

**Continuous subcutaneous insulin  
infusion therapy:**

**An exploration of the lived experiences of  
children with Type 1 diabetes mellitus  
aged 5-11 years.**

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## ABSTRACT

### **Continuous subcutaneous insulin infusion therapy: the lived experiences of children with Type 1 diabetes mellitus aged 5 to 11 years.**

In the United Kingdom, the use of continuous subcutaneous insulin infusion therapy (also known as insulin pump therapy) for children with Type 1 diabetes mellitus is increasing. As the most intensive form of insulin therapy, daily management is complex and demanding. However, although many studies have investigated the effectiveness of this treatment in improving blood glucose control, much less is known about children's own experiences of it, particularly those in the pre-adolescent age group. Therefore, this study aimed to explore in depth how children aged 5 to 11 years with Type 1 diabetes experienced insulin pump therapy in the context of their everyday lives. A hermeneutic phenomenological research design was used, informed by the work of Heidegger. Fifteen children were recruited from two National Health Service paediatric diabetes clinics in England. Data were collected using in depth interviews conducted in children's homes.

The findings highlighted how children were simultaneously enabled and disabled by insulin pump therapy. As such, its meanings were both complex and nuanced. In particular, this form of treatment had a significant impact on children's lived bodies - that is, not just their physical, fleshy bodies but also their emotional and psychological well-being and sense of self. The presence of the technology played a central role in these experiences. Children's active involvement in the management of their own bodies and minds were also revealed. However, despite the considerable effort and hard work that this involved, most children experienced their treatment with satisfaction and enthusiasm.

This study generates new knowledge by proposing that in experiencing insulin pump therapy a young child inhabits a particular type of body. This is defined as the new and original concept of *the lived technological body* and aims to capture the impact this treatment had on children's bodies and minds and the ambiguities and hard work involved in inhabiting and maintaining such an entity.

The findings call for a holistic and contextualised approach to insulin pump therapy in childhood that encourages clinicians to understand this form of treatment as more than simply a bio-medical experience.

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Finally, I dedicate this thesis to the memory of my partner Bas. We often talked together about the possibility of me trying to do this - I hope my efforts would have made you proud.

## **DECLARATION**

I declare the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed: 

Dated: 03.12.2018

## **CHAPTER 1 – INTRODUCTION AND BACKGROUND TO THE STUDY**

### **1.1 Introduction**

This hermeneutic phenomenological study explores in depth the lived experiences of children aged 5 to 11 years who use continuous subcutaneous insulin infusion therapy (CSII) for the management of Type 1 diabetes mellitus (T1DM). In this opening chapter, background information relating to T1DM is discussed, along with an explanation of CSII therapy and the advantages and disadvantages associated with this form of treatment. The rationale for the study is then examined and the research question and aims described. A discussion of the significance of the research follows in addition to a brief explanation of the theoretical stance adopted for the study. An outline of the structure of the thesis concludes the chapter.

### **1.2 Incidence of Type 1 diabetes mellitus in childhood**

T1DM is one of the most common, severe chronic diseases of childhood (Compas et al 2012). The United Kingdom (UK) has the fifth highest incidence of T1DM among children in the world and it is predicted that for children younger than 15 years, prevalence will rise by 70% between 2005 and 2020 (Cizza et al 2012; Patterson et al 2009). The latest National Paediatric Diabetes Audit (NPDA) report (Royal College of Paediatrics and Child Health [RCPCH] 2017) shows that diabetes affects approximately 27,115 children and young people under the age of 19 years in England and Wales. Moreover, its incidence is rising with the greatest number of children being diagnosed between the ages of 9 to 14 years (RCPCH 2017).

### **1.3 The aetiology and management of Type 1 diabetes**

T1DM is an auto-immune condition that results in the selective destruction of the insulin-secreting beta cells in the pancreas (Mandrup-Poulson & Nerup 1995). The exact cause of this is unknown, although genetic (polygenic) factors are important (Hanas 2015). Environmental factors such as viral infections may also be involved, although this remains unclear (Craig et al 2009).

The total loss of insulin production that occurs from the auto-immune reaction has major implications for the metabolism of carbohydrates, fats and proteins and leads to chronic hyperglycaemia (Craig et al 2009). Without exogenous insulin replacement, diabetic ketoacidosis (DKA) occurs rapidly (Craig et al 2009). DKA is a serious, life-threatening complication of T1DM and is due to the combined effects of a deficiency in



circulating insulin and increased levels of counter-regulatory hormones, such as adrenaline and cortisol (Wolfsdorf et al 2007). This leads to an accelerated catabolic state which results in ketonaemia, metabolic acidosis and a self-perpetuating cycle of increased stress hormone production (McFarlane 2011). If this situation is not interrupted by the replacement of insulin, fluid and electrolyte therapy, death will result (Wolfsdorf et al 2007). T1DM is also associated with significant long-term vascular complications that result from prolonged periods of hyperglycaemia and duration of the condition (Hanas 2015). These include blindness, renal failure and coronary heart disease. Moreover, in addition to DKA, other acute metabolic emergencies can occur, particularly hypoglycaemia which can lead to convulsions, coma and very occasionally death (Department of Health [DH] 2007).

A diagnosis of T1DM places substantial demands on children and their families (Compas et al 2012). Current treatment is time-consuming and requires a relentless and life-long regime of blood glucose testing, insulin administration and dietary restrictions (Jaser & White 2010). Moreover, management is complicated by a range of factors specific to childhood. These include children's variable insulin sensitivity; unpredictable food intake and physical activity; cognitive ability and communication skills; the level of self-care and the availability of patient support at home and in school (Campbell 2008). Children's susceptibility to hypoglycaemia, particularly at night, presents additional challenges and is the most feared complication of T1DM by both children and their parents (Campbell & Waldron 2014). As such, this diagnosis is recognised as a condition that can present children and their families with a significant source of stress. This in turn, can hinder adherence to treatment, reduce quality of life and contribute to lasting emotional, social and behavioural difficulties (Compas et al 2012; Pinquart 2013).

There is now unequivocal evidence that intensive insulin therapy in the form of multiple daily injections (MDI) or CSII therapy is associated with improved glycaemic control and as such, a reduced risk of developing long-term complications (Diabetes Control and Complications Trial [DCCT] 1993; Epidemiology of Diabetes Interventions and Complications [EDIC] Research Group 2003). Consequently, in the UK the use of either MDI or CSII therapy is now recommended for all children and young people with T1DM (The National Institute for Health and Care Excellence [NICE] 2015). However, although the latest national data suggests that bio-medical outcomes are improving for children and young people in this country, overall glycaemic control remains poor

compared to other European nations (RCPCH 2017). As such, current national policy and clinical standards reflect an urgency to “normalise” blood sugar control for children and young people as safely as possible (Campbell & Waldron 2014).

#### **1.4 Technologies used in CSII therapy**

MDI regimes typically require four or more subcutaneous injections of insulin a day using both rapid and long acting insulin that differ in their speed of action and duration (NICE 2015). In contrast, CSII therapy involves a continuous subcutaneous infusion of rapid-acting analogue insulin that is delivered via an electronic pump worn externally on the body (Misso et al 2010). The pump is powered by batteries and is pre-programmed to deliver low volumes of basal insulin each hour throughout the day and night (Rodgers 2008). Larger boluses of insulin are activated by the user as needed to cover meals and to correct hyperglycaemia (Misso et al 2010). Temporary changes to the basal rate of insulin (referred to as a temporary basal rate or “TBR”) can be made to reflect the need for different insulin requirements as a consequence of illness, exercise or a change in daily activities, thus mimicking the body’s normal response mechanism (Rodgers 2008).

There are a number of different types of insulin pumps and they vary in the ways they are connected to the body. However, for the purpose of this study, the pump is defined as a medical device that contains a refillable reservoir of insulin attached to an infusion set and cannula, rather than a “patch” pump which sits directly on the skin. The cannula is usually inserted into the subcutaneous tissue of the abdominal wall or buttocks and is held in place by adhesive tape. Cannulas must be repositioned every two to three days or replaced earlier if problems occur, such as pump failure or if high blood glucose/ketone levels develop. The latter can result from illness or blockages in the flow of insulin (occlusions). In this study, children used insulin pumps that were manufactured either by Roche Diagnostics or Medtronic. These two devices are similar in size and have features and functions that are common to both. However, each has additional characteristics that can be useful. In particular, the Medtronic pump is also waterproof whilst the pump by Roche has a “handset” which is used not only as a blood glucose meter but also as a means of controlling features on the pump remotely without having to physically handle it (Rodgers 2008).

In addition to the insulin pump and cannula, there are a range of other technologies that children and their parents must use in order to manage CSII therapy optimally. These

include devices for monitoring blood glucose/ketone levels and for inserting cannulas. Insulin pens and needles are also required in case of pump failure or occlusions, as well as computer technology in order to download and analyse data from insulin pumps and meters. The use of all of these devices inevitably adds to the complex nature of this treatment and thus the potential burden of care for both the children themselves and their families.

### **1.5 The advantages and disadvantages of CSII therapy in childhood**

The aim of CSII therapy is to improve blood sugar control by delivering insulin continuously and in a way that mimics the secretory pattern of the normal pancreas (Hanas 2015). By so doing, it is the most physiologically matched method of administering insulin that is currently available (Phillip et al 2007). This provides a number of important benefits for those using this form of treatment. In particular, it substantially reduces the variation in insulin absorption rates – that is, less than 3% for CSII therapy compared with up to 55% for MDI regimes (Lauritzen et al 1983). This results in more consistent blood glucose patterns, which can have a positive impact on both treatment satisfaction and physical well-being (Hanas 2015). In addition, when compared to MDI regimes, insulin pump therapy has been shown to lead to a reduced risk of cardiovascular mortality (Steineck et al 2015), reductions in severe hypoglycaemia and hospitalisations for DKA and sustained improvements in glycaemic control (de Bock et al 2011; Johnson et al 2013). Recent national data reflects this by showing that the median HbA1c levels for children and young people using CSII therapy in the UK is 62.2 mmol/mol compared to 68 mmol/mol for those using MDI therapy (RCPCH 2017). (HbA1c or glycosolated haemoglobin is a marker of overall glycaemic control and provides a measure of long-term risk of vascular complications). As a result of these improvements in outcomes, the use of CSII therapy in the UK has gained increasing popularity among clinicians as well as children and their families (Ghatak et al 2015).

In this country, NICE (2008) recommendations allow insulin pump therapy to be initiated in children who are less than 12 years old if MDI regimes are either not practical or are considered inappropriate. Typical reasons for children using this treatment, therefore, include needle phobia, high HbA1c, wide fluctuations in blood glucose or hypoglycaemia unawareness (Hanas 2015). However, despite its potential benefits, insulin pump therapy is not suitable or even desired by all patients and their

families (de Bock et al 2011). As the most intensive form of insulin therapy, it is considered to be a particularly demanding form of treatment that requires high levels of competence, effort and commitment by both children and their parents/carers in order to ensure its safe and effective use (Alsaleh et al 2012; Campbell 2008; Valenzuela et al 2006). To achieve optimal blood glucose control, clinical guidelines in the UK advocate monitoring capillary blood glucose levels at least five times every day; testing blood ketone levels if control is high and careful assessment of carbohydrate containing foods every time food is eaten (NICE 2008). Moreover, general disease awareness is required in order to manage both high and low blood glucose levels, sick days and routines at school appropriately. Whilst these issues are common to MDI therapy, CSII therapy requires a significant number of additional tasks and invasive procedures that need to be carried out frequently (Weissberg-Benchell et al 2007). For example, cannulas must be changed regularly in order to reduce the possibility of skin infections and maintain consistent insulin absorption (Rodgers 2008). In particular, frequent decisions must be taken about when and how to adjust basal/bolus doses of insulin to reflect food intake, exercise levels and variations in daily routines in order to proactively avoid adverse fluctuations in blood glucose control that could lead to hypo or hyperglycaemia (Weissberg-Benchell et al 2007). Moreover, patients who use insulin pump therapy have a potential risk of developing DKA rapidly as a result of line disconnection or pump failure (Johnson et al 2013). Consequently, any occlusions need to be detected in a timely manner and mechanical or technical failure addressed swiftly (Rodgers 2008). All of this, therefore, requires not only constant vigilance both at home and in school and the ability and willingness to trouble-shoot and understand the technology, but also an increased need for treatment and disease focussed behaviours (Alsaleh et al 2012; Johnson et al 2013). As such, careful patient selection is crucial in order to ensure that children achieve the best outcomes when using this form of treatment (NICE 2008).

## **1.6 Rationale for the study**

The rationale for this study evolved initially from personal reflections that followed a “disturbance” (Mason 2002:139) that occurred several years ago in my clinical practice as a children’s diabetes specialist nurse. Within this practice, increasing numbers of children and young people had been (and continue to be) commenced on insulin pump therapy to manage their condition. During a conversation with an eleven year old boy about his treatment, he tearfully described how he made a deliberate effort to conceal his insulin pump from his friends at school in order to present a “normalised” self to his

peers. His distress was troubling and subsequently triggered an increasing concern about how other primary school aged children may be experiencing CSII therapy in the context of their everyday lives. I wanted to understand more about what it was like for them and how they made sense of it.

However, as I started to delve into the literature for answers, it became increasingly clear that there was a scarcity of research investigating children's own experiences of insulin pump therapy, particularly for those in their pre-adolescent years. I found this surprising given the considerable demands associated with its use. Moreover, I was concerned about this particular age group's lack of "voice" in the current discussions relating to CSII therapy in childhood. Clinicians cannot assume that they know or understand children's perspectives of this treatment. Children's illness experiences are unique and will influence their beliefs and interpretations about not only themselves as individuals but also the ways in which they deal with a medical condition and the treatment regimes used to manage it (Brady et al 2015). Therefore, greater understanding of children's views and concerns is important for ensuring that health service provision is both relevant and responsive to their needs. Given this context, I considered that a research study that gave primacy to the views of pre-adolescent children and which explored their own experiences of living with insulin pump therapy in depth merited further exploration.

## **1.7 The aims of the study**

The overall aim of the study was to gain a deeper understanding of children's lived experiences of using CSII therapy.

### *The research question*

How do children aged 5-11 years with Type 1 diabetes experience and respond to insulin pump therapy in the context of their everyday lives?

### *The research objectives*

1. To capture the child's own voice and take seriously what they say.
2. To generate a holistic and interpretive description of the nature and range of children's lived experiences of insulin pump therapy and to uncover the meanings children ascribe to them.
3. To offer insights that help to inform the clinical practice of healthcare practitioners and which promote holistic and humanely sensitive care.

## **1.8 Utility and significance of the study**

The scope of this study is framed in part by an escalation in the past decade in the use of CSII therapy as a treatment strategy for children and young people with T1DM in the UK (Ghatak et al 2015; Gosden et al 2010). Its use in this country gained momentum in particular following the publication of a Technology Appraisal of insulin pump therapy (TA151) by NICE (2008). This document endorsed for the first time the use of CSII therapy as a primary treatment option for the paediatric population. Since then, the number of children using this treatment in England has been increasing steadily (RCPCH 2017). For example, 15.8% of all paediatric patients were using insulin pump therapy in 2013-2014. However, current data indicates that this has now risen to 27.9% and that its use is greatest in younger age groups – that is, children less than 14 years (RCPCH 2017). Moreover, following the implementation of the Best Practice Tariff (Randell 2012) for paediatric diabetes in England, and the subsequent improvements in clinical staffing levels within paediatric units, it is anticipated that use of insulin pump therapy will continue to rise further (Ghatak et al 2015). Given this context, the study presented here is considered to be not only timely but also highly relevant to current clinical practice.

In addition to this, there is now widespread acknowledgement within the National Health Service (NHS) of the importance and value of seeking children's expertise in the development of effective service provision (DH 2002). For example, the recently implemented Friends and Family Test (NHS England 2014) is based on the fundamental principle that all patients receiving care from the NHS should be given the opportunity to provide feedback on their experiences and be empowered to do so where appropriate. This includes children and young people. Asking children about their illness experiences is an important initial step towards achieving these goals. This study, therefore, is a response to this call for healthcare services to take account of children's views and to recognise them as valid and valuable.

## **1.9 The research perspective**

The phenomenon under study is children's lived and contextualised experiences of using CSII therapy. Therefore, an interpretive hermeneutic phenomenological methodology was used to deepen understanding of "how it is" to be a young child using this form of treatment. In particular, some of the existential-hermeneutic ideas that

underpin the work of Heidegger (1889-1970) and Merleau-Ponty (1908-1961) are used to inform the research process and to illuminate the findings respectively.

### **1.10 Defining “lived experiences” and “technology”**

#### **Lived experiences**

This study focuses on children’s “lived experiences”. Although definitions vary, this term typically refers to the phenomenological notion of the life-world (*Lebenswelt*) – that is, the taken-for-granted “everyday world of common experience” (Bullington 2013: 2). We are immersed in this lifeworld which consists of essential and interrelated features that encompass amongst other things beliefs, values and assumptions as well as dimensions related to interpersonal relationships (relationality), embodiment and selfhood (corporeality), and sense of time and space (temporality and spatiality) (Ashworth 2003; van Manen 1997). Therefore, in this study, “lived experiences” is employed to draw attention to and explore the nature and meaning of children’s lived situation and social world in relation to using pump therapy rather than “some inner subjective realm” of consciousness (Finlay 2011:3).

#### **Technology**

Most people in contemporary western societies have developed a close dependency on a wide variety of technologies to function in everyday life, such as glasses to improve vision as well as information and communication technologies such as computers and mobile phones. However, for the purpose of this study, the term “technology” refers specifically to medical devices that are used for therapeutic purposes in order to improve or maintain the health status of children with long-term medical conditions.

### **1.11 Organisation and structure of thesis**

The thesis is comprised of six chapters. As a guide for the reader, an outline of the remaining chapters is detailed below.

**Chapter 2: Literature review.** This chapter focuses on a critical evaluation of existing literature relevant to the study. It aims to demonstrate gaps in current knowledge, to illuminate the context within which the study is set and to justify the proposed research question. The conceptual framework adopted for the study is also discussed.

**Chapter 3: Methodology.** This section explores the philosophical underpinnings that guide the research process and considers my role and position as an adult researcher investigating children's worlds. An examination of the ethical challenges encountered and the methods employed to answer the research question is also given. The latter includes a discussion on the use of semi-structured interviews and the process of conducting a thematic analysis of the findings. Much of this section reflects approaches that are specific to conducting research with children. A debate on issues of rigour in phenomenological research concludes this chapter.

**Chapter 4: Findings.** This chapter presents the findings and key meanings that insulin pump therapy had for the children. Themes are identified and selected data from the children's interviews is used to illustrate these.

**Chapter 5: Discussion.** In this chapter, findings are considered in relation to previous research, the methodological approach and the theoretical framework that underpins the study. I also introduce the concept of "*the lived technological body*" and consider how this adds meaning to the research topic and other literature.

**Chapter 6: Conclusion.** This final chapter revisits the research question and describes how I have met the aims and objectives of the study. Implications for clinical practice and professional knowledge are explored, along with the strengths and limitations of the study and proposed methods for disseminating the findings. I also make explicit how this study makes an original contribution to clinical knowledge and practice. Finally, I present some personal reflections on the process of completing the investigation.



## **CHAPTER 2 – LITERATURE REVIEW**

### **2.1 Introduction**

This chapter explores existing literature relevant to the topic of insulin pump therapy in childhood. A description of the strategies that were used to search the literature both at the start and throughout the course of the study is presented. A broad narrative review of both empirical and theoretical work follows in order to place this present study in context, beginning with an overview of literature investigating the psychological impact of chronic illness in childhood generally, as well as research that explores children's experiences of T1DM. As described in chapter 1, technology, (primarily in the form of the insulin pump), is integral to the practice of CSII therapy (NICE 2008). As such, a consideration of wider literature that is technology specific is then examined, including work that explores children's experiences of living a technology assisted life using a range of different medical devices and some of the key theoretical debates that are influential in the sociological analyses of medical technologies. This is followed by a focussed discussion of empirical research that examines what is known to date about CSII therapy in childhood and children's own experiences of this form of treatment. The specific processes and criteria that were used to structure this part of the review are described. An explanation of the conceptual frameworks that were chosen to underpin the study and which served as a guide to interpret and explain the data is then presented. The chapter concludes with a summary of the current gaps in knowledge concerning CSII therapy in childhood and an explanation of why further research is needed.

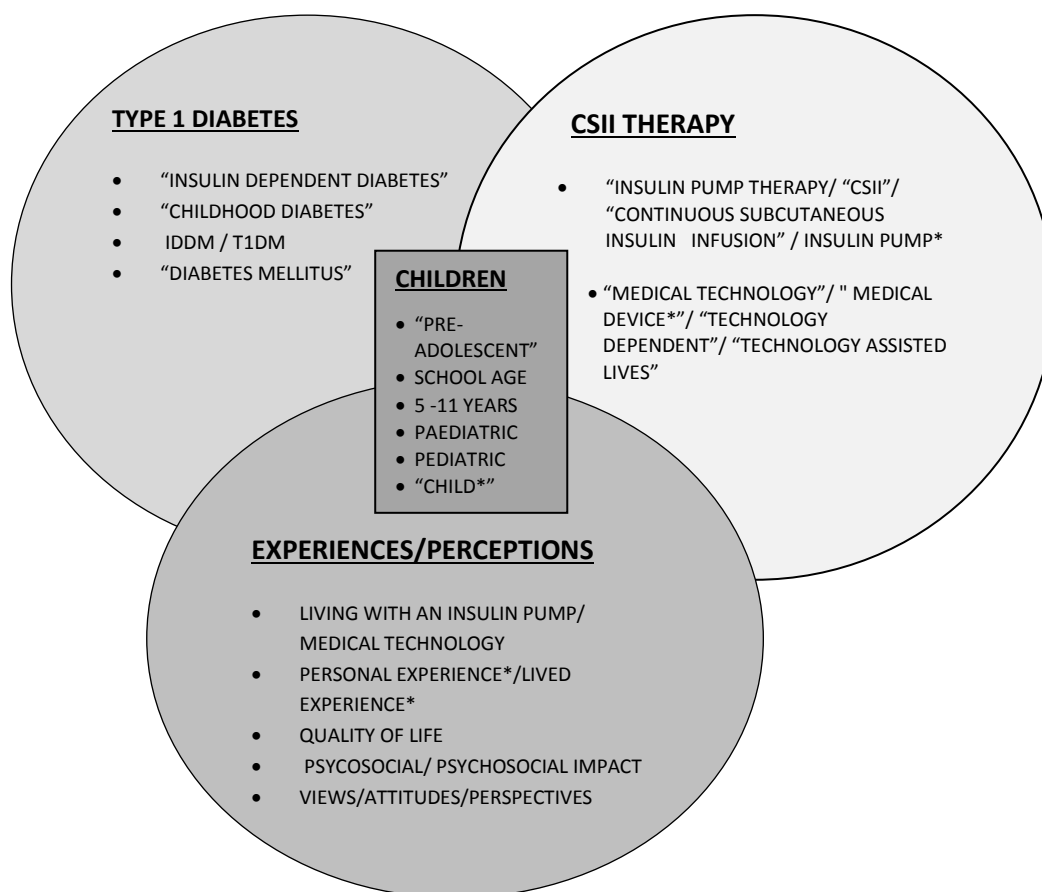
The role of a literature review in qualitative research can be contentious (Holloway & Galvin 2017). Aveyard (2014) maintains that a preliminary review of related material at the beginning of a study is important, not least in order to ensure that no other work has already researched the same phenomena and in the same way. Moreover, Creswell (2009) suggests that it helps to define the appropriateness of future research questions and provides a framework for establishing the importance of a study. However, others argue that delving into the literature too deeply in the early stages of the research process can be detrimental to the inductive nature of qualitative research because this can predispose a researcher to pre-judgements about the nature of a particular phenomenon and thus, influence too heavily the process of discovery that underpins this type of research (Finlay 2011; van Manen 1990).

For this study, reviewing the literature involved an iterative and flexible process, rather than one that was linear or rigidly focussed. Mindful of the importance of adopting an inductive approach, the initial search for relevant material at the beginning of the study was regarded as more of an orientating exercise (Finlay 2011). As such, it was conducted primarily to establish the gaps in current knowledge about CSII therapy in childhood and to discover whether this current investigation would be likely to contribute in a meaningful way to clinical knowledge and practice. As the study progressed, I have frequently revisited this literature as well as searched for new material as novel concepts and issues emerged. Nonetheless, I recognise that following this process may have contributed to my pre-understandings and assumptions. However, throughout the course of the study, I made a conscious effort not to follow only familiar and expected horizons of knowing. Moreover, the decision to adopt a hermeneutic interpretive lens for the study meant that reviewing the work of others was always about entering into a “conversational dialogue” with them rather than accepting their insights uncritically (van Manen 1997). Therefore, exploring the literature served to challenge my own pre-understandings and interpretations and provoked thinking that not only opened up but also kept open different possibilities of investigating and understanding the experience of insulin pump therapy in childhood.

## **2.2 Methods used for searching the literature**

A number of different strategies were used when searching the literature in order to try and ensure that this process was both comprehensive and systematic (Aveyard 2014). Initially, at the start of the study, a Venn diagram was employed to organise visually the core areas of literature most likely to yield relevant material related to the research topic (Figure 1). The “essence” of each category identified was then captured by brainstorming keywords, phrases and related synonyms associated with each. Using Boolean logic and wild card characteristics, different combinations of these key words as well as Medical subject headings (MeSH), were used in the fields of title and abstract to search a series of electronic databases. One example of this strategy was “CSII therapy” OR “insulin pump therapy” AND child\* OR paediatric. Additional words and terms were used as the study progressed - for example, “human/machine interface”, stigma, body image, “unhomelikeness”, “adjusting to chronic illness” as well as particular words used by the children themselves such as “feeling in control” and “being different”.

**Figure 1:** Initial literature search: keywords and subject headings used



Throughout the study, literature was identified by accessing each of the following electronic databases individually - Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and British Nursing Index (BNI). The websites of Diabetes UK, the National Institute for Health Research (NIHR) Health Technology Assessment programme and the National Institute for Clinical Excellence (NICE) were also scrutinised. In addition to electronic searching, a “snowballing strategy” (Greenlagh & Peacock 2005:1064) was implemented whereby literature was accessed in a way that was responsive to the study as it unfolded and to the literature already obtained. This included scrutinising reference lists, citation tracking and hand searching key clinical and policy guidelines as well as recent copies of frequently cited journals. Finally, personal, clinical and research knowledge of the topic and networking with colleagues was also brought to the process.

### **2.3 Chronic illness in childhood and its psychological impact.**

Increasing numbers of children and young people in the UK are affected by chronic illnesses and medical conditions (Kossarova et al 2016). A disease or illness is defined

as chronic if it lasts for more than three months and is a condition that is not curable or one that does not resolve spontaneously (Stanton et al 2007). It encompasses a wide range of both psychological and physical conditions such as disability, cancer, asthma, cystic fibrosis, chronic pain and tension headaches as well as type 1 and type 2 diabetes (Compas et al 2012).

In the literature, chronic illnesses and their treatments are generally conceptualised as having a significant impact on children's emotional, psychological and physical well-being (Christie & Khatun 2012). This may have negative consequences for their social relations, behaviour, education and adherence to treatment regimes (Compas et al 2012). Historically, quantitative approaches grounded within medical and psychological frameworks tend to dominate research in this area (Darbyshire et al 2006). Thus, there is a focus on the physiological and biomedical outcomes of a chronic illness (such as, glycaemic control for children with T1DM) and, in the case of the psychological literature, children's emotional adjustment and adaptation to it. Much of this latter body of work claims that children and teenagers with chronic illnesses and disabilities typically experience a diminished quality of life. For example, the results of a recent meta-analysis incorporating more than 600 studies concluded that, on average, children and young people with physical illnesses such as arthritis, diabetes, asthma and epilepsy experience lower levels of self-esteem compared to healthy peers (Pinquart 2013). Impaired self-esteem was found to be greater in adolescents and girls (Pinquart 2013). An additional meta-analysis (Pinquart & Shen 2011) integrating the results of 569 studies, found that chronic illness was also a risk factor for higher levels of behavioural problems, such as anxiety, depression and aggression. The authors suggest that such difficulties may be the result of peer rejection, (particularly if the illness is visible), frightening physical symptoms, (for example, hypoglycaemia), or illness related frustrations such as being teased (Pinquart & Shen 2011). The findings from these two investigations (Pinquart 2013; Pinquart & Shen 2011) appear reliable and valid. Each one was conducted rigorously – that is, both unpublished and published literature was accessed and search strategies, sampling decisions and effect sizes are clearly presented.

A meta-analysis involves the use of standardised procedures to integrate and summarise statistically the findings of large numbers of quantitative studies that investigate a specific topic (Bryman 2012). Outcomes from a meta-analysis may include for example, a more precise estimate of the overall effect of a treatment or of risk factors for disease that may not have been apparent in individual studies using smaller samples. As such,

they can serve as an important tool for research utilisation (Polit & Beck 2006). The studies described above by Pinquart (2013) and Pinquart & Shen (2011) provide clinicians with important information about the processes that can mediate the effects of chronic illness on a child's psychological well-being. This in turn, may help practitioners to develop and deliver appropriate psychosocial prevention and intervention programmes to support children and their families more effectively (Pinquart 2013). However, the value that such work necessarily places on objectivity, measurement, quantification and generalisability, means that central issues relating to context, meaning and perceptions may be neglected as well as the variations that might occur between individuals. Therefore, by so doing, the full "nuanced complexity" of the illness experience is missed (Darbyshire et al 2005: 467). These shortcomings have contributed to the dominance of quantitative approaches in understanding chronic ill health in childhood being increasingly questioned in recent years (Brady et al 2015). In addition, as previously highlighted, there is a growing recognition of the need for and value of health-related research that is both child-focussed and which also promotes a child's right to be heard and to express their views (United Nations 1989; DH 2002). This interest has been fostered in particular by the sociology of childhood (James & Prout 2015). Key features of this theoretical paradigm include conceptualising children as subjects or participants of enquiry rather than mere objects of concern and as knowledgeable social actors who actively and competently participate in shaping their social worlds through their interactions with others (James & Prout 2015). In the context of chronic illness, therefore, children are recognised as key informants in relation to their own lives and as more than competent to provide valid and valuable insights into their own condition (Darbyshire et al 2005).

As a result of these developments, in the past few decades research investigating children's and young people's experiences and understandings of health and illness has increased (Brady et al 2015). Nevertheless, previous research has argued that overall the perspectives of younger children remain under-researched (Earle et al 2006; Gannoni & Shute 2009; Spratling et al 2012). Instead, there has been a tendency to focus more on the experiences of teenagers or proxy accounts from parents (Christensen & James 2008; Gannoni & Shute 2009; Sutcliffe et al 2003). However, the concerns of teenagers are unlikely to reflect those of younger children as a result of differences in physical and cognitive development, experiences and social competencies (Christensen & James 2008). Moreover, others argue that it is a mistake to assume that children experience a

phenomenon in a similar manner to their parents(s), or that the latter are fully aware of and thus able to provide a comprehensive account of their child's views (Bergnehr & Nelson 2015; Gannoni & Shute 2009).

A range of reasons have been cited for the lack of attention that has been given to the child's voice in research. For example, Sartain et al (2000) suggest that a reluctance to seek out children's own unique perspectives may be especially true for those with chronic illness because they are frequently associated with potentially negative outcomes and uncertain futures. As such, parents themselves may not want to talk about their child's illness and, driven by a desire to protect them, may not encourage their children to talk either. Others (Alderson 2000; Mayall 2002) argue that within the medical field in particular, traditional views of a stage-like progression in children's cognitive development, typically dominates thinking. As a consequence, there has been a tendency to start from a presumption of incompetence in younger children (Woodgate 2001). Therefore, younger children's abilities to express views that are interesting and relevant are often underestimated or considered untrustworthy (Mayall 2002). As a result, their views may be overlooked (Sutcliffe et al 2003) or disregarded (Curtis et al 2004). However, seeking out their perspectives may be especially relevant for children with a chronic illness such as diabetes. Not only do they experience sustained contact with health care services over many years, but also they possess a "reservoir of expertise" (Roberts 2008) about how their lives are affected by their condition. Therefore, research that elicits information directly from these children is too important to disregard.

#### **2.4 Children's experiences of T1DM**

The lack of younger children's own views about T1DM and its management has been highlighted in previous literature (Alderson et al 2006; Herrman 2006; Sutcliffe et al 2003). However, this gap in knowledge has begun to be addressed more recently. The literature search identified five studies that had a clear and significant focus on the experiences of pre-adolescent children with T1DM. Three were conducted in the UK (Curtis-Tyler 2012; Miller 1999; Sutcliffe et al 2003), one in Brazil (Sparapani et al 2015) and one in America (Nabors et al 2003).

Two studies (Curtis-Tyler 2012; Sutcliffe et al 2003) explored children's understanding of T1DM and their experiences as partners in their own diabetes care. Despite the young age of the participants, both of these investigations highlighted not only how

knowledgeable many of the children were in terms of understanding their own condition, but also their active and reliable role in managing aspects of their treatment. For example, some children as young as four years old were able to do their own blood tests and insulin injections, could understand and explain their condition to others and recognise and interpret bodily sensations associated with hypoglycaemia themselves (Curtis-Tyler 2012; Sutcliffe et al 2003). Nevertheless, not every child was adept at sharing the management of their care and overall the age at which a child took on responsibility for this varied considerably (Sutcliffe et al 2003). Issues of time and convenience, rather than age, were found to influence the extent to which care was shared with other family members (Curtis-Tyler 2012). Both studies also described how children learned about and understood their condition via their everyday experiences of their illness, bodily sensations and social relationships with others. However, by way of contrast, Curtis-Tyler (2012) found that in the clinic setting, T1DM was understood and discussed differently - that is, in primarily biomedical terms and in ways that neglected children's social contexts and which relied on proxy accounts from their mothers. Thus, children's position during these consultations was largely peripheral and passive. This differed from their active participation in their treatment at home (Curtis-Tyler 2012).

Across most of the studies that were identified (Miller 1999; Nabors et al 2003; Sutcliffe et al 2003; Sparapani et al 2015), a number of common themes were found. A key feature to emerge from these accounts was the personal inconvenience, disruption and physical discomfort that treatment caused (Miller 1999; Sutcliffe et al 2003; Sparapani et al 2015). For example, children particularly disliked the pain associated with blood glucose monitoring and insulin injections (Miller 1999; Sparapani et al 2015) and most were unhappy about the dietary restrictions it imposed (Miller 1999; Sparapani et al 2015; Sutcliffe et al 2003). The desire to be seen as "normal" (Miller 1999; Sparapani et al 2015; Sutcliffe et al 2003) and the ways in which structures within school could challenge this were also prominent, particularly in relation to inflexible school routines and teachers' lack of knowledge about diabetes (Nabors et al 2003). In an effort to protect and promote their "sameness", some children did not like their peers to know about their condition (Sparapani et al 2015; Sutcliffe et al 2003), whilst others altered their regime by omitting snacks or skipping insulin injections (Miller 1999).

Overall, these studies provide some useful insights into what it may be like for children to experience T1DM, particularly in terms of the social and practical difficulties that they may face in the context of everyday life. Moreover, the studies by Curtis-Tyler

(2012) and Sutcliffe et al (2003) draw attention not only to what young children can “do”, but also how their expertise about their condition may be affected by issues of power and their relationship with adults in particular settings (Curtis-Tyler 2012). However, there are a number of methodological weaknesses in some of these studies. For example, only limited information is given about the characteristics of participants in two of the investigations (Miller 1999; Sparapani et al 2015) and overall, few of the researchers included a critical examination of their own role, biases and influence on the research process. As such, confidence in both the trustworthiness of the findings and their transferability to other settings is reduced (Polit & Beck 2006). However, of particular significance to the context of this current investigation is that the majority of participants in all of the studies reviewed were using MDI regimes. Only two (Curtis-Tyler 2012; Sutcliffe et al 2003) included children who were using insulin pump therapy. Moreover, the numbers were small - that is, two children (aged 8 and 9 years) in the study by Curtis-Tyler (2012) and just one (aged 11 years) in the research conducted by Sutcliffe et al (2003). The accounts from these children revealed the convenience of CSII therapy (Curtis-Tyler 2012; Sutcliffe et al 2003) as well as their advanced levels of skill and competence in managing their own care (Sutcliffe et al 2003). Moreover, whilst the descriptions of children using MDI regimes stressed the disruption that their condition imposed on their lives as well as their sense of difference, no such concerns were expressed by those using CSII therapy (Sutcliffe et al 2003). These findings suggested that despite the increased demands associated with CSII therapy, children may still experience this form of treatment positively. However, detailed accounts of their specific experiences were limited. As a consequence, Sutcliffe et al (2003:47) concluded that “further research to find out the benefits of being on a pump in relation to children’s concerns would be useful” (Sutcliffe et al 2003:47). The extent to which this has been addressed to date in other literature is discussed in the following sections of this chapter.

## **2.5 Children’s experiences of living a technology assisted life**

As highlighted previously, technologies are an important feature of CSII therapy. Therefore, this next section turns its attention to a consideration of literature that explores the experiences of children who use other medical technologies to manage different health conditions. By so doing, a further dimension is added to understanding the context within which this current study was conducted.



In the past twenty years, advances in medical technology and care have enabled increasing numbers of children with complex health care needs to not only survive but also to live at home with their families, rather than in hospital (Halfon & Newacheck 2010). In the literature, many of these patients are described as being “technology dependent” (Wang & Barnard 2004:38) or “medically fragile” (Spratling 2012:118). These terms relate specifically to children who have extensive needs in that they require not only medical equipment for the sustenance of “vital body function” (Wagner et al 1988:3) but also continual, comprehensive care for the prevention of further morbidity or death (Mentro & Steward 2002). Many require frequent hospital re-admissions, numerous clinic visits and significant levels of nursing and medical care every day in order to address their needs (Earle et al 2006). Technology-dependent children represent a diverse group and their need for technology may vary in terms of the type and number of devices they require, as well as their level of dependence on it (Wang & Barnard 2004). For example, children may be reliant on “high-tech” technologies such as mechanical ventilation that is used continuously and which requires the constant presence of highly trained carers. Conversely, they may use relatively “low-tech” devices such as those required for a colostomy, which demand less frequent nursing support (Wang & Barnard 2004:38).

Similar to much of the qualitative literature on chronic illness in childhood, research studies that specifically consider the perspectives of pre-adolescent children who are described as technology-dependent are equally limited. Instead, the emphasis has been on reporting the views of either parents (Kirk et al 2005; Montagnino & Maauricio 2004; Toly et al 2012) or the experiences of families as a group (Noyes 2006; Heaton et al 2005). In many of these studies, the phenomenon of “caregiver burden” and the hardships and everyday life stressors associated with caring for a medically fragile child is emphasised (Mentro & Steward 2002).

Of the few studies found that focussed exclusively on the child’s perspective, several investigate experiences of technologies that provide respiratory assistance (Earle et al 2006; Noyes 2006; Spratling et al 2012). For example, Earle et al (2006) explored the views of five Canadian children/teenagers (ages 4.5-17 years) who required home ventilation devices such as BiPAP (Bi-level Positive Airway Pressure). Four of the children used this only at night. Children described their physical and emotional relationship with the ventilator as “okay” and regarded it as only one small part of their lives (Earle et al 2006: 270). Other themes related to children’s positive hopes for the

future, wanting to be seen as a normal child and the importance of school and developing friendships in fostering this desire. Similarly, an American study by Spratling et al (2012) explored the perspectives of five children aged between 6 and 12 years old who were living with a tracheostomy. Friends were also prominent in these children's accounts. However, in contrast to the study by Earle et al (2006), this was related in particular to the significant amount of practical help they provided for the children in the school setting. Two additional themes identified were concerned with the importance of educating others about their condition and feelings of "being the only one" (Spratling et al 2012:122). The latter theme was related to children's concerns about not knowing others with a similar condition, rather than feelings of difference. The findings from these studies (Earle et al 2006; Spratling et al 2012) extend understanding of the impact that medical technologies may have in a child's illness experience, particularly in terms of their influence on social relationships and the role that friends may play in supporting children's well-being. However, as previously stated, the medical needs of the children in these two studies were complex, aside from those associated with the technology they depended on. As such, their illness and treatment experiences may be different from those with chronic illnesses such as T1DM who generally require less intensive care and support (Wang & Barnard 2004). Moreover, the complexity and visibility of the technologies used in CSII therapy are unlike those required for children needing respiratory assistance. Therefore, the extent to which findings can be transferred to children using insulin pump therapy is unclear.

As a result of these limitations, the literature search was extended to include an examination of the experiences of children with other medical conditions and who were using different types of technologies. One study (Kirk 2010) in particular was found that addressed some of these issues. This investigation was conducted in the UK. The aims of this research were to explore how children and young people (n=28) experienced a variety of different medical technologies as well as the ways in which these devices influenced identities and social relationships. As such, this investigation was of particular interest to me because it reflected something of the nature of the original disturbance described in Chapter 1 that prompted this current investigation. One or more of the following technologies were used by each participant - mechanical ventilation, tracheostomy, oxygen therapy, enteral/parenteral feeding, peritoneal dialysis or intravenous therapies. Children's / young people's accounts revealed that "living an ordinary life" (Kirk 2010:1798) was an important goal. Furthermore, regardless of age

and the type of device being used, the predominant meaning that they ascribed to the technology was one of ambivalence. As such, they were regarded as having both enabling and disabling effects on the participant's lives. For example, whilst the technology was valued for its ability to sustain and improve the health of patients, it was also experienced as an ongoing source of discomfort and intrusion. Moreover, it was found that the presence of the technologies posed a threat to identities and as such, many of the participants engaged in ongoing strategies to "normalise" their bodies and their lives (Kirk 2010: 1796). For example, treatment strategies were sometimes altered to allow them to take part in everyday activities and some children/young people were selective about the information they gave to their peers about their condition.

The findings of Kirk's study (2010) suggest that whilst medical technologies may bring profound benefits, they may also carry a sense of ambivalence and influence notions of selfhood. By so doing, children may have to actively employ strategies in order to incorporate them successfully into their identities and everyday lives. However, a number of issues influence the usefulness of the findings in relation to the context of the study presented here. Firstly, only children over 8 years old were interviewed and the majority of participants (n=19) were aged between 12 to 19 years. As previously discussed, younger children's concerns may differ from teenagers' (Christensen & James 2008). This may be especially the case in relation to identity development and the particular challenges that the older age group are known to experience with this (Bee & Boyd 2004). Moreover, similar to much of the other literature, the views of children and young people were considered together and comparisons made between each age group are limited. Furthermore, the majority of technologies analysed were implanted devices that were either hidden completely or revealed only when children/young people undressed and their use was mostly contained to home and night-time. However, this differs from insulin pump technology that is not only attached to a child's body continuously but also it has to be used frequently during the day and sometimes at night. As such, it is possible that its constant physical presence may contribute to making a child's condition more "visible" which in turn may influence strategies used by them to maintain the appearance of normality. Moreover, the high levels of intervention required may potentially stigmatise children by marking them out as different from their peers and thus may carry additional implications for their daily life experiences and developing personal and social identities. Therefore, the ways in which the findings that Kirk (2010) highlighted apply to both younger children and to those using CSII therapy

is uncertain. This suggested that research investigating these social realities and the extent to which insulin pump technology is regarded by children as “friend or foe” would be of value.

