EXPLORING THE LIVED EXPERIENCE OF PHYSICAL ACTIVITY AND TECHNOLOGY FOR ADOLESCENTS LIVING WITH TYPE 1 DIABETES AND PARENTS AS CO-USERS

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DECLARATION OF AUTHENTICITY AND AUTHOR'S RIGHTS

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.

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SUMMARY OF THESIS PUBLICATIONS AND AWARDS

Chapter 4

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Chapter 5

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Scholarship award (SICSA, October 2019)

Tiree Tech Wave – awarded with Professor Alan Dix, Swansea University. Graduate support and PhD training on the island of Tiree, Scotland. Tiree Tech Wave is an event that brings together technologists, artists, designers, philosophers, academics and practitioners who are interested in exploring the edges of technology and the potential of technology on the edges.

Images of Research (Shortlisted entrant, 2019)

University of Strathclyde, images of research competition https://www.imagesofresearch.strath.ac.uk/take_part.htm. Poster presented at awards ceremony (See Appendix N for image).

Diabetes UK Professional Conference (2020)

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I wish to dedicate this PhD to my children, Katie, and John. Katie for always being a supportive, loving sister and daughter. It wasn't easy for all of us when our John was diagnosed with type 1 diabetes at age 4. We also lost a dear friend during my PhD to DKA. His sad passing at age 19 really hit home the message of how severe and burdensome this condition can be. I cannot make type 1 diabetes go away. One day, I will forgive myself for that.

Love, always. Mum.

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GLOSSARY OF TERMS

Adolescent	The World Health Organization (WHO) defines an adolescent as any person between ages 10 and 19. This age range falls within WHO's definition of young people, which refers to individuals between ages 10 and 24.
Autoimmune	Autoimmunity involves a misdirection of the body's immune system against its own tissues, causing a large number of diseases (British Society for Immunology).
Caregiver	A family member, or paid helper who regularly is involved in the care of the adolescent and has a direct input into the care of their diabetes.
DCCT	Diabetes Complications and Control Trial
Glycaemia	Referring to the presence of levels of glucose in the blood
HbA1c	A measure of how well controlled blood glucose has been over a period of about 3 months
HCI	Human Computer Interaction
HCP	Health Care Professional
MoSCoW	"Must have, Should have, Could have, Won't have": A design thinking tool used to prioritise user choice.
MVPA	Moderate to Vigorous Physical Activity
NHS	National Health Service, publicly funded health care system in the United Kingdom
PA	Physical Activity
PAR	Participatory Action Research is a research approach often found in public health research based on reflection, data collection, and action with communities and participants.
Psychosocial	Involving both psychological and social aspects
Socio-technical	A broad term which combines people-oriented and technology-oriented practices.
Technology	For the purpose of this thesis, technology refers to digital health technologies which may involve computing programming, connectivity, software, and sensors for type 1 diabetes management and physical activity applications. Applied in general wellness to applications as a medical device. This includes technologies intended for use as a medical product, as companion diagnostic, or as an adjunct to other medical

	products (devices, drugs, and biologics). This is in line with FDA statement on the definition of Digital health technology
T1D	Type 1 diabetes

ABSTRACT

Background: Digital technologies for both type 1 diabetes (T1D) self-management and for physical activity are developing at pace. In both fields, for example, technology is moving towards using sensors, artificial intelligence, and algorithms to predict, monitor and track (and in some cases regulate) both movement and glucose variation. This automation offers an opportunity to significantly reduce human burden related to managing physical activity levels and controlling glucose levels safely. However, little is known about the nature of the use of technology to support physical activity (PA) of adolescents living with type 1 diabetes, and the role of parents/caregivers as co-users.

Aims: To explore the lived experience of adolescents (and their parent caregivers) when managing both type 1 diabetes and physical activity and to understand better how technology can support these interactions.

Methods: The PhD thesis presents three qualitative lived experiences studies with adolescents living with T1D (and their caregivers). The first study presents past experiences explored by asking adults to reflect on childhood physical activity whilst living with type 1 diabetes, using social media digital stories. The second study, focused on current interactions and experiences of physical activity, technology, and type 1 diabetes, using photovoice (photographs and narratives written by the adolescents and their parents. The third study used online design workshops to explore the future needs and requirements of adolescents (and their caregivers) for how technology can better support physical activity while managing type 1 diabetes.

Results: Across three qualitative empirical studies, key themes highlighted unmet needs of technology to support engagement, and participation of physical activity. Study 1 revealed psychosocial factors related to diabetes self-management which can affect physical activity behaviours. Peer support and education was established as an important aspect of intervention design, along with the requirement for person-centred educational content. Study 2 reported similar findings of psychosocial impact and challenges involving reliance and risk, whilst using immature technology, for both adolescents and their parent/caregivers as co-users. The need for more interoperable technology was established in study 2. Study 3 showed the need for interventions to encourage mastery and empowerment, for technology troubleshooting/risk management.

Conclusion: Physical activity is a complex area for those who live with type 1 diabetes, and for those who are directly involved in the care of someone living with type 1 diabetes. This PhD highlights long-standing unmet needs regarding psychosocial care and appropriate peer support and education. Usability of technology for physical activity is affected by factors such as human burden in type 1 diabetes. Present technology does not yet meet the needs of adolescents and their parents/caregivers to participate in physical activity without added life risk or concern for health.

A re-examination of current physical activity guidelines for adolescents living with type 1 diabetes is necessary and this should include socio-technical solutions to support participation in physical activity with type 1 diabetes. Adolescents and their parents/caregivers as co-users should be involved in the design of these physical activity guidelines to design meaningful, appropriate, and person-centred informed recommendations.

1 INTRODUCTION

Type 1 diabetes (T1D) is a life-threatening autoimmune condition. There are many daily challenges to face including treatment decisions, psychosocial factors, and socio-technical interactions which serve to avoid life threatening severe health risk (Delamater et al., 2018; Silverstein et al., 2005). Living a healthy life with this complex condition has been discussed in research for many years. Improved knowledge and comprehension, along with positive coping strategies have become a focus in research (Davidson, Penney, Muller, & Grey, 2004; Iturralde, Weissberg-Benchell, & Hood, 2017). Included in self-management strategies for health is the participation in physical activity (PA). There is strong evidence for PA improving physiological and psychological wellbeing. However, a lack of understanding of the role of technology to support PA in adolescents who live with T1D still exists (Aman et al., 2009; Mitchell, Kirk, Robertson, & Reilly, 2016; H. Quirk, Blake, Tennyson, Randell, & Glazebrook, 2014). Those living with T1D can be at higher risk of cardiovascular disease, and other complications, with evidence pointing towards deleterious health effects beginning in childhood (Katz, Guo, Cheema, & Laffel, 2018). Greater understanding of the lived experiences of interactions with technology and PA for adolescents living with T1D, and their parents/caregivers, can potentially help to develop recommendations for the design of effective interventions and tools to support meaningful engagement with PA for those living with T1D.

1.1 Statement of the problem

Although rapid acceleration of technology has offered provision of home monitoring, management, and treatment options for people living with T1D, little attention has been given to the ways in which adolescents use and view technologies. This is true in the context of PA. It is known that current recommendations for PA levels are not being met. Exploring adolescent motivations and feelings in relation to the support from technology to be physically active is not widely known.

There currently lacks a gap in understanding potential target behaviours and experiences to best support adolescents to be active using technology, when living with T1D. Many safety trials and scalable studies, which prove the efficacy of diabetes treatment, have been measured. However, the intersection with adolescent needs, and the needs of the parents/caregivers (as co-users) for PA and diabetes technology have yet to be discussed.

1.2 Proposed solution

Adolescents with T1D and their parents/caregivers are extensive service users in terms of NHS treatment and resources. Many families also self-fund technology not currently offered through current NHS prescribing pathways. Therefore, consideration of their technological interactions with PA may improve understanding of person-centred factors. Understanding lived experiences can provide knowledge of behaviours taken by adolescents (and parent/caregivers) in their everyday lives to support PA routines. By raising awareness of the socio-technical factors which have an impact on/or support PA for health, designing interventions can be aligned with technological devices. This understanding has the potential to improve quality of life and add cost-benefit value to a healthcare system which already prescribes the concept that PA should become part of a daily self-management routine. Translating challenges and barriers into solutions could improve PA engagement and find solutions to reducing physical and psychological outcomes such as burden and distress for those living with T1D and their parents/caregivers.

This thesis will study lived experiences of adolescent populations living with T1D and their parents/caregivers, to explore challenges and successes with PA and technology from a person-centred perspective. The findings will be used to build a set of recommendations towards possible solutions for technologies to encourage PA participation for adolescents living with T1D which are derived with, and from, the voices of those living with T1D and their family support networks.

1.3 Thesis overall aims & objectives

The overall aim of this thesis is to understand the lived experience of PA and the role of technology in the lives of adolescents living with T1D and their parents/caregivers. The overall objective is to raise the voice of those living with the condition, and their parents/caregiver's voices, through respectful, ethical, and creative methods. These methods allow for rich, emotive, and powerful explorations of their positive and negative personal stories. Sharing these findings with peers, diabetes healthcare professionals, parents, and teachers, can help to build appropriate and meaningful recommendations which aim to support adolescents living with T1D to participate in PA whilst using technology

1.4 Research Questions

The overall research question for this thesis is:

"What socio-technical factors play a role in the support of physical activity for adolescents living with type 1 diabetes, and their parents/caregivers as co-users?"

To answer the main thesis research question, it is vital to understand psychosocial and socio-technical processes defined by the users themselves – as experts. Communication and collaboration with participants involves co-design, participatory action modes of research, to increase citizen-led engagement and to elucidate data, which best represents the population studied.

Adolescents living with T1D have previously been referred to as hard-to-reach populations. Challenging this bias through the application of novel methods, which consider the adolescents and their primary caregivers (often parents) as experts, is approached through three using different design methods. This iteration of different methods offers a novel approach, which to our knowledge, has not been approached with adolescents and their parents/caregivers to provide context and rich description. Furthermore, iterative development of design choices informed from results from each of the three empirical studies aims to provide a continual trustworthy representation of the individuals who took part. On this basis, we present novel, empirical data, which may benefit educators, sports related personnel, clinical and technical stakeholders and those living with T1D (and their parents/caregivers).

1.5 Structure of this thesis

Overall, the thesis can be broadly split into two main areas of focus: the human experience of PA when living with T1D; and the role technology plays within those experiences. A temporal frame of past, present, and future will be presented within the thesis in three qualitative studies. These studies capture lived experiences of 1) adults who grew up with T1D, 2) adolescents with T1D engaging with technology and PA in the present day, and 3) considerations towards future developments from adolescent and their parents/caregivers.

Chapter 2 introduces key concepts referred to in the thesis and reviews current literature related to the topic of the thesis. Chapter 3 presents details of the overarching methodological approach that was adopted for this thesis. From this point, the thesis is divided into three main parts. Part 1 of the thesis will introduce ‘The Past’, via a study exploring the use of social media ‘stories’ to gather past childhood lived experiences of PA from adults diagnosed as a child with T1D. Part 2 of the thesis introduces the second study in Chapter 5. This study used Photovoice to explore current lived experiences of adolescents living with T1D, and their parents in using technology for PA. Part 3 of the thesis, Chapter 6 provides findings of future prospection from the third study titled “Triple T (Teens, T1D, Tech) PA design workshop”: co-designing recommendations for future technologies supporting engagement with PA. The remote, online workshops were held with adolescents and parents to consider their future with technology, in terms of what they would like to see change. Chapter 7 provides an overall discussion on the findings and methods used. Chapter 8 provides a synthesis of studies 1-3 to form the basis of recommendations towards intervention design by healthcare providers, technologists, and policy makers to improve physical activity engagement for adolescents living with T1D.

Study specific research questions for this thesis are outlined below:

Study 1

RQ 1.1: What retrospective lived experiences do adults report in relation to physical activity when diagnosed with type 1 diabetes as a child?

RQ 1.2: What reflective meaning can be derived from experiences of physical activity, in terms of sharing advice to their younger self's?

This led to the second study which takes the thesis to current timelines of adolescent (and parent/caregivers) experiences using the latest technology for PA in T1D. The research questions for this study were:

Study 2

RQ 2: What is the role of technology in physical activity for adolescents living with type 1 diabetes and their parents?

Translating current experiences and personal stories from current experiences toward future action and solutions, it was necessary to consider divergent thought processes (thinking '*outside-of-the-box*') towards possible future PA experiences supported by technology when living with T1D. A remote co-design workshop method was used to explore this in study 3 with the following research questions:

Study 3

RQ 3.1: What current experiences do adolescents and parents identify as important (both positive and negative), when using technology to support type 1 diabetes and physical activity?

RQ 3.2: What do adolescents and parents construct and illustrate as potential design considerations (social and technical) with regards to digital/technology support for engaging in physical activity when living with type 1 diabetes?

1.6 PhD motivation

This PhD project extends current knowledge on the interaction of technology with PA for adolescent living with T1D. A novel approach brings the parent/caregiver voice and adults reflections from childhood, building a bridge between early experiences and the interplay of support from others in both technology use and engagement with PA. The findings have important implications for future research, technology development and design of interventions aimed at clinical practice and educational services.

2 BACKGROUND

The aim of this Chapter is to introduce the thesis in relation to previous related research intersecting type 1 diabetes, technology, physical activity and to explore what if anything has been done to research lived experiences in this area.

This is a narrative review, which used the following search strategy from August 2018 – February 2019, using the following keywords: type 1 diabetes, T1D; physical activity, PA; adolescent; young; youth; technology; lived experience; perceptions; attitudes; qualitative. Databases used included: EBSCOhost; PsychINFO; MEDLINE PubMed and ACM digital Library. These broad search terms allowed for the scoping of all relevant information was captured.

2.1 Type 1 diabetes

Type 1 diabetes (T1D) has also been referred to as Insulin-Dependent Diabetes Mellitus (IDMM) or juvenile diabetes or shortened to T1D, especially across social media platforms. Type 1 diabetes is fundamentally different to other types of diabetes mellitus in the diagnosis, treatment, care, and frequent monitoring. It is known that T1D is brought about by an autoimmune attack on the cells of the pancreas (β-Cells) which produce insulin. This leads to complete insulin insufficiency which requires replacement by infusion or injection of analogue insulin, for the rest of the person's life. Complete insulin insufficiency is an acute life-threatening emergency.

In the UK, 8% of all cases of diabetes are attributed to T1D. It is estimated that over 470,000 people currently have a diagnosis of T1D in the UK (Diabetes UK, 2019). Globally, prevalence estimates show that there are over 1 million children (<20 years of age) with T1D (International Diabetes Federation, 2019). In the UK alone, there are almost 40,000 children with the condition, with figures continuing to increase (Diabetes UK, 2019). Most children are diagnosed between the ages of 10-14 years, however the prevalence for under 5 years is also growing. Diabetes UK state that over 3000 new cases of T1D are diagnosed in children every year. For most cases, the adolescent population are showing the greatest rise in incidence. According to the World Health Organisation (WHO), an adolescent is someone between the ages of 10 years and 19 years. Some studies refer to people within this age group as youth, adolescent, teenager, young person, or child. It is acknowledged that much heterogeneity is witnessed when using the term adolescent, often dependant on the country of study origin. For this reason, this thesis will maintain the use of the word adolescent in line with the WHO clarification.

2.1.1 ***Treatment***

At diagnosis, and lifelong thereafter, immediate, and ongoing insulin replacement is necessary for survival. Dose response titrations and adjustments are required to metabolise blood glucose levels through daily frequent, self-monitoring, measuring and calculation. These steps are often managed by the person living with the condition should they have the appropriate cognition, awareness, and support to do so. In terms of children and adolescents, assistance, and support from trained healthcare professionals (HCPs), parents and caregivers, daily is vital to sustain health. Therefore, treatment support by primary caregivers in the context of this PhD are considered as an important aspect of home management.

Currently, national guidelines for clinical practice inform treatment goals. Treatment types and health measures have been developed through decades of patient research, clinical science, and collaborations between government, charities, academia and health industries (Adolfsson et al., 2018; National Institute for Health and Care, 2016a). Education of treatment decisions, and long-term health awareness, is the cornerstone of adapting to a new life with many precarious factors (Bangstad et al., 2009).

Research on understanding the physiological/biological effects of living with T1D has a tradition of focusing on the prevention of long-term complications of T1D. These complications can include deterioration of nerve cell health and vascular cell damage and are the result of dysregulation of blood glucose (Adolfsson et al., 2018; National Institute for Health and Care, 2016). Ischaemic Heart Disease (IHD) and Cardiovascular disease (CVD) are risk factors related to reduced life expectancy for those diagnosed with T1D (Rawshani et al., 2018). It is important therefore to introduce self-management behaviours which can be achieved and supported for long-term prevention of diabetes complications and to support individual wellbeing. An important component of self- management of T1D is PA. Akin to the general population, PA can have a positive impact on long-term health for someone with T1D and participation is recommended in clinical guidelines.

2.1.2 ***Glycaemia***

Glycaemia refers to levels of glucose in the blood, or blood glucose. In a healthy person, the body regulates this to maintain a healthy state known as homeostasis. Without this tightly controlled state, dysregulation of glucose in the blood occurs, causing risk of injury to the body over time. A drop in blood glucose below normal range is known as hypoglycaemia. Hypoglycaemia has acute consequences physiologically if untreated with fast-acting glucose. Clinically, hypoglycaemia can cause irreversible and permanent trauma ranging from cardiovascular, neurological and cognitive functioning (McCrimmon & Sherwin, 2010).

After a diagnosis of T1D, glucose levels are often measured using an overall three-month average blood test known as the HbA1c test. This test refers to the numerical value assigned to haemoglobin/glucose association on red blood cells over the average period. Current evidence states that a patient who lives with T1D, showing lower HbA1c results, can prevent or delay complications such as visual impairment/blindness, kidney damage, nerve cell damage and vascular risks (DCCT, 1994). The Diabetes Control and Complications Trial (DCCT), a multi-centre study was seminal in creating epidemiological research into the identification, detection and prevention of complications linked to intensive treatment of T1D, compared with conventional treatments.

2.1.3 ***Physiology of glucose metabolism***

It is important to understand how a healthy pancreas would function during periods of PA, in comparison to those living with T1D. A functioning feedback loop from the hormones secreted by the pancreas (insulin and glucagon) can act in response to PA to maintain health and homeostasis. The metabolic function of a healthy pancreas therefore supplies hormones which are necessary to supply energy and metabolites to major organs and muscles during respiration and PA. This is reliant on healthy β-cell function (which release insulin) and α-cell health (which release glucagon) to feedback signals which maintain safe blood glucose levels. This is shown in graphic representation in Figure 2-1.

This feedback signal is considered by technologists and biomedical engineers to establish biomimetic predictive technology. This is discussed further in section 2.3.4. The impact of the lack of this feedback (between glucagon and insulin), and the kinetics between this and metabolites becomes even more complex for technology to achieve, in the context of PA with T1D. This is highly relevant when considering methods to prevent exercise-induced hypoglycaemia (Teixeira & Malin, 2008).

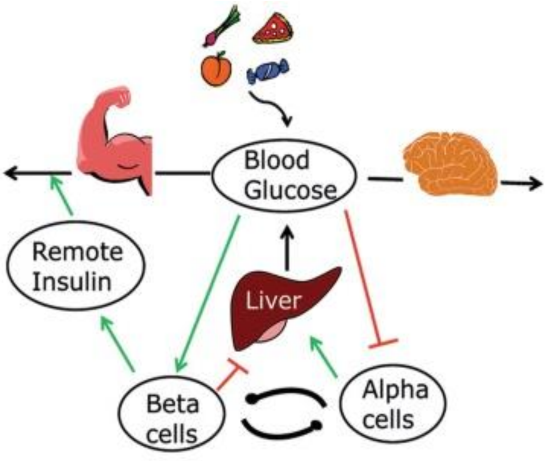


Figure 2-1. Blood glucose homeostasis and cellular feedback loops

Blood glucose serves to supply energy at a cellular level to the human body. Blood glucose homeostasis is depicted in Figure 2-1 showing the feedback loop, previously mentioned, between the β-cells (insulin producing cells) and α-cells (glucagon producing cells) in the pancreas. Insulin producing β-cells promote the uptake of glucose from the blood through muscles and bones. As glucose is metabolised, levels decrease in the blood. Should this decrease become threatening to life (hypoglycaemia), chemical signalling to alpha cells to release glucagon will act on the liver secretion of glycogen. This release of glycogen helps to raise blood glucose levels if they fall below safe levels. This feedback loop is driven by the requirements of the body to receive a constant tightly controlled, blood glucose level, sometimes referred to as normoglycaemia. The interactions between these hormones and other signals in the body are complex, and often include dietary factors – shown as food in the Figure 2-1 by Garzilli and Itzkovitz (2018). When the brain is starved of glucose, or in a state of hypoglycaemia, cognition can be affected, and motor/nerve function can be reduced. A worse-case scenario would be a severe hypoglycaemic episode resulting in loss of consciousness, or perhaps seizure, and/or loss of life. Thus, it is important to consider the severity of the condition when gathering evidence of factors which can increase hypoglycaemia.

*2.1.4 **Dysregulation of glucose and complications***

For over ten years, thousands of people with T1D were studied in clinical trials relating to the measurements of complications and types of treatment. Indicators included metabolic function tests from detection of glucose variables, lipid states (atherosclerosis and cardiovascular health), microalbumin (measuring kidney health), fundus photography (retinal imaging of vascular eye health). These controlled trials were large-scale and longitudinal, serving to offer the largest medical and robust evidence for intensive treatment, to date (DCCT, 1994). Furthermore, follow-up trials have continued to observe durability of the initial findings. The most recent observational study, leading on from the Diabetes Control and Complications Trial (DCCT), is known as Epidemiology of Diabetes Interventions and Complications (EDIC). From this follow-up, it was concluded that intensive insulin replacement was effective for reducing long-term complications for those living with T1D. Specifically, from this large cohort trial, a 35-76% reduction in microvascular complications was reported including, improved glomerular filtration rates (kidney health), for those using intensive treatment methods with near-normal glycaemia of median HbA1c of 7%, the comparison with conventional treatment showing a higher HbA1c (9%). The hypothesis being - improvements can be seen over the lifespan for vascular health using intensive treatment.

The research from the DCCT, and EDIC studies, can broadly be defined as a major influence and were key in changing the way diabetes is managed and treated. Leading the way in developing health screening and management of T1D which led to improved quality of life, and HbA1c, for those living with the condition. However, it was shown that the intervention led to increased patient burden, risk of hypoglycaemia and weight gain. Therefore, the influence of the HbA1c measurement in a clinical setting, can be considered as only one part of the picture of health.

In summary, the evidence supporting the treatment of T1D, and the rationale for maintaining a near-normal glycaemic state is validated by treatment aims to preserve cell health, organ health, and mental health. However, as shown in the next section, maintaining this state of health in the context of PA comes with many challenges.

2.2 Type 1 diabetes and physical activity

Physical Activity (PA) takes many forms, occurs in many settings, and has many purposes (e.g., daily activity, active recreation, and sport). Health-enhancing PA includes cardiovascular; muscle and bone strengthening; and balance training (Department of Health and Social Care, 2019). Most of the research exploring PA and T1D has focused on quantitative methods and the impact of PA on HbA1c. There is a lack of qualitative research exploring how PA interacts with T1D on an individual and/or psychosocial level (Barbara J Anderson et al., 2017; Clements et al., 2016).

To show just how recent our understanding is of PA and T1D, one latest study explored the effects of prolonged aerobic exercise (60mins moderate) on blood glucose of youths with T1D. This was led by a team of experts in Canada (Michael C. Riddell et al., 2019). This team reported out of 120 youths tested, only 4 had stable blood glucose during an exercise period, with over 93 having a significantly clinical drop in blood glucose. Youths measured had a wide variation in their pre-exercise glycaemia. However, the suggested conclusion from the study showed that having a higher pre-exercise blood glucose was only “*marginally protective”* against exercise-induced hypoglycaemia. It is widely known that hypoglycaemia, and the fear of, exists as a major barrier for this age group. A greater negative correlation between pre-exercise glucose and change during exercise was noted with those on multiple daily insulin injections (MDI) as opposed to those using insulin pump therapy, also known as continuous subcutaneous insulin infusion (CSII).

The debate which arises from this research shows that, even with adaptive behaviours, such as changing dietary and insulin decisions to accommodate exercise, the effect of insulin replacement, with reduced pancreas function leads to risk and experiences of hypoglycaemia. The lack of stable blood glucose during exercise therefore contributes significantly to PA barriers.

2.2.1 ***HbA1c and physical activity***

For those living with T1D, the damaged function of the feedback between insulin and glucagon requires human behavioural adaptations. One of which is to aim for healthy overall blood glucose, to a near-normal level. Previous research establishes correlations with sedentary behaviours and overall higher glucose levels. Therefore, as levels of sedentary behaviours are currently a growing concern for this population (Leclair E, 2013; MacMillan, Kirk, Mutrie, & Robertson, 2014), understanding motivations and behaviours in relation to PA are vital. Furthermore, evidence strongly reports that children and adolescents with T1D often fail to achieve age-specific targets for glycaemic control, and HbA1c can worsen over time, through to young adulthood (Clements et al., 2016).

Overall glucose levels are measured by a test known as the HbA1c test, as discussed in section 2.1. Effects of exogenous insulin during PA on HbA1c outcomes, have yet to show concrete evidence of improvement on glycaemic control (Aman et al., 2009; Chimen et al., 2012). It has been suggested by Kennedy et al. (2013) that HbA1c may not the most sensitive marker for establishing a correlation between PA and glucose control. In a systematic review with meta-analysis by Kennedy et al. (2013) on exercise and T1D, they reviewed thirteen studies to explore evidence that exercise improves control of blood glucose (as measured normally by HbA1c tests). However, through meta-analysis, it was shown that there was a lack of current evidence that HbA1c is improved through exercise. It was suggested that most trials were not long enough and that studies of "*greater than 25 weeks*" should be designed to establish a significant drop in HbA1c. Inadequate reporting of intensity, type and duration of exercise was also noted, as well as types and amounts of dietary adjustments all of which have substantial effects on HbA1c, and variations in glucose change. Heterogeneity of study design, evidence focus (diet, hypoglycaemia, insulin reductions) and methods do show benefits of PA but give no details of the lived experience, user interactions with technologies, and human factors which affect glycaemia. The associations between all these elements of being active is still unclear in research.

However, a global study which recruited almost 6000 adolescents from over 20 countries and 5 continents, highlighted a strong correlation between quality of life and overall glucose (HbA1c). The lower the HbA1c, the more frequently adolescents were exercising for >30mins per day, alongside other behaviours related to dietary measures. It was also found that female participants had lower quality of life than male adolescents (Barbara J. Anderson et al., 2017). An additional notable example provided by Hilliard, Mann, Peugh, and Hood (2013) of determinants for quality of life in adolescents with T1D, showed that poorer quality of life reported measures correlated with higher HbA1c, less frequent blood glucose management with longer duration of the condition. Therefore, factors associated with improving quality of life could have an important impact on diabetes management.

Improving quality of life measures through the benefits of PA has been approached in research. In a systematic review by Absil, Baudet, Robert, and Lysy (2019) positive quality of life measures, as well as metabolic, fitness and body size parameters were reported. Although the study showed little improved blood glucose results, the evidence to support the benefits of PA on psychological and physiological health stands strong.

This suggestion is further reported by MacMillan, Kirk, Mutrie, Matthews, et al. (2014). Improvements on HbA1c through PA were found, alongside other reported health benefits in 8 out of 12 studies. This review points towards evidence for moderate PA of ≥ 60 mins having a positive effect on lowering

HbA1c. Additionally, this review highlighted a lack of studies exploring the effect of PA on quality of life, which is often reported using standardised health questionnaires (Ingersoll & Marrero, 1991; Palamenghi, Carlucci, & Graffigna, 2020; Pereira, Tonin, Carneiro, Pontarolo, & Wiens, 2020). There was evidence of intervention heterogeneity making it hard to draw a true comparison across studies. The authors encourage a shift from research exploring "what" we should be promoting in terms of PA towards the direction of "how" we should promote PA as the guiding force to help improving health and wellbeing in this group.

2.2.2 ***Benefits of physical activity***

Current research has shown that PA in youth with T1D, is challenging but can result in positive health benefits (Barbara J. Anderson et al., 2017; M. C. Riddell et al., 2017). These health benefits are not only important to protect vascular health, but also for quality of life measures (Aman et al., 2009; Codella, Terruzzi, & Luzi, 2017). As PA has shown to improve insulin sensitivity and other health benefits such as fitness levels (V02max), lipid levels (HDL-cholesterol) and endothelial health (vascular health), the evidence suggests that, overall, being active is important for people living with T1D.

Physical activity benefits have been suggested in the latest guidelines published by experts in different countries (Adolfsson et al., 2018; Colberg et al., 2016). Furthermore, research suggesting a focus on cardioprotective measures with children diagnosed early in life, is based on evidence that age of onset is of vital importance in terms of morbidity issues and cardiovascular health (Rawshani et al., 2018). Through statistical analysis of a nationwide Swedish register of over 27000 people the authors found significance in those who were diagnosed with type 1 diabetes before 10 years of age, stating that this resulted in loss of 17·7 life-years (95% CI 14·5–20·4) for women and 14·2 life-years (12·1–18·2) for men from cardiovascular related health factors. This further strengthens the argument for health improvement through regular PA attainment.

Aside from this evidence, it is important to consider which current barriers are known to identify areas for improvement which may not have been explored in self-report quality of life studies.

2.2.3 ***Barriers to physical activity***

It is known that dysregulation of glycaemia (hypoglycaemia and hyperglycaemia) both cause serious health consequences for the person living with T1D and can be induced by PA (M. C. Riddell et al., 2019). The threat of, and experience of, hypoglycaemia is a major barrier and risk factor reported to be associated with PA for those living with T1D. One major challenge for participation in PA for those living with T1D has been identified as the emotions of fear of hypoglycaemia. In this study, the results point towards negative emotions having a strong positive correlation with higher HbA1c and negative wellbeing (Brazeau, Rabasa-Lhoret, Strychar, & Mircescu, 2008). We begin to see that emotional wellbeing through the participation of appropriate PA requires an individualised approached, as backed-up by claims discussed earlier by Faulkner, Michaliszyn, and Hepworth (2010).

Therefore, the debate for prevention of barriers must address exercise-induced hypoglycaemia. Prevention of serious side effects for adolescents with T1D is key for understanding participation patterns in PA behaviours (Leclair E, 2013; MacDonald, 1987; Tonoli et al., 2012). These side effects can be thought of as physiological metabolic activities through the replacement of exogenous insulin. However, self-management behaviours during times of exercises requires carefully calculated dose control with constant re-evaluation of dietary influences according to age, weight, injection techniques, injection site health, insulin type, and patterns of PA (Bangstad et al., 2009). In this, we see the convergence of physiology with human behaviours, often described as psychosocial factors.

Self-management behaviours can be followed to try to prevent hypoglycaemia with current treatment types and technologies. This requires a deep level of understanding of the action of insulin on changing metabolic demands of musculoskeletal nutrients during different types of exercise, and having the will, or focus, to act/change behaviours (Riddell et al., 2017). Self-management also requires intensive education, understanding and the ability to navigate many types of technologies, different insulin dose adjustment patterns, forward planning, and dietary education. It has been shown by King, King, Nayar, and Wilkes (2017) in a qualitative study that often the pattern of behaviour for adolescents is to mal-adjust blood glucose to prevent hypoglycaemia (allow the glucose to be higher than normal range). However, as previously shown by M. C. Riddell et al. (2019) this behavioural adaption only offers minimal protection from risk of unstable glycaemia during exercise. In the study, richer meaning was provided, reporting that participants felt low mood, emotional burden, and wishing they didn't have diabetes. There was extensive worry and lack of understanding of the condition. This recent work gives evidence to the fact that lived-experience research can capture perceptions and emotions related to this at-risk group.

In summary, if adolescents are struggling to cope with diagnosis, they need support to accept life with a chronic, life-threatening condition before the issue of promotion of PA can be taught. Physical activity can improve physical and psychological wellbeing, but without the tools to prevent exercise-induced hypoglycaemia, risk to life appears to be the major barrier influencing PA behaviours.

2.2.4 ***Promoting physical activity***

To promote PA in the adolescent population with T1D, it is essential to understand the complex factors required to maintain glucose control and the associated lived experience of these actions. In a group of children aged 9-12 years a theoretical behaviour change intervention was developed to test the research design process, the intervention design and to explore feasibility. (E.

