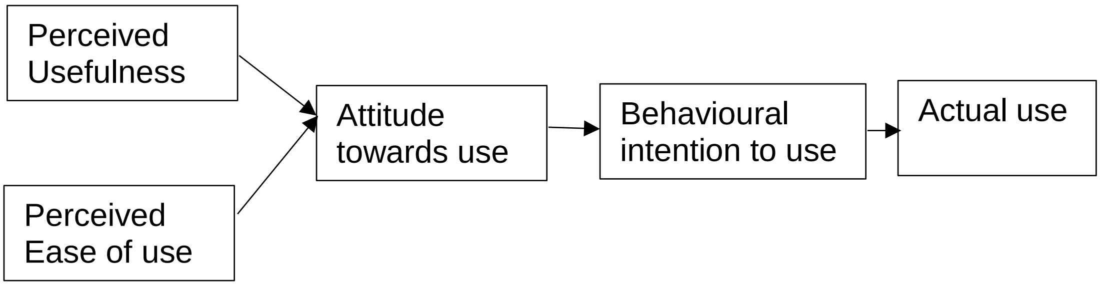


Figure 15. An example of the technology acceptance model, as described by Davis (1989).

Both frameworks have interoperability towards health care attitudes, behaviours and usage which can be applied towards the basis of this study. Although not exclusively as separate models – rather combined as a new approach. The integration of these models has been applied in other studies (Ahadzadeh, Pahlevan Sharif, Ong, & Khong, 2015). Ahadzadeh examined women in Malaysia who perceived health risks using internet searches due to the rise in chronic health conditions. They agreed that both models have their own strengths. However, in combing both models, the purpose of health and technology related research benefits from a combinatory approach.