## **2.6 The sociology of medical technology**

The overwhelming presence of technologies in modern society has led to the suggestion that human existence itself is so thoroughly intertwined with machinery and equipment that it has become “technologically textured” (Ihde 1990:1). Within healthcare, new medical technologies are constantly being developed and increasingly deployed not only within the hospital setting but also in the home environment (Nettleton 2013). However, despite this shift from “biographical medicine” to “techno-medicine” (Pickstone 2000), it has been suggested that instrumental, deterministic characterisations of technology has tended to dominate the biomedical model of health (Sandelowski 2002; Zitzeilsberger 2004). As such, technologies are commonly assumed to be little more than tools that are there to be used as a resource by clinicians and which are largely inert, neutral “things” that do nothing in themselves (Ihde 1990). Consequently, analysis of medical technology generally is primarily concerned with investigating the functionality and efficiency of purpose of medical devices, rather than inquiry into the ways in which they may be experienced by users within a relational context (Zitzeilsberger 2004).

However, within the discipline of sociology, the central role played by technologies and the rapid pace of technological innovation in healthcare has generated a plethora of questions and issues that researchers are keen to study (Nettleton 2013). As a result, sociological literature (both theoretical and empirical) on health technologies is substantial. Much of this work is associated in particular, with science and technology studies (referred to by the acronym STS). STS reflects an area of study that is both diverse and innovative in its approaches (Sismondo 2010). Its overall focus is on examining not only technology but also science and more specifically, the notion that both are social products - that is they are socially shaped and patterned by the circumstances of their creation and use (McDonnell et al 2009). In relation to medical technology, STS perspectives raise a range of important issues concerning its place and use within health and healthcare. While there are theoretical distinctions between the different approaches, common to most is the methodological principle that the use of technology in everyday lives and practices should not be taken for granted. Instead,

technology is problematised and taken seriously when exploring both health and social phenomena (Nettleton 2013). The following discussion explores a few key aspects of this work that has particular relevance to the context of this present study.

### *Theoretical perspectives*

There are a range of theoretical perspectives that are influential in the sociological analyses of medical technologies. Timmermans & Berg (2003) usefully identify three that feature on this continuum and which have gained prominence in recent years. The first two focus primarily on the social impact of medical technologies, whilst the third approach privileges a more dynamic interplay between technology and society (Sismondo 2010).

Technological determinism is an approach that conceptualises medical technology as largely neutral and as such, tends to exclude it from analysis (Nettleton 2013). In particular, technologies are regarded as all powerful and primarily harmful to society (Timmermans & Berg 2003). For example, reproductive technologies such as In Vitro Fertilisation are seen to fuel oppressive patriarchal control over childbirth (Nettleton 2013). However, this view has been uniformly criticised for its reductionist approach and tendency to “ascribe super technological powers to tools and practices” (Timmermans & Berg 2003: 100) that do not stand up to empirical scrutiny. By way of contrast, a social essentialist approach regards medical devices as blank slates on which individuals or groups impose their own meanings and interpretations (Nettleton 2013). They function, therefore, as “sociological catalysts” that “generate interactions or social meanings but do not act, affect, or evolve in themselves” (Timmermans & Berg 2003:101). As such, similar to technological determinism, technologies are presumed to be neutral, passive and separate from people. Moreover, the focus of this approach is on exploring the social processes by which technologies are rendered meaningful and as such, it has been criticised for failing to unpack “what is technological in medical technologies” (Timmermans & Berg 2003:103). As a result of these limitations, there has been a turn more recently towards an alternative framework labelled as “technology-in-practice” (Timmermans & Berg 2003:103).

Technology-in-practice reflects a more complex and dynamic approach towards analysing the role of technology and draws on the theoretical traditions of STS. In this literature, devices are typically conceptualised as active players in medical encounters and as such, the emphasis is on understanding what technologies *do* and how they

contribute to social relations and processes involved in illness and its management (Prout 1996). These ideas are grounded in Actor Network Theory that not only questions what “things” are, but which also presumes that both human and non-human “actors” can create or “enact” social outcomes and processes (Nettleton 2013). The metaphor of a “network” is used to capture the way in which this is achieved. Thus, all entities - including technologies, machines, individuals, and groups – are considered to exist in relation to each other (Nettleton 2013). By so doing, they mutually “shape each other in complex knots” (Michael 2000:5) via ongoing actions and interactions (Sismondo 2010). For example, in an exploration of clinician’s use of rapid appraisal technologies such as surgical robots, spinal implants and smart infusion pumps, Ulucanlar et al (2013) suggest that a range of socio-technical factors interact to produce technology “identities”. These gave each device a distinctive character that was socially constructed and contingent and which actively mediated their desirability, acceptability and adoptability. Similarly, Prout’s (1996:198) classic work concerning metered dose inhalers (MDI’s) for the treatment of asthma found that the design and implementation of this device were influenced by “a shifting network of socio-technical relations”. Issues related to compliance and social control was central to this process. For example, misuses of the inhaler by patients shaped the ways in which technicians were required to modify its design. Similarly, the MDI itself reconfigured power relations between clinicians and users by granting a level of autonomy to the latter in the treatment of their own condition. Nevertheless, at the same time, biomedical control was maintained by the “metering abilities of the MDI which in turn encoded biomedical judgements, concerns and purposes” (Prout 1996:207).

This literature brought a sociological perspective to the research problem that I had yet to consider. In particular, it suggested the value of thinking critically about the medical technologies used in CSII therapy. More specifically, technology-in-practice theory conveyed the possibility that these devices might occupy an active role, that their use could be influenced by context and practical concerns and that both the technology and the children who use it might co-create, shape and reshape each other (Prout 1996). As such, when applied to research, devices become an empirical issue and thus, part of the analytic agenda.

### *Empirical research – recent developments*

As previously highlighted, there is now a substantial body of sociological empirical work exploring the dynamic relationship between health technologies and society. Much of this literature examines technologies that are used within the hospital setting and which are defined as complex and advanced (Timmermans & Berg 2003). For example, biotechnologies associated with genetics, tissue engineering and stem cell research features strongly and has provoked numerous moral and ethical questions that demand consideration (Nettleton 2013). However, more recently, social science authors have become increasingly interested in investigating the sociological impact on an array of smaller, commonly used and seemingly mundane, home-care technologies. In this literature, these devices are typically referred to as personal health technologies (PHT's) or near-body devices (Fox 2017) that are designed to be used by a single individual, primarily outside of healthcare facilities. They are also mobile (that is wearable, implanted or carried) and “enable users to monitor physiological processes or body activity, are frequently communication-enabled and sometimes intervene therapeutically” (Fox 2017:136). Contemporary PHT's, therefore, include blood pressure monitors, self-tracking devices such as *Fitbit* and *Nike Fuelband*, cardioverter-defibrillators (ICD's) and pumps for delivering therapeutic doses of drugs such as insulin and analgesia (Fox 2017; Lupton 2014).

The potential for such technologies to improve patient outcomes, (particularly those with chronic illness), reduce healthcare expenditure and enhance personal wellbeing via for example, self-monitoring of fitness levels and other bodily functions, is frequently emphasised in both the media and medical/public health literature (Lupton 2014). However, sociological research offers a different and more critical perspective. For example, focussing on adult's experiences of “place”, Oudshoorn (2011:135) found that the beeping sounds made by ambulatory ECG recorders were experienced as “disruptive actors” that made patient's heart condition apparent to others. As a result, patients' relationship with public spaces changed such that shopping malls and trains were transformed “into scary spaces in which patients' failing bodies were exposed to others” (Oudshoorn 2011:135). Similarly, blood glucose monitors for patients with T1DM have been shown to demand much from their users and create a sense of failure when the data generated from them indicate poor glycaemic control (Mol 2009). However, the participants in these texts are usually adults rather than children. Moreover, I could find only one article that specifically considered insulin pumps. In this paper, Fox (2017)

adopts a materialist perspective in order to critically discuss four specific PHT's – namely, blood pressure monitors, *Fitbit*, ICD's and insulin pumps. In relation to the latter, Fox (2017) suggests that this particular technology removes patients' responsibility for self-management because users simply have to wear a device and follow any instructions it provides. As a result, he argues that a previously “expert” patient with sophisticated understanding of their condition and treatment is replaced with someone who is “dumb” and “passive” (Fox 2017: 142). However, whilst intriguing, the focus of the article by Fox (2017) is on exploring the micro-politics that surround PHT's and their use, rather than patient's lived experiences of them. As such, its relevance to the context of this study is debateable.

Thus, it would seem that to date, the technology used for CSII therapy and children's experiences of it has largely escaped the sociologist's eye. This gap in knowledge suggested that a study that incorporated an understanding that these devices are more than just pieces of machinery and which recognised that their relevance and meaning *might* lie in the practical circumstances in which they are used, could contribute important insights to the existing sociological literature on PHT's. This in turn, could generate a deeper understanding of the full impact that CSII therapy might have for children and bring a sociological sensitivity to the study of this treatment strategy that has yet to be considered in the current medical literature.

The next section of this chapter returns to the paediatric medical literature and examines in detail what is known to date about children's experiences of insulin pump therapy.

## **2.7 Children's experiences of CSII therapy**

For this part of the review, a structured process was followed in order to not only search and critique current literature that specifically investigated CSII therapy in childhood but also to identify any gaps in the existing research base. The search terms that were used are highlighted in Figure 1 and an account of the strategies that were followed to identify and appraise relevant work is documented below.

Studies that were identified electronically using combinations of the search terms and through snowballing strategies were retrieved and critically appraised if the following criteria applied:

- Study samples included children with T1DM.



- Children were defined as pre-adolescent, primary school-aged children between 5 to 11 years.
- Studies reported the child's perspective/views/experiences of their treatment either independently or in association with biomedical outcomes.
- Studies were in English in order to prevent translation bias.

Studies that investigated the experiences of families as a whole or which reported exclusively on the views of parents or teenagers/young adults, were not the focus of this current study and as such were not included in the literature review. Moreover, since the Diabetes Control and Complications Trial (DCCT 1993), not only has the management of T1DM altered dramatically but also insulin pump technology itself has advanced significantly, particularly in terms of its safety and size (Rodgers 2008). Therefore, on this basis, I decided to include only those studies from 1993 to the present day as earlier studies would have reflected not only different clinical practice but also obsolete technology and as such, children's experiences of CSII therapy.

After application of the eligibility criteria, eleven studies were found that related specifically to children's experiences of CSII therapy - five described the combined views of children/young people using this treatment (Barnard et al 2008; Ferrari et al 2016; Low et al 2005; Maniatis et al 2001; Orlander et al 2007) and six investigated quality of life in combination with biomedical outcomes (Cohen et al 2003; Juuliusson et al 2006; McMahon et al 2004; Nuoboer et al 2008; Skogsberg et al 2008; Weintrob et al 2003). The findings of each paper retrieved were reviewed using the critical appraisal checklists for randomised controlled trials, cohort studies and qualitative research produced by the Critical Appraisal Skills Programme (CASP 2017). These design specific tools not only prompted me to ask the most relevant questions for each paper, but also ensured a consistent approach. As such, they were considered preferable to other more generic appraisal tools available.

Overall, the review revealed numerous studies that investigated CSII therapy and its impact on biomedical outcomes, particularly in terms of its effect on glycaemic control and frequency of hypoglycaemia and DKA. Quantitative studies dominate this body of work. For example, a recent Cochrane review (Misso et al 2010) reporting data from 7 paediatric randomised controlled trials (RCTs) conducted primarily in North America, concluded that CSII therapy provided better metabolic control compared to children/young people using MDI. This was also demonstrated by a Health Technology

Assessment review (Cummins et al 2010) which reported evidence from a wider range of sources including RCTs, observational studies and representations from parents and industry. A statistically significant decrease in the incidence of hypoglycaemic events was also shown in this study.

Although important, biophysical outcomes such as these do not necessarily reflect children's personal experiences of managing insulin pump therapy or capture the psychosocial contexts that may contribute to these. In an attempt to address this, some studies have incorporated quality of life (QoL) measurement as secondary (rather than primary) aims of their investigations. Six studies were identified in the literature search that measured QoL in this way and which included only children and adolescents aged between 4 to 19 years. Four RCTs compared CSII therapy with MDI (Cohen et al 2003; Nuboer et al 2008; Skogsberg et al 2008; Weintrob et al 2003), and two observational studies prospectively followed children after starting CSII therapy (Juuliusson et al 2006; McMahon et al 2005). All of these investigations used self-report questionnaires to collect data. The Diabetes Treatment Satisfaction Questionnaire (DTSQ) (Bradley 2013) and/or The Diabetes Quality of Life Questionnaire for the Young (DQOL-Y) (Ingersoll & Marrero 1991) were the tools most frequently used. The DTSQ consists of eight questions designed to measure satisfaction with diabetes treatment regardless of the type of therapy used. The DQOL-Y uses 51 questions to rate life satisfaction, impact and worries associated with T1DM. Both questionnaires have been shown to be valid, reliable and sensitive to clinical change (Bradley 2013).

Findings from the studies that were identified suggest that overall, treatment satisfaction was high for those using CSII therapy (Cohen et al 2003; Juuliusson et al 2006; Skogsberg et al 2008; Weintrob et al 2003). For example, Juuliusson et al (2006) found that adolescents' satisfaction with pump therapy was related to more freedom and flexibility in their lives, (particularly in relation to meals), reduced feelings of dependency and greater ability to self-care. However, the impact of CSII therapy on QoL outcomes was mixed. In three of the RCTs (Cohen et al 2003; Nuboer et al 2008; Weintrob et al 2003) there were no significant differences in QoL outcomes between treatment groups, whilst one study (McMahon et al 2005) found that the impact of diabetes score fell for patients. However, this latter study also reported that worries about diabetes and satisfaction with life remained unchanged (McMahon et al 2005).

QoL has been defined as a multi-dimensional and primarily subjective assessment of life that reflects “an individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organisation Quality of Life Group 1998:15570). Over the past three decades, this construct has increasingly become an important focus of health care research and it is generally accepted that assessment of clinical trials and evaluation of illness outcomes are strengthened by measurement of the impact on QoL in addition to biomedical outcomes (McDougall 2016). However, there are a number of methodological weaknesses in the studies that were reviewed which affect the reliability of the findings. For example, the number of participants recruited to the RCTs (Cohen et al 2003; Nuboer et al 2008; Skogsberg et al 2008; Weintrob et al 2003) was generally low (between 16-72 per study). These studies, therefore, were probably underpowered. As such, the possibility of detecting significant results would have been reduced, increasing the likelihood of type 2 errors (Polit & Beck 2006). In addition, in two studies (McMahon et al 2005; Weintrob et al 2003), the observation periods were 3.5 months and 6 months respectively. As such, this may not have been long enough for children to have fully developed the skills and confidence required to use CSII therapy to its full potential (Blair et al 2015). More importantly, whilst self-report questionnaires have some advantages over other methods such as structured interviews (for example, the possibility of anonymity), there are several challenges related to their use in children (Christie et al 2011). In particular, the majority of QoL questionnaires available have been developed based on “expert” and/or the opinion of parents rather than from children’s own reports about what QoL actually means for them (McDougall et al 2016). Therefore, the data captured by these tools reflect proxy measures which may not be truly representative of children’s actual experiences (McDougall et al 2016). Moreover, questionnaires do not necessarily take into account differences in children’s cognitive and literacy abilities (Christie et al 2011) and some may find lengthy questionnaire’s such as the DQOL-Y boring or irrelevant (Sutcliffe et al 2003). Questionnaire fatigue may also be a particular problem for younger children which may increase the likelihood of central tendency error (Polit & Beck 2006). More specifically, the DQOL-Y tool that was used by four of the studies reviewed (Cohen et al 2003; Juuliusson et al 2006; McMahon et al 2005; Weintrob et al 2003) has not been validated for children under the age of 13 years (Bradley 2013). Yet the age of participants across these studies ranged from 4-19 years. Therefore, the results of the studies that used this tool cannot be seen as valid.

The mixed evidence on QoL outcomes and the relative absence of the child's own voice in these accounts makes it difficult to arrive at any definitive judgements about how children themselves experience CSII therapy and its possible psychosocial impact. Qualitative research methods such as interviews and focus groups are recognised as some of the best methods for exploring subjective experiences in depth in order to reveal their structure and meaning (Bryman 2012). However, literature that specifically examines this in relation to insulin pump therapy in detail and from the perspective of the child / young person themselves was found to be limited, particularly for those of primary school age. As previously highlighted, the literature search identified five studies. One of these (Ferrari et al 2016) explored the combined experiences of children and teenagers aged 7 to 15 years (mean age 11.8 years) using either MDI or CSII therapy. However, the majority of the findings were presented collectively such that it was difficult to determine the specific nature of participants' experiences for either group. Therefore, this study was excluded from further analysis. The remaining four papers are reviewed in the following discussion. Two of these studies were conducted in America (Low et al 2005; Maniatis et al 2001), one in the UK (Barnard et al 2008) and one in Sweden (Orlinder et al 2007).

Of the four studies found, only one examined exclusively the experiences of children and teenagers separately from their parents (Orlinder et al 2007). This particular investigation followed a group of twelve girls aged between 7 to 15 years old (mean age 10.8 years) over a period of two years. Its aims were to not only establish their opinions and concerns regarding their treatment, but also to discover the reasons for girls transferring from MDI to insulin pump therapy. Biomedical outcomes such as glycaemic control and body mass index were also measured. The main reasons given by the girls for initiating pump therapy were due to previous experiences of unstable blood sugar control and a wish to try out this form of treatment. Both positive and negative written statements about CSII therapy were given, with greater flexibility in sleeping and eating being the most frequently cited positive aspect and the size of the pump and it "getting in the way" being the most negative feature. Nevertheless, the study concludes that the majority of the girls preferred CSII to MDI therapy. However, one eight year old girl was reported to have discontinued pump therapy after five months because of pain related to cannulas and a dislike of being questioned by peers about the pump.

Although this study by Orlinder et al (2007) considered the views of children/ teenagers over an extended period of time, only the views of girls were sought. Moreover, questionnaires and a visual analogue scale were the main instruments used to collect data. The latter was used to determine treatment satisfaction by asking participants to tick on a scaled line whether they preferred MDI or CSII. The former included just two open ended questions that asked girls for positive and negative statements only about their treatment. Therefore, details about their wider experiences are limited. Moreover, visual analogue scales are subject to response set biases that are created by a range of factors such as the effect of social desirability in respondents' answers or a tendency to select extreme response alternatives (Bryman 2012). In this study, questionnaires were administered to girls in the presence of their parents and at the time of a routine appointment with their diabetes nurse. Therefore, it is possible that the former in particular may have influenced the degrees of satisfaction that were reported.

The three remaining studies describe the combined views of children / young people and their parents together (Barnard et al 2008; Low et al 2005; Maniatis et al 2001). However, the aims of each and the interview techniques used differ. As such, the level of detail given in these accounts concerning children's own views about their treatment varies. For example, a study by Maniatis et al (2001) explores the perspectives of fifty-two children/young people aged between 7.6 to 23.6 years (mean 17 years) and their parents. The purpose of the study was twofold – to describe daily management issues and primary reasons for initiating pump therapy as well as to assess changes in parental anxiety and involvement following their child's transfer to CSII therapy. The majority of participants and their parents cited improved blood sugar control and increased flexibility in lifestyles as the primary reasons for initiating pump therapy. However, the details relating to children's / young people's daily management of their diet, exercise, cannula insertions and frequency of blood glucose monitoring is limited and focus largely on the strategies participants were using, rather than describing how they were experiencing these particular aspects of their treatment in their everyday lives. For example, home blood glucose monitoring and the management of diet were described only in terms of the frequency this was done and the methods used to calculate insulin doses for meals respectively. Similarly, although fourteen children/young people were reported to be needle-fearful, no descriptions were given about the meanings this had for them or the actual ages of those affected. Additionally, information regarding the tools used to collect data was poorly described and the views of children, young people

and their parents were not considered separately and nor were comparisons made between and within these groups.

By way of contrast, the focus of a study by Barnard et al (2008) was to identify specific components of quality of life most important to children and teenagers with T1DM (n = 15, age range 9-17years, mean age 12.07 years) and their parents and also to assess the ways in which CSII therapy positively influenced these domains. Interviews were conducted using a questionnaire and administered via the telephone. Children and teenagers' views on aspects of life most important for their QoL were found to differ from those of their parents. Family, friends and school were most frequently cited by the former whilst parents considered health and family to be the most important. Nevertheless, the overall impact of pump therapy on quality of life was positive for all of the participants. Of the 9 children in the study (mean age 10.2 years), the beneficial impact on family and friends were related to feelings of greater independence and the convenience and flexibility of the regime, particularly in relation to food and mealtimes. The positive effects on school life were also related to greater independence as well as not having to inject insulin at school. None of the children mentioned family relationships and interactions. Moreover, since the focus of the study was on the positive effects of CSII therapy on their lives, disadvantages associated with this treatment were not mentioned.

Low et al (2005) report similar findings. Using a combination of biochemical outcomes and semi-structured interviews, the psychosocial issues and metabolic outcomes of insulin pump therapy were explored with eighteen young adolescents (age range 11-18 years, mean age 13.9 years) and their parents. Consistent with other research, modest improvements were found in glycaemic control. In addition, the authors concluded that pump use was not associated with any social difficulties and in general, both parents and teenagers reported high levels of satisfaction with the treatment. The greatest and most important benefits cited by all the participants were improved blood sugar control and greater freedom and flexibility, particularly with eating. Ease of insulin administration, greater independence and enhanced social opportunities were additional benefits described by the teenagers themselves (Low et al 2005). Of the few concerns that were reported, practical issues were highlighted rather than difficulties related to body image, appearance and self-consciousness. For example, wearing the insulin pump at night and during exercise was problematic for some and clothing and fashion was an issue for some of the teenage girls (Low et al 2005). However, the latter was in terms of

difficulties with securing and accessing the pump rather than with their physical bodily appearance.

Taken together, these studies add some detail to the more objective, measurable findings of the quantitative studies previously described. By so doing, they provide a fuller description of experiences surrounding CSII therapy in childhood from the perspectives of those who use it. In particular, its positive aspects and the ways in which it is perceived to benefit the lives of children and young people are emphasised. However, similar to the study by Orlinder et al (2007), findings are limited by a number of methodological constraints. For example, two of the studies (Low et al 2005; Maniatis et al 2001) were conducted more than a decade ago and as such, investigated the use of technologies that are now out of date. As mentioned previously, insulin pump technology has become increasingly more sophisticated in recent years (Rodgers 2008). For example, the pumps are smaller in size than their predecessors and have more advanced features that can provide additional benefits, particularly in terms of controlling blood glucose levels, accessing stored data and calculating insulin doses. Therefore, although more complex, they enable more effective blood glucose control and overall are safer to use and more discrete compared to previous pumps (Rodgers 2008). As such, the role that these newer insulin pumps play in user's perceptions and views of their treatment may differ from those studies that investigate experiences related to older models (Alsaleh et al 2012). Furthermore, in the study by Barnard et al (2008) participant's experiences were explored using The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle et al 1993). This instrument is designed specifically for the assessment of QoL. Therefore, more general experiences and views of CSII therapy were not explored. Additionally, successful completion of the SEIQoL (O'Boyle et al 1993) requires the ability to think abstractly and about aspects that determine a person's QoL. As such, its use with children under the age of 12 years has been highlighted as problematic (Wagner et al 2004). Lastly, the ages of the children / young people across all the studies varied considerably and there is limited reference to how this influenced findings. No comparisons are made across different age groups in three of the studies (Low et al 2005; Maniatis et al 2001; Orlinder et al 2007) and only one (Maniatis et al 2001) explored the experiences of children as young as 7 years old. However, in the study by Maniatis et al (2001), the average age of participants was 17 years. Only three of the fifty two participants were less than 12 years old and no details of the actual ages of these children are given. Therefore, no

studies to date have investigated the views of children younger than 7 years and overall there is a bias towards the perspectives of teenagers. As such, the voices of children who are using insulin pump therapy in the middle years of childhood remain elusive in the current literature.

This scarcity of data relating to the experiences of children using insulin pump therapy has been highlighted in a recent review of the literature (Alsaleh et al 2012). As a result, the authors of this report concluded that further research into how this form of treatment is experienced in the context of children's daily lives and social contexts is needed. Moreover, it is suggested that questions that concern in particular "social interaction, a child's autonomy in carrying out management tasks in relation to age and use of pumps at schools" (Alsaleh et al 2012: 145) have yet to be adequately addressed in the existing literature. Given the demands associated with CSII therapy, knowledge of such issues are important in order to understand more fully its social and personal impact on children's lives. As such, how children experience, are affected by and act towards a pump assisted life needs further investigation (Alsaleh et al 2012).

## **2.8 Choosing a conceptual framework for the study**

Research concerning childhood chronic illness has traditionally adopted theories grounded in cognitive developmental theory or those associated with psychological functioning and adaptation (Compas et al 2012). However, these frameworks have been criticised for taking a deficit centred perspective and for focussing largely on outcomes, such as the absence or presence of psychological symptoms or age-related competencies (Darbyshire et al 2006). Given that the emphasis of this study was to prioritise children's own perspectives of their everyday experiences of CSII therapy and to present a detailed and holistic account of them, alternative frameworks were considered to be more appropriate.

### *Technology-in-practice*

I was anxious about employing too much theory at the beginning of the study because of the risk of generating biases and preconceptions that might have prevented me from keeping an open mind (Finlay 2011). Therefore, after reading the sociological work on technology, I initially chose technology-in-practice theory to "cradle my thinking" (Dillow 2009:1343). A number of its underlying concepts were found to be useful. This was particularly in terms of the emphasis this perspective places on rendering health



technologies not only as strange, but also as active players in the illness experience, rather than taking them for granted. However, as previously discussed, technology-in-practice theory is grounded in Actor Network Theory. As such, when applied to research, a distinctive methodological approach is required. This typically involves undertaking detailed ethnographic case studies which privilege in depth description of specific objects as they travel through settings (Nettleton 2013). As such, unlike phenomenological perspectives, it not only decentres the individual but also, analysis focuses on “flows of affect” (Fox 2017: 139) within networks of human and non-human entities rather than subjective experiences, meanings and interpretations (van Hout et al 2015). Therefore, although I continued to use some of its underlying principles as a general “orientating lens” for the study, applying this theory in full proved problematic given its particular philosophical underpinnings. Moreover, as the study evolved, and the findings began to emerge, notions relating to the body in lived experience, the body-object/body-subject and the body-machine relationship as well as ideas relating to children’s agency and intergenerational relationships became increasingly significant. As a result, I chose to employ additional frameworks that drew more specifically on the work of Merleau-Ponty (1962) and the Sociology of Childhood (James & Prout 2015). Both were more in keeping with the aims of the study and its methodology and provided a useful lens through which to make better sense of children’s experiences. An examination of some of the key concepts that underpin these frameworks are sketched out in the following discussion.

### *Phenomenology and the lived body*

To speak of the body phenomenologically is to understand it in a particular way. The notion of the body as a lived entity is essential to phenomenology (Dahlberg 2011) and the idea that the body (rather than consciousness) is the “ground” or site of all lived experience and knowledge are fundamental concepts (Finlay 2006). The focus is on how it is experienced at both a subjective level (feelings, emotions, perceptions), as well as at an inter-relational one and as such, there is an emphasis on body-world interconnection (Finlay 2011).

More than any other theorist, the phenomenological philosopher Merleau-Ponty privileges the body as an active constituent in interaction and meaning making (Finlay 2006). For him, “the body is the vehicle of being-in-the-world” (Merleau-Ponty 1962:82). As such, he suggests that the body not only connects us to the world, but also

is integral to our perceptions and the processes by which people make sense of and understand their experiences of the world (Howson & Inglis 2001). Therefore, phenomenology argues for the human body to be understood as more than a biological entity or “thing”. Moreover, it rejects the Cartesian idea of a mind and body that is split into separate and distinct entities and as such, the notion that mental processes are independent from the physical world (Finlay 2011). Instead, phenomenology emphasises a holistic approach and maintains that the body and that which it perceives cannot be disentangled from each other (Finlay 2011). In particular, the notion of embodiment is used. This concept has multiple definitions across a variety of disciplines. However, phenomenological perspectives understand this term in thoroughly relational ways to signify not only the intertwining of mind and body but also to convey the dynamic and reciprocal relationship between the whole person and the external world (Einstein & Shildrick 2009). Thus, bodies are lived and experienced *in relation to* other bodies, spaces, materials and objects (Lupton 2012). They are, therefore, embedded in context. As such, bodies and world cannot be separated - they interact and are dependent on each other. The body, therefore, not only “understands” the world but also “inhabits” it (Merleau-Ponty 1962:179) and by so doing, meaning is made both corporeally and cognitively (Howson & Inglis 2001).

A further central aspect of Merleau-Ponty’s philosophy relates to the way in which he distinguishes between different modes of experiencing the body. In particular, he differentiates between the subjective body (body-subject) and the objective body (body-object). The former refers to the body as lived and felt from the inside (Galvin & Todres 2013) - that is, the emotional, thinking, perceiving body (Finlay 2011). It is, therefore, a state of being, operating silently in the background, engaging with the world and providing an “automatic and context-sensitive pre-understanding of everyday situations” (Fuchs & Schlimme 2009:572). Thus, the lived body is regarded as the source of all our subjectivity, an embodied consciousness, whereby subjectivity and corporeality are thoroughly intertwined (Howson & Inglis 2001). By way of contrast, the body-object refers to the body as known by others - that is, when it becomes a physical object for scrutiny not only by us but also others. In this case, the body becomes explicit, objectified and is experienced as a material, biological thing (van Manen 1998). Together, these two different modes of experiencing the body constitute “an ongoing, fluid and hardly noticed foundation of all experiencing” (Fuchs & Schlimme 2009:571). As such, the body, although never completely absent, is normally

not noticed very much and therefore is experienced in the mode of “near self-forgetfulness” (van Manen 1998:5).

### *The lived body and Illness*

The lived body is frequently extensively involved in many cases of illness (Svenaues 2000b). In the literature, chronic illness is typically regarded as something that is disruptive to people’s bodies, not only physically, but also in terms of the ways in which it can threaten self-identity and undermine “taken-for-granted assumptions about possessing a smoothly functioning body” (Charmaz 1995:657). Moreover, Svenaues (2000a) argues that there is an essence of the illness experience that can be understood best in terms of Heidegger’s (1962:233) notion of “unheimlichkeit” or more literally, “unhomelikeness”. For Heidegger, our being-in-the-world is always pervaded by a sense of not being quite at home in the world (unhomelikeness). Whilst this is challenging, this way of being attunes us to the world and motivates us to make sense of it. It is, therefore, a necessary and important characteristic of human existence. However, for those experiencing illness, this existential “mode” of being in the world is emphasised such that a sense of unhomelikeness is constantly present (Svenaues 2000a). When in this mode, the lived body, in particular, announces itself as “a broken tool” (Svenaues 2000b:134) and “other” (van Manen 1998) to its owner. As a result, it is no longer possible to live in a “passed-over relation” to the body (van Manen 1998:6) - that is, it becomes “present” and can no longer be taken for granted. Instead, the ill body not only obstructs and alters our “thrownness” (Heidegger 1962: 174) in the world, but it also becomes an object for our conscious attention. It is then, transformed from a lived body to object-body (van Manen 1998). Illness, therefore, is much more than just physical symptoms, diagnoses and treatments. It also involves a “changed physiognomy of the world” (van Manen 1998) and as such, the loss of “easy and unmindful living” (Dahlberg 2011: 25).

### *The Sociology of Childhood*

During the 1990’s, an alternative theoretical framework for the study of childhood emerged within sociology. This “new” sociology of childhood challenged dominant psychological accounts of child development as well as socialisation theory which conceptualised children as outcomes of social processes (Prout 2000). Both these perspectives positioned children as passive, incompetent and incomplete (James & Prout 2015). Instead, the contingent character of childhood is now emphasised by

highlighting this as being socially constructed (Morrow 2011). As such, children's roles and activities as well as childhood itself, is understood to vary across different socio-cultural contexts rather than being seen as a single, simple phenomenon (James & Prout 2015).

As highlighted previously, a number of key features underpin this perspective. However, Brady et al (2015) argue that two of these are of particular significance to research studies that explore child health and well-being. Firstly, children are viewed as a specific (minority) group, rather than simply an age-range (Morrow 2011). As such, they need to be understood in relation to other social groups. Therefore, the ways in which children's lives are structured through their relationships with adults (intergenerational relations) and how they are listened to and taken account of in different social settings, including school and at home, are central topics that need to be considered in order to understand children's experiences of dealing with health and illness (Brady et al 2015). Secondly, the concept of agency is a core issue such that children are perceived as active, social agents who shape the social structures and processes around them (Morrow 2011). To advance understanding of child health, therefore, attention should be paid to how agency is not only enacted by children but also how this may be constrained or affected by "structural" factors – that is, specific settings, practices and policies (James & Prout 2015).

Conceptualising childhood as socially constructed reflects the epistemological and ontological concerns that underpin constructionism (James & Prout 2015). This is a philosophical approach that is based on the idea that "reality" is negotiated in everyday life through people's interactions and interpretations with each other and their environment. Reality, therefore, is socially constructed and as such, regarded as ongoing, dynamic and subjective (Crotty 2009). Constructionism is based on relativist and interpretive assumptions and as such, is embodied in most qualitative research methodologies, including phenomenology (Crotty 2009). Therefore, adopting the sociology of childhood as an additional framework was considered to be consistent with the methodology used in this study. Moreover, this approach aims to privilege children's "voices" by emphasising that "their social relationships and cultures are worthy of study in their own right, independent of the perspective and concerns of adults" (James & Prout 2015:7). This reflected the focus and central aims of the study and thus provided an additional important reason for its use.

The ways in which the conceptual frameworks that were chosen helped to inform the study and illuminate its findings are discussed in Chapter 5.

## **2.9 Summary**

This chapter has presented an analysis of a range of both clinical and theoretical literature related to the topic of CSII therapy in childhood. Since it is inappropriate for a researcher conducting a phenomenological study to predict its outcome, the literature I reviewed prior to data collection did not include research that I thought *might* be relevant to potential findings. Instead, this work was accessed as the findings emerged and is considered in a later chapter.

Overall, the review revealed that there is a dearth of research that investigates younger children's own perspectives of CSII therapy. Moreover, of the few studies that have included this age group, no research could be found that described their experiences in depth or separately from those of teenagers and/or their parents. As such, an understanding of their unique perspective of insulin pump therapy is currently incomplete. Similarly, unlike the considerable amount of empirical work investigating the biophysical outcomes of CSII therapy in childhood, the general impression to date is that knowledge about its impact on children's lifeworld is unclear and limited in the amount of detail given. In addition, the existing psychological literature and research exploring experiences of MDI regimes, suggests that children with T1DM may experience their condition negatively. Moreover, studies that explore children's experiences of other medical technologies indicate that living a technology assisted life may influence identities and social interactions with peers. However, in the CSII related literature, there is a bias towards reporting only the positive outcomes and experiences associated with this treatment strategy. Furthermore, issues related to children's autonomy, agency, identity, experiences in school and interactions with family and friends have yet to be addressed. Therefore, further research would be beneficial in order to gain a more complete understanding of its existential impact.

Given the demands of insulin pump therapy, the ambiguities and omissions in current research findings and the increasing numbers of children in the UK commencing this therapy, there appears to be a need for alternative ways of evaluating it. In particular, research that respects the younger child's right to voice their own views of this treatment without being constrained by pre-determined concepts set out in questionnaires is required (Alsaleh et al 2012). Moreover, qualitative studies that give a

detailed and holistic understanding of the nature and range of children's experiences and which recognises the context within which medical technologies become workable and integrated into people's lives would make a useful contribution to the existing evidence base. Given this context the following research question was proposed:

*How do children aged 5-11 years with Type 1 diabetes experience and respond to insulin pump therapy in the context of their everyday lives?*

The study presented here attempts to address this question. To my knowledge, it is unique in that it is the first to examine specifically and in detail pre-adolescent children's experiences of insulin pump therapy from their own perspective. It reveals rich data regarding the issues children confront in the context of their everyday lives, as well as the strategies they employ to deal with these concerns. By so doing, it aims to make a valuable contribution to the current debates concerning CSII therapy in childhood.

In the next chapter, the focus shifts to consider the methodology adopted for the conduct of this study. I present my own personal worldview and detail my choice of an appropriate methodology to address the study's aims and objectives. An explanation of the methods I adopted to conduct the investigation and the ethical considerations that were required are also given. By so doing, a decision trail is provided from which readers can judge the rigour and trustworthiness of the research presented.

## **CHAPTER 3 – METHODOLOGY**

### **3.1 Introduction**

This chapter explores the many theoretical, practical, and ethical issues that informed the selection of methods that were used to enact the study as well as my choice of Heideggerian hermeneutic phenomenology as an appropriate underlying philosophical framework to address the research question. It begins with a description of my role and position as an adult researcher investigating children's worlds as well as one who adopted a qualitative research design. The philosophical assumptions underpinning Heidegger's phenomenological approach in particular will then be explored and compared to my own worldview. This is followed by a discussion of the ethical challenges that were addressed and the methods I employed and reflects approaches that are specific to conducting research with children. The rationale for the decisions taken is described throughout the text.

### **3.2 My role and position as researcher**

#### *The adult researcher investigating children's worlds*

For adult researcher's wishing to gain access to children's worlds, assumptions about children's agency and concerns relating to power dynamics between children and adults will influence the choice of role that they adopt (Kellett & Ding 2004). For example, researchers (notably within psychological paradigms) who view children as developmentally incomplete will typically adopt the stance of a detached observer (Mayall 2008). Conversely, others may rely on a fully involved, "least-adult" role (Mandell 1991:40) whereby the researcher endeavours to suspend all adult-like characteristics and notions of difference, such that children accept the adult as one of themselves (Mandell 1991). However, for this study neither of these roles was considered to be appropriate. A detached stance assumed adult superiority and as such did not acknowledge that the children themselves were to be active contributors to the research process but rather, simply passive subjects (Christensen & James 2008). Moreover, attempting to become "one of the children" seemed unrealistic and suggested that the power issues that inevitably exist in the adult-child relationship could be glossed over (Kellett & Ding 2004). Instead, I adopted a position that situated itself in between these two extremes. Thus, I invited children directly to help me to explore and understand what it meant for them to be a young child using insulin pump therapy in the context of their everyday lives. To do this, I endeavoured to present myself as someone

who, as an adult, did not have this knowledge and that, although I had experiences of being a child myself and knowledge of pump therapy as a specialist nurse, these understandings were incomplete (Mayall 2008). Conceptualising the role of the researcher in this way respected children as experts in their own experience of CSII therapy, whilst also recognising the need to work with power imbalances, rather than pretending that they did not exist or assuming adult superiority.

### *Researcher subjectivity*

This study used a hermeneutic phenomenological methodology to generate an interpretive description of children's experiences of pump therapy. An intrinsic feature of this approach is that the researcher "acts as the main research instrument" (Holloway & Galvin 2017). As such, there is an acceptance that they are a central figure who influences every stage of the research process, including how data is gathered, interpreted and presented (McConnell-Henry et al 2009). Therefore, research is typically regarded as co-constructed – that is, produced collaboratively by participants, researcher and their relationship (Finlay 2002). Thus, for this investigation, unlike the detached and value neutral stance adopted by positivist approaches, close and personal involvement was a pre-requisite. As a result, it was inevitably conducted with a degree of subjective bias.

The issue of subjectivity and the extent to which researchers should bring to the fore ground their personal experience, knowledge and preconceived assumptions (pre-understandings) about the phenomenon being studied is the subject of considerable debate in the literature (van Manen 1997). All phenomenologists concur that researchers should engage in a "phenomenological attitude"- that is, they should strive to adopt a sense of openness in order to meet the phenomenon being studied in as fresh a way as possible (Finlay 2009). However, there is disagreement about what this change of attitude involves and how it should be operationalised. Thus, some researchers aim to "bracket" or set aside personal biases in order to render themselves as "non-influential and neutral as possible" (Finlay 2009:12). However, my own position on this question reflects the stance adopted by hermeneutic phenomenologists such as Heidegger. Thus, I believe that since our own embodied subjectivity and embeddedness-in-the-world is essential for the "knowing" process, it is neither possible nor desirable to set aside or hold in abeyance prior understandings of phenomena (Heidegger 1962). Therefore, in this study, I regarded my subjectivity as a resource rather than a problem (Finlay 2002).



Nevertheless, whilst subjectivity was embraced, it was also important that I constantly scrutinised my pre-existing beliefs in order to become consciously aware of how they impacted on both the research process and also the findings (Finlay 2009). Therefore, a “dialectic movement” between restraining my subjectivity and using it reflexively as an important (but not rigid) frame of interpretive reference was utilised (Finlay 2009:11).

#### *Declaring pre-understandings*

Since I felt unable to set aside my personal experiences and former pre-understandings that related to the research topic, it is important that these are declared for the purpose of authenticity and trustworthiness (Lincoln & Guba 1985).

I approached this study as an experienced nurse who has spent the majority of my professional career working with children and young people. Since 1998, I have been practising as a paediatric diabetes specialist nurse (PDSN), caring predominantly for those with T1DM and their families. For me personally, the “essence” of this role is to promote child-centred, holistic care that focuses on understanding both the child’s and their families’ uniquely personal realities as human beings living with, experiencing and adapting to chronic illness and its treatment. Being deeply interested in children and in discovering the meanings that underpin their experiences of the world inevitably influenced the focus of enquiry and methodology that I selected for this study.

In recent years, a core component of my role as a PDSN has been to initiate insulin pump therapy for a growing number of children and teenagers. From my clinical experience and observations, I understand CSII therapy to be a demanding form of treatment, not least because of the relentless nature and sheer numbers of tasks involved in its daily management. Therefore, at the time of the study I was, (and continue to be), professionally immersed in the debates and rhetoric that surround CSII therapy in childhood. Whilst I was hopeful that this familiarity with the research topic would have some benefits, I also expected that it would have its drawbacks, particularly in terms of being able to attend openly and actively at all times to children’s views and feelings.

My overall perceptions of children and their status in society are nuanced. Thus, rather than regarding them solely in developmental terms, I perceive children to possess experiences, knowledge and competencies that are not less than adults, but which are different (Punch 2002). Moreover, congruent with the theoretical concepts expressed in the “new” sociology of childhood previously discussed, I view them as knowledgeable,

social actors shaping as well as being shaped by the world around them (James & Prout 2015). Therefore, I believe they possess interpretive competence (Christensen & James 2008) and as such, to be capable narrators of their own experiences of using CSII therapy. These views guided the decisions I made about not only the role I adopted (as previously discussed), but also the methods that I used to explore children's experiences. I address the latter in greater detail in the following sections of this chapter.

The next section describes the process of decision making that led me to choose a hermeneutic phenomenological methodology for this study, informed primarily by the work of Martin Heidegger (1889-1976).

### **3.3 Identifying an appropriate research methodology**

The overall aim of the study was to generate a holistic and empathic understanding of children's experiences of CSII therapy in the context of their everyday lives. Its emphasis was to explore the "emic" (insider) perspective and the meanings that individual children ascribed to their experiences. Researchers that privilege these ideas typically locate themselves within the qualitative research paradigm (Denzin & Lincoln 2005). However, there is no single unifying epistemology and research practice that characterises this approach (Denzin & Lincoln 2005). Instead, it straddles numerous research traditions, its focus is multi-paradigmatic and no single methodological practice is privileged over another (Patton 2002). Navigating my way through the maze of competing perspectives was daunting. However, after exploring the literature in depth and comparing the key theoretical assumptions underpinning different approaches, a phenomenological methodology was considered to have the greatest potential for addressing the concerns related to my particular question. I decided not to adopt Grounded Theory or an Ethnographic approach. Ethnography emphasises the study of culture and thus typically focuses on investigating the implicit values and traditions of groups of people, rather than individuals (Bryman 2012). Conversely, Grounded Theory is embedded within the principles of symbolic interactionism and as such, focuses on how meaning is negotiated and understood via social processes and interactions with others (Starks & Trinidad 2007). However, whilst it was likely that social processes would be involved in children's experiences of insulin pump therapy, this was not the central object of concern for this study. Moreover, research underpinned by grounded theory privileges explanation and the generation of robust and

abstract theory (Nicholls 2009b), neither of which reflected the explicit aims of my study. As such, adopting such an approach for my question did not seem appropriate.