Knox et al., 2019). The primary focus of the clinical trial involved feasibility, acceptability and fidelity of the intervention which was built using an intervention programme website, self-report diary, and pedometer, during group activities with goal setting as a behavioural focus. The intervention focused on motivational aspects, qualitative interviewing, and stakeholder involvement (parent and health care professionals). This mixed method approach gave rise to evidence that behavioural factors are interconnected with physiological outcomes. Results from this study show that recruitment was a challenge with n=49 out of a possible 154 suggested from the clinical area. However, completion rates and retention were found to be feasible with participants, parents, and clinicians. Feasibility and acceptability of the trial was successful. One limitation, discussed by the researchers was that the focus was to measure PA rather than self-management and that further, larger-scale, ethnically diverse studies are required. It was also noted that the clinic was considered a research positive place, which created bias in the study. Interestingly, from a PA-educational point of view, Healthcare Professionals (HCP's) expressed burden on their time with the study, and uncertainty of what was expected of them. This highlights the uncertainty of the role of HCP's in encouraging PA, communicating about PA and their involvement in clinic within this context. This aligns with research by (MacMillan, Kirk, Mutrie, Moola, & Robertson, 2016) in which HCP's were uncertain of how to promote PA, and their level of knowledge and expertise on specific PA parameters.

2.2.5 ***Current guidelines for physical activity and type 1 diabetes***

In terms of understanding current debates for PA, and the stimulus for healthy living, guidelines have been developed. The latest PA guidelines for the general population of children and adolescents in the UK suggests, for 5-18 years, the aim of 60 minutes per day across a week. Positive health outcomes of PA include the improvement of neurological health, musculoskeletal development, weight management and social skills. Building confidence and improved wellbeing such as sleep and mood are also considered a positive outcome of PA participation (Department of Health and Social Care, 2019;

Who, 2010). For diabetes specific guidance, the International Society for Pediatric and Adolescent Diabetes (ISPAD) and the American Diabetes Association have developed reports with experts in clinical, academic and PA backgrounds. In the UK, there also exists NICE guidelines which briefly touch on the monitoring of glucose and dietary adaptations in PA for those with T1D (Adolfsson et al., 2018; National Institute for Health and Care, 2016b; M. C. Riddell et al., 2017) . The ISPAD guidelines refer to the fact that they were established using adult populations and may not be accurate for children or youth populations. However, there are comprehensive considerations for developmental context in youth throughout the guidelines with mentions of spontaneity and lack of planning. The guidelines further establish that new technology offer a range of tracking, monitoring, and provision of visual data should the devices be open to data sharing between manufacturers. The reported guidelines then follow considerations and risk management for PA participation including increasing monitoring, dietary intake, dose adjustment and prevention of post-exercise hypoglycaemia.

Importantly, the discussion for ongoing training for healthcare professionals mentions that regular attendance at camp events may give detailed, contextual training and education of the specific barriers and lack of understanding surrounding PA and T1D for both healthcare practitioners and those living with the condition. At present, it is unclear if there are such camp events happening in the UK, and it is unclear what training, or continuing education is occurring. The ISPAD guidelines are rigorous and clinically informed. Covering all aspects of constant monitoring and dose adjustment, consideration of insulin replacement types, and the effects of aerobic/anaerobic catabolism and anabolism throughout. In essence, if anything, the guidelines are complex, and difficult to see how real-life adherence would be possible every day (Adolfsson et al., 2018). The adaptive mechanisms of managing frequent episodes of hypoglycaemia are briefly discussed with a view to avoidance of daily exercise.

The American Diabetes Association confirm that "*Blood glucose responses to PA in all people with type 1 diabetes are highly variable based on activity type/ timing and require different adjustments*". These guidelines again are developed by experts in clinical and PA fields. Recommendations for adjunctive treatment with continuous glucose monitors for adolescents are briefly mentioned. However, they state that "*There is insufficient evidence on the ideal type, timing, intensity, and duration of exercise for optimal glycemic control*" (Colberg et al., 2016). Therefore, all guidelines do state wide variation and non-generalisable scope. For this reason, the adoption of a person-centred PA approach is important.

The current ISPAD and ADA guidelines and reports are derived from evidence based, metabolic and clinical rationale for the benefits of PA. It is also clear that complex factors are required to be comprehended when considering PA. What is not currently known, is if the adolescent population living with T1D know of, or/and are influenced directly by these guidelines, adhere to them, or use them for education and practical tips. Guidelines at present do not mention specific prescriptive, programmes of education to the adolescent population with T1D for PA. Guidelines usually suggest that ongoing, adequate, and intensive education surrounding the management and provision of PA should be maintained (M. C. Riddell et al., 2017). This contributes to ongoing, complex debate in the field. If adolescents are not currently meeting PA goals, is it due to the poor translation and education of how to be physically active with T1D through these guidelines? With many challenges to face, it is worth involving people living with T1D and their parents/carers to explore barriers and benefits to move towards solution-based thinking in the development of guidelines.

Faulkner et al. (2010) aimed to address the promotion of personalised-prescribed PA based on these ISPAD guidelines with adolescents 12–19-year-olds (via clinic), who were not physically active. The study showed a low participation rate of only 30%. Individually prescribed exercise programmes of

60min MVPA were developed. Participants wore the Actigraph® accelerometer to measure physical activity and self-reported quality of life using questionnaires (Diabetes Social Support Questionnaire – Family (DSSQ-Family) and the Diabetes Quality of Life Measures for Youth (DQOL)). Results reported that there was no change to HbA1c in a 6-week period. However, evidence suggested that frequent 60min moderate exercise sessions improved cardiovascular fitness and family support to be active improved. Suggestions from the study were to improve family-based strategies to improve promotion of current guidelines. This level of family involvement is not mentioned in current guidelines. With many parents acting as co-users of technology to help assist and care for their adolescent living with T1D, this area requires further investigation.

Further evidence points towards parental exercise behaviours as the influencing factor for incentivising these guidelines. Parental exercise profile acting as a motivating factor to increase PA. Although current general population guidelines focus on the duration of PA as a measure (60mins MVPA), changing sedentary behaviours must be approached with different understanding. In a T1D specific study which looked at whether insulin pump Vs injection therapy was influential for PA behaviours, it was shown that there was no association with treatment type. They concluded that parental PA was an influencing factor to help encourage healthier PA habits in adolescents living with T1D (I. Michaud, M. Henderson, L. Legault, & M. E. Mathieu, 2017). Again, placing the co-users and parents/caregivers as an important factor in PA behaviours.

Establishing how PA guidelines translate in real-life environments is important to establish their feasibility. Although there is strong evidence for PA improving psychological factors and wellbeing, there remains a lack of understanding of adolescent perceptions, in real world environments, to support PA (Aman et al., 2009; Mitchell, Kirk, Robertson, & Reilly, 2016; Quirk, Blake, Tennyson, Randell, & Glazebrook, 2014). Furthermore, leading evidence points to challenges in school environments and the lack of clarity to promote safe and effective PA for adolescents living with T1D. For a population who are known to experience barriers to reach consistent PA goals, this area requires further important address. The movement in tackling the promotion, attainment, and support of PA in adolescents living with T1D requires a wider focus. Calls for research to learn from unsupervised approaches and the application of behavioural based on theory, qualitative research and practical knowledge has been stated (Foster et al., 2019; MacMillan, Kirk, Mutrie, Moola, & Robertson, 2014; H. Quirk, Blake, Tennyson, et al., 2014; Spencer, Cooper, & Milton, 2010). As there is a widespread technological aspect to managing T1D, a new era of understanding the role of different technologies in this context is also required.

2.3 Type 1 diabetes and technology

This section of the thesis aims to discuss technologies used to monitoring and managing T1D.

The processes of management and treatment of T1D has drastically changed since the 1970s. In his expert role as a diabetes endocrinologist, Dr Larry Deeb, MD, published his findings on the years of growing technological focus since the 1970s. His article draws attention to his many years working with children and teens and shows comparisons from the days when a once or twice a day injection of impure insulin was administered, to the technological ecosystem we now see. In this context, Dr Deeb discusses the true cost of living with T1D technology, to help educate others:

> *"Perhaps the best way to look at the true cost of technology is through the lives of real patients. Their experiences may give clues to issues facing diabetes professionals as we try to improve the lives of people with diabetes."* (Deeb, 2008, p. 78)

Before discussing types of technology, Dr Deeb stated that T1D is an all-encompassing condition, with inherent burden. He reported that reducing the amount of constant diligence to manage the condition with technology has not yet been achieved.

2.3.1 ***Technology for treating and managing type 1 diabetes***

Insulin is a life-saving treatment for T1D, first injected into a human in 1923 (Rosenfeld, 2002). Since then, different types of insulin, and different delivery mechanisms have been developed. Insulin pen injection devices were introduced in the 1980s. Evidence began to suggest that pen devices improved dose delivery – especially in smaller increments of insulin (units of insulin). As patients began to inject more frequently, a reactive development to patient burden was to develop a system to limit daily injections.

Insulin pump therapy, or Continuous Subcutaneous Insulin Infusion CSII, usability and feasibility was successfully developed from the late 1970s onwards (Bode, Sabbah, Gross, Fredrickson, & Davidson, 2002). As the technology improved, the size of the device went from the size of a backpack to the size of a small pager. A pocket-sized insulin pump, now exists to infuse insulin through a motorised pump, connected tubing, and a soft subcutaneous cannula, to offer the person living with T1D a different way to deliver insulin into the body, as opposed to multiple daily needle injections. The cannula is suggested to be changed frequently to prevent skin infections from the sited cannula, and insulin blocking in and around the cannula environment. It has been suggested that there may differences in health and overall glucose control for adolescents using CSII as opposed to those using traditional pen injections, or multiple daily injection (MDI) therapy to replace insulin (Boland, Grey, Oesterle, Fredrickson, & Tamborlane, 1999).

Glucose measurement and monitoring provides numerical output on current devices which inform those living with the condition, their caregivers, and healthcare professionals on the daily and long-term glycaemic patterns.

Glucose can be tested by blood, interstitial fluid, and urine analysis. Blood testing is performed through capillary finger-prick testing glucose meters and testing strips, and venous blood. Glucose sensors placed on the skin, which puncture the skin, allow for measurement of glucose in Interstitial fluid instead of blood. Finger-prick testing of blood glucose levels are often referred to in literature as Self-Management of Blood Glucose (SMBG)(Clarke & Foster, 2012).

As technology has evolved, the means to accurately test, monitor, display, and interpret glucose data for those living with T1D have been varied. Firstly, as mentioned, finger-pricking capillary blood samples have been known as a standard practice since the early advent of glucose meters, testing strips, lancet devices (to prick the finger) and glucose algorithms were invented from 1980s (Hirsch, 2018).

From here, continuous glucose monitoring (CGM) devices appeared at the end of the 20th century, after 50 years of glucose monitoring using SMBG testing methods mentioned above. These devices, as described in detail by Yoo and Lee (2010) have been developed using scientific laboratory technology, to define equations related to glucose concentrations through enzymatic and substrate reactions which translate to the user as a numerical value. The numerical value is the output displayed to the end user. In terms or glucose numbers, these data are indicative of glucose control at a physical level. Refinement and testing of glucose monitoring devices have improved over the decades (Moser et al., 2016). Barriers related to cost, availability, patient factors and lack of training still exist in the uptake of use of CGM technology. According to Agarwal and Cappola (2020) with the imminent commercial release of the artificial pancreas system, improving these barriers require urgent consideration. From the physical monitoring to the psychological effects of glucose monitoring, research has considered the human effects relating to psychosocial outcomes. Psychologically, quantifying the self and self-management of glucose contributes to diabetes distress and negative emotions (Virginia Hagger, Christel Hendrieckx, Jackie Sturt, Timothy C Skinner, & Jane Speight, 2016). In section 2.6, lived experience research in the T1D space discusses more of these important factors in the lives of adolescents living with the condition.

2.3.2 ***Current advancements in diabetes technologies***

Whilst there are many technological advancements, such as glucose sensors and algorithmic controlled closed-loop systems, many current options still require user involvement and regulatory approval to offer dose-adjustment automation. At present, frequent daily interactions involve self-administered dose consideration through many lifestyle variables (entering carbohydrates, physical activity, height and weight) (Hovorka, 2011). As discussed earlier, the mimicking of a healthy pancreas is the overruling approach in treating a person with a diagnosis of T1D. In terms of technology, the term applied in some contexts is biomimetic. In a movement to reduce user burden and facilitate more of a biomimetic experience, proposed systems included a closed loop insulin pump and glucose sensor with algorithmic control and research trials of dual-hormone insulin pump technology (El-Khatib, Russell, Nathan, Sutherlin, & Damiano, 2010; Tauschmann & Hovorka, 2018). A system which replicates normal physiology and would include a feedback loop using insulin and glucagon replacement with assistive communication, described in section 2.1.3. This technological consideration relies on pharmaceutical development of glucagon stability and the kinetics of absorption profiles, when infused similarly to insulin molecules (Peters & Haidar, 2018). In this example, dual hormone replacement could be viewed as the technological lynchpin on which many of the other peripheral systems operate. In a study by Taleb et al. (2016) adults were measured during periods of moderate and high intensity interval training whilst comparing single hormone (insulin only) insulin pumps and dual hormone (insulin and glucagon) pumps. Out of 17 adults that took park, 71% using single hormone remained within safe glycaemic range (4-10mmol/L) as opposed to 100% in the dual hormone system. During high intensity interval exercise, 11% of participants in the single hormone trial experienced exercise-induced hypoglycaemia vs 0% of dual hormone trial participants. It was reported that for those who took part in the continuous moderate exercise (60 mins at $V0_{2\ \mathrm{peak}}$), more glucagon was required. There were no reported side effects in the trial. As yet, testing this system in children or adolescents has not occurred.

An interesting take on the digital '*ecosystem*' of treatment and monitoring of glucose variation, and some varying factors is further discussed by Nathaniel D Heintzman (2016). This review showcases a proposed setting for integrated, interoperable, and collaborative digital technology in the daily life of a persona. In this proposed situation, a person arrives at a restaurant for a meal. The meal, glucose dynamics, interpretation and sensing are connected to wearable devices, wireless signals, and interoperable systems. This review suggests that this timeline is not so far in the distance, as it used to be. We already have continuous glucose monitors (CGMs), intelligent wearable devices (smartwatches, clothing), insulin delivery through sensor-augmented insulin pump systems and open API software structures for developers to collaborate in the race for interoperability. However, as stated by Bailey (2018), there is much heterogeneity of systems and patent regulations.

In summary, diabetes technology is moving towards reducing the burden of monitoring and dose-adjustment for those living with T1D to reduce patient burden. However, engagement in PA is context specific and the merging of technologies to meet specific PA demands has the potential to fully support engagement in PA. Section 2.4 discusses technology in PA and summarises potential for future advancement to benefit those living with T1D.

2.4 Technology for engaging with physical activity

Physical activity is commonly measured through the intensity of energy expenditure. The term Metabolic Equivalents (METs) represents resting energy sitting quietly and is commonly calculated to be 3.5 mL O2·kg−1·min−1 in a standard 70-kg person (Strath et al., 2013). Objective methods of measuring PA focus on energy expenditure, physiological markers, and sensor methods for motion. In certain domains objective measurement of PA is concerned with the frequency of PA, type of activity, length, or duration of activity. Physical activity self-monitoring and measurement, using commercially available technology is described below.

Physical activity measurement, analytics, and data sharing are possible for individuals at home. Wearable devices which use sensors to track activity to display physiological outputs of PA are becoming increasingly popular. The data provides an opportunity for individuals to learn about their own and others PA behaviour. Common devices can all with Bluetooth frequencies, GPS, and wi-fi enabled interaction and allow social networking app connection. On element of measurement across common PA devices is the heart rate. As the heart rate changes through PA this detection can provide a wearable, transportable, and convenient method for detection of PA. Section 2.4.1, discusses the incorporation of this data for those living with T1D.

Accelerometers, often found in commercial products, can measure movement in addition to intensity and duration of PA (Dominick, Winfree, Pohlig, & Papas, 2016). In research the use of accelerometers in PA studies to determine tracking accuracy is wide (An, Jones, Kang, Welk, & Lee, 2017; Brickwood, Watson, O'Brien, & Williams, 2019; Evenson, Goto, & Furberg, 2015). Most smartphones now have integrated accelerometery technologies to detect motion and activity. However, accuracy and detection are areas for improvement as testing continues. For those living with T1D, PA accuracy and the measurement of energy expenditure would require accuracy for dose adjustment of insulin as shown in the feedback diagram in figure 2-1 Should accuracy be limited, morbidity and mortality risk increases (Arif, Bilal, Kattan, & Ahamed, 2014; Chen & David R Bassett, 2005; Lee & Kwan, 2018). In a recent systematic review on the objective measurement of PA in adults, it was found that subjective measures were more common practice, for example self-reporting diary entries or feedback questionnaires. Since 2006, the percentage of studies which included objective measurement (e.g., pedometers for step-counts) of PA has more than doubled. It was hypothesized that this may be due to the commercial development and availability of reliable wearable devices such as Fitbit® and Apple watch. From 109 studies included in their review, most of the objective measurement was performed using wearable devices which recorded step-count data. Accelerometery as an objective movement to distinguish between PA and inactivity has been used to observe populations for some time, but the reviewers feel there is room to build research evidence in the evaluation of objective measurement in PA interventions using these technologies (Silfee et al., 2018).

In terms of objectifying accuracy for walking and running, testing of wrist worn devices continues. Recently, a study which measured objective accelerometery data using self-report running data, identified when participants were running and when they were not running, due to aggregation of three separate accelerometery measures. These are referred to triaxial metrics. However, accuracy of smart device in daily life as measured by Degroote, De Bourdeaudhuij, Verloigne, Poppe, and Crombez (2018) reported systematic bias in individual devices for the objective and accurate measurement of mild to vigorous PA during 15-min intervals. In terms of real-time feedback, the study suggests these devices are not accurate.

There currently exists no standard for the accurate measurement of PA using devices which communicate PA patterns via a worn device. However, accuracy for step-count, intensity using accelerometery and kilocalories are developing with algorithmic sensitivity. There is a breath of research which focuses on accuracy, validity, and evaluation of PA devices (Evenson et al., 2015). In terms of accuracy, the measurement of energy expenditure would be a considerable factor related to insulin dosing (See Figure 2-1 in relation to energy requirements and cellular function in a healthy individual).

One major concept of the digital health movement in PA is to make the invisible – visible. In his paper approaching current debate on the social interplay with devices, algorithms and self-perception, Williamson (2015) provides strong evidence that PA related health devices provide profound impact on the ways people see themselves, in terms of healthy behaviours, skills, competencies, fitness, body image and self-generated health data. This '*quantified self*' as a concept, whereby people view their personal informatics and define themselves through numbers, he argues, is marketed also to youth. The perspective of learning about our own health is captured in the term '*biopedagogy*' by the author. Interestingly, the discursive approach leads the reader to reflect on the ways in which we act as health surveillants on our PA behaviours. Overseeing our own health in terms of output from a device and becoming attentive to the ways in which devices track and measure our health as an emerging health movement. This also relates to research conducted with glucose tracking and monitoring. Showing a parallel in health behaviours with the general population and those living with T1D.

In a study by Kordonouri et al 2017, whereby 11 adolescents and young adults were recruited as a multicentred study and taken on an extreme trek through mountainous terrain for several days, testing feasibility of technology was trialled. The study was focused on diabetes specific technology (continuous glucose monitoring devices) which are designed with precision algorithms to detect exercise-induced hypoglycaemia. It was stated that the effectiveness of the trial and technology was suited to those participants who were well educated. This important factor highlights the need for an educated mind to first establish health literacy, understand health measurements, understand T1D and the effects of exercise and to understand their own perception of health when undertaking PA with T1D. Although the focus of the study was to determine if modern diabetes technology could allow for successful glucose control under extreme PA settings, there was no mention of any adjunctive PA devices, tracking, or interactions.

In contrast to technology for managing PA in diabetes, there exists a breadth of research on diabetes technology effectiveness for glucose monitoring and management, studied from a biomedical point of view. Standards for measurement of glucose and diabetes related outcomes have also been established (the pharmaco-technological movement has become part of the diabetes treatment landscape). For example, in continuous glucose sensing, a fine cannula translates interstitial glucose levels into a numerical value and establishing the statistical relevance of this and patient outcomes have been rigorously measured (Bergenstal et al., 2013). These glucose value can then inform people, with a degree of validity, through a visual display via connected devices such as an insulin pump, smartphone app, or third party wearable device (Nathaniel D Heintzman, 2016). As yet, PA technology especially in the context for managing T1D requires further validation. Managing PA in terms of measuring, detecting, or capturing PA with technology in the adolescent population living with T1D is relatively new in terms of understanding.

2.4.1 ***Current advances in physical activity technology for type 1 diabetes***

In T1D research it is known that PA causes dysregulation of glycaemia. Therefore, detecting levels of PA in this context would be deemed essential. However, the question arises of how the interplay between PA measurements (frequency, duration, intensity) inform, detect, and affect types of behaviours of adolescents living with T1D. In their paper discussing benefits and limitations of measuring glycaemia with technology and exercise in T1D, Tagougui, Taleb, and Rabasa-Lhoret (2019) report the developments in glucose sensing, real-time monitoring and intelligent dose-adjustment, through controller algorithms. Suggesting that we are moving in a direction where glycaemic changes are manageable with insulin dosing. However, they further argue that PA detection still awaits consideration in this loop. One barrier they discuss, is that PA detection in this context, may require yet another wearable device for someone who already chooses to use continuous glucose monitoring and insulin pump cannulas under the skin.

Although the discussion seems to be developing, there has been limited research in this area to date. However, three main studies draw focus to this emergent priority (Breton et al., 2017; Dadlani, Levine, McCrady-Spitzer, Dassau, & Kudva, 2015; Turksoy et al., 2018). In a recent closed-loop trial, with insulin pumps and sensor augmentation with CGMs using algorithmic control, PA capture was tested. Concerns regarding disruption to Bluetooth connectivity and data security is raised as a usable barrier for these immature systems are still being tested. Connection stability being a priority for considering insulin dosage decisions would be essential. However, this study does suggest that PA involvement within closed-loop trials and further developments of technology is necessary. Testing of "*artificial pancreas*" systems are ongoing, as is the integration of PA metrics. Suggestions from the study state attaching accelerometery devices to sensors under the skin or attached to the skin. As the movement of glucose sensing wearable devices is progressing rapidly, the combination of both may not be too far in the distance.

In a review by Olga Kordonouri and Riddell (2019), a range of apps were discussed showing benefits and limitations for use. Many apps showed an educational element – offering suggestions for pre-exercise glucose levels, logging behaviours and dietary information and providing reminders. Some apps discussed showed benefits relating to connectivity with current proprietary technologies i.e., Medtronic insulin pumps or Dexcom CGMs. A further layer which is novel to the field is application of machine learning to a system which builds heart rate metrics with glucose (CGM devices) and insulin pumps (CSII) which is discussed in the following section. Connecting with popular technology in the fitness industry – Fitbit® and Apple watch, this app named "*DiaBits*" appears to be the first app on the market to integrate fitness data. Although this novel and much needed approach to the detection of PA is progressing, Olga Kordonouri and Riddell (2019) call for urgent clinical and scientific evaluation of these apps for safety around insulin treatment in the context of PA. They conclude that evidence around the safety of these apps is currently 'scarce'.

As discussed, technology to monitor glucose levels using machine learning science to inform and adjust insulin dose are part of closed-loop artificial pancreas system research trials (Elleri et al., 2013). Considerations towards including heart rate, step count or other PA measures are an emerging, novel, focus. The first trials which looked at heart rate measurement in a model with sensor-augmented insulin pump therapy, trialled 13 adult participants during mild aerobic exercise for 45 minutes using a treadmill. Glycaemia was reported to reduce during the exercise period. Outputs measured were heart rate through accelerometery, glucose and insulin through diabetes technologies. This group established recommendations for a PA dosing algorithm and associated tuning parameters for glucose regulation. The trial showed that using when combining PA parameters with current technology, exercise detection was 99.5% specific, and 97% sensitive (Jacobs et al., 2015). A further artificial pancreas system demonstrated that heart rate metrics can safely be added to the system as means to inform of PA. However, this trial did not report statistical significance in the reduction of exercise-induced hypoglycaemia in the adolescent population tested, during and after the exercise period tested (60 mins). One strength of the artificial pancreas with heart rate system, showed a longer duration with glucose in a healthy range (Breton et al., 2017), which would suggest a reduction in fear of hypoglycaemia should feasibility trials develop further in this direction. Whilst these studies are moving the discussion towards to nature of technological change, it is important to consider how these would work in free-living environments.

Dovc et al. (2017) studied spontaneity in PA with youth in a closed loop setting. This study is one which draws attention to not only "*during*" effects of exercise, but also the "*before*" and "*after*" effects. The authors suggested in a first of its kind, a RCT investigating efficacy of a closed-loop insulin delivery system was not programmed (unannounced) to adjust for PA. Carbohydrate intake as a strategy for preventing exercise-induced hypoglycaemia was prevented in twenty adolescents with T1D who were expert CSII users. Closed loop trial (with algorithm) Vs open loop (without algorithm) showed that participants were within safe glycaemia range for 84% compared to 68% of the time. Closed loop efficacy showed that there were less events of hypoglycaemia and hyperglycaemia following moderate, and high intensity bouts of exercise, despite no advanced programming or carbohydrate adjustment. Critically, this area of future development may add positive effects in the treatment for eating disorders linked directly to those living with T1D (Toni et al., 2017).

In relation to the app "*DiaBits*" mentioned earlier, training a machine learned algorithm from 60 days of aggregated heart rate, step-count, glucose, and insulin dosing data provided a 93% prediction accuracy for 60 minutes ahead of time in a study with child participants living with T1D. Fitbit technology with artificial closed-loop pancreas system being the first trial of its kind, showing possible future advancements in the PA technology field for those living with T1D. Predicting for time ahead of planned/unplanned exercise and prevention of hypoglycaemia, and the tuning of the algorithms seems to be the course for further testing in this critically developing domain (HAYERI, 2018).

In summary, although current ISPAD guidelines highlight that, PA measures specific to children and adolescents, may need some adaptation. The very nature of the adaptation should be considered for the individual, their level of experience/knowledge and current goals. This individualised approach is to ensure that, evaluation and application of interventions are successful and articulate the personalised needs of the individual – designed by the factors which influence them. This is the central core aim of lived experience research. Lived experience research and T1D will be discussed in section 2.6. Person-centred focus is an approach often found in user studies and within Human and Computer Interaction (HCI) domains.

2.5 User experience research and Human Computer Interaction focus

The journey of technological advancements has been tailored towards precision, sensitivity, replicability, and safety to protect people living with T1D against life risk. Despite this, barriers still exist in terms of glycaemic stability, accessibility, cost, and burden for those living with the condition and their caregiver, despite technological advancements (Deeb, 2008).

The emergence of diabetes technologies has been shown to bring specific human-interaction challenges which has been approached by investigating psychosocial, usability and functionality factors. This PhD research aims to determine factors related to the context of lived experiences of PA and technologies, for youth with T1D, suggested as a timely priority for research (Knox, Glazebrook, et al., 2019).

For the adolescent who currently chooses to treat T1D with popular technology options such as insulin pumps, continuous glucose monitors and third party mobile connected apps, their lived experience will involve regular human behavioural factors. These may involve behaviours such as constant attention to treatment decisions, and prompt interactions from alerts and alarms by real-time glucose excursions (Rodbard & therapeutics, 2016). Famously, a RCT of a system using CGMs technology to reduce hypoglycaemia through the night became headline news when it was established that managing T1D requires over 180 health-related decisions each day (Digitale, 2014).

There are many challenges to understanding technology, the interaction, and the effect of PA (Knox, Quirk, Glazebrook, Randell, & Blake, 2019). In a systematic review by Knox & Quirk, real world evidence of technology-based interventions was researched. It was found that this area of research is becoming a priority (Knox, Quirk, et al., 2019). The current challenge, according to Knox et al, is to understand better the needs of the adolescents, their caregivers (or peer support network) in how technology can support or enhance meaningful engagement with PA. In their review by Quirk et al (2019), examined interventions with regards to technological impact on the self-management of T1D in children and young people. It was concluded that there is a current lack of evidence to support the impact when it comes to the management of PA with technologies. In terms of self-efficacy, PA studies were limited with only one included. This study was related to text message reminder services to adolescents aged 11-18 years. This randomised controlled trial sent reminders to the group with T1D, and no reminders to the control group. The trial used pedometers and text messaging as a motivational approach to increase PA in adolescents. No significant change in behaviour was found. (Newton, Wiltshire, & Elley, 2009).

Many point-of-care tools are given to the person living with T1D with the view that parents/caregivers will also become co-users of the technology. Operating these tools and interacting with daily insulin dose functions and adjustments, directed by measured glucose results, is the foundational aim in the preservation of health and physiological wellbeing. Complexity of managing dose responses occurs when titrations of insulin require intensive training, quick-thinking, and risk awareness. All of which are dependent on comprehension of the user, of the co-user and accuracy of the technological device to be considered reliable.

Analogue insulin replacement does not replace a fully functioning pancreas. Without many interactions and intense understanding of the risks involved with insulin replacement therapy, clinical goals and demands of constant measuring and monitoring can become overwhelming and difficult to engage with. Psychosocial factors alongside technological use play an important role in the health and wellbeing of those living with the condition. T1D is a life-threatening condition which can affect behaviours and life experiences.

More understanding of the influence and context with which technology can be applied, to support everyday PA including play, exercise, sport, and fitness in the life of the adolescent with T1D, is also required. The International Diabetes Federation highlight the requirements for manufacturers to consider person level needs, from a “pharmaco-technological” perspective (Patterson et al., 2019). With an increase in technological inter-operability with web based and third party applications, the T1D community often engage and interact with a variety of modalities which involve monitoring, and self-management of the condition. Olga Kordonouri and Riddell (2019) review on element of technological support - mobile smartphone applications and the effectiveness for people living with T1D. They acknowledge the vast challenges that T1D brings with PA and write recommendations for immediate consideration for better design “We see an urgent need for the scientific evaluation of diabetes health app effectiveness and safety around insulin dose adjustment strategies for exercise” (Olga Kordonouri & Riddell, 2019, p. 55). In summary, however, better understanding of barriers, challenges and/or successes are required to find out what the person with T1D needs in terms of technological support for PA (Knox, Quirk, Glazebrook, Randell, & Blake, 2019).

2.6 Lived experience in type 1 diabetes research

Lived experience research is placed within the phenomenological and interpretive ontologies within realist, qualitative research paradigms. The methodology seeks to explore, understand, and make-meaning of personal experiences and transformations from those experiences. The method does not seek to critique the individuals’ experiences, rather to find ways of comparing reasons why certain factors may influence and shape experiences. These factors may be every day, habitual life rituals or routines, or interactions with others and objects. Emotional responses to lived experience research often occur for both the researcher, the participants, and readers. It is suggested by Boylorn (2008) that the evoking of emotional response through this methods contributes to its ‘*verisimilitude*’.

A notable systematic review of qualitative research in the lived experience of T1D by Spencer, Cooper, and Milton (2010) made a clear distinction that social relations and support are vital to health improvement of adolescent's with T1D. HbA1c measurement as clinical standard stands out as a key measurement of self-management behaviours, but this limits research from understanding the individual and personal experiences, and what factors influence them. One drawback of randomised control trial approaches, given the complexity of living with the condition, is that they overlook the emotive connection between lived experience in causation to this glucose measurement.