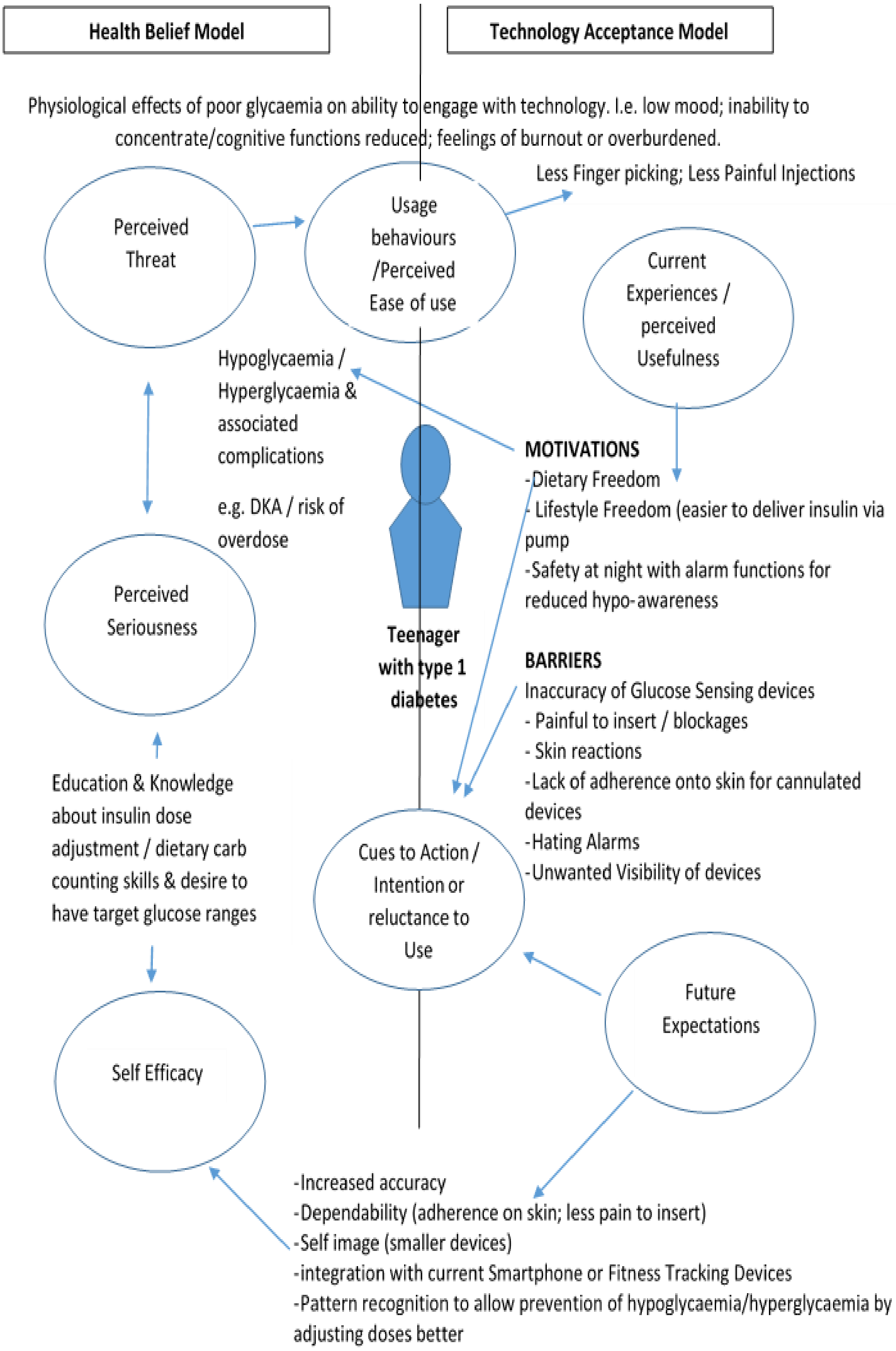


Figure 16. Conceptual Framework of usage of diabetes health digital technology to manage glycaemia. The influence of technology shows the desire to engage and treat/prevent changes in glycaemia, whilst showing motivations and barriers currently experience by the adolescent in this thesis (Cochrane, D., 2018).

6.7 Limitations

In this study, the need to compile an understanding of technology was addressed – alongside the life of the adolescent who is living with type 1 diabetes. It was often found that literature presented these issues separately and without a deeper grasp on understanding the health psychology as an integrated research approach. As the research involved a small study, with input from parents/caregivers and adolescents (not solely adolescents), the findings do not imply that only teenagers face these issues. It can also be considered that parents/caregivers may have affected results during each data set, which can attribute to type 1 diabetes being a family wide issue. The focus on this age group was due to the fact that much research points towards the teenager assuming self-care / self-management to improve their glucose "control". One limitation of this study would be that it should not be taken as evidence for the entire teenage population, as there were success stories of participants feeling happy with their current experience of technology (survey data), although these were minimal.

Further bias from the data sets can be applied to the self-selected groups who have an interest in technological issues. Further research is required to limit this area of bias in groups who may choose to use different methods in managing type 1 diabetes. The lack of further in-depth interview data, showing positive experiences/attitudes with technology supports this point.

During interviewing, it became apparent that emotional detachment of one's own experiences as a parent of a child with type 1 diabetes, was necessary. This helped to create a professional approach, but also to allow for greater empathy with the participants own experiences, aside from feeling of being connected with the participant and their parent. Although having expertise in managing a child for twelve years with type 1 diabetes, through different treatment plans and regimens, brought additional effort to minimise bias when researching such a closely related topic. Therefore, all instances of researcher bias were consciously examined. As Lerum (2001) explains, the connection between a researcher and societal issues cannot always be objective - “Along with bringing such personal benefits, such scenarios illustrate the interconnectedness between self and society, which in turn illustrates the impossibility of any researcher being completely objective” (p. 474).

Although there were overarching themes throughout the data, reports gathered from specific sources i.e. interviews gave richer, more personalised details of feelings and emotions. This may have been experienced due to the empathetic nature the researcher approached the participants’ with. From an epistemological approach, the participants may have answered the questions differently, had they not been interviewed with a parent of a teenager with type 1 diabetes, and with their own parents/caregivers present also.

Chapter 7 Conclusions

In conclusion, this research study unveiled the complexities of living with type 1 diabetes for the adolescent, which they and their families experience. These complexities are strongly associated with barriers found when using current diabetes technologies. Moreover, these barriers can lead to a withdrawal from use. Improvements in accuracy and application, with reduced visibility of technologies for managing glycaemia are needed to maximise user engagement and benefit. However, many benefits were highlighted from participants to show that the motivators for using technology can greatly help to improve lifestyle; dietary freedom; overall glucose ranges and give a sense of empowerment. This mix of experiences draws a conclusion that living with type 1 diabetes is a very personal experience, and therefore personalised digital diabetes care could be effective to help address challenges. In Chapter 5, Table 3 shows a grouping of sub-themes highlighting areas of research interest by categories which are further explained as future implications in sections 7.1 & 7.2.

Puberty and maturation of the self-managing adolescent with type 1 diabetes, should be assisted with accurate devices – giving them support whilst navigating changes to their physiology during this period of moving away from parental/caregiver support. However, the barriers and motivators adolescents experience when using digital health technologies (such as insulin pumps and continual glucose monitoring devices) are linked, not only with maturation, but also to usability and functionality issues which are causing increased fear and burden.

The main issues experienced from technology involved inaccuracy – with severe, life-threatening errors and failure of technology occurring; skin irritations; pain and visibility of technology causing self-image stigma; fear of risk of technology failing and discomfort. These issues raise challenges in educational developments, but also bring awareness of why some participants in this study chose to revert from using technology back to pen injection therapy.