### *Phenomenology*

The focus of interest for phenomenology is the realm of subjectivity (consciousness) and thus, how people perceive, understand and experience the world (Bullington 2013). The “lifeworld” (lived experience) and the ways in which the world “appears” (shows itself) to human beings are vital areas of study (McConnell-Henry et al 2009). The former is conceptualised as a world made up of pre-reflective, taken-for-granted experiences or “happenings” (Todres & Wheeler 2001:3) that are lived before we “know” about them. As such, it is more complex and greater than what is “seen” or “known” about. The task of phenomenology is to return to, and clarify this “continuous stream of experiential happenings” (Galvin 2010:169) that has been “blocked from sight by the theoretical patterns in front of them” (Ray 1994:118), to question it and bring it to linguistic meaning (Moran 2000).

However, the processes by which this lifeworld is revealed varies between a diverse range of approaches, each incorporating different ontological and epistemological understandings (Dowling 2011). Debates centre essentially on whether the aim is to seek out and describe the general characteristics (essence) of a phenomenon or whether to focus instead on individual (idiographic) experience via the explicit use of interpretation (Tuohy et al 2013). Below, I explore these distinctions further in terms of their relevance to this particular study.

### *Husserl and Descriptive Phenomenology*

Descriptive phenomenology primarily follows the philosophy of Husserl (1859-1938) whose life project was to establish this perspective as a rigorous science and thus reflect the objective stance adopted by the natural sciences (Bullington 2013). Husserl defined phenomenology as the study of the essential structures (essences) of conscious experience (Moran 2000) and his aim was to explore the conditions by which we come to know/discover the world as they appear to consciousness. Influenced by Cartesian dualism, he emphasised our relationship with the world as that of us as “subjects” knowing “objects” (experiences of phenomena) through a state of pure consciousness (Moran 2000). Consciousness, therefore, is the medium between people and the world (Giorgi 2005). Moreover, fundamental to its structure is intentionality - that is, it is

always being directed at and related to something (Tuohy et al 2013). As such, all thinking is always thinking about something (van Manen 1997).

In order to understand and describe the nature of consciousness scientifically, and in a way that would assure methodological trustworthiness, Husserl sought a philosophy without presuppositions (Dowling 2011). Using the radical practice of phenomenological reduction or epoche whereby the “natural attitude”, (a world of internal beliefs and assumptions), is suspended or bracketed, an idealistic condition of consciousness called transcendental subjectivity is sought (LeVasseur 2003). What remains after this process of reduction, are “the things themselves” (van Manen 1997: 184) or essences which are the real intended meanings of phenomena (Todres 2005). From these particulars, Husserl believed common features or universal essences of phenomena could be identified which must be *described*, devoid of all assumptions and “as given”. These universal essences represent absolute truths from which fresh or unanticipated meanings can be revealed (Wojnar & Swanson 2007).

In general, researchers who conduct a descriptive phenomenological study stay faithful to Husserl’s original project and utilise steps that are consistent with his philosophical phenomenological vision (Giorgi 1997). Giorgi (1989) argues that four core elements characterise such work. As such, the research is rigorously descriptive and stays close to “what is given”; the intentional relationship between participants and their situation is explored and, overall, the aim is to describe, in a “broadly normative and scientific sense” (Finlay 2011:94) the typical essences or general structures/characteristics of human experiences through the use of imaginative variation. The latter involves a process of asking questions and freely altering or removing possible meanings in order to distinguish essential features of a phenomenon, rather than incidental ones (van Manen 1997). A further characteristic is that phenomenological reductions are applied. However, the ways in which this is done varies. For example, Giorgi (2008) insists that researchers who follow his method must adopt a rigorous and scientific approach that includes bracketing all knowledge, theory and beliefs about the phenomenon throughout the research process. However, those who use Dahlberg’s descriptive lifeworld approach view the reduction as both a being open and a bracketing at the same time and have coined the term “bridling” (Dahlberg 2011:27) or reigning in previous knowledge and beliefs in order to prevent them from having an uncontrolled effect on evolving understandings (Finlay 2011).

The descriptive phenomenological approach has become a popular methodology in nursing research (Tuohy et al 2013). Not least it offers methodological guidelines and disciplined procedural steps that can help to ensure scientific rigour and it can provide powerful insights into the “whatness” of a phenomenon (Todres 2005). As such, I initially found this approach appealing. However, some aspects were problematic. For example, given the different contexts that each child would be situated within, I was unsure whether it would be possible to discover the essential, unequivocal “essence” of children’s experiences of CSII therapy. In addition, the notion of bracketing was challenging. LeVasseur (2003) argues that the central Husserlian concept of intentionality contradicts the requirement for bracketing – that is, if consciousness is always conscious of something, (intentional), there cannot be such a thing as detached reflection. Moreover, as previously discussed, I believed that my pre-understandings and extensive experience as a PDSN could become sources of knowledge that would help to sensitise me to the meanings attached to children’s experiences. As such, putting these to one side might have risked misunderstanding or misjudging children’s accounts. Therefore, for these reasons, I concluded that to utilise a Husserlian approach for this study would be incongruent with both its aims as well as my personal positioning as a researcher.

#### *Heidegger, Gadamer and Hermeneutic Phenomenology.*

The two key philosophers who inform hermeneutic interpretive phenomenology are Heidegger (1889-1976) and Gadamer (1900-2002). An overview of their writing is explored below.

#### *Heidegger*

Heidegger (1889-1976) shifted the philosophical debate from Husserl’s study of the structures of consciousness to one of ontology, focussing instead on the “*question of the meaning of Being*” (Heidegger 1962:1) and the essential structures that constitute human existence. In his seminal work *Being and Time*, Heidegger argues that the human condition is inextricably tied to and constituted by Time, of which “history” - that is, a “*context of events and effects*” - is a fundamental part (Heidegger 1962:430).

The concept of *Dasein* (literally “being-there”) is central to Heidegger’s philosophy and he uses this term to refer to the specific mode of Being of humans (Moran 2000). He argues that an important aspect of our Beingness is a preoccupation with finding meaning in one’s life and a “concern” (*Sorge*) not just for our self but also for the

welfare of others (Moran 2000). Therefore, any interpretation of human experiences must take into account the involvement of the person themselves rather than from an objective, theoretical position (Moran 2000). Heidegger (1962:167) also suggests that the world of *Dasein* is a “with-world” - that is, inescapably social and shared with others (Finlay 2011). Thus, we communally experience the world and through our relationships and connections with each other, we influence and are influenced by others (Tuohy et al 2013). However, it is our “being-in-the-world” that is a particularly significant structure of human existence. Thus, rather than Husserl’s description of humans as detached, self-contained subjects existing in a world of objects, Heidegger specifically picks out human beings’ inescapable embeddedness in and dynamic relationship with the surrounding world:

*“Self and world belong together in the single entity Dasein.*

*Self and world are not two beings, like subject and object”*

(Heidegger 1962:297)

“Person” and the “world”, therefore, are not only inseparable (Rapport 2005), but also they co-constitute each other (Koch 1995). Here, “world” means “a context, an environment, a set of references...within which any meaning is located” (Moran 2000:233). Thus, our “historicality” (socio-cultural backgrounds), temporality, spatiality, tradition, and language all provide a “ready-made” (Crotty 1998:96) way of understanding the world which implicitly constructs and influences individual views of reality and ways of thinking. Heidegger argues that we are “thrown” into this pre-existing world which we mostly take for granted and engage in without thinking (Nelms 2015). Therefore, although Husserl recognised the temporality and historicality of human existence, Heidegger’s phenomenology emphasises the notion of context and its significant impact on both human existence and lived experience (McConnell-Henry et al 2009).

### *Questioning Technology*

An important aspect of Heidegger’s later philosophy explores his thinking in relation to technology and in particular the ways in which he believes contemporary human life has become increasingly dehumanised by its effects (Galvin & Todres 2013). In his essay “*The Question Concerning Technology*”, Heidegger (1977) argues that technology has so engulfed or “enframed” the modern world that calculative ways of thinking dominate and everything is increasingly understood within a technological framework.

Consequently, other more “authentic” modes of existence are either overshadowed or completely blocked (Thomson et al 2011). To guard against such technological dystopia, Heidegger (1977) asks us to “open ourselves” to the essence of technology in order to enter into a “free relationship” with it. This means not only a requirement to question it critically and constantly but also to recognise that technology’s way of revealing the “truth” is only one of many other ways of knowing and understanding the world (Zitzelsberger 2004).

### *Phenomenology and Hermeneutics.*

For Heidegger, gaining access to the being of life required a phenomenology centred not only on ontology but also hermeneutics (Moran 2000). Hermeneutics privileges the art of interpretation in context and the creation of shared meanings in order to achieve understanding (Walters 1995). As such, Heidegger rejected Husserl’s emphasis on description as well as the concept of phenomenological reduction. Instead, by emphasising our embeddedness in the world, he argues that interpretations and understanding are “situated” and dependent on not only an individual’s pre-understandings but also their historical context (Geanellos 1998). As such, it is not possible to understand anything from a purely objective position.

Heidegger regarded interpretation as a fundamental and inevitable characteristic of our being-in-the-world (Finally 2011). Thus, central to his philosophy is the notion that interpretation is predetermined by a background of presuppositions which he called fore-structures – that is, some initial point of view, judgement or “*vague, average understanding*” of being (Heidegger 1962:25) that we have in advance of interpretation and from which the interpreter can never be free (Geanellos 1998). Thus, he says:

*“Whenever something is interpreted as something, the interpretation will be founded essentially upon fore-having, fore-sight and fore-conception. An interpretation is never a presuppositionless apprehending of something presented to us”* (1962: 191-192).

However, whilst they enable understanding, they may also conceal or distort it (Moran 2000). As a consequence, although they can never be made completely explicit, Heidegger (1962:195) insists that we scrutinise our fore-structures and do not allow them:

*“to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out these fore-structures in terms of the things themselves.”*

Understanding, therefore, comes from recognising our preconceptions as influences and biases.

#### *The hermeneutic circle*

To make interpretation possible, Heidegger (1962:195) conceived of the notion of “*a circle of understanding*”. He understood this to involve “*a relatedness backward and forward*” between that which is already known, new understandings and back again, rather than the closed or “vicious” process involved in circular reasoning (Heidegger 1962:28). Thus, understanding is achieved via a circular process of continuous re-examination of presuppositions (Tuohy et al 2013). This reciprocal activity means that understandings are not only constantly revised but also open to multiple possibilities (Geanellos 1998).

#### *Gadamer*

Gadamer (1900-2002) developed hermeneutic interpretation further by emphasising the conditions required for understanding to take place (Fleming et al 2002). As essentially “*language beings*” (Crotty 1998:87), he viewed language as the central medium by which being-in-the-world is shaped, revealed and understood (Crotty 1998). Similar to Heidegger, he also argued that since “*pre-judgements*” (prejudices) that originate from our historicity are vital for the “*knowing*” process (Fleming et al 2002), they should not and cannot be ignored or eliminated. Moreover, awareness of this “*historically effected consciousness*” (Rapport 2005) is essential in order to make these pre-judgements transparent to ourselves and allow new understandings to arise. However, understanding this “*horizon*” can only take place through our own present “*horizon*”. Thus a circular “*fusion of horizons*” takes place whereby the horizon of the present cannot be formed without the past (Crotty 1998). These horizons are not “*hermetically sealed*” (Moran 2000:252) and mutual understanding comes not through their abandonment but more via a merging or overlapping with others.

Smythe (2011:38) suggests that using words “*how*” and “*experience*” in a research question is indicative of a hermeneutic phenomenological approach because it implies both a desire to reveal “*the ‘way’ of something or how it ‘is’ in the living of it*” as well



as reflecting a shift from knowing “what” to an understanding of how it is to “be”. This emphasis reflected the aims and purpose of my study. Moreover, I was interested in adopting a process that would emphasise the diversity and range of children’s experiences of their treatment and how the context of their life situation influenced these. As such, adopting a hermeneutic phenomenological methodology for this study seemed appropriate. However, as with descriptive phenomenology, many different variations exist, each of which has their own particular emphasis and methods. Of these, I initially considered Interpretative Phenomenological Analysis (IPA) (Smith et al 2011). However, IPA is wedded to a specific theoretical framework that prioritises cognition and “sense-making” (Finlay 2011:140), rather than a more holistic and contextual focus on lived experience. Therefore, for this study, I chose to draw more generally on some of Heidegger’s key concepts in order to not only achieve the depth of understanding that I wanted but also to reflect the specific position that I wished to adopt in the research process. These included his writings on technology as well as concepts related to “unhomelikeness”, “lifeworld existentials” (van Manen 1997) and being-in-the-world. This latter notion was particularly influential because it provided a way of approaching the research topic that encouraged a focus on issues of context and how this “situatedness” co-constructed, sustained and gave meaning to children’s everyday lives, rather than searching for meanings outside of their social, spatial, material and temporal contexts. Since the literature review had highlighted a dearth of understanding about how young children experienced CSII therapy in the context of their daily existence, adopting this aspect of Heidegger’s philosophy seemed particularly relevant. The explicit attention that Heidegger gives to interpretation, fore-structures and the hermeneutic nature of understanding was also appealing. Thus, although it was important to examine my pre-existing beliefs and experiences related to CSII therapy by adopting the phenomenological attitude, these concepts recognised that researchers cannot help but bring themselves into the research process in order to better understand the world (Finlay 2011). Moreover, when combined with the children’s perspectives, they became an integral feature of the “fusion of horizons” essential for understanding (Gadamer 1985). This element of Heidegger’s philosophy played a significant role in the analysis of the data that was generated from the discussions with the children and will be explored in greater depth in a later section of this chapter. Therefore, overall, applying the philosophical traditions of Heidegger to my inquiry, rather than those of Husserl, seemed more appropriate. By doing so, I felt that I would

be more able to generate a deeper, richer and more holistic understanding of children's experiences and as such meet the specific intent of the study.

### **3.4 My personal world view and its relationship to the study**

Heidegger's emphasis on understanding things in context and interpretation as the means by which humans come to view reality and attach meaning to it, places hermeneutic phenomenology firmly within the relativist paradigm of interpretivism (Weaver & Olson 2006). As highlighted in Chapter 2, epistemologically, constructionism underpins this approach (Crotty 1998). As such, all knowledge (and therefore all meaningful reality), is not "found" but co-constructed by and between the interactions and interpretations that human beings have with the world and is influenced by context and our position in time and space. Since this way of sense making will be open to multiple interpretations, no one "truth" or valid interpretation is possible (Guba & Lincoln 1994). Ontologically, therefore, the single, objective, quantifiable reality of positivism is replaced by notions of relativism, subjectivity and *possibilities* of meaning (Nicholls 2009a).

In many aspects, this interpretivist worldview is congruent with my own personal beliefs concerning the nature of reality and the human condition. The relative and tentative nature of knowledge and the view that "reality", (both physical and social), is not straightforward but is instead multi-layered and meaningfully constructed via interpretive interactions with our culture reflects much of my own mind set. However, such relativism does create feelings of uncertainty and "fuzziness". Complete subjectivity is hard to imagine, as is the idea that all reality is entirely constructed. For example, it is difficult not to subscribe to the fact that many objects / "things" exist in the world independent of social convention, as real physical entities "out there", and will continue to do so even when they are not being observed or thought about (Nicholls 2009a). Nevertheless, I find certain aspects of positivism and its claims for universal, (albeit probabilistic), truths also problematic. For example, no inquiry can ever be completely value-neutral and the belief that social realities can be reduced to objective, discrete and measurable entities in the same way as physical realities fails to recognise the uniqueness of individuals and the complexities imposed by context.

Thus, my own ontological and epistemological positioning is not exclusively "purist" in nature. For me, reality and knowledge is both "found" as well as socially constructed – that is, they are a "mixture of the subjective and objective, fact and interpretation,

consciousness and thing” (Sadler 1969 in Crotty 1998:151). As neither strongly realist nor excessively relativist, my philosophical stance, therefore, is more aligned to “milder” forms of relativism that are reflected in approaches such as critical realism and pragmatism. Both these perspectives accept that all knowledges are partial, although the extent to which they embrace such relativism varies. Ontologically, critical realism asserts that whilst reality exists independently of human thoughts about it, empirical claims about its nature are always interpreted through social conditioning and as a result, are contingent and situated (Wahyuni 2012). Particular attention is paid to processes rather than outcomes and causal explanations are prioritised (Weaver & Olson 2006). Moreover, what makes this approach “critical” is its emancipatory axiology – that is, a concern with change and transforming the status quo in order to counteract inequalities and injustices (Weaver & Olson 2006). However, whilst I am sympathetic towards this agenda, my own worldview reflects a “softer” and more agnostic form of relativism that is typically associated with pragmatism (Burke Johnson & Onwuegbuzie 2004). No single system of philosophy underpins this perspective (Creswell 2009) and notions of inter-subjectivity (mutual recognition) are central to arguments about paradigm incommensurability (Morgan 2008). Epistemologically, either or both observable phenomena and subjective meanings are regarded as being equally able to provide acceptable knowledge of the world and a balanced, democratic, common-sense perspective is emphasised (Burke Johnson & Onwuegbuzie 2004). Moreover, truth and meaning is determined by the practical consequences of actions in the world (Burke Johnson et al 2007). Adopting such a stance as this is perhaps not surprising given the multi-faceted types of knowledge I require for my practice as a children’s specialist nurse and the emphasis this perspective places on action and workability (Shaw et al 2010). For me, the complex practice of nursing is neither exclusively empirical nor completely textual or aesthetic. Instead it is a mediation of all types of knowledge, including “what works best”.

Although there are undoubted differences between the assumptions that underpin pragmatism and interpretivism, for me, as *philosophies*, they have enough in common for them to sit comfortably alongside each other. Indeed, some do not regard pragmatism as a third or separate philosophy, situating it instead within interpretivism itself (Crotty 1998), or viewing it more as an “ideological position available within any paradigm” (Giddings & Grant 2007:53). Nevertheless, whilst the philosophies themselves have similarities, the way each are applied to and positioned within the

actual conduct of social science research differs significantly. This, in turn, has implications for the types of knowledge each generate (Weaver & Olson 2006).

Pragmatism largely puts aside epistemological and ontological issues in favour of a practical and instrumental approach (Holloway & Galvin 2017). As such, it is typically employed by those who conduct mixed methods research which uses both qualitative and quantitative approaches within the same study (Morgan 2008). However, such theoretical indifference has led to extensive questioning about how the actual practicalities of squaring objectivist with constructivist accounts of the same phenomena can be done, particularly as “the latter may deny the reality of the very phenomena the objectivist account seeks to investigate” (Bryman 2007:16). Moreover, others have suggested that often quantitative methods have dominance over the qualitative and as such studies tend to generate types of knowledge that reflect post-positivist assumptions in its search for and analysis of truth (Giddings & Grant 2007; Holloway & Galvin 2017). The possibility of generating positivistic based knowledge caused me some concern as a wealth of such knowledge concerning the use of CSII therapy for children already existed. The literature review revealed a gap in knowledge about how it actually “is” for young children to experience this type of therapy for managing their Type 1 diabetes, as told by the children themselves. Therefore, it was primarily empathic knowledge that was being sought rather than positivistic understanding. As such, although pragmatism is more reflective of my personal worldview, adopting a mixed method approach for this study would have been inappropriate.

By way of contrast, the potential for research grounded in existential phenomenology to generate empathic knowledge is being increasingly recognised, particularly within the discipline of nursing (Galvin & Todres 2013). Discourses concerning the types and levels of knowledge most useful and relevant for the practice of nursing, (and therefore the research paradigms best able to generate it), has been extensive (Carper 1978; White 1995; Weaver & Olson 2006). More recently, “embodied relational understanding” (Galvin & Todres 2013:147) has been conceptualised as the kind of empathic knowledge that is especially relevant for nursing practice. As a synthesis of all types of knowledge, this integrates the “head” (objective knowing), “hand” (actionable knowledge) and “heart” (empathic knowledge) to evoke a way of knowing that is contextual and holistic (Galvin 2010). Grounded in lifeworld theory and the interrelated concepts of embodiment, intersubjectivity and contextuality, such knowledge

“humanises” caring practice which, without this emphasis, would become overly technical and functional (Galvin & Todres 2017). Moreover, although phenomenological knowledge has neither a prescriptive nor overtly critical agenda, the expressive, evocative aspects of phenomenological texts can allow the reader to suddenly “see” phenomena differently (van Manen 1997). As such, the type of knowledge generated can be transformational in that it can enlighten understandings and perceptions of the meanings of everyday situations which, in turn, can alter actions and influence future ones (Van der Zalm & Bergum 2000). These arguments were inevitably influential in determining which methodology I chose for this study. The notion that a study underpinned by a phenomenological worldview would contribute knowledge that would be practically useful to nursing practice in particular was both important as well as congruent with my own beliefs about the purpose of conducting nursing research. Therefore, whilst I may not have been able to subscribe entirely to the philosophical assumptions associated with the hermeneutic phenomenology of Heidegger, when translated to research endeavour, its relevance to the discipline of nursing and emphasis on the person and context of their existence met the specific intent of my study. As such, I believed that this approach offered the best chance of answering the research question posed.

### **3.5 The Research Process**

In the literature, there has been some debate about whether research with children necessarily requires different methods and “special” ethical standards from those used for adults (Kirk 2007; Punch 2002). For example, if children are perceived as competent social actors, there is no obligation to see them as “other” and therefore special “child-friendly” methods are not required (Harden et al 2000). However, in this study, although I conceptualised children as competent beings, I did not believe that it was appropriate to employ solely adult related methods. For me, issues related to age and power (rather than a child’s competence), as well as my desire to respect their individuality necessitated a different approach. As such, the methods that I employed moved “back and forth along a continuum” (Punch 2002:338) in a way that acknowledged power inequalities as well as a child’s age, experiences, competencies and individual preferences. The remainder of this chapter is devoted to an examination of these methods and a discussion of the challenges associated with ensuring the ethical integrity and “trustworthiness” of the study.

## *Ethics*

### *Gaining ethical approval*

Gaining access to enter the research field was complex and the approval process took over eight months to complete. Nevertheless, a favourable ethical opinion was obtained eventually from the NHS Research Ethics Committee on 6<sup>th</sup> June 2014: REC reference number: 14/EE/0166 (Appendix 1). Since I also intended to recruit children from two different “host” sites within the NHS, it was also necessary to seek approval for the study and a letter of access from the Research and Development departments at each location (Appendices 2 & 3). The following discussion highlights the main ethical issues that required consideration and the strategies used to address them in a way that not only recognised power imbalances but which also endeavoured to ensure that children were given a choice about their participation (Masson 2006).

### *Consent and Assent*

#### Parental Consent

In the UK, when children under the age of 16 years are considered for participation in research, both the law and authoritative research ethics guidelines require the informed consent of at least one person who has parental responsibility for a child, in addition to the child’s own assent (National Institute for Health Research [NIHR] 2012). Therefore, for this study, the informed consent of one parent/legal guardian was sought in advance of seeking the child’s assent. This was done in order to avoid a situation where a child who may have wished to participate in the study was then denied the opportunity as a result of their parent’s refusal to allow this.

#### Child Assent

Although not a legally endorsed process, in this study seeking a child’s assent was critical because it reflected my beliefs concerning the ethical significance of shared decision making and the principles behind “nothing about me without me” (DH 2010). However, definitions of assent differ (Baines 2011). For this investigation, a child’s assent was defined as their expressed, affirmative agreement to participate in the study rather than just a failure to object (Diekema 2006). Children’s readiness to give their assent was based on my own professional judgement as well as observations of their behaviour for any active or subtle signs of dissent. In addition, I tried to ensure that children had enough time to think about their participation by encouraging them to ask questions and to “repeat back” their understandings of the nature of the research.

### Information provision

For parents' and children's consent to be valid and meaningfully given, it was important that they understood the nature and purpose of the study and any potential risks and benefits associated with it (Twycross & Smith 2017). Lambert & Glacken (2011) caution against using an approach that is one-way and researcher-centred for this aspect of the process. Therefore, for this investigation, opportunities for children and their parents to discuss the study verbally and ask questions that were important to them were provided, both at the time of first meeting them at their outpatient clinic and prior to their interview at home. In addition, written information in the form of participant information leaflets was also provided. Three types of participant information leaflets were used - one for children aged 5-7 years (Appendix 4); one for those aged 8-11 years (Appendix 5) and one for parents (Appendix 6). The language used and the layout of each differed. To increase engagement, clipart and a question and answer format that outlined the "who, what, why and how" of the project was used in the design of the leaflets given to the children (Twycross & Smith 2017). Prior to the start of the study, two colleagues' children, (aged 7 and 10 years old), reviewed initial drafts of these documents and as a result of their feedback, my photograph was added and the font and some of the images were enlarged.

### Voluntary Participation

Children were advised that their participation in the study was entirely voluntary and it was stressed that they could withdraw from the process at any time without giving a reason (NIHR 2012). However, ensuring that the children actually felt able to decline or withdraw their participation was challenging due to the inherent disparities in power between me and them. I was conscious that the younger children in particular may be reticent about expressing their dissent because of beliefs that I may be "sad" or "mad" if they withdrew (Ondrusek et al 1998), or because of a reluctance to disagree with or disobey an adult (Kortessluoma et al 2003). Moreover, because of children's status as both child and patient, they (and their parents) may have felt compelled to participate out of fear, gratitude or beliefs that their decision may alter the care they were receiving (Allmark 2002).

It was not possible to eliminate power imbalances completely. Nevertheless, I was constantly mindful of them and a number of strategies were used to try and minimise their impact. Importantly, assent and consent was treated as a process rather than a

single act (NIHR 2012). As such, children's and parent's willingness to participate was confirmed at every stage of their involvement. Written consent / assent (Appendices 7 and 8) was obtained at the time of children's interviews, with both the child and parent being requested to date and sign forms themselves (NIHR 2012). In addition, verbal consent/assent was renegotiated frequently, including during and after the interviews. Moreover, children were advised that if they did not want to answer a question during the interview, they could say "pass", and if they wished to stop or withdraw they were given a red card to hold up (Shaw et al 2011). To make this easier for children, these latter strategies were rehearsed with them before the interview (Kirk 2007). As will be discussed in Chapter 4, the red card was used only by the youngest child in order to pause (rather than terminate) the interview on two occasions.

#### Prevention of harm

Although the research topic was not considered to be overly sensitive or emotionally charged, there was the potential that talking about feelings and experiences of insulin pump therapy could be intrusive for children and, as a consequence, result in a range of negative emotions, including distress, guilt, embarrassment or loss of self-esteem (Kirk 2007). Therefore, a protocol was used (Appendix 9) to help me recognise signs of emotional distress and the degree of intervention that might have been required (Draucker et al 2009). The local child and adolescent mental health service (CAMHS) or the child psychology service attached to children's own paediatric diabetes unit was available to use if required. However, none of the children needed to access these services.

#### Confidentiality

Confidentiality and its limits were detailed in the information sheets and explained verbally to participants and their parents. Children were advised that information would not be shared with their parents or the diabetes clinic unless I was concerned that there was a risk of harm to themselves or others. In addition, they were reassured that personal identifying information would be removed from written transcripts and documentary notes and that pseudonyms would be chosen to protect their identities. I had hoped to allow the children to choose their own pseudonyms. However, the ethics committee disallowed this because it was felt that this would increase the possibility of children's identities being revealed. Therefore, these were chosen for the children by me. Tapes and transcripts were stored separately from a site file containing all the



written identifiable information related to the study and both were kept in locked filing cabinets. On completion of the study, tapes will be erased and documentation will be archived in compliance with information governance guidelines (DH 2009).

### ***Recruitment to the Study***

#### *Sampling strategy*

According to Bryman (2012), most sampling techniques in qualitative research entail purposive sampling of some kind in the sense that a researcher will purposefully select individuals that maximise understanding of a phenomenon. In this study, a purposive selection strategy guided primarily by the principles of adequacy and appropriateness was used (Morse 1991). As such, children who had not only first-hand knowledge of insulin pump therapy (appropriateness), but also who were willing to provide data that was rich enough to communicate the sense of CSII therapy to others (adequacy) were purposefully selected to participate in the study. However, as will be discussed, sampling decisions were also inevitably moderated by a number of practical and logistical issues.

#### *Sample Size*

For this study, the NHS ethics committee required an indication of the number of children likely to be recruited prior to granting their approval. I found this decision difficult as no specific guidelines exist for pre-determining sample size in phenomenological study (Guest et al 2006). Nevertheless, since this approach seeks neither generalisation nor replication, sample size is rarely large and suggestions range from at least 6 participants (Morse 1994), up to between 10 and 25 (Creswell 2009; Guest et al 2006). Based on these guidelines and my desire to conduct a deep and detailed analysis of individual children's experiences, a sample size of ten children who met the study criteria was proposed. However, once the recruitment process started I soon realised that I had completely underestimated children's enthusiasm and interest in participating in the study and consequently, the final sample size comprised of fifteen children.

#### *Inclusion and Exclusion criteria*

The principal criteria for the selection of children included the following:

1. Informed consent given by an adult with parental responsibility and informed assent given by their child.

2. Male and female children with T1DM using CSII therapy who were aged 5-11 years and who had no other co-morbidities.

This age group was chosen primarily because this reflected the nature of the original “disturbance” that prompted the study and also because the literature review revealed that children under the age of 12 years are the least heard in the research relating to CSII therapy. Children with co-existing conditions were not included because this might have increased the complexity of care they required and as such altered experiences of pump therapy.

3. Children who had used CSII therapy for at least 6 months prior to the start of the study.

In order to reduce the risk of over burdening children at the time of first commencing pump therapy, only those who had been using it for 6 months or more were invited to participate.

4. Children who are English speaking.

At the time of recruitment for the study, the NPDA showed that the ethnicity of the majority of children with T1DM (75.7%) in the study area was White British. The next largest ethnic groups were either Asian (2.2%) or Mixed Race (2%) (RCPCH 2015). Therefore, the number of children unable to speak English and who were also using pump therapy was likely to have been very small. Moreover, language is of central importance to qualitative research, and as such I was concerned about the inherent difficulties associated with translating the meanings of children’s accounts accurately when needing to use an interpreter (Temple & Young 2004). Therefore, only those children who are able to speak English were selected for the study.

#### *Site Selection and Access*

Children were selected from two separate National Health Service paediatric diabetes units located in the South of England. Both ethical and pragmatic concerns determined this decision. At the time of the research, an average of 30 children / young people per centre were known to be using CSII therapy in England (Ghatak et al 2015). The age distribution of these patients was unknown. However, anecdotal evidence suggested that each unit had approximately 6 - 10 children who would fall within the age bracket required for this study. Therefore, two sites were selected in order to increase the

potential pool of participants. Lack of funding for travel expenses prevented a wide catchment area and ethical concerns precluded the recruitment of children with whom I had an existing professional relationship (Butler 2003). As a result, children from neighbouring paediatric diabetes services were invited to participate. In one of these sites, I was acquainted with the eight children who participated as a result of previous contact that I had with them two years earlier when I was working as a PDSN. However, I was not known to any of the remaining seven children who were recruited from the second site.

### *The recruitment process*

The process of recruitment involved several stages. Prior to commencing the study, I met with the local Consultant and PDSN from each site to seek their endorsement for the research and to request their help with making the initial approach to children. Once ethical approval had been obtained, potential participants who met the study criteria were identified by their clinicians who then sent them and their parents a letter inviting them to participate in the study and outlining its purpose (Appendix 10). Enclosed with this letter was a copy of the relevant participant information sheets previously discussed (Appendices 4-6). This letter was sent 2 weeks prior to a child's next routine diabetes outpatient appointment.

At each of the identified recruitment sites, designated clinics were held specifically for children/young people using CSII therapy. Therefore, to promote greater awareness of the research and its purpose, I obtained permission to attend these clinics from both the clinicians and the research and development departments at each site. As such, after children and their parents had completed their clinic appointment, they were invited to discuss the study in greater depth with myself if both expressed an interest in doing so. At this stage, participant information sheets were read with the children and parents and any questions about the study and their role within it were answered. I had planned to then contact parents the following day (or longer if they wished) to establish whether their child would like to participate in the study. However, in reality, the majority of children and their parents felt that they had already been given sufficient time to consider this and as such, dates for interviews were typically set at the time of their clinic appointment. Nevertheless, each family was contacted again a few days prior to the actual interview, in order to confirm that they still wished to take part in the study.

### *The Sample*

During the first few weeks of the recruitment phase, sixteen children who met the study criteria were identified by the clinics and sent an invitation letter. Although I had originally decided on a sample of ten participants, fifteen of the children invited during this time wanted to be part of the study. As such, I chose to interview all of them. The only child who did not wish to participate was 5 years old (reasons unknown). Children's ages ranged from 6 to 11 years and 10 participants were boys and five were girls. At the time of the children's interviews, eleven children attended primary school and two children (Zoe & Adam) had recently (within the last month) transitioned to secondary school. All of the children had used MDI regimes prior to commencing CSII therapy and were now using either a Medtronic or Roche insulin pump. The duration of treatment varied from eight months to eight years. Table 1 provides further details.

**Table 1: Participant list** (For reasons of confidentiality, all names have been changed)

<b>Participant Pseudonym</b>	<b>Gender</b>	<b>Age (years)</b>	<b>Duration of CSII therapy</b>	<b>Insulin Pump Model</b>
Paige	Female	11	3 years	Roche
Zoe	Female	11	8 years	Medtronic
Ryan	Male	11	18 months	Roche
Adam	Male	11	2 years	Medtronic
Beth	Female	10	8 months	Roche
Holly	Female	10	4 years	Medtronic
Harry	Male	10	2 years	Roche
Charlie	Male	9	3 years	Medtronic
Billy	Male	9	2 years	Medtronic
Ella	Female	8	4 years	Roche
Will	Male	8	4 years	Roche
Jordan	Male	7	5 years	Roche
Jack	Male	7	3 years	Roche
Josh	Male	7	2 years	Roche
Luke	Male	6	2 years	Roche

My original intention was to include children who were 5 years old. However, only one child was using CSII therapy at the chosen recruitment sites at the start of the research and as discussed, they declined to participate. Nevertheless, I had hoped that other

children in this age group would commence CSII therapy during the time I had allocated to complete the recruitment process. Unfortunately, this did not happen at either site. In order to try and address this gap, I considered approaching other NHS Trusts. However, after careful consideration, I elected not to do so. This was primarily for pragmatic reasons, including travelling costs, my own work commitments, the complexity and time-consuming nature of NHS approval procedures and uncertainty about whether this would actually be successful. Nevertheless, overall, the recruitment strategy that I chose enabled the selection of children with a diverse range of experiences and characteristics for in depth study. Moreover, as will be demonstrated in the next chapter, these children were able to provide information that was both rich and meaningful. As such, the final sample met the criteria for both appropriateness and adequacy (Morse 1991) and thus, a deeper understanding of the variety of ways that children live and experience insulin pump therapy was generated.

### ***Data Collection***

The goal of hermeneutic phenomenology is to transform lived experience into rich, textual accounts that enable their meaning and significance to be understood (Smythe 2011). In phenomenological research, the most extensively used tool for achieving this is via in depth interviews (Sandelowski 2002). According to Docherty & Sandelowski (1999:179) a combination of cued and free recall enables researchers to better access children's "scripts" (familiar, repeated experiences), rather than using free recall alone. Therefore, for this study I chose individual, semi-structured interviews rather than an unstructured, open-ended format and an approach that encouraged a dialogue or "conversational relationship" (van Manen 1997:66) between myself and the children. Focus groups were considered inappropriate because they do not so easily tap into the detail of individual accounts or necessarily ensure that each participant's voice is equally heard (Holloway & Galvin 2017). Interviews were conducted face-to-face and were digitally recorded. Overall, they proved to be eventful, challenging and immensely enjoyable.

### ***Practice Interviews***

Although I have extensive experience in talking with children, I was conscious that asking "how it is" to use insulin pump therapy would be different from the usual biomedical discussions that I normally engaged in as a paediatric specialist nurse. Therefore, prior to the start of the study, a "test" interview was conducted with a

colleague's children who were of similar age to the study group but healthy and not involved in any ongoing health care provision. This was helpful and provided an opportunity for me to practice using the digital recorder, consider how to phrase and pace questions generally and rehearse how best to use the "Stop" and "Pass" cards.

Interviews are inherently social encounters. As such, each one may be influenced not only by the nature of the interviewer-participant relationship, but also by a range of contextual factors. The following discussion considers the ways in which such issues were addressed in this study.

### *The Interview Setting*

Children were interviewed in their own homes. This choice of setting helped to balance power dynamics to some extent in the sense that I was in effect a guest in their home (MacDonald & Greggans 2008). However, it also created a number of practical challenges and sometimes unexpected events. These included requests by the children to "interview" family pets as well as themselves and having to negotiate interruptions such as dealing with drinks being spilled over the recorder or because children needed to do a blood test because they felt hypoglycaemic. Moreover, whilst most of the older children were comfortable sitting at a table during the interview, others could not confine themselves to one space. Thus, whilst still telling their stories, children would fetch things to show me, bounce on the sofa and run out of the room to collect a favourite toy or to get something to eat. For Luke (the youngest child), this also involved him clambering out of the window of the summerhouse where the interview was being conducted and swinging across the garden on a rope talking loudly as he disappeared. These "kinetic conversations" (Irwin & Johnson 2005:826) seemed to help children relax and express their experiences more freely. Therefore, rather than trying to control these situations, I learned to "go with the flow" and to always expect the unexpected.

### *Maintaining confidentiality*

Ensuring privacy when conducting research with children can be difficult to negotiate, especially in the home setting because of the presence of siblings and parents or general interruptions associated with daily family life (Shaw et al 2011). In this study, I wanted children to feel comfortable enough to express their views and as such they were given the choice of being interviewed with or without their parents present. The majority of children chose the latter and it was possible for most interviews to be conducted in a quiet, private space away from other family members. However, two children (both

aged 9 years) had their parents close by in an adjacent (open-plan) room and the mother of one of the youngest children (aged 7 years) stayed in the room throughout the interview. If parents were present, it was stressed that the focus of the interview was on hearing the child's voice rather than parents' own feelings and thoughts. Gardner & Randall (2012) suggest that parents' presence can limit children's responses and direct their interactions due to their desire to either protect their child or present their family positively (Gardner & Randall 2012). However, in this study, children seemed to be reassured by their parents being near them. They talked openly about their experiences and although parents' occasional prompts and comments did direct children's accounts sometimes, they mostly served to "scaffold" children's stories instead (Irwin & Johnson 2005:827). For example, phrases such as "What did you do when..." and "How about..." provided cues for the children and by so doing enhanced the completeness of their accounts in a way that might not have been possible otherwise.

### *The Interview Process*

Each child participated in one interview which lasted between 30 and 90 minutes. Some argue that conducting several interviews with each child can help to clarify earlier responses and provide opportunities to validate information given at the first contact (Wise 2002). However, for this study, I was concerned that multiple interviews may have been too intrusive, given the demands families face not only in terms of caring for a child with a long-term health condition, but also the time pressures associated with everyday life. Therefore, during each interview, it was important to ensure that I had understood the meaning of children's accounts if this appeared unclear. Summarising what they had said and asking if this reflected their experiences helped this process.

Prior to the start of each interview, I explained the study again to parents and children, confirmed their willingness to participate in it and discussed and completed the relevant consent and assent forms. In addition, children were reminded that there were no right or wrong answers to the questions I would be asking. Drawing materials were made available for children to use if this helped them to feel more at ease whilst we were talking. However, only two chose to use these. To help establish rapport and to alleviate any anxiety generated by the unfamiliarity of the interview situation (Alderson & Morrow 2011; Kortessluoma et al 2003) I initially chatted informally with the children about what they had done that day as well as their favourite pastimes. We also practised how to use the "stop" and "pass" cards and children were encouraged to play with the recorder and have some fun listening to our voices (as well as many other unimaginable

noises!). Building rapport with young children can take time, particularly if an adult is a stranger (Irwin & Johnson 2005). Therefore, as might be expected, this stage seemed easier for both me and the children I had known in the past compared to those that I had not met before. Therefore, adopting an individualised approach, being patient and treating children with respect were crucial aspects of this particular part of the process.

An interview guide was used to explore children's understandings and experiences of their treatment (Appendix 11). Its structure and content was informed by worked examples of interview schedules found in the literature (Sutcliffe et al 2003) as well as the gaps in knowledge about CSII therapy identified in the literature search. Thus, the topic areas centred on both children's daily experiences of insulin pump therapy itself as well as their relationships at home and at school and their social life. The guide served as more of "a rough itinerary" rather than dictating the direction of the interview and as I gained confidence I referred to it less and less. Instead, the emphasis was on active listening and following the children's narratives and priorities whenever possible. This strategy allowed them at least some control over the process and as such, helped to shift the balance of power further (Shaw et al 2011). Topics and questions were revised and modified after each interview as new areas for exploration were identified. For example, I initially asked children general questions about having diabetes. However, their replies invariably focussed on their current treatment rather than their condition as a whole. As a result, these questions were used less frequently than the others as the interviews progressed. Similarly, the phrase "you get used to it" cropped up frequently in the first few interviews and so the content of subsequent interviews was adjusted to allow me to explore this concept in greater detail.

All of the children were eager to describe their experiences. In general, younger children's accounts tended to be shorter and their experiences were usually expressed in concrete terms, such as events that had happened recently, their relationships with peers and the physical sensations that they experienced as a result of their treatment. Older children's accounts were more detailed and included more complex, embedded descriptions, such as expressions of difference and views concerning their sense of agency. In keeping with the principles of phenomenological inquiry, broad open ended questions were asked whenever possible. For example, "Can you tell me what it was like?" and "What happened when...?" However, this was not always the case, and in reality the style and sequence of questioning, use of prompts and probes were adapted to reflect a child's age and preferences. For example, one of the younger children (Josh



aged 7 years) struggled to answer open questions, perhaps because he was either unable or too uncomfortable to do so. As a result, his response was often “I don’t know”. Therefore, for him I focussed more on direct questioning and “show and tell” techniques using his own insulin pump and blood glucose meter as props. Whilst this did not tap fully into his experiences, this strategy helped to identify openings for further questions and may have allowed him to feel more comfortable with the interview process.

Visual aids have been shown to be useful for engaging and sustaining a child’s interest during interviews as well as encouraging expression (Kirk 2010; Stalker & Connors 2003). As such, children were also invited to draw spidergrams in order to encourage a concentrated focus on specific issues. This method proved particularly useful for exploring the best and worst things about their treatment. Most of the children seemed familiar with the concept of a spidergram and as such were able to draw these themselves. To prevent my own “adultist” assumptions being imposed onto them (Punch 2002), children were asked to talk about and explain each thing they wrote or drew. In this way, children’s own meanings and perceptions of them were more likely to be preserved and, as such, the credibility and sensitivity of the data analysis was better maintained (Shaw et al 2011). On completion of the interviews, children were thanked for their participation and given the opportunity to ask any questions. They were also invited to choose a small gift from a “treasure bag” of items and offered a summary of the study’s findings once it had finished if they wished (Twycross & Smith 2017).