As noted in several psychosocial areas of literature, adolescence is a period in one's life whereby emotions, development and transitions are inherent in the general population. However, the added complexity of living with T1D brings further significant factors which contribute to negative emotions and distress (Hagger et al., 2018). Teenagers' abilities to be independent in diabetes management are embedded within relationships with parents, peers, health professionals and teachers. This warrants further investigation in the UK and other settings, using rigorous qualitative research methodologies. Lived experience research will improve understanding and offer new perspectives of influencing factors which may shape the experiences of adolescents and their supporting others in living with T1D (Spencer et al., 2010, p. 372)

Learning from someone who has first-hand experience of living with T1D can be developed through various methods including interviewing, personal accounts, and many different creative communicative means. In a two-year preclinical trial developed from longitudinal personal stories of living with diabetes, the Family Centred Experience (FEC) program tested the impact of personal stories of diabetes on medical students. The results of which showed a positive effect on the education and learning of the medical students, in such a way that they connected deeper to understand that diabetes is more that the scientific explanations. Personal stories challenged assumptions of the medical students and motivated their medical directives, and direction of medical focus. The paper does not evaluate the reflective effect of sharing a personal story only to show that narrative can be powerful in diabetes medicine:

> "*First-person narratives of living with diabetes allow for learning in affective, experiential, and cognitive dimensions, stimulate self-reflection and perspective-taking, and enhance growth through the challenging of previous assumptions, beliefs, and perspectives. This type of learning is transformative and may result in a shift in students' perspectives*…" (Kumagai, Murphy, & Ross, 2008, p. 315315)

Furthermore, in educational approaches, the use of stories from those living with diabetes in marginalised groups was found to be an effective strategy to improve understanding and address the argument that elements of self-management may not be represented in structured education programmes. In order to inform practice, using explicitly coded narratives, as well as implicit narratives, are often used in context-dependent health research (Greenhalgh et al., 2011). In this ethnographic, quasi-naturalistic study, patients spoke of their lives with diabetes in a group setting. The participants were living in deprived, ethnically diverse areas of London. Clinical members were present at the group discussion, which appeared to gather emotive, personal stories. Having a clinical person attend such groups may contribute to participant bias, and response bias. Although the group chose topics for discussions, it was intimated that clinical staff may respond to issues covered during the storytelling sessions. Although these themes portrayed the changing identity, and practical diabetes management within a health-care system for those feeling vulnerable, fearful and requiring cross-cultural help and support, the use of storytelling as a method to educate and inform, challenge assumptions and highlight complexity was again shown strongly in this work. Greenhalgh et al. (2011) appeal to the reader that to make meaning out of health stories is to be aware of the sense we make of our lives, over time:

> "*Bruner argued that we make sense of our lives by retrospectively and prospectively turning our experiences into stories. Stories are defined by chronology (unfolding over time)"* (Greenhalgh et al., 2011, p. 3737).

2.7 Summary/conclusions

Physical activity is an important part of T1D self-management. However, current support for the adolescent to participate in PA remains challenging. Research shows there is a lack of age-specific educational support and guidance, with added evidence for technological gaps. Individuals experience T1D and PA in different ways, adding a personal element to generating a successful solution. The current combination of pharmaceutical assistance, monitoring and measuring is currently one of trial and error, leaving much of the safety and risk management of systems to the user (M. C. Riddell et al., 2019). Should the adoption of PA data be appropriate for inclusion to system learning, in the near future, this may offer a clearer insight into the complexity of self-management in this context. The development of dual hormone systems with machine learning capabilities according to research may help to reduce burden in relation to PA lived experiences (HAYERI, 2018).

At present, lived experience research is required to explore perceptions of current technologies including the types of technologies used, the challenges and opportunities presented, for the individual and their supporting others (as co-users). Gaining insight from lived experience will allow development of more person-centred understanding, to be applied to design of future technologies and interventions.

3 OVERARCHING METHODOLOGIES

This PhD exists within the qualitative paradigm. According to Scotland (2012) a paradigm is supported by ontology, epistemology, methodology and methods. Altogether, this theoretical axiom serves the purpose of "providing academic discussion, intellectual comprehension, and debate".

This Chapter first situates the ontological, epistemological, and methodological iteration taken in this PhD. Secondly, the Chapter presents the overarching approach of using Participatory Action Research (PAR) and the relevance in decisions when designing each study. PAR will be described in detail in section 3.3. Thirdly, mixed qualitative methods were applied to address the overarching research topic in three empirical studies. Lastly, the Chapter provides details of researcher characteristics and reflexivity.

3.1 Ontology and epistemology

Ontological perspectives are characterised by understanding the nature of reality, whilst epistemological matters undertake the theory relating to knowledge (Denzin & Lincoln, 2005; Scotland, 2012). Understanding and defining problems related to supporting PA and technology was viewed from an interpretivist/constructivist ontology. This is taken to mean that no single reality exists, that an objective truth is not known about a subject and that there is no universal truth about a matter that a person has their own unique, individual perspective on reality. This ontological position was taken to gain deep, rich, contextual, lived experiences of individuals, rather that gaining a positivist, hypothetical driven scenario. The epistemological approach sought to explore how participants made sense of their own realities, and their world views (Kinsella, 2006). This perspective was adopted due to success of previous literature in making sense of identifying the current problem area exists. (Dash, Goyder, & Quirk, 2020; MacMillan, Kirk, Mutrie, Moola, et al., 2014; H. Quirk, Blake, Tennyson, et al., 2014).

In this PhD, each study approached lived experiences through different qualitative theoretical lenses. Medical Research Council (MRC) guidance recommends an iterative process, to design suitable interventions identified by the qualitative studies (Craig et al., 2019). The studies in this thesis can be considered for evidence in the Development stage of the MRC complex health intervention framework (figure 3-1), as well as providing some insights in relation to design considerations and piloting stages. Figure 3-1 highlights the different stages of complex health intervention design:

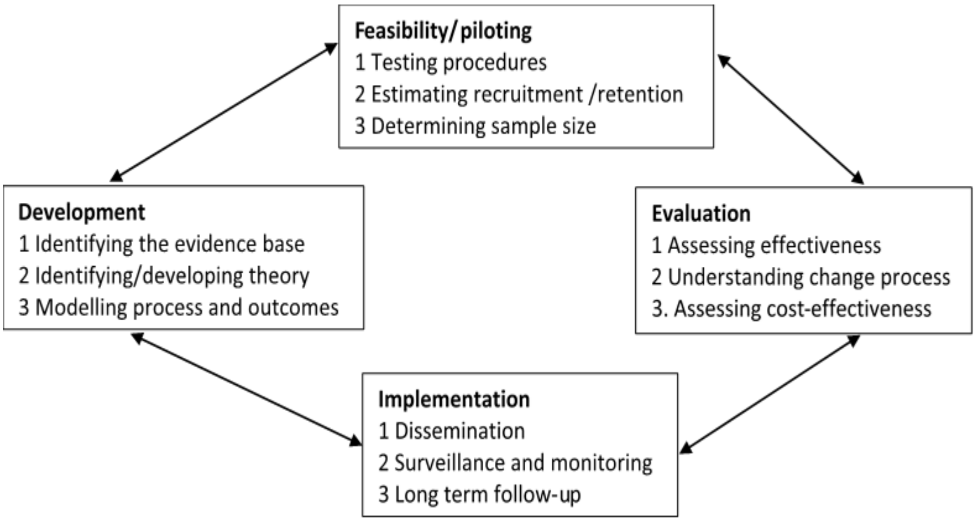


Figure 3-1The updated MRC Complex Intervention Framework by (Craig et al., 2019)

In terms of alignment with the MRC framework, it was established in Chapter 2 that a gap in deep understanding of the person-centred focus was missing in the context of the role of technology to support PA in T1D.

Each empirical study reports a temporal lens, guided by the life-course perspective. The World Health Organisation developed the life-course perspective in terms of large-scale, longitudinal lived experiences, and researching the trajectory of health and wellbeing. In alignment with this, the NHS in the UK, established perspectives on improving wellbeing which do include PA engagement – across the life-course. Literature was explored which focused on complex health and psychological perspectives of the past self, the current self, and the preferred future self. Study Chapters 4, 5, and 6 report findings of past, present, and future consideration of lived experiences and the role of technology to support PA for T1D. Phenomenological considerations were consulted when choosing a method to identify what the problems are, and to portray the collective voice of participants through participatory action research (PAR).

3.2 Participatory Action Research

Exploring the reasons why adolescents use technology to understand daily interactions, helps researchers to define health behaviours. By placing value in social power, as intensive service users, the three PhD studies were situated in PAR methodologies. Asking adolescents to provide their own world view can potentially address the power imbalance and liberate children and adolescents in research, as discussed by M. Hill (2006).

In a review by Dearden and Rizvi (2008), participation methods activate theories of raising the voice of people who are perceived as disadvantaged. The process of participation for people (as actors - not subjects) in their review was shown to be emancipatory. The review highlights the submissive relationship that participants may have experienced through hierarchical systems such as health. Participation levels and styles of participations are discussed as attributable to the successes within a project.

Clarifying goals, reducing conflict, and promoting language which supports a collaborative approach between researcher and participants (co-researchers), can build self-advocacy, enhance researcher and co-researcher relations, and maintain motivation to illuminate and enhance a positive interaction. These strategies aid the development of a positive participatory research environment. Establishing a neutral environment, whilst communicating the value of participants’ knowledge during a participatory research project was the goal of all empirical studies in this PhD.

In terms of quality control, suggested by Cook (2012) strategies for building trustworthiness to participatory research include:

- Allowing time for discussion
- Explaining core concepts – for example, meetings, focus groups, co-production, co-design.
- Providing practical help and support during data gathering, collection, sharing and discussions.
- Providing help to get to meetings/focus group events.
- Maintaining communication with co-researchers over the duration of time they may feel there are gaps.

According to Lawson (2015), there are five elements to be considered as the foundation, purpose, and outcome of PAR. Each of the five steps identify stakeholders as being central to the generation of new knowledge which policy makers can learn from, without the threat of power imbalance or 'globalization'. In this context, globalization refers to the generalizability of research to sell an evidence-based policy – in short, one size fits all. PAR aims to break those boundaries and set value for the individual, for the stakeholder as a valuable entity – often referred to in other research as a person-centred approach. The market ready, one size fits all, approach that generalisable research methods bring a lost voice. Lawson et al, further argue that the oppression of generalizing social research data, in populations with real life concerns adds to a potential to cause harm. Therefore, a strength of the PAR method in qualitative research is to raise perceived value in the relationships between the researcher, the implementation, the stakeholder, and the evaluation of the data.

Research identifies differences between the views of adolescents and parents in the context of T1D research, suggesting that parents view their world in a completely different way to the adolescent. Thus, parental perspectives alone cannot be relied upon as proxies for children's views (Walker et al., 2016).

Children and adolescent have shown a positive willingness to be part of their health care direction and choice. It is suggested that involving them, and listening to what matters to them, establishes a right to be heard (Alderson, 1993). Adolescents with T1D are long-term users of health services, who have extensive experience of NHS services. During early adolescence, clinical consultations involve parents/caregivers until the child turns age 16 (https://www.nhs.uk/conditions/consent-to-treatment/children/). Therefore, it is of vital importance that the adolescent and parent/caregiver voice is heard to develop opportunities to build and contribute health developments which may impact their future health.

Transitioning with a chronic illness, is not the focus of this PhD. However, it is important to signpost that the adolescent population living with T1D are pursuing common transitory periods of complex change with a life-threatening condition to manage. Critical developmental experiences including attending after school events, school trips, camps, or sleepovers without the aid of parents with extensive T1D knowledge may leave the adolescent in a high-risk environment. Additionally, leaving school, starting college/university, or finding employment and navigating relationships other than parental influences all orient the adolescent toward independent living (Gorter, Stewart, Woodbury-Smith, & development, 2011; Nguyen et al., 2016).

3.2.1.1 The origins, history, and theories of PAR.

Action research, of which PAR is situated within has origins from the 1940s by Kurt Lewin. Lewin was a psychologist, often referred to as the founder of “social psychology” who focused on creating research in the social science field. As far back as this, Lewin wrote that even though there was plenty of good-will and enthusiasm to deal with issues and problems, people seemed lacking of ways to action change. He began to enquire of what the current issues were, what risks where happening and what changes needed to take place to improve lives of people and practitioners (Lewin, 1946).

3.2.1.2 The ‘principles’ of PAR

Action research brings participants to a direction of the factors and forces at play of their experiences with human interactions. Scientists and researchers can play a role to help participants reach awareness of improving factors and forces which yield unwanted behaviours, or less than optimal outcomes. However, the principles of PAR are unique in that the journey of finding out what really matters is driven and processed by the participants. The participants also develop thinking on how the findings should be used, in a collaborative environment.

Within the area of community based participatory research, PAR aims to address complex, multivariate issues within communities – families, peers, teachers, policy makers. This community element applies to the diabetes community, who often refer to themselves (through social media) as the diabetes online community (DOC). Culturally, people with diabetes often see themselves a community which shares experiences, support, and comradeship in dealing with complexities and severity of the condition, often misunderstood, or misrepresented by the wider population. Therefore, community based participatory research is a highly relevant method to use for diabetes research.

3.2.1.3 What constitutes ‘research’ in PAR?

PAR is political in nature. There are two forms of PAR. The first form hands a token gesture to community members to participate in generating data, where the researcher takes control of the analysis and generation of results. The second form, of which this PhD involves in, is where the participation is guided as a form of co-research. In terms of the participants voices which are raised through this process, comes that of danger to exclude voices of those who chose not to enrol or be involved. Designing research questions and aims should be aligned with the interpretation of phenomenon. Ways to overcome small sample size are to focus on rich data gathered through this person-centred, co-researcher method.

3.2.1.4 The 'stages' of the PAR process and ensuring rigour

According to Restall (2010) there are eight stages which are generic to the process:

1. What is the goal of the project/research? – identifying a goal.
2. Who will be involved? – inclusion criteria for participants
3. Funding a project
4. Data collection methodology – interviews, focus groups, photographs, media
5. Data analysis methods and interpretations
6. Presentations of results
7. Taking action – how will the results bring about action?
8. Evaluation – how will the efficacy of the process be measured?

Application of data sources and methods of exploring lived experience results in establishing rigour within action research data. Having reflexive methods for the researcher, ensures a limitation of bias both of design and selection in the initial phases, and of analysis and interpretation towards the end of the project. The following sections will discuss the influence of PAR methodology from design to implementation.

3.3 Study methodologies and theoretical lens

An overview of each empirical study methods and the methodological approach used is described in Table 3-1. A theoretical lens gives a framework to the developing interpretive mind of the researcher. The following sections will discuss each study approach in detail, with descriptions of approaches chosen and guiding theories.

Table 3-1. Overview of research approaches included in PhD

Title	Methodology	Methods
Study 1 – Using social media to understand adults' experiences of PA as a child living with T1D.	Interpretive, phenomenological study with realist ontology.	Crowdsourcing for digital stories of lived experiences from adults and narrative of the stories to identify themes.
Study 2 – Using photovoice to explore the role of current technology in PA by adolescents living with T1D	Qualitative visual and narrative storytelling. Guided by photovoice theory and heavily routed in co-deign methods to collaboratively sense make over the materials that represented the lived experiences (Latz, 2017).	Co-design workshops using participatory action research tool photovoice. Participants as active co-researchers submitting digital photo and narrative stories representing lived experiences. Co-coding and mutual sense making of the stories.
Study 3 - Using Design Thinking to co-create recommendations for the preferred future of technology in the support of PA for T1D	Design thinking with post-phenomenology theory as a guide (Ihde, 2008).	Design thinking workshops using Mural whiteboard methods to capture design ideas visually and textually in a collaborative workshop setting.

3.3.1 ***Lens applied in study 1***

The aim of study 1 was to explore adults' retrospective experiences of PA as a child living with T1D and how that reflection would contribute to advice one would offer to their younger self.

Identifying with the sense of past self, and what may feel to be gone, gives a view of emotional affect in relation to self-belief models. These feelings of discrepancy, between lived experiences of the past and which beliefs would affect how one would behave in current time, are addressed in studies which describe self-discrepancy theory. Self-discrepancy theory was established by E T. Higgins (1987). He and his colleagues suggest that emotional incompatibility can generate negative emotions dependent on beliefs of the self in particular contexts. Domains of the self are developed in this theory as concepts of the actual self; the ought-to self; and the ideal self. The author describes these concepts as:

> "*The ideal self is the self that an individual strives to be and includes the individual's dreams and aspirations. The ought self reflects who the person thinks they should or ought to be, including their duties and responsibilities*" (E. Tory Higgins, 1989, p. 2).

In a paper directed at learning from one's younger self, the therapeutic nature of asking oneself to reflect and review past behaviours, with a view to correction or learning new behaviours was discussed by (Kowalski & McCord, 2020). If participants had felt they had regrets, then this reflection would aid them to be more aligned with their ideal self in the future. As shown in papers which begin to take different stakeholders perceptions of the wider determinants of health in T1D, there is misaligned priorities and assumptions from both parents and healthcare professionals at times (H. Quirk, Blake, Dee, & Glazebrook, 2014; Helen Quirk, Blake, Dee, & Glazebrook, 2015). By asking the people living with T1D, themselves, about themselves, we begin to develop an idea of who that 'self' is. It is clear that the person living with the condition, as '*the self'*, be the instigator of the inquiry (self-reflection) and the provider of knowledge, in establishing key discussion topics for improving and promoting PA behaviours. An argument for developing the voice of the person living with the condition was clear from previous clinical focused research. A method which was sensitive to the developing self, through childhood and moving into the future space was required. Therefore, the best-fit theory of self-discrepancy theory was approached to guide understanding the data and forming the research question.

3.3.2 ***Lens applied in study 2***

In study 1, we saw that digital story telling through social media was applied to explore the retrospective identified self. The second study carried forward the lens of identity, with a focus on current experiences using photographs and voice, known as photovoice. According to Bloustien and Baker (2003) "*the photograph is a powerful tool in the representation of identity*".

Photovoice uses photographs taken by participants as the data source with their choice of annotated narrative. Photovoice is a participatory action research methodology based on the understanding that "*people are experts on their own lives*" (C. C. Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004). Using photovoice can bring unheard social issues to the public forum and allow visual impact to drive change. Traditionally Photovoice was used in community settings to try to bring about social change. However, the application is far reaching in health science also (Catalani & Minkler, 2009; Walker et al., 2016; R. L. Woodgate, Zurba, M., Tennent, P., 2017; Yi-Frazier et al., 2015). Media portrayal of diabetes and the different types of diabetes has contributed to stigma, miscommunication, assumption-building myths, and harm (Browne, Ventura, Mosely, & Speight, 2014; Schabert, Browne, Mosely, & Speight, 2013). As a researcher who uses photovoice methods in children with health conditions, Ripat and Woodgate (2011) describe the intersection between culture, disability, and technology to widen the discussion on the socio-cultural environmental factors related to assistive technology. Success was shown in their previous photovoice studies promoting consciousness raising in adolescents living with disability and families living with complex health needs. Combining interviews with photovoice was used to enhance narrative and interview data (Ripat, Woodgate, & Bennett, 2020; Roberta Lynn Woodgate, Edwards, & Ripat, 2012; Roberta L Woodgate & Leach, 2010).

Critical consciousness plays a role in the recognition of behaviours and self-reflection through photovoice research. In her book, directing researchers to use photovoice in education and research, Latz (2017) backs theory of small scale interactions and interpretations of these from the school of thought known as symbolic interactionism, developed by Herbert Blumer in1969. This phenomenological approach to social research looks at the interpretation of meaning behind interactions Latz (2017). The identification, narration, ideation, and presentation of data in a photovoice study symbolises meaning behind interactions. This critical approach seeks to represent the voice as ethically as possible in research within lived experience. Latz (2017) states that this raising of critical consciousness allows participants to develop skills to reflect on their lives. To empower themselves to take note of their behaviours and have the space to identify their own knowledge, attitudes, and behaviours. Representing themselves can build esteem, self-efficacy, and relations. This has also been termed as psychological empowerment. The consideration of participants as 'co-researchers' was applied throughout study 2, in alignment with photovoice theory (Latz, 2017). The goal of photovoice methodology being closely linked to unearthing a private, lived experience and giving power to unheard populations, required allowing agency, respect, and implicit calls for the voice of the participant to be heard as equals. Bridging power imbalances in academia and clinic can only seek to build a collective aim for improved health and wellbeing of this population. The creators of photovoice felt strongly about this identification when they created the acronym VOICE – Voicing Our Individual and Collective Experience (C. Wang & Burris, 1997). For this reason, Latz (2017) also argues the aspect of raising the voice and sharing power/authority (Warne, Snyder, & Gillander Gådin, 2013). transcends disciplines and theory.

It could be argued that blurred boundaries of human factors and associated wearable/interactive health technologies also co-exist for adolescents living with T1D. It could be explored that the technology exists with as much importance as the human does when there's a 'co-dependency' of such life-giving and life-saving function. Post-phenomenological theory aligns with this notion that the relationship between the human and technology constantly shape each other (further discussed in section 3.4.3).

In summary, in the health domain, it is argued that photovoice not only builds critical analysis of lived experience but has the potential to change lives (Budig et al., 2018; Jarldorn, 2018; Plunkett, Leipert, & Ray, 2013; Roberta Lynn Woodgate et al., 2012; R. L. Woodgate, Zurba, M., Tennent, P., 2017).

3.3.3 ***Lens applied in study 3***

Study 2 data explored actions taken by participants whilst using certain types of technology (See Chapter 5). Offering a technological, interactive picture of lived experience and worldview ontologies. Post-phenomenology theory was adopted in study 3 to explore experiences of the materialism of technology. "*Beginning from the phenomenological recognition that tools, artifacts, instruments are taken into human experiential praxis*" (Ihde, 2008, p. 7).

Study three involved participants reflective accounts of their interactions with artifacts, as technology, through design workshops, supported by voice (online interviewing), image and metaphorical imagery (whiteboard data). Experiences of interactions with technology were discussed using design thinking approaches. The Interaction Design Foundation define this as:

> "Design Thinking is an iterative process in which we seek to understand the user, challenge assumptions, and redefine problems in an attempt to identify alternative strategies and solutions that might not be instantly apparent with our initial level of understanding"(Interaction Design Foundation, 2020).

The workshops were developed with design thinking concepts as a guide to train participants. Design thinking can be thought of as a term used in human-centred and Human-Computer Interaction (HCI) domains. Rather than jumping forwards to a solution, this innovative approach iteratively moves from problem areas to solutions. The key stages of design thinking are:

- Empathise
- Define
- Ideate
- Prototype
- Tests

Study 3 was designed to explore methods to empathise, define and ideate, moving from discussion of problem identification to possible solutions. One prompt to elicit needs analysis and convergent thinking is the Rose, Thorn, Bud tool. This tool has been adapted to be useful in software design, and other platforms (https://medium.com/research-methods-2021/rose-thorn-bud-44906e93a76).

A post-phenomenological view was used to facilitate a temporal view of future requirements of adolescents with T1D, who use technology for PA. Discussing actions, and interactions and exploring change. This adaptation of design thinking with future thinking was approached to progress the PhD thesis toward solution-based thinking.

As suggested by Ihde (2008) technological agency, through a post-phenomenological lens, is mediated through the embodied experiences, background noises, viewing data regarding the human, and listening to the prompts relayed to the human. Specifically, in terms of this PhD, a smartphone may be used by a user to text, share narrative, or images. Many considerations for self-management of T1D are related to prediction of glucose, prevention of future episodes of hypoglycaemia, especially in terms of exercise-induced hypoglycaemia. Prediction and prevention are associated with future thinking.

Bromberg, Lobatcheva, and Peters (2017) describe an intervention design which prompts and modulates future thinking investigating the effect of episodic future thinking on impulsive decision making with a sample of healthy adolescents:

> "*Because adolescents are both prone to show risk-seeking and impulsive behavior, and at the same time make a sensible target-group for prevention programs, it is particularly relevant to explore the episodic effect in the adolescent population*". (Bromberg et al., 2017, p. 2)

Johnson, Blum, and Cheng (2014) further develop this approach in their review of future orientation, informing program and intervention designers of the operational and conceptual frameworks to improve outcomes for adolescents. They highlight normative behaviours which are affected by collective influences, in their framework as shown in Figure 3-2. This figure situates the relationship between behaviours and time in the transition from early childhood to adulthood. Study 3 adopted design thinking prompts, and scenarios which were created to initiate a preferred personal future, displayed on a whiteboard, designed by the participants.

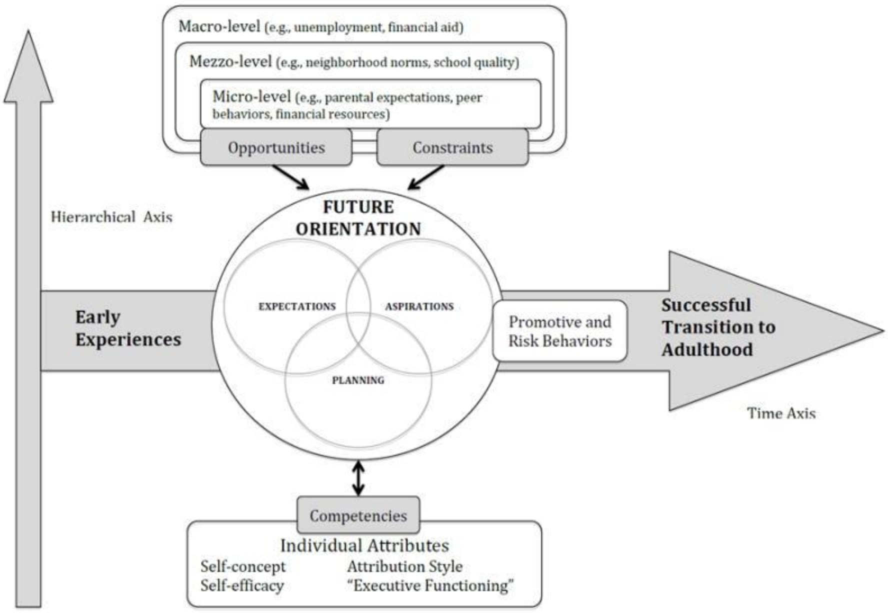


Figure 3-2 A conceptual framework outlining future orientation as reported by Johnson et al. (2014).

To facilitate this future orientation, back-casting has been described as a tool for imagining a past event and then developing a story in a forward direction. A desire for the future comes from this thought sequence which can facilitate discussion on how to affect change (Iversen, 2005). In scenario planning, '*out-of-the-box*' thinking is employed to imagine that the future change already exists or can be seen in the mind's eye. This future orientation then connects with how the participants wish to change present day by realising the prototype or creating ideas which lead to a prototype (Iversen, 2019; Nakagawa, Hara, & Saijo, 2017). In study 3, the whiteboard design and research question design were informed by this theory. Firstly, the sequence of asking participants to think about their current existing individual experiences in terms of a "*Bad Day Vs a Good Day*". Secondly, by introducing a second whiteboard to discuss what change to a possible future self could occur. Changing the axial stance from "*what is it like for you?*" towards "*how might we change this?*".

Therefore, in study 3, activities were designed with to facilitate both convergent and divergent thinking. Allowing participants to bring their own problem areas, technology interactions, and then inviting them to think creatively of constructing possible future selves.

> "*Good future study design must balance the divergent and convergent processes in order to facilitate a process where the use of the two different ways of thinking produces a result which is exploratory and creative and rooted in facts, numbers, and explicitly stated rational assumptions"* (Iversen, 2019).

3.3.4 ***Insider/dual position and researcher characteristics***

Additional to the research paradigm and theoretical stance, researcher motivation and position was considered. Reflexivity in this PhD has been practiced enhancing subjectivity and interpretation, as an '*insider/ dual-position'* role exists of the researcher's own lived experiences as a person caring for someone diagnosed with T1D. As opposed to consideration of bias, which implies deterioration of objective truth, reflexivity and subjectivity is a strength of the research procedures within this PhD. Applying this subjectivity through a reflexive lens was approached throughout each empirical study.

In terms of the practice of reflexivity and the alignment with qualitative paradigms, the researcher developed extensive and meaningful field notes for all studies. These notes included observations of personal emotions, immersing oneself with quiet, contemplative space to be mindful of emotional reactions to data items, and revisiting the data later with equanimity and a beginner's mind. Practicing walking and sitting meditation, throughout the PhD, also helped the researcher with personal wellbeing and task management (Beck, 2008). Concepts relating to non-reactivity and emotional equanimity in Buddhist reading was applied as part of researcher training. This approach helped the researcher to learn to bracket emotions and assumptions when exposed to highly emotive lived experience, especially in terms of stories relating to deteriorating health, and mortality. This practice was essential for the researcher to create strength in the subjective lens applied to the data. A strong desire for change, societal understanding and challenging of assumptions already exists within researchers own lived experiences.

However, when researchers and participants share experiences there is a danger of participants withholding information, if they assume the researcher will understand implied references. There is also a constant requirement to deliberate and questions if separation from the data is required to minimize the voice of the researcher. Hesitation existed when disclosing personal experience in most instances. If a topic yielding positive influence helped to develop trust and a relationship with participants, revealing that the researcher was also a parent of a child diagnosed with condition may have facilitated improved data collection of deep lived-experience stories. Thus, a balance exists in establishing connection, relationships, rapport and distance (Berger, 2015).

Ethically, maintaining quality control in qualitative research requires reflexivity, according to Berger (2015). To appreciate the connectedness of the researcher's own experiences with the research ontology, epistemology and methodology adds trustworthiness of the data. Processes involved in self-critical reflection allow awareness of affiliation, personal experiences, beliefs, and biases. There is much debate about the congruence of the term reflexivity in research, especially in the social science domain. However, D'cruz, Gillingham, and Melendez (2007) suggest reflection of researchers to include the terms "*What we know and how we know become the foci of scrutiny*", which are relatable in this PhD.

By drawing on reducing power imbalance and seeing the '*insider*' role as a strength, and a positive aspect of research strategies, methods were chosen to enhance the voice of the participants. Many steps along the way were taken to involve research team members, dissemination at academic events, research group meetings, and peer discussion to further build transparency, and quality control measures.

In determining the ontological and epistemological position as an '*insider*' the researcher approached various literature which addresses this perspective. Hayfield and Huxley (2015) establish that knowledge is co-created in this space between those who are living with similar experiences to yourself as a researcher. This gives context for the term '*insider'*. As proposed by Charmaz (2006) the founder of constructivist grounded theory, "*we are part of the world we study, and the data we collect*".

3.4 Chapter summary

Throughout the PhD, the application of three different methods to triangulate data in the timeframe provided was practiced. Triangulation can be considered as the convergence of knowledge from the use of different sources. Chapter 8 discusses the convergence of knowledge gained in this PhD. Additionally, triangulation of the data allowed for the development of quality procedures in qualitative research such as trustworthiness. Triangulation can be argued as a pluralistic paradigm statement. Some philosophers state that the origins of triangulation are of positivist realms, arguing that there is an objective view of reality on which different tools are used to cut through and develop meaning. Whereas, others come from a constructivist realm showing that triangulation can deepen scope and unearth deep/rich meaning (Seale, 1999).

4 PART 1: The Past - Using social media to understand adults' experiences of physical activity as a child living with type 1 diabetes

The study was published in a peer-reviewed journal:

Morrow, D., Lennon, M., Kirk, A., & Muirhead, F. (2021). Using social media to understand adults' experiences of physical activity as a child living with type 1 diabetes. Practical Diabetes, 38(3), 8-13. doi:https://doi.org/10.1002/pdi.2335

(See Appendix L)

4.1 Overview of Study

The aim of study 1 was to understand retrospective experiences of adults from their childhood regarding engaging with PA while growing up living with T1D. Personal digital storytelling was adopted as the method using social media to reach out to adults who were willing to share advice to their younger selves about what they understand now about engaging with (or not) PA when they were younger and what role having a T1D diagnosis at the time had on these experiences.

It addresses the following research questions:

RQ 1.1: What retrospective lived experiences do adults report in relation to physical activity when diagnosed with type 1 diabetes as a child?

RQ 1.2: What reflective meaning can be derived from experiences of physical activity, in terms of sharing advice to their younger self's?

4.2 Motivation and Background

As discussed in detail in Chapter 2, current challenges exist in facilitating engagement with PA for adolescents living with T1D. These are known to include both physical and psychosocial barriers. Attitudes towards teaching physical education have changed over time from a medico-health model (PA for therapy in disability) towards a physical 'fitness' approach. This has affected how people learn about PA and in turn has influenced how those behaviours may be 'carried-over' to adult years.

For adolescents with T1D, peer support is perceived as a positive experience for self-management (Lu et al., 2014). Furthermore, specific peer-to-peer mentoring from those living with the condition, can further lead to positive results in terms of developing knowledge and insight (Simmons, 2013).

Research has also found that active family accompaniment and positive role modelling, enjoyment, and self-efficacy are all key factors for participation in PA for 7-18-year olds (Simmons, 2013; Wilkie, Mitchell, Robertson, & Kirk, 2017). Additional evidence reports parents acting as educators to those in the community who lack understanding and knowledge about T1D. Parents accompany their child when participating in PA, due to increased risk of hypoglycaemia and their experiences with lack of trained personnel (H. Quirk, Blake, Dee, et al., 2014). Therefore, the sharing and imparting of information occurs at local level and is supported, and driven by parents, who are motivated to encourage their child outside the home. Parental support also helps change communities to become inclusive places where youth feel safe to participate in PA (H. Quirk, Blake, Dee, et al., 2014).