The exploration of these lived experiences is a valuable contribution to the current research and fast-moving technological industry, which serves to support the adolescent with type 1 diabetes. Future developments in diabetes digital health technology should include:

7.1 Clinical Practice & Future Research

Evidence collected relating to barriers show a need for further clinical research to help support adolescents through a challenging period of learning and growth.

In terms of focus, research focusing on low mood, frustration and lack of understanding technology (and the constant demands this puts onto the adolescent and their parents/caregivers) – would help to build a structured, frequent and up-to-date educational support. Specifically improving mental wellbeing and psychological support in the community by engagement with schools to help direct cultural change in the wider setting. This approach may help to see a reduction in instances of feeling bullied in the school environment and experiences of social embarrassment for the adolescent. As has been shown in this study and many others discussed earlier, self-image, the development of the self and type 1 diabetes are closely connected – therefore, helping the adolescent (and thus the parents/caregivers) to learn and grow with this fast-paced developing industry may improve self-efficacy and self-care measures as they mature.

Therefore, adolescent mental health issues relating to type 1 diabetes and that of coping with emerging technologies are recommended for future research focus.

7.2 Technological Design Considerations

Relating to the participants experiences of inaccurate blood glucose readings from glucose monitoring devices, insulin pump failures (and in one case - experience of hospital admission with diabetic ketoacidosis) - highlighted the immaturity of device design and functionality, developmental issues and safety aspects which should be improved to increase adaptability and uptake for this vulnerable group. Drawing from the main findings it is suggested that technological advancements include the following:

- Improved mobile phone App connectivity with current insulin pump/CGMs systems.
- Further Integration with data from insulin pumps/CGMs with devices such as smartphones.
- Safety testing with regards to cannulation issues – blockages; loss of signal and insertion.
- Visibility issues with devices – considerations for watches or wearable devices which cause less stigma and unwarranted questioning.
- Possible market availability of dual-hormone led technology to enable a physiological feedback mechanism to prevent risk of hypoglycaemia/hyperglycaemia (see iLet, BetaBionics).

References

Abbott. (2017). FREESTYLE® LIBRE flash glucose monitoring technology gains reimbursement approval from the United Kingdoms National Health Service [Press release]. Retrieved from http://abbott.mediaroom.com/2017-09-13-FreeStyle-R-Libre-Flash-Glucose-Monitoring-Technology-Gains-Reimbursement-Approval-from-the-United-Kingdoms-National-Health-Service?fref=gc&dti=748445301888935

Abraham, M. (2015). Performance of a predictive algorithm in sensor augmented pump therapy in the prevention of hypoglycaemia in patients with type 1 diabetes. *Journal of Paediatrics and Child Health, 51*, 1-1. doi:10.1111/jpc.12913_1

Ahadzadeh, S. A., Pahlevan Sharif, S., Ong, S. F., & Khong, W. K. (2015). Integrating Health Belief Model and Technology Acceptance Model: An Investigation of Health-Related Internet Use. *J Med Internet Res, 17*(2), e45. doi:10.2196/jmir.3564

Anderson, B., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *J Pediatr, 130*(2), 257-265.

Babler, E., & Strickland, C. J. (2016). Helping Adolescents with Type 1 Diabetes “Figure It Out”. *Journal of Pediatric Nursing, 31*(2), 123-131. doi:http://dx.doi.org/10.1016/j.pedn.2015.10.007

Barnard, K. D., Wysocki, T., Allen, J. M., Elleri, D., Thabit, H., Leelarathna, L., . . . Hovorka, R. (2014). Closing the loop overnight at home setting: psychosocial impact for adolescents with type 1 diabetes and their parents. *BMJ Open Diabetes Res Care, 2*(1), e000025.

Basu, A., Dube, S., Slama, M., Errazuriz, I., Amezcua, J. C., Kudva, Y. C., . . . Basu, R. (2013). Time Lag of Glucose From Intravascular to

Interstitial Compartment in Humans. *Diabetes, 62*(12), 4083-4087. doi:10.2337/db13-1132

Boland, E., Monsod, T., Delucia, M., Brandt, C. A., Fernando, S., & Tamborlane, W. V. (2001). Limitations of Conventional Methods of Self-Monitoring of Blood Glucose. *Diabetes Care, 24*(11), 1858.