Immediately after each interview, contextual notes were made in a journal critically reflecting on what happened during the conversations and exposing personal reactions and biases that might have influenced the interview process. Key issues that emerged were used to both refine questions for subsequent interviews and to modify the methods I employed. For example, entries included reminders of the need for me to “stay curious” and to be careful about the use of prompts when I was having difficulty making sense of a child’s experiences sometimes. For the latter, I realised that these words or phrases were sometimes taken up by the children and used by them to continue with their stories. This could have potentially changed the meanings of their experiences and so I changed the type of prompts I used. I discovered that the question “is there anything else?” was particularly useful for helping children to elaborate or expand on the meanings behind their experiences.

## **Data Analysis**

In this study, the data generated from the interviews was co-created in dialogue between me and the children and by so doing, we were both involved in the construction of meaning. Therefore, many “voices” were present in the data (Koch & Harrington 1998). Moreover, specific to researching children, Bricher (1999) warns that there are inherent dangers in adults analysing children’s perspectives because of the tendency for them to process a child’s talk through “adultist” ways of thinking. The challenge, therefore, for this investigation was to try and ensure that the analysis of children’s interviews privileged their voices rather than my own and that it was also anchored in their experiences and meanings, rather than as I would have them to be as a result of imposing my own biases and assumptions (Cohen et al 2000). This demanded “a phenomenological attitude” (Finlay 2009:12). As such, I tried to remain open at all times to the “other” and by so doing, “see” things differently. In addition, explicit and critical self-aware analysis (reflexivity) was required in order to bring the pre-understandings that I brought to the study to the foreground and thus increase my awareness of how they might distort the phenomena I was analysing. To assist this process, I recorded them in a journal. Although I did not attempt to “bracket” these assumptions, articulating them in this way forced me to continuously scrutinise and question them in the light of new evidence that was gathered during the analysis process (Finlay 2009).

### *The Transcripts*

Data analysis began concurrently with data collection and, as such, I began searching for and thinking about the possible meanings of what children said from the time of the first interview. The recorded conversations with the children were transcribed verbatim as soon after completing the interviews as possible, noting content as well as interactional details such as pauses, emphasis on words, laughter, etcetera (Pollock 1991). A lack of research funding precluded the use of a professional transcriptionist. Therefore, transcription was completed by me. Although this process was very time consuming, it allowed me to immerse myself in the data and as such sensitise myself more effectively to key issues as they emerged.

The transcripts and field notes that were made during the interview process produced an unwieldy mass of data. The use of computer software packages was considered at this stage, not least because of their effectiveness in organising and retrieving large volumes

of data (Holloway & Galvin 2017). However, whilst this may have made the analysis less cumbersome, such technology can cause distancing between the researcher and the data, resulting in “loss of meaning and context” and data that is “sterile and dehumanised” (St. John & Johnson 2000:396). This was not congruent with the aims of this study which demanded a focus on context and meaning. As such, I explored the literature for alternative strategies.

#### *Choosing an analytical framework*

There are no universal or clear-cut guidelines for analysing phenomenological texts. As such, Finlay (2011) argues that it is acceptable for a researcher to evolve an approach that works best for them, providing this reflects phenomenological principles. For this study, I wanted a strategy that would facilitate a predominantly interpretive (rather than purely descriptive) analysis of children’s accounts, as well as one that would explicitly acknowledge the hermeneutic circle that is essential for gaining understanding (Heidegger 1962). Moreover, it was important that the approach used was not only phenomenologically sensitive to revealing the complexity of children’s lifeworld, but also provided some level of procedural direction. However, finding a ready-made analytical approach that met these aims was challenging. As previously discussed, I initially considered Interpretative Phenomenological Analysis but rejected this approach primarily because of its emphasis on revealing individual’s “sense-making” rather than the relational nature of experience (Finlay 2011:140). Moreover, its prescriptive technique reflects positivistic leanings and has led to criticisms that this can cause the process of analysis to stagnate which in turn may lead to reductionist descriptions rather than more holistic accounts (Finlay 2011). Other frameworks advised collaborative approaches using interpretive teams, primarily as a means of validating a researcher’s interpretations (Crist & Tanner 2003; Rapport 2005). However, this search for consensus also reflects positivist ideals. Hermeneutically, interpretations can never be final and will always vary depending on the individual interpreter’s perspective. Therefore, the notion that it is possible to achieve complete agreement amongst a team of others was problematic.

#### *Thematic Analysis*

Instead, I chose a thematic analysis of children’s transcripts that was guided by methods advocated by both Fleming et al (2003) and van Manen (1997). For this study, “theme analysis” reflected a process whereby important patterns of meaning (themes) within the

data were identified and analysed (Braun & Clarke 2006), rather than “some frequency count or coding of selected terms in transcripts” (van Manen 1997:78). In addition, the notion of “theme” was understood in a particular way. Firstly, the themes identified, capture and describe an aspect of the “essential structures” (van Manen 1997:87) that make up children’s experiences of insulin pump therapy, rather than being conceptualised as categorical statements or generalisations that are seen to fit all the participants in a study. As such, they served as a tool for unlocking the meanings of children’s experiences (van Manen 1997). Secondly, each theme represented repeated patterns of meaning, although the prevalence of this varied. Thus, whilst most themes were made up of comments by the majority of children, a few consisted of the views of a smaller number of participants. This allowed not just the “general” but also the “particular” meanings to be revealed and by so doing enables both the similarities and the differences in children’s experiences to be better understood.

In order to uncover and isolate the thematic aspects of children’s experiences, I evolved an approach that incorporated elements of van Manen’s (1997) methods for analysis as well as the procedural steps advocated by Fleming et al (2003). Although both reflect an interpretive approach, neither one on their own took account of all the other aspects that I was anxious to include in the analytic process. Underpinned by Gadamerian philosophy, Fleming et al (2003) identify a cycle of analytical steps that specifically reflects the hermeneutic circle. Thus, a systematic movement from the “gestalt” (whole) understanding of the transcripts, to an examination of each statement or section of the texts, both in isolation and back to the whole is advocated in order to expose their meanings. However, whilst this approach was useful for guiding the *process* of analysis, I found that I needed a phenomenological *focus* for interrogating the data. As such, I chose to weave van Manen’s (1997: 101) “lifeworld existentials” into the analysis as a means of exposing children’s lived experiences and their rich meanings. Reflective of the wider phenomenological literature (Merleau-Ponty 1962), van Manen (1997) argues that the four fundamental existentials of *lived space* (spatiality), *lived body* (corporeality), *lived time* (temporality) and *lived human relation* (relationality) “pervade the lifeworld of all human beings regardless of their historical, cultural or social situatedness”. As such, they are particularly helpful for guiding interpretations and reflections during phenomenological analysis. Thus, I *loosely* structured the analysis against themes related to how children experienced their bodies as both object and subject in relation to their treatment (*lived body*), as well as how they experienced

different lived spaces/environments (*spatiality*), their temporal way of being in the world (*temporality*), and the ways in which they made sense of their relationships with others (*relationality*).

An account of how this strategy was applied to this study is given below. The steps that are described were not mutually exclusive and the process inevitably involved more than simply moving from one phase to the other in a neat, linear fashion. Instead, it was a “more recursive process where movement is back and forth” (Braun & Clarke 2006:86) between the different phases as needed. Moreover, it was ongoing, “messy” and emergent, involving many “iterative versions” (Finlay 2011:228) and considerable reflexive thinking in order to make explicit the meaning of children’s lived experiences.

### *Conducting the analysis*

#### Step 1: Fundamental meaning

*“All interview texts should be examined to find an expression that reflects the fundamental meaning of the text as a whole”* (Fleming et al 2003: 118)

Each transcript was analysed individually in turn and then in relation to each other as a whole. The process of theme identification began by reading each transcript multiple times in order to get a sense of the overall meaning or “gestalt” of each child’s experience. To capture this and ensure that I did not lose the particular voices and experiences of individual children, I then wrote a short interpretive summary of each transcript. Rather than trying to account for every detail, I tried to “step back” at this stage and consider the most pertinent issues as well as particularly powerful, surprising or poignant moments in the text (Finlay 2011:230). I then reflected carefully on this summary whilst re-reading each transcript and listening again to the audio recordings.

The overall fundamental meaning that emerged across all of the transcripts was that insulin pump therapy changed children’s lives and altered their lived bodies in ways that were both disabling and enabling. Despite having to work hard to navigate these simultaneous and disparate experiences, most (although not all) experienced their treatment with an overall sense of satisfaction and positivity. This fundamental meaning is discussed more fully in the following chapter.

#### Step 2: Identification of themes

This stage of the process requires that:

*“ .....every single sentence or section should be investigated to expose its meaning for understanding the subject matter”*  
(Fleming et al 2003:118)

In this phase, each interview text was scrutinised in more detail, section by section. Significant statements and phrases that stood out and which seemed to be particularly revealing of children’s experiences of their treatment were underlined and allocated a key word/phrase in the margins of the text. These words/phrases formed preliminary themes and closely reflected children’s own words.

### Step 3: Expansion of understanding

*“Every sentence or section is then related to the meaning of the whole text and with it the sense of the text as a whole is expanded”*  
(Fleming et al 2003:118)

During this stage, the analysis became more interpretive and understanding deepened. Key words/phrases and their associated significant statements were individually contemplated in relation to the transcript as a whole as well my own pre-understandings and the lifeworld existentials previously discussed. From this, a list of themes (the essential structures of children’s experiences) that were more abstract and which evoked the meanings of children’s experiences were formulated. Each transcript was then re-read whilst simultaneously listening to the corresponding recordings of children’s interviews and reflecting on the themes that had been generated. This process was completed for all fifteen interview transcripts, with significant statements being highlighted and further themes being continually developed. Many of the themes generated were found to challenge my assumptions and pre-understandings. For example, a repeated pattern found in the data was related to children’s mastery of the technology and as such I had to abandon quickly my belief that younger children would be heavily reliant on adults for this aspect of their treatment.

After all of the transcripts had been analysed in this way, connections, similarities and differences between all of the themes that had emerged were identified. Particular attention was paid to possible alternative meanings or themes that differed from or contradicted more dominant ones. By so doing, new themes were added and others discarded. Each theme was recorded on different coloured file cards for easier retrieval, along with extracts of data (significant statements) from across the transcripts that matched the theme and notes that reflected my own interpretation of how this “structure” was thematic of children’s experiences of their treatment. Examples of the processes followed in steps 2 and 3 are illustrated in Table 2.

**Table 2: Examples of the analysis process**

**Example 1**

**Structure of experience (Theme):** Bodily pain and discomfort

**Significant statements:**

*“...when it [the cannula] goes in at a dodgy angle it really hurts” (Jack 7 yrs)*

*“I scream...AAGHH!” (Billy 10 yrs)*

*“...when you change it [the cannula], it really hurts” (Ella 8 yrs)*

**Key word / phrase:** Cannulas can really hurt

**Notes:** For young children, experiencing insulin pump therapy means repeated exposure to recurrent and painful bodily experiences.

**Example 2**

**Structure of experience (Theme):** Convenience and flexibility.

**Significant statements:**

*“It’s much easier than injections. Less needles, easier with sports, foods, anything really” (Adam 11 yrs)*

*“I do my blood sugar and then zap myself with insulin. That’s it” (Ella 8 years)*

*“I don’t have to fiddle around with a needle....it’s just an easier way of getting insulin in” (Harry 10 yrs)*

**Key word / phrase:** Pump therapy is easier than injections

**Notes:** Experiencing pump therapy means that children are able to contend with the demands of their condition more easily.

**Step 4: Representation of shared understanding**

*“the identification of passages that seem to be reflective of the shared understandings between researcher and participants”* (Fleming et al 2003: 119)

This last step involved a final analysis of the data whereby individual themes were organised into clusters that loosely reflected the lifeworld existentials of spatiality, temporality, relationality and corporality (van Manen 1997). This process resulted in six overarching themes and associated subthemes being created that aimed to capture the overall complexity and ambiguity of children’s experiences. These are presented in Table 3 below.

**Table 3: Final thematic structure of the data**

<b>DISRUPTED BODIES – DISRUPTED LIVES</b>	
<ul style="list-style-type: none"> <li>• Bodily pain and discomfort</li> <li>• “It wakes me up”</li> <li>• Being constantly attentive</li> <li>• Disrupted school routines</li> <li>• Restricted physical activities</li> <li>• Feelings of ambivalence and dislike</li> </ul>	The disabling effects of insulin pump therapy on children’s lived bodies & everyday lives.
<b>TRANSFORMED BODIES – ENHANCED LIVES</b>	
<ul style="list-style-type: none"> <li>• “It has its downfalls, but it’s still great”</li> <li>• “No more injections!”</li> <li>• Feeling safe and in control</li> <li>• Convenience and flexibility</li> </ul>	The enabling effects of insulin pump therapy on children’s lived bodies & everyday lives.
<b>BEING EMPOWERING – FEELING DISEMPOWERED</b>	
<ul style="list-style-type: none"> <li>• “There’s loads of things I can do”</li> <li>• Being responsible &amp; taking decisions</li> <li>• Being watched</li> <li>• Not being trusted &amp; feeling frustrated</li> </ul>	Children’s expressions of agency & autonomy and how the lived space of school influenced this.
<b>SHAPING IDENTITIES - BEING DIFFERENT AND THE SAME</b>	
<ul style="list-style-type: none"> <li>• Spoiled identities</li> <li>• “I feel the same”</li> <li>• Feeling different &amp; the challenge of disclosure</li> </ul>	How children experienced relationships with peers and the challenges involved in negotiating identities.
<b>GETTING USED TO IT</b>	
<ul style="list-style-type: none"> <li>• “I was pretty scared”</li> <li>• “I’ve got used to it”</li> <li>• Hoping for a cure</li> </ul>	Children’s experiences of pump therapy in relation to time - past, present & future.
<b>FEELING SUPPORTED – BEING UNSUPPORTED</b>	
<ul style="list-style-type: none"> <li>• Everyone helps</li> <li>• “My friends just take care of me”</li> <li>• Being excluded</li> </ul>	Children’s experiences of pump therapy in relation to their connections with family, close friends and others.

Since interpretations can never be final, this stage of the analysis could have continued indefinitely. However, time constraints eventually dictated the number of times this whole cycle was repeated. The “story” that each of the themes tell and their meanings are discussed in the following chapter. These passages represent the shared understandings between me and the children and aims to provide the reader with an account that may allow them to “see” CSII therapy in childhood differently from current understandings.



### **3.6 Issues of Trustworthiness in Qualitative Research**

The inherent subjectivity associated with all qualitative research has led to extensive debate and criticisms about its credibility and, as such, how best to demonstrate its trustworthiness (“truth value”) and quality (Koch & Harrington 1998). However, there is little consensus about this. Arguments range from those advocating the rigorous application of positivist validity criteria (Morse 2015) to the notion that, since there is no unified qualitative research paradigm, the use of any pre-determined, universal criteria is inappropriate (Rolfe 2006). As such, it becomes the responsibility of the reader rather than the writer to appraise a study’s credibility (Rolfe 2006). However, whilst this may be true to some extent, I agree with others who argue that scientific writing requires rigour (Holloway 2005) and that efforts should be made to establish that a study is credible (Bryman 2012).

Finlay (2011) advocates the use of evaluation criteria that specifically reflects the relativist stance of qualitative researchers, rather than adopting those that echo the realist perspectives of quantitative researchers. Strategies, therefore, should acknowledge that generalising findings is not the aim of qualitative work and that “truth” is fragile, situated and contingent. For phenomenological work, four specific criteria are suggested for judging its quality - rigour, relevance, resonance and reflexivity (Finlay 2011). Rigour relates to whether there is evidence of systematic and careful research conduct whilst relevance refers to the value of a study in terms of its applicability and contribution (Finlay 2011). In this study, for the former, I have endeavoured to conduct the research systematically and in a way that demonstrates coherence and consistency in its design. Extensive quotes from the children who participated in it are used and themes are unpacked in detail. By so doing, some transparency is provided in relation to how conclusions have been reached. In addition, I have considered carefully the ethical issues related to conducting research with children as well as my relationship with them and how my presence and positioning might have influenced the research process and outcomes. In terms of relevance, the findings of the study add to the body of knowledge about CSII therapy in childhood by providing a rich and detailed account of what it may be like for children to experience this form of treatment. By so doing, they offer practitioners insights that may help to inform their practice in some way. The third dimension concerning resonance is more difficult to evidence because it asks whether the research findings are sufficiently powerful or vivid enough to “draw the reader in” (Finlay 2011:265). Ultimately,

therefore, this is something that only the reader themselves can judge. Nevertheless, in describing the children's experiences, I have tried to use language that is more expressive rather overly medical or technical in a deliberate effort to provoke empathic understanding and perhaps a more emotional response in the reader. Finally, reflexivity relates to the extent to which the researcher has taken into account their own subjectivity and positioning in the research. This particular aspect is addressed in the discussion that follows.

In the literature exploring the issue of rigour in social science research, the work of Lincoln & Guba (1985) has been particularly influential. As such, I considered it important to use their criteria as an additional tool for assessing the trustworthiness of this study. Four are advocated - transferability, credibility, dependability and confirmability. Creswell (2012:253) suggests that researchers "should engage in at least two of these criteria in any given study". The following discussion considers the extent to which these were applied to this investigation.

#### *Triangulation, member checks and peer scrutiny*

According to Lincoln & Guba (1985) ensuring a study's credibility is especially important for establishing the quality of a study. Credibility refers to a study's truthfulness and techniques that can be used to promote this include triangulation and member checking (Shenton 2004). Triangulation typically refers to the use of different methods or data sets to investigate the same research question in order to either verify findings or to offer a more comprehensive account of phenomena (Morse 2015). However, whilst I believe that this strategy can help to obtain "completeness", it may also produce a raft of inconsistent and contradictory findings and as a consequence, lead to studies that are less, rather than more, credible (Morse 2015). An alternative way to promote credibility is via member checking – that is, presenting texts back to participants for their validation (Lincoln & Guba 1985). However, for this study, this technique also seemed questionable, particularly given the young age of the children who participated in it. In the process of analysis and writing, data is always transformed by the researcher and taken to a more abstract and theoretical level for an audience of peers and academic scholars (Bryman 2012). Therefore, asking children to validate such an account seemed inappropriate. Furthermore, both member checking and triangulation reflect positivistic assumptions that a single, absolute account of social reality is feasible, rather than interpretivist beliefs that the social world is multifaceted and as

such, “truth” is provisional and contingent (Bryman 2012). Therefore, I decided not to use either of these strategies for this study.

Instead, I elected to achieve this principle by using alternative approaches. For example, during the interview process, credibility was enhanced by the use of techniques such as reframing, repeating and expanding questions as required (Krefting 1991). These methods helped to verify children’s accounts and thus, my interpretations of them. I also chose to open the study up to the scrutiny of others (Morse 2015; Shenton 2004). Similar to the principle of member checking, peer examination involves the researcher discussing the research process and findings with impartial colleagues (Krefting 1991). As a doctoral student, this took the form of regular conversations not only with my academic supervisors but also with a clinical supervisor. These collaborative discussions allowed me to test out developing ideas and interpretations and in particular, helped to broaden my horizons of understanding and expose my personal preferences, assumptions and prejudices. In addition, I have also periodically discussed my study with clinicians and peers as well as presented my work at doctoral conferences. Questions, observations and feedback that resulted from these encounters enabled me to reflect more critically on the research and thus, refine its design and methods more effectively. Taken together, these strategies offered a way of reducing investigator bias and by so doing, played an important role in efforts to promote the study’s credibility.

#### *Reflexivity and audit trails*

In qualitative research, the principles of reflexivity and an audit trail are now well established methods for demonstrating both the confirmability and dependability of a study (Bryman 2012). However, the notion of reflexivity has been described as a “notoriously slippery concept” (Bryman 2012:394) in the sense that it is understood in a multitude of different ways and can be applied to the research process at many different levels (Finlay 2011). For this study, I chose to follow the advice of Finlay (2011:265) who refers to this concept as essentially “a researcher’s self-awareness and openness about the research process”. Techniques for illustrating engagement in reflexivity can include incorporating sections of a researcher’s journal into the thesis (Koch 1994). However, primarily for pragmatic reasons (limited space) I have chosen to integrate ongoing “reflective commentary” (Shenton 2004:68) throughout the text instead. As such, I have endeavoured to make explicit my central role in the study and examined the impact of my position as an adult researcher investigating children’s worlds,

particularly in relation to issues of power. In addition, I have been careful to state my own epistemological and ontological stance and to be overt about my own assumptions and prejudices and the ways in which this influenced the research design and methods. It was also essential that I demonstrated transparency. Critical to this process, is an audit trail which for this study is illustrated via a detailed report of the decision making processes that were followed for each part of the research process. This allows readers an opportunity to trace the course of the research step by step and by so doing provides an additional way of evaluating the overall quality of the study.

### *Thick description*

Thick description refers to a rich, thorough description of the phenomena under investigation, including the processes followed during its conduct (Shenton 2004). As such, it is linked to the audit trail previously discussed. Providing thick descriptions can be important for promoting both the credibility of a study as well as its transferability (Lincoln & Guba 1985). This is because it helps to not only portray the reality of the participants but also it permits judgements about contextual similarity and thus, the extent to which findings might be transferable to other individuals or settings (Polit & Beck 2006). However, this latter concept is a debated issue in the literature. Some argue that since the results in qualitative research are specific to a particular context and to a small number of participants, the transferability of findings to other settings is inappropriate (Shenton 2004). However, Lincoln & Guba (1985) propose that if readers believe their situations to be similar to that described in a study, it *may* be appropriate for them to relate the findings to their own positions (Lincoln & Guba 1985). Nevertheless, since a researcher is only aware of the “sending context”, making inferences about a study’s transferability is inappropriate (Shenton 2004). Instead, their role is to provide enough detail for the readers themselves to make this judgement. Therefore, for this study I have endeavoured to provide descriptive data concerning the sample of children who participated in the study as well as the exclusion and inclusion criteria used. In addition, accounts have been obtained from children of different ages and gender and with varied treatment experiences, including those whose views contradicted the more commonly occurring ones. Morse (2015) suggests that such “negative cases” are often critical for understanding a phenomenon as a whole and as such can greatly strengthen the quality of a study.

### **3.7 Summary**

Many factors determined the methodology used to underpin this research inquiry and the choice of methods employed. This included personal ideologies and professional values as well as a desire to choose techniques that would maximise children's abilities to express their own views and engage them actively in the construction and reconstruction of knowledge.

This chapter has endeavoured to make explicit, and give a rationale for, the decisions taken throughout the course of the research process in order to ensure that its theoretical perspective, methodology and methods both "fit" the aim of the inquiry as well as interconnect and inform each other (Crotty 1998). By so doing, it offers an audit trail that may enable readers to establish not only its range of relevance and possible transferability, but also to judge its quality and trustworthiness more effectively.

In the next chapter, I offer the findings of the study which emerged from the interviews held with all of the children.

## CHAPTER 4 - FINDINGS

### 4.1 Introduction

This chapter presents the findings of the study. In the account that follows, children's stories have been re-presented in a way that reflects the shared understandings between both the children and me as the researcher. Therefore, it inevitably incorporates my own interpretations and experiences. However, as far as possible, I have endeavoured to ensure that the perspectives of the children are not only privileged throughout, but also are revealed in a way that enables their experiences to be heard and understood.

The findings form one possible account of how young children experience insulin pump therapy. As such, they can only be presented as partial, tentative and emergent. Moreover, since interpretations can continue indefinitely, it is recognised that another researcher may have unfolded a different story. Nevertheless, they attempt to capture the complexity of the children's experiences by highlighting not only the ambiguities involved in living with insulin pump therapy, but also by presenting an account of experiences that children shared as well as those that were unique to particular individuals.

As previously highlighted, in general, younger children's responses to questions about their experiences tended to be less detailed than those given by the older children. Nevertheless, overall, all of their accounts were insightful and revealed a range of diverse and often contradictory experiences. As a consequence, the meanings that CSII therapy had for them were multi-layered, intertwined and frequently paradoxical. Findings for the study are presented as themes. Within each of these themes are sub-themes. Whilst these themes are differentiated, they are not separate. Each is interlinked and together encapsulates the essence of how it "is" for the children in this study to experience insulin pump therapy in the everyday. Six main themes emerged:

- Disrupted bodies - Disrupted lives
- Transformed bodies - Enhanced lives
- Being empowered - Feeling disempowered
- Shaping identities: Being different and the same
- "Getting used to it"
- Feeling Supported - Being Unsupported

Each theme includes a range of experiences and will be explored and illustrated using verbatim extracts from children's accounts to demonstrate grounding in the data. Where a word is implied, but not stated, it has been included in square brackets [ ]. To ensure confidentiality, participants have been given pseudonyms.

## **4.2 DISRUPTED BODIES – DISRUPTED LIVES**

### **Overview**

This first theme reflects children's accounts of the ways in which their treatment intruded on their physical bodies and consciousness and disrupted their everyday living. In particular, they described how, as a site for technological intervention, their bodies and bodily routines were disrupted by painful cannula insertions, uncomfortable infusions of insulin and pump alarms. Moreover, relations with the world were changed as frequent treatment processes and constant decision-making meant reduced opportunities for easy, unmindful living.

### **Disrupted Bodies**

#### ***Bodily pain and discomfort***

Insulin pump therapy changed children's experiences of their body viscerally. In their accounts, they described how it felt "in their bodies" when having to undergo invasive procedures and the strategies they used to control such events. A particular concern was related to the insertion of cannulas into their bodies. All of the children described this as the most difficult aspect of their pump therapy and as such, was the primary reason for disliking their treatment.

*"Yeah, the worst, the particular worst thing, is the  
cannulas"* (Jordan 7 yrs)

*"Changing the cannula.... I don't like it. It's better  
than the injections, but I don't like doing it"* (Adam 11 yrs)

This procedure was associated with negative feelings and emotions - in particular, pain anxiety and tension. For many children, this seemed to be especially the case when the abdomen was used as the insertion site.

*“On your tummy sometimes it feels really uncomfortable.  
Then you wait a while and it doesn’t get better.[I get] very  
upset, because I have to take it out...take it out of one place  
and put it back in another”* (Beth 10 yrs)

*“When it goes in at a dodgy angle it really hurts my belly  
button”* (Jack 7 yrs)

*“Sometimes I get quite tensed up.....kind of...I never  
normally do it around my tummy ‘cos I hate that”* (Harry 10yrs)

Other treatment procedures were also felt bodily. For some of the children, the administration of boluses of insulin via their pumps was also felt as pain.

*“If it’s a really big dose, then you can feel it and it hurts”* (Paige 11 yrs)

*“Sometimes the pump can annoy you because when you give  
the insulin, it stings you”* (Jordan 7 yrs)

For Charlie, boluses were experienced bodily as a feeling of cold from within.

*“Well, if the insulin is cold, you can feel it running through”*

The children talked about the strategies that they actively employed in order to manage cannula insertions. Billy described two different techniques that helped him to gain control over the intense pain that he experienced during this procedure.

*“[I] scream!.....AAGH! Mummy you’ve chosen the wrong place!”*

*“Alfie [the family dog] helps me when I am crying because...the  
set change... I just stroke him and he knows”* (Billy 10 yrs)

Others talked about how they tried to shield their bodies from the pain by becoming self-sufficient or by being stoic. Individualised strategies were described, including distraction and breathing techniques.

*“I sort of ...normally I kinda just hold my fingers tight when it  
hurts. And when it’s in the night, I just cuddle my Teddy”* (Beth 10yrs)



*“Sometimes I have to like really control my breathing.*

*If I was holding my breath when it went in, it would hurt  
a lot more”*

(Adam 11 yrs)

*“I just leave it and go out and play football”*

(Jack 7yrs)

For young children, therefore, experiencing insulin pump therapy may mean exposure to recurrent and painful bodily experiences. This may require them to alter the ways in which they relate to this pain in order to manage these events successfully. Nevertheless, for most children in this study, cannula changes were experienced as an ongoing challenge.

***“It wakes me up”***

Not only did this treatment change bodies viscerally, it also meant disruption to bodily routines, particularly in relation to sleeping patterns at night. Children highlighted how nights could often be disturbed by the presence of the technology - in particular, insulin pumps vibrating and alarming and the subsequent feelings of annoyance that this caused for them.

*“When it beeps I have to tell Daddy. And it really annoys me  
because it wakes me up so I want them to stop it vibrating....*

*because it hurts and I get really scared”*

(Beth 10 yrs)

*“It keeps going off. It keeps saying occlusion, occlusion. Then*

*I wake up in the middle of the night and it starts going wrong.*

*It’s just really annoying”*

(Jack 7 yrs)

*“Sometimes it double beeps in the night and then I go*

*and tell Mum and she sorts it out”*

(Josh 7 yrs)

For others, getting to sleep and staying asleep could be problematic as a result of the technology encroaching on bodies and requiring children’s attention.

*“Sometimes it falls out of its cage and pokes you”*

(Charlie 9 yrs)

*“It’s quite annoying when you are lying in bed and it [the pump] goes behind you. It feels like you can’t get comfortable and you don’t know what it is. It feels like an annoying person”* (Jordan 7 yrs)

*“The downfall of the pump....because of the wire when I sleep in bed.... it gets wrapped round me and then I have to sort of get up when I’m just about to go to sleep. It’s just so annoying”* (Billy 9 yrs)

The subsequent tiredness and fatigue was a problem for some children and had detrimental effects on getting to school on time and relations with friends.

*“Well, on school nights it bugs me because sometimes.. I accidentally ....they [parents] wake me up but then I fall back to sleep”* (Charlie 9 yrs)

*“It makes you feel very grumpy. My best friend knows when I’ve had to do that [wake up]”* (Paige 11 yrs)

Therefore, experiencing insulin pump therapy may also mean reduced opportunities for undisturbed and restful sleep which may then have detrimental effects on children’s well-being and their interactions with others.

### ***Being Constantly Attentive***

In addition to altered bodily sensations and routines, insulin pump therapy also intruded on and modified children’s consciousness and way of being in the world. Children’s accounts suggested that managing their treatment required a constant state of attentiveness. Thus, bodies, technologies, foodstuffs and other “happenings” all needed to be attended to and an ongoing process of adjusting, thinking and figuring out was needed. Children’s attachment with the world, therefore, was changed.

Some of this attentiveness was driven by felt bodily sensations – in particular, those associated with hypoglycaemic episodes. In the experience of pump therapy, children’s bodies during hypoglycaemia typically became strange and more difficult to control.

*“I kind of like get tired, just get a weird feeling in my tummy”* (Harry 11 yrs)

*“You feel a bit tingly and hot..and then you feel like  
you can’t walk anymore”* (Will 8 yrs)

*“Like sometimes I’m in another world...I don’t really  
feel like doing anything”* (Zoe 11 yrs)

These bodily episodes required more than a simple judgement call from children. It meant being alert to the body’s signals and then taking action. The frequency with which Ella and Charlie use the word “I” in the following accounts suggests the level of effort that the children themselves engaged in when experiencing hypoglycaemia on pump therapy.

*“I feel really weird and tired. I go and tell Mum and Dad.  
I do my blood sugars. I tell them what it is. And if I have  
a hypo, I can’t reach the orange juice on top of the fridge  
So Mum just gets it down”* (Ella 8 yrs)

*“If I’m low before I go to sleep, I can’t get to sleep.  
I wake up a lot of the time thinking about..I think  
am I low or am I not. And it bugs me sometimes”* (Charlie 8 yrs)

Children’s accounts also revealed the conscious, reflective thinking that they frequently employed in order to successfully negotiate every day taken for granted activities. For example, for these children, mealtimes involved more than the physical acts of eating and drinking. In their talk, children revealed how much they had to learn and remember, particularly in terms of knowing about the carbohydrate content of everything they ate.

*“When it comes to working out the carbs...say it was a cupcake..  
I’d probably bolus 30 [units of insulin] if it was vanilla. If it was  
chocolate, then it would be 35 ‘cos it’s always a bit more ‘cos  
it’s got more sugar in it. I have to guess sometimes”* (Paige 11 yrs)

*“I know some carbs. For a medium slice of bread it’s about  
60[grams] in the carbs. For a packet of crisps it’s about 16, 17, 18”*  
(Will 8 yrs)

Children also had to appreciate the ways in which blood sugar levels framed the food and drink options available to them.

*“My Mum adjusts my puddings so I don’t go high”* (Holly 10yrs)

*“So, I bought a pot of sweets..I checked myself when I wanted to eat them and I was high. And when I’m high I can’t eat them”* (Paige 11 yrs)

Moreover, judgements had to be made about the appropriate type of insulin dose needed in order to best match the body’s digestion of different foods:

*“If you [are] having cheese or anything that is slow digesting you go into dual wave bolus or square wave or if it’s something normal, you just do normal bolus”* (Charlie 9 yrs)

*“If it was something like pizza or pasta, I could give myself an extended bolus. But if I wasn’t going to, I’d just deliver”* (Harry 10 yrs)

Thus, despite being young, experiencing pump therapy means that children have to think about food in complex ways. They not only must understand how it affects their bodies physically, but also they have to learn to adjust food preferences and make difficult treatment decisions. Such attentiveness may be required many times each day.

Everyday physical activities also required children’s attention. Their accounts revealed the additional work needed to protect their bodies when taking exercise primarily because of technology’s presence.

*“When you play football, you have to pull your shirt down over it [the cannula] so that it doesn’t like get pulled”* (Will 8 yrs)

For the girls, dancing could be problematic. Bodies and technology had to be adjusted to complement each other.

*“When I’m doing like dance, I normally have my pump in front.. ‘cos if it’s behind, we do a lot of rolling and stuff. I do worry about catching my thumb on it”* (Beth 10 yrs)

For others, the movement of the pump against their bodies was uncomfortable and made exercising difficult.

*“Well, like when I do PE at school it’s quite annoying*

*because it like jumps about and hits me”*

(Jordan 7 yrs)

Therefore, living with an insulin pump means that children’s physical competencies are altered and as such, new ways of moving in the world have to be learned. It means protecting themselves and having to be alert to possible harm. In addition, children must be mindful of the technology itself. Unexpected “happenings” must be noticed and signs of malfunction addressed. As such, attention must be paid not just to what technologies are supposed to do, but also to what they “happen” to do.

*“Air bubbles in the line, you can’t see them. And when air*

*bubbles come, we have to figure out why it’s high”*

(Billy 9 yrs)

Therefore, for the children in this study, it would seem that opportunities for easy, unmindful living were diminished. New ways of managing everyday routines had to be learned and frequent decisions had to be taken. This supposes hard work. Thus, “doing” pump therapy depends on children being actively engaged in considerable illness work. Their accounts revealed not only the extent to which they themselves were active partners in their daily care, but also their willingness and capacity to engage in the management of their condition and their competence in doing so. As such, in enacting insulin pump therapy, it seems that a great deal of physical and emotional effort is needed in order for children to incorporate it into their everyday lives.

### **Disrupted Lives**

As well as influencing children’s lived bodies and bodily routines, their therapy also shaped and constrained aspects of their everyday lives. Thus, children described how it interrupted experiences in school and sometimes imposed restrictions on opportunities to engage fully in physical activities and social interactions with peers.

#### *Disrupted school routines*

During the conversations, many of the children spoke of how their learning could be disrupted and lessons missed as a result of problems with the technology, particularly the insulin pump.

*“Sometimes the pump can get in the way of my learning because it can start beeping, saying that it’s run out of battery or something”* (Beth 10 yrs)

*“Sometimes my pump will beep at school which is kinda low battery or occlusion. Then I have to go to the school office. And then I missed the whole English lesson”* (Harry 10 yrs)

Moreover, regardless of age, break-times were often experienced as rushed and pressurised. The need to carry out treatment processes during these times interfered with opportunities for social interaction with their peers.

*“It’s a time waster because if I’m about to have lunch, all my friends are about to have lunch, but I still need to do a finger prick and I’ve got to weigh out my food”* (Adam 11 yrs)

*“Like sometimes at school when they’ve [friends] got my lunch box and they are going to save me a space and I’m having to wait ‘cos I’ve got to do my blood sugars and stuff. And I try and do it as quickly as possible so I don’t have to sit in separate seats”* (Paige 11 yrs)

*“Sometimes, it’s so late because Miss S has to do my sharpie all the time and then I’m the last one going outside”* (Luke 6 yrs)

Others worried about not having enough time to complete their treatment and, as a result, being late for their classes.

*“I worry about timings at break because getting from my lesson to my form takes about five minutes and then you have got about ten minutes left to do the insulin and eat and to get to the lesson”* (Zoe 11 yrs)

*“It takes time...and if I have one minute to go...’cos sometimes it [the infusion set] gets slightly jammed and you can’t get it off and then it makes you late for lessons”* (Billy 9 yrs)

### ***Restricted physical activities***

Whilst all of the children gave descriptions of a wide range of physical activities in which they participated, many also bemoaned restrictions that their treatment imposed on opportunities for some forms of exercise. This finding related specifically to the children who were using the Roche insulin pump. Of substantial concern to most was the impact that this technology had on opportunities to swim as a result of it not being waterproof. Consequently, this activity was often experienced as a rushed affair characterised by a sense of inconvenience and urgency.

*“You can only go in [to the pool] for an hour. Then, once you go out, you wouldn’t want to go back in. So then it would be over. I get annoyed because I don’t have as much time as I want”* (Beth 10 yrs)

*“I have to take it [the pump] off and it’s only allowed off for an hour, so I’ve got to get in as quick as possible”* (Charlie 9 yrs)

Therefore, it seems that insulin pump therapy does not always fit easily into children’s everyday lives. It means lifestyle interruptions that may reduce opportunities for engaging fully in social activities and relationships. This presents children with additional challenges which, along with everything else, must be actively negotiated and managed by them.

## **4.3 TRANSFORMED BODIES - ENHANCED LIVES**

### **Overview**

Despite the intensive demands that insulin pump therapy appeared to impose on the children, a second major theme that emerged was the ways in which this treatment transformed their bodies and, for most, enhanced their emotional and psychological well-being. This theme reflects children’s accounts of how the technology in particular enabled their bodies to be freed from multiple and invasive insulin injections as well as offering opportunities for experiencing a sense of freedom, physical safety and a sense

of control over their bodies. As a consequence, most of the children highly valued their treatment. However, the accounts of two children were different. One was characterised by a sense of ambivalence towards their therapy whilst the other revealed an active dislike of it.

### **Transformed Bodies**

#### ***“It has its downfalls, but it’s still great”***

Although sometimes difficult, the defining emotion attached to most children’s accounts of their everyday experiences of pump therapy was one of enthusiasm and satisfaction. For most, the language that characterised their overall feelings of pump therapy was unequivocal rather than ambivalent in nature.

*“Well, if I had to choose between injections and a pump,  
it would definitely be a pump”* (Paige 11 yrs)

*“I’d say it was great. It has its downfalls, but it is still great”  
My pump has given me back my childhood ... it honestly has”*  
(Billy 9 yrs)

*“It’s perfect and I don’t want to change”* (Ryan 11 yrs)

#### ***“No more injections”***

Children’s positive feelings about their treatment were grounded in a variety of reasons. However, above all else, pump therapy was experienced favourably because it enabled children’s bodies to be liberated from frequent and invasive injections of insulin. Irrespective of age, when children talked about their lived experiences, the freedom from multiple insulin injections that pump therapy offered was emphasised and as such, frequently cited first. Speaking loudly whilst simultaneously writing in bold letters on her spidergram, Paige explained:

*“NO MORE INJECTIONS! The pump means that you don’t  
have to keep injecting and constantly taking the needle in  
and out every meal time”* (Paige 11 yrs)



*“So, what’s good about the pump is that I don’t have to inject every meal time. I don’t have to inject every day”* (Billy 9 yrs)

*“It’s a lot better getting stabbed once instead of getting stabbed ten times”* (Jack 7 yrs)

When remembering injections, Charlie’s language conveyed a sense of the fear that this regime had imposed on his life.

*“It’s better than having injections because I’ve been told by Mum and Dad that I used to hide from my injections”* (Charlie 9 yrs)

### ***Feeling safe and in control***

Children also highlighted the advantages of insulin pump therapy in terms of how the technology enabled them to more precisely administer and adjust insulin doses. This aspect seemed to be particularly important for children.

*“Well, if I’m high, I can adjust so that it will give me the right amount of insulin... because if I used to be high, we had to inject. But if you do it on here [the pump]...if I’ve got too much insulin going round, it says I don’t have to give anything or 0.2 [units] or whatever”* (Charlie 9 yrs)

*“I can turn down the insulin. I can cut out the insulin..whereas on injections you can’t cut out the insulin...it’s much easier just to cut out the insulin..or turn it down so I’m having less insulin if I know I’m gonna drop”* (Adam 11yrs)

However, it was not only about what the technology could actually do. Due to its potential for stabilising blood sugar control, for many these devices also generated opportunities for children to feel more in control of their bodies.

*“My BG [blood glucose] is more controlled. Then I don’t loose weight and I don’t get rotting teeth probably”* (Billy 9 yrs)

*“It corrects so your bloods aren’t as high all the time. So it controls it a bit more. It controls your blood a bit more”* (Ryan 11 yrs)

*“Well, it [injections] would be annoying because if you stuck insulin in and you dropped...so, say I was high and I dropped low, it’s not like the pump you can adjust and suspend. So, I would just keep going high and low”* (Charlie 9 yrs)

As a consequence, insulin pump therapy evoked peace of mind and a sense of safety and security.

*“The good thing is that it never stops giving me insulin”* (Jordan 7 yrs)

*“You feel safe about the insulin going in...you feel secure.. that it is, you feel definite that it’s happening, that you put in the carbs and it’s going to give you the right amount of insulin”*  
(Beth 10 yrs)

*“It would probably be a lot more unstable [using injections] because it’s easier to manage with the pump because I know exactly how much is the right amount”* (Paige 11 yrs)

## **Enhanced Lives**

### ***Convenience and flexibility***

Children’s positive stance was also related to the ways in which pump therapy helped them to contend with their condition more easily. As Adam explained:

*“It makes me feel that it’s much easier to cope with diabetes”* (Adam 11yrs)

In particular, it brought a new-found experience of eating whereby dietary restrictions could be relaxed and food could be enjoyed. Being able to eat sweet, sugary foods was especially important. Jack’s comment captured this aspect perfectly:

*“I can eat cake!”* (Jack 7 yrs)

Children also described how the technology removed previous ties and limitations such that they no longer had to undress when an insulin dose was required or make complex mathematical calculations.

*“I can set the basal rates and stuff which is really useful. Not having to work out all the doses ‘cos it’s quite hard..a lot of maths”* (Paige 11yrs)

*“You don’t have to pull down my trousers and inject...it just allows me to do things which injections wouldn’t”* (Billy 9 yrs)

Moreover, many children described its convenience. Daily life on multiple injection therapy was remembered as being awkward and time consuming. By way of contrast, pump therapy was spoken about in terms of the increased flexibility and sense of freedom that it created.

*“I don’t have to fiddle around with a needle. I’ve just got to tell my monitor how many carbs I want. It’s just an easier way of getting it [insulin] in instead of the hassle”* (Harry 10 yrs)

*“I just zap myself. Do my blood sugar and then zap myself with insulin. That’s it”* (Ella 8 yrs)

*“It’s much easier than injections. Less needles, easier with sports, foods, anything really”* (Adam 11 yrs)

Therefore, being a young child using insulin pump therapy means greater normalisation of bodies and everyday lives. Whilst it was experienced physically as sometimes painful and uncomfortable by all the children, the benefits it brought most of them in terms of fewer episodes of bodily pain compared to injection therapy, its convenience, flexibility and feelings of safety and freedom appeared to outweigh the intrusions it sometimes made on them.