Asking adults who have lived with T1D through childhood about their experiences with PA as a child, is a potentially novel approach to understanding what the underlying factors are that influence engagement with PA (as a child and now as an adult). Adults may reveal memories which were pivotal in their lives, which also acts to form a cognisance of their current PA patterns. This novel method of collecting adults' childhood experiences as retrospective data through social media, on a platform where natural sharing and imparting of diabetes health related information presently occurs, gives an opportunity to deepen current understanding of experiences related to PA - from the perspective of someone who has lived through childhood with the condition and in turn, help inform future interventions that aim to increase PA in adolescents living with T1D.

4.3 Methods

4.3.1 ***Study design***

This study involved asking people (adults) on social media (Facebook and Twitter) to share memories of their experiences of engaging with PA as a child living with T1D. It was a qualitative crowd sourced approach to collating narratives to understand better what factors affected meaningful engagement with PA as a child, and to explore if and how any barriers or facilitators from past experiences could be taken forward for use in designing better interventions for current adolescents living with T1D.

A total of 24 researcher request Tweets were posted between 11 June 2019 to 11 July 2019. Facebook research requests were shared 26 times by the author on their own Facebook wall and throughout Facebook groups mentioned in section 4.3.2, during the same period. These requests were also shared by independent others (PhD peers) 3 times.

4.3.2 ***Participants, Ethics and Recruitment***

Adults diagnosed with T1D as a child, who were aged 18 and over were asked to reply to a research request (a post) to share their experiences of PA as a child, and advice they would offer to their younger selves. On Facebook, diabetes pages including two private (members only) groups: T1D in Scotland (https://www.facebook.com/groups/Type1D) and T1D UK (https://www.facebook.com/groups/t1duk) enabled purposive, targeted recruitment. These groups pages were chosen for convenience as the researcher was a member. On Twitter popular hashtags such as #t1d, #type1diabetes, #gbdoc #physicalactivity and #doc was included in authors tweets (on her own personal account) to purposefully attract those who are interested in T1D (#gbdoc represents Great Britain diabetes online community, and #doc represents diabetes online community). The advert used to recruit participants for inclusion is shown below. By replying to the advert participants were able to reply publicly or by private message with their experiences in tweet format. Momentum was generated by tweeting the advert, pinning the advert to the authors account and re-sharing on Facebook and Twitter. Participant information is shared in Appendices B and C.

4.3.2.1 Research advert:

"*Looking for adults diagnosed as a child with #type1diabetes to help with my research @UniANON. Please tell me what were your experiences with*

#physicalactivity as a child? And what would you tell your younger self? @theGBdoc #T1d #GBdoc #type1diabetes #doc, happy for you to DM if you want privacy. Please read for further information, consent, and privacy statements [insert google docs link to the participant information sheet, consent and University of Strathclyde privacy statement]". Study image contained Ethics ID960.

4.3.3 ***Data Collection***

Participant consent was informed through providing a participant information and consent document attached to study adverts. Interested people could message the researcher about any ethical or study information if required. Participants were made aware of their right to opt in or opt out at any time. Researcher provided transparency that researcher as author posts would be deleted after study analysis and reporting. Facebook posts and tweets were then manually imported into MS Excel, with all identifiable information manually removed. This was done by copying the replies without the authors names/handles and pasting directly into a cell on a worksheet (See Appendix D). The copied information was assigned a participant ID number.

4.3.4 ***Data analysis***

Comments/replies were thematically analysed as qualitative data with research team discussion to limit bias. Through examining the data (reading and re reading the posts) and- applying thematic analysis to generate codes key themes were then created using the application of a six-step process (Braun, 2013; Saldaña, 2015). Coding strategies were both inductive and constructivist as described in study Chapters 4, 5 and 6.

Throughout the analysis processes, saturation and sampling were considered with duration of recruiting. Decisions to close recruitment were based upon timescale, resources, and team satisfaction of completeness of codebook development and when no new themes were being generated from new posts (See Appendix F). Lack of definition of saturation exists for thematic analysis studies for the use of social media studies (Ando, Cousins, & Young, 2014; Saunders et al., 2018). Refinement and naming of codes and themes were achieved after the first 26 data items were analysed. Applying the codebook to the remaining 42 data items gave confidence that saturation was achieved from the data corpus. Team discussion and coding verified these decisions.

4.4 Findings

Over a one-month period Twitter and Facebook engagement data is shown in Table 4-1. The engagement was generated through liking, sharing, retweeting, and commenting.

Table 4-1. Social Media engagement

	Twitter	Facebook
Likes	96	19
Retweets/shares	83	26
Public replies to Research questions	35	10
Private replies to research questions	9	14

People who showed interest were replied to on the page where they made the comment. In some instances, private messages were received also from interested people. In total, data analysis was performed on 68 posts from 42 unique people (combined from Twitter and Facebook), which consisted of 6498 words total.

After the coding process six key themes were identified in relation to participants experiences with T1D and PA as a child, as shown in Table 4-12 below with exemplar quotes for each theme. These were (1) Acceptance; (2) Education & knowledge; (3) Support; (4) Coping behaviours; (5) Identity; (6) Perceptions of control.

Table 4-2. Experiences with type 1 diabetes and physical activity - example excerpts

Key theme	**Analytical interpretation**	**Example Excerpt**
Theme 1: Acceptance	A number of participants spoke of accepting that T1D did not stop them being active. Underlying interpretations were made to suggest these participants have accepted the change to their health.	*"Never treat this condition as a disease- don't let it rule you- and live the life you want to live- you can do whatever you put your mind to - there are definitely people out there with more issues than T1D" [ID6, Facebook].* *"I don't think it made much difference to my PA except afterwards I always carried glucose tabs. I was an obsessive swimmer before & after diagnosis, no real problems"* [ID24, Twitter].
Theme 2: Education & knowledge	Participants directly spoke of a lack of knowledge, a lack of education and uncertainty in how to manage T1D in the context of PA. Wider meaning was also interpreted from the data when participants spoke of uncertainty from others – assumptions from others about what they could eat or drink and myths about what T1D is.	"*I would definitely have liked more advice around managing diabetes and sport shortly after diagnosis and with regular updates!*" [ID19, Twitter]. "*Okay so I used to do a LOT of sports before I was diagnosed aged 8 and then the hypos exercise brought me gave me a massive blow. I basically stopped any and all exercise because I didn't know how to not have hypos during exercise*." [ID 1, Twitter.] "*I remember when I first got my insulin pump my coach for swimming asked my DSN, if that means the pump would make me swim faster? She looked at my coach in shock thinking she has no idea what she's talking about… Save to say, my DSN wasted 30 minutes speaking to someone who had no real understanding what t1 was about*." [ID 12, Facebook].

Key theme	Analytical interpretation	Example Excerpt
Theme 3: Support	Participants spoke of parental, peer, and formal teaching relationships. This theme was named to describe the patterns in the data linked with support they perceived in these relationships. Both negative and positive examples were found in the data.	"*My parents were responsible for managing my diabetes and were incredibly anxious. They prevented me going out alone… it to some extent deprived me of my childhood, and by-proxy made me less physically active*." [ID15, Facebook]. "*I went on a Diabetes UK holiday when I was 10, we took part in loads of activities, and I began to learn how to manage exercise – surrounded by other people trying out techniques and support by lots of healthcare professionals.*" [ID1, Twitter].
Theme 4: Coping Behaviours	Prevalent language of adjusting to life with a diagnosis of T1D aligned with different coping behaviours. Participants spoke of adjusting their diet to try and cope with exercise and T1D. Some participants spoke about access to treatment in relation to self-management, changing sport choice, and avoidance. Acceptance showed attitudes related to resilience. Uncertainty and negative emotions were also experienced.	"*The increase in independence with managing my diabetes was somehow too much when it came to PE days, and I often miscalculated insulin doses I hated PE, and this made it even more annoying!*" [ID 4, Twitter]. "*I was diagnosed in 1990 when I was 8. I remember eating a "Tracker bar" before taking part in sport at school. I was always nervous in case I had a hypo*." [ID 4, Facebook]. "*I avoided p.e. at all costs and eventually just stopped taking my p.e. kit in and ran my sugars above 13 whenever I had p.e. because at the time it was recommended that you didn't do any exercise if your bloods were above 13. I ended up becoming really unfit*". [ID 14, Facebook].

Key theme	Analytical interpretation	Example Excerpt
Theme 5: Identity	Participants spoke of feelings attached to feeling embarrassed when needing assistance due to exercise induced hypoglycaemia in social settings. Not wanting others to see ways in which the condition can affect them or hiding in public toilets to inject insulin was an identified pattern.	"*I didn't want other people to see me inject*." [ID1, Twitter]. "*I remember my first hypo happening at school not long after I started insulin. It was so embarrassing… It was all around the school that I had collapsed. I didn't do PE for about a month after that."* [ID21, Twitter]. "*Yeah, I was 11, I remember my first hypo happening in p.e. at school not long after I started insulin. It was so embarrassing. I started feeling funny but didn't want to say anything so carried on.*" [ID 14, Facebook].
Theme 6: Perceptions of control	Many participants used language related to "control". A sense of control of blood glucose, a sense of controlling their body and controlling their impending risk of exercise induced hypoglycaemia was interpreted as an important pattern in the data in relation to the research question	"*With regards to PA I really struggle to get my control correct. My control in general is very good*." [ID 23, Twitter] "*Understand your body and how it reacts to exercise and learn to avoid the hypo it before it becomes a problem*." [ID4, Facebook].

4.5 Discussion

In this study we took the novel approach of asking adults who have lived with T1D through childhood about their experiences with PA as a child. Asking children directly is potentially limited as they have not lived through the experience to be able to reflect on how it affects their PA later in life. The use of social media also enabled rich and meaningful reflective data to be collected, which has helped build a deeper understanding of the factors which affect facilitation and engagement with PA for a child living with T1D. These were: (1) Acceptance; (2) Education & knowledge; (3) Support; (4) Coping Behaviours; (5) Identity; and (6) Perceptions of control.

4.5.1 ***Theme 1 Acceptance***

Some participants' attitudes linked with resilience and acceptance describes a less fearful approach towards enjoying sport and not allowing fear to overrule their behaviours. An attitude of acceptance was found in data which seemed to portray perceptions of pragmatism and being able to adjust to life with T1D in the context of PA induced hypoglycaemia. This theme showed a paradoxical viewpoint from participants who felt less resilient.

4.5.2 ***Theme 2 Education & knowledge***

Individual experiences of challenges with education, related to understanding T1D in the context of PA, and how to reduce the risk of hypoglycaemia in PA was reported in the data. Adults who spoke of their now inactive lifestyles, drew attention to their lack of support and education as a child as an unmet need. Unfortunately, some participants described long term complications, which they perceived as a result of inactivity through lack of education and knowledge as a child.

In terms of addressing these long standing unmet needs, Simmons (2013) appeals for increased support. Peer support may come in many different forms to tackle a growing prevalence of youth facing challenging diabetes related experiences, one of which we know to be PA. A shift from education delivered solely from clinicians has now diversified to influences from online sources (social media, blogs, vlogs) from peers and families/caregivers - due to ubiquitous and pervasive presence of technologies.

4.5.3 ***Theme 3 Support***

The importance of support from others, and education, independent of technology was identified in this study. Many adults reported relationships and types of support experienced as a child. Reported adaptive behaviours towards PA and their attempts to reduce risk of hypoglycaemia through dietary control was notable. More than one participant spoke of others' confusion about what they could eat or drink, and the risk of hypoglycaemia related to PA not being well understood. By contrast, relationships which offered educated support, accompaniment, and assistance with treatment advice were reported as a positive experience, often linked to parental figures. This further supports the need for education and support outside of the home with people other than parents.

Peer relations were reported including friends' curiosity, help and assistance as a positive experience. This aligns with benefits of peer support. Interestingly, the type of peer support received from others with T1D, and at diabetes camp were reported as positive experiences in building confidence and education – learning from others with T1D. One participant spoke of their parent also living with T1D, and that they were not as scared as others with T1D due to this relationship. Their parent adjusted insulin and treated hypoglycaemia without giving them an experience of uncertainty or fear. This again strengthens the ability of peer-peer mentoring and relations as a source of positive learning.

4.5.4 ***Theme 4 Coping behaviours***

The influences of PA on coping behaviours were met by dietary adjustments such as eating more to try to prevent hypoglycaemia; treatment factors such as the lack of provision of equipment to test blood glucose levels, and behaviours linked to avoidance. Some participants reported that having a lack of equipment was a positive experience as a child – they spoke of the less they knew the easier it was for them. Due to the novel introduction of some technologies, it was apparent that many participants felt they could not carry equipment around, due to lack of portability. Some participants also felt that injections were restrictive and only performed in the home setting. It was clear that the lack of technology in this generation affected self-management.

Physically, participants drew focus to experiences of feeling less stamina for physical ability, linked to maintaining position in team sport contexts. One coping behaviour linked with this was to change sport type. These adaptations after diagnosis showed a personal approach to coping behaviours. Data gathered shows ongoing challenges for participation in PA with different people experiencing different outcomes – despite a diagnosis of the same condition. This is consistent with previous research that identified that personalised 'advice and encouragement' around managing diabetes for exercise' is vital for successful PA participation in this population (Faulkner et al., 2010).

4.5.5 ***Theme 5 Identity***

Codes and themes were generated from the data to describe the way participants felt in the presence of others whilst treating or managing T1D. For wishing to have privacy, to describing their emotions of living with T1D. Language surrounding not wanting to be seen or singled out from others was interpreted as social factors related to identity. Drawing attention to oneself being avoided in terms of people knowing about T1D.

4.5.6 ***Theme 6 Perceptions of control***

Participants drew focus to the feelings of control in their lives in the context of PA and T1D. Judgements towards self, and the use of exercise as a means of control was reported. The interpretation of the data to understand the participants experiences were centralised as perceptions of control. In vivo coding of the word control was found throughout the data in this respect.

Based on these findings, using Twitter and Facebook allowed space for the voice of a captive audience to be heard, by those who shared their experiences related to T1D and PA. Benefits of using social media included giving participants the option of providing public or private communication, with a community of whom they interact with frequently. By sharing their first-person stories in their own voice with natural language style participants also had no constraints of participant bias, clinical perceptions of hierarchy or the practicalities of travel burdens. Some participants sent messages of thanks for the opportunity to discuss their experiences in childhood, of which that they had never been asked. However, this limited the recruitment to only those who were currently registered as users on Twitter and Facebook. New social media research in adult populations has shown valuable qualitative results which explore current barriers (Oser et al., 2019). Further research could explore relationships with childhood experiences and adult PA behaviour trajectories.

In a study by Wilkie et al. (2017), factors for motivation for the participation in PA of adolescents of today, mirror those found in this study with adults who reflect back to their youth. By asking adults to reflect on their experiences, allows the recall of memories which may have influenced their childhood or current adult based PA behaviours. Long-term effects of inadequate support could cause devastating health complications which may be delayed or prevented through better support to be physically activity (Adolfsson et al., 2018; Chimen et al., 2012; M. Riddell & Iscoe, 2006; M. C. Riddell et al., 2017). Although this study allows a brief snapshot of memories of lived experience, research exists showing data of early life experiences on the influence of adult health. Haas (2007) reports limited data in the field of retrospection in adulthood health. Stating that, life-course research can be used to identify health ‘trajectories’ from childhood to adulthood in terms of morbidity and mortality measures. Further research including social and demographic information would strengthen the validity of using retrospection in this population to determine wider factors related to the participation in PA.

4.6 Conclusions

Our contribution to the field from the findings suggest childhood PA experiences of adults diagnosed with T1D as a child are similar to some current experiences of children and youth with T1D in terms of education and knowledge and psychosocial factors (MacMillan, Kirk, Mutrie, Moola, et al., 2014; Wilkie et al., 2017). Psychosocial barriers; diabetes care patterns; lack of understanding and lack of knowledge to navigate challenges in the context of managing T1D and PA were reflected upon. Using social media as a source to gather experiences was a useful method to generate rich qualitative data on lived experience. Asking adults who have gone through personal experiences with PA in childhood, has enabled key factors relating to unmet needs to be better understood. Findings have strengthened the urgency for improvement of PA behaviours through localised support and education. This will lead to a supportive, empowering collaboration of parents/caregivers and those in the wider community to adopt positive, behaviour change for adolescents with T1D.

4.7 Chapter summary

By asking adults to reflect on their childhood experiences of PA and T1D we sought to determine underlying factors associated with the lived experience of PA for adolescents living with T1D. Attempts were made to understand from a phenomenological approach that adolescents are agentic, they grow into a space of autonomy and create health behaviours from this age. It was found that a lack of technological support was experienced for the self-management of T1D. Participants reflected to childhood in terms of wishing they had insulin pumps or glucose sensors when they were younger.

In the experiences of those who felt acceptance towards their condition, a sense of resilience and confidence to be physically active were present, in comparison with negative emotions and reduced PA behaviours in others. Individual responses and attitudes towards diagnosis of T1D and coping behaviours can be used to inform more person-centred approaches in building confidence, body positivity and a framework to reframe capability specific to controlling blood glucose and PA.

5 Part 2: The Present - Using photovoice to explore the current role of technology in physical activity for adolescents living with type 1 diabetes (and parents)

Study 1 presented adults reflecting upon their childhood memories of PA. One main factor emerging from the data was the lack of technology in their lived experiences of being physically active. This Chapter presents a follow up study to further explore this.

This study has been submitted for publication: **Morrow, D.** (2021) Letting the World See Through Your Eyes: Using Photovoice to Explore the Role of Technology in Physical Activity for Adolescents Living with Type 1 Diabetes [Under review: manuscript submitted for publication to ACM SIGCHI].

5.1 Overview of Study

Study 2 was a 6-month qualitative photovoice study with 29 participants (adolescents living with T1D and their family members). The aim of Study 2 was to derive meaning and develop detailed information on what people's interactions with technology looks like, what adolescents and their parents perceive as challenges and successes with regards to interacting with technologies (for PA engagement and/or diabetes management more generally). The results are discussed in terms of (i) the captured lived experiences of adolescents living with T1D (and their family) in relation to their engagement with PA and the role that technology plays in this and (ii) the use of photovoice for empowering adolescents living with life-long health conditions by providing space for their voice to be heard within research and intervention design.

This study addressed the following research question:

RQ 2: What is the role of technology in physical activity for adolescents living with type 1 diabetes and their parents?

5.2 Motivation and Background

Technology can play an integral role both in managing T1D (monitoring blood glucose for example) and in engaging in a healthier lifestyle more generally (tracking fitness for example). The role that technology plays in active lifestyles in adolescents living with T1D, ranges from social and peer support in online communities, to PA and glucose monitoring using devices and apps (such as Fitbit or continuous glucose monitors). To design successful and meaningful digital interventions that promote and/or support adolescents' engagement in PA, more needs to be understood about the daily experiences of adolescents living with T1D. Giving adolescents a voice to explore what PA means to them and what role technology plays in their active lifestyle could generate insight into how to design better digital PA interventions.

5.3 Methods

5.3.1 ***Study Design***

This study design involved the use of photovoice over a 6-month period to understand experiences of technology and PA while living with T1D.

5.3.2 ***Participants, Ethics and Recruitment***

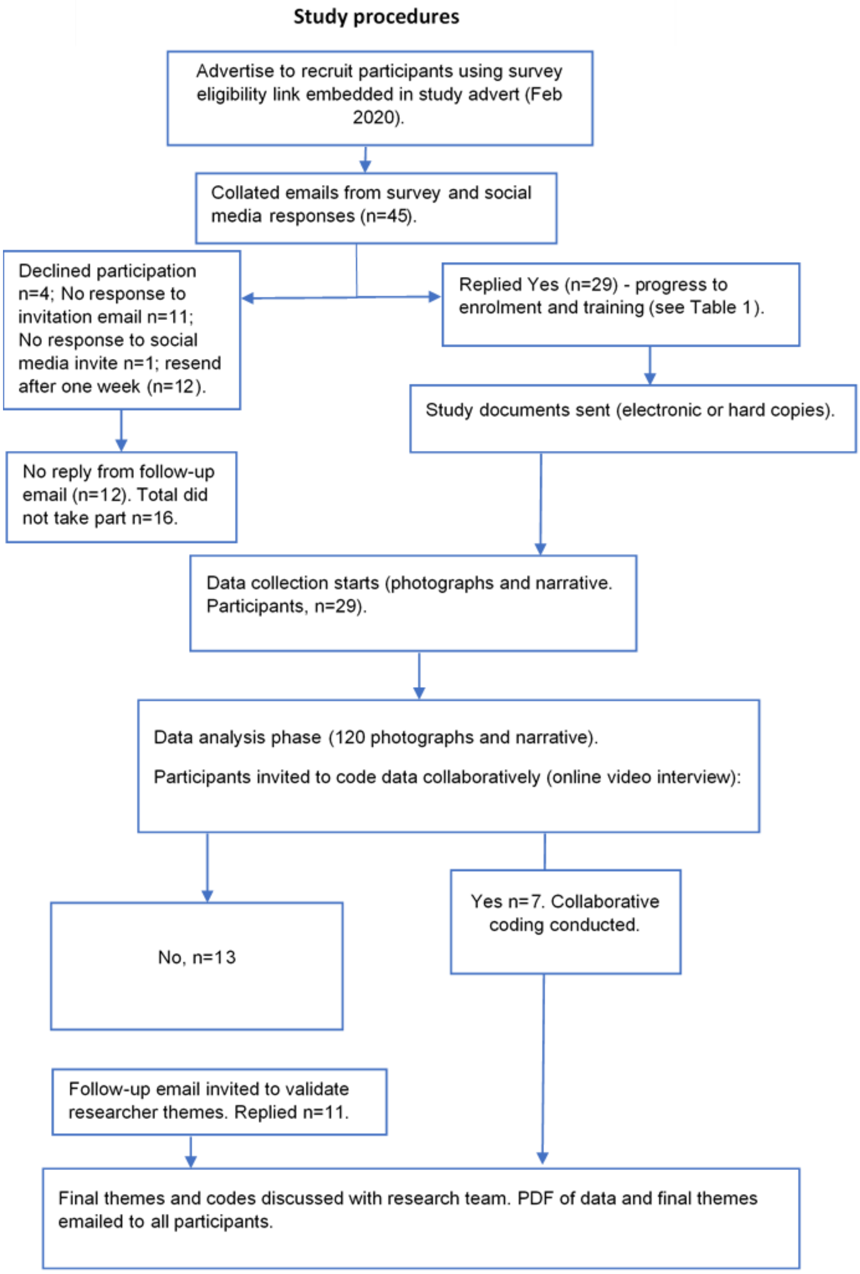
Participants (N=29) were adolescents with T1D and their parents (see Table 5-2 for details). Participants were recruited as co-researchers from the outset. Figure 5-1 illustrates the study methods.

In a population who may disengage with health care during adolescence, it was important that the method of using photovoice was communicated as a safe, non-paternal, friendly space with continual support and empathy (Zaidi, 2021). Entering a private world with the use of visual and narrative data was emotive and personal. Therefore, the photovoice space for submission, and training were designed with sensitivity.

Participants were recruited via adverts posted on social media (Twitter and Facebook) from February to July 2020. On Twitter, hashtags such as #T1d #gbdoc (Great British Diabetes Online Community), #type1diabetes and #doc (Diabetes Online Community) were used to target recruitment. Facebook groups relating to parents and caregivers of children living with T1D were also approached. The study was conducted under Departmental Ethics Board approval (See Appendix G for study protocol). To comply with ethical regulations, if the adolescent was under 16, parents were asked to submit the data on their child's behalf. If the adolescent was 16-18 years old, their own submission was agreed during consent. Participants were told that data would be removed from private messenger or email once analysis was performed (see participant information in Appendix G). Data generation and communication was staggered throughout a 6-month period, depending on the date of received consent. Once recruited participants were referred to as co-researchers throughout.

Support and training were provided by the researcher throughout the study. An orientation video created by the researcher was designed to provide the research aims, photovoice definition, brief photography skills (zooming and capturing), and the use of language as narrative (https://youtu.be/bhvFEBDuAxk). Use of the 'SHOWeD' terms helped co-researchers to facilitate self-motivation in capturing their lived experiences (Wang & Redwood-Jones, 2001). This mnemonic allowed for co-researchers to think about their image in a critical sense, raising questions such as: *What do you* ***S****ee here? What is really* ***H****appening here? How does this relate to* ***O****ur lives?* ***W****hy does this situation, concern, or strength* ***E****xist? and What can we* ***D****o about it?* The environment in which photos were taken was chosen by the co-researchers. The image was chosen by them, and the accompanying words were written solely by them. A private Facebook group for co-researchers – providing helpful tips, and neutral examples of photographs with narrative was created for those who wished to join. From consented participants, 60% joined the group and 7 individuals commented on posts.

Through this training, a coaching relationship between the researcher and co-researchers developed.



Advertise to recruit participants using survey eligibility link embedded in study advert (Feb 2020).

Collated emails from survey and social media responses (n=45).

Declined participation n=4; No response to invitation email n=11; No response to social media invite n=1; resend after one week (n=12).

Replied Yes (n=29) - progress to enrolment and training (see Table 1).

Study documents sent (electronic or hard copies).

No reply from follow-up email (n=12). Total did not take part n=16.

Data collection starts (photographs and narrative. Participants, n=29).

Data analysis phase (120 photographs and narrative).

Participants invited to code data collaboratively (online video interview):

No, n=13

Yes n=7. Collaborative coding conducted.

Follow-up email invited to validate researcher themes. Replied n=11.

Final themes and codes discussed with research team. PDF of data and final themes emailed to all participants.

Figure 5-1. Flow diagram of study methods.

5.3.3 ***Data Collection***

Participants were invited to upload photos (via their own smartphones to private social media messages with the researcher) with accompanying reflective text to represent their day-to-day experiences specifically relating to the role of technology in engaging (or not) with PA. Data (photos and text) was immediately transferred to a secure University password protected server location. One-to-one video discussions (collaborative coding sessions) were later also recorded with consent (audio and visual), for transcription as supplemental data, along with additional researcher field notes. COVID-19 restrictions on social meeting were in place in the latter stage of this study, therefore remote video conferencing was found to be an acceptable and essential study adaptation.

5.3.4 ***Data Analysis***

Photographs and "voice" were analysed following the six phases of reflexive thematic analysis created by Braun and Clarke (2020). Initial coding was inductive, data driven and involved assigned codes in preparation for later discussion with co-researchers for approval/change. Data analysis focused on co-researcher's experiences of interactions with technologies, the role of technologies and their PA behaviours, including what type of activities they are involved with and the importance of the technology and other people in enabling and empowering their lifestyle.

Analysis was performed both collaboratively and solely by the researcher, depending on co-researcher's choice. During collaborative analysis, whilst looking at each photograph and narrative, co-researchers were asked to think about why they shared a particular photograph. Prompting and developing critical thought was encouraged using the 'PHOTO' mnemonic (Hussey, 2006) shown below, to label meaning, define interactions and experiences during this collaborative coding process.

P – Describe your Photo
H – What is Happening in your photo?
O – Why take a picture of this?
T – What does this photo Tell us about your life?

O – How can this photo provide Opportunities to help your life?

Co-researcher’s reviewed their data with the researcher during video interviewing. Theme refinement and language changes occurred during this analysis stage (see Table 5-1 for an example). Moving from individual photographs and narratives across their overall data helped the co-researchers identify possible themes. This stage was considered important in terms of co-design and co-participatory elements of the study. For participants who agreed to online video interviews, their input, reflections, and opinions on the choice of initial codes were critical for establishing trustworthiness in the findings. This was taken in consideration when reporting the final themes. For co-researchers who did not agree to video discussion, an email was distributed with their coded data for member/sense checking. If co-researchers did not reply to the email, the codes were assumed acceptable and further rounds of analysis were conducted with research team members. After second cycle collaborative discussions, themes generated were noted and further analysed by the research team independently before a further round of approval by co-researchers. Any discrepancies were reconciled with co-researchers and analysis was agreed. Table 5-1 below provides an example of theme refinement through collaborative video discussion.

Table 5-1. Initial coding example with data excerpt ID11 shown in Figure 5-2

Narrative	Initial codes	Co-researcher interview - codes	Theme refinement
“Adolescent ID11: “I use the phone to message my mum when I’m in my room or when she is out of the house. (Mum ID11: It’s a good thing because he can just message me).	Teen messaging mum – helps independence. Perceived as good by mum	Benefits of technology – communicating remotely about T1D for parental support	Communication and immediate support (Benefits of technology)
Adolescent ID11: It makes me feel safer because I can use the phone to	Feeling safe	Parental emotions: peace of mind	Emotional impact
send my blood readings a to my mum. It is also good because it distracts me from my diabetes, and I can think about other things that are	Messaging blood sugar data to mum when away	Technology improves T1D perceived safety	Resilience & positivity
not to do with diabetes.”	Freedom from thinking about diabetes	Teen resilience	

5.4 Findings

In total, 8 dyads (parent & adolescent with T1D) took part as well as five parents individually and eight adolescents individually – totalling 29 co-researchers. One participant data set was sent by two sisters who were both living with T1D. Table 5-2 describes co-researchers who took part. Average age of the adolescents was 12.9 yrs. In total, 120 photographs were submitted with accompanying narrative totalling 8,934 words. The data was thematically coded by the researcher and then collaboratively with the participants via live internet calls and chat groups. Four key themes and 12 subthemes were generated: (i) benefits of technology; (ii) complexity & difficulty; (iii) emotional impact; (iv) reliance & risk. Example data is shown to represent the 12 subthemes in Figures 5-2 - 5-13. The full data set (120 photographs) can be found, organised into themes, in Appendix H.

Table 5-2. Photovoice participant description

Participant description	N
Teen only (male)	3
Teen only (female)	6
Parent & teen (male)	10
Parent & teen (female)	6
Parent only (female teen)	1
Parent only (male teen)	3

We asked co-researchers to share their experiences relating to the four main topics/questions described in the methods section above. We present these descriptively here in terms of each of the four key themes that emerged from the data analysis phase described in 3.3 then discuss what each of these means for the future design for technology to support diabetes management in section 5.5.

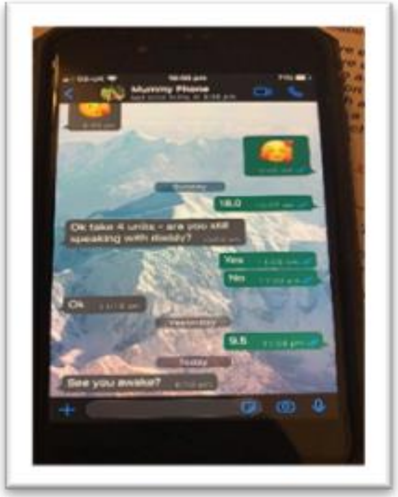
5.4.1 *Theme 1: Benefits of technology*

One of the key themes was people’s experiences of and expectations for the benefits of technology in diabetes management and engagement with PA. Figures 5-2 - 5-4 show some examples photos with narratives that illustrate 3 of the sub themes within this theme.

Communication & immediate support (Figure 5-2) – shows text communication between mother and son, sharing health advice remotely. This sub-theme relates to co-researchers narrative surrounding being able to contact parent/adolescent using smartphones by text, or message to ask for advice. Participant’s data was interpreted to show that immediate communication regarding health advice offered a sense of safety and peace of mind. This subtheme also relates to the benefit of communication for both adolescents and parents, in the role of supporting independence for PA and being able to engage in activities with a degree of freedom from parental involvement.

Passivity (Figure 5-3) – was identified as a subtheme when co-researchers spoke of their technology adjusting insulin dosage frequently, without them having to interact with the technology. Included in this passive experience was a sense of trust that technology would suspend delivery of insulin if the user was moving towards hypoglycaemia. This ‘just in time’ effect of hypoglycaemia prevention is further supported by the user feeling trust in the system to alert them. Allowing them to enjoy being active through a hands-free system which would “beep” or “alarm” if they were “hypo” or “hyper”.

Glanceability (Figure 5-4) shows a participant parent looking at a wrist-worn device, offering remote data visualisation of her adolescent child’s glucose data. This image represents participant descriptions of being able to easily view patient-generated data on devices which are connected. By looking at graphs, and real-time data, users are able to make quick health decisions, and parent/caregivers are offered informed choice on whether they need to intervene. This real-time glance of data can mean that the participant may feel able to resume being active after a quick glance. Parents as co-users and adolescents both mentioned they liked this aspect of current technology. Adolescents mentioned that they hoped more wrist-worn devices could scan their blood glucose levels (example – Fitbit ID20, See Appendix H for full data).