Bolinder, J., Antuna, R., Geelhoed-Duijvestijn, P., Kroger, J., & Weitgasser, R. (2016). Novel glucose-sensing technology and hypoglycaemia in type 1 diabetes: a multicentre, non-masked, randomised controlled trial. *Lancet, 388*(10057), 2254-2263. doi:10.1016/s0140-6736(16)31535-5

Bonora, B., Maran, A., Ciciliot, S., Avogaro, A., & Fadini, G. P. (2016). Head-to-head comparison between flash and continuous glucose monitoring systems in outpatients with type 1 diabetes. *Journal of Endocrinological Investigation*, 1-9. doi:10.1007/s40618-016-0495-8

Borges, U., Jr., & Kubiak, T. (2016). Continuous Glucose Monitoring in Type 1 Diabetes. *J Diabetes Sci Technol, 10*(3), 633-639. doi:10.1177/1932296816634736

Borus, J. S., & Laffel, L. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current opinion in pediatrics, 22*(4), 405-411. doi:10.1097/MOP.0b013e32833a46a7

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*: SAGE Publications.

Brazeau, A. S., Nakhla, M., Wright, M., Henderson, M., Panagiotopoulos, C., Pacaud, D., . . . Dasgupta, K. (2018). Stigma and Its Association With Glycemic Control and Hypoglycemia in Adolescents and Young Adults With Type 1 Diabetes: Cross-Sectional Study. *J Med Internet Res, 20*(4), e151. doi:10.2196/jmir.9432

Buckingham, B., Chase, H. P., Dassau, E., Cobry, E., Clinton, P., Gage, V., . . . Doyle, F. J. (2010). Prevention of Nocturnal Hypoglycemia Using Predictive Alarm Algorithms and Insulin Pump Suspension. *Diabetes Care, 33*(5), 1013.

Chiasson, J.-L., Aris-Jilwan, N., Bélanger, R., Bertrand, S., Beauregard, H., Ékoé, J.-M., . . . Havrankova, J. (2003). Diagnosis and treatment of diabetic ketoacidosis and the hyperglycemic hyperosmolar state. *Canadian Medical Association Journal, 168*(7), 859.

Choudhary, P., Olsen, B. S., Conget, I., Welsh, J. B., Vorrink, L., & Shin, J. J. (2016). Hypoglycemia Prevention and User Acceptance of an Insulin Pump System with Predictive Low Glucose Management. *Diabetes Technol Ther, 18*(5), 288-291. doi:10.1089/dia.2015.0324

Chowdhury, S. (2015). Puberty and type 1 diabetes. *Indian Journal of Endocrinology and Metabolism, 19*(Suppl 1), S51-S54. doi:10.4103/2230-8210.155402

Chowdhury, T. A., & Escudier, V. (2003). Poor glycaemic control caused by insulin induced lipohypertrophy. *BMJ, 327*(7411), 383.

Christie, D., Thompson, R., Sawtell, M., Allen, E., Cairns, J., Smith, F., . . . Viner, R. M. (2016). Effectiveness of a structured educational intervention using psychological delivery methods in children and adolescents with poorly controlled type 1 diabetes: a cluster-randomized controlled trial of the CASCADE intervention. *BMJ Open Diabetes Res Care, 4*(1), e000165. doi:10.1136/bmjdrc-2015-000165

Clarke, W., Jones, T., Rewers, A., Dunger, D., & Klingensmith, G. J. (2009). Assessment and management of hypoglycemia in children and adolescents with diabetes. *Pediatric Diabetes, 10*, 134-145. doi:10.1111/j.1399-5448.2009.00583.x

Cryer, P. E., Davis, S. N., & Shamoon, H. (2003). Hypoglycemia in Diabetes. *Diabetes Care, 26*(6), 1902.

Dashiff, C., Vance, D., Abdullatif, H., & Wallander, J. (2009). Parenting, autonomy and self-care of adolescents with Type 1 diabetes. *Child: Care, Health and Development, 35*(1), 79-88. doi:10.1111/j.1365-2214.2008.00892.x

Dashiff, C. J., McCaleb, A., & Cull, V. (2006). Self-Care of Young Adolescents With Type 1 Diabetes. *Journal of Pediatric Nursing, 21*(3), 222-232. doi:https://doi.org/10.1016/j.pedn.2005.07.013

Davidson, M., Penney, E. D., Muller, B., & Grey, M. (2004). Stressors and self-care challenges faced by adolescents living with type 1 diabetes. *Applied Nursing Research, 17*(2), 72-80. doi:http://dx.doi.org/10.1016/j.apnr.2004.02.006

DCCT. (1993). The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-Term Complications in Insulin-Dependent Diabetes Mellitus. *New England Journal of Medicine, 329*(14), 977-986. doi:10.1056/nejm199309303291401

Diabetes Research in Children Network Study, G. (2007). Impaired Overnight Counterregulatory Hormone Responses to Spontaneous Hypoglycemia in Children with Type 1 Diabetes. *Pediatric Diabetes, 8*(4), 199-205. doi:10.1111/j.1399-5448.2007.00248.x

Diabetes uk. (2016). Facts & Stats.