### ***Ambivalence and Dislike***

However, whilst experiencing pump therapy was positive for most children, this was not the case for all of them. Two children spoke of pump therapy differently. The

account from Beth (aged 10 years) conveyed more of a sense of uncertainty and ambivalence about it. Compared to the other children, she had been on pump therapy for the shortest period of time (eight months). Moreover, her narrative revealed a sense of difference from others and a lack of close friendships in the school setting whom she could trust and share her experiences of pump therapy with (see Theme 4.5). As such, her response may have been mediated by interrelationships between treatment duration and her perceptions of stigma and social support.

*“It’s difficult....but worth it. It can be really hard sometimes”*

Nevertheless, even though she experienced greater ambivalence towards her therapy, freedom from injections helped her to frame her feelings about it in a more positive light.

*“I wouldn’t say it was bad. Worse...then good because it is better than injections”*

However, for Luke, pump therapy meant significant disruption to both his physical and emotional well-being. At the age of 6 years, Luke was the youngest participant and had been using pump therapy for two years. During the conversation, he was constantly on the move, running in and out of the summerhouse, swinging on a rope outside and drawing pictures of black, angry spiders whilst talking. He also asked for the interview to be stopped twice - once because he wanted to hear his voice on the audio-recorder and the second time when he was asked if he felt different to others. He was not overtly distressed on either occasion and happily continued the conversation after a short pause and a change of topic. Whilst his account of his treatment experiences was similar to Beth in terms of feelings of difference, unlike her, Luke talked of close friends at school who supported him with his therapy. However, his descriptions of his treatment were conveyed with a mood of loathing and dislike. The vivid language that he used throughout his interview conveyed a sense that for him, there was nothing positive about his therapy. He began his interview with the following words:

*“Well, it’s really, really, really horrible”*

This dislike appeared to be partly embedded in his views about the impact of his treatment regime not only in terms of the way it appeared to dominate his life

*“My whole life is spent having tubes and injections”*

but also because of the intrusions it made on his body. For Luke, the frequency of blood tests (sharpies) scarred his body

*“You see these dots? That’s what happens when you have loads of sharpies all the time”*

and cannula insertions were experienced with a sense of fear and dread.

*“I run off and hide..so I don’t have to have it. I try to find the best hiding place but then Mummy keeps on finding me”*

Whilst these bodily experiences had similarities with the accounts of other children, unlike others Luke’s dislike of pump therapy also appeared to stem from the impact of the illness itself. His accounts were characterised by a sense of sadness and wishful thinking. He seemed to yearn for a return to life before diabetes.

*“Well, I’d change everything about all my life so I could go back to being two again when I didn’t have any diabetes. And I keep saying to Mummy, I wish diabetes was a myth”*

His words also conveyed a strong desire for normalcy and a wish to belong to the ‘well-world’ of his siblings.

*“I always think about what the cure is going to be.... I just wish I was like Rory and Sam”*

Luke’s negative views of his condition seemed to influence not only his attitudes towards his treatment regime, but also impacted on his sense of self worth, resulting in feelings of inadequacy and low self-esteem.

*“It feels like I’m dumb.... I mean not good for anything, because I have diabetes”*

Therefore, the experience of insulin pump therapy may not always be regarded positively by all young children. For some, time and strong peer relationships may be particularly important mediators in enabling children to adjust to the demands this regime places on them. However, for those who perceive their illness negatively, pump

therapy may be experienced as especially disruptive to bodies and lives and something that impacts heavily on their emotional way of being-in-the-world.

#### **4.4 BEING EMPOWERED – FEELING DISEMPOWERED**

##### **Overview**

A third major theme involved the notion of empowerment – that is, the ways in which insulin pump therapy appeared to give children the means to not only take greater personal responsibility for their own health care but also to participate more in making treatment related decisions for themselves. By so doing, children’s sense of agency and autonomy were enhanced. Much of this theme centres on children’s expressions of their competency and confidence with the technology itself. Despite their young age, many were able to use these artefacts with considerable dexterity and were highly knowledgeable about their functionality. However, children’s accounts suggested that this aspect of their experiences was contingent on the everyday places that they inhabited - in particular, the lived space of school. In this setting, children’s active role in managing their own condition was at odds with how they were supported in this particular setting. For many of the older children this was experienced as disempowering and created feelings of tension and annoyance that had to be actively managed by themselves.

##### **Being Empowered**

###### ***Being responsible and taking decisions***

Although none of the children were fully independent with their treatment, it was evident that many exercised considerable independence in terms of their technical mastery of the technology. Operating the required technologies appeared to be taken in their stride. A range of different skills and levels of expertise were described. Whilst talking, all of the children were keen to demonstrate their proficiency at using the technology – particularly in relation to the insulin pump itself. They seemed proud of their capacity to master these artefacts and this appeared to provide them with a source of great satisfaction.

All of the children could perform blood glucose monitoring independently and were, to a greater or lesser extent, able to interpret the results, including the youngest in the study.

*“Sometimes it [the meter] double beeps two times. When it’s [blood sugar] low...it has a red line, a red box and it has red all over it. And then if it’s high, it’s blue. It’s fine if it’s green”* (Josh 7 yrs)

*“Well, it [the meter] comes up with like blood really high. And then it has an exclamation mark and a little triangle. I see what the blood is and tell Mum”* (Luke 6 yrs)

However, as might be expected with young children, the complexity of the insulin pump itself meant that in general the youngest were unable to operate this independently.

*“My pump is very confusing ‘cos there’s lots of buttons on the outside and the inside”* (Jordan 7 yrs)

Nevertheless, this was not always the case. Ella and Jack appeared to have no difficulty in navigating the pump technology themselves to deliver the appropriate dose of insulin for their meals. The specialised language and jargon they used, (“bolus”, “connected”, “carbs”, “TBR”), and the simple ease with which they demonstrated the procedures whilst talking, indicated their level of expertise and understanding.

*“I have to do this...I press that and that one. I press down. I press OK. Then it starts connecting. And then you type in the carbs and bolus”* (Jack 7 yrs)

*“I can do stuff like...do my blood sugars and do my insulin. I basically put in how much carbs there is and then I just press confirm and then confirm and then I just stand still until it’s finished”* (Ella 8yrs)

Will was also able to alter the delivery of background insulin (temporary basal rate [TBR]) himself.

*“I know how to do it....the TBR. You go onto that and then you do the percent that you want and then you press tick”* (Will 8 yrs)

From the age of 9 years, children talked of and demonstrated an increasing range of technical skills that they had mastered and which they performed independently on a frequent basis every day. Many of the advanced features of the pump technology were used. Billy described how he was able to decide and then choose different basal rates of insulin (patterns) to reflect his specific daily circumstances as well as retrieve stored records of previously administered insulin doses (bolus history). Each feature involves not only conscious decision making processes, but also the competency to navigate through the pump technology correctly. He talked with confidence and his words evoked a sense of the pleasure and pride that came with its mastery.

*“[I can] select patterns, give a bolus, put in my blood glucose, turn on the light! Go to the main menu..err..go to my bolus history..there’s loads of things I can do!”* (Billy 9 yrs)

A few spoke of how they could also change their own infusion sets and cannulas unaided.

*“I can put in my carbs by myself, test my levels myself. I sometimes put in my sets [cannula] myself”* (Holly 10yrs)

*“I had an occlusion that day and I had to change it all [cannula and infusion set] at lunchtime”* (Paige 11yrs)

## **Feeling Disempowered**

### ***Being watched***

However, experiencing insulin pump therapy also meant that in certain spaces children’s practical skills and competencies in managing their own care was sometimes not recognised by others. As such, it appeared that children’s sense of autonomy and agency were both extended and limited by the technology. This was especially the case in the specific context of school.

In general, children’s accounts conveyed a sense that school was a supportive, social place that they largely enjoyed. However, whilst attentive, the nature of the support given and how this was experienced varied. As might be expected, a few of the youngest children spoke of teachers administering their insulin for them at mealtimes.



*“My teachers put in the insulin”*

(Josh 7 yrs)

This appeared to be the same for Ella, even though she was able to carry out these tasks herself.

*“They [teachers] do my blood sugars and insulin and stuff  
like that”*

(Ella 8 yrs)

However, for the other children, the role of school staff seemed to be primarily one of supervision rather than performing actual treatment processes. Children described how staff would invariably contact parents if problems occurred with the technology itself.

*“She [my mother] has to come in to sort my pump out or change  
my needle”*

(Jack 7 yrs)

*“I tell Mrs. H [teacher] and she phones my Mum. And then  
my Mum comes and sorts it out. And then it’s all sorted and  
she goes back to work”*

(Ella 8 yrs)

Moreover, most children described how school staff supervised and watched children’s own self-management of their insulin pump care.

*“I do it on my own. They are just there next to me”*

(Jack 7 yrs)

The use of language such as “she wants”, “she has to” and “I have to” conveyed a sense that children were required to do this rather than having a choice about it.

*“I have to do the basal [insulin] and the teacher has to watch  
me put my bolus in”*

(Charlie 9 yrs)

*“Before I go home and at lunchtime, I go to Matron’s  
office to do a blood test ‘cos she just wants to know  
I’m alright. She wants me to go to the office and do  
it there”*

(Adam 11 yrs)

Not only were children’s actions watched, many were also required to simultaneously explain to those supervising them what they were doing. Insulin pump therapy, therefore, altered children’s relations and interactions with teachers - that is, as experts

in the use of the technologies, the children themselves became the teachers. As such, traditional roles seemed to be reversed.

*“She [teacher] has to watch. I tell her I’m doing these carbs and I’m doing this multiwave [insulin] and I’m doing this and that”* (Will 8 yrs)

*“When I’m changing my cannula, they come along and supervise. They don’t help, help. But they make me explain to them what I’m doing and I have to talk through the process”* (Beth 10 yrs)

*“I have to show them...I show them what to do”* (Josh 7 yrs)

Embedded in children’s language was a sense that some teaching staff may have been somewhat alienated by the technological demands of pump therapy and that although they acted as supervisors, they may have lacked the necessary understanding and expertise to actually do this effectively. Charlie’s words seemed to capture the essence of this particular aspect of children’s experiences.

*“They watch me because they want to learn”* (Charlie 9 yrs)

### ***Not being trusted and feeling frustrated***

The accounts given by the youngest children did not convey any major struggles with the nature of the support at school. However, a number of children in the older age group appeared to experience this level of surveillance differently. Their narratives suggested that school staff lacked faith in children’s abilities. As a consequence, teachers seemed to have difficulty in entrusting children with responsibility for their own care, even though they were clearly able to demonstrate their skill and expertise.

*“They are watching me and not sort of giving me my own independence”* (Billy 9 yrs)

*“They make me talk through the process. I’m like ‘this is going to take twice the time’”* (Paige 11 yrs)

*“And I usually go really fast!...and they [teachers] say ‘can you do that again’. I can do it most of the time on my own”* (Charlie 9 yrs)

*“Each time I do it, it’s like ‘you’re going too fast’ and I’m just pressing the buttons going up with the carbs. They want me to just do one..two.. (counting slowly)”* (Beth 10 yrs)

Therefore, for some children, enacting pump therapy in the context of school may mean that an ambiguous sense of agency is experienced. On the one hand, the technologies opened up opportunities for them to exercise expertise and skill in the management of their own condition. On the other hand, their competence and maturity was not fully recognised by others and as a consequence, their agency was restrained. For these children, such ambiguity generated feelings of uncertainty and frustration.

*“It feels like I don’t know how to manage my diabetes”* (Billy 9 yrs)

*“It takes ages to explain what I’m doing. I just need to do it”* (Paige 11 yrs)

For Charlie, his teachers’ reluctance to consult him and to acknowledge his experience when a problem with his insulin pump occurred was experienced as especially irksome. Talking with frustration in his voice he said:

*“Sometimes they don’t ask me and it just gets me really annoyed. They just always phone a member of my family. And I’m like why don’t you ask me?”*

For others, the effect of teacher’s over-surveillance provoked additional emotions. Beth’s self-belief and confidence appeared to be affected.

*“I feel a bit insecure when they [teachers] help. I feel like they don’t trust me to put in the right carbs”*

However, although these children found teacher’s over-involvement as burdensome, their narratives suggested that they had not only learned to accept this as inevitable but also it was something they were reluctant to challenge. Here, it seemed that social norms and power relations associated with this setting implicitly defined children’s role

as healthcare actors and the degree of agency and autonomy that they were able to exercise.

*“I don’t say ‘why don’t you ask me?’ because that would be like ‘Charlie don’t be rude’”* (Charlie 9 yrs)

*“I understand why they are doing it, but I don’t if you see what I mean. I don’t really want to tell them ‘cos that would probably put them off and I don’t want to be unkind”* (Billy 9 yrs)

Therefore, for some, experiencing pump therapy may mean having to modify their otherwise active role in their illness management in order to reflect the nature of specific relationships and contexts. In school, it appeared that a relatively passive and conforming role may be necessary. Thus, it would seem that “places” matter because they participated in shaping children’s sense of empowerment, influenced their actions and altered their relationships with others.

#### **4.5 SHAPING IDENTITIES: BEING DIFFERENT AND THE SAME**

##### **Overview**

A further prominent theme to emerge from children’s accounts centred on the ways in which experiencing insulin pump therapy also influenced their identity. This was not just in terms of their own self-conception (personal identity) but also related to their social (public) identity and the way others perceived and defined them – in particular their peers. Children’s narratives highlighted the tensions and challenges experienced in shaping and managing these and by so doing revealed an additional layer of complexity to the identity or “body work” they were required to undertake in order to incorporate their treatment into their being and everyday lives. For a few children, this aspect seemed to be a particularly difficult part of their therapy.

##### ***Spoiled Identities***

From children’s narratives, it appeared that it was their treatment regime, rather than their diagnosis of diabetes itself, that influenced the shaping of their social identity the most. The presence of the technology in particular symbolised their difference to others and by so doing presented a threat to children’s ability to “pass” as normal and present a

non-different identity to others. The size of the insulin pump and its continual presence on their bodies altered their physical appearance and by so doing “told” others of their condition by making it readily visible to them.

*“It [the pump] doesn’t look very good and I don’t like it.*

*I would wish it to be sort of smaller because people can see”*

(Beth 9 yrs)

*“They [friends] notice the pump itself. That’s the only downfall.*

*If they could make an invisible one that would be useful”* (Billy 9 yrs)

*“Well, it’s like when I stand up .....there’s all of this...I’m*

*not very happy about it. It makes me feel strange ‘cos there’s*

*a massive square, rectangly blob”*

(Will 8 yrs)

*“I don’t really want people seeing and noticing. It [the pump]*

*does make me feel very self-conscious*

(Paige 11 yrs)

Insulin pump alarms compromised their desire for normalcy further. Children described how these generated unwanted attention from their peers and signalled their difference in highly visible ways. For Paige, immediate action was required to diminish the tension this caused.

*“If something goes wrong with my pump...when it went off in*

*the class, an occlusion, which can happen....I ran to the*

*toilets ..because it’s quite loud and everyone heard it. So,*

*I just ran to the toilets. Because it was really embarrassing*

*‘cos everyone started looking at me”*

(Paige 11 yrs)

Other children described more emotional responses.

*“It’s like embarrassing when it’s one of those moments*

*when your whole class goes like randomly silent. And then*

*it goes beep, beeeep..as they go silent. It’s just embarrassing”*

(Will 8 yrs)

*“It goes beeeep, beeeep, bep, bep. It’s really annoying.*

*I feel quite embarrassed”* (Holly 10 yrs)

In their accounts, many children talked of how the pump’s visibility provoked a stigmatising response from others. At the time of commencing their treatment, comments from peers at school was particularly common.

*“They just see something weird on my tummy. They just was...they were like..what’s that? What’s that black thing?*

*What’s that black thing?”* (Jack 7 yrs)

*“Yeah..like the first few days, I was bombarded with ‘what’s that?’, ‘what have you done? It looks painful’. ‘What’s that.. drugs or something?’”*

(Harry 10 yrs)

*“It used to bump up in my school uniform and they would be like..what’s that, what’s that, what’s that. Pointing it out out all the time”*

(Holly 10 yrs)

For some, these comments from classmates were ongoing and as such seemed to be a continual challenge.

*“I feel a bit annoyed sometimes, ‘cos sometimes I’m in the middle of something and they just come up and say what’s that?”*

(Ryan 11 yrs)

*“It’s really annoying when they say ‘what’s that?’. That is really annoying”*

(Luke 6 yrs)

However, for Billy the visibility of the technologies resulted in responses from his peers that were particularly negative. Talking quietly, Billy described how others labelled him as different.

*“Well, because I wear my bum-bag to carry all my meter and things...at school I was getting nicknamed ‘bum-bag boy’ because of my bum-bag. They call me ‘diabetic boy’ too”*

(Billy 9 yrs)

Thus, for many of these children, it appeared that the visibility of the pump therapy technology on their bodies “marked” them out as different and by so doing “spoiled” their social identity. In experiencing insulin pump therapy, therefore, the technology itself may alter the way that a child is socially identified and categorised.

In an effort to avoid or ameliorate the effects of this stigma, children described a number of different and sometimes elaborate strategies that they used. This “body work” seemed to be driven primarily by their desire to normalise their bodies and to create and maintain an unspoiled identity for their peers. The older children (particularly two of the girls) talked most about this aspect and seemed to experience greater struggles with this than others. Nevertheless, a few of the younger children also described how they experienced and managed the persistent questioning from classmates. Their language conveyed a sense that they may have felt a lack of personal control over these situations and as a result caused tension and conflict for them.

*“I shouted at them GO AWAY!”* (Jack 7 yrs)

*“It makes me feel horrible....can you just stop asking the questions over and over”* (Holly 10 yrs)

For others, their talk reflected a concern to be able to manage their treatment unobtrusively and in a way that did not draw attention to themselves. As such, their task was to, as far as possible, render invisible their pump equipment and other artefacts. Threats to their identity were particularly high when children were changing for PE at school. In this situation, the risk of others seeing their pump and cannula on their body had to be minimised by either not changing their clothes at all

*“I never change my top [for PE] because I don’t want anyone to see my belly button”* (Jack 7 yrs)

or by adjusting clothing in some way to hide these objects from view.

*“Sometimes when people ask ‘what is that?’ I try to pull my shirt down so people can’t see it anymore”* (Will 8 yrs)

For Paige, passing herself off as normal seemed particularly demanding. Not only did the act of changing clothes itself involve a complicated process, efforts had to be made to purposefully conceal her body in order to avoid the judgement of others.

*“I put my two tops together ‘cos we have to change into our PE tops. So, I ruffle up the top and as I take my head out of the polo shirt I put the new one on at the same time. So that not really anyone can see. And I always make sure I’m in the corner, so no-one from behind can see”* (Paige 11 yrs)

Moreover, it also meant trying to normalise the technology in order to minimise the risk of stigma further.

*“So lots of people were asking about why I have this machine on my table. I used to tell people it was a calculator ‘cos I didn’t want them knowing”* (Paige 11 yrs)

Other strategies of concealment were used to mitigate the effects of being noticed. Billy and Paige talked of the personal and private coping techniques they employed in order to protect their sense of self when faced with taunts from their peers. Thus, for some children, the lived experience of pump therapy may be a somewhat secret affair, whereby the technology must be concealed and emotions managed privately. As such, there may be an additional layer of complexity to the attentiveness that is required in the everyday “doing” of pump therapy.

*“I just get on with it.....just ignore it [name calling]”* (Billy 9 yrs)

*“I don’t like it when other girls in my class see ‘cos some are quite mean and make jokes and whisper. I don’t really show that I am self-conscious ‘cos that’s when they all will start...they will be going like ‘Oh! she’s self-conscious’ and make jokes and make me feel uncomfortable”* (Paige 11 yrs)

### ***“I feel the same”***

However, whilst the reactions of peers to the visibility of the technology threatened children’s social identity, this did not always and invariably lead to internalisation and alterations in children’s personal sense of self. It seemed that although the treatment regime served as a constant reminder of their condition, it was only in this sense that they felt different from others. In their construction of themselves as children, most



were keen to emphasise their normalcy and “sameness” with their friends. Irrespective of age, their self-definition drew on language that promoted them as ordinary, active children who were essentially the same as their peers in terms of their daily lives, activities and aspirations. This included descriptions of going to school, participating in sports and clubs, their friendships and hopes for the future. Whilst these self-presentations may have been partly a way of minimising their spoiled social identities, they also suggested that children did not want to be defined by their illness. For them, their identity was based on self, not their need for pump therapy. Some explicitly used the word “normal” to define themselves.

*“I’m just another normal person....like that doesn’t  
have diabetes. I like feel normal”* (Ryan 11 yrs)

Others drew on language that emphasised their sameness or non-difference to their friends.

*“I’m just the same as them”* (Will 8 yrs)

*“I just don’t feel different”* (Adam 11 yrs)

Many of these children seemed to be able to accept the stigmatising impact of the technology and, as such, felt relatively untouched by it. For some, despite its visibility, these objects appeared to have become an extension of their embodied existence.

*“It feels like it’s [the pump] not there. You don’t think  
about it”* (Ryan 11 yrs)

*“It’s kinda tucked away...it’s kinda easy. I have it, but  
it doesn’t make me different”* (Harry 10 yrs)

Moreover, these children chose revealing strategies in order to manage their identities when interacting with others. They appeared relatively comfortable with answering questions and talking about their treatment when their peers showed interest. Nevertheless, their language does suggest an attempt to minimise the significance of these and by so doing strike a balance between their willingness to disclose and dealing with any consequences that might result from doing this. Explanations were usually

factual and pragmatic and the responses from their peers appeared positive and supportive.

*“I normally just explain that I need it [the pump] and they’ve got insulin and I don’t. And they just normally understand and don’t mind about it”* (Zoe 11 yrs)

*“I said that I have diabetes and it’s [the pump] full of insulin so it keeps my blood sugar levels down”* (Ryan 11 yrs)

*“I just say.. well, it’s [pump bag] got a pack with a pump in it. Then they’re like ‘Oh!’ and then they just go away”* (Will 8 yrs)

### ***Feeling different and the challenge of disclosure***

However, not all of the children had a strong sense of personal normalcy. A few (especially two of the older girls) described feeling different from others and as such, seemed to have more fragile perceptions of themselves. Paige described how this sense of difference was experienced with varying degrees of intensity and stemmed primarily from the presence of the technology.

*“Sometimes I feel different. Sometimes I don’t. I do feel like I can always go to them[friends]. But sometimes when my pump goes ‘beep, beep, beep’ you feel really different and everyone is looking at you”* (Paige 11 yrs)

For others, being “the only one” with diabetes in their class at school signified their difference from others.

*“I’d feel better if there was actually someone else in my class with diabetes. And there’s not. I feel different”* (Beth 10 yrs)

*“I feel unhappy because they [friends] don’t have diabetes. And I’m the only one in the school”* (Jordan 7 yrs)

The language used by both of these children to describe their feelings about this revealed a mix of strong emotions. For Jordan, his sense of difference was experienced with sadness and resentment.

*“[I feel] quite unhappy, quite angry”* (Jordan 7 yrs)

However, for Beth being the only one in school meant not only a sense of shame but also extreme fear that those around her in this setting may not have the experience and knowledge to support her appropriately.

*“I feel kind of mortified and petrified. Because I feel different and [because] not many people know exactly about it like the specialists do”* (Beth 10 yrs)

Feeling different did not just cause these children emotional difficulties. It also required additional stigma management and body work. For Beth and Paige, this meant choosing to control information given to their peers about their need for pump therapy. Unlike others who openly discussed their condition, it seemed that these two girls engaged in a process where they regularly had to make a decision about whether or not to reveal or conceal their treatment to others. Paige chose to divulge information about her pump therapy only to a select and trusted group of friends. The decision about who to tell seemed to involve a difficult process of weighing up the pros and cons of disclosure in terms of how others would respond.

*“There are people who would keep it to themselves and there are people who would spread it. So you have to sort of talk about it to some people and not to others”* (Paige 11 yrs)

However, for Beth no such friendships appeared to be in place for her at school. Talking in a quiet, hushed voice she said:

*“I don’t like have a proper friend that I can trust”*

The lack of a supportive network of friends meant that she felt unable to share information about her pump therapy with any of her peers. As a consequence, she purposefully concealed it.

*“I don’t really feel like telling them...It doesn’t feel right I just don’t feel comfortable about telling them anything”*

This need for secrecy appeared to be driven by an expectation of others lack of empathy and understanding.

*“They don’t really care about it”*

However, whilst this may have afforded her some protection, this may have also reduced opportunities for valuable peer support and exacerbated her feelings of difference. Therefore, for some children, the stigma attached to their treatment and their condition itself may negatively affect their social networks by reducing the size of these to include only those children considered to be trustworthy and loyal.

Thus, for most children in this study, experiencing insulin pump therapy enabled a strong personal sense of normalcy, despite a “spoiled” public identity generated by the presence and visibility of the technologies. Nevertheless, this meant that children had to take difficult decisions and make hard choices, including whether to conceal or reveal their need for technological assistance to others and selecting specific strategies to use in order to do so. This is difficult work and something they were required to do largely on their own as this took place mostly within their peer group at school. For a few, this seemed to be particularly demanding.

#### **4.6 “GETTING USED TO IT”**

##### **Overview**

Experiencing insulin pump therapy imposed change and a new temporality on children in the sense that it also involved an ongoing and gradual process of adaptation and adjustment. In their accounts, children’s frequent use of the phrase “you get used to it” reflected this process and thus the nature of this particular theme. They described a time of initial uncertainty and disruption before moving slowly into a time of feeling more comfortable with their treatment regime as they incorporated new habits and bodily routines and established a new way of being-in-the-world. Children’s active participation as well as time and experience were required to achieve this. In addition, their descriptions also included a time of looking into the future and anticipating possibilities. As such, living with and experiencing insulin pump therapy meant being situated in a lifeworld that was fluid and unfolding rather than one which was fixed and static.

***“I was pretty scared”***

For some children, the moment of commencing pump therapy stood out as a time of change and was characterised by feelings of anxiety, unease and discomfort. Whilst others did not remember this time due to their young age, for those who did, beginning treatment meant experiencing a period of uncertainty. These emotions took the form of “not understanding” and “not knowing” and arose primarily from the novelty and unfamiliarity of the technology and a concern about its physical impact on their bodies. Children described a lack of information about the safety aspects of using pump therapy

*“I thought something was going to go wrong because when I heard the Consultant conversation...and they were saying stuff like if it goes wrong it can sometimes be bad”* (Beth 10 yrs)

as well as a lack of understanding about how the insulin pump itself would be attached to their body.

*“I thought it [the pump] would stay in me and it would hurt all the time”* (Ryan 11 yrs)

*“I was worried about wearing it at night ‘cos I would roll over on it and it would hurt”* (Paige 11 yrs)

As a consequence, children were left feeling frightened and confused.

*“I got scared ‘cos I didn’t know what it would be like”* (Ryan 11 yrs)

*“They were saying all these things I didn’t really understand and she got me really worried”* (Beth 10 yrs)

Children’s uncertainties were also expressed in terms of not knowing how their bodies might respond to painful procedures, particularly cannula changes.

*“I was pretty scared and then they injected on to me and I found it kinda hurt a bit and I screamed”* (Holly 10 yrs)

*“The first time I started using it everything worried me, ‘cos like when I was first having it, what worried me was*

*like there would still be really hurting needles”* (Will 8 yrs)

***“I’ve got used to it”***

However, whilst experiences of past time were mostly characterised by a sense of anxiety, children did not generally attribute the same emotions to their present situation. Instead, the present stood out as a time when children were gradually making sense of the previously unfamiliar and moving slowly towards building a “new normal”. When talking about their current experiences of their treatment, they explicitly used words such as “You will get used to it” and “I’ve got used to it”. This was especially the case when children described the ongoing emotional and physical adjustments they had to make in order to accommodate the pain associated with cannula insertions. For many, this meant adopting coping strategies that enabled them to reinterpret the meaning of their experiences. For Charlie, this involved changing his perceptions of the cannulas as a way of offsetting the pain associated with its insertion into his body.

*“Well...the cannula doesn’t hurt even though the needle is big.*

*I’ve got used to it and it doesn’t hurt”* (Charlie 9 yrs)

For others, strategies of acceptance and positive thinking were employed. Children’s use of language such as “it’s ok though” and “it’s just the first one” reflects the efforts they made to infuse positive meaning into these otherwise negative situations.

*“Sometimes when it really, really hurts I sometimes cry...*

*but yeah, it’s ok though. I get used to it”* (Will 8yrs)

*“You can feel it going in at first because it’s a new spot.*

*It’s just the first one and you get used to it”* (Harry 10 yrs)

Getting used to insulin pump therapy also required physical adaptations to be made in order for children to accommodate the continual presence of the insulin pump on their bodies.

*“It [the pump] does slip up and down and I can always*

*feel it...whenever I sit down. I’m sort of getting used to it”* (Paige 11 yrs)

*“When I did get my pump, I was sort of getting used to it*

*being on my body”* (Beth 10 yrs)

In addition, children's descriptions concerning this aspect of their treatment invariably included references to the passage of time.

*"The most helpful thing in getting used to my pump..  
is just having it for such a long time"* (Will 8 yrs)

*"It helps with the days...the days....you get better.  
You get used to it more ...the days"* (Ella 8 yrs)

The primary benefits of such time appeared to be less pain from invasive procedures and a reduction in levels of overall worry.

*"Well, it hurts at first point when you basically knew...  
but at the end of it when you start getting used to it, it  
doesn't hurt"* (Ella 8 yrs)

*"Over time I lost my worry"* (Beth 10 yrs)

For some, time also enabled the technology to be incorporated into their bodies such that it was no longer viewed as a foreign object but instead had become "part of them".

*"I don't feel it....I'm just used to having many needles"* (Billy 9 yrs)

*"It feels like it's [the insulin pump] not there. You don't  
think about it"* (Ryan 11 yrs)

*"I don't notice it [the pump]"* (Zoe 11 yrs)

Thus, "getting used to it" required some amount of time to pass in order for children to begin to make sense of their treatment experiences, for the technology to become part of their body and to adjust to a new way of being in the world.

In addition to the temporal element of getting used to their therapy, some of the older boys also made reference to the role repeated experiences played in this process. Harry described how he had become adept at "tuning in" to his own body as a result of repeated episodes of high and low blood sugar levels.

*“Just having those situations a lot...do I feel low? Do I feel high? And you get used to how you feel and then you remember that feeling”* (Harry 10 yrs)

Others talked of how the repetitious nature of their regime helped them to overcome initial difficulties and enabled them to accumulate knowledge, confidence and expertise in self-management.

*“At the start, you get a bit annoyed. You have to keep doing it. But then it’s all fine because you get used to it”* (Ryan 11 yrs)

*“It’s not hard to learn. You just get used to it and soon you will be like me..going really fast on it” [the pump]* (Charlie 9 yrs)

*“I’ve got used to it all...just ’cos I’ve constantly got to do it”* (Adam 11 yrs)

Thus, it would seem that the meanings attributed to children’s experiences of pump therapy modify with the passing of time. For most, the more time passes, the more accustomed they become to their treatment and the presence of the technology on their body. However, this process is far from passive and inevitable. Instead, “getting used to” insulin pump therapy demands purposeful efforts by the children themselves to accommodate the treatment regime and to achieve a more “homelike” way of being-in-the-world. This work is constant and ongoing and involves a journey that uniquely unfolds with experience and the passage of time.

### ***Hoping for a cure***

Nevertheless, despite children’s positive accounts of getting used to their therapy, their descriptions of hopes and expectations for the future conveyed an underlying desire for a normal life without diabetes. This was especially important for Luke.

*“My hopes...this is just my hope. I WISH that diabetes was turning into a myth when I grow up”* (Luke 6 yrs)

Will’s comment encapsulates many of the other children’s aspirations about this.

*“[I hope to be] a boy without a pump”* (Will 8 yrs)



For Zoe, the reality that a cure might not be possible mediated her response. Instead, her account conveyed a sense of not allowing her condition to stop her from carrying out everyday activities.

*“[I hope] for a cure and that’s what everyone wants. But probably just to carry on life and don’t let it [diabetes] put me down and stop me doing things”* (Zoe 11 yrs)

Unlike experiences of past times, children did not seem to worry about their future. Instead, this time was experienced with a sense of optimism and as one of change and possibility. Thoughts of the future revolved around their desired career, (for example, becoming a doctor, scientist, singer or footballer), and their hopes for the advancement of technology. This centred on a desire for technologies that would be not only self-regulating

*“It’s kinda something doctors are working on. It’s practically an artificial pancreas..we don’t do anything at all.....sugars, fingers, carbs. Not even change a battery or anything”* (Harry 10 yrs)

*“I would change it so it like does it all automatically. They are working on that pump at the moment”* (Ella 8 yrs)

but which would also support their desire for normalcy and non-difference for others.

*“You could eat whatever you like..lots of sweet stuff because it’s like a cure, but it’s not a cure”* (Ella 8 yrs)

Thus, living with insulin pump therapy influences a child’s temporal way of being in the world. Integrated elements of past, present and future time are involved. For the children in this study, the past was experienced as a time of uncertainty whilst the future was characterised by anticipation and possibilities as they hoped for a body freed from illness or treatment that was less intrusive. The present, however, stood out as a time when children gradually made sense of their therapy as they worked hard to “get used to it” and incorporate it into their bodies and everyday lives.

## 4.7 FEELING SUPPORTED – BEING UNSUPPORTED

### Overview

This final theme illuminates how the availability of support and help from others was central to helping children navigate the complexities of their treatment regime and incorporate it into their daily lives. Children described how at home, tasks and responsibilities were shared between themselves, parents and siblings whilst at school the support of close friends helped children's sense of belonging and feelings of "sameness". However, in contrast, a lack of available support in spaces "in between" home and school meant that participation in some everyday, ordinary childhood activities were sometimes restricted, leading to feelings of exclusion and isolation.

### *"Everyone helps"*

For all of the children in this study, home life was experienced as a space in which their pump therapy was enacted in an inclusive atmosphere of teamwork and collaboration. Their descriptions of the support they received in this setting conveyed a sense of family cohesion and an atmosphere of collaborative team work that included all family members. Zoe's comments were typical of the descriptions given by others.

*"Everyone helps. Like if I feel low or something, my brothers know to get Mum or Dad or to get my tester so I can test myself. Then Mum and Dad know what to do. And I know some of what to do but some things I don't"* (Zoe 11 yrs)

Within this setting, the burdens and responsibilities of managing their treatment were shared. As might be expected with young children, parents played a key role in this. Problem-solving and helping with specific treatment related procedures characterised children's accounts of the strategies parents used to support them. Parental assistance with carbohydrate counting was frequently mentioned

*"They tell me how much I have to stick in my pump... They look how many grams in the whole bag and then they work it out. And 'cos my Dad's got an 'A' in maths, he's really good"* (Charlie 9 yrs)

*“Well, my Mum puts my carbs on my hand when I go into school...she writes on my hand 57 or 64 [grams]”* (Ryan 11yrs)

in addition to needing support with cannula changes and refilling of insulin reservoirs, which suggested that these tasks may be particularly difficult for young children to carry out independently. Nevertheless, children were actively included in their treatment and encouraged to be involved in treatment tasks and decision making. Parent’s support seemed to be sensitively attuned to children’s capabilities.

*“Mum does the sandwiches or I do the sandwiches and she writes the carbs for what she does”* (Paige 11yrs)

*“When I needed to put a temporary basal [rate] on I phoned her [Mum] up and she told me how to put it on”* (Will 8 yrs)

None of the children found their parents involvement difficult or intrusive. For most, mothers appeared to take the primary role in supporting adherence to children’s treatment regime.

*“She helps me with a lot, a lot of stuff”* (Will 8 yrs)

*“My Mum sorts it out”* (Josh 7 yrs)

However, fathers and siblings were equally important providers of support and care and appeared to have particular roles and responsibilities assigned to them. As such, fathers were often described as the parent who was entrusted with helping children with the most painful aspect of their treatment – that of cannula insertions.

*“Mum will do the set changes, but mostly Dad does it”* (Zoe 11 yrs)

*“I can do it...but mostly Dad does that”* (Harry 10 yrs)

The support of siblings was also important and was predominantly orientated around the help they gave children during episodes of hypoglycaemia. Children described how their siblings could not only recognise their symptoms of low blood sugars and seek the help of others:

*“When I feel bad and I’m laying down on the bed  
he [brother] usually tells Mummy”* (Luke 6 yrs)

*“When I look floppy she [sister] can tell and she  
goes and tells Mum”* (Will 8 yrs)

but also how they would protect the children by watching over them.

*“She [sister] just looks out for me during the day  
in case I’m low or I’m high”* (Adam 11 yrs)

*“Once I was feeling ill. And he [brother] went ‘Mum!  
Charlie is feeling ill!’ And without me even telling him  
he came into my room and he said ... ‘I’ll sit here until  
Mum comes”* (Charlie 9 yrs)

Children valued and appreciated the support of their siblings and talked about how this enhanced their self-esteem and sense of belonging.

*“I feel good and cared for”* (Will 8 yrs)

*“I feel happy”* (Zoe 11 yrs)

Therefore, it would seem that enacting insulin pump therapy in the lived space of home meant the active involvement of all members of the family. In this particular environment, parents and siblings appeared to “scaffold” children’s own efforts in dealing with the challenges associated with their treatment in a way that was sensitive to a child’s particular needs. Thus, for these children, experiencing insulin pump therapy in this particular space seemed very much a family affair.

### ***“My friends just take care of me”***

The importance of supportive relationships was not limited to children’s home life. Friends, especially those that were close, were frequently mentioned in children’s accounts of their treatment experiences, particularly in relation to the school environment. Whilst children typically described play and companionship as essential features of these relationships, a salient feature to emerge was the key role friends

played in strengthening feelings of normalcy by accepting children as an ordinary and equal peer.

*“So, they [friends] don’t treat me like I’m diabetic. So....just leave me to play by myself”. They treat me the same way they treat everyone else”* (Charlie 9 yrs)

*“I’m just another normal person...like that doesn’t have diabetes. So....they just treat me like everyone else”* (Ryan 11 yrs)

Friends also helped to normalise experiences at school. Their companionship at mealtimes was especially appreciated and helped children to feel included and involved in everyday school routines.

*“Every day I take one friend in early to have lunch with me”* (Harry 10 yrs)

*“Sometimes she comes with me. Sometimes she goes in first with my lunch box and saves me a space”* (Paige 11 yrs)

The practical support that friends gave to children in this environment was also important. The younger children described how they were helped during hypoglycaemic episodes at school

*“C tells the teachers if I’m feeling bad. He’s my friend”* (Luke 6 yrs)

*“They know..they hold me when I’m wobbly..they tell the teacher that I am going to have to move”* (Jordan 7 yrs)

whilst others talked appreciatively of the role friends played in reminding children about their treatment tasks

*“My friend just takes care of me. She’s like my Mum. ‘Test your levels, test your levels, put in your carbs, put in your carbs!’* (Holly 10 yrs)

*“He just asks me every time...’did you do this?.. did you do that?’*

(Charlie 9 yrs)

Other particular qualities of friendship that children emphasised were those of closeness and understanding and an ability to express caring.

*“He has always been there for me. He just sticks around me. He understands”*

(Charlie 9 yrs)

*“Some of my friends are good. Some of them understand”* (Jordan 7 yrs)

Thus, in the experience of insulin pump therapy, close friendships may buffer the impact of the treatment regime to some extent and make an important contribution to children’s sense of belonging and well-being in this environment. Although experiences with others in school may have been more challenging, as previously described, in general, close friendships may provide these children with important opportunities to experience acceptance, validation and a sense of being included.

### ***Being Excluded***

However, whilst the support of family at home and close friends at school enhanced children’s experiences of their treatment, a lack of appropriate support from others prevented children from being able to engage fully in social activities outside of these settings. In particular, pump therapy appeared to impinge on most of the children’s ability to participate in sleepovers at friends’ houses and extracurricular activities at school were experienced either infrequently or disallowed altogether. This appeared to be primarily the result of others “carefulness” or lack of knowledge about their treatment regime.

Sleepovers seemed to be particularly difficult and most children were excluded from this activity which led to a sense of annoyance and disappointment. Some children saw their parents’ anxiety as the main barrier to them being able to do this.

*“Mum doesn’t like me to, ‘cos she thinks that my bloods will go high or I won’t count carbs for my dinner or get my carbs wrong”*

(Ryan 11 yrs)

*“Mum doesn’t really want me to go because the parents  
wouldn’t really know a lot about it”* (Adam 11 yrs)

Others attributed their non-participation to a lack of appropriate support in this setting as a result of others insufficient understanding and awareness of their treatment and diagnosis.

*“I’m not allowed to go on sleepovers ‘cos sometimes  
people don’t really understand my diabetes”* (Holly 10 yrs)

*“I don’t really get invited probably because of my diabetes  
and they don’t know how to manage it”* (Billy 9 yrs)

*“I don’t think many people want me to come because of  
having to do all the stuff about my pump”* (Beth 10 yrs)

Thus, in experiencing insulin pump therapy, the behaviour and perceptions of others may pre-empt a child’s ability to choose whether or not to participate in certain social activities and as such may impact further on both their relations with others and the stigmatising effects of their treatment.

Participation in some extra-curricular activities at school was also constrained for most children, particularly residential trips away. Beth and Adam were the only children who had taken part in such activities independently. The sense of achievement and feelings of self-worth that this seemed to generate for Beth was evident when she talked about doing this.

*“I was quite worried about managing it all. I felt  
quite glad actually. I felt really pleased that I had  
managed to do it”* (Paige 11 yrs)

However, children’s attendance was usually only possible with conditions attached. This was primarily due to a lack of school staff being available to support them appropriately and respond to children’s needs in this environment. For several children this meant that parents had to accompany them on these events. Whilst some were untroubled by this, others expressed a concern that the presence of their parents would signal their difference to others and hinder their experience.

*“There’s this trip where it’s basically being without your parents so you can learn things. But if they are there..it’s not really the trip it wanted to be, because..it would be better just to have the trip”* (Charlie 9 yrs)

For others, their participation was dependent on them acquiring the necessary technical skills and competence to manage their treatment regime independently whilst away. However, children worried about their ability to achieve this. For Zoe, having to do her own cannula changes prevented her from being able to go.

*“I probably would go if it wasn’t a week long because I would have to do two to three [cannula] changes on my own and I wouldn’t really want to do that”*

For others too, there was a sense that these demands felt overwhelming and, as such, their participation was jeopardised. The possibility of exclusion from these activities was experienced with a sense of sadness, disappointment and worry.

*“I will have to manage my whole diabetes. All of it, including my pump. I don’t think I will be able to do it. I want to go. I want to be able to go”* (Billy 9 yrs)

*“[I feel] kinda scared. I want to go, but I don’t want to go”* (Holly 10 yrs)

Thus, experiencing insulin pump therapy as a young child may prevent some from being able to fully engage socially in everyday childhood activities. By so doing, opportunities for participating in the shared world of others and age appropriate independence from parents may be reduced. Moreover, the degree to which children feel parents, teachers, classmates, and close friends care for them, listen to them and generally treat them as a person who matter may be crucial for helping them incorporate their treatment into their everyday lives.

#### **4.8 The Fundamental meaning of CSII therapy for young children: A summary of the key findings.**

In this chapter, the overarching themes and subthemes drawn and interpreted from children’s accounts of their experiences of insulin pump therapy have been described.



The children spoke about how their treatment changed their everyday lives and in particular, altered their bodies and minds in ways that both helped and hindered them. Thus, it meant a body/mind that was disrupted by pain and discomfort, interrupted sleep, episodes of hypoglycaemia, restricted physical competencies and a constant state of attentiveness. It also interrupted school routines and meant exclusion from some social activities. Moreover, it spoiled identities by “marking” children out as different and for many, this acted as a barrier to achieving and presenting to others a preferred “normal” body and self. Insulin pump therapy also imposed change such that time and experience was needed in order to gradually adjust to a new and different way of being-in-the-world. However, at the same time, it was experienced as convenient and flexible. More importantly, it freed children’s bodies from multiple injections of insulin and enabled them to feel safer and more in control of them. By so doing, their bodies were transformed and for most, their emotional well-being was enhanced. Moreover, it both limited and extended opportunities for children to actively participate in the management of their own condition and thus influenced their role as healthcare actors. As such, it was not only empowering but also disempowering.