18.0

Ok take 4 units - are you still speaking with daddy?

Yes

No

Ok

9.5

See you awake?

Figure 5-2. Communication & Immediate Support

“I use the phone to message my mum when I’m in my room or when she is out of the house. (Adolescent ID11)

Mum ID11: It’s a good thing because he can just message me.

“It makes me feel safer because I can use the phone to send my blood readings a to my mum. It is also good because it distracts me from my diabetes, and I can think about other things that are not to do with diabetes”. (Adolescent ID11)

Figure 5-3. Passivity

“My amazing technology. I'm lucky to have been one of the first children/young people in the UK to be given the Medtronic 670g hybrid closed loop system, which uses the Guardian 3 sensor to track my glucose levels and then adjusts the micro bolus it gives every 5 minutes based on the trend it sees, using a very clever algorithm”. Adolescent ID18

Figure 5-4. Glanceability

“Being able to keep track of my son’s blood glucose levels remotely has been life changing. [son] and I are able to sleep soundly at night knowing that an alarm will wake us should our son’s levels fall dangerously low. [son] and I can be in work meetings and have peace of mind that [son] is ok with a babysitter”. Mum ID10

5.4.2 ***Theme 2: complexity & difficulty***

The second key theme captured the essence of complexity and difficulty which related to co-researchers describing a variety of challenges including transitioning to independence, uncertainty of how to manage T1D and PA, and parental burden experienced.

Transitions from parent (Figure 5-5). Co-researcher's often mentioned being accompanied by parents and communicating using smartphones for messaging, or attending to technology alerts, often at sport events with accompanied parental involvement from the side. This data often represented complex decisions, and difficulty surrounding comprehension of how to adjust dose for PA, or how to troubleshoot technological issues. Navigating this transition with the role of technology in the example provided shows an adolescent self-managing glucose at the side of a football pitch. The parent's narrative shows that the period of transition from childhood to adulthood, and parental freedom/independence, causes fear and concern.

Uncertainty & PA induced hypos (Figure 5-6). This relates to data in the photos and narrative in which co-researchers expressed difficulty and complexity surrounding prediction, prevention and treatment of hypoglycaemia related to PA. The example provided describes aspects of being included in sports, and the benefits of being active, despite a "rollercoaster" of glycaemic variation for a long duration after the exercise has occurred. This example provides data which was prevalent throughout when adolescents were active and experienced exercise-induced hypoglycaemia. Often the narrative from the adolescents in this context showed negative emotions including "hate" and parental emotions including "worry" and "fear" (See Appendix H for all data).

Parental burden in facilitation (Figure 5-7). This sub theme represents data which was provided by parents as co-researchers who often accompany their child to events, they interact with their child's diabetes technology before, during, and after activity. They engage with technology (example listening to and attending to continuous glucose sensor alarms through insulin pump connectivity) on behalf of their child. Parents encourage and support their child to be active – whilst engaging in prediction management behaviours “behind-the-scenes”. This was spoken of by many parents in the study as a difficult but necessary part of their child’s PA experiences. In Figure 5-7, the parent shares narrative that whilst her adolescent is asleep, they make preventative decisions for predicting a day of activity and hot weather. Appendix H provides further data showing different types of physical activity and many narratives of parents supporting their adolescent to be physical active.

Figure 5-5. Transitions from parent

“My son is getting to the age where he no longer wants or feels he needs me on the sidelines telling him to eat a carby snack pre-match or shouting for him to come off the pitch to treat a hypo. I am glad and not surprised he wants to be more independent but feel nervous about the prospect of him coping alone”. Mum ID10

Figure 5-7. Uncertainty & PA induced hypos

“The after-effects of exercise are something we never seem to get right! The night after can be a rollercoaster of over treating lows to crazy highs. But as long as he’s got to play his sports, the long nights are so worth it”. Mum ID12

Figure 5-6. Parental burden in facilitation

“I know he wants to play tennis today; it is very hot already... considering a temporary basal, or extra carbs or both?! The heat will make his BG drop very fast. It’s 7.30am and I’m about to do my own workout so I’ll have a think while I do that. Don’t think the diabetes brain ever switches off as a parent...but for now, I’m glad * does. He’s still sleeping unaware I’ve just calibrated his pump”. Mum ID12

5.4.3 ***Theme 3: Emotional Impact***

Key theme 3 relates to the data in which co-researchers describe their feelings and emotions. Data representing parental emotions and adolescent emotions were rich and powerful. Many emotions pointed towards a relationship between navigating transition, support from others, and the role of technology for managing T1D in interrupting or impeding the ability to engage in PA with ease, spontaneity, and fun. A few co-researchers spoke of their gratitude for technology. There were instances of dualistic emotions expressed in the same data item. This represents mixed emotions. Language used by co-researchers represented worry, fear, anger, and resilience.

Confidence through support in Figure 5-8 the subtheme is illustrated which represents a sense confidence involved when PA experiences are supported by others. Co-researchers spoke of sports groups, friends, social media support groups and elite sport camp experiences as shown in the example below. Data showed narratives from both adolescents and parents. As figure 5-8 shows sport events which are designed for those living with T1D can be a great source of confidence building, learning, and sharing with others during the activity who also live with T1D. The example shows a sporting league for ice hockey teams who are sponsored by a pharmaceutical supplier of insulin pumps in Canada. Other data, provided in Appendix H, shows evidence that online peer support can offer advice, and someone to connect with to build confidence. This highlights the need for support to be accessed through technology but also through physical activity events which act to train not only PA stamina and fitness, but also act to provide practical, peer and professional support at the time of activity.

Resilience & positivity in Figure 5-9 shows an example of an adolescent female, dancing whilst wearing a glucose sensing device, to assists with glucose monitoring (see Appendix H for further submissions from participant ID17). This participant describes positive emotions, a sense of acceptance and determination. The attitude of acceptance from the adolescent in figure 5-9 speaks of resilience and positivity in terms of being active despite the diagnosis of T1D. This attitude speaks of an area for psychosocial intervention to explore ways of addressing negative emotions to improve PA engagement. This data provides a paradoxical viewpoint to the image shown in Figure 5-10 where the adolescent is experiencing negative emotions.

Teen – negative emotions (Figure 5-10) captures the experiences relating to negative emotions specifically by teens. In the example given the adolescent expresses hate towards his diagnosis of T1D, when hyperglycaemia requiring medical support, encroached in his ability to take part in PA. This example provides evidence that hyperglycaemia requires immediate medical intervention, as do instances of hypoglycaemia. This immediate medical intervention can happen at any time. When this occurs during PA or interrupts PA participation, negative emotions can be experienced. The participant explains how this event prevented participation in timetables sporting events in school. Therefore, an awareness is required (in educational. Timetable and regimented settings) that T1D can disrupt participation for PA when living with T1D, and the emotional response to this, can have an effect on adolescents living with T1D.


[redacted]

Figure 5-8. Confidence through support

“An elite hockey camp for Type 1 Diabetics and I learned how to treat my Diabetes both on and off the ice along with making new friends”. Adolescent ID7

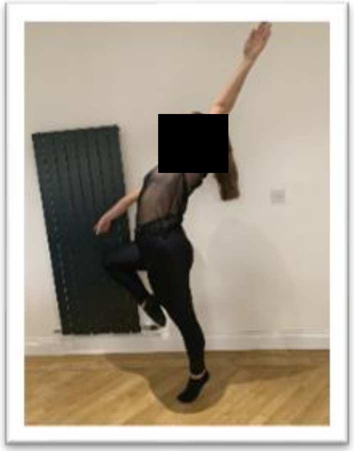

[redacted]

Figure 5-9. Resilience & positivity

“I am doing dance in the photo; I have danced since a very young age and during my diagnosis of type one diabetes it was a really good thing for me to be able to escape my illness and allowed me to express my anger/emotions through the motion of dance. Adolescent ID17


[redacted]

Figure 5-10. Teen – negative emotions

“I was in class today just not feeling quite right and when [teacher] came to help me carb count my snack. I thought that I didn’t need my blood sugar checked as I wasn’t having a snack, but we checked it anyway and it was 22 and my ketones 0.7.

I had to go to the medical room while Mrs Y phoned my Mum. I had to do a pen injection and cannula change so I missed all of my break and game of football AND I HATE IT ALL!” Adolescent ID 6

*5.4.4 **Theme 4: Reliance & Risk***

The fourth key theme captures experiences in relation to health risk caused by technological failures (example insulin pump, cannula, continuous glucose monitoring technology).

Tech fails and severe life risk (Figure 5-11) represents co-researcher's data related to managing T1D when technology fails. Specifically, reports of cannula failings (in situ devices), glucose sensors adhesion issues, loss of signal from glucose sensors and smartphone app signal loss causing life risk. The impact on adolescents was shown to cause disruption to PA participation, and a demand on parents and caregivers to intervene. Furthermore, interpretation of this data was linked to adolescents not hearing alarms from devices. During PA adolescents either didn't hear an alarm, or they heard it, but ignored it to continue their activity. Alarm functions serve to provide a warning system when the impact of glucose variability may be life threatening. This function, and the threat to life when technology fails brings negative emotions, and fear. Showing a relationship with theme 3.

Trust & vigilance in Figure 5-12 depicts the subtheme which provides interpretations of a sense of trusting technology and the relationship this creates with vigilant behaviours. In the example shown, the parent felt that remote monitoring after an active day gave clear indication of life risk, despite technologies best effort to stave off exercise-induced hypoglycaemia. Vigilance and prediction of life risk is reported by parent/caregivers throughout the data. In the context of PA, the underlying interpretation of vigilance is dependent on trusting technology to work, and balancing fear that T1D is an unpredictable condition. In relation to the overall theme, this sub-theme highlights the need for technology to be reliable.

Alerts & vigilance represented by Figure 5-13 relates to the technology alerting the user to a health risk and the complex relationship with the choice/ability to attend to these alerts. In the example provided, the user felt their attention was not captured by the alerts enough to warrant behaviour change at that time. When they experienced further sequential alerts and a serious level of hypoglycaemia the user then decided to take action, to treat their hypoglycaemia. Vigilance in this theme is related to the dependence on alerts and the decision to either rely on those alerts, or to ignore them. In this sense, the participants exercise a sense of control on whether to respond to alerts, and when to respond to alerts.

Figure 5-11. Tech fails and severe life risk

“Aftermath of a day of exercise, extreme weather and set failure. High bloods and increased ketones…pen injection to the rescue. I feel sick and light-headed and dizzy. When my pump stops working properly it makes me realise how much I need it to keep me well. I'm angry because I've had such a good day and then this happens.” Adolescent ID2

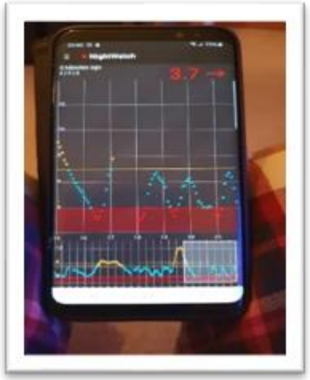


Figure 5-12. Trust & vigilance

“The exercise induced hypo YOYO! Remotely monitoring my sons blood sugar levels via an app on my phone. An active day of swimming and dog walking means hours later his blood sugars have plummeted into the red for danger zone several times, despite his pump suspending his background insulin. I treat a hypo only to find another one on the horizon. My pyjamas are on but there is no chance of sleep”. Mum ID1


[redacted]

Figure 5-13. Alerts & Vigilance

“This was whilst I was walking my mile with [Anon]. My pump started beeping at me. It altered to the fact my bloods were dropping…2 arrows pointing downwards but my pump had suspended on low… unfortunately I hadn't noticed that alert. My bloods dropped to 2.7 and I had to treat my hypo…but I was so wrapped up in walking and talking to [anon], who is captain of and [anon] who is one of my favourite players I would have probably ignored my body, but my pump did its job”. Adolescent ID 2

5.5 Discussion

This study involved using photovoice to understand lived experience of adolescents living with T1D with a focus on the role of technology for engaging in PA. Our intention was to understand these interactions, and the needs of the adolescents and their parents. The study methods aimed to help adolescents and their parents become active agents to identify their needs, their challenges, or successes based on real lived experiences using photovoice. The four key themes generated were (i) benefits of technology; (ii) complexity & difficulty; (iii) emotional impact; (iv) reliance & risk. A discussion of the themes set in the wider context of published literature in relation to both technology and PA and psychosocial factors is offered. We also share our recommendations for the future design of technology to support the lived experiences of adolescents engaging in PA while living with T1D.

5.5.1 ***Benefits of technology***

There are a range of technologies involved in diabetes management including insulin pumps with associated cannulas, glucose meters and glucose sensors, from many different manufacturers and models. Passive technologies (using controller programming and artificial intelligence) were perceived to be of significant benefit. People in the study commented on how lucky they felt to be able to access some of the devices. Others talked about how hands-free dose adjustment could play a role in enabling adolescents to be free to take part in PA in that for people involved in competitive sports, being able to glance, hands free during play/activity was a significant enabler. This aligns with previous reports linked to positive quality of life, when the technology was tested for home use in early trials [47].

Being able to communicate and/or share blood glucose data to others via the devices is also perceived to be of huge benefit. Glancing at the info on a smartphone or other device provided peace of mind and a greater sense of independence both for the adolescent and/or parent. Peace of mind was also shown as a key theme by Burckhardt et al. (2019) in their study related to remote monitoring. This overlap of easing psychosocial burden is mirrored in our study.

A lack of technology specifically to support PA was reported in our study. Only two participants from a possible 29 spoke of engagement with wearable PA technology, one of which showed visualization of blood glucose data transmitted from a glucose sensor device. Benefits of such technology were however depicted in terms of feeling "freedom" to go to work (the parent) and trusting in the data whilst sleeping at night for example. Further research is needed into how PA technologies can support adolescents living with T1D and how to support engagement with these technologies.

5.5.2 ***Complexity & difficulty***

There are many factors which relate to the challenges experienced in living an active lifestyle with T1D. Adolescents long to become independent from parents during such activities to be free to enjoy PA without being called from the side-lines to eat or drink. Parents however often feel like the gatekeepers, facilitating and/or being responsible for 'safe play' or 'safe participation' in sports given the potential risk to life. Parents also appear to be very mindful of the amount of forward planning that is required when supporting upcoming periods of PA or specific events. This gatekeeper effect was noted in previous research [49]. There is also evidence for lots of behind the scenes planning and calculations by parents. The uncertainty of how to prevent exercise-induced hypoglycaemia, or the correct and safest strategies to cope with dose adjustment to prevent late onset hyperglycaemia are prevalent. Overcompensating with food changes, dose adjustment guesstimates and managing the uncertainty of glucose variation occur despite their best efforts to create a safe PA experience for their child. There is a need for ongoing consideration of the family role in supporting active lifestyles of adolescents living with T1D.

5.5.3 ***Emotional impact***

Parents who use glucose sensing devices linked to insulin pump delivery systems spoke of fear of PA induced hypoglycaemia. Waiting by the swimming pool, staying at the cricket pitch, attending school activities despite using advanced sensing technologies. In critically analysing this relationship, a sense of vigilance was present due to experiences of past technological failures. and vigilance are therefore important factors. Choudhary, Olsen, Conget, Welsh, Vorrink and Shin [2016] stated that confidence in the use sensor-augmented insulin pump systems does exist, and sensitivity of the signal to reduce insulin delivery can be a success, but our data shows that the lived experiences of this can in fact vary from device to device and person to person. Parents talked of feeling grateful for the technology but also spoke of technological immaturity. Loss of signal, loss of data and lack of connected devices were described as “scary” from parents, and “worrying” from teens. Our findings show there is a lack of trust in the technology which further contributes to psychological burden of worry, fear, and anxiety. Troubleshooting these failures and navigating risk was an important part of daily diabetes management and technology does not yet seem to currently negate all the psychological and emotional burden. As suggested by Borus and Laffel [2010], unless closed-loop systems are offered and tested on a wider scale, these issues related to burden, and sub-optimal glucose control will continue to be experienced.

Visual displays of for example glucose data on smartphone apps, wearable devices, and insulin pumps were reported as a positive experience related to reliance. The benefit of good display design for glancing at real-time data can provide an opportunity to respond to and treat a life-threatening event (hypoglycaemia or hyperglycaemia) in a timely fashion. Setting alarms on smartphones and using social media to connect with others was shown to be useful.

Nocturnal exercise-induced hypoglycaemia is a frequent fear and concern, and technology can provide a trustworthy alert function which allows parents to sleep better and have peace of mind. However, our data reveals that the technology may not be advanced enough yet to prevent night time risk and parents in our study reported frequent sleep disruption and emotional impact. This continues from existing work which looked at nocturnal hypoglycaemia associated fear [52, 53]. New research suggests a move towards assessing parental sleep disruption as a call for intervention support, showing a clear relationship between T1D management and sleep disruption for both the person living T1D and the parent [54].

5.5.4 ***Reliance & risk***

In relation to diabetes technologies, experiences reported in this study often related to failed glucose sensors, cannulation or injection site failure, and skin issues (allergy to adhesion and adhesion reliability). Insulin pump failures and encroachment on PA were also reported. Co-researchers in our study experienced managing device failures by troubleshooting during, or after PA. There were stories shared which portrayed frustration at device failures and the subsequent failure to be active due to these events. Often the narrative shared expresses emotions in relation to reliance and risk, for example, the adolescent feeling angry. Implications for disruption to play, type, and duration of activity were revealed in our study. There are some similarities in our study to previous research which addresses the type and duration of PA and the barriers associated with use of technologies [55]. Similarities included water exposure, encountering others during activity and adhesion of the devices on the body.

Further interruption to PA through risk as a factor includes alarms, and alerts acting as warnings, and deterrents. Alerts and alarms are intended to offer peace of mind and communication to prevent severe risk. We see from our study however that this deterrent does not always have the desired effect, especially if adolescents are enjoying their activities, do not hear the alerts or alarms or do not want to be interrupted. The technology can in this sense be perceived to be intrusion and can result in ignoring the device or alarms. Adolescents in our study used strong emotive words to describe these interruptions and spoke of feeling “hate”, “angry” and “annoyed” when interrupted by their insulin pump alarms or alerts. Not hearing alarms or avoiding alarms due to fear of exclusion was also reported across our data. This finding aligns with other reports of “alarm fatigue” by Shivers, Mackowiak, Anhalt and Zisser [2013].

In terms of peace of mind versus fear of hypoglycaemia, the key theme of “reliance and risk” captures co-researcher’s varied experiences. On the one hand, experiences of reliance relate to the critical, life-saving aspects of technology (important warnings of alarms) but on the other hand, a strong sense of fear when the technology requires troubleshooting or negatively disrupts daily life.

5.6 Conclusion

The findings of this study highlight health perceptions of the adolescent and their parents, and their emotive, descriptive, ways in which technology supports them to be (or not to be) physically active. Our study showed for example that barriers and facilitators both exists and are often hard to disentangle. For example, feeling grateful for technology but also feeling a sense of burden with current systems. The photovoice process itself led to rich, reflective, meaningful data of individual perspectives and provided empirical knowledge to show significant psychological and socio-technical burden for both adolescents and parents in the management of PA with current technology for T1D.

Our findings demonstrate that current technology does not yet address the complex needs of adolescents living with T1D to enable participation in PA without health risk. We offer the following recommendations based on the findings for how technology can be improved to better support adolescents and their parents/caregivers:

(i) Technologies monitoring diabetes and physical activity need to be more interoperable with each other (e.g., reporting and/or combining accelerometery data and glucose data in one place). Viewing data together, in one place, provides the opportunity to visualise how each data set may affect one another.

(ii) Diabetes and physical activity technologies should seek to incorporate benefits of "hands free" experiences (being able to glance at data easily and quickly while being active).

(iii) Diabetes and physical activity interventions need to facilitate and promote peer support by considering adolescents and parents/caregivers as central, active agents.

(iv) Interventions and technologies for physical activity for people with T1D should provide psycho-educational support for navigating independence for both those living with type 1 diabetes and their parents/caregivers, especially during transition periods.

(v) Criteria for access and choice to usable and accurate technologies (for example, glucose sensing technology with algorithmic dose controlled systems and/or fitness tracking devices) needs to be increased and improved to reduce health inequality and economic pressure on families to self-fund current options.

(vi) Diabetes and physical activity digital educational content should be personalisable to technological choices i.e., pump/CGM/activity tracking, and individual users (adolescent/parent/teacher/coach for example).

(vii) Government need to invest further in multi-disciplinary team approaches to support management of type 1 diabetes and physical activity across the whole of the UK. Multidisciplinary involvement (diabetes specialist nurse, dietician, psychologist, sports therapist/coaches) can offer tailored, person-centred support for adolescents living with type 1 diabetes and their parents/caregivers

Self-reflection and agency provided impact for both our adolescent participants and parent participants during feedback from interview transcripts. The fact that T1D is an invisible condition, with serious impact on quality of life, requires an uncovering of unsaid and undisclosed experiences. In the data, an overall sense of powerlessness of adolescents, in their desire to be independent from parental accompaniment, when outside of the home was noted. Our data also suggests that parents carry practical burdens such as interacting with technology to aim to prevent risk to life for their child, and also to reduce adolescent burden. This insight reduces assumptions surrounding the phrase self-management. Showing that parents/caregivers as co-users are deeply impacted and bring influence on PA engagement and support through the co-use of technology. Parents/caregivers have experiences with that technology creates family tension, fear, and conflict which was reported in the theme describing emotional impact. Our data shows a strong relationship with parental fear and burden to facilitate PA.

We would therefore recommend that family participatory co-design methods should be used more often in the design and development of digital health and wellbeing interventions, to increase agency and inform PA and technology interventions, which are aimed at adolescents living with T1D and their parents/caregivers.

5.7 Chapter summary

This study gathered an in-depth lived experience perspective through visual and text-based narratives of co-researcher’s daily interactions with technology and engagement in PA. The process of generating and then reflecting on both the visual and textual data provided a truly reflective and collaborative process which would not have been possible via other methods such as interview. The construction of data through visual modality evoked an emotional reaction throughout the project for them and for the researchers. Parents and adolescents mentioned during discussions that they had never stopped to think of their situation in this way before.

Visual and narrative data allowed adolescent's and their parents to tell their stories through their photos and their words. Sharing visual data of their technology which is often hidden beneath clothing or hidden due to feelings related to identity gave co-researchers a chance to make their daily lives more visible. Although photovoice can be delivered through postal design toolkits, disposable cameras and paperwork, our study was designed from the outset to be delivered online. We believe this increased engagement and retention in the study for this hard to reach adolescent population (Jarldorn, 2018).

Through these explorations, the participants as co-researchers identified both positive and negative effects of managing PA with technology whilst living with T1D. These factors can be used to form guidance towards a roadmap of future technological considerations and intervention design.

6 Part 3: The Future - Using Design Thinking to co-create recommendations for the preferred future of technology in the support of physical activity for type 1 diabetes

It was evident from study 2 that challenges with PA brought negative emotions to the participants. A picture of risk management and resilience clearly portrayed the need for clinically informed support, to ensure safety and wellbeing, through self-management of T1D before, during, and after PA whilst using technology. However, it was not yet established from study 2 what participants perceptions of trustworthy technology would look like and what changes would benefit their lived experiences with PA. The final study of this PhD thesis aimed to address the exploration of future design criteria of technology in tackling these risks and negative experiences.

6.1 Overview of Study

The aims of this study were to answer the following research questions:

RQ 3.1: What current experiences do adolescents and parents identify as important (both positive and negative), with technology when engaging in physical activity?

RQ 3.2: What do adolescents and parents construct and illustrate as potential design considerations (social and technical) with regards to digital/technology support for engaging in physical activity when living with type 1 diabetes?

An online, interactive, design workshop method was taken as the best-fit approach in line with the research questions as the software allowed for remote working, and online video interviewing with camera/audio on or off:

6.2 Motivation and Background

There is strong evidence for PA improving psychological factors and wellbeing. There is also however a lack of understanding of the role of technology in terms of future change to suit the needs of adolescents who live with T1D, in the support of PA (Aman et al., 2009; Mitchell et al., 2016; H. Quirk, Blake, Tennyson, et al., 2014).

In HCI research, a space for considering participants as co-designers and active participants for informing technological interventions continues to build.

> ‘Recommendations for human-centred design principles and activities throughout the life cycle of computer-based interactive systems. It is intended to be used by those managing design processes, and is concerned with ways in which both hardware and software components of interactive systems can enhance human system interaction’ (International Organisation for Standardisation, 2019).

This study sought to add to this by inviting the participants to use creative and innovative design thinking to illustrate their possible future technology needs (Harper & Aflatoony, 2021; Nunes et al., 2015).

The concept of design thinking in this study facilitates the exploration of meaning of future requirements. This design was formed through iteration from data gathered in studies 1 and 2 which identified unmet needs. This is achieved through identifying what needs to change between present technology and the preferred future technology - in terms of engagement with PA and T1D management.

Engaging youth with collaborative arts-based participatory methods may allow for contextual relevance to youth, which is often missed when adult academics lead studies. Positioning the adolescent and their parents/caregivers as "*insider-experts*", rather that subjects to be studied from an outsider point of view has been shown to have direct and indirect benefits in research and beyond (Jacquez, Vaughn, & Wagner, 2013). Direct benefits include translatable, acceptable, and culturally relevant research for the youth population and indirect benefits include a sense of empowerment and ownership.

Currently, to our knowledge there are no studies which have approached future thinking with adolescents living with T1D in the context of PA behaviours and technology using co-design approaches.

6.3 Methods

This study involved an online design workshop approach through arts-based participatory principles with adolescents living with T1D and their parent/caregiver who is involved in their diabetes management. Data collection was facilitated through a group/collaborative approach with images and text using the whiteboard application MURAL (www.mural.co). MURAL is an online whiteboard and interactive application which allows members to host and facilitate online workshops). Table 6-2 below details the activities involved in each whiteboard session and the title of the whiteboards.

*6.3.1 **Participants, Ethics and Recruitment***

Nine workshops were held over a one-month period with participants who were either adolescents attending without parents (16 years and over) or adolescent and parents together (N=25). Table 6-1 provides a description of the participants.

Table 6-1 Participant descriptions for study 3

Participant description	Adolescent age	N	Workshop Number
Female	18	1	1
Mother & son	12	2	2

Mother & daughter	14	2	2
Mother & son	11	2	3
Mother & daughter	13	2	3
Mother & daughter	13	2	3
Mother & son	11	2	4
Female	17	1	5
Female	16	1	6
Mother & daughter	13	2	6
Mother & son	16	2	7
Mother & son	16	2	7
Mother & daughter	12	2	8
Mother & daughter	15	2	9

Participants were recruited via adverts posted on social media (Twitter and Facebook) from March 31st until May 31st May 2021, until responses met recruitment targets (between 5 (10 people) and 15 families (30 people)). After receiving and reading the advert (via social media and/or by email), interested readers chose to register for the study by clicking an eligibility registration link. Participants were made aware that to take part, they must currently use technology for T1D and/or PA or other and have ready access to online technology (web browsers for the design workshop (internet connected device with trackpad/mouse capabilities installed with Zoom or Microsoft Teams installation). Details of the participant information and recruitment eligibility survey are provided within Appendices. Participants were also made aware of the University of Strathclyde Privacy notice found here Privacy_Notice_Research_Participants_Oct18.pdf (strath.ac.uk) and Ethics ID 1086.

Email confirmation was gathered which then led to a "*welcome*" email with study instructions and a consent form. Participants were asked to read through the digital participant information sheets and consent form to agree/consent to take part by return email or through a message privately delivered to the researcher through social media should they wish to opt-in for the study. Following received consent, a scheduling tool was used to assign a suitable date and time for each participant(s).

6.3.2 ***Workshop methods***

The first MURAL whiteboard activity acted to train the participants in the use of the software and to introduce icebreakers for relationship building. Initial warm up and welcome exercise provided space and time for co-design practices to form - initiating feelings, attitudes, and normative scenarios in which participants explored lived experiences. In MURAL whiteboard activity 2, prompts helped participants understand the research goal which provided motivation for taking part. To facilitate creating constructs of the future, scenarios tools were used in MURAL activity 3 (see Table 6-2).

In previous design thinking workshops, group size recruitment size ranges from between two and six participants (Webster et al., 2015). In a review of a participatory designed study using photovoice in public health, by Catalani and Minkler (2009), no relationship was found between group size and quality of participation.

Table 6-2. Design thinking workshop tasks

	Activity 1 (MURAL board 1)	Activity 2 (MURAL board 2)	Activity 3 (MURAL board 3)
What?	**“Welcome and warm up” –** Introduction to MURAL activity **Time allocated: 20 minutes**	**“Experiences - Bad day Vs Good Day”**: Experience mapping MURAL activity about experiences participants map as “worse day” Vs “perfect day” in terms of PA with T1D and technology. **Time allocated: 30-35 minutes**	**“Room 101”** - MURAL activity (Rose, Thorn, Bud and MoScoW) to illustrate potential features of technology for supporting PA in T1D. **Time allocated: 30-35 minutes**
Why?	To induce engagement and introduce; ice breaker tasks grounding in the research aim.	To help participants to think about their own experiences, open discussion, deepen participants understanding of the driving forces, and connections and relationships between tech interactions, and PA engagement (Current challenges and opportunities) before talking about the future.	Identifying socio-technical needs and requirements for PA engagement in the future (identify what needs to change between the present and the preferred future).

Participants were asked if they understood the task before taking part. Tasks were structured, clear, timed, and interactive (see Table 6-2). Participants were introduced to each task with neutral introductory examples provided by the researcher (the researcher was careful not to introduce bias in this communication). Participants were then invited to replicate these tasks using examples of their own lived experiences, relevant to their realities (with quiet space and prompting from the researcher should they ask for it in the Zoom chat window). Repeat example iterations were included in the session to ease participant's experience. If participants felt they wanted to take on the role of host/mediator or helper other participants, this was valued and encouraged – to help enable equanimity between researcher, parents, and adolescents. This communication was important to allow the participants to share and establish agency, trust, and respect. Participants were treated as experts. Having choice over communication medium (video and audio) was facilitated.

Participants shared their data in a synchronous form with other group members (at the same time). After each task was complete, the researcher summarised the data items using a round table approach to ask questions of the participants input. It was hoped that this reduced interruption and unwarranted domination of participant members.

6.3.3 ***Data Collection***

Participants were invited to attend online, virtual design workshops (via their own laptop or PC devices using either Google Chrome (v.51), Safari (v.9), Firefox (v.46), and Microsoft Edge (v.43). If troubleshooting was required, the researcher offered help and assistance in the use of Zoom and MURAL by email and throughout the online design workshop (Zoom was used to communicate with the researcher).