Diabetes UK. (2017). diagnostic criteria for diabetes. Retrieved from https://www.diabetes.org.uk/professionals/position-statements-reports/diagnosis-ongoing-management-monitoring/new_diagnostic_criteria_for_diabetes

Doe, E. (2016). An analysis of the relationships between peer support and diabetes outcomes in adolescents with type 1 diabetes. *Journal of Health Psychology*. doi:10.1177/1359105316656228

Englert, K., Ruedy, K., Coffey, J., Caswell, K., Steffen, A., Levandoski, L., & for the Diabetes Research in Children Study, G. (2014). Skin and Adhesive Issues With Continuous Glucose Monitors: A Sticky Situation. *Journal of Diabetes Science and Technology, 8*(4), 745-751. doi:10.1177/1932296814529893

Eren-Oruklu, M., Cinar, A., & Quinn, L. (2010). Hypoglycemia Prediction with Subject-Specific Recursive Time-Series Models. *Journal of Diabetes Science and Technology, 4*(1), 25-33.

Finner, N., Quinn, A., Donovan, A., O'Leary, O., & O'Gorman, C. S. (2015). Knowledge of carbohydrate counting and insulin dose calculations in paediatric patients with type 1 diabetes mellitus. *BBA Clinical, 4*, 99-101. doi:http://dx.doi.org/10.1016/j.bbacli.2015.09.002

Francescato, M. P., Geat, M., Stel, G., & Cauci, S. (2012). Accuracy of a portable glucose meter and of a Continuous Glucose Monitoring device used at home by patients with type 1 diabetes. *Clin Chim Acta, 413*. doi:10.1016/j.cca.2011.10.012

Giani, E., Snelgrove, R., Volkening, L. K., & Laffel, L. M. (2016). Continuous Glucose Monitoring (CGM) Adherence in Youth With Type 1 Diabetes. *Journal of Diabetes Science and Technology*, 1932296816676280. doi:10.1177/1932296816676280

Glowinska-Olszewska, B., Tobiaszewska, M., Luczynski, W., & Bossowski, A. (2013). Monthly use of a real-time continuous glucose monitoring system as an educational and motivational tool for poorly controlled type 1 diabetes adolescents. *Advances in Medical Sciences, 58*(2), 344-352. doi:10.2478/ams-2013-0024

Gonder-Frederick, L., Nyer, M., Shepard, J. A., Vajda, K., & Clarke, W. (2011). Assessing fear of hypoglycemia in children with Type 1 diabetes and their parents. *Diabetes management (London, England), 1*(6), 627-639. doi:10.2217/DMT.11.60

Gray, W. N., Dolan, L. M., & Hood, K. K. (2013). Impact of blood glucose monitoring affect on family conflict and glycemic control in adolescents with type 1 diabetes. *Diabetes Research and Clinical Practice, 99*(2), 130-135. doi:http://dx.doi.org/10.1016/j.diabres.2011.12.020

Guilhem, I., Leguerrier, A. M., Lecordier, F., Poirier, J. Y., & Maugendre, D. (2006). Technical risks with subcutaneous insulin infusion. *Diabetes & Metabolism, 32*(3), 279-284. doi:10.1016/S1262-3636(07)70281-1

Guo, J., Whittemore, R., & He, G.-P. (2011). The relationship between diabetes self-management and metabolic control in youth with type 1 diabetes: an integrative review. *Journal of Advanced Nursing, 67*(11), 2294-2310. doi:10.1111/j.1365-2648.2011.05697.x

Heinemann, L., & Freckmann, G. (2015). CGM Versus FGM; or, Continuous Glucose Monitoring Is Not Flash Glucose Monitoring. *J Diabetes Sci Technol, 9*(5), 947-950. doi:10.1177/1932296815603528

Herzer, M., & Hood, K. K. (2010). Anxiety symptoms in adolescents with type 1 diabetes: association with blood glucose monitoring and glycemic control. *J Pediatr Psychol, 35*(4), 415-425. doi:10.1093/jpepsy/jsp063

Hex, N., Bartlett, C., Wright, D., Taylor, M., & Varley, D. (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabetic Medicine, 29*(7), 855-862. doi:10.1111/j.1464-5491.2012.03698.x

Hill, J. (2008). Insulin pump therapy: Working together to implement NICE guidance. *J Diabetes Nurs, 12*(10), 382-385.

Hoevenaar-Blom, M. P., Spijkerman, A. M. W., Kromhout, D., van den Berg, J. F., & Verschuren, W. M. M. (2011). Sleep Duration and Sleep Quality in Relation to 12-Year Cardiovascular Disease Incidence: The MORGEN Study. *Sleep, 34*(11), 1487-1492. doi:10.5665/sleep.1382

Hoey, H., Aanstoot, H.-J., Chiarelli, F., Daneman, D., Danne, T., Dorchy, H., . . . Åman, J. (2001). Good Metabolic Control Is Associated With Better Quality of Life in 2,101 Adolescents With Type 1 Diabetes. *Diabetes Care, 24*(11), 1923.