These simultaneous and disparate experiences were mediated by a range of elements that included not only time but also children’s relationships with and the support of others, the everyday environments they inhabited and in particular, the presence of the technology. They also created both challenges and opportunities. Children worked hard to navigate their way through the tensions this presented. Yet despite the considerable effort that this involved, most saw themselves as normal, active children who were the same as their peers. Moreover, in their accounts it was the positive rather than the negative meanings associated with their therapy that children emphasised. As such, although sometimes difficult, CSII therapy was experienced mostly with a sense of enthusiasm and satisfaction.

In the following chapter, I discuss these findings in depth and consider how they contribute to current literature and existing research.

## CHAPTER 5 - DISCUSSION

### 5.1 Introduction

In this chapter, the findings of the study will be explored in the context of demonstrating how they add further insight and understanding to existing theory and literature. In addition, the new and original concept of *the lived technological body* for children with insulin pumps will be introduced and discussed. This idea is derived from the six themes described in Chapter 4 which draws attention in particular to the complex ways in which children experienced their lived bodies when using insulin pump therapy, their active involvement in managing these experiences and the central role that the technology played in this. A discussion of *the lived technological body* forms the structure for this chapter. Its specific characteristics and how these are supported by the themes are described, as well as its similarities and differences to the bodies of children who depend on other medical technologies. This is followed by an examination of how this concept differs from traditional dualist understandings about what child bodies “are”, as well as how they may be lived and experienced by those who inhabit them. By so doing, this study adds in particular to knowledge about the contextual contingencies of children’s lived bodies and thus, offers a more complex and nuanced way of understanding young children’s embodied experiences of chronic illness.

A range of philosophical, psychological and sociological texts will be used to illuminate the findings of the study. Key concepts central to the Sociology of Childhood as well as Merleau-Ponty’s (1962) notions of embodiment and his theorising in relation to the lived body (as discussed in Chapter 2) are used in particular. However, due to the richness of the data that was obtained, I found it difficult to situate all the findings within these particular frameworks. As such, other influential theories belonging to sociological and psychological perspectives have also been used as a way of explaining the complexity of how children experienced their treatment. These include literature relating to the human-machine interface, Goffman’s (1968) work concerning the phenomenon of stigma and identity and psychological concepts that consider body image, locus of control and children’s adjustment to chronic illness. This eclectic approach is supported by Todres (2001:7) who suggests that “compared to more specialist disciplines, nursing research often approaches phenomena that cannot easily be reduced to psychological, medical or sociological frameworks...instead viewing the holistic approach as more relevant”.

## **5.2 Introducing the concept of the lived technological body for children with insulin pumps.**

Merleau-Ponty (1962:82) argues that the body is integral to any understanding of human experiences - it is the “horizon latent in all our experience...and anterior to every determining thought”. Thus, it is the instrument “for experiencing, doing, being and becoming” (Finlay 2011:29).

In this study, the children talked extensively about how insulin pump therapy impacted on their bodies as a whole - that is, on their physical body (body-object) as well as their emotions, feelings, perceptions and sense of self (body-subject) - and how both were altered by their treatment in ways that were simultaneously enabling and disabling. Their bodies, therefore, were at the centre of children’s treatment experiences as well as an active and integral component of the ways in which they understood and made sense of it. Moreover, these body-related experiences and sensations appeared to be contextually embedded in the sense that they were shaped and mediated by an entanglement of biological, emotional and temporal processes as well as by the places children inhabited and intergenerational relationships. However, it was the technology in the form of the insulin pump and cannulas in particular, that was central to these changed conditions of embodiment. Children’s accounts of their experiences revealed that when used by them in the context of their everyday lives, these technologies appeared to be more than just physical objects and instruments for controlling blood glucose levels. Instead, these devices occupied an active role, shaping experiences of both bodies and minds, reconfiguring social interactions and power relations and influencing the desirability and acceptability of their treatment as a whole. This differs from deterministic, biomedical views of medical technologies that conceptualise artefacts as largely neutral, inanimate entities which in themselves have neither meaning nor act or effect the interactions and activities of those who use them (Timmermans & Berg 2003). Instead, the results of this study suggest that both child and technology not only acted but also were “acted upon” and by so doing, the reciprocal, dynamic relationship between technology and user is highlighted. This finding, therefore, reflects the underlying assumptions of technology-in-practice-theory (Timmermans & Berg 2003) as well Heidegger’s (1977) views concerning the significance of “things”. Thus, he suggests that an object’s “authentic meaning” is dependent on how it is used in actual practice, and within a “relational context of specific uses” (Idhe 1993: 40). Therefore, the meaning of a particular technology is neither pre-given nor revealed if it is studied

separately as a physical thing. Instead, as illustrated by the findings of this study, its meaning and significance lie in its actual use and within a human-world context (Svenaeus 2000b). As such, they exist in a way that is fundamentally embodied.

As a result of the prominence of the body in children's accounts of their treatment and its interactions with the technology in particular, I suggest that when young children enact insulin pump therapy they live in and experience a specific type of lived body – that is, a *lived technological body*. It is this particular body that is the body “present” and as such, the one that children who use this form of treatment must explicitly attend to everyday, as well as being the one through which they perceive the world, relate to others and learn about themselves. This body, then, discloses the world and in the world this body is disclosed (Finlay 2003). Its specific features are discussed in detail below.

### **5.3 Defining the lived technological body**

The notion of *the lived technological body* is conceptualised as being an entity that is unique to the bodies of young children who use CSII therapy and the nature of the technology used in this form of treatment. It is proposed as an explanatory concept to convey how the children in this study experienced their bodies relationally when using insulin pumps and the hard work involved in inhabiting and managing such a body. It attempts to bring together dimensions of all of these particular children's diverse body-related experiences into a single concept and is my interpretation of the complex ways in which a child's physical body, mind and context (world) works together in the experience of insulin pump therapy.

Five key characteristics underpin *the lived technological body*. These are supported by the six themes identified in the previous chapter and intertwine and interact with each other. Figure 2 attempts to illustrate these connections graphically. More specifically, it is a body that is:

1. Complex, relational and dynamic
2. Lived and experienced ambiguously.
3. A site of difference.
4. Shifting and changing.
5. High maintenance in the sense that it is shaped and honed primarily by the vigilance and hard work of its owner, but also by the social spaces children

inhabit, their relationships within these environments and the type of support that emerged from this.

**Figure 2: The Lived Technological Body- key features and their associated themes.**



[Original in colour]

The first characteristic (a body that is complex, relational and dynamic), reflects the nature of *the lived technological body* when conceptualised as a whole and as such, is informed by all of the themes collectively. The other four aspects mirror either one or a number of themes that are considered to *best* illustrate their nature and meaning.

The first section of the discussion that follows explores each characteristic of *the lived technological body* and their associated theme(s) in turn, beginning with the idea that it is a body that is lived and experienced ambiguously. The similarities and differences between the bodies of children who use insulin pumps and those who are dependent on other medical devices will also be explored. However, as described in Chapter 2, few studies have focussed explicitly on young children's experiences of living with medical

technologies in the management of chronic illness. Therefore, this aspect of the discussion is necessarily limited. The chapter concludes with an exploration of *the lived technological body* as a whole and the ways in which this concept differs from traditional, reductionist accounts of childhood bodies in general.

#### **5.4 The lived technological body - A body lived & experienced ambiguously**

In the literature, there has been increasing interest in the relationship between the human body and technologies and how body experiences and identities are altered by the human-machine interface (Kirk 2010). A number of themes are evident in this work including in particular notions about body-machine liminality; embodied interactions with technology; the dialectical relationship that exists between humans and technology, and the body as a site for the (re) production of identity (Buchanan-Oliver & Cruz 2009; Howson 2013). The first of these themes reflect notions of hybridity and the inseparability of body and machine, such that the boundaries between the two are conceptualised as being blurred, fluid and malleable (Howson 2013). These ideas are explored extensively in popular culture via themes such as cyborgs (Haraway 1985) and the “bionic man” of the 1970’s (Buchanan-Oliver & Cruz 2011). This fusion of body and machine calls into question boundaries between nature and culture and as a consequence, has led to increasing uncertainty about not only what the body actually “is”, but also what it means to be and have a body (Shilling 2012). The second theme of embodied interaction explores the sensory body and more specifically, the pain or pleasure that is experienced when humans interact with technology. For example, the pleasure of interacting with technology has been explored particularly in relation to computer technologies and experiences of immersive video games and creation of avatars (Idhe 2002). However, in general the literature relating to these two themes have tended to focus on the enhancing capabilities of technology. Moreover, the body being considered is usually that of an adult and one that is free from illness (Kirk 2010). Therefore, their relevance to the bodies of children who use insulin pumps is unclear. Instead, the debates relating to identity and the dialectical experience of the human-machine relationship are more consistent with the key characteristics that make up the nature of *the lived technological body*. This is explored in greater depth below.

Literature that investigates the dialectical relationship that exists between humans and technology in general, encompasses polarised perspectives that emphasise in particular notions of control and freedom (Buchanan - Oliver & Cruz 2009). Thus, technologies

are seen to have the capacity to both control and emancipate bodies as well as the potential to both enable and disable human capability and functionality. In this study, a prominent feature to emerge from children's accounts was the way in which their bodies and minds were both disrupted and enhanced by the medical technology that they were required to use as part of their treatment. Thus, the insulin pump and cannulas were seen to both enhance and constrain children's physical bodies as well as their emotional well-being and sense of self. As such, an important distinguishing feature of *the lived technological body* is that it is a body that simultaneously helps and hinders the young children who inhabit it. It is, therefore, lived and experienced ambiguously.

This ambiguous way of experiencing the body is consistent with Merleau-Ponty's (1962) notions relating to the body-object / body-subject as highlighted in Chapter 2. The following discussion considers how *the lived technological body* for children with insulin pumps is experienced as both a material, biological "thing" (body-object) as well as an emotional, perceiving body (body-subject).

#### *The lived technological body - a body and mind disrupted*

This section focuses primarily (although not exclusively) on the theme Disrupted Bodies – Disrupted Lives and as such, explores how *the lived technological body* incorporates a mind and body that is disabled by insulin pump therapy.

According to phenomenological thinking, in illness the body as a whole can be altered such that it becomes an object of attention not only by us, but also by others (Finlay 2011). Moreover, drawing explicitly on Heidegger's (1962) philosophy, the a priori "unhomelikeness" of life may also be emphasised (Svenaeus 2000a). In this study, the specific nature of the "unhomelikeness" experienced by the children is reflected in particular by the themes "Being constantly attentive" and "I was pretty scared" which revealed how pump therapy seemed to engender in children a constant state of vigilance as well as strong emotions when they first started using it. Children's accounts of the latter highlighted how at this time, confronted with unknown technology, the previously familiar became unfamiliar. As a result, their emotional way of being in the world was characterised by feelings of uncertainty, fear and anxiety. The findings showed how the children had to work hard to minimise this attunement to the world. This included having to incorporate new habits and routines, adapt to wearing the technology and learn new ways of being-in-the-world in order to gradually "get used to" their treatment and thereby achieve a more homelike state of being-in-the-world. Nevertheless, the

constant presence of the technology appeared to alter their state of consciousness such that there was always a need for ongoing attentiveness. Although apprehension and anxiety has been described by children newly diagnosed with T1DM (Ekra & Gjengedal 2012; Koller et al 2015), the emotions they experience at the time of starting to use a particular medical device, including insulin pumps, has not been described in the existing literature. However, the need for carefulness and ongoing vigilance in relation to pumps has been reported in studies exploring the views of teenagers/young people using CSII therapy. This was primarily in terms of worries about interpreting pump alarms, the medical consequences of pump failure and inadvertently damaging the pump (Low et al 2005). Conversely, research findings investigating the experiences of children using technologies such as mechanical ventilation and tracheostomies do not describe such concerns. This may be because of the constant availability of teams of support workers that were employed to help these children manage their complex health needs and associated technologies (Kirk 2010). Therefore, the findings of this study suggest that *the lived technological body* for children with insulin pumps means inhabiting a subjective body that is perhaps especially “technologically textured” (Idhe 1990:1). As a consequence, therefore, opportunities for easy, unmindful living may be reduced (Dahlberg 2011).

In addition to the “unhomelikeness” experienced by the children in this study, their narratives also suggested that they frequently experienced their bodies as objects, primarily as a result of the technology. This is illustrated in particular by their accounts of the ways in which the continual presence of the insulin pump on their bodies prevented not only restful, undisturbed sleep but also their participation in some leisure and sporting activities. Moreover, its presence disrupted experiences at school and led to physical restrictions such that new and different ways were required in order to eat, sleep, exercise and play. Furthermore, the technology also changed a child’s physical appearance, creating the potential for stigma and, for many, disrupted social relationships with peers and influenced a child’s sense of identity. Therefore, congruent with Merleau-Ponty’s ideas relating to the body-object, at these times, *the lived technological body* as a material, biological thing, is also an entity that frequently becomes explicit – that is, it becomes something that children notice as well as something that attracts the attention of others.

Such experiences are similar to the ways in which other medical devices have been found to intrude on children’s lives and bodies. For example, Kirk (2010) reports how



the noise from devices such as enteral feeding pumps kept children awake at night. Similarly, the time demands of care routines associated with children/young people who had a greater dependency on technologies, such as those with tracheostomies and ventilators, limited their participation in school and social lives generally (Heaton et al 2005). However, in this current study, the body as object made itself “present” to children, in particular, when it became a source of physical pain, discomfort and anxiety as a result of the intrusion caused by the need for cannulas. Without exception, the insertion of these objects into their bodies was experienced by all of the children in this study as the most difficult and disruptive part of their treatment. As such, this was the main reason for disliking it. Needle phobia is a recognised criterion for instigating insulin pump therapy (NICE 2008). Therefore, it is perhaps not surprising that children in this study experienced cannula insertions with fear and pain. However, the prominence they gave in their accounts about this aspect of their treatment suggests that although these uncomfortable sensations may decrease with time, such issues remain a substantial concern for young children, especially in terms of the pain experienced. Moreover, considerable effort was required by the children themselves to enable them to cope with and modulate the bodily pain associated with this procedure.

Children with chronic illness in general often require repeated and invasive needle stick procedures (Slifer et al 2002) and for many, these can be the most fearful aspect of their medical care (Karlsson et al 2014). Research literature suggests that repeated exposure to painful stimuli can reduce a child’s pain threshold and as a consequence, initiate a progressive amplification of pain responses over time (Walco 2008). This may result from changes in both physiological processes (such as alterations in pain pathways as a result of increased nociceptor neuron sensitivity), as well as psychological ones, including the development of anxiety and stress which results in increased levels of pain, and fear-avoidance responses (von Baeyer et al 2004; Walco 2008). Moreover, it is suggested that this sensitisation process may be more likely to occur in children who are younger (von Baeyer et al 2004) particularly if they are exposed to repeated painful procedures such as those associated with peripheral venous access procedures (Rogers & Ostrow 2004). This situation can change immature pain pathways and thus alter the sensation of pain and reduce the pain threshold (Walco 2008).

Research that reports on young children’s subjective experiences of pain when using CSII therapy is limited. Orlinder et al (2007) found that cannula changes were experienced as difficult and painful by two girls (17%). However, this study employed

the use of questionnaires and as such details of their physical and psychological impact are lacking. In the study presented here, the descriptions children gave in relation to this aspect of their treatment were detailed and sometimes graphic. For two children, cannula insertions appeared to evoke a sensitising reaction such that they experienced not only on-going emotional distress, but also particularly high levels of pain and fear. Thus, Billy (aged 9 years) reported excruciating levels of pain with this procedure whilst Luke (aged 6 years) described how he ran away and hid when cannula changes were due. Such experiences are similar to those that have been described by children undergoing regular venepuncture for conditions such as liver transplantation (Wise 2002). However, most of the children in the study presented here described a different response - that is, one of habituation (von Baeyer et al 2004). Thus, they talked of how they had, at least to some extent, become accustomed ("got used to") to the repeated pain and anxiety that they experienced with cannula insertions. Time and experience, therefore, appeared to be important mediators in this process. However, the findings also highlighted how, despite their young age, many of the children actively employed a range of positive coping strategies that have been identified as particularly helpful for dealing with needle-stick procedures, including self-control, distraction and basic relaxation techniques such as breathing deeply (Ulman et al 2009).

Studies investigating the prevalence and duration of fear, distress and pain associated with insulin administration for children with diabetes are limited and findings are mixed. Of those studies found, all use self-report questionnaires and pain-rating scales to evaluate responses. For example, a survey of 23 children (age range 4.9 to 16.2 years with a mean age = 9.9 years) conducted by Howe et al (2011) found that overall, fear of insulin injections was more prevalent than pain (40.9% versus 22.7%). Nevertheless, 22.7% of participants reported moderate to severe levels of pain, with no significant differences found in the younger cohort of children (less than 9 years old). However, for the majority, significant improvements were shown over time with only 9.5% overall continuing to report difficulties 6 to 9 months following diagnosis (Howe et al 2011). By way of contrast, a comparative study of needle stick procedures by Hanas & Ludvigsson (1997) found that overall, levels of pain and needle fear were low and that this was not related to duration of diabetes. Moreover, this was particularly the case for children and adolescents (age range 10 to 18 years) who used insulin pump therapy compared to those using other devices such as insulin pens and syringes. However, although this study included a large cohort of participants (n=158), just eight children

(mean age of 14 years) were using insulin pump therapy and experiences of pain was evaluated when taking a bolus of insulin via the pump, rather than when inserting a cannula. Only one study was identified that reports specifically on cannula insertions (Cemeroglu et al 2015). Patients aged between 6 to 17 years on MDI or CSII therapy were enrolled onto this prospective, cross-sectional investigation (n=150). Most of the participants were on CSII therapy (n=110) and male. Fifty of these children were aged between 6 to 10 years of age. Fear of cannula changes was found to be not only more common in this age group, but also this was significantly greater than the fear experienced by those on multiple daily insulin injections ( $p=0.010$ ). In addition, there was no effect of the duration of diabetes on these scores. However, the focus of this study was on establishing the prevalence of needle phobia rather than experiences of actual pain associated with cannula insertions and responses were provided only by children's primary caregiver, rather than the children themselves.

The characteristics of *the lived technological body* for children with insulin pumps challenge some of the above findings. Thus, whilst it is recognised that fear and pain may be related, the most prominent bodily sensation that the children in this study described was pain rather than needle phobia. Moreover, although the descriptions they gave of "getting used" to their cannula changes suggests that time had modulated the pain associated with this procedure and possibly their coping strategies related this, all of the children continued to experience pain which remained problematic for most and intense for a few. These consistencies and discrepancies with previous research may partly reflect differences in the design and focus of the study presented here. For example, objective pain scales that provide a single rating that best represents participants' experiences are likely to yield different results from interviews that capture a range of subjective experiences some of which may be more influential than others. As such, it is difficult to draw any conclusions about these findings and it would certainly be wrong to assume that all children will just get used to this aspect of their pump therapy. Nevertheless, young children's descriptions of their reactions to cannula insertions and the range of coping strategies that they used have not been reported in any detail in the current literature. Therefore, this dimension of *the lived technological body* provides new and important insights into this particular aspect of insulin pump therapy in childhood. It also adds to the paediatric literature relating to procedural pain by underlining the importance of contextual factors in determining individual responses to needle pain, particularly in terms of the ways in which developmental and

experiential elements may shape such experiences. However, comparative studies would be useful for determining which of the many cognitive, developmental and experiential elements may be the most important predictors of pain experienced by children during cannula insertions, especially for those of primary school age.

*The lived technological body - a body and mind enhanced*

Just as *the lived technological body* is disrupted by the technology, the theme “Transformed bodies – Enhanced lives” highlights how it is also simultaneously enhanced by its presence. Other studies describe the positive impact that medical devices in general have for the bodies of children with different medical conditions. For example, in addition to its life sustaining benefits (Earle et al 2006; Heaton et al 2005; Kirk 2010; Spratling et al 2012), they were also seen to enhance social participation and relationships. The latter was particularly associated with artificial feeding. These devices not only removed the pressure on children to eat full meals thereby improving relationships with parents (Kirk 2010), but also increased children’s energy enabling them to participate more fully in social activities (Heaton et al 2005). However, in this current study, congruent with existing paediatric research exploring CSII therapy (Barnard et al 2008; Orlinder et al 2007), this aspect was related in particular to the benefits of not having to administer repeated and painful insulin injections into their bodies. Moreover, unlike the studies investigating other medical technologies, children’s accounts also revealed how their emotional, affective way of being in the world was also significantly transformed. Thus, although the technology generated a need for ongoing attentiveness, at the same time many of the children described how its use helped them to feel safe and in control of their bodies. This in turn, seemed to contribute to a sense of empowerment and less uncertainty.

Ratcliffe (2008) suggests that affective phenomena such as feelings safe and in control should be understood as more than emotions because they are not intentional states – that is, they are not directed *towards* something specific, such as feeling angry. Instead, he draws on Heidegger’s concept of “moods” and thus, our attuned relationship with the world, and refers to them as “existential feelings” (Ratcliffe 2008). As such, congruent with the findings in this study, they involve our bodily relationship with the world. Moreover, he suggests that they serve as background orientations which permeate and shape all experiences, activities and thoughts. As previously discussed, our way of being in the world can be altered when illness is experienced. As a consequence, people

may talk of feeling isolated from others, uncertain, indifferent to everything, or not being at home in the world (Ratcliffe 2008). However, in this study, although a feeling of unhomelikeness was present, it seems that the technology simultaneously promoted positive feelings whereby many of the children seemed to feel that their bodies, and therefore their world, were more stable and certain compared to when they were using MDI therapy. Therefore, it is possible that children's expressions of independence, empowerment and feeling safe and in control were significant factors in fostering a positive attitude towards their treatment. Nevertheless, this was not always the case. As reflected by the accounts of Beth (aged 10 years) and Luke (aged 6 years), feelings of isolation and an ongoing sense of unhomelikeness impacted negatively on these children's emotional way of being in the world and therefore, their subsequent ambivalent or negative appraisals of their condition.

These specific features of *the lived technological body* contribute to existing knowledge in a number of ways. Firstly, they support the psychological literature by confirming the importance of emotional factors in a child's adjustment to chronic illness and their adherence to treatment regimes (Thompson & Gustafson 1996; Gonzalez et al 2016). Ratcliffe (2008) suggests that in general, this discipline has a tendency to use a range of fairly standard terms to describe the ways in which people may be affected by illness, such as anger, fear, sadness and grief. Therefore, the emotions that constitute *the lived technological body* for children with insulin pumps contributes affective "depth" to our understanding of children's adjustment by highlighting how their embodied, emotional way of being may be influenced by particular treatment therapies and the role that existential feelings may have in determining this. More specifically perhaps, they are consistent with literature that draws attention to the crucial role that perceptions about control play in the experience of chronic illness (Compas et al 2012). The concept of health locus of control (LOC) is frequently used in research investigating this topic. This construct refers to beliefs about whether the outcome of a health condition is contingent on one's own behaviour - internal LOC - or determined by chance, fate or other people - external LOC (Thompson & Gustafson 1996). In general, internal LOC is associated with better psychological and health outcomes compared to those with external LOC (Thompson & Gustafson 1999). Studies have examined this topic extensively in the adult population. However, research with young children in particular is limited and no studies were found that explored LOC specifically in relation to their use of medical technologies. A recent American study by Nazareth et al (2016) used

questionnaires to examine the relationship between LOC and various health outcomes in 163 children/young people aged 6 to 17 years with a range of chronic illnesses, including cerebral palsy, kidney disease and T1DM. The findings suggested that there was no association between LOC and treatment adherence or school absences. However, stronger internal LOC was associated with fewer hospitalisations and visits to emergency departments. Moreover, those who felt they themselves could control the outcome of their condition were more likely to have better self-management skills than those who believed their disease course depended on others or chance. Although the focus of the study presented here differs, children's descriptions of feeling in control and their active involvement in their care lends some tentative support to these findings and suggests that their internal locus of control may have been strong. However, the average age of participants in the study by Nazareth et al (2016) was 12 years and no details were given about treatment regimes being used for those with T1DM. Further research, therefore, would be useful in order to delineate how developmental factors, treatment regime and perceptions of control influence outcomes in children using CSII therapy.

The contradictory descriptions that the children gave about the ways they experienced their bodies when using insulin pump therapy and the role that the technology played in this, is consistent with other accounts given by both adults (Gately et al 2008; Lehoux et al 2004; Lupton & Seymour 2000) as well as children / young people who live technology assisted lives (Kirk 2010, Stayt et al 2015). These studies explore experiences of a wide range of medical devices that vary in the degree of visibility, patients' level of dependence on the technology and the setting within which they are used. Despite this variability, all of this literature concludes that, as a result of its benefits and drawbacks, the dominant position that medical technologies occupy in patient's lives is primarily one of ambivalence. However, in the study presented here, only one child (Beth aged 9 years) appeared to convey this particular emotion, possibly as a consequence of a combination of factors that included not only the felt stigma that resulted from the insulin pump's visibility, but also the short duration of her treatment and, as previously mentioned, feelings of isolation. Therefore, consistent with the existing CSII related literature, (Barnard et al 2008; Low et al 2005; Orlinder et al 2007) the majority of children were enthusiastic and positive about their treatment. This particular finding challenges much of the psychological literature that typically finds children and young people with chronic illness to be at an increased risk of

psychological maladjustment (Pinquart 2012) and emotional problems (Layte & McCrory 2013). However, some suggest that this body of work is frequently underpinned with hidden “negative assumptions” that reflect the notion that children will inevitably dislike their therapies and struggle to adapt to them (Darbyshire et al 2006; Koch 2000). Consequently, findings tend to privilege the negative effects and “burden” of illness on children and young people (Bury 1991). Therefore, in general, positive meanings and dimensions of the chronic illness experience are given less prominence. However, the concern of this current study was to investigate the experience of living with illness and the shifting meanings that were created by those affected by it over time. Bury (1991:452) suggests that examining matters from this interpretive perspective enables the “unfolding” and “emergent” nature of chronic illness to be taken into account and the diversity of experiences to be acknowledged. As a consequence, similar to this study, both the positive and negative effects of chronic illness may be more easily revealed and by so doing, a more balanced account may be achieved.

A number of factors may have contributed to the positive appraisals that the children in this study gave of their treatment, despite their experiences of pain. It is possible that for them the benefits of using the technology simply outweighed any inconveniences experienced. This may have been related in particular to the opportunities that CSII therapy offered in terms of being able to lead a life that was more like their peers as a result of its flexibility and convenience compared to the demands associated with MDI therapy (Barnard et al 2008). In addition, children’s descriptions of “getting used” to their treatment suggest that their positivity may also have been influenced by the passage of time. This is consistent with other studies that have found a significant correlation between children’s positive attitudes towards type 1 diabetes in general and longer disease duration (Amer 2008). Demographic variables such as a child’s age, gender and socio-economic status were not found to be associated with this. Further research investigating the ambiguities underlying the use of insulin pump therapy for young children with diabetes would be useful for clarifying the extent to which patient - situation specific variables may make an empirical difference to experiences of this treatment and children’s attitudes towards it.

## **5.5 The lived technological body – A site of difference**

A further compelling finding that emerged from children’s narratives related to the ways in which their treatment appeared to influence both their personal sense of self as well

as their public identity. This reflects an additional prominent discourse in the literature generally that was highlighted earlier which conceptualises the body as a site of difference between individuals, with technology playing a key role in the (re)production of such difference. These differences impact significantly on the construction and maintenance of identity (Buchanan-Oliver & Cruz 2009; Howson 2013). In literature related to adults, discussions that consider this perspective sometimes adopt a critical approach, and focus on issues of identity related to class, gender and ethnicity. For example, it is suggested that visual technologies in particular are implicated in the construction and re-enforcement of gendered and ethnic bodies which in turn, produces inequitable power relations and hierarchical structures in society (Buchanan-Oliver & Cruz 2009). However, of greater relevance to the concept of *the lived technological body* are debates that consider notions of self and identity and the ways in which these may be altered or threatened by patient's use of medical technologies.

In this study, the theme Shaping identities: Being different and the Same illustrates how *the lived technological body* inhabited by children who use insulin pumps is undeniably a site of difference from others because of the ways in which they described how the presence of the insulin pump and cannulas "marked" it as such in a very tangible and visible way. As a consequence, their bodies became an object for scrutiny by peers in particular, and by so doing, children's identities were constantly under threat. It is widely accepted that stigma may be attached to those whose bodies are seen to differ from social norms and expectations (Beale 2010). Stigma is typically conceptualised as a social and interactive process (Gray 2002), whereby the reaction of others "spoil" normal identity (Nettleton 2013). Although challenged more recently (as will be discussed below), the work of Erving Goffman (1968) continues to be influential in understanding the ways in which those with chronic illness experience stigma and the impact this may have on their social interactions and the management of self (Nettleton 2013). Of particular relevance to the nature of *the lived technological body* is his suggestion that the likelihood of experiencing stigmatisation is dependent on the visibility of the stigma, the extent to which others are aware of it and the ways in which its presence may impede the flow of interaction. Moreover, Goffman (1968) distinguishes between those whose attributes can be hidden and are therefore only potentially stigmatising ("the discreditable"), and those whose condition is visible ("the discredited"). He suggests that for the latter, the priority is to control the flow of



information about “these blemished aspects of self” (Nettleton 2013:85) in order to minimise differences and maintain a desired self-identity.

In the paediatric literature on stigma, it is not only medical technologies that are central in the (re)production of difference. Thus, conditions that result in visible changes to a child’s physical appearance such as obesity (Martin 2015) and juvenile arthritis (Tong et al 2012) as well as those that are associated with strict, intensive treatment regimes such as cystic fibrosis (Williams et al 2009) and T1DM (Freeborn et al 2013) may also threaten identities and create the potential for stigma and spoiled identities. However, the latter explores predominantly the experiences of children/young people using MDI regimes. Moreover, in the wider health literature, previous work has frequently portrayed T1DM as a condition that is largely “invisible” in the sense that it is possible to hide or conceal it from others (Joachim & Acorn 2000; Kelly & Field 1996). Therefore, although an individual’s sense of personal identity may be influenced by the routines and practices that are required to manage it, a “normal” public identity can be maintained, so long as the latter are able to remain private and concealed from others (Kelly & Field 1996). In this present study, experiences of stigma emerged as an important issue for most of the children. Their condition it seemed was continually evident as a result of the visibility of the technology on and in their bodies. As such, the children’s ability to conceal it from others and “pass” as normal was threatened and social interactions were altered, particularly in relation to peers at school. Nevertheless, other paediatric research suggests that stigma is not invariably attached to those who use medical devices (Gabe et al 2002; Kirk 2010). However, the nature of the technology is an important influencing factor in this. Thus, inhalers have come to symbolise the relative normality of asthma in childhood (Gabe et al 2002), whilst devices that can be concealed (for example, gastrostomies) or those which are only required at night or in the space of home, (for example, overnight oxygen therapy and ventilation masks) are less obtrusive and thus more able to support a “normal” presentation of self (Earle et al 2006; Kirk 2010). However, insulin pumps do not have this status due to their continuous presence on children’s bodies and because their use cannot be contained in time or space. Therefore, whilst most of the children in this study were found to have incorporated their treatment into their personal identities such that they described themselves as the same as their peers, it appeared that the majority experienced a “spoiled” public identity.

More recently, Goffman's (1968) orthodox view of stigma has been questioned in the health literature because of the overemphasis it places on enacted stigma - that is, the situational response and discriminatory behaviours of others towards those who are perceived to be different. Instead, it is argued that felt stigma, (a feeling of shame and an expectation of discrimination), is more disruptive for those who experience chronic illnesses such as epilepsy (Scambler 2009). Moreover, not only can felt stigma be more prevalent than enacted stigma, but also it can cause the most anxiety (Scambler 2009). Both can overlap and the impact can be damaging, not only in terms of influencing identity but also because they can limit opportunities for social support and lead to withdrawal and low self-esteem (Gray 2002). It is difficult to be certain about the extent to which the children in this study experienced these different dimensions of stigma. However, children's descriptions of the questioning they experienced about their bodily appearance and the taunting and name-calling expressed by Billy and Paige suggest that most children experienced instances of enacted stigma, particularly in the school setting. In addition, children's accounts of their embarrassment caused by pump alarms and the desire to hide their bodies from the view of others suggest that many may have been worried about additional discriminatory responses by classmates. Moreover, Beth and Paige's reluctance to talk openly about their condition with others, as well as Beth's expressions of fear, shame and social isolation suggest that felt stigma may have been especially difficult for a few.

Responses to stigma can vary (Nettleton 2013). However, congruent with the work of Goffman (1968), in this study, controlling information about their condition and self-presentation (impression management) appeared to be central to the children's efforts to minimise their difference from others and to maintain their desire to be like their peers. The strategies they used to manage the visibility and presence of the technology varied. Reflective of studies investigating the experiences of children dependent on other medical devices (Kirk 2010), this included deliberate attempts to mask or hide any signs of bodily difference when in public settings as well as being selective about the nature of the information they disclosed to others. The latter related in particular to two of the older girls (Beth and Paige aged 10 and 11 years respectively). Gendered and age differences in the construction of identity has also been found in other literature exploring children's views of both medical technologies (Kirk 2010) as well as cystic fibrosis (Williams 2000; Williams et al 2009). Similar to this study, Williams et al (2009) and Kirk (2010) also found that older children (particularly those of secondary

school age and above), were more likely to engage in behaviours aimed at creating and maintaining an unspoiled identity for peers compared to younger children. This would seem to confirm the notion that children's sense of normalcy is likely to vary over time (Williams et al 2009). Thus, as children get older and accumulate life experiences, they might be more aware of social, as opposed to personal, definitions of normalcy which may then influence their own self-presentations (Williams et al 2009). However, unlike the investigation presented here, two of these studies (Williams 2000; Kirk 2010) found that it was boys rather than girls who tried to make their condition as invisible as possible, particularly in public settings.

It is premature to draw conclusions about the factors that may have determined the reactions and behaviours of Beth and Paige in this study. However, it is possible that they were related to concerns about body image. Body image is a broad concept and can be used, amongst other things, to refer to body satisfaction, appearance evaluation and body concern (Howson 2013). It is defined as a person's own perception, thoughts and feelings about their body, size and shape and is strongly related to impression management (Bailey et al 2016). Thus, concerns about physical appearance, perhaps as a result of the reactions of others, may create a poorer body image. Moreover, a negative body image may result in greater self-presentational concerns and thus, increased efforts to preserve / maintain a favourable image to others (Bailey et al 2016). In this study, the descriptions that Beth and Paige gave about feeling self-conscious and their more intense engagement in impression management tactics suggest that they may have been dissatisfied with their bodies and as such, had a body image that was more negative than the other children who participated in this study.

Many investigations have examined body image perception in those with T1DM and the links in particular between body dissatisfaction, self-esteem and "diabulaemia" or eating disorders (Callum & Lewis 2014; Colton et al 2015). In the literature that specifically explores CSII therapy, findings are inconsistent. For example, Tullman (2013) found that the constant presence of the insulin pump led to a heightened sense of body awareness whilst Low et al (2005) found no body image concerns. However, the bulk of the literature exploring this topic, relates to experiences of female adolescents and young women. Very little research to date has explored body image perception in young children with either T1DM or those using specific medical devices. A recent study conducted in Italy by Troncone et al (2016) has investigated this issue in both healthy children (n=219) as well as those diagnosed with T1DM (n=81) aged between 5 and 10

years old. A body image rating scale was used to assess body size perception and satisfaction in addition to figural drawings made by the participants themselves. The findings revealed that many of the children from both groups were critical of their bodies and as such typically showed a preference for a thinner body than their perceived current size. The authors argue that this finding most probably reflects the cultural preference for slimness and the “slender ideal” (Grogan 2010:41) that currently dominates modern western societies and the media. However, in this study, no details were given regarding the treatment regime used by the children with T1DM. Moreover, concerns regarding the utility of using drawings as an assessment technique have been raised, including the impact of a child’s artistic ability (Flanagan & Motta 2007). Therefore, the relevance of this research in relation to the findings of this study is unclear. Further research exploring the impact of insulin pumps and cannulas on body image would be useful, especially in terms of the effects that age and sex may have on this.

Despite the disruption children experienced in relation to their public identity and the hard work involved in dealing with the responses of others, the findings suggest that the majority of the children seemed to have been able to accommodate these discrepancies and successfully incorporate their treatment into their own personal identities. As such, most presented themselves as ordinary, active children rather than children who were sick or unwell. Their condition, therefore, did not appear to be central to their own personal self-definition. Thus, whilst *the lived technological body* for children with insulin pumps engenders feelings of difference, it simultaneously fosters a sense of normality and “sameness”. This contradicts accounts given by other children and young people, where descriptions of their experiences of chronic illness in general such as rheumatoid arthritis, asthma and epilepsy revolve around concerns with self-identity (Tong et al 2012) and feeling different from others (Lambert & Keogh 2014). However, congruent with this investigation, other research has also found that children may define themselves in ways that emphasise their normalcy and non-difference from peers, including those living with autism (Mogensen & Mason 2015), cystic fibrosis (Williams et al 2009), liver transplantation (Wise 2002) and also medical technologies (Kirk 2010). This particular feature of *the lived technological body* may simply reflect children’s reports of fewer painful needle stick procedures, greater dietary freedom and overall convenience of their treatment regime. As a result, they could eat the same foods

as their friends and deal with the demands of their condition more easily, thereby engendering feelings of similarity rather than difference.

Children's relationships with friends may also have been influential in reinforcing their sense of non-difference from others. The importance of close friends in supporting a child's sense of normalcy is well recognised across the paediatric literature, including those using medical technologies (Kirk 2010; Lambert & Keogh 2014; Spratling et al 2012). Moreover, for children / teenagers with T1DM it has been suggested that not only is the role of friends primarily one of emotional support but also this type of care is orientated in particular towards helping children feel accepted (La Greca et al 1995). The descriptions given by the children in this study of the understanding and sensitivity shown by friends towards their condition confirm this to some extent. It is also possible that this finding lends support to the concept of normalisation. This notion has been identified as a particular coping strategy that is commonly used by families and children as a way of dealing with the impact of chronic illness on both daily life and an individual's biography (Williams et al 2009). Kelleher (1988) has described this concept as a cognitive process that may involve "bracketing off" or de-centering the effects of illness or treatment in order to soften its impact on a person's self-identity such that it remains relatively unaffected. However, in contrast, Knafl & Deatrck (1986) suggest that normalisation is a process that consists of four key attributes. These include defining life as essentially normal, minimising the social consequences of the illness and engaging in behaviours that demonstrate normalcy to others. The accounts that the children in this study gave of themselves as well as the strategies and resources they used to manage their identity reflects something of this latter conceptualisation in particular.

*The lived technological body* for children with insulin pumps then, is centrally important in shaping the identities of the young children who inhabit it and as such, reflects further how children experience their body relationally when using CSII therapy. As discussed in the literature review, evidence of the impact that insulin pump therapy may have on the personal and social identities of preadolescent children is limited in the current literature on CSII therapy in childhood. This new concept, therefore, adds to both the health and sociological literature on childhood diabetes by exploring conceptualisations of normalcy and stigma for young children living with insulin pumps, highlighting in particular the challenges that may be involved in negotiating these issues in the context of their everyday lives. It also contributes to

symbolic interactionist theory by confirming the importance of social experiences in identity development and thus the notion that this is fundamentally social in nature and primarily the product of interactions between self and significant others (Nettleton 2013). Nevertheless, in this body of literature, the impact of social interactions on the “selves” of adults with illness is often understood in more general terms such as Bury’s (1982) concept of “biographical disruption” and Charmaz’s (1983) notion of “loss of self”. However, as discussed, in the study presented here, children’s accounts were more nuanced. Thus, whilst they experienced “biographical disruption” to some extent in terms of their social identities, most children seemed able to create and maintain a personal sense of normalcy. Therefore, the relevance of these more traditional explanatory concepts to the findings of this study is debateable. Instead, conceptualisations that take into account the different dimensions of identity - that is both personal and social definitions - may be more meaningful (Williams et al 2009). With this in mind, Shakespeare’s (1996:94) description of identity as “narrative” may have more value for understanding this particular aspect of *the lived technological body*. He suggests that this metaphor “focuses on the stories we tell about ourselves and our lives, and constructs accounts which encompass plot, causality and conflict”. As such, identity is conceptualised as complex, individualised and composed of different layers and perspectives. Future research would be helpful in unravelling further the complexities involved in constructing and maintaining an identity as a young child living with insulin pump therapy. Longitudinal studies exploring how conceptualisations of normalcy may shift over time, as well as studies exploring the influence of age, gender and treatment modality on such issues could be especially useful.

## **5.6 The lived technological body - A shifting & changing body**

To inhabit a *lived technological body* as a young child is to also experience a body that is shifting and changing. This particular feature reflects the frequent references that the children in this study made in relation to the importance of “getting used to” their treatment and its impact on their bodies over time. This finding illustrates something of Heidegger’s (1962) belief that temporality is central to human existence. Unlike the traditional view of time, Heidegger (1962) regarded time in terms of temporal horizons or dimensions that include the *now*, the *no longer* and the *not yet*. Therefore, time in this sense is fluid and unfolding. As a consequence, all experiences and our understanding of them entail temporal horizons of past, present and future rather than being merely an

accrual of events (McConnell-Henry et al 2009). In this study, the “nowness” of children’s current experiences carried with it a sense of coherence with their experiences of the past and expectations for the future. By so doing, these findings reveal something further about the day to day challenges children may face and the cognitive processes they may follow in their response and adaptation to pump therapy and the way they make sense of it in their everyday lives.

Children’s accounts of the processes involved in getting used to the impact of the technology on and in their bodies have not been described in the existing literature related to either CSII therapy or other medical devices. In this current study, their experiences reflect the suggestion that cognitive processing is an important feature in a child’s adjustment to chronic illness in general (Thomson & Gustafson 1996). According to Piaget’s (1957) theory of development, children construct a series of complex cognitive schemas or “scripts” for salient experiences and use these for interpreting and making sense of their world. There is no one unified theory that provides a complete account about exactly how this process takes place (Bjorklund 1997). Nevertheless, when applied to the study of children’s understanding of illness, Piaget’s (1957) emphasis on the influence of increasing age and level of cognitive maturity dominates much of the research investigating this topic (Crisp et al 1996). However, reflective of other studies investigating the experiences of children with cancer (Stewart 2003) and cystic fibrosis (Crisp et al 1996), the findings of this study challenge Piagetian theory by suggesting that a more gradual and active process is involved. Thus, with time and experience, children’s thoughts about their pump therapy were re-organised, new skills were learned and strategies altered to accommodate the challenges involved in incorporating their treatment into their lives. Therefore, “getting used to it” appears to be more reflective of constructivist approaches that see children building up their understanding of the world around them as a result of an accumulation of their own unique experiences in specific content areas (Sutherland 1992). As such, it would seem that *the lived technological body* for children with insulin pumps incorporates a body/ mind that requires the capacity to navigate, accommodate and adjust to constantly changing conditions and ways of being in the world.