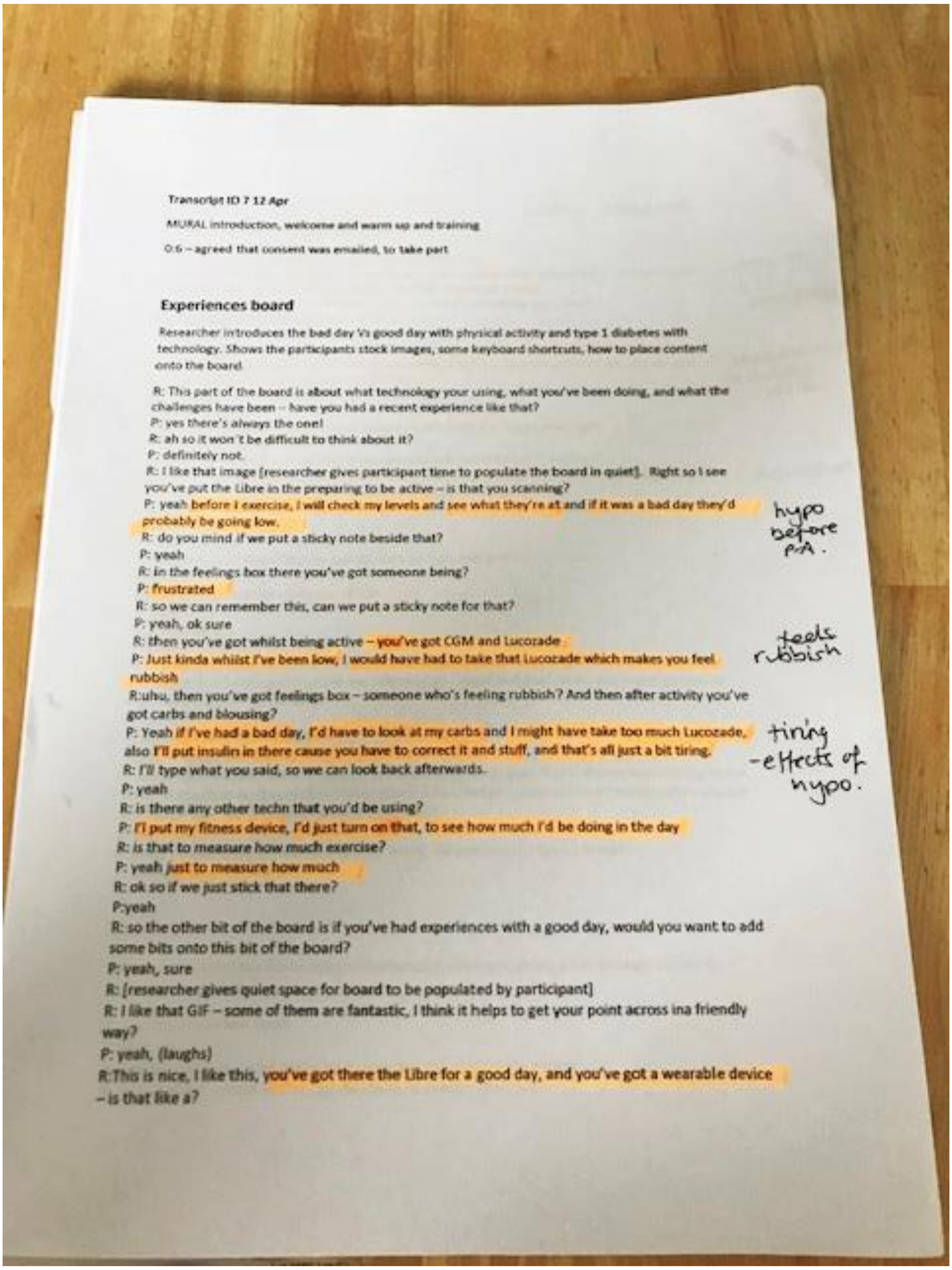
Participants were invited to add post-it notes and/or images to the mural board for each timed task – as trained by the researcher. Investigative questions (see appendix I in study protocol) allowed the researcher to prompt discussion and initiate thought during data collection. A PDF file format of the completed whiteboard was immediately transferred to a secure University password protected server location. Audio discussions (during workshop sessions) were recorded with consent, for transcription. No visual participant video data was captured or recorded, only whiteboard data was imported for analysis (see Figure 6-2 as an example).

Chat function was enabled between researcher and participants for ease of communicating one-to-one, should sensitive issues arise. Participants were not able to use the chat function between each other, for safeguarding. Participants were also made aware that the researcher would be taking written field notes to help with analysis which would not include any personal identifiable information.

Pilot testing with target populations and experienced researchers was conducted. Please see Appendix I for the findings from these pilots and adjustments made to protocol after pilot testing.

6.3.4 ***Data Analysis***

Researcher familiarisation with data included reading and marking data (MURAL board data and interview transcript data) with highlighter pens (see Figure 6-1 and 6-2 for examples).



Transcript ID 7 12 Apr

MURAL introduction, welcome and warm up and training

0:6 – agreed that consent was emailed, to take part

Experiences board

Researcher introduces the bad day Vs good day with physical activity and type 1 diabetes with technology. Shows the participants stock images, some keyboard shortcuts, how to place content onto the board.

R: This part of the board is about what technology your using, what you've been doing, and what the challenges have been – have you had a recent experience like that?
P: yes there's always the one!
R: ah so it won't be difficult to think about it?
P: definitely not.
R: I like that image [researcher gives participant time to populate the board in quiet]. Right so I see you've put the Libre in the preparing to be active – is that you scanning?
P: yeah before I exercise, I will check my levels and see what they're at and if it was a bad day they'd probably be going low.

hypo
before
P.A.

R: do you mind if we put a sticky note beside that?
P: yeah
R: in the feelings box there you've got someone being?
P: frustrated
R: so we can remember this, can we put a sticky note for that?
P: yeah, ok sure
R: then you've got whilst being active – you've got CGM and Lucozade
P: Just kinda whilst I've been low, I would have had to take that Lucozade which makes you feel rubbish

feels
rubbish

R:uhu, then you've got feelings box – someone who's feeling rubbish? And then after activity you've got carbs and blousing?
P: Yeah if I've had a bad day, I'd have to look at my carbs and I might have take too much Lucozade, also I'll put insulin in there cause you have to correct it and stuff, and that's all just a bit tiring.

tiring
-effects of
hypo.

R: I'll type what you said, so we can look back afterwards.
P: yeah
R: is there any other techn that you'd be using?
P: I'l put my fitness device, I'd just turn on that, to see how much I'd be doing in the day
R: is that to measure how much exercise?
P: yeah just to measure how much
R: ok so if we just stick that there?
P:yeah
R: so the other bit of the board is if you've had experiences with a good day, would you want to add some bits onto this bit of the board?
P: yeah, sure
R: [researcher gives quiet space for board to be populated by participant]
R: I like that GIF – some of them are fantastic, I think it helps to get your point across ina friendly way?
P: yeah, (laughs)
R:This is nice, I like this, you've got there the Libre for a good day, and you've got a wearable device – is that like a?

Figure 6-1 - Example of highlighting interview transcript Study 3

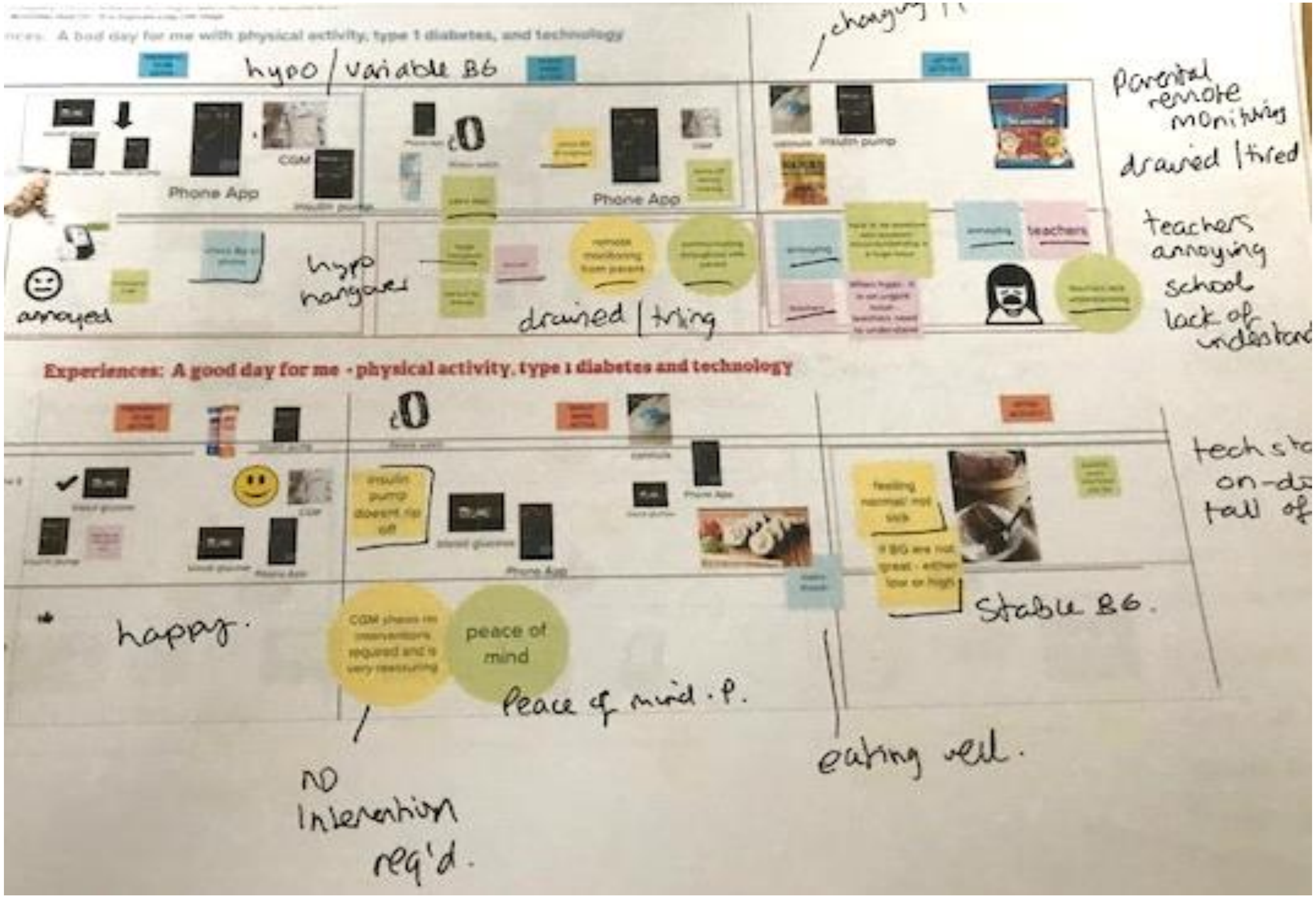


Figure 6-2 - Example of written field notes and data familiarisation (MURAL board 2)

The use of post-it notes to organise data and move interesting, coded items around, into groups for similarities and categories was performed, along with informal note taking (similar to a scientific lab logbook) during interviews (see Figures 6-3 and 6-4 below).

Figure 6-3 examples of coding, categorising, and Bud data familiarisation

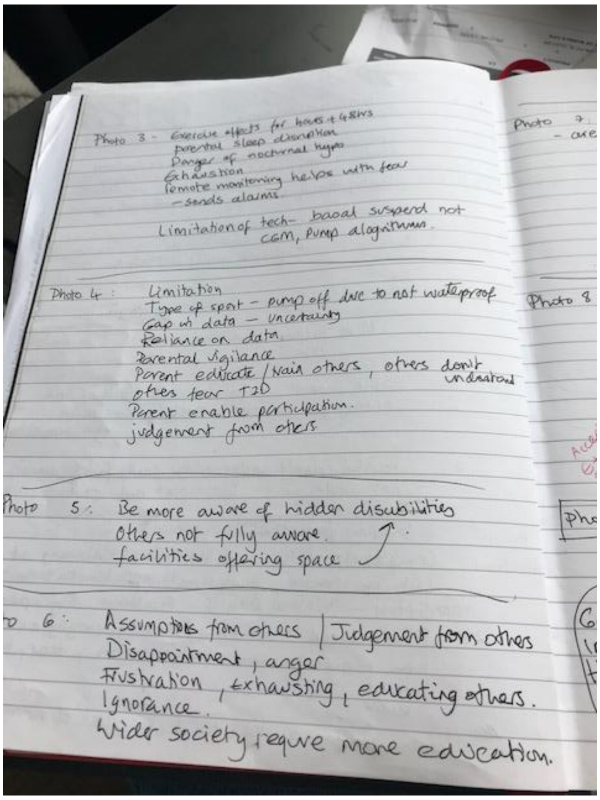


Photo 3 - Exercise effects for hours + 48hrs
parental sleep disruption
Danger of nocturnal hypo
Exhaustion
remote monitoring helps with fear
– sends alarms

Limitation of tech – basal suspend not CGM, pump alogrithms.

Photo 4 : Limitation
Type of sport – pump off due to not waterproof
Gap in data – uncertainty
Reliance on data
Parental vigilance
Parent educate / train others, others don't understand
others fear T2D
Parent enable participation.
judgement from others

Photo 5 : Be more aware of hidden disabilities
Others not fully aware.
facilities offering space

6 : Assumptions from others | Judgement from others
Disappointment, anger
Frustration, exhausting, educating others.
Ignorance.
Wider society require more education.

Photo 7
– are

Photo 8

Figure 6-4 - Example of field notes in logbook

Transcription of verbatim audio interview data was carried out which enabled listening and re-listening (see appendix J for an example transcript). Revisiting the data in several iterations was carried out, with time away for reflection and review. This was conducted until iterations concluded central core concepts in the data, and no new themes were found.

> "*Themes do not passively emerge from either data or coding; they are not 'in' the data, waiting to be identified and retrieved by the researcher. Themes are creative and interpretive stories about the data, produced at the intersection of the researcher's theoretical assumptions, their analytic resources and skill, and the data themselves. Quality reflexive TA is not about following procedures 'correctly' (or about 'accurate' and 'reliable' coding, or achieving consensus between coders), but about the researcher's reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process*." (Braun and Clarke 2019)

During first cycle data coding in response to RQ 3.1 the underlying ideology was concerned with – *what is this data about*? Notes and characterisations of the data followed this line of interpretation. During second cycle data coding in response to RQ 3.1 the underlying ideology focused on the latent meaning in the data - *is it possible to categorise the initial codes*? Finally, third cycle data processing and coding in response to RQ 3.1 was directed by the underlying ideology – Can *I look for patterns and relationships within all categories, to determine if a central concept is driving the data into a higher-level theme*?

6.4 Findings

Out of 88 responses to the recruitment survey, 25 people were recruited after agreeing by email to take part (see Table 6-2). Thematic analysis of the data generated themes relating to MURAL boards 2 and 3. Each MURAL board was thematically analysed to answer each of the research aims as shown below. Results are reported in the order of these research aims.

(i) To understand what adolescents (and their parents) identify as positive and negative experiences with technology for engaging with PA when living with type 1 diabetes.

(ii) To identify and articulate a clear set of recommendations for the future design and meaningful use of future technologies for engaging with PA for adolescents living with type 1 diabetes.

6.4.1 ***Results in respect of research aim (i)***

MURAL board 1 was designed to train the participants in the use of the software. No data was collected for analysis from this board. MURAL board 2 *"Experiences - Bad day Vs Good Day*", included data for analysis in relation to the research aim (i). Analysis of the practical steps and interactions with technology, populated by the participants on the MURAL boards generated interpretation of the data to construct the following 5 themes. These themes led to greater understanding of positive and negative lived experiences with current technology for engaging with PA:

- Theme 1: Wearable factors
- Theme 2: Social acceptance & identity
- Theme 3: Negative emotions
- Theme 4: Glycaemic stability offers positive emotions and PA enjoyment
- Theme 5: Presence, preparation & prevention

In the following sections, images from MURAL board 2 *"Experiences - Bad day Vs Good Day*", will be provided to allow visual representation of the data. These figures will be aligned with the 5 key themes stated above. Audio transcript excerpts are provided to offer deeper meaning, as participants spoke with the researcher whilst adding content onto the whiteboard.

6.4.1.1 Theme 1: Wearable Factors.

One of the key themes related to effects of **Wearable Factors**. Narrative in the example provided by mother and son aged 11, diagnosed at age 4 (typed on post-it note by participants) shows images in reference to wearing technology, in respect to cannula issues "*dodgy cannula*", and the impending glycaemic variation due to this wearable device (see excerpt below from a mother and son dyad).

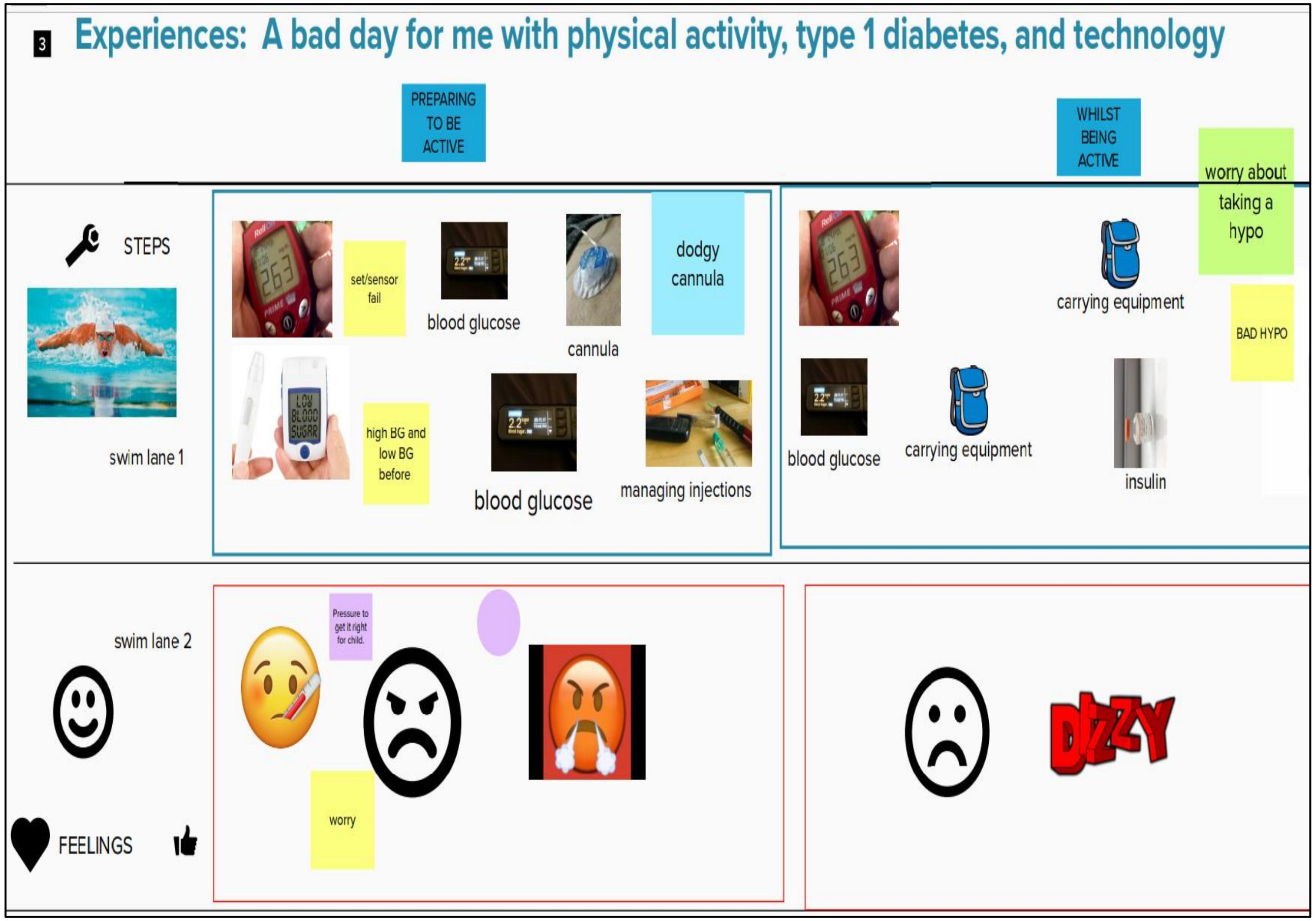


Figure 6-5. Theme 1 - wearable factors

Audio excerpt:

> “we’ve had a few dodgy cannulas going into swimming pools, coming off and issues with that …Tired because even highs do the same thing as well, because he’s been active, and maybe there’s a treatment and then he’s high and then he gets grumpy (asks teen – teen agrees). So, there can be definite mood changes as well. And yeah, definitely at night time like what [anon] said, then you’re left maybe 24 / 48 hours afterwards then you’re left having to deal with the consequences of that technology and that exercise. So, you end up having to put on temp basals during the day and it changes everything really, and you’re having to try and figure out everything the next day and what’s going to happen with it all” ID15.

6.4.1.2 Theme 2: Social Acceptance & identity.

Another key theme of the MURAL board “*Experiences - Bad day Vs Good Day*” was generated as **Social Acceptance & Identity**. The excerpt below show’s data from a female, age 18, diagnosed at age 16. Populating the board was performed with periods of engagement with the researcher to discuss post-it notes and visual data. This participant spoke centrally about social factors which pointed towards feelings of awkwardness and acceptance. As the participant moved around the board, populating areas, the researcher discussed this theme. Audio transcript, supplements this data by providing richer meaning, as shown in the excerpt below:

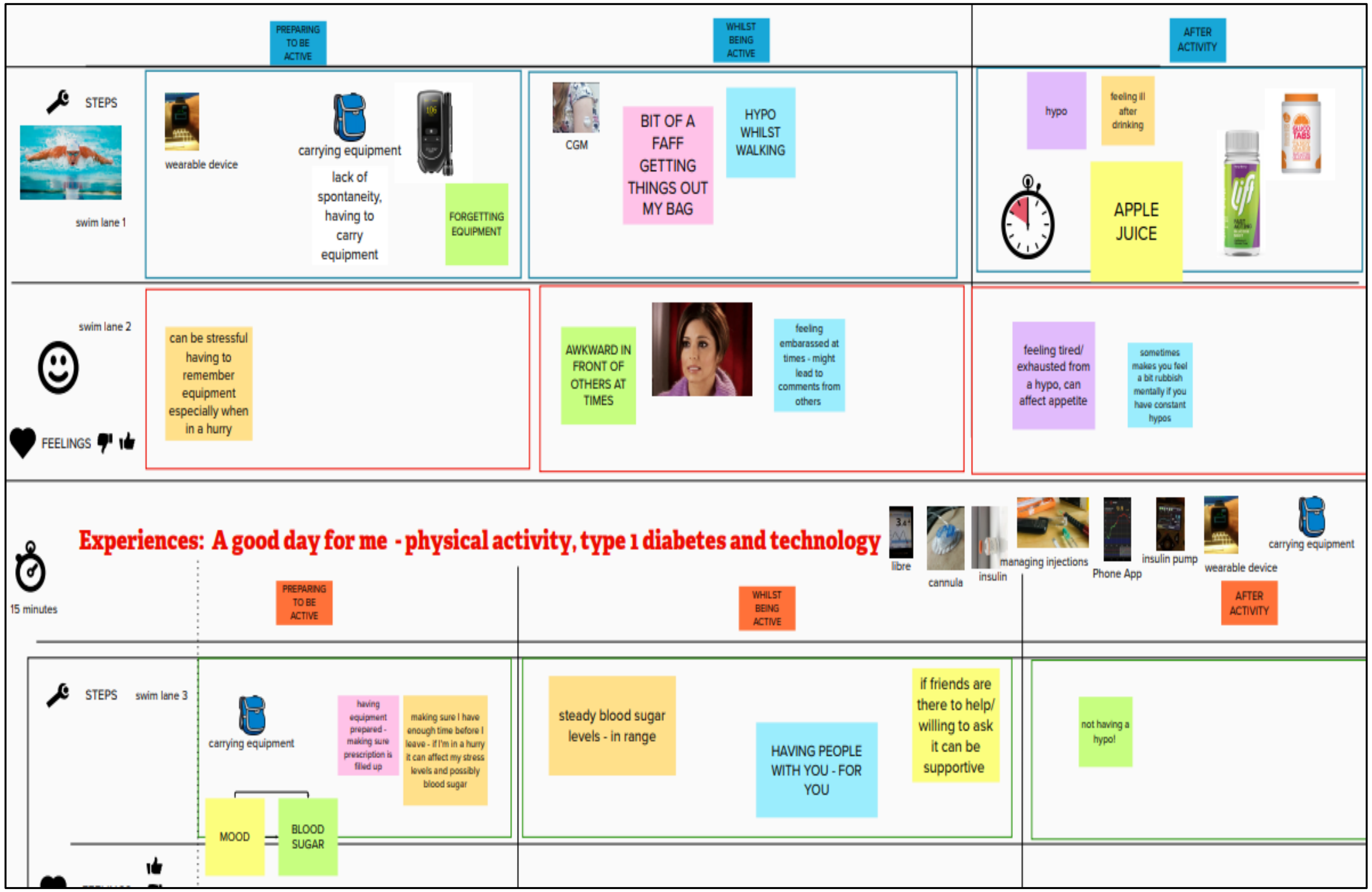


Figure 6-6. Theme 2 - Social acceptance & identity

Audio excerpt:

> "It's so irritating… sometimes when I'm at college I'm getting my pen and it's fiddly and I'm trying to inject under the table, I don't want everyone to look, if I'm in a lecture, I don't want to be the centre of attention. Also, if I'm wearing a long sleeve t-shirt, I have to do my belly. It's awkward to inject. You get to college, and you've realised you're wearing tights and long sleeves and there's nowhere to inject and it's so awkward" ID16

6.4.1.3 Theme 3: Negative emotions.

On the Bad day area of the MURAL board "*Experiences - Bad day Vs Good Day*", a key theme of **Negative emotions** captured data relating to visual images supplemented with post-it note data referring to emotion language such as "*grumpy, frustrated, annoyed, stressful*" etc. A male participant aged 13, diagnosed at age 10, provided data in the following excerpt. Experiences related to using smartphone apps, scanning glucose using Freestyle Libre, and carrying equipment are shown. In this example, parent and adolescent discussed populating the board together, with privacy from the researcher, without microphone. Once they felt they had completed the task, they chose to switch on the microphone. This was to allow privacy, and agency. The audio transcript below is taken from the parent's voice, acting to represent their joint "offline" collaborative discussions:

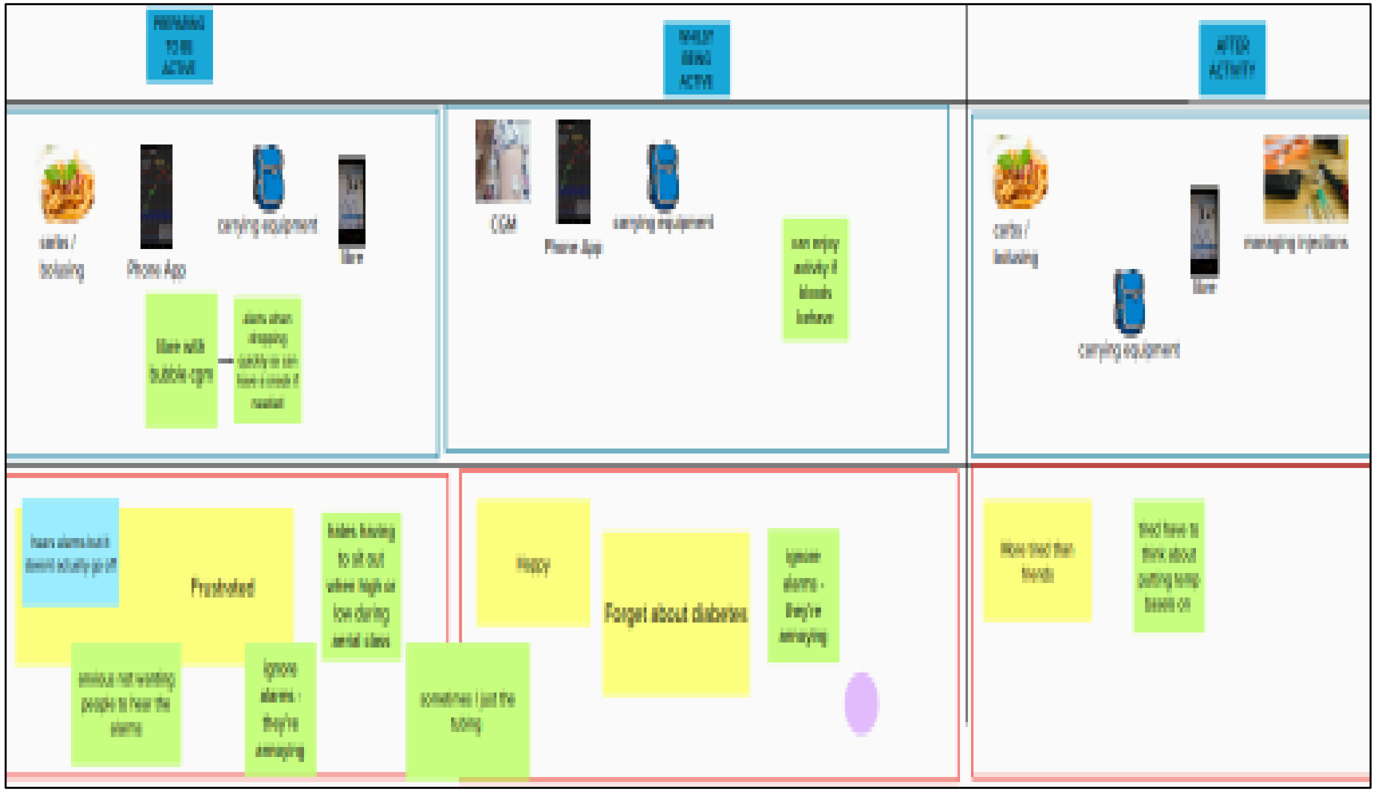


Figure 6-7. Theme 3 - Negative emotions

Audio excerpt:

> P11: (Parent) I actually found that quite interesting talking with H there. I thought he was being objectionable, but he really wasn't (laughs). So, he always has to have the equipment on him and do the carbs before and after and all that stuff, but when he was talking about his feelings he's fed up before he does any exercise because he knows he needs to prepare and for what he's going to do." ID11

6.4.1.4 Theme 4: Glycaemic stability offers positive emotions and PA enjoyment.

When discussing experiences as "good and bad", participants often reflected that the comparison, for them, between good and bad relates to stability of blood glucose. The key theme constructed from data relating to this is titled **Glycaemic stability offers positive emotions and PA enjoyment**. The following example is provided by a female participant aged 12, diagnosed at age 7 years.

Happiness in this excerpt is often experienced before PA. The participant wanted to show that on a bad day, they start off feeling "happy" – in relation to their love of PA. However, as the day progresses, the participant offers data relating to a decline in mood, blood glucose variability and negative emotions. Moving onto the good day area of the whiteboard, this participant (and many others) populated post-it notes and images to suggest happiness, restfulness, and peace of mind all in relation to stable blood glucose. The audio transcription again offers deeper context to this excerpt (see below):

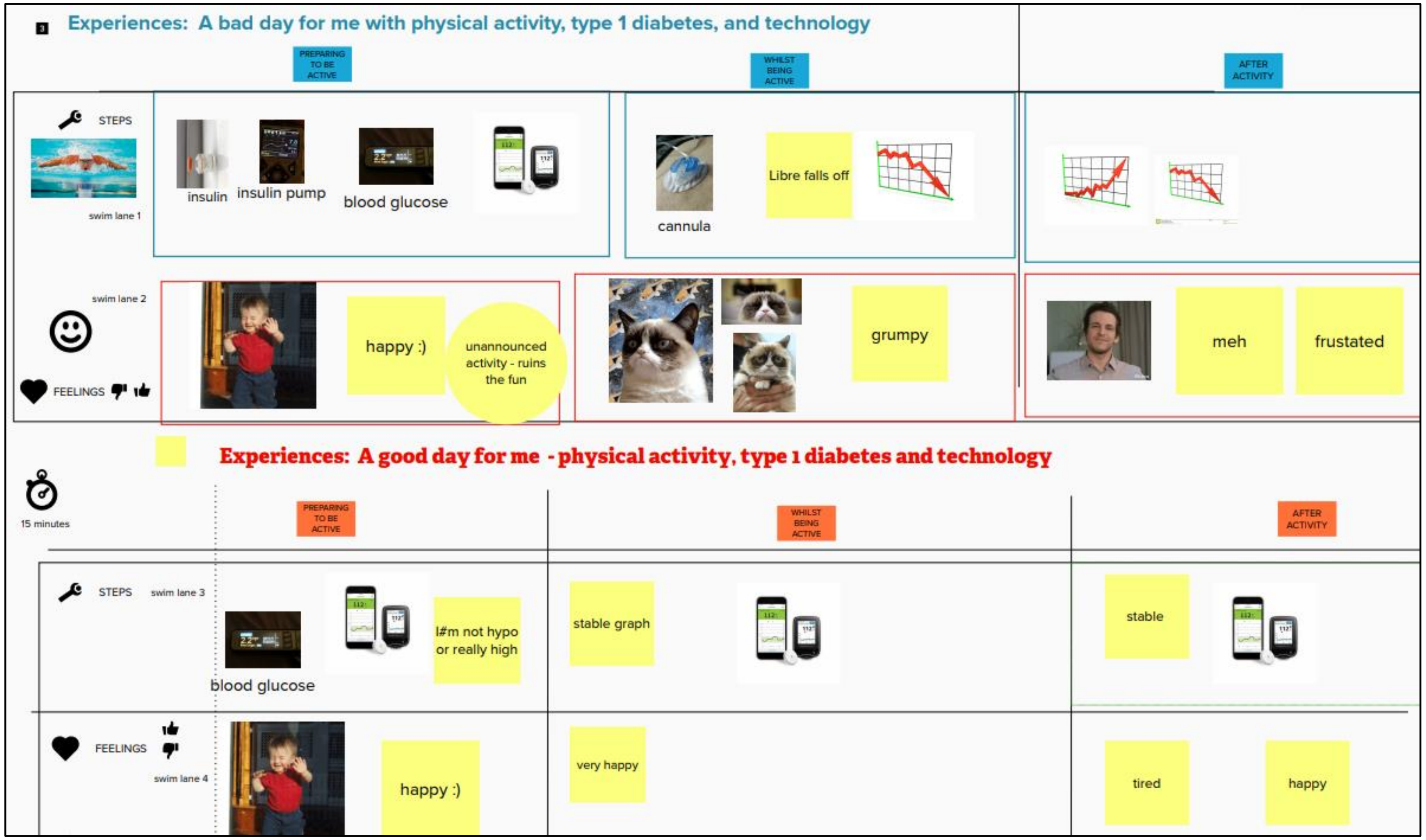


Figure 6-8. Theme 4 Glycaemic stability offers positive emotions and PA enjoyment

Audio excerpt:

> "P:(teen) So I enjoy being active! I usually have lunch first, then I have activity. I might be that my insulin set falls off, and the Libre falls (sighs) and then I go hypo, and then afterwards, I go up. Be then I go back down.
>
> R: I think from the board, you start off feeling quite happy? because you told me you enjoy being active?
>
> P: that is accurate
>
> R: anything that you want to say about that as well, mum do you want to add anything?
>
> P: (mum) no I feel that's accurate, normally all our sporty mishaps have been when there's been too much active insulin on board, so it's that unannounced activity, it's that, jumping on a trampoline at a friend's house or whatever erm that just sets things, and it kinda ruins the fun because it's, yeah, it ruins the fun." [ID29].