Imkampe, A. K., & Gulliford, M. C. (2011). Trends in Type 1 diabetes incidence in the UK in 0- to 14-year-olds and in 15- to 34-year-olds, 1991–2008. *Diabetic Medicine, 28*(7), 811-814. doi:10.1111/j.1464-5491.2011.03288.x

Ingerski, L. M., Laffel, L., Drotar, D., Repaske, D., & Hood, K. K. (2010). Correlates of glycemic control and quality of life outcomes in adolescents with type 1 diabetes. *Pediatric Diabetes, 11*(8), 563-571. doi:10.1111/j.1399-5448.2010.00645.x

Irwin, M. R., Victor, J. S., & Marshall, H. B. (1988). Social Learning Theory and the Health Belief Model. *Health Education Quarterly, 15*(2), 175-183. doi:10.1177/109019818801500203

Jain, V. (2014). Management of Type 1 Diabetes in Children and Adolescents. *The Indian Journal of Pediatrics, 81*(2), 170-177. doi:10.1007/s12098-013-1196-3

Johnson, S. R., Cooper, M. N., Davis, E. A., & Jones, T. W. (2013). Hypoglycaemia, fear of hypoglycaemia and quality of life in children with Type 1 diabetes and their parents. *Diabetic Medicine, 30*(9), 1126-1131. doi:10.1111/dme.12247

King, A. B., & Armstrong, D. U. (2007). A Prospective Evaluation of Insulin Dosing Recommendations in Patients with Type 1 Diabetes at Near Normal Glucose Control: Basal Dosing. *Journal of diabetes science and technology (Online), 1*(1), 36-41.

Kordonouri, O., Hartmann, R., & Danne, T. (2011). Treatment of type 1 diabetes in children and adolescents using modern insulin pumps. *Diabetes Research and Clinical Practice, 93*, S118-S124. doi:http://dx.doi.org/10.1016/S0168-8227(11)70027-4

Kumah-Crystal, Y. A., Hood, K. K., Ho, Y.-X., Lybarger, C. K., O'Connor, B. H., Rothman, R. L., & Mulvaney, S. A. (2015). Technology Use for Diabetes Problem Solving in Adolescents with Type 1 Diabetes: Relationship to Glycemic Control. *Diabetes Technology & Therapeutics, 17*(7), 449-454. doi:10.1089/dia.2014.0422

Laffel, L. (2016). Improved Accuracy of Continuous Glucose Monitoring Systems in Pediatric Patients with Diabetes Mellitus: Results from Two Studies. *Diabetes Technology & Therapeutics, 18*(Suppl 2), S2-23-S22-33. doi:10.1089/dia.2015.0380

Laffel, L. M., Wentzell, K., Loughlin, C., Tovar, A., Moltz, K., & Brink, S. (2006). Sick day management using blood 3-hydroxybutyrate (3-OHB) compared with urine ketone monitoring reduces hospital visits in young people with T1DM: a randomized clinical trial. *Diabetic medicine : a journal of the British Diabetic Association, 23*(3), 278-284. doi:10.1111/j.1464-5491.2005.01771.x

Lansing, A. H., Berg, C. A., Butner, J., & Wiebe, D. J. (2016). Self-control, daily negative affect, and blood glucose control in adolescents with Type 1 diabetes. *Health Psychology, 35*(7), 643-651. doi:10.1037/hea0000325

Laverty, S. M. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods, 2*(3), 21-35. doi:10.1177/160940690300200303

Leelarathna, L., & Wilmot, E. G. (2018). Flash forward: a review of flash glucose monitoring. *Diabetic Medicine, 35*(4), 472-482. doi:10.1111/dme.13584

Lerum, K. (2001). Subjects of Desire: Academic Armor, Intimate Ethnography, and the Production of Critical Knowledge. *Qualitative Inquiry, 7*(4), 466-483. doi:10.1177/107780040100700405

Monaghan, M. C., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2009). Nighttime caregiving behaviors among parents of young children with Type 1 diabetes: associations with illness characteristics and parent functioning. *Fam Syst Health, 27*(1), 28-38. doi:10.1037/a0014770

Murphy, H. R., Rayman, G., & Skinner, T. C. (2006). Psycho-educational interventions for children and young people with Type 1 diabetes. *Diabetic Medicine, 23*(9), 935-943.