Studies investigating children’s adjustment to T1DM typically employ risk-resistance models as a framework for studying the complex relationships between child, family and the many other interrelated factors that may determine a child’s adaptation to their condition (Christie & Khatun 2012). It is suggested that emotional, physical and

psychological difficulties may occur when risk factors are raised and resistance factors are low. The former includes disease characteristics (including its visibility), functional independence and psychosocial stressors whilst the latter takes account of socio-ecological and interpersonal factors as well as stress processing and coping strategies (Whittemore et al 2010). The role that each element plays in a child's adjustment is complex (Christie & Khatun 2012). However, in general, the literature suggests that positive self-perceptions and attitudes towards their condition (Amer 2008); high levels of support from both family and friends and the use of accommodative coping strategies (Whittemore et al 2010) foster positive adjustment to T1DM. Conversely, factors that negatively influence this include low self-esteem (Immelt 2006) and the use of emotionally focussed coping strategies and mental disengagement (Compas et al 2012). The findings of this study lend some support to this work and to the conceptual risk-resistance model that underpins it. Thus, Luke's negative attitude towards his illness in general may have influenced his extreme dislike of pump therapy. This, in combination with his coping strategies of denial, wishful thinking and avoidance, may have in turn fostered his low self-esteem and influenced his ability to adjust to his treatment. By way of contrast, the other children's purposeful efforts to infuse events with positive meaning and their use of accommodative coping strategies such as acceptance and distraction techniques represent attempts to maximise their "fit" with the demands of their treatment (Compas et al 2012). Such positive appraisal can help replace anger and sadness with satisfaction and pride (Christie & Khatun 2012).

The notion of *the lived technological body* as an entity that is shifting and changing provides further support to the psychological literature by highlighting the importance of factors other than just age to young children's adjustment to chronic illness and how these may contribute to or impede adaptation to living a technology assisted life. Future research that investigates such issues in greater depth for those who use insulin pump therapy would enable a more comprehensive understanding and assist in the development of interventions that could promote a child's positive adjustment and adaptation to the challenges of this treatment strategy in particular.

### **5.7 The lived technological body - A high maintenance body**

The fifth and last important dimension of *the lived technological body* is that it is an entity that is high maintenance and one that demands significant reserves of energy, effort and emotion from all of those who care for it. As illustrated in Figure 2, this



characteristic derives from the themes highlighting the active role children played in the managing their own bodies as well as their identities and the crucial role played by others at home, school and elsewhere in supporting this. Thus, *the lived technological body* for children with insulin pumps is one that is shaped and honed primarily by the vigilance and hard work of its owner, but also by the social spaces children inhabited and the patterns of interaction between adults and children that takes place within these environments.

The idea that *the lived technological body* accommodates a child who is not only young but also an active, intentional and often competent and resourceful healthcare actor, differs from traditional sociological and medical perspectives that depict children's bodies as mostly passive and conforming when they are ill (Brady et al 2015). However, in line with the sociology of childhood and its concern to position children as competent social actors (James & Prout 2015; Harden et al 2000), a growing body of literature now demonstrates children's agency and their active participation in the management of their bodies and minds when living with chronic illness in general. Thus, congruent with the findings of this study, children have been shown to be not only highly knowledgeable about their condition (Curtis-Tyler 2012; Sutcliffe et al 2003) but also to view themselves as having a key role to play in their own healthcare (Curtis-Tyler 2012; Gabe et al 2002; Kirk 2010). In this study, this manifested itself in children's accounts of the considerable "illness work" (Corbin & Strauss 1985) they carried out every day, as well as the identity or "body work" (James 2000; Corbin & Strauss 1985) they engaged in. Moreover, their descriptions of "getting used to it" conveyed the ongoing and forever changing nature of this work. As such, children negotiated physical symptoms, took charge of the technology sometimes, participated in treatment related decisions and, as previously discussed, regularly employed strategies to create and maintain an unspoiled public identity. Therefore, although the extent of this work varied with age, children participated actively in managing not only their physical bodies but also the creation of themselves.

The process of forming and supporting a coherent and stable social identity and self-concept are fundamental aspects of growing up for all children and young people (Bee & Boyd 2004). However, for children whose bodies differ from the norm, this work may become particularly urgent (James 2000). As previously discussed, for the children in this study the findings revealed how they had to engage in a conscious strategy of action in order to re-present their self to their peers in particular and thus enable them to

“pass” as normal, and to essentially “fit in”. This differs from the experiences of children using technologies associated with peritoneal dialysis, oxygen therapy and gastrostomies (Kirk 2010). These devices were not immediately apparent to others because they were contained to home and overnight use only. Therefore, although not removed completely, threats to these children’s identities were less than those using technologies that were more visible. As such, their need for body work was reduced. It is possible that the type of body work used by the children in this current study may have provided them with an immediate sense of control. However, it has been suggested that this can also have significant psycho-emotional effects long term not only because of the constant fear of exposure but also because it may prevent children from fully integrating into their peer group (Sentenac et al 2013). Although the children in this study did not reveal such emotions in their narratives, the findings do suggest that the stigma of CSII therapy adds additional burdens which involve not only high levels of motivation, but also difficult and ongoing lines of identity work. Moreover, since much of this work appeared to happen mostly within the school setting, children had to negotiate this largely on their own. It is possible therefore that this could be the most emotionally intense and demanding of all the work that is involved in maintaining *the lived technological body* for children with pumps. This may be especially true for older girls who, as this study’s findings illustrate, may be more likely to engage in particularly high levels of self-presentational behaviours.

The concepts of patient empowerment and self-management are now central to both government policy (NHS England 2014) and clinical practice strategies for achieving positive health outcomes for those with chronic illness, including children with T1DM (NICE 2015). Evidence suggests that active participation in treatment regimes has positive long term benefits for children, including improved decision making skills, a sense of autonomy and thus, better treatment adherence (Chisholm et al 2011; Wales et al 2007). Moreover, if begun early, this may enhance compliance during adolescence (Wales et al 2007) and promote greater acceptance of their condition (Koller et al 2015). Existing studies have shown that CSII therapy fosters a sense of control and greater independence in diabetes related tasks for teenagers (Low et al 2005; McMahan et al 2005). However, the nature and extent of younger children’s competencies when using insulin pumps as well as those dependent on other medical devices, have received little attention. In the present study, children’s confidence and independence in using the insulin pump and their expert use of clinical jargon reflected their expertise and

resourcefulness in managing some aspects of their condition independently. This was an unexpected finding not only because of their young age, but also because of the technological sophistication of the insulin pump. A possible explanation for this could be that children today are part of a digital generation and as such, technology forms a key part of growing up. Smart phones, computers, tablets, social media and video games are just some of the vast array of technologies that children are exposed to and which are used by them regularly in their everyday lives. Such is their competence with these devices that it has been suggested that by the time children leave primary school, many far exceed the technology skills of their caregivers (Curtis 2013). Therefore, for the children in this study, being “technologically savvy” may have enabled them to feel comfortable and confident with the technological demands of their treatment. This, in turn, seemed to generate a sense of accomplishment and pride. These particular findings contribute to a deeper understanding of the concept of autonomy in young children and more specifically, the way in which this may evolve and be related to treatment modality for those with T1DM. Future longitudinal research that explores this issue in greater depth, particularly from the child’s perspective, would help to establish appropriate expectations for self-care and assist in the design of intervention programmes that promote this transfer of responsibilities as the child matures.

However, whilst insulin pump therapy appeared to promote a sense of empowerment, the theme Being Empowered – Feeling Disempowered also revealed how this characteristic was contingent on the particular social environments in which children lived, the nature of intergenerational relationships within these spaces and the type of support that emerged from this. Thus, within the family home there seemed to be an enabling, interactive environment that fostered negotiation, collaborative working and opportunities for children to develop skill mastery and thus a sense of independence. Tasks were shared and respect for each other’s knowledge and participation in healthcare activities were shown. The nature of the child-adult relationship in this environment, therefore, appeared to be one that recognised children’s status as healthcare actors who had the ability and right to participate in their own care. This differs from work investigating the sharing of treatment responsibilities between teenagers and their parents and the conflicts and difficulties that are often experienced by them (Dashiff et al 2005; Timms 2014). However, the importance of a team-work approach described in this present study is consistent with other literature investigating not only adolescents’ experiences of CSII therapy (Low et al 2005) and their use of

other medical technologies (Kirk 2010), but also the experiences of younger children with asthma and cystic fibrosis (Beacham & Deatrick 2015) and those with T1DM using MDI regimes (Koller et al 2015; Newbould et al 2008). In research exploring insulin pump therapy, the division of healthcare between parents and teenagers varied. Thus, similar to this study, parents helped with set changes and mechanical problems whilst the teenagers themselves were responsible for testing and bolusing insulin (Low et al 2005). However, for those using devices such as gastrostomy feeding, peritoneal dialysis and intravenous therapies, the nature of parental support differed in that it focussed on helping children adjust the timings of and work around their treatment regimes in order to enable participation in social activities in particular. This was not discussed by the children in this current study, possibly reflecting the convenience and flexibility of using insulin pumps compared to other technologies. A number of other studies (Chisholm et al 2011; Berg et al 2007) have investigated how sharing responsibility for diabetes related tasks may influence health outcomes. Findings suggest that collaborative partnerships that maximise the behavioural and cognitive involvement of children in their treatment are associated with better metabolic outcomes, self-care behaviour and psychological health, including positive mood. Whilst the focus of the present study differs from this work, children's descriptions of supportive family relationships and their overall positive attitude and satisfaction with their treatment lends some empirical support to this research. Moreover, they serve as a general reminder of the crucial role parents play as mediators and facilitators in the division of healthcare tasks for children living with chronic illness in general.

Nevertheless, whilst most of the children in this study seemed able to exercise their role as healthcare actors within the private domain of home, the themes revealed that other social spaces such as the school setting appeared to constrain some children's agency and personal autonomy, particularly those that were older. In this space, teachers "hyper-vigilance" and reluctance to fully acknowledge children's mastery of the technology was evidence of this. Many paediatric studies, including this one, highlight the overly protective behaviour of parents towards children's diagnosis of not only T1DM (Freeborn et al 2013; Marshall 2009), but also asthma and epilepsy (Lambert & Keogh 2014) and juvenile arthritis (Tong et al 2012) and the exclusion from social activities that can result from this, including sleepovers and school residential trips (Freeborn et al 2013; Sparapani et al 2015; Wilson & Beskine 2007). However, in the school setting, evidence has suggested that the level and type of support provided by

staff for children with T1DM can be experienced as highly variable (Kirk et al 2012; Smith et al 2008). For example, whilst some children had access to trained staff (school nurses or first aiders), for others no advice was available when they felt unwell or needed help with medications (Smith et al 2008). Similar to the findings of this study, this could mean that parents had to accompany their child on school trips in order for them to be able to participate (Smith et al 2008). Other studies also describe how the presence of medical technologies can lead to children's exclusion from school life (Kirk 2010). However, to date, detailed descriptions of the nature of the support offered to children requiring the support of medical devices and their relationships with staff in the school setting is lacking.

It is difficult to be certain about the reasons for the type of over-protection that children experienced in this study. In common with the findings of recent research (Januszczuk et al 2016), it may have been that school staff were simply not equipped with the knowledge and skills required to support children appropriately with this complex treatment regime. However, it is possible that this aspect of children's experiences may also reflect contemporary western conceptualisations and images of the body of a child and the social and cultural components that make up these ideas. In particular, the child's body is constructed as vulnerable and therefore, in need of protection by parents and professionals in both practice, as well as in political and legal discourse (Christensen 2000; Howson 2013). Adults, therefore, are perceived as being in charge of, and having responsibility for the child and their body whilst at the same time, children are positioned as the dependent and passive object (Christensen 2000). Children's inherent vulnerability - that is, their physical weakness and lack of knowledge and experience - makes this protective model understandable. However, some suggest that adopting vulnerability as a "master identity" for children is problematic because of the way it influences adult approaches towards them (Christensen 2000: 40). For example, Christensen (2000) found that in children's actual experiences of vulnerability - that is, when they were unwell or involved in minor accidents at school - their bodies were "objectified" by adults such that children's own subjective experiences of their bodies were often ignored or minimised. Thus, teachers frequently either reprimanded children for over-dramatising or ignored their complaints. The children themselves, however, just wanted to share their experiences of their body. Similarly, adult perceptions of a child's vulnerability have meant that in practice, children are now subject to a high degree of restraint and regulation (Howson 2013).

Thus, congruent with the findings of this current study, children's own experiences of the social spaces they inhabit, including school, point to increasingly high levels of protection, restriction and surveillance (Howson 2013).

In this study, the type of support offered by the teachers was resented by some of the children and limited opportunities for developing their self-management skills and independence. Moreover, the children's apparent reluctance to challenge this suggests that the level of autonomy provided by the technology was not only spatially defined but also mediated by and in intergenerational relations that were inflected with issues of power and the ways children are listened to in different social settings (Brady et al 2015). This reflects theoretical discussions in the literature about children's "structural vulnerability" (Lansdown 1994:35) – that is, the ways in which they are vulnerable not just because of "nature" but also because of their lack of power and civil rights. The principles that underpin the United Nations Convention on the Rights of the Child (UN 1989) have been highly influential in trying to address this aspect of children's vulnerability, especially in terms of promoting children's right to participate fully in decisions that affect their lives and health. However, Lansdown (1994) argues that this latter principle exposes in particular the tension between a view of children who are in need of protection and on the other hand, people with basic civil rights. As a consequence, similar to the findings of this study, research investigating the dynamics of children's interactions and relationships with adults in both school as well as healthcare settings, suggest that children do not always feel valued, listened to and taken seriously. For example, Mayall (1998) explored children's experiences of their positioning at home and in primary school, with a specific focus on everyday health maintenance, (rest, eating, drinking, going to the toilet), and how far the children themselves participated in this. Congruent with this current study, children's positioning differed between the two settings. Thus, at home, parents valued children's contribution to their own care and encouraged them to take charge of their bodies. However, in contrast, at school, relationships were founded on adult direction, rigid timetables and constructions of children as socialisation projects rather than participating people. Consequently, generational processes and power relations were characterised by relatively fixed parameters that devalued children's competence as healthcare actors and restricted their agency. Similarly, studies investigating the dynamics of children's interactions with healthcare professionals have found that children are often excluded from consultations in paediatric diabetes outpatient clinics (Curtis-Tyler 2012).

Moreover, clinicians have been found to dismiss or reframe children's own bodily sensations and experiences of for example, chronic pain, to fit professionals own paradigms of understanding (Carter 2000). As a consequence, children felt that their voices were muted or ignored. Thus, despite a recognition that children are active, social beings it seems that we may still be far from complying with the principle of participation advocated by the United Nations (UN 1989).

These characteristics of *the lived technological body* provide clear evidence in support of the sociology of childhood and its central concern with issues related to the interplay of agency and structure and how this plays out in the context of intergenerational relationships (James & Prout 2015). In particular, they contribute to more recent and critical sociological conceptualisations of agency that argue against simplistic definitions of this notion as just the property of the rational, competent subject or something that is unconstrained and inherently positive for children (Esser et al 2016; Valentine 2011). Instead, more connected, relational forms of agency are proposed that emphasise “the materiality and performativity of agency as well as the ambiguity of children's voices” (Esser 2017:287). As such, it is argued that children gain agency via their interactions with a whole range of entities. This includes not only intergenerational relations and children's social contexts but also their connections with material objects (Esser et al 2016). Thus, as the findings of this study illustrate, the sort of agency that emerges can be both constrained and enabled and as such, experienced by children as “complex, multidimensional and ambivalent” (Valentine 2011:348). These ideas in turn, have led more recently to the idea that childhood is no longer simply a social construction. Rather, it is increasingly being recognised as a *general* construction that considers childhood as “an emergent property of interactions between persons, discourses, technologies, objects and bodies” (Esser 2017:288).

The preceding discussion has examined the findings of the study in detail and considered the ways in which the themes support the notion of *the lived technological body* and its particular characteristics. Compared to the bodies of children using other medical devices, some of its features are similar. This is particularly in terms of it being a site of difference because of the technology's continuous presence and the way it is simultaneously disrupted and enhanced by its presence as a result of its benefits and drawbacks. However, other dimensions are different. Thus, rather than pump technology occupying an ambivalent position in children's lives, *the lived technological body* is characterised overall by feelings of positivity, safety and control and an ongoing

attentiveness. Moreover, it incorporates features that have not been described in the current literature in the sense that it is a body that takes time to adjust to the technology's presence and it is an entity whose agency and autonomy is constrained sometimes by intergenerational relationships and specific environments. *The lived technological body*, therefore, is unique to children who use insulin pumps.

The discussion that now follows adopts a theoretical lens and explores how *the lived technological body* when considered holistically, differs from traditional conceptualisations of the body of a child. By so doing, I hope to illuminate further the phenomena of CSII therapy in childhood.

### **5.8 The lived technological body: an original contribution to understanding the body in childhood.**

Traditional theoretical perspectives relating to childhood bodies typically reflect polarised forms of thinking and practices by adopting either naturalistic / biomedical or social-constructionist positions (Prout 2000). These views are summarised below.

#### *The naturalistic/ biomedical perspective*

Following the emergence of medical sciences and developmental psychology, the biomedical approach has come to dominate contemporary western discourses about children's bodies (Horschelmann & Colls 2010). This view maintains that the body is a real, biological entity that exists as a self-contained phenomenon and which is unaffected by the social context within which it is found (Howson 2013). Thus, a socio-biological approach argues that all human behaviours and social interactions are primarily biologically, environmentally and genetically determined (Nettleton 2013). Bodies, therefore, are regarded as largely passive. In addition, unlike phenomenological perspectives, a Cartesian mind/body dualism is privileged whereby the mind and body are considered distinct from each other and as such, are treated separately (Nettleton 2013). Within the discipline of medicine, a mechanical metaphor is also frequently adopted such that human bodies are conceptualised as a complex biological "machine" made up of separate and distinct physiological systems that can be "fixed" by medical interventions (Shilling 2012).

Biological and physiological theories of the body are, of course, important and are often regarded as the most accurate interpretation of the body (Nettleton 2013). However, they have been criticised for reducing the body to the status of an object (Prout 2000). Moreover, in the case of children, such representations have led to the suggestion that



their bodies become knowable and significant only in relation to clearly demarcated stages and universal norms against which physical, behavioural and psychological development is analysed and categorised (Horschelmann & Colls 2010). As a result, social and cultural dimensions are neglected.

#### *The social-constructionist perspective*

Social-constructionist perspectives challenge these biomedical conceptualisations of the body by arguing instead, that it is an entity that is primarily socially created rather than a natural construct (Howson 2013). As such, the body reflects and is contingent on societal contexts, ideologies, and discourses (Finlay 2006). There are a number of different perspectives that draw on the works of a wide range of scholars (Nettleton 2013). These include Foucault's notions of power and the ways in which bodies are regulated and trained by institutions and Elias's "civilizing process" that examines in detail how western society shapes how people behave, express emotion and relate to natural bodily functions (Howson 2013, Nettleton 2013). In contrast, and more specific to the context of this study, Armstrong's (1983) influential work on surveillance medicine argues that within paediatric medicine, the reality of a child's body is the effect of the professional discourses which describe them. Consequently, it is increasingly being constructed as a problem. Thus, an array of different categories of children has been created, including "nervous children, delicate children, neuropathic children, maladjusted children, difficult children, oversensitive children and unstable children" (Armstrong 1983:15).

Social constructionist approaches have proved invaluable in terms of providing an alternative conceptual space for thinking about the non-biological aspects of a child's body (Prout 2000). However, its emphasis on the pervasive influence of social dimensions in the construction of bodies has led to the suggestion that much of this work reveals a "cultural" reductionism similar to the "biological" reductionism reflected in biomedical/naturalistic models (Prout 2000). Moreover, sociological treatments of the body have tended to either take the material body for granted or emphasised how the "biological" is primarily shaped by "the social". Thus, an interrogation of how both may interact, shape and influence each other is missing (Horschelmann & Colls 2010).

#### *The lived technological body - complex, relational and dynamic.*

As previously highlighted, the new concept of *the lived technological body* is specific to young children using CSII therapy and the nature of the technology used in this form of

treatment. It differs from approaches to the body that privileges either representational/discursive understandings or biological/natural ones. Instead, the results of this study argue for the bodies of children using insulin pumps to be understood differently - that is, as not only more complex but also as an entity that foregrounds its relational and dynamic nature. Its complexity relates to it being multi-dimensional and the product of an ambiguous amalgamation of biological, social, phenomenological *and* technological events, processes and experiences. It is relational and connected because it is thoroughly intertwined with and dependent on other bodies, spaces and in particular, objects and materials. It is also a body that is particularly dynamic because it is inhabited by a very active agent and requires effort and time in order to “get used to it”. As such, *the lived technological body* is considerably more heterogeneous, “messy” and active than the traditional, simplistic accounts of the nature of children’s bodies that conceptualise them as largely passive, discrete and independent entities.

This type of body corresponds to more recent theoretical debates that argue for a more “fully embodied” sociological account of children’s bodies (Horschelmann & Colls 2010; Williams & Bendelow 2003). These texts attempt to reconcile the dualist approaches described earlier. As such, they continue to stress the powerful influence social processes and environments have on the ways in which children’s bodies are represented, produced and understood (Horschelmann & Colls 2010). However, they also emphasise sociological notions of agency and seek to acknowledge how body, mind and context work together by incorporating the phenomenological concepts of embodiment as well as lived themes and emotion laden issues (Williams & Bendelow 1998). Previous studies have typically focussed on the interplay of body and society and the ways in which this may influence children’s sense of belonging in the world. For example, Holt (2010) investigated the experiences of children with achondroplasia and Asperger’s syndrome who attended an integrated primary school and found that the materiality of their bodies intertwined with peer relationships such that they were not always presented as “other”. As a consequence, empathic relationships between disabled children and their peers were able to be forged.

However, it has been suggested that whilst this perspective attends to children’s phenomenological way of being in the world and highlights their bodily connections with discourses, spaces and social processes, entanglements with the material world are rarely examined in the paediatric literature, particularly for those whose bodies are ill

(Horschelmann & Colls 2010; Kraftl 2013; Prout 2000). The neglect of the material dimensions of everyday life has also been highlighted by others who argue that research approaches in general often render technology invisible because they have a tendency to relegate it to the background as context (Maller 2015). This present study, therefore, is a response to these criticisms. Thus, *the lived technological body* for children with insulin pumps is a body that makes “embodiment central rather than peripheral, and puts minds back into bodies, bodies back into society and society back into the body” (Williams & Bendelow 1998:1). However, it also broadens the picture by including a detailed analysis of children’s material world and emphasising in particular, children’s relationship with medical artefacts and its “morphological impact” (Einstein & Shildrick 2009: 294). Drawing on actor-network theory, Prout (2000:14) believes that such multifaceted bodies are best conceptualised as “translations”. As such, what produces and maintains them:

*“is not simply biological events, not only the phenomenology of bodily experience, and not merely structures of symbolic and discursive meaning - although all of these are important - but also the patterns of material organisation and their modes of ordering”*

What emerges from this particular perspective, therefore, is an account of children’s bodies as complex and hybrid – that is, entities that are transformed (or translated) as a result of its interaction with a wide range of heterogeneous elements (Prout 2000). As such, what becomes important is a detailed examination of the processes by which these elements mutually enrol, constitute and order each other in the construction and maintenance of children’s bodies (Prout 2000). Although such an analysis differs from the focus of the study presented here, the notion of *the lived technological body* does reflect this heterogeneous character of childhood bodies and thus adds empirical support to the conceptualisation of them as “translations”.

Viewing the body of a young child using CSII therapy as *the lived technological body*, therefore, both extends and challenges traditional understandings of what child bodies “are” as well as how they may be lived and experienced by those who inhabit them. In particular, this notion expands phenomenological ideas about the contextual contingencies of the lived body by reminding us in particular of the importance of material objects and artefacts in the creation of meaning and the need to consider more

closely how they may redefine bodies and influence how they act, are experienced and constructed in chronic illness. It also unsettles traditional biomedical conceptualisations of children's bodies by accommodating a view of them as active and emergent, rather than a focus only on what they *are*. As previously highlighted, in paediatric medicine, a child's body is typically viewed as a biological entity that must be monitored, measured and screened (Horschelmann & Colls 2010; Howson 2013). In the context of this study, this emphasis has led to an ever increasing pre-occupation with scrutinising the biophysical parameters of a child's body, particularly in relation to glycaemic control and HbA1c levels. This focus has increased still further following the recent implementation of the Best Practice Tariff (DH 2013) and the Quality Standard QS125 (NICE 2016) which bring with them financial penalties if targets and biological outcomes are not achieved. However, the notion of *the lived technological body* for children with insulin pumps argues for a more integrated and interpretive stance that involves an understanding of young children's bodies in context rather than as simply biological entities and thus recognises their contingency and complexity (Einstein & Shildrick 2009). By so doing, a more comprehensive and nuanced understanding of children's embodiment in the experience of using insulin pump therapy may be possible. This in turn, could enable greater appreciation of its impact and by so doing, facilitate the delivery of care that is more relevant to the needs of a young child and their family. In the context of ever increasing numbers of children using this treatment strategy, such knowledge is both relevant and timely.

## **5.9 Summary**

In summary, this chapter has examined the meanings of the study's findings and considered how they may contribute to the existing dialogue concerning not only CSII therapy but also to the general experience of illness in childhood and the embodied experience of technology. I have also discussed my own contribution to knowledge by presenting the notion of the *lived technological body* as a new concept for understanding better the nature of children's bodies in illness and more specifically, children's experiences of insulin pump therapy in all its complexity.

In the next chapter, the implications of the study's findings for clinical practice will be discussed, in addition to its limitations and personal reflections on the process of its completion.

## **CHAPTER 6 – CONCLUSION**

### **6.1 Introduction**

In this final chapter, I consider whether the aims and objectives of the study have been achieved and explore its implications for clinical practice and professional knowledge. This is followed by a discussion of the study's strengths and limitations as well as further recommendations for future research and plans for disseminating the findings. Lastly, a summary of its contribution to existing knowledge and understanding of CSII therapy in childhood will be given, in addition to some personal reflections on the process of completing this investigation.

### **6.2 Achieving the aims and objectives of the study**

The aim of this study was to use a hermeneutic phenomenological approach to gain a deeper understanding of the lived experiences of pre-adolescent children who use CSII therapy as a treatment for T1DM.

The research objectives were:

1. To capture the child's own voice and take seriously what they say.
2. To generate a holistic and interpretive description of the nature and range of children's lived experiences of insulin pump therapy and to uncover the meanings children ascribe to them.
3. To offer insights that help to inform the clinical practice of healthcare practitioners and which promote holistic and humanely sensitive care.

To my knowledge, the study presented here is unique. Firstly, it has focussed explicitly on the views of children aged 6 to 11 years. To date, previous research investigating subjective experiences of CSII therapy has largely neglected this particular age group. Instead, understanding of this topic has been based primarily on the views of teenagers/young adults and/or their parents. Secondly, this investigation has explored in detail the diverse and often paradoxical ways in which young children experience, understand and negotiate living with insulin pump therapy in the context of their everyday lives. The findings emphasise how this treatment, from a child's perspective, has both a positive and negative presence in their lives. As a consequence, its meaning is complex and nuanced. More specifically, they reveal the physical and psychosocial impact of insulin pump therapy by providing an insight into how it both disrupts and

transforms children's physical bodies, emotional well-being and identities as well as their relationships with others and opportunities for independence and agency. The technology was central in these experiences. In addition, they illustrate how children actively engaged in illness and identity work in order to incorporate their treatment into their bodies and everyday lives and how children's intergenerational relationships and social environments influenced these processes. This study, therefore, begins to address the gaps in current literature relating to CSII therapy and by so doing, enables a deeper and more holistic understanding of its existential impact for this particular age group.

The following section of this chapter considers how the third objective of this study has been achieved by exploring the implications of its findings.

### **6.3 Implications for practice and professional knowledge**

The notion of *the lived technological body* and the findings from this study that underpin it, has important implications for how professionals and parents approach, interact, communicate and involve children who use insulin pump therapy. The following discussion considers some of these and presents key recommendations for future practice.

1. The concept of *the lived technological body* is central to understanding the specific experiences of young children who use CSII therapy. It foregrounds the "messiness" of their bodies and its interconnections with their everyday world as well as the tensions, ambiguities and hard work that is involved in managing this. As such, clinicians are encouraged to understand this form of treatment as more than simply a biomedical experience. Instead, an approach to care that emphasises the "lived experience" perspective and a view of these particular children's condition as complex, relational and dynamic is recommended. This, in turn, could encourage the delivery of support and advice that is holistic, child-centred and empathic rather than a preoccupation with technological ways of thinking and measuring the biomedical effects of CSII therapy that currently dominates much of clinical practice. This could be operationalised by offering training and education to health professionals in order to enhance their understanding of the demands involved in living with this form of treatment for young children. The themes that characterise *the lived technological body* could act as a platform for these interventions as well as a framework for encouraging clinicians to develop and evaluate pump-specific support programmes for children and their families.

2. Conceptualising the bodies of children who use insulin pumps as active, points to the importance of promoting practices that not only engage with children's narratives about their own personal and social experiences of CSII therapy but which also acknowledges their competence as healthcare actors. This has implications for clinicians particularly in terms of how they communicate with these children, value the contribution they make to their own healthcare and work in partnership with them. However, developing partnership in healthcare inevitably involves an alteration in the power imbalance that has traditionally characterised paediatric medicine and is, therefore, ultimately dependent on clinicians relinquishing some of this. Moreover, ensuring effective communication requires a belief in the validity of young children's perspectives as well as providing them with real opportunities to express these views (Landsdown 1994). In this study, the findings revealed how children were not only keen to talk at length about their treatment but also demonstrated strong experiential understandings about their condition. In terms of clinical practice, therefore, it may be helpful for clinicians to openly encourage children to talk about their views and experiences of pump therapy and also to frame these discussions in terms of children's physical sensations, emotions, everyday activities and social relationships rather than focussing solely on the biological outcomes of CSII therapy. Implementing this may require structural changes such as ensuring enough time is available for consultations as well as clinicians developing skills in listening to children with respect and speaking with them in partnership.
  
3. The idea that *the lived technological body* is an entity that is simultaneously empowered and disempowered sheds light on the relational elements of children's agency when using insulin pump therapy and the ways in which this was dependent on different environments, issues of power and intergenerational relationships. These findings have particular implications for schools and how children's agency was controlled and restrained in this setting. Providing opportunities for children to exercise their agency and participate in managing their own healthcare can be challenging. Whilst this study showed that many of the children were competent and capable learners, the findings also revealed that they were on a learning journey and their abilities develop over time and with experience. However, it is through participation that children gain independence and confidence in managing their own treatment when away from their parents. This means providing them with

opportunities to practice coping with and solving pump-related challenges, as well as a serious commitment to respecting children and their right to participate in matters of importance to them. To facilitate this, clinicians could help children to develop sound decision-making skills by providing ongoing age-appropriate interventions that enhance their understanding of CSII therapy and use of the technology. In addition, PDSN's could work in collaboration with school nurses to provide regular support and skills training in CSII management to teaching staff. It may be helpful to include in this, discussions about what aspects of care young children can be appropriately involved in. This may improve teachers' confidence in children's ability to manage some aspects of their own treatment and thereby reduce the possibility of children being not only overly controlled and regulated but also excluded from activities. By so doing, the children themselves would have an additional space to experience and develop their independence and decision making skills. This, in turn, could increase their self-esteem and ultimately enhance treatment adherence. At a health policy level, although there has been a shift in understanding children as social actors, the findings of this study suggest that listening to children in institutional settings and promoting children's participation needs greater emphasis.

4. Understanding the *lived technological body* as an entity that children must get used to, suggests that clinicians should consider a child's adjustment to insulin pump therapy not simply as an outcome but as more of a gradual process that requires them to respond to repeated and ongoing challenges. As such, clinicians are encouraged to provide advice and support for these children that is thoughtful and timely and which takes into account the stage and duration of an individual child's treatment. In addition, children and their families could be offered the opportunity to learn about and be better prepared for the challenges that accompany the use of this particular treatment both prior to starting it and repeated at different developmental stages. The themes used in this study could be used to inform this and to develop coping strategy education tools that could be taught to children to help promote positive adjustment and better quality of life.
5. In this study, parents, siblings and close friends seemed to provide a crucial source of support for children. This finding argues for the importance of clinicians encouraging friends and family to both become and stay actively involved in a



child's treatment. This could involve providing them with education either individually or in groups, to develop their own understanding of insulin pump therapy and the valuable role that they play in helping children adjust to it. In addition, actively enquiring about children's social contexts may also be important, particularly for patients who might be finding the treatment difficult. If children's friendships are found to be fragile or limited, clinicians could initiate opportunities for them to meet with others of a similar age who are also using insulin pump therapy. These particular recommendations might enhance a child's sense of belonging and thus, greater satisfaction with their treatment.

6. The notion of *the lived technological body* as a site of difference, revealed the challenges that can be involved in maintaining a sense of normalcy when using CSII therapy as a young child. Children's accounts suggest that they could benefit from support and interventions that help them to develop self-esteem and a positive body image in order to prevent, reduce or cope with the potentially stigmatising effects of insulin pump therapy. In addition, clinicians could ensure that evaluation of a child's perception of self, coping behaviours, friendships and attitude towards their treatment is incorporated regularly into their clinical practice.
7. Children's descriptions of the disruption CSII therapy caused to their bodies physically in terms of pain and fear also have important clinical implications, not least because previous research has suggested that health care practitioners (especially physicians) frequently underestimate or overlook the presence of needle difficulties for children with diabetes generally (Simmons et al 2007). Specific to insulin pump therapy, children with a more intense fear of cannula changes may avoid changing them at the recommended frequency, causing higher blood glucose levels and thereby putting them at greater risk of long term health complications (Cemeroglu et al 2015). The varying degrees of pain and fear experienced by the children in this study suggest that an individualised rather than a blanket approach should be used by clinicians when supporting children with this aspect of their treatment. It has been suggested that a failure to manage early pain experiences may result in both physical and psychological changes that are both damaging and long lasting (Walco 2008). Therefore, assessment of a child's memories of earlier painful experiences may be particularly important for those children who experience more intense difficulties with cannula changes. It would also be beneficial to discuss the

reality of this procedure with children and their families prior to them commencing this treatment in ways that are honest and developmentally appropriate (von Baeyer et al 2004).

8. Lastly, the results of the study indicate a framework for a more complex view of medical technology that starts from the child's perspective and which understands the considerable influence that these devices may exert on their experiences of illness. It is envisaged that findings will be used to educate not only professionals and parents but also insulin pump companies about how insulin pump technology has the potential to both greatly enhance children's lives as well as it having negative meanings and implications. Children's experiences of pain, stigma, disrupted sleep and restricted physical activities have specific implications for those who are involved in the production and marketing of the technology. In particular, they suggest that children would benefit from advances in its design that enable all insulin pumps in the future to be not only waterproof but also smaller in size and more discreet. The production of devices that promote less painful cannula insertions would also be helpful. This will require discussions with technology designers to enhance their understanding of children's experiences specifically and a commitment from them to take their views seriously.

#### **6.4 Strengths and Limitations of the study**

##### *Strengths*

A particular strength of this study is its use of a qualitative methodology. Adopting this approach provided an opportunity for children to be engaged more meaningfully perhaps in research endeavour as a result of their own experiences being positioned at its centre. More specifically, the use of a methodology underpinned by hermeneutic phenomenology appeared to fit well with the aims of this investigation, particularly in terms of its ability to capture the complexity and ambiguity of children's experiences via descriptions of their ordinary, everyday lives (Finlay 2003). In addition, as discussed in Chapter 3, the philosophical orientation of phenomenology and its holistic, dynamic, contextual and individualised approach to human existence is increasingly being recognised as compatible with the worldview of nursing. Therefore, an additional strength of this investigation may lie in its relevance for nursing practice and the potential for findings to humanise the delivery of care (Galvin & Todres 2013).

### *Limitations*

As with all research, there are limitations to this study. As previously discussed, hermeneutic phenomenological research does not seek to find absolute truths or definitive answers to research questions. Instead, findings are recognised as tentative and at best, can only “provide an occasional glimpse of the meaning of human experience” (van Manen 2002:7). Moreover, these meanings are context bound and socially situated (Todres 2005). Therefore, for this study, conducted in two sites in South England with a small number of participants, its results will not *necessarily* be transferable to all other settings and the wider population of children using CSII therapy.

A further limitation is the fact that a phenomenological study is always only one interpretation. For this study, interpretations of children’s experiences are presented which were informed by their narratives as well as my own personal experiences of CSII therapy as a paediatric diabetes specialist nurse. Therefore, it is recognised that readers of this study and other researchers may have their own interpretations and will, as a result, highlight different experiences and meanings.

This study is also limited to some extent by the characteristics of the children who participated, as well as the particular sampling strategy that was employed. In relation to the former, the majority (10) of the participants were boys and all of the children were white British. In addition, at the time of the study, there were limited numbers of children using CSII therapy who were 5 years old. None of these children came forward to participate. It is possible, therefore, that children in this particular age group as well as those from other ethnic backgrounds could experience other issues as a result of developmental or cultural differences respectively. In addition, the “voices” of boys may be more prominent in the findings of this study than those of girls. Nevertheless, the aim of this study was to explore children’s experiences in depth, rather than studying contrasting cases and comparing results. Moreover, many of the experiences that children described were common to all of them. Where gender-related differences were apparent, this was made clear in the findings.

A particular criticism of purposive sampling techniques is that samples are biased because of the nature of the selection process (Bryman 2012). Thus, for this study, a specific group of children who had in depth knowledge about the research topic were deliberately sought out and invited to participate. Therefore, those who agreed to

participate were a selected group whose experiences may have been different to those who did not take part in the study. However, I would argue, that a purposive sampling was best suited for achieving the principles of adequacy and appropriateness. An unbiased, randomly selected sample would not have met these aims. Thus, as Morse (1991: 138) argues, bias was “used positively as a tool to facilitate the research”.

Many of these limitations are not just peculiar to phenomenological research. For example, small sample sizes are features of many qualitative research approaches and as such, are equally vulnerable to criticism. As such, I concur with Giorgi (2000) who argues that a researcher’s choice of method can never be wholly justified and that ultimately the limits of the chosen approach have to be accepted.

## **6.5 Suggestions for future research**

Since phenomenological research can only provide partial answers to any research question posed, there is much scope for further qualitative research to be conducted into how children experience insulin pump therapy. The concept of *the lived technological body* could perhaps be used as a useful heuristic for identifying specific aspects of children’s experiences that could be explored further. As discussed previously in Chapter 5, further research investigating experiences of pain, autonomy and identity management would be especially valuable. Findings from such work could build on and develop those identified in this investigation. Moreover, similar research could be conducted with other children who require the support of technologies that reflect those used in insulin pump therapy in terms of its visibility and frequency of use.

This present study concentrated on the experiences of children who were aged 6 - 11 years. Therefore, longitudinal research could usefully explore the experiences of both pre-school and secondary school age children in order to establish how experiences of pump therapy and coping strategies develop over time and according to different settings. In addition, studies investigating the experiences of school staff and the contribution that peers may play in helping children adjust to their treatment would also be informative. Similarities and differences in accounts would help to corroborate children’s reports and findings could generate deeper understanding of the strategies that children use to manage social interactions and construct and maintain their identities.

## 6.6 Dissemination of findings

Research is of limited use if findings are not communicated to others. Therefore, implementing a dissemination strategy that involves not only healthcare professionals, and other researchers but also the children themselves has been important. As such, throughout the course of the research, “work in progress” presentations have been given annually to peer researchers and practitioners at the Festival of Postgraduate Research, Brighton University. In addition, giving feedback to the children who took part in this study has been a priority. All of the children expressed an interest in learning about the results. As such, an information sheet that summarised the findings of the study (Appendix 12) has been sent to all of them. This highlighted the results that were thought to be of key interest to the children as well as my intentions to talk with clinicians about the accounts they gave of their experiences. I also hope that the findings will be used to inform the design and publication of an information leaflet for pre-adolescent children to help them prepare for insulin pump therapy properly as currently such material is very limited.

An important objective of this study was to promote greater understanding of children’s experiences of insulin pump therapy in order to encourage clinical practice that is both holistic and child centred. It is recognised that influencing practice at the coal face is inevitably context dependent. Clinicians may have entrenched ways of working, be deeply sceptical about qualitative research in particular and, as previously discussed, are caught up in an outcome driven practice environment with limited resources. Nevertheless, with increasing numbers of children using CSII therapy, this research is considered to be timely and as such may be more likely to be of interest to them. As such, I intend to present the study’s findings at national and regional paediatric diabetes conferences as well as at local multi-disciplinary meetings. Publication in peer reviewed practitioner journals, particularly *Diabetes Care for Children & Young People* and *Paediatric Nursing* is also planned.

It is hoped that by using this combination of strategies, the findings will be placed in the hands of those most directly affected by it, and as such, may better ensure that they are used to the benefit of the child and their family.

## **6.7 Summary of study's original contribution to knowledge**

This study makes an original contribution to clinical practice and knowledge by increasing awareness and generating new understanding of the ways in which pre-adolescent children experience and manage insulin pump therapy in their everyday life. More specifically, deeper awareness about how this treatment influences a child's physical body, their emotions, identities, sense of agency, social relationships and experiences at school have been described. I have also developed the new and original concept of *the lived technological body* as a tool to illustrate the complex ways in which CSII therapy alters children's bodies and minds and the ambiguities and hard work that result from this. This idea encourages a contextualised and holistic view of children's bodies and by so doing may help clinicians to understand the experience of CSII therapy in childhood in ways that are more nuanced and complex than previously available.

## **6.8 Personal reflections of the research process**

This final section of the thesis represents a summary of many reflections that were recorded in a research journal throughout the duration of the study. They relate in particular to my "positionality" and its impact on the research process. I also reflect on personal and professional development that has resulted from the research experience.

Smythe (2011:51) asserts that by choosing to adopt hermeneutic interpretive phenomenology to guide a research study "is to open oneself to a journey of thinking, where thoughts 'come' and knowing emerges". For a novice researcher, such as myself, undertaking this "journey of thinking" has been simultaneously daunting and exciting. It has involved unforeseen struggles, illuminating moments and learning to be "comfortable within the realms of uncertainty, ambiguity and mystery" (Welch 2004:206). Issues of power and the ambiguous nature of my role as both nurse and researcher were especially challenging. Both meant that I needed to constantly and deliberately examine and be alert to how my "positioning" was affecting the research process and its outcomes. Throughout the study, every effort was made to address the power inequalities between myself and the children. Nevertheless, it is possible that my "adulthood" (that is, my age and status as a clinician) could have restricted children's openness and engagement in the process as a result of, for example, shyness, embarrassment or perhaps a desire to please or to present themselves in a favourable light. However, in general, there was little evidence of this. Children were eager to

participate in the study and their accounts described both positive and negative experiences of their treatment. Therefore, it is possible, that they recognised themselves as experts in a topic that was of interest to someone typically in a more powerful position than themselves. As such, participating in the study might have been both an empowering and positive experience for them.