6.4.1.5 Theme 5: Presence, preparation & prevention.

The final theme came from looking across the data set and represents language of this participant (female aged 17, diagnosed at age 5). A sense of instances in predicting, preventing, and being organised with practical aspects of managing the effects of PA on glycaemia were presented. Therefore, the key theme of Presence, preparation & prevention was generated. Participants reflected on being prepared, and shared experiences of the paradoxical effects of not being prepared. As shown in the excerpt below in Figure 6-5, when PA is unannounced or spontaneous, the participants experienced negative emotions, and felt a sense of greater glucose variability. In the excerpt below, the participant speaks of the frustration felt on a bad day when spontaneity and a lack of present awareness to reduce dose is experienced. The data further explains provides evidence of positive emotional experiences when participants felt able to be present and prepared for PA.

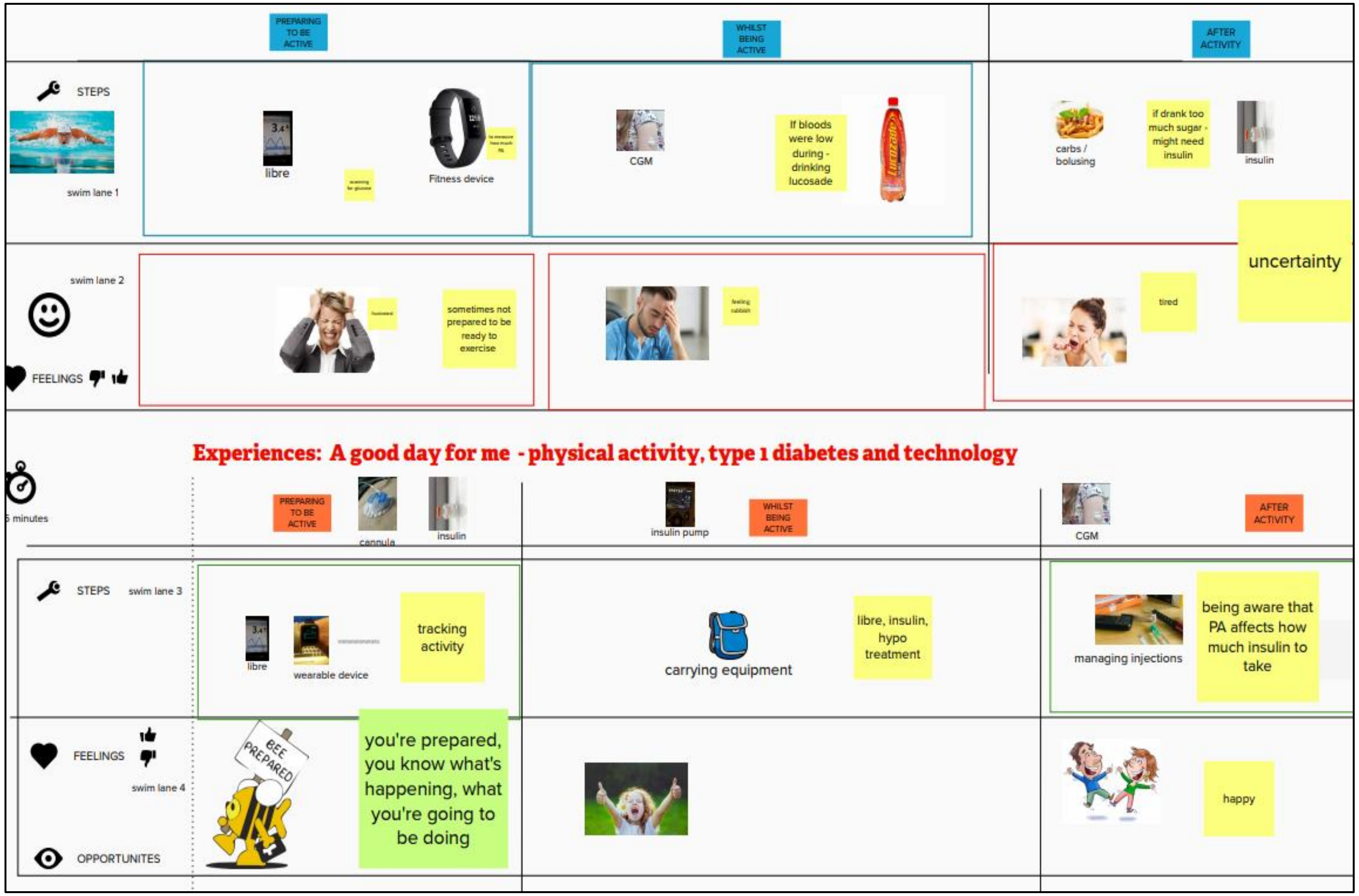


Figure 6-9. Theme 5 Presence, preparation & prevention

Audio excerpt:

> "P: probably that if you've done exercise that you have awareness to not take as much insulin because on a bad day you might have dismissed it, or not realised the effect of exercise on your bloods, and you've not decreased the insulin, because you didn't have awareness.
>
> R: being aware PA affects how much insulin to take? Are you happy with that?
>
> P: I'm happy with that yeah.
>
> R: I'm wondering if there's anything you want to talk about before moving on?
>
> P: Just like to say if you're prepared, you know what kind of activities you're going to be doing, so you know how to prepare, that's a good day and you can judge it" [ID7].

6.4.2 ***Results in respect of research aim (ii)***

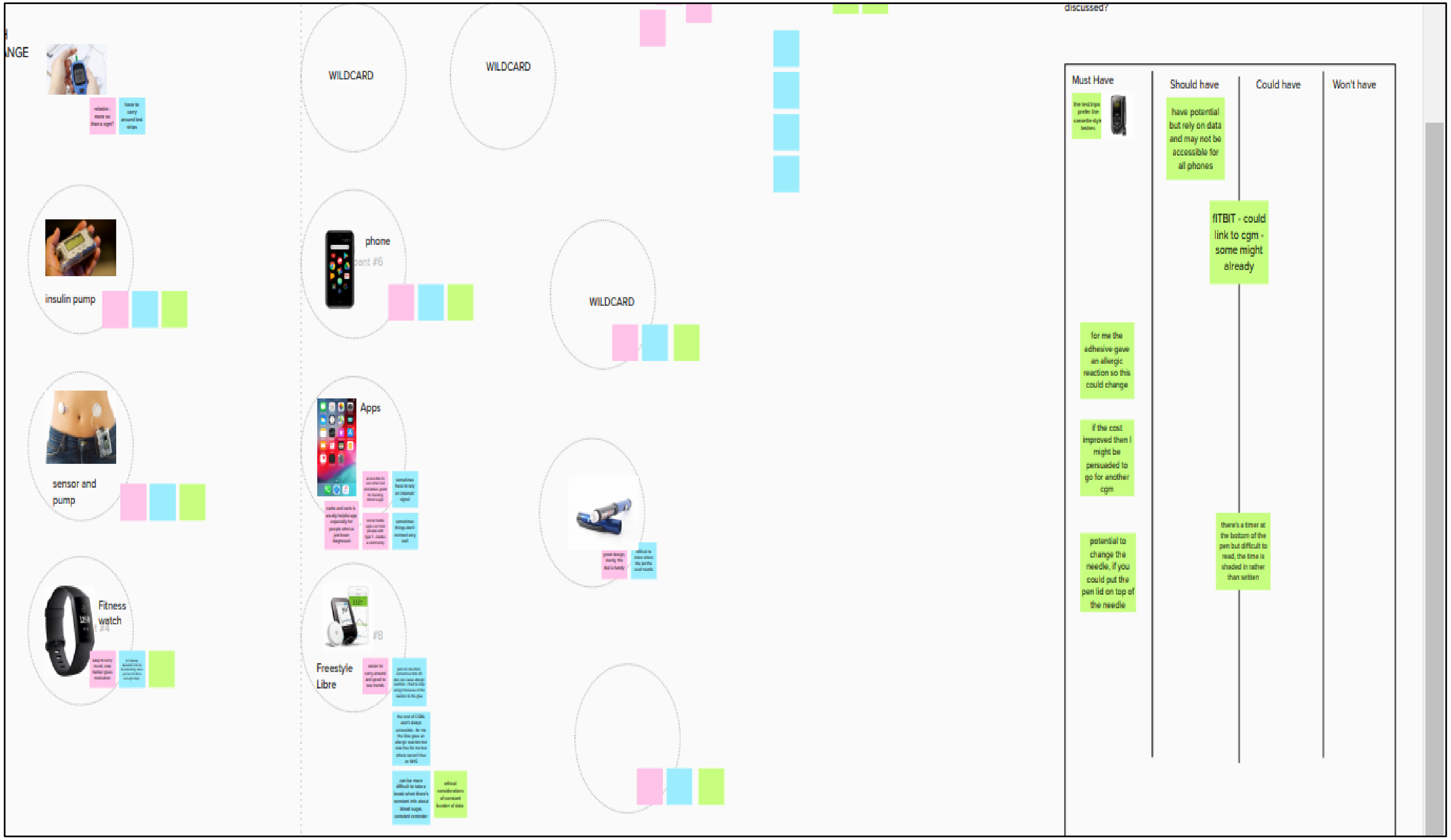
To respond to research aim (ii), thematic analysis was performed of the data presented by participants when populating the "**Room 101**" whiteboard (MURAL 3 activity). Rose data was written on pink post-it notes, thorn data on blue post-it notes and bud data on green. Rose portrayed positive aspects of technology, Thorn a negative experience of technology and bud, an aspect of technology for change. Figure 6-6 shows an example of a MURAL board with the rose, thorn and bud post-it-notes aligned next to common technology images. A complete table of all data is provided in Appendix J, which gives full details of all Rose, Thorn, and Bud data.

Prioritisation of data was performed by participants, using moving Bud data to the MoSCoW tool (dragging post-it notes) on the far right of the MURAL board, as shown in an example below (https://conceptboard.com/blog/moscow-prioritization-method-template/). Thematic analysis of all Bud data constructed

5 key themes. These themes are reported below with additional transcript data taken from audio recordings of the remote, virtual design workshops.

- Theme 6: Improve attachment experiences
- Theme 7: Connected devices reduces user burden
- Theme 8: Improve accuracy
- Theme 9: Personalisation of devices
- Theme 10: Funding and policy changes – health equity

The image below (Figure 6-6) is provided to give an idea of the scale of the area of the whiteboard in MURAL activity board 3 “Room 101”, showing the placement of all post-it note data beside images of common types of technology used by participants. New images of technology could be added onto the board labelled as a “Wildcard” area of the board. In this introductory example, this participant has populated the areas of the board relevant to their experience and then moved their Bud data to the MoSCoW area of the board before completion of the task.



reliable - more so than a cgm?

have to carry around test strips

have potential but rely on data and may not be accessible for all phones

fITBIT - could link to cgm - some might already

for me the adhesive gave an allergic reaction so this could change

if the cost improved then I might be persuaded to go for another cgm

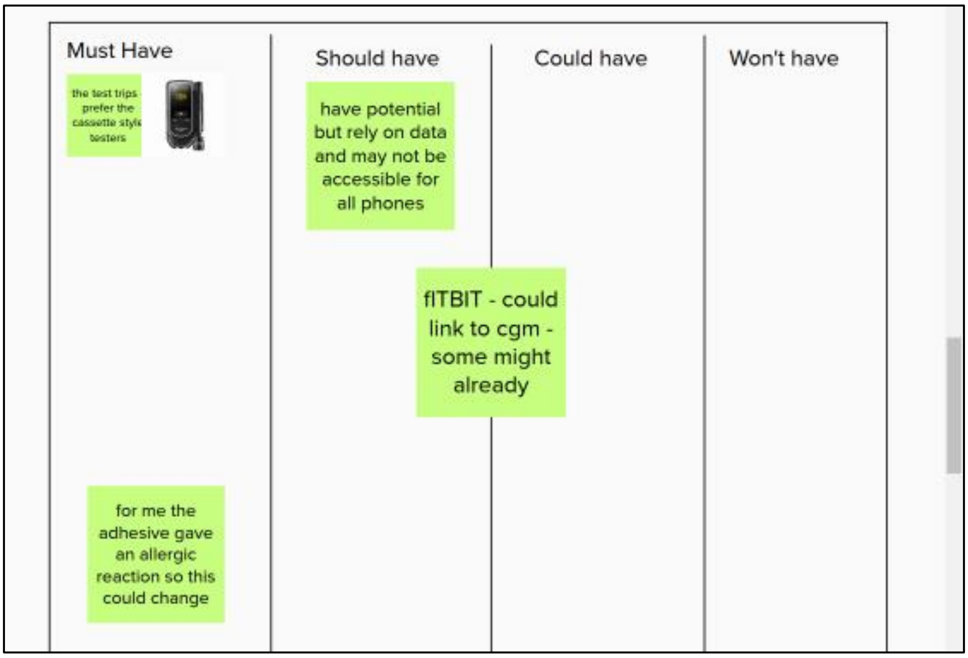
potential to change the needle, if you could put the pen lid on top of the needle

there's a timer at the bottom of the pen but difficult to read, the time is shaded in rather than written

Figure 6-10. An example of a populated MURAL board 3: "Room 101" showing the layout of images and post-it notes

6.4.2.1 Theme 6: Improve attachment experiences

In prioritising data by moving Bud (green post-it notes) to the MoSCoW area of the MURAL board, participants were able to represent their perceived greatest need for changes to technologies of their choice, through their lived experiences. Many participants experienced barriers related to "wearable factors" as described in section 6.5.3.1. Regarding wearable factors, this participant expressed a desire for the adhesive to be changed on the Freestyle Libre device, to prevent allergy. Many other participants reported issues related to skin experiences and attaching devices in-situ. This data became the foundation for the theme **Improve attachment experiences**. In audio transcript, it was shown that this barrier caused a following disengagement with technology due to skin irritation (see below):



the test trips prefer the cassette styl testers

have potential but rely on data and may not be accessible for all phones

fITBIT - could link to cgm - some might already

for me the adhesive gave an allergic reaction so this could change

Figure 6-11.Theme 6 Improve attachment experiences

Audio excerpt:

> "P: … I had the Libre for a few months, and it was fine, but I started to get an allergic reaction to the adhesive, so I had to stop using it, which was so annoying, and it was a really bad allergic reaction – like my skin was so bad. And then I tried again a couple of months ago and the same thing happened, which is so annoying, and it was pain because I almost had a taste of like, how good it was and how easy it was and then

> they were like “no you can’t have it because of how allergic I got with it” which was understandable but really annoying at the same time, but
>
> R: So, think in terms of the green square do you want to put in anything about the adhesive?
>
> P: F or me it was really frustrating because I didn’t have to pay anything on the NHS but all the other ones I would have to pay for and obviously for me they weren’t really, I don’t have the money every month for the Dexcom, but the only one available on the NHS is the one that I can’t use. Because it’s gonna be like a massive rash on my arm” [ID16]

6.4.2.2 Theme 7: Connected devices reduces user burden

Data from these patterns of experiences provided evidence for barriers stemming from perceived interactions with fragmented devices (many different devices performing different tasks). There were reports of technology that currently exists to offer a streamlined experience. However, participants felt this area for development requires improvement in connectivity. Participants spoke of the connection of devices in terms of reducing burden or making their lives easier. Out of the 25 people who took part, only 2 participants currently use a closed-loop system with insulin pump and algorithmically controlled glucose sensing device. However, these participants wished to comment on changes they still feel requires attention and change.

The following example shows evidence of the need for post-workshop member checking. This workshop involved three families. After the workshop, one member emailed to say they didn’t feel they managed to communicate enough and wished to add data. From the example shown, the data shows a clear wish for connected device consideration. The email communication (post-workshop) is provided, as well as audio transcript data:

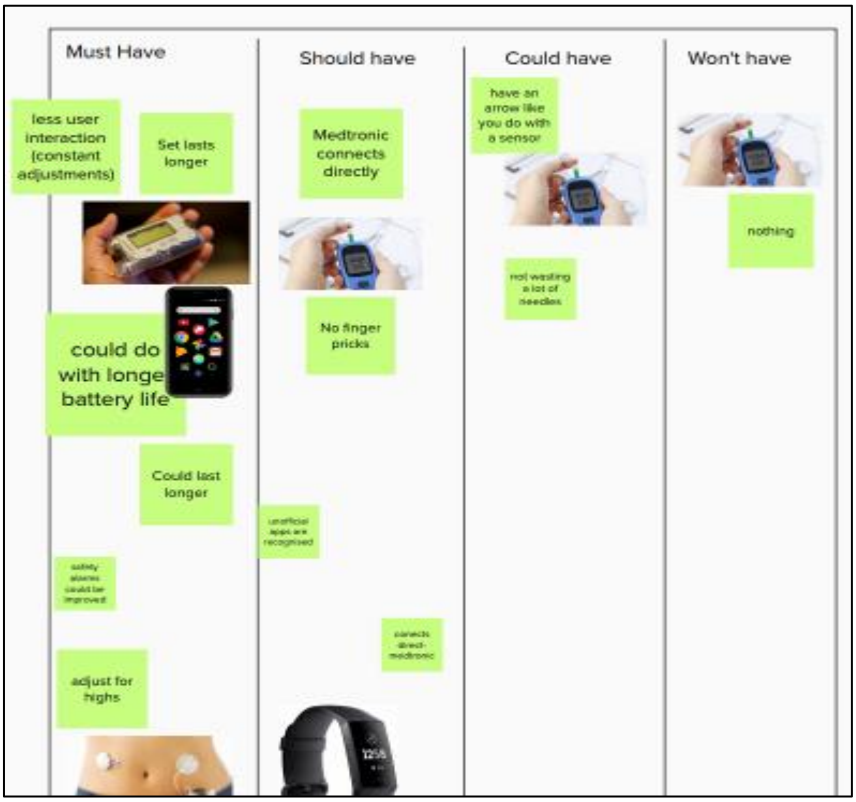


Figure 6-12. Theme 7 Connected devices reduces user burden

Audio excerpt:

> “R: who put “less user interaction”?
>
> P: that was us – we were talking about insulin pumps – we were saying they’re good but they still do need a lot of, they need a lot of input and interactions from the users and erm in an ideal world we would love something like the iLET which requires less user interaction, from our side, erm cause even with an insulin pump, you’re constantly having to make adjustments, constantly having to enter carbs and connect with other things “ [ID15]

Email excerpt [ID15]:

> “Hi Diane,
>
> See below further comments that we would like to add to the ROOM 101 section:
>
> *Insulin Pump:*
>
> Bud; Could do with improved alarms and better connectivity with apps

> Bud; Could be more discrete and more stylish
>
> Bud: battery life and cannula life should be extended
>
> *Sensor and Pump:*
>
> Thorn: blue tooth technology can be prone to connectivity issues
>
> Thorn: sensors can fail
>
> Thorn: sensors and sets cause pain on insertion
>
> Thorn: medical tape on sensors can cause skin rash
>
> Bud: closed loop technology has the potential to create a true artificial pancreas
>
> Bud: Smart Algorithms for blood sugar control and app connectivity could be improved
>
> Bud: sensor and cannula lifetime could be improved"

6.4.2.3 Theme 8: Improve accuracy

Participants who were using technology to quantify and communicate blood glucose levels found current technology to be inaccurate. Some participants prioritised this data as a "Must have" change using the MoSCoW tool. The theme **Improve accuracy** reports the felt sense that, although there is a range of glucose sensing devices, without connectivity features (to other devices) and trust, participants were still reverting to finger prick blood test using a blood glucose meter (glucometer). This relates to MURAL whiteboard 2 "*Experiences – Bad day Vs Good day*" data where participants spoke of carrying equipment. On-skin technology, without accuracy, requires carrying equipment around to have a sense of trustworthy, fall-back options, when accuracy is compromised. Furthermore, this data also highlights a relationship between accuracy and negative emotions such as frustration and annoyance, as shown in the audio excerpt below which accompanies Figure 6-9.

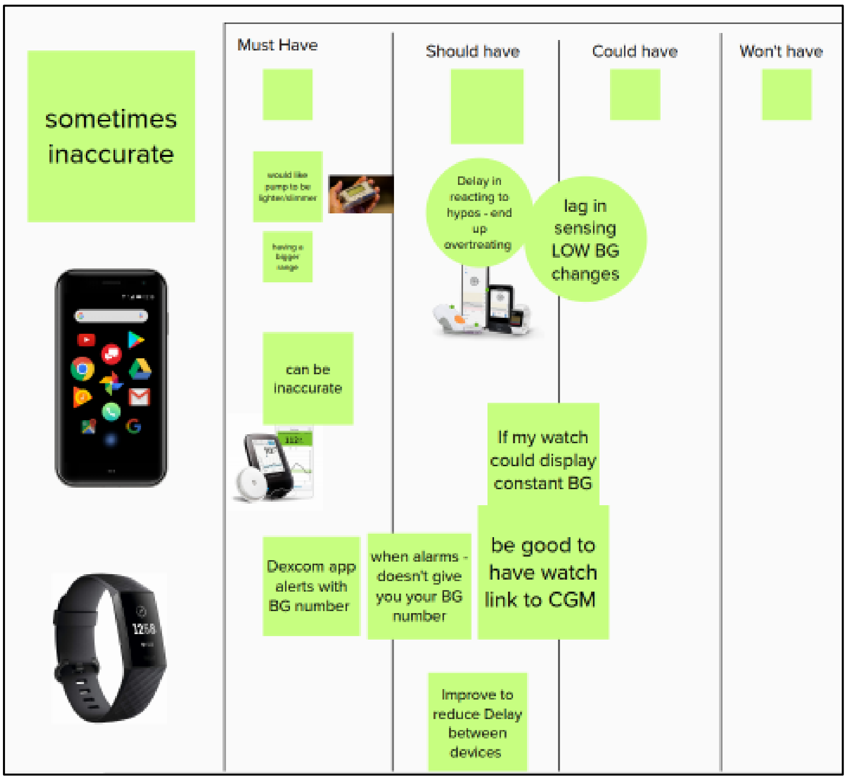


Figure 6-13. Theme 8 Improve accuracy

Audio excerpt:

> "P: Sometimes they'll show me I'm low and I'm not actually though, I'm like 5.0, I mean it's annoying, they're really good for a general sense of direction but, I still have to do a blood test." [ID6]

6.4.2.4 *Theme 9: Personalisation of devices*

After sharing Rose and Thorn data, many participants pointed towards making a change to visual, sound, and alert functions of current technology. This created the basis for the theme **Personalisation of devices**. Descriptions of changing the size and weight were also reported "*smaller and tubeless (pump)*" [ID40]; "*would like pumps to be slimmer*" [ID6]; "*make volume louder and connect by Bluetooth (BGM); if it was significantly smaller, he would think about it (Pump); …carrying about heavy tech, needs to be lighter (pumps)*" [ID11]. These were found to be personalisable attributes which appeared to be individual when looking across the data. For example, participants who used insulin pens offered data about changing the needle guard shape to accommodate the insulin pen lid when travelling or storing the pen in their bags. For others, personalisable attributes related to technology which vibrates, alerts, and prompts were shared. In the example below data from a female participant aged 15, diagnosed at age 10, the data shows a desire for a change to a specific type of insulin pump. This pump was chosen because it was smaller than other pumps on the market. The participants expressed a feeling that it lacks important functions which causes the participant considerable effort each day “*bolus calculator not on pump and takes longer to work out for food correction - would be good to have this on the pump (pump)”* [ID20]. In relation to MURAL board 2 “experiences – Bad day Vs good day” participants often mentioned the need to carry equipment around and social factors related to acceptance and identity. Personalisation often referred to volume, colour and the effects of technology making diabetes more visible to others, as would carrying around medical equipment during PA.

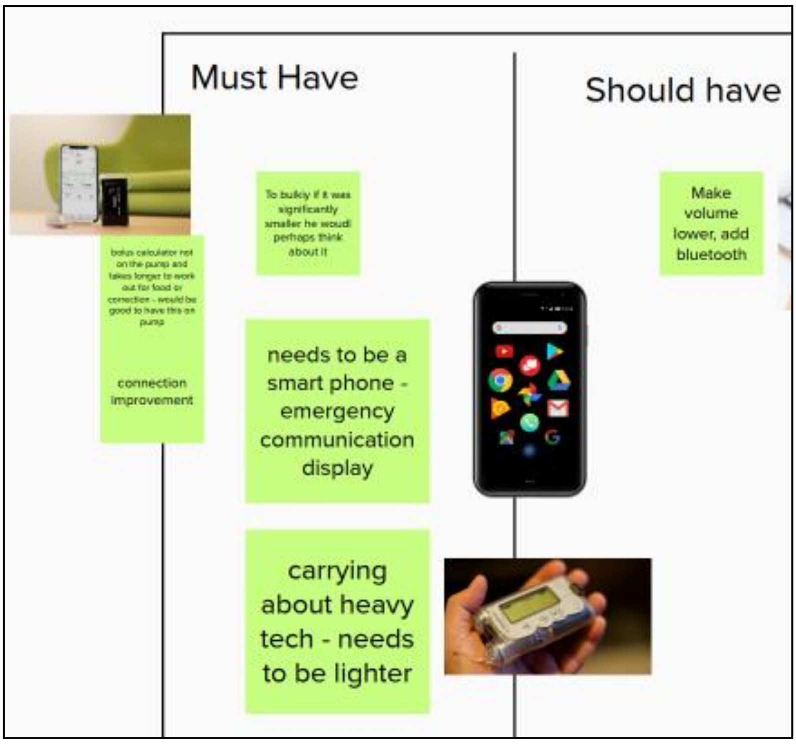


Figure 6-14. Theme 9 Personalisation of devices

Audio excerpt:

> “The annoying thing about that pump is that fact that she’s got to have her phone to type in carbs which is annoying, you know, if she was able to do boluses without

> having to, like she has to work it out on the phone but then has to type it out into the pump – yeah it's the bolus calculator" [ID11].

6.4.2.5 Theme 10: Funding and policy changes – health equity

Data representing participants access to technology, and improvements to cost of current options contributed to the generation of the final theme **Funding and policy changes – health equity**. The example shown in figure 6-11 was populated by two families of male adolescents aged 16. Both parents and adolescents contributed to the MURAL board with data which reflected cost implications for funding technology.

Looking at announced G7 - considerably smaller and less complex. Accuracy issues and irritation unknown

Regular insulin - fits our meal profile better, but is difficult to get

waiting on an upgrade

If PIP would be offered to young people it would help them fund their technology

Better support for cgm technology, limited by price

More access to answering messages as it has limited functions. Reliable alarms on the watch such as vibrations

Wanting an upgrade to dexcom

Libre could link with pump

government policy should change to allow hybrid closed loop

would really like a CGM that connected to my pump

hybrid closed loop should be funded

continuous CGM connection

would prefer a CGM

would self fund but when teen becomes independant - the cost may be a burden. Also got to fight for others

Perhaps improvements in links to other functions, for example direct access of data between cgm and meteer

my phone for watch to have b.g. reading

not really needed now as i am on a pump

Figure 6-15. Theme 10 Funding and policy changes – health equity

This workshop recording was unsuccessful. However, researcher field notes captured both families desire to have government offer financial aid or change current policy and medical criteria to offer continuous glucose monitoring on prescription, which is currently limited to strict NICE criteria. The researcher took note that both families felt emotionally negative about access to technology currently. One parent expressed her current role in participating with contacting NHS CEO board members and parliamentary figures to advocate for her son and others, with the support of a family group in her local area.

Based on the above themes, and the interactions described by participants, we challenge assumptions and align with current evidence in literature, by unpicking richer meaning surrounding PA and the role of technology in the following discussion.

6.5 Discussion

Throughout this study it was the researcher's intention to build community engagement by inviting participants to discuss their future potential through self-reflection and co-design methods to explore health choices with technology to support PA in T1D. Building a bridge between academia and the online community for those living with T1D was explored with scenario development using the online design workshops in this current study.

Design thinking tools such as maps, and diagrams are key to developing understanding between the researcher and the participants. The diagrams helped to stimulate conversation, using visual prompts to define complexities, support language, and overcome barriers for free discussion. This reduced tension and eased the development of online relations while using the whiteboard tool.

A discussion of the themes gathered from each MURAL board activity will now be provided. In MURAL board 2 "*Experiences - Bad day Vs Good Day*" –data was populated by participants in distinct temporal stages during a day – "*before activity", "during activity" and "after activity*". This helped the participants to identify when events related to technology and PA were happening for them in their daily experiences. Since the technology acts to relay, predict, communicate, and intervene with T1D based on time, the board was designed to identify timing of PA.

6.5.1 ***Wearable factors***

Participant's data reflected interacting with technology, which is sometimes worn on the skin, and carried in backpacks when out of the house. Frequent mentions of carrying around equipment and wearing technology physically on the skin produced factors involving skin irritation, pain, adhesion issues and visibility of diabetes. Often participant's experiences on a bad day reported frequent, heavy interaction, with a narrative reflecting a sense of overwhelm and constant demand. Paradoxically, on a good day, participants reported less interaction with technology felt like a positive experience. This data was interpreted to reflect similarities known in research topics such as alarm fatigue, user burden and diabetes distress (Hagger, 2018; Messer et al., 2020; Shivers, Mackowiak, Anhalt, & Zisser, 2013)

6.5.2 ***Social acceptance & identity***

Experiences related to unwanted curiosity or attention from others was discussed when using diabetes related technology. Often this was mentioned in the 'Bad day' area of MURAL board 3, using language typed onto post-it notes images with text. However, audio support to elaborate on interesting data items gave deeper insight, as shown in the examples provided. Discretion of devices and choices to scan and view data on Smartphone was one way in which adolescents felt they could cope with technology interactions which they perceived affected their identity. This area is predominantly new in the research literature and could offer an interesting space to develop positive body experiences with a view to understanding ways to build comfort, and confidence in social settings. For adolescents to explore identity, participatory approaches such as sketching and drawing have been approached previously in research (Webster et al., 2015). These were adapted in this current study using MURAL whiteboard image selection and placement functions (Liesch & Elertson, 2019)

6.5.3 ***Negative emotions***

It is well documented in literature that diabetes distress, depression, and low mood occurs for the adolescent population living with T1D (Hagger et al., 2018). The data in this study, provides further adolescent and parental specific data with the added context of the role of technology in these emotions when PA occurs. A discussion surrounding the predictive behaviours which lead to frustration, (when an expectation that technology will be reliable and trustworthy does not occur) became apparent from the participants in this study. The agency of the technology in causing negative emotions captures a complex nature when engaged in PA while living with T1D. Examples of this agency are concerned with troubleshooting technical issues and interruption when having fun or impeding PA. Agency can also be seen as possible causable factors in creating negative emotions experienced through unwanted attention from others.

6.5.4 ***Glycaemic stability offers positive emotions and PA enjoyment***

After disclosing what a bad day looked like, participants offered a comparison when they perceived they had a ‘good day’ with PA and technology. Often this portrayed happiness, positive emotions and many post-it notes with the words “stable BG” or “bloods were stable”. This gives weight to the emotive sense that when technology and PA work in harmony, emotions can be positive. In terms of emotion equanimity this area offers a great deal of future scope in teaching how to deal with unplanned events, difficult emotions, and building resilience in a space where participants often feel vulnerable. These themes are mirrored by a recent qualitative study involving adolescents from age 13 to 25 years old who took part in focus groups to establish challenges to PA whilst living with type 1 diabetes (Fried et al., 2020). The question of how to offer glycaemic stability as a standardised, regular area of care, when using current technology to manage type 1 diabetes and PA may be answered by ongoing closed-loop, (algorithmically operated) insulin pump and sensor technology systems (Barnard et al., 2014; Zaharieva et al., 2020). However, as seen from this study, not everyone currently wants to wear technology on the skin or has financial means/fit criteria for access to this technology.