Murphy, H. R., Wadham, C., Hassler-Hurst, J., Rayman, G., Skinner, T. C., on behalf of, F., . . . Teamwork Study, G. (2012). Randomized trial of a diabetes self-management education and family teamwork intervention in adolescents with Type 1 diabetes. *Diabetic Medicine, 29*(8), e249-e254. doi:10.1111/j.1464-5491.2012.03683.x

NICE. (2015). *diabetes type 1 and type 2 in children and young people diagnosis and management*. Retrieved from London:

Nokoff, N., & Rewers, M. (2013). Pathogenesis of type 1 diabetes: lessons from natural history studies of high-risk individuals. *Annals of the New York Academy of Sciences, 1281*(1), 1-15. doi:10.1111/nyas.12021

O'Connell, M. A., Gilbertson, H. R., Donath, S. M., & Cameron, F. J. (2008). Optimizing Postprandial Glycemia in Pediatric Patients With Type 1 Diabetes Using Insulin Pump Therapy. *Diabetes Care, 31*(8), 1491.

Palladino, D. K., & Helgeson, V. S. (2012). Friends or Foes? A Review of Peer Influence on Self-Care and Glycemic Control in Adolescents With

Type 1 Diabetes. *Journal of Pediatric Psychology, 37*(5), 591-603. doi:10.1093/jpepsy/jss009

Patterson, C. C., Dahlquist, G. G., Gyürüs, E., Green, A., & Soltész, G. (2009). Incidence trends for childhood type 1 diabetes in Europe during 1989–2003 and predicted new cases 2005–20: a multicentre prospective registration study. *The Lancet, 373*(9680), 2027-2033. doi:http://dx.doi.org/10.1016/S0140-6736(09)60568-7

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*(5 Pt 2), 1189-1208.

Pelicand, J., Maes, M., Charlier, D., & Aujoulat, I. (2012). Adolescence et diabète de type 1 : « prendre soin de soi » et équilibre glycémique. *Archives de Pédiatrie, 19*(6), 585-592. doi:http://dx.doi.org/10.1016/j.arcped.2012.03.010

Pickup, J., & Keen, H. (2002). Continuous Subcutaneous Insulin Infusion at 25 Years. *Diabetes Care, 25*(3), 593.

Pickup, J. C., Freeman, S. C., & Sutton, A. J. (2011). Glycaemic control in type 1 diabetes during real time continuous glucose monitoring compared with self monitoring of blood glucose: meta-analysis of randomised controlled trials using individual patient data. *BMJ, 343*.

REPOSE. (2017). Relative effectiveness of insulin pump treatment over multiple daily injections and structured education during flexible intensive insulin treatment for type 1 diabetes: cluster randomised trial (REPOSE). *BMJ, 356*.

Riddell, M. C., Gallen, I. W., Smart, C. E., Taplin, C. E., Adolfsson, P., Lumb, A. N., . . . Laffel, L. M. (2017). Exercise management in type 1 diabetes: a consensus statement. *The Lancet Diabetes & Endocrinology, 5*(5), 377-390. doi:https://doi.org/10.1016/S2213-8587(17)30014-1

Riddell, M. C., & Iscoe, K. E. (2006). Physical activity, sport, and pediatric diabetes. *Pediatric Diabetes, 7*(1), 60-70. doi:10.1111/j.1399-543X.2006.00146.x

Ritchie, J. L., J, Spencer, L. (2003). *Qualitative research practice : a guide for social science students and researchers*. London: Sage.

Rodbard, D. (2016). Continuous Glucose Monitoring: A Review of Successes, Challenges, and Opportunities. *Diabetes Technology & Therapeutics, 18*(Suppl 2), S2-3-S2-13. doi:10.1089/dia.2015.0417

Ruud, J., Steculorum, S. M., & Brüning, J. C. (2017). Neuronal control of peripheral insulin sensitivity and glucose metabolism. *Nature communications, 8*, 15259.

Schmidt, S., Schelde, B., & Norgaard, K. (2014). Effects of advanced carbohydrate counting in patients with type 1 diabetes: a systematic review. *Diabetic medicine : a journal of the British Diabetic Association, 31*(8), 886-896. doi:10.1111/dme.12446

Scholte, R. H. J., van Lieshout, C. F. M., & van Aken, M. A. G. (2001). Perceived relational support in adolescence: Dimensions, configurations, and adolescent adjustment. *Journal of Research on Adolescence, 11*(1), 71-94. doi:10.1111/1532-7795.00004

Seaquist, E. R., Anderson, J., Childs, B., Cryer, P., Dagogo-Jack, S., Fish, L., . . . Vigersky, R. (2013). Hypoglycemia and diabetes: a report of a workgroup of the American Diabetes Association and the Endocrine Society. *The Journal of Clinical Endocrinology & Metabolism, 98*(5), 1845-1859.