Many health researchers are also clinicians. Hay-Smith et al (2016) argue that dilemmas created by this dual role are common for practitioners who conduct research that involves patients as informants, even if the latter are not their own, as was the case in this study. They suggest that this is primarily experienced in situations where a clinician's "sense of clinical duty comes into apparent tension with ethics and methodological demands" (Hay-Smith et al 2016:2). As a result, role confusion and conflict can occur. In this study, my role as both a PDSN and researcher was both an advantage and disadvantage. Thus, my familiarity with the research topic equipped me with "cultural intuition and insight" (Berger 2013:5) that assisted the process of data collection and analysis. For example, pump therapy has its own distinct "language" and as such, is peppered with jargon and abbreviations such as "TBR", "carbs" and "square wave". Awareness of this enabled me to know not only what to ask and how to ask it but also, to understand and probe children's responses in a way that others without this knowledge might have missed. However, as previously highlighted, this "insider" position can simultaneously result in a researcher imposing their own biases and preconceptions onto the research, leading to a lack of critical distance and inability to "hear" other voices (Holloway & Galvin 2017). It was, therefore, necessary to constantly guard against this. For example, I was aware that I had an assumption (based primarily on my preparatory reading) that, despite the demanding nature of CSII therapy, children's descriptions of their experiences would probably be largely positive. I was surprised, therefore, when children talked about many negative aspects and found myself "honing in" on these. Consequently, when reflecting on my initial analysis, I found that I was being more critical of the treatment than the children were themselves. This realisation forced me to re-examine the original data and thus go on to present a more balanced account and as such, better reflect children's actual descriptions.

A further tension created by my dual role concerned issues related to role conflict. This was triggered in particular during my interview with Luke. Prior to embarking on the study, I had considered carefully the possibility that the interviews could provoke distress or strong feelings. However, I was unprepared for the intensity of Luke's

emotions and considerable dislike for his condition. His revelations evoked the temptation to slip into my role as a nurse in order to try and help him to feel better. I resisted this but left the interview with a strong sense of “unfinished business” and considerable angst about whether I had done the right thing. Although Luke made it clear during his interview that his parents were aware of his feelings, I wondered if I should have discussed these further with all of them after the conversation had finished. However, I was also mindful that Luke’s story was given in confidence and the idea of revoking this made me feel extremely uncomfortable. Moreover, he seemed to want to relate his story and did not appear distressed during the conversation. Congruent with the literature on this subject, it is possible, therefore, that the interview was therapeutic because it allowed him an opportunity to express his feelings and have them acknowledged in a way that had not been available to him before (Hay-Smith et al 2016). Nevertheless, I often think about this interview and wonder how Luke is managing now.

Since the aim of any study is the generation of knowledge, it is important to reflect also on what I have learned from the research experience. Overall, I have learned much. If I were to conduct the study again, I would want to adopt an approach that not only involved children as participants but which also allowed them to be actively engaged in all stages of the process, including its planning, data analysis and dissemination. This fully collaborative approach can be challenging and requires not only researcher experience and funding, but also substantial time investment to ensure children have the adequate training and support required to prepare them for their role (Shaw et al 2011). Nevertheless, it is being increasingly recognised as important, not least because it better ensures that researchers stay mindful of children’s perspectives throughout the process (Twycross & Smith 2017). Just as there are aspects of this study that I would do differently, so too are there some that I would recommend to other novice researchers conducting similar research. This includes in particular, a preparedness to personally attend clinics during the recruitment process. This invaluable advice was given to me by my academic supervisors and, although arduous and extremely tiring, greatly influenced the success of this part of the process.

Along with the suggestion that hermeneutic phenomenological research involves a “journey of thinking”, Smythe (2011:51) also argues that this approach can enable researchers to “re-connect with what it means to be human, and discover afresh what is already known, but perhaps forgotten, hidden or put aside”. For me, conducting this



study has generated a far deeper understanding about what it might mean to be a young child living with insulin pump therapy. Immersed in the complexities of everyday clinical practice, constrained by time and a focus on targets and outcomes, it can be all too easy to forget the intricacies and ambiguities that this treatment carries for the children themselves. The awareness and empathic knowledge that the findings have generated are already informing my clinical practice. Thus, I believe that I am more attuned now to children's experiences and by so doing, have become a better practitioner. Moreover, as I have come to understand others, I have learned much about myself and "inner world". I did not start out with knowledge of my relativist worldview or the extent to which this could influence the methodological choices made during the research process. Rather my starting point, (as for most practitioner/researchers no doubt), was a real life, practice based issue that needed answering. However, I now realise that as researchers, our values, assumptions and experiences saturate every part of the research process from the questions we ask, to the theoretical framework we select and to the research roles we adopt. As such, the kind of knowledge produced and how that knowledge is generated reveals something about who we are.

Finally then, I submit this report hoping that its findings expand traditional knowledge of CSII therapy in childhood in ways that may help practitioners deliver more holistic care whilst also knowing that "the discovery of meaning is never finished" (Gadamer 1985) and as such, there is still much to learn and understand about children's experiences of it.

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## Appendix 1: NHS Research Ethics Committee Approval Letter

**Study title:** Continuous subcutaneous insulin infusion therapy: an exploration of the lived experiences of children with Type 1 Diabetes mellitus aged 5-11 years.

**REC reference:** [REDACTED]

**IRAS project ID:** 140452

Thank you for your letter of 24 May 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, [REDACTED] [nrescommittee.eastofengland-essex@nhs.net](mailto:nrescommittee.eastofengland-essex@nhs.net).

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the **REC** in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The **REC** will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the **REC** may cause delay in obtaining permissions.

A Research Ethics Committee established by the Health Research Authority

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact [REDACTED] the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### Non-NHS sites

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper	[REDACTED]	17 March 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		04 March 2014

A Research Ethics Committee established by the Health Research Authority

Letter from sponsor		12 September 2013
Letters of invitation to participant [Parent Invitation letter]	2.0	10 May 2014
Other [CV of Nina Dunne]		12 March 2014
Other [Distress Protocol]	1.0	10 March 2014
Other [GCP completion of Informed Consent in Paediatric Research for Nina Dunne]		23 May 2014
Other [CV of Dr Kay Aranda]		14 March 2014
Other [Nina Dunne - GCP certificate of completion]		20 May 2014
Other [Interview Guide]	1.0	10 March 2014
Participant consent form [Assent form - 5 to 11 years]	1.0	10 March 2014
Participant consent form [Parents]	2.0	10 May 2014
Participant information sheet (PIS) [5 to 7 years]	2.0	10 May 2014
Participant information sheet (PIS) [8 to 11 years]	2.0	10 May 2014
Participant information sheet (PIS) [Parent]	2.0	10 May 2014
REC Application Form	140452/580615/1/611	19 March 2014
Research protocol or project proposal	1.0	10 March 2014
Response to Request for Further Information [By letter/email from ]		24 May 2014
Summary CV for Chief Investigator (CI)		17 March 2014

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

##### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely  
PP



Chair

Email: [nrescommittee.eastofengland-essex@nhs.net](mailto:nrescommittee.eastofengland-essex@nhs.net)

*Enclosures:* "After ethical review – guidance for researchers" [SL-AR2]

*Copy to:*



## Appendix 2: Research & Development Department Approval Letter (Site 1)

Ms Caroline Spence

Dear Ms Spence,

Re: **Final [REDACTED] Research Department Approval Confirmation**

Title: **Continuous subcutaneous insulin infusion therapy: an exploration of the lived experiences of children with Type 1 Diabetes mellitus aged 5 - 11 years.**

R & D Ref. No: **2014-STU-01** Ethics Ref. No: **14/EE/0166**

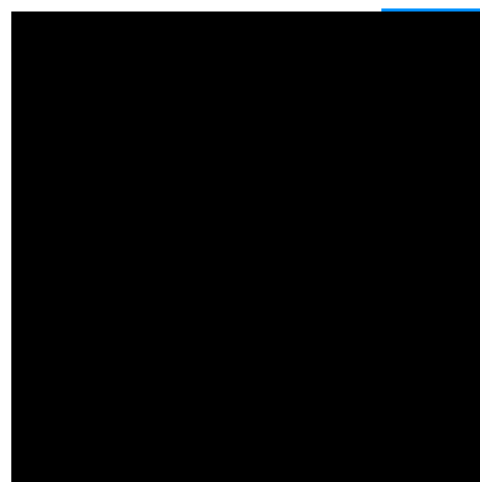
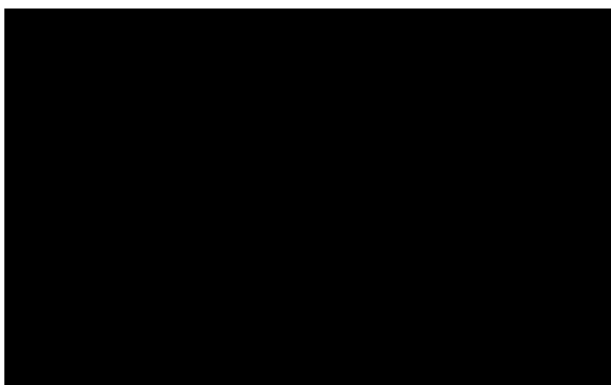
Thank you for completing the R&D Approval procedure for the above study. This letter confirms that this research proposal has approval to commence at [REDACTED] Foundation Trust.

The conditions of this trust approval require you as Principal Investigator to ensure the following:

- You have returned a signed '**Principal Investigator Agreement**' outlining your responsibilities in the conduct of this research study before you commence.
- You and your research staff are required to be aware of and adhere to responsibilities, as detailed in the protocol and Clinical Trial Agreement, as well as comply in full with ICH / Good Clinical Practice, UK Law, DH Research Governance Framework (2005), Data Protection Act (1998), Freedom of Information Act (2000) and current EU Legislation – please see the references listed below.
- All serious adverse events should be reported to the Sponsor in accordance with the protocol and copied to R&D within 7 days of becoming aware of the event. The Trust Incident Reporting System should also be used if applicable.
- All recruitment to this study must be recorded on E-DGE, a web-based Clinical Research Management System. Please contact R&D for registration details.
- All research team members involved in the study have attended Good Clinical Practice (GCP) training within the last 2 years.

Please note that this Trust approval only applies to the versions of documents listed below. Any changes to the protocol can only be initiated following further approval from the Ethics Committee via a protocol amendment. The Research Department must also be notified of any changes to the study or the documents below.

### Appendix 3: Research & Development Department Approval Letter (Site 2)



Dear Caroline

**Full Study Title:** Continuous subcutaneous insulin infusion therapy: an exploration of the lived experiences of children with Type 1 Diabetes mellitus aged 5-11 years.  
**IRAS No. :** 140452  
**REC Ref:** 14/EE/0166

I am writing to inform you that you have Trust approval to proceed with the above named project. This letter acknowledges that you have all the necessary internal and external regulatory approvals. Details of your research project and any associated supporting documentation will be stored on an electronic database administered by the R&D Department. The sites covered by this approval include:



The documents reviewed for this approval were:

Document	Version	Date
Letters of invitation to participant [Parent Invitation letter]	2.0	10 May 2014
Other [Distress Protocol]	1.0	10 March 2014
Other [Interview Guide]	1.0	10 March 2014
Participant consent form [Assent form - 5 to 11 years]	1.0	10 March 2014
Participant consent form [Parents]	2.0	10 May 2014
Participant information sheet (PIS) [5 to 7 years]	2.0	10 May 2014
Participant information sheet (PIS) [8 to 11 years]	2.0	10 May 2014
Participant information sheet (PIS) [Parent]	2.0	10 May 2014
REC Application Form	140452/580615/1/6 11	19 March 2014
Research protocol or project proposal	1.0	10 March 2014
Response to Request for Further Information [By letter/email from ]		
SSI 140452/624461/14/650		

**Conditions of Approval**

The approval covers the period stated in the Research Ethics Committee (REC) application and will be extended in line with any amendments agreed by the REC. Research must commence within 12 months of the issue date of this letter. Any delay beyond this may require a new review of the project resources.

#### **Amendments**

Project amendment details dated after the issue of this approval letter should be emailed to the R&D Office for formal approval at [REDACTED]

#### **ICH-GCP Monitoring**

The Trust has a duty to ensure that all research is conducted in accordance with the Research Governance Framework and to ICH-GCP standards. In order to ensure compliance the Trust undertakes random audits. If your project is selected you will be given 4 weeks notice to prepare all documentation for inspection.

#### **Pathology Services at [REDACTED]**

If you will be using the pathology services at [REDACTED] to analyse samples for research purposes only (i.e. not taken to inform standard clinical care), these samples must be booked in for processing by the CIRU laboratory assistants. Please call [REDACTED] for advice.

#### **Imaging services at [REDACTED]**

If research participants will undergo imaging investigations that are additional to standard care you are reminded that referrals should be clearly identified with a research sticker. For further advice please contact [REDACTED]

I wish you luck with your project and would be grateful if you could inform me when the project is complete, or due to be closed on this site.

Yours sincerely



Head of Research & Development

## Appendix 4: Participant information sheet (5-7 yrs)



### A study about Young Children's Experiences of Insulin Pump Therapy

#### INFORMATION SHEET FOR CHILDREN AGED 5 - 7 YEARS

This information is intended to be given to and/ or read to the child by their parent or person who looks after him or her.



#### Would you like to take part in a Study?

Hello! My name is Caroline. I am a nurse and I work with children who have diabetes. This is my photo!



I am trying to learn about what it is like for children who use insulin pumps every day to treat their diabetes. I plan to listen to what children have to say about this and to then write a report about what they think.

#### Why have I been asked to take part?

I am asking you to be part of the study because you are using an insulin pump so you can tell me what it is really like to live with it.

Take time to decide if you would like to take part. Think about it and talk with your parents or the person who looks after you. Taking part will not change your treatment in any way.

#### What will happen to me if I Take part?



If you agree, I will come to your home to talk with you for between half an hour and an hour. You could do some drawing while we talk if you want to.

I would like to talk to you on your own, but you can have someone with you if you want. I would also like to record what you say. No one else will hear these recordings and they will be destroyed once they are typed up.

#### Why is the study being done?

I hope that the study will help doctors and nurses look after children using insulin pumps better in the future.

[Original in colour]



### Is it private?

Your diabetes Doctor and Nurse in the clinic will know about the study and your parents or the person who looks after you will know you are taking part. I will not tell anyone that you are taking part, or anything else about you. Whatever you say to me is private. The only time I might have to break this promise is if you say you or someone else is being hurt. If so, I would talk with you first about the best thing to do.



Everything that I learn from the study will be kept in a safe place. I may show parts of the report to 2 other people who are helping me with the study. When I write about what everyone has told me I will not use your real name. I will give you a pretend one.

### Do I Have to Take Part? What if I change my mind?

No, it's up to you. Just say if you don't want to carry on. Nobody will mind. Even if you say "yes", you can stop at any time. You don't have to say why you want to stop. If you don't want to answer a question, just say "pass". You don't have to tell me anything unless you want to.

If you agree to take part in the study, I will ask you to write your name on a special form called an "assent form". This is to say you understand the study and what will happen to you. I will give you a copy of this form to keep as well as this sheet.

### What if I there is a problem?

I hope you will enjoy talking with me. A few people may get upset when talking about their lives and if they want to stop, we stop. I can put them in touch with someone to help, if they wish.

If you are unhappy about anything you can talk to me and I will do my best to answer your questions. If you continue to feel unhappy or wish to complain, you can talk to your parents or the person who looks after you about how to do this.

### Any Questions?



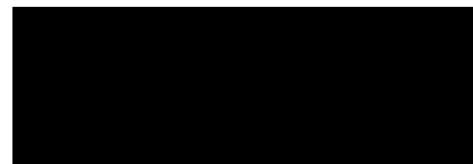
If you have any more questions or would like to know more, you, or your parents, or the person who looks after you can call me on [REDACTED] or you can use a computer to e-mail me at [REDACTED]. If you would like to speak to someone else or are worried about the study, you can ask your parent or the person who looks after you how to do this.

**What happens next?** If you agree, I will ring you at your home to see if you want to take part. If you do, I will arrange a time that suits you to come and talk with you. Remember, you don't have to take part if you don't want to.

**THANK YOU FOR READING THIS.**

[Original in colour]

## Appendix 5: Participant Information sheet (8-11yrs)



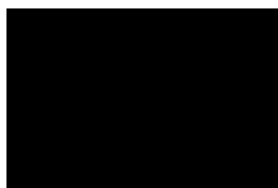
### A study about Young Children's Experiences of Insulin Pump Therapy

#### INFORMATION SHEET FOR CHILDREN AGED 8 - 11 YEARS



#### Would you like to take part in a Study?

Hello! My name is Caroline. I am a nurse and I work with children who have diabetes. This is my picture!



I am doing a study about children who use insulin pumps to treat their diabetes. I am interested in learning about what it is like for children to use an insulin pump every day. I plan to listen to what children have to say about this and to then write a report about their views.

Before you decide to take part it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully. Talk about it with your parents or the person who looks after you if you want to.

#### Why is the study being done?

I hope that the study will help doctors and nurses to understand more about what it is like for children using insulin pumps to treat their diabetes. This may help us to provide better care to children in the future.

#### Why have I been chosen?

You have been asked because you are using an insulin pump so you can tell me what it is really like to use and live with it every day. In total I hope 8 – 10 children will take part.

[Original in colour]



### What will I have to do?

If you agree to take part, I will arrange to meet with you at your house where I will talk with you for between 30 minutes and an hour. I would like to talk to you on your own, but you can have someone with you if you want. If you agree, the conversation will be recorded. No one else will listen to the recording and it will be destroyed once it has been typed up.

### Do I have to take part?

No, it is up to you. You do not have to. If you would like to take part and then change your mind that is OK. Nobody will mind. Whether you take part in the study or not, you will still go on having the same care at your clinic.

If you agree to take part in the study, I will ask you to write your name on a form called an 'assent form'. This is to say you understand the study and what will happen. You will be given your own copy of this form to keep as well as this information sheet.

### What if there is a problem?

When we talk, I may ask about how having a pump has affected your life. It may be that thinking about these things might upset you. If that happens, we can talk about something else or we can stop altogether. It will be your choice. You do not have to talk about anything that you do not want to. If you don't want to answer a question, just say "pass". If you continue to feel unhappy, I can put you in touch with someone to help, if you wish.

### Will my answers be kept private?

Your diabetes Doctor and Nurse know about the study and your parents or the person who looks after you will know you are taking part. What you say to me at our meeting is private. But if you tell me that you or someone else is in danger of serious harm I would need to talk to someone about this who might be able to help. I would talk with you first about the best thing to do.



Everything I learn about the study will be kept in a safe locked place. I may show parts of the report to 2 other people who are helping me with the study. When I write the report I will not use your real name so no one will be able to tell who you are. I will give you a pretend one.

### What happens when the study stops?



The results of the study will be written in a report. I hope the report will be put into magazines that doctors and nurses read. If you like, I can send you a copy of the report.

[Original in colour]

**What will happen next?**

I will phone you at your home in the next week to see if you would like to take part. If you agree, I will arrange a time to come and talk with you. If you do not want to take part, that is OK - it is your choice.



**Who can I speak to if I have more questions?**

If you have any questions or would like to know more, you or your parents or the person who looks after you can speak to me: [REDACTED]

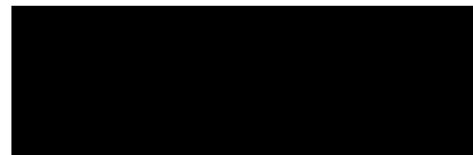
[REDACTED]

I am studying at the University of Brighton. If you have any problems about the study and you would like to talk with someone else, you can contact [REDACTED]

[REDACTED]

**THANK YOU FOR READING THIS.**

[Original in colour]



**A study about Young Children’s Experiences of Insulin Pump Therapy**

**INFORMATION SHEET FOR PARENTS**

**Invitation**

I would like to invite you and your child to take part in a research study. Before you decide, it is important for you and your child to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your son or daughter and others if you wish to. Take time to decide whether you would like your child to take part. Please ask if there is anything that is not clear.

**Part 1** tells you the purpose of the study and what will happen if you take part

**Part 2** gives you more detailed information about the conduct of the study

\*\*\*\*\*

**PART 1**

**What is the purpose of the study?**

Research has shown that using insulin pump therapy can bring many benefits but that it can also be demanding because of the extra care and attention required. However, as yet little is known about what school age children think of this form of treatment from their own perspective. Therefore, I am interested in finding out about children’s experiences and views of pump therapy and how this treatment affects their daily lives. I hope that if we have more information and greater understanding about this it will help health care professionals to give better and more informed care to children who use pump therapy in the future.

**Why has my child been chosen?**

Your child has been chosen to participate because they are aged 5 -11 years and are using insulin pump therapy as treatment for their Type 1 Diabetes. In total, I hope to have 8 – 10 children participate.

**Does my child have to take part?**

Your child is under no obligation to take part in the study and they can withdraw at any time without giving any explanation. A decision to withdraw at any time, or a decision not to take part, will not affect their medical care or legal rights.

### **What will happen if they take part?**

Should you and your child agree to participate in the study, I will arrange a convenient time and place to come and talk with your son or daughter. The interview will take place only once. I will ask you and your child to sign a consent form to say that you are happy to be involved in the research. I will then ask your son or daughter some questions about their experiences of pump therapy in their everyday life, such as what it is like using it at school and who helps them with their treatment routine. They may like to do some drawing during the conversation and I may use some spidergrams to help with parts of the discussion about who helps them with their treatment.

As I am interested in understanding your child's own experience of pump therapy, it would be most helpful to interview them by themselves, without your presence in the room. However, if they would prefer someone to stay with them, this will be okay. It is expected that the interview will last up to an hour. The interview will be audio recorded and later transcribed word for word. After it has been typed up, the audio recording will be destroyed. No identifying information such as your child's name will be included on the transcription.

### **What are the possible risks of taking part?**

There are no known risks to taking part in the study. However, in the interview I may ask your child some questions about how they feel their insulin pump therapy has affected their life. It may be that thinking about this upsets them. If this happens, the interview can be stopped if they wish. I will have a written procedure to follow to help me recognise when children might be getting upset and what to do should this happen.

If your child would like to talk more about any concerns they have, contact numbers or a referral to people who can offer appropriate additional support can be given to you.

### **What are the benefits of taking part?**

Many children enjoy the opportunity to give their views and talk about their experiences. By taking part in the study, their participation will help us to gain a better understanding of what it means for school aged children to use this form of treatment. It is hoped that such information can help us to have a better understanding of children's needs and therefore help us to provide a better service for those using insulin pump therapy in the future.

## **PART 2**

### **What happens if my child doesn't want to carry on?**

You and your child are free to stop taking part in the study at any time without giving a reason.

### **What if there is a problem?**

If you have a concern about any aspect of this study or want to complain, you can speak to me, Caroline Spence, and I will do my best to answer your questions. If you remain

unhappy and wish to complain formally, you can do this through the Patient Advice and Liaison Service (PALS). You can contact them on [REDACTED] or [REDACTED]. If PALS are unable to help you, you can make a formal complaint by writing to the Chief Executive, [REDACTED].

### **Will taking part be confidential?**

All information which is collected will be kept strictly confidential. No personal information from the interview will be disclosed to anyone unless your child reveals something that may indicate they might harm themselves or the researcher is worried that someone else might be harming them. If this happens, the researcher may have to talk to other professionals about these issues.

All information about the study will be stored in a locked filing cabinet. I may show parts of your child's transcript to my academic supervisors who will be helping me with my study. Your child's name, personal details or any other information that could identify them will not be used in any transcripts or any reports arising from the study.

### **What will happen to the study results?**

The results of the study will be written up by the researcher as part of her nursing doctorate. A copy will be kept in the University of Brighton library. Also, it is hoped that the research will be submitted for publication in professional journals and the results presented at national conferences for other health care professionals involved in the care of children with diabetes. A summary of the findings will also be sent to school nurses. I may use quotes from your child's interview when writing up the research to illustrate the findings. If this is done, any identifiable information will be removed.

All children who take part in the study will be sent a newsletter giving them a summary of the study's results.

### **Who is organising the study?**

This study is being done as part of a professional doctorate qualification in Nursing and is being supervised by the University of Brighton.

### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the East of England - Essex research ethics committee.

### **Contacts for Further Information:**

If you have any questions please do not hesitate to contact me:

[REDACTED]

[REDACTED]

[REDACTED]

I am studying at Brighton University. If you have any concerns about the study and would like to speak to someone else you can contact [REDACTED]

[REDACTED]

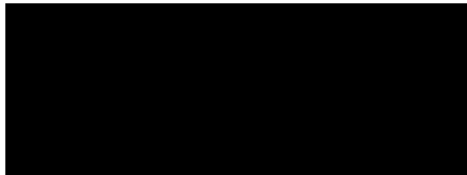
[REDACTED]

**This information sheet is for you to keep. You will also be given a copy of your child's consent form to keep.**

**THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION LEAFLET.**



**Appendix 7: Consent Form for Parents**



**A study about Young Children’s Experiences of Insulin Pump Therapy**

Consent Form for Parents

**Participant Identification Number:**

**Project Title:** Young children’s experiences of insulin pump therapy

**Name of Researcher:** 

**Please initial box**

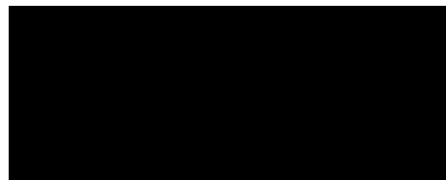
1. I confirm that I have read and understand the information sheet dated 10<sup>th</sup> May 2014 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my child’s participation is voluntary and that they are free to withdraw at any time without giving any reason and without their medical care or legal rights being affected.
3. I understand that the interview with my child will be audio taped. I understand that when a report is written about the study, quotes from my child’s interview may be used but all identifying information will be removed.
4. I am aware that my child may be referred to appropriate support services if required.
5. I agree that my child can take part in the above study.

Name of Patient	Date	Signature

Name of Parent/Legal Guardian	Date	Signature

Researcher	Date	Signature

## Appendix 8: Assent form for children



### A study about Young Children's Experiences of Insulin Pump Therapy

Assent Form for Children Aged 5-11 years  
(To be completed by the child and their parent/guardian)

#### Participant Identification Number:

**Project Title:** Young children's experiences of insulin pump therapy

Child (or if unable, parent on their behalf) to circle all they agree with:      Please circle

Have you read (or had read to you) information about this study?      Yes/ No

Has somebody else explained this study to you?      Yes / No

Do you understand what this study is about?      Yes / No

Have you asked all the questions you want?      Yes / No

Have you had your questions answered in the way you understand?      Yes / No

Do you understand it's OK to stop taking part at any time?      Yes / No

Are you happy to take part?      Yes / No

If any answers are "no" or you don't want to take part, please **don't** sign your name!

If you do want to take part, please write your name and today's date:

Your name (or special mark)

\_\_\_\_\_

Date \_\_\_\_\_

Your parent or guardian must write their name here too if they are happy for you to do the study:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of parent or guardian or carer

Signature

Date (dd-mm-yyyy)

The Nurse who explained this study to you also needs to sign:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

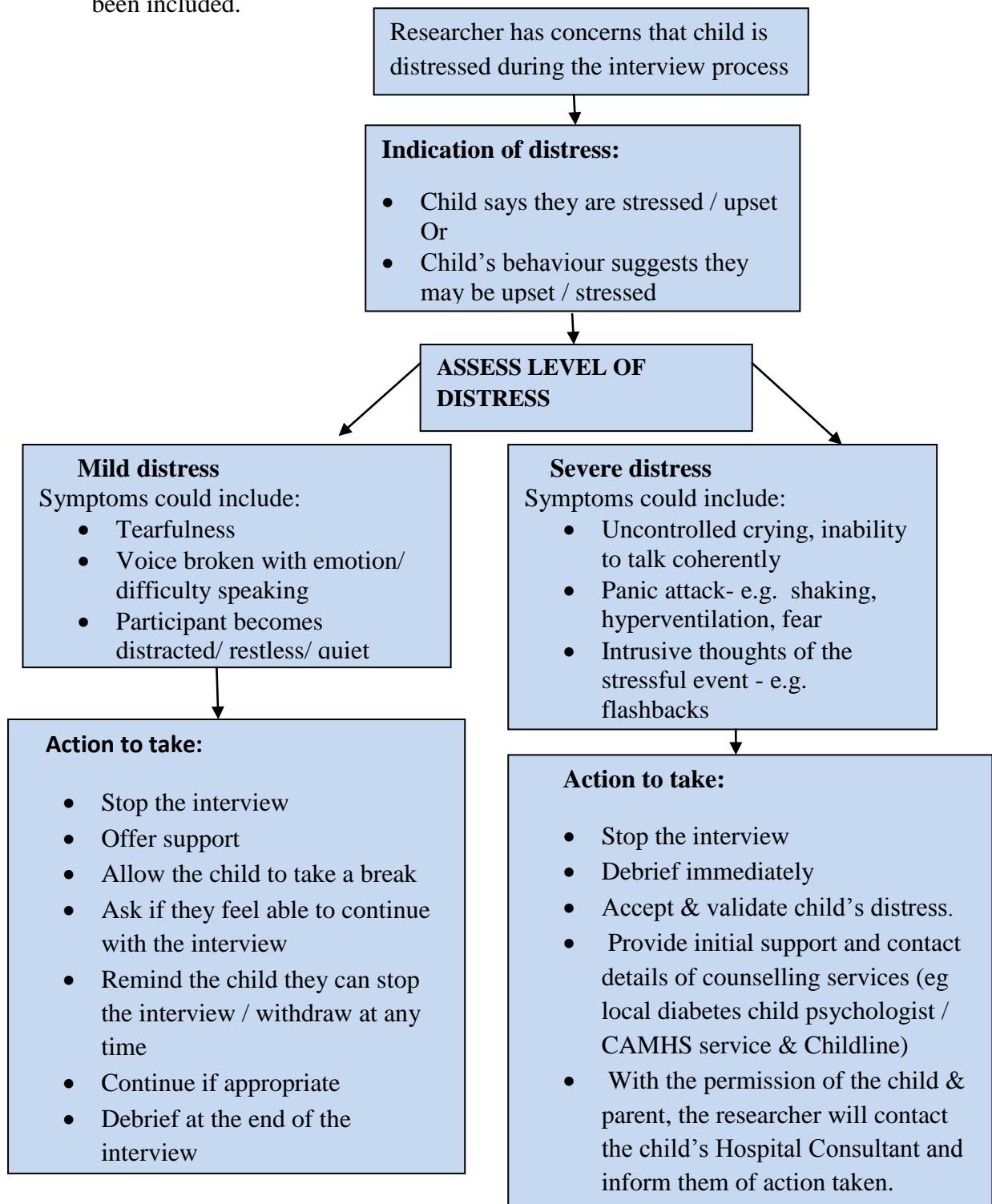
Researcher

Signature

Date (dd-mm-yyyy)

## Appendix 9: Distress Protocol

The following flow chart will be used to guide the researcher's response should a child exhibit emotional distress during the course of the interview. This tool outlines the potential signs of distress that the researcher will look out for and the appropriate action that will be taken depending on the level of the child's distress. For the purpose of this study, distress is defined as an emotional response over and above what would normally be expected when discussing a sensitive issue (Draucker et al 2009). It is not expected that extreme distress will occur or that the relevant action will become necessary. However, in the unlikely event that this does happen, management of this situation has been included.



## Appendix 10: Parent Invitation letter







### A study about Young Children's Experiences of Insulin Pump Therapy

#### INVITATION LETTER FOR PARENTS

Date:

Dear.....

, a children's diabetes specialist nurse, is conducting a research study about children's experiences of insulin pump therapy. The study is being done as part of a professional doctorate qualification and is supervised by the . It has been reviewed and given a favourable opinion by the   


We would like to invite your child to take part in the study. The study is about insulin pump therapy and the impact this form of treatment may have on children's day to day lives. We are asking your child to participate because they are aged between 5 and 11 years old and because they are currently using pump therapy to manage their diabetes. With your child's help, we would like to find out more about how young children experience, respond to and incorporate insulin pump therapy into their everyday lives. It is hoped that the research will provide better understanding of the issues involved and from this enable better and more informed care and advice for children using pump therapy in the future.

The study involves each child completing a single interview at home that will last between 30 minutes to an hour, depending on their age and how much they wish to say. The interview will be audio recorded and the recording will be destroyed after it has been typed up. Questions will be asked about your child's day to day experiences of pump therapy, including how it affects their life at home, in school and in their relationships with others. As we are interested in gaining your child's own experience, it would be most helpful to interview them on their own, without your presence in the room. However, if they would prefer you to stay with them, this will be okay. It is expected that this will be a positive experience for children, as many enjoy having the opportunity to voice their own personal views.

We have enclosed an information sheet about the study for you to read and discuss with your child. Please also feel free to contact [REDACTED] to discuss any questions you may have. Contact details for her can be found at the end of the information sheets.

Your child is not obliged to take part in the study and if they do not want to it will not affect the standard of care they receive. However, if you think that your child might like to take part and you would be happy for them to do this, please discuss this with us at your next diabetes outpatient appointment. More information will be available at this clinic and there will be the opportunity to discuss the study further with [REDACTED] should you wish.

Thank you for your time.

Consultant Paediatrician  
Specialist

Children's Diabetes Nurse

## Appendix 11: Interview Guide

### Pre amble:

- Introduce myself. Explain purpose of interview and its structure / why it is being done.
- Reaffirm assent. Rehearse how to say “pass” and when to hold up a red card.
- Provide paper, coloured pens / crayons if children would like to draw whilst talking.
- Confidentiality – all answers will be kept confidential. Your name will be changed so that you cannot be recognised from the answers you give when the study is written up. Your diabetes doctor will know that you are taking part in the study but your answers will not be discussed with anyone other than my university supervisors who are helping me with the study. Confidentiality will only be broken if I am worried that you or someone you know is at risk of being harmed.

*So that I can get to know you a bit more, can you tell me a bit about yourself and your family? Is that OK?*

- Who is in your family?
- What kinds of things do you like doing? Favourite TV programmes / films / music?
- What have you done today? How do you spend your spare time?

*1. Thank you. Next I would like to ask you about your general views about having diabetes. Is that OK?*

- Thinking about your diabetes, how do you feel about it?
- What is it like to have diabetes? How does it affect you?
- Are there any good things about having diabetes?
- Are there any not so good things about having diabetes?
- Is there anything else important about having diabetes that you would like to say?

*2. Thank you. Next, I would like to ask you more particular questions about what it is like for you living with your insulin pump. Is that OK?*

- Let's go back to when you first started your pump treatment. Can you tell me what it was like? What happened? Who did you tell? What did they say?

- What is it like using your pump now? What do you think and feel about it now?
- How does it affect you? (eg eating, sleeping, playing, exercise, hobbies)
- Are there any good things about your treatment? (use spidergrams / props)
- Are there any not so good things about it? Why? How do you manage the hard things? (use spidergrams / props)
- Does your treatment help / stop you from doing things? If so, why? How do you manage?
- Who helps you with your treatment at home? How do they help? Would you like this to be different? If so, in what ways? (use spidergrams)
- Do you ever have a sleep over / stay for tea with a friend / stay with your grandparents / go to parties? What happens with your pump then?
- Everyone is partly different. Are there ways that you feel different from your friends /siblings? How does that make you feel? (use spidergram)

**3. Thank you. We have talked a bit about what it's like for you living with your pump generally and at home. Now I would be really interested in finding out what it is like for you when you are at school. Is that OK?**

- Thinking about school, what is it like wearing your pump there?
- What happens at break times / when you do PE / go on school outings or residential trips?
- Who do you tell about your treatment? What do you say? What do they say? What happened when you told them? How did that make you feel?
- Who do you not tell? Why? How does that make you feel?
- Who helps you at school with your treatment? Is this help ok? Would you like anything to be done differently? (use spidergram)
- Has anything changed at school since you started to use your pump? How come? How does that make you feel?
- Do you ever have any problems with your pump at school? If so, what happens? How do you fix them?

**4. Thank you. Finally, can I ask you some more general questions about pump treatment? Is that ok?**

- What do you think life would be like without a pump?
- What has been helpful in getting used to your treatment? What has not been helpful? Why? Is there any other support that you would like?

- With your experience in mind, if someone like you started on a pump and asked you what it was like, what would you say? What advice would you give them?
- If you could, is there anything you would like to change about your pump treatment? The pump itself?
- Pretend to be your teacher / best friend / parent / brother / sister! Think about one message you would like to tell them about your pump. Would you write it down and tell me about it?
- Thinking about the future, what are your aims? Hopes? Worries?

### *Closure*

- Is there anything else important or that you think I should know to help me understand your experiences of living with an insulin pump better?
- Is there anything you would like to ask me? Would you like a copy of the research findings?

**Thank you for talking with me. Is there anything you would like to ask me?**



## Appendix 12: Summary of research findings for children

### YOUNG CHILDREN'S EXPERIENCES OF INSULIN PUMP THERAPY

#### SUMMARY OF STUDY FINDINGS FOR CHILDREN

- **What was the study about and why was it done?**

The study was about children who use insulin pumps to treat their diabetes. I wanted particularly to get children's views about their treatment and to understand what it is like for them to use an insulin pump every day.

- **Who did I speak to?**

In total, I spoke with 15 boys and girls who were between 6 and 11 years old. I listened to what you had to say and have written a report about your views.

- **What I found**

I found lots of interesting things - this is just a short outline of the main things that you said.

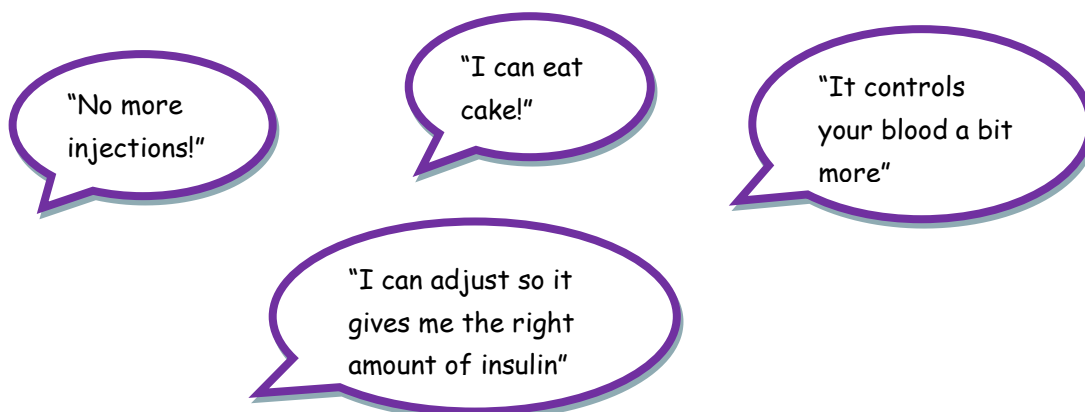
Most children like using an insulin pump to treat their diabetes, even though it can be difficult at times.

A few children did not like it. This may be because they have not been using the pump for very long or because having diabetes is especially difficult for them.

It takes time and lots of practice to get used to everything.

- **The best things about your treatment**

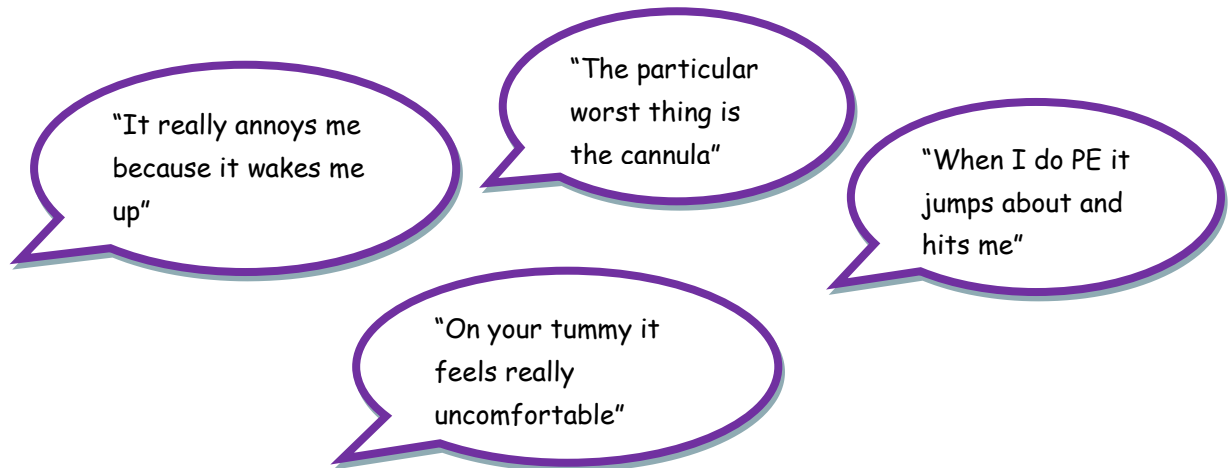
You do not have to have so many injections. You can also eat more of your favourite foods and control your blood sugar levels better. Here are some of the things you said you liked:



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- **The things you do not like about your treatment**

Cannulas are painful, especially if they are put into your tummy. Sometimes, giving insulin through the pump hurts too. You can't swim for very long if your pump is not waterproof and you have to be careful about the cannula and pump if you dance or play football. The pump alarms and wakes you up at night and you can't go to sleepovers at your friend's house. This is annoying for you. Here are some of the things you said:



- **Being at school**

You like going to school and seeing your friends.

Teachers help you with your treatment and watch you when you need to use your pump. Explaining to teachers how the pump works can be annoying. Some of you would like to be able to take more control of your own care when you are at school.

Children in your class notice the pump and ask you lots of questions about it, especially when you first start your treatment and when you are changing for PE. This can be annoying. It is also embarrassing when the pump alarms in class. Sometimes you miss your break-time or have to hurry to get things done so you can sit with your friends at lunchtime. Going away on school trips on your own is difficult and can make you feel sad when you can't go.

- **The importance of friends**

Most children feel the same as their friends. A few children feel different and this makes them careful about who they talk to about their treatment.

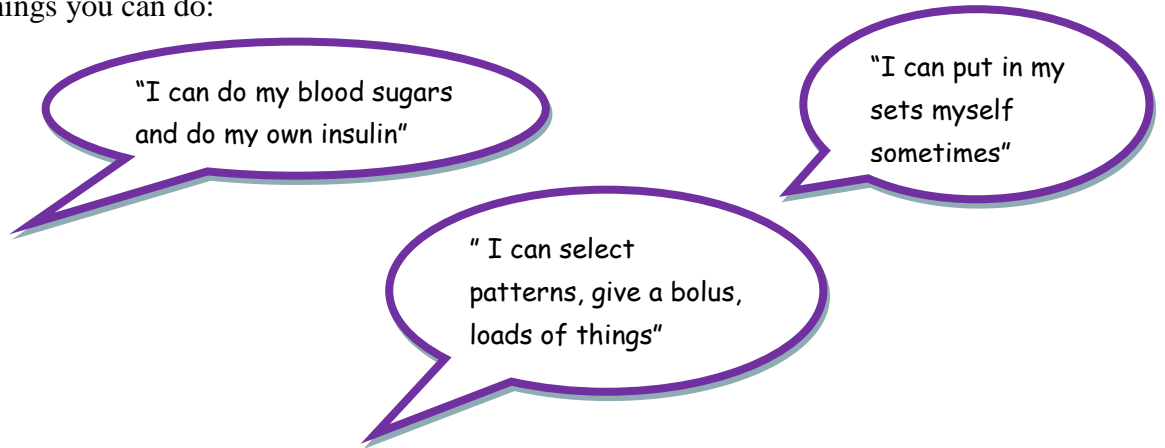


Close friends are important for helping you feel ok about your treatment. They understand you, sit with you at break-times and treat you the same as everyone else.

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- **It's hard work**

Using an insulin pump everyday is hard work. You have to think about and do lots of things all the time. You are good at looking after yourself and are experts at using the insulin pump. There are loads of things you can do on your own. Here are some of the things you can do:



- **What happens next?**

I plan to talk to doctors and nurses about what I found. I hope this will help them to understand more about what it is like for children to use an insulin pump. This may help us to give better care to children in the future.

- **Any questions?**

If you have any questions or would like to know more, you or your parents, or the person who looks after you can speak to me: [REDACTED]

**THANKYOU VERY MUCH TO EVERYONE WHO TOOK PART IN THE STUDY**

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