6.5.5 ***Presence, preparation & prevention***

Awareness of oneself, of the somatic sensations of the body's glucose levels were discussed by some participants in the study. A sense that when one is aware of how they physically feel, either before, during or after activity this can act as a felt sense to prompt interaction with technology to adjust insulin dose. In this space of cognisance, participants spoke of the need to be prepared for PA and the paradoxical experiences which follow consequently when awareness is absent, or PA is unplanned. The negative emotional effects felt in congruence with this were a sense that spontaneity was not achievable without life risk. In some data, participants spoke of positive emotions when they had prepared their equipment and medication with enough time to be active. This data captures direct new insights into the effects of temporal considerations with awareness. Questions that participants ask themselves to predict a safe experience. One parent participant expressed a sense of guilt in not predicting well enough to reduce risk "*pressure to get it right for child*" (typed on a post-it notes on the Bad day area of MURAL board 2). On the same board, the same participant spoke of "*predicting*" and "*worrying*" at night, after a day of PA. In contrast with this, the participant expressed a feeling of "*peace of mind*" in the Good day area of MURAL board 2. This emotive reflection of the awareness, prediction, and prevention, of risk was populated by some participants in their wish to communicate that current technology does not negate risk or worry. Furthermore, this participants' adolescent currently wears the most up-to-date closed-loop technology with algorithmic controlled glucose sensor devices (Medtronic 780g with Guardian sensor 3 system) as shown in researcher field notes and email excerpt (provided on page 166).

6.5.6 ***Improve attachment experiences***

The concept represented by this theme captures participants desires to feel free of pain on inserting of devices (cannulas related to insulin pump and continuous glucose monitoring). Across both MURAL boards 2 & 3, participants spoke of devices falling off, being painful both to connect and remove. The relationship of these devices to PA was also discussed in terms of waterproof characteristics, contact sport adjustment, glycaemia affected through having to disconnect devices. Participants further shared the relationship of disconnecting devices which led to glycaemic variation later in the day, leading to further negative feelings and emotions. The correlation between mood and glycaemic variation is known in literature. Therefore, if a device which is critically involved in communicating with an insulin pump cannot be worn, or falls off, the result may be unstable glycaemia and negative mood. This relates to the "*Bad day Vs Good day*" area of data collection, where participants discussed feeling "frustrated", "annoyed", "grumpy", "tired" and "exhausted" following a day of adhesion problems and disconnecting devices to allow participant in certain types of PA.

6.5.7 Connected devices reduce user ***burden***

This theme speaks of the central concept that participants are using many different devices to achieve, as close to a burden-free experience with PA, as possible. Many spoke of devices "*not talking to each other*". A desire for a streamlined experience was interpreted in the data. Through discussion whilst summarising data, participants mentioned they sometimes use several apps in the day to achieve a clear idea of carbohydrate count, insulin dose calculations, duration and intensity of PA and communicating with others.

Positive statements about the ease of use, discretion, and quickness of being able to glance at data (wrist worn watch devices) highlights the concept of this theme:

> "*Can just look at your wrist instead of phone because teachers think you're on your phone, it's more discreet (watch device); you can swipe away alarms on watch don't need to go into phone (watch device); phone works well with technology and easy to contact people when you need someone (Phone*)" [ID20].

6.5.8 ***Improve accuracy***

Participants felt that their current choice of devices were "*sometimes inaccurate (Freestyle Libre)* "[ID6]. Reporting that devices created interactions involved in the maladaptive treatment of hypoglycaemia. This area causes concern with users when the devices were experienced to be inaccurate in terms of reaction time to alert them of hypoglycaemia:

> *"Delay in reacting to hypos – end up overtreating (Dexcom CGMs*)" [ID 23].

When considering that devices may offer alarm functions, often this inaccuracy leads to mistrust of alarms and a desire to switch them off, to reduce interrupted enjoyment of PA. Therefore, a relationship exists within our data of accuracy and annoyance.

6.5.9 ***Personalisation of devices***

Weight, size, colour, shape, and texture were all discussed by participants in terms of insulin pumps, CGMs, insulin pens, cannulas and worn devices. Discretion of device was related to participants experiences of size of devices. Often a desire to have devices all connected to one, wrist worn watch device was reported as a "should have" in the MoSCoW tool:

"*If my watch could display constant BG, be good have watch link to my CGM" Bud data*" [ID23].

Visibility and worn experiences of devices in relation to attachment were also shared – *"more flush with skin so less able to be knocked off (cannula)*" ID29; "*Could be more discrete and more stylish*" ID36. Personalisation was also discussed in terms of age appropriateness - a young adolescent may not have access, or should not have access, to a smartphone which may place them in a vulnerable situation for theft:

"Prefer a child of this age not to carry a covetable /stealable / valuable item – also not appropriate for a young child to have a smartphone for their own use! An age-appropriate purpose designed wearable item?" [ID 25].

6.5.10 Funding and policy changes – health ***equity***

When participants had populated MURAL board 3 with their preferred future experiences with technology, many mentioned lack of funding or access issues related to technology – "*Don't use it as it isn't funded (Dexcom CGM)*" [ID29]. They felt that if they did begin to self-fund technology, that it would cause a health inequity and financial burden for their adolescent and others:

> "*Better support for CGM technology, limited by price (CGM); government policy should change to allow hybrid closed loop (sensor & pump), would self-fund but when teen becomes independent - the cost may be a burden. Also got to fight for others!*" [ID48].

A recent article describes the health inequity of CGM usage causing patients to seek buying options which are more affordable, in a space known as a grey market (Onisie, Crocket, & de Bock, 2019). This highlights the growing divide in affordability for these devices.

6.6 Conclusion

Reflecting on the generated themes in the "Room 101" MURAL activity 3 whiteboard, which used the "*Rose, Thorn, Bud*" design thinking tool along with the "*MoSCoW*" tool to prioritise data, it was possible to understand the agency involved with timing, and interactions with technology for PA related events, types of activity, and related health factors affecting engagement behaviours.

The contribution to the field, in this study, gave meaning to the gaps in technological support for PA whilst living with T1D. The distance between lived experiences of self-managing T1D and the agency of the technology to inform, and actively change PA behaviours, was contextualised through creative, metaphorical, and scenario forming communication. Therefore, developing a space which includes imagery, visual metaphorical, and future scoping of change by including those with lived experience as experts was important for, not only the adolescents living with T1D but of the parents/caregivers also, (as co-users of the technology).

Future research may look at ways to develop coping strategies towards mastery and empowerment, to cope with experiences where technology incidents cause a negative emotional response, and related negative PA reactions. Future-thinking scenario communication facilitates sensitive health areas to be explored allowing adolescents and their parents to think of new ways of viewing their PA behaviours. This can help to show solutions and positive possibility towards building new coping strategies.

In summary, technology has good intentions going forward to reduce burden for PA support, but there still exists gaps in improvement of psychosocial and emotional factors, specifically for adolescents and their parents as co-users.

6.7 Chapter summary

This Chapter offered a future perspective of participants needs of technology which can support their future PA behaviours when living with T1D. Using online, virtual whiteboards to portray design thinking tools was an effective medium to approach research through a creative lens. Participants found this method enjoyable, especially during a global pandemic when outdoors restrictions where in place.

The themes identified in MURAL activity 2 were linked to study 3 themes with regards to psychosocial factors and emotional effects of PA engagement whilst living with T1D and the use of technology. However, further novel themes were presented during this study relating to '*presence and awareness'* (previously undisclosed). These findings inform future specific technological adaptations and social policy change requirements, as suggested in recommendations shown in Chapter 8.

7 DISCUSSION

This PhD aimed to explore experiences of physical activity and technology for adolescents living with type 1 diabetes, and their parents/caregivers as co-users. In gathering first person accounts of lived experience, using different methods and theoretical lenses, a novel contribution of knowledge to this area of research was provided throughout this PhD. The novel findings support suggestions that PA guidelines must include socio-technical factors, and that there is a current gap between the needs of adolescents to engage in PA with current technology.

7.1 Outline of Chapter

The aim of this Chapter is to collate evidence of all three PhD empirical studies to provide the overall contribution to current research in the field of PA and T1D. Firstly, a brief overview of the findings in the thesis is presented. Following this, the Chapter will outline a discussion of each study and situate findings within previous research. Strengths and limitations of each method are also discussed in this Chapter.

7.2 Overview of the findings

In study 1, 42 people took part in the use of social media digital storytelling. The 6 key themes identified were:

(1) Acceptance; (2) Education & knowledge; (3) Support; (4) Coping behaviours; (5) Identity; (6) Perceptions of control.

In the second study, 29 families took part in the photovoice study. Four key themes were generated from 120 photographs with narrative:

(1) benefits of technology; (2) complexity & difficulty; (3) emotional impact; (4) reliance & risk.

Lastly, in study three, 25 people took part (over six workshops) in a design thinking workshop. The second part of the design workshop (MURAL activity 3) looked at future considerations. From here, five key themes were constructed:

(1) Improve attachment experiences; (2) Connected devices reduces user burden; (3) Improve accuracy; (4) Personalisation of devices (5) Funding and policy changes – health equity.

7.3 Findings in relation to using social media to explore lived experiences (study 1)

The first qualitative study was led to establish perceptions and experiences of physical activity for adults reflecting on childhood experiences with T1D. The aim of this study was to explore childhood from someone who had lived through challenges and their worldview of coping mechanisms and strategies. This study showed benefits and barriers of PA were expressed. Benefits of PA in T1D on reflection were perceived as meaningful relationships which built support. Participants fondly reflected on parental support and clinical support. However, many did recall much confusion from teachers, sports coaches and the wider community adding to negative support experiences.

Barriers mainly focused on the lack of technology to support PA, and the adaptive changes to diet and treatment factors. These findings show complexity in the management of glycaemia and human factors. In Chapter 2, research identified current mal-adaptive behaviours of adolescents with regards to managing spontaneity, uncertainty and negative emotions in the context of PA and T1D (Absil et al., 2019; Brazeau, Rabasa-Lhoret, Strychar, & Mircescu, 2008; E. Knox et al., 2019; MacMillan, Kirk, Mutrie, Moola, et al., 2014). From a reflective stance, the past aligns with current unmet needs of supporting the emotional, and psychosocial factors involved with PA engagement. Due to the lack of technology, participants discourse rarely mentions language associated with targets, goals, and overall glycaemia

(HbA1C). The culture of technological interaction, now presents, data and language surrounding care-at-home science. Participants could reflect on wishing they had technology when they were younger to prevent complications and to assist with making PA easier to engage with. The evidence suggests that early intervention, with technology to support PA engagement with supportive materials and networks may form longstanding PA behaviours into adult life. Recommendations in Chapter 8 discuss this with a view to intervention design.

In terms of feasibility of using social media, it was clear that using social media to a attract participant groups who frequently interact with sharing health stories was found to be convenient and natural to the researcher. The researcher had formed a network for peer support over the past 14 years, parenting a child with T1D. Connections were based on common experiences, sharing knowledge, and raising awareness. Having awareness from the inside of this additional parenting role allowed the researcher to empathise with other parents throughout the research. The researcher became interested in exploring lived experience to further explore language that participants used, and their perceptions of their experiences in terms of the ontological position of understanding life with T1D and PA. Although this PhD does not approach ethnography, or autoethnography, the self-revealing element of positioning oneself is necessary to act as a praxis between theory, participants experience and reporting of results. The responsibility of a qualitative researcher, to state positioning, adds ethical strength to research. Maximising and utilising the position as an insider has been shown as the common pathways to explore the voice of the researcher, alongside the voice of participants, especially in feminist research. These views have been studied in research as early as the 1970s, suggest Wilkinson and Kitzinger (2013).

Using the recruitment methods employed in this study, the target sample size of 20 was exceeded successfully within a one-month period. This information may assist future researchers with online study recruitment methods. Theory which assisted the study to allow participants to reflect, provided a '*lessons learned*' viewpoint to carry forward when asking participants what advice they offer to their younger self. In this model, offering peer support to past self, allowed reflection, and meaning to form from past behaviours. Building a picture of PA behaviours that could have been improved in the past.

7.4 Findings in relation to using photovoice to explore lived experiences (study 2)

Knowledge gained from study 1, significantly informed the research choice and direction of this study. Visual data (120 photos) and accompanying participant narrative unpicked hidden lived experiences of adolescents and of their parents (as co-users) through visual depictions of their technology and PA. Photovoice facilitated an opening to communicate and alleviating the mystery behind living with T1D.

The participants (defined as co-researcher's) were involved with critical analysis of their data. Positioning their power of lived experiences by highlighting vivid, emotional explorations of interactions with technology. The findings presented current barriers and benefits of using technology to support PA in T1D. In this study, novel findings related to risk and reliance were generated. Much technology requires troubleshooting and attention to reduce risk to health. Co-researchers expressed concern with spontaneity and uncertainty for PA engagement using technology. These findings correlate with Study 1 findings (despite using up-to-date technologies in diabetes management). Risk, uncertainty, and adaptive coping behaviours were shown in both studies.

In contrast, the technological arena can appear to offer real-time data to inform risk or PA behaviours. Adolescents and parents provided a picture or wearable wrist-worn devices being used to glance at glycaemia. However, no mention of the effects of PA specific data (heart rate or step count) and its effects on glycaemia, were discussed. A general awareness of PA induced glycaemic variation was presented. However, technology can offer PA data and glycaemic data (wrist-worn devices). Lived experience data showed no integration of these metrics. As presented in Chapter 2, section 2.4.1, research to integrate PA/heart-rate metrics with diabetes management is a new area of consideration. This may be the reason why co-researcher's felt their technological interactions provided a glanceable option at glycaemia, but not streamlining or interaction with PA data is possible. Parents as co-users were often acting to reduce risk, prevent and predict PA uncertainty on glycaemic variation. The role of parents in this context can be considered when designing sharing of data and enabling cross-device interoperability. This is discussed in Chapter 8.

In previous research, parental PA profile was discussed in terms of ways to assist promotion of PA in adolescents living with T1D (I. Michaud, M. Henderson, L. Legault, & M.-E. Mathieu, 2017; Mitchell, Kirk, Robertson, Wilkie, & Reilly, 2017). The co-researchers in the study 2 mentioned support from others in terms of peers and sports camps, but no mention of parental taking part in PA with adolescents was discussed in terms of family profiles of PA. A tone of adolescent transition to independence was threaded throughout the data. Discussions of parents remote monitoring glucose levels or waiting at the side of football or rugby fields/in the background at dance events. The age group of 10-19 years concerned with Study 2, and adolescent specific maturity may be a factor in this data. These findings give context to the movement of technology to manage T1D moving towards reducing burden, as discussed in section 2.3.2.

Complexity and emotional experiences were shared throughout study 2. This reaffirmed interpretation from study 1 data. Adolescents expressed negative emotions when glycaemia was varied, and technological factors impeded PA engagement. H. Quirk, Blake, Tennyson, et al. (2014) cited in Chapter 2, recognised the paucity of research exploring psychological factors experienced in this context. Study 1 and 2 findings frequently interpreted negative emotions through language and text. It is known in research that diabetes distress covers unpleasant emotions and low mood (Virginia Hagger, Christel Hendrieckx, Jackie Sturt, Timothy C Skinner, & Jane Speight, 2016). However, study 1 and 2 findings unpick the meaning behind the long-standing unmet need to address emotional factors, and the gap in services to understand that PA support for T1D should attend to targeting emotional support.

Strengths in using photovoice were found through the co-design approach. Coding data, with co-researcher's, facilitated a collaborative framework and generated trustworthiness in the findings by co-validation of meaning in the photos and narratives that represented lived experiences of the participants. Guided discussion (online video) diminished perceived control and power relations and acted as a bridge between academics.

Methodological challenges for the researcher were in identifying personal reactions and statements which triggered personal experiences. This study was the greatest challenge to learn skills required to bracket bias when necessary and develop the insider/outsider strategies as discussed in the previous section. Reflective memo journaling was employed to detach from personal experiences when necessary.

7.5 Findings in relation to using Design thinking (study 3)

In terms of current and advancing technology, study 3 looked to asking participants of their perceived future desires. Positioning scenario and future thinking within design thinking allowed for the exploration of contrasting and comparing current technologies, with identifying areas for change and prioritising these changes. These were shared by participants in connection with their current PA experiences.

The findings explored lived experiences in terms of Good day Vs Bad day, to allow for normative behaviours and experiences to be identified, before progressing to solution-based thinking. This is explained in Chapter 6, section 6.3.3, and in Table 6-1.

Participants were able to share their comparison of good and bad days with T1D and PA through their interaction with technology. In response to research question 6.1 themes related to psychosocial factors were found throughout all workshops. A relationship between glycaemia stability and position emotions were found. A novel theme, undisclosed in other studies to the researcher's knowledge provided evidence of language surrounded presence and mindful attention to preparing for PA. This evidence does related to previous research identifying spontaneity as a barrier to PA (Absil et al., 2019).

In response to research question 2, areas for change and future direction of technological support for PA and T1D resulted in novel findings. Participants discussed specific usability factors included connected devices and interoperability to streamline their experiences. This was initially explored in study 2. However, in study 3 design thinking facilitated further exploration of this area.

Furthermore, participants in study 3 highlighted accuracy as an important factor to support PA in T1D through technology support. Current PA guidelines and target attainment was not discussed by participants (Adolfsson et al., 2018). However, step count language was shared by some participants. This evidence supports an adolescent awareness of health measurements using wrist-worn devices. These findings provide evidence of awareness of health and wellbeing goal setting. Goal setting with technology for T1D and PA in adolescents was discussed by E. C. L. Knox et al. (2019). In accordance with future research looking at accuracy of PA devices (discussed in section 2.4), the scope and reach for developing this area would seem to be open for improvement.

Methodological effectiveness of using design thinking with online whiteboard proved successful in gathering deep, reflective, insight into lived experiences and future expectations for technological change. One strength in the use of design thinking was the ability to facilitate creative thinking. A space for those living with T1D to portray how they might change things, was provided. Additionally, having a group setting using design thinking tasks facilitated relationships and camaraderie between adolescents and parents, as a form of peer support. Often this population feel misunderstood and strongly desire that others understand just how difficult T1D and PA participation can be (H. Quirk, Blake, Dee, et al., 2014).

To reduce researcher bias, strategies for reflexivity included allowing participants to create their own areas on the whiteboard, whilst still providing neutral scenario's. Exploring ways to prompt critical thinking by asking participants what they would like to improve, guided by their current experiences, in the rose, thorn, bud designs was found to be acceptable and enjoyable.

Once recruited, the participants felt that the online method and the use of virtual whiteboard space gave them the option to turn off their video and microphones for private debate and discussion (between parent and child), whilst having control of keeping their private home space away from the camera. This benefited the participants to feel natural and populate the board without the need for confirmation bias. Technological troubleshooting and communicating with others on the workshop were facilitated by the researcher.

7.6 Limitations of studies

In concern with reach, it was hoped that by using Twitter, not only Facebook, in study 1 would encourage a global influence. However, the majority of data when looking at IP address details came from the UK. Respondents did question reach "*is this a UK only study?*". Cultural factors and educational structures may show a heterogeneous sample and include more variations of lived experience which could be investigated longitudinally.

The effectiveness of using social media offered convenience to participants to reply immediately. However, this does mean timing for the study is not always based on one time zone. Replying to queries expediently, may mean a 24-hour approach to a working day. One alternative method is content analysis which employs machine programming to read narratives on social media. However, by providing a direct question and allowing private messaging for replies, a qualitative study can gather richer, meaningful data in response to the research goals.

Furthermore, in terms of project timing, asking participants for feedback, after taking part, created a barrier. Delays in replying and no replies were found. Retention of participants was important to establish member agreement with data analysis. There was a perception that once they had commented on the research advert, they would not be contacted further. Twitter and Facebook often prompt people with notifications, but unless participants have this function enabled, it is quite possible for them to not reply. Therefore, gathering data requires timely responsiveness of the researcher, and effort to engage participants. In summary, using social media can allow for greater reach, and representativeness of the population. For phenomenological interpretation, it is important not to lose meaning in the individual accounts of lived experiences, which can sometimes be portrayed in a semantic sense on social media platforms.

In study 2, limitations of using photovoice are related to prior knowledge, training, and developmental ability to think critically, also discussed previously by Latz [2017]. There is currently a lack of standardized quality measures in place to guide and replicate a photovoice study. The researcher developed learning and training from a combination of reading materials, peer-reviewed journals, books, and video footage, to explore how best to lead civicengagement, engaging youth and facilitate independent thought. In summary, photovoice allowed for collaborative practice, empowerment, ownership, and identification of behaviours which were perceived as important, by the participants, to communicate to others.

Specific to study 3, limitations of design thinking involved the lack of time to produce prototypes of devices which participants discussed. Future research may involve lo-fidelity, creative methods to design and innovate technological prototypes discussed in MURAL activity 3. For example, some participants mentioned they would live to have "*one app that does it all, rather than using 4 different apps*" [ID25]. Furthermore, to represent more adolescents, a larger study which recruited participants from wider socio-economic backgrounds would perhaps strengthen the argument for funding policy change.

7.7 Chapter summary

A key strength of triangulating using different methods in qualitative research enabled a deep reflection and critical analysis of the problem focus. By gathering different data types, from those who had lived through childhood, to those who are currently living with T1D, gave a spatial nuance to identifying and exploring needs and gaps. To compare past, present and future allowed strength to define gaps in service, technological requirements, and patient behavioural needs.

One limitation is the lack of standardised methods for reporting using these methods. In terms of quality assurance, many interventions require this level of investigation and rigour. However, substantiating this with additional, supplemental qualitative data adds trustworthiness. The PhD could also be limited in the scope of reach with participants mainly recruited on a national level. Many other technological issues exist in other countries, and cultures which would provide a further, global, and collaborative perspective to future studies. Within time and budgetary constraints, the methods chosen were applicable, peer-reviewed, and trustworthy in alignment with ontological and epistemological choices stated in Chapter 3.

Regardless of the approach taken by designers, and health care professionals, this PhD provides a starting place to address overlooked human factors in the role of interacting with technology which is moving at pace. Translating the users' needs inclusive of PA behaviours, as opposed to viewing them in isolation, can improve health outcomes. The following Chapter will synthesize these findings into suggested recommendations for intervention design and practice improvement.

8 CONCLUSION AND RECOMMENDATIONS

This PhD presents original, significant areas where improvement can be offered to support PA engagement using technology, for adolescents living with T1D and their parents/caregivers. The overall thesis question stated in section 1.4 was the guiding value for conducting the three empirical studies. The thesis identified gaps in healthcare service practice, technology, and guideline policy, which are now presented as potential recommendations for change.

Overall thesis question - "what socio-technological factors play a role in the support of physical activity for adolescents living with type 1 diabetes, and their parents/caregivers as co-users?"

8.1 Study specific recommendations

As each study had a temporal lens and approached the problem of how best to support PA with technology for adolescents living with T1D, the following recommendations in Table 8-1 as specific to each study.

Table 8-1. Recommendations in concordance with study data

Study	Themes	Recommendation
1	Acceptance; Education & knowledge; Support; Coping behaviours; Identity; Perceptions of control.	• With regards to current treatment, condition specific negative emotions continue to exist. Consider offering psychological therapy measures specific to life stages i.e., newly diagnosed families, and during life changes- such as change of school, adolescence and leaving school. • Build peer support for parents and families as an adjunct to therapy, understanding how these forms coping behaviours. Creating adolescent working groups (*as experts*) into primary care initiatives. Establishing this peer support within a PA environment, regularly. • Continue using and implementing different language in policy, literature, education, and healthcare settings which reframe perceptions of “controlling” (sic) glycaemia, as this appears to be closely linked with identity and coping behaviours.
2	Benefits of technology; complexity & difficulty; emotional impact; reliance & risk	• Explore different educational modes (digital) to improve comprehension with individuals and parents, offering open dialogue and immediate communicative support. • Improve user support and systems for reporting user experiences, faults, repairs, and fails – HCPs, manufacturers, and suppliers. • With respect to emotional support, offering counselling and therapeutic help to adolescents living with T1D and parents/caregivers. (To reduce family/parent burden and diabetes distress).
3	Improve attachment experiences; Connected devices reduces user burden; Improve accuracy; Personalisation of devices; Funding and policy changes – health equity	• Manufacturers to address adhesion of devices, skin irritation factors, waterproofing and pain on insertion. • Consider making cannulated devices a single port to reduce wearable devices on different parts of the body. • Consider connecting devices through single-port and reduce siloed data. • Improvement of algorithms and accuracy metrics. • Funding criteria and access to be reviewed and realigned with evidence which supports improved health outcomes from Time in Range studies (Pease et al., 2020).

8.2 Implications for practice and research

In this section the implications of the findings in practice and research are presented. Firstly, implications for practice – addressed to the non-academic audience are discussed. Academic research implications discuss the conceptual contribution of this project, and future areas for concern.

8.2.1 ***Practice level change***

In the past two to three decades, a change towards PA for health and wellbeing and the prescribing of PA in primary care, has brought about a paradigm shift away from intensive fitness training and stamina focus to everyday wellbeing. The term salutogenesis refers to this ideology (McCuaig & Quennerstedt, 2018). Moving health and wellbeing away from a pathogenic lens, towards enabling empowerment and mastery, especially when living with a health condition. The findings in this PhD provide potential for addressing promotion of PA and the role of technology for adolescents living with T1D using a person-centred approached. The findings also share insight for patient agency in the role of combining patient generated health data, at home, to support clinical training/interactions and discussions. Other long-term health conditions may benefit from consulting the recommendations in line with self-management practices. The Scottish government already has in place a plan for service design with includes a person-centred approach. In terms of including the adolescent and their parents/caregivers, the design of health service for PA support through access and support with technology should be included for those living with T1D (Scottish Government, 2019). Including shared decision practices with adolescents and their parents (as co-users and caregivers) can enhance empowerment and mastery at home with technology. As PA experiences often occur in a school/education environment, upskilling of teachers and formal sports coach personnel will also widen the support network for adolescents. Professional training and cross-discipline events with registered Diabetes education providers may assist with the delivery and implementation of this training. At present, digital education platforms do exist, with up-to-date connections to diabetes service providers, NHS, and patient experts (www.mydiabetesmyway.scot.nhs.uk/#gsc.tab=0).

8.2.1.1 Emotional experiences with type 1 diabetes and physical activity using technology

Emotional experiences were prominent across all three studies. Suggesting that emotional effects are prevalent when considering PA and T1D through interactions with technology. Psychological support and normalising this as part of practice, should no longer be considered in isolation. Research now focuses on 24-hour behaviours, seeing PA as part of health and wellbeing behaviours, not as separate experiences (Reilly et al., 2020). Advancing this concept with adolescents living with T1D, and that of parent/caregivers with regards to carer burden, is strongly recommended.

Derived from the data gathered in all three studies, there is much heterogeneity in technology use. However, common emotional factors which influence behaviours related to PA and T1D are seen in these users. Having support in PA is not a new concept (Mitchell et al., 2016). It is seen as a crucial aspect of PA promotion. However, involving adolescents in the discussion surrounding the role of technology could be incorporated into peer group events. Progression of development to clinical excellence and guidance in a person-centred approach is further advised to address emotional experiences. Implications for practice require upskilling of healthcare professionals on adopting person-centred approaches in regular clinic settings. This may involve group and peer settings (Papoutsi et al., 2017).

Out of all participants, only one (across all studies), mentioned the involvement of a healthcare professional in helping them with PA support (Morrow, Lennon, Kirk, & Muirhead, 2021). This highlights a discussion area for HCP training and upskilling to include PA as part of care routines. The success of camp events gives background and relevance to the success in which adolescents feel confident during expeditions and extreme sports (O. Kordonouri, Vazeou, Scharf, Wursig, & Battelino, 2017; Ly et al., 2015). From here, it can be suggested that taking part in PA is not a physiological issue. More so, it is the socio-technical issues and psychosocial factors which impact PA behaviours. Positive emotions were strongly linked with glycaemic stability from participants using technology to manage T1D and PA. Critically evaluating this, the movement towards CGMs and insulin pump technologies which adjust dose through algorithmic controllers can be approached to increase positive experiences. However, access to this technology remains a salient point.

8.2.2 ***Clinical guidelines and advice for physical activity support***

A re-examination of current guidelines to include socio-technical factors which may impede participation in 60 minutes of MVPA with T1D is necessary. At present, T1D specific guidelines discuss measuring and monitoring of glucose and PA specific adjustments (Adolfsson et al., 2018). It is unclear if there are specific UK guidelines for the participation and support of PA for adolescents living with T1D, and the management there of with technology. However, producing advisements based on inclusion of T1D specific support should be a priority. It is advised that communicating the complex and life-threatening risk of hypoglycaemia and hyperglycaemia, as an effect of participation in PA and/or technological barriers, to be the rationale for all training and educating of sport related personnel, teachers, and those directly involved with the care of an adolescent in this context.

A multi-disciplinary working group to combine NICE guidelines with ISPAD and Government policy may help to address the lack of representation of adolescents living with T1D and their families, who use technology to self-manage the condition.

8.2.3 ***Technological level change***

Studies 2 and 3 added evidence for the ongoing barriers to PA engagement through technological specific factors. These factors cause emotional and social effects when participating in PA. Through the avoidance of social settings, ignoring or switching off alerts and alarms, to being assisted with parents to events due to a lack of trust in the technology to keep their child safe whilst participating in PA. Furthermore, severe technological fails and the need to re-insert cannulated devices in schools, or on sports pitches, leaves adolescents feeling negative effects of using technology. Participants in both studies referred to a sense of intrusion and interruption to their PA choice and duration and to their sleep patterns following a day of being active. Therefore, present technology does not meet the needs of adolescents and their parents/caregivers to participate without added life risk or concern for health.

Positive aspects of technology experienced in study 2 and study 3 were found to be relatable to the ability to share data with supporting others, to change noise levels of alarms and personalise their devices. This data also showed an area for concern with health disparity and access. It appeared from the data that only a select few of the participants across studies 2 and 3, were using closed-loop, sensor augmented pump therapy. Arguments to build funding criteria and improve access to this technology are shown in relation to the positive emotional effects when participants felt their glycaemia remained stable during and after PA.

Although current technology does not offer anything as close to a cure, of a functioning healthy pancreas, the movement towards smaller devices, and streamlined devices seems pleasing to participants of study 3. However, a clear and obvious gap for the integration with PA specific devices was illuminated in the data. From study 2, only one participant mentioned wearing a PA specific device, and from study 3, those who do currently wear a wrist-worn PA device, state they wish it could display their glucose data. One participant from study 3 did mention that they have an app (AAP – Samsung) with combines the data from their glucose sensor with their wrist worn device. Out of a possible 45 participants, this figure highlights a clear market gap for technological improvement. Consideration towards wearable factors, on skin, and personalisation of functions, as well as accuracy will be required to ensure

CE mark safety regulations for this high-risk group.

8.2.4 ***Academic level change***

Good intentions of health care service providers are not enough. It is imperative that academia, government, and policy makers, align with recommendations to include lived experience data as patient-driven evidence. All case mortality and morbidity in regards to cardiovascular outcomes, for those diagnosed in childhood, reflect the severity of the lack of support to promote PA in this population (Rawshani et al., 2018). The experiences of adults in study 1, reflecting on childhood experiences, illuminated a long-standing unmet need with current adolescent experiences of PA participation. In terms of support through education, emotional support and access to technology, an academic involvement to progress the scalability of interventions, over a longer duration would help to advance behaviourally targeted PA promotion in health service. Addressing these factors should aim to reframe PA participation towards a supportive, and positive space in which adolescents living with T1D feel supported in a PA environment.

8.3 Chapter summary

In conclusion, it is evident that adolescents living with T1D can be physically activity, through the support of technology. However, at present access to technology shows disparity in populations. Educational support and emotional support to cope with the effects of PA on T1D are ongoing and personalization of devices could bring a more hands-free experience to viewing health data in real-time situations. When one considers being active, moving, running, walking – whatever the context, this moves towards improving streamlining of devices and increasing support would seem to build a positive, confident, and capable space for adolescents to feel inspired to participate in PA. The importance of parental support and involvement, as caregivers and co-users of technology should be inclusive of intervention design, to improve family relations and caregiver burden.

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Thesis Appendices can be found in a separate file.

End of thesis