Seiffge-Krenke, I., Laursen, B., Dickson, D. J., & Hartl, A. C. (2013). Declining Metabolic Control and Decreasing Parental Support Among Families With Adolescents With Diabetes: The Risk of Restrictiveness. *Journal of Pediatric Psychology, 38*(5), 518-530. doi:10.1093/jpepsy/jst006

Sherwin, R. S., & Sacca, L. (1984). Effect of epinephrine on glucose metabolism in humans: contribution of the liver. *Am J Physiol, 247*(2 Pt 1), E157-165.

Shivers, J. P., Mackowiak, L., Anhalt, H., & Zisser, H. (2013). “Turn it Off!”: Diabetes Device Alarm Fatigue Considerations for the Present and the

Future. *Journal of Diabetes Science and Technology, 7*(3), 789-794. doi:10.1177/193229681300700324

Sikaris, K. (2009). The Correlation of Hemoglobin A1c to Blood Glucose. *Journal of diabetes science and technology (Online), 3*(3), 429-438.

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British journal of pain, 9*(1), 41-42. doi:10.1177/2049463714541642

Sparring, V., Nyström, L., Wahlström, R., Jonsson, P. M., Östman, J., & Burström, K. (2013). Diabetes duration and health-related quality of life in individuals with onset of diabetes in the age group 15—34 years – a Swedish population-based study using EQ-5D. *BMC Public Health, 13*, 377-377. doi:10.1186/1471-2458-13-377

Steineck, I., Ranjan, A., Nørgaard, K., & Schmidt, S. (2016). Sensor-Augmented Insulin Pumps and Hypoglycemia Prevention in Type 1 Diabetes. *Journal of Diabetes Science and Technology, 11*(1), 50-58. doi:10.1177/1932296816672689

Suchy, Y., Turner, S. L., Queen, T. L., Durracio, K., Wiebe, D. J., Butner, J., . . . Berg, C. A. (2016). The relation of questionnaire and performance-based measures of executive functioning with Type 1 diabetes outcomes among late adolescents. *Health Psychology, 35*(7), 661-669. doi:10.1037/hea0000326

Thabit, H., & Hovorka, R. (2016). Coming of age: the artificial pancreas for type 1 diabetes. *Diabetologia, 59*(9), 1795-1805. doi:10.1007/s00125-016-4022-4

Tufford, L., & Newman, P. (2010). Bracketing in Qualitative Research. *Qualitative Social Work, 11*(1), 85. doi:10.1177/1473325010368316

Victor, N. S., Nejhdeh, G., Stanislav, T., Nirubasini, P., & Timothy, W. J. (2010). Clinical Evaluation of a Noninvasive Alarm System for Nocturnal Hypoglycemia. *Journal of Diabetes Science and Technology, 4*(1), 67-74. doi:10.1177/193229681000400109

Weinger, K., Jacobson, A. M., Draelos, M. T., Finkelstein, D. M., & Simonson, D. C. (1995). Blood glucose estimation and symptoms during hyperglycemia and hypoglycemia in patients with insulin-dependent diabetes mellitus. *Am J Med, 98*(1), 22-31. doi:http://dx.doi.org/10.1016/S0002-9343(99)80077-1

Woodward, A., Weston, P., Casson, I. F., & Gill, G. V. (2009). Nocturnal hypoglycaemia in type 1 diabetes—frequency and predictive factors. *QJM: An International Journal of Medicine, 102*(9), 603-607. doi:10.1093/qjmed/hcp082

Wysocki, T., & Greco, P. (2006). Social support and diabetes management in childhood and adolescence: Influence of parents and friends. *Current Diabetes Reports, 6*(2), 117-122. doi:10.1007/s11892-006-0022-y

Zaykov, A. N., Mayer, J. P., & DiMarchi, R. D. (2016). Pursuit of a perfect insulin. *Nature Reviews Drug Discovery, 15*(6), 425.

Ziegler, R., Freckmann, G., & Heinemann, L. (2016). Boluses in Insulin Therapy. *Journal of Diabetes Science and Technology, 11*(1), 165-171. doi:10.1177/1932296816653142

Ziegler, R., Heidtmann, B., Hilgard, D., Hofer, S., Rosenbauer, J., Holl, R., & for the, D. P. V. W.-I. (2011). Frequency of SMBG correlates with HbA1c and acute complications in children and adolescents with type 1 diabetes. *Pediatric Diabetes, 12*(1), 11-17. doi:10.1111/j.1399-5448.2010.00650.x

Appendices

Appendix A: Interview Transcripts

Appendix B: Survey Data Report

Appendix C: Prevalence of sub-themes

Appendix D: JDRF Opinion Poll data

All Appendix data is available upon request to:diane.cochrane@strath.ac.uk, Marilyn.lennon@strath.ac.uk, Alison.kirk@strath.ac.uk