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University of Southampton

Faculty of Environmental & Life Sciences

School of Health Sciences

**The factors that support people living with Type 1 diabetes to incorporate an
insulin pump into their everyday lives**

by

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Thesis for the degree of Doctor of Philosophy

September 2019

University of Southampton

Abstract

Good self-management (SM) of Type 1 diabetes (T1D) has the potential to avoid or delay life-threatening and life-limiting complications and improve quality of life, yet is characterised by a demanding, multi-component regimen. The use of insulin pump therapy is growing internationally and has been posited as a way to support better SM of T1D. However, as a complex new technology unique challenges are faced, including complicated requirements for troubleshooting, incorporation and adaptation and carrying an object on the body 24/7. Providing people with SM support to incorporate this technology could improve the lives of people with T1D. However, the dominating biomedical approach to treatment of T1D and incorporation of insulin pump therapy is not enabling appropriate SM. In response, this thesis explores the SM needs of this population and tests a new approach to SM support which is sensitised to a social network approach, underpinned by Social Cognitive Theory. This approach could enable people with T1D to self-manage better and reduce challenges of introducing and living with an insulin pump by examining interactions with wider personal social networks and utilising these personal networks to support SM.

Three papers make up the core of this thesis. The first describes a Critical Interpretive Synthesis (CIS), which examined what is known about the lived experience of insulin pump therapy. The second paper describes focus groups with insulin pump users and healthcare professionals (HCP), examining problems and challenges to SM using insulin pumps and the potential of a social network intervention to support SM. The third paper describes the implementation of a social network intervention (named GENIE) with people initiating insulin pump therapy over 6 months using qualitative semi-structured interviews, questionnaires and intervention outputs (number, frequency of contact and value of network members and uptake of new activities), and was analysed using thematic analysis.

Three themes were identified from the CIS which revealed and enlightened the complex process of incorporation of an insulin pump: there were evidently tensions between expectations and experiences in adoption and early adaptation of the device; and a need for negotiation of responsibility and accessing support; and a process of reflexivity, active experimentation and feedback. The focus groups identified key SM needs during incorporation of pump therapy and described the necessary contents of an intervention to support SM with pump therapy and strategies for implementation. Four themes of importance were ascertained: a need for access to tailored and appropriate resources and information; specific social-support preferences; capacity and knowledge of pump clinic HCPs; professional responsibility: "risks and dangers". The third paper captured the process of adjustment and incorporation of the device over time. Key themes included: The independent nature of managing diabetes; overcoming the challenges and illness-burden of pump therapy; the need for responsive and tailored emotional and practical support, and; useful resources when incorporating a pump. GENIE was thought to be novel and beneficial through determining the resources and support people with T1D require when incorporating a pump, visualisation of support networks to consider and mobilise support and the ability to identify and engage in new activities as needs changed.

It was identified that SM support needs to be flexible, personalised, and perceptive of the wider context of personal communities and access to resources. Collective participant needs often fluctuated, requiring an initial period of intense support and contact, largely from HCPs and peers, for active-experimentation and adjustment, but in a manner that was sensitive to their life schedules. This thesis offers a new understanding of the SM needs of people with T1D using pump therapy, and provides a means in which to support this population to self-manage using a novel and evidence-based approach which utilizes a system-wide approach to SM support. While this work addresses specific T1D and pump therapy needs, it can also provide an exemplar for incorporation and adaptation of other new technologies in diabetes and other long-term-conditions, and demonstrates the use of a SM support tool which can be adapted and sensitised as necessary.

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Research Thesis: Declaration of Authorship

Print name:	Claire Reidy
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Title of thesis:	The factors that support people living with Type 1 diabetes to incorporate an insulin pump into their everyday lives.
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I, Claire Reidy, declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly while in candidature for a research degree at this University;
2. Where I have consulted the published work of others, this is always clearly attributed;
3. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
4. I have acknowledged all main sources of help;
5. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
6. Parts of this work have been published as:

Reidy, C., Foster, C. and Rogers, A. (2019). A novel exploration of the support needs of people initiating insulin pump therapy using a social-network approach: A longitudinal mixed-methods study. *Diabetic Medicine*. Early view.

Reidy, C., Bracher, M., Foster, C., Vassilev, I., Rogers, A. (2018). The process of incorporating insulin pumps into the everyday lives of people with Type 1 diabetes: A critical interpretive synthesis. *Health Expectations*. (4):714-29.

Reidy, C., Kennedy, A., Pope, C., Ballinger, C., Vassilev, I., and Rogers, A. (2016). Commissioning of self-management support for people with long-term conditions: an exploration of commissioning aspirations and processes. *BMJ Open* 2016;6:e010853. doi: 10.1136/bmjopen-2015-010853

7. The first paper was designed, conducted, analysed, interpreted and written by the author of this PhD with supervision, advice and comments from Professor Anne Rogers and Professor Claire Foster. The design, conduct and write up for the second paper have been

Research Thesis: Declaration of Authorship

overseen by the project supervisors, Professor Anne Rogers and Professor Claire Foster. They are therefore listed as co-authors on each of the above papers. In addition, colleagues Dr Mike Bracher and Dr Ivalyo Vassilev provided an advisory capacity for systematic review methodology and supported with title screening and are therefore listed as co-authors. Professor Anne Kennedy, Professor Catherine Pope, Dr Claire Ballinger and Dr Ivalyo Vassilev assisted with design of the second study, training of user researchers and commenting on write up. This work informed the protocol of this PhD work.

8. The third paper is currently being peer reviewed at the Journal of Medical Internet Research (JMIR) (submitted 11th March 2019) and is titled 'Integrating self-management needs and theory to implement a web-based self-management tool for people with Type 1 diabetes using an insulin pump'. This paper was designed, conducted, analysed, interpreted and written by myself with supervision, advice and comments from Professor Anne Rogers and Professor Claire Foster.
9. This thesis was designed, analysed, interpreted and written by myself with supervision, advice and comments from Professor Anne Rogers and Professor Claire Foster.

Signed:

Date:

Acknowledgements

First and foremost I would like to express my utmost thanks and appreciation to my supervisors, Professor Anne Rogers and Professor Claire Foster, for their ongoing support and guidance throughout this entire PhD journey. I have had the opportunity to be challenged, to reflect and to be completely out of my comfort zone, whilst being supported throughout. I will always be grateful for this opportunity.

I would also like to acknowledge all of the participants of the research and insulin pump services who have all made this research and PhD journey possible, and made the journey enjoyable. I have felt incredibly fortunate to hear the stories and experiences of participants within this research (both people with diabetes and clinicians) and hope that I have done these accounts justice.

Finally I would like to thank my incredible friends, family and colleagues for being there to support me throughout, for putting up with my hermit ways and lack of contact, for being a voice of reason or comfort, and for troubleshooting with me whenever I needed it. I would particularly like to thank my partner, Mark Sandilands for being there with me through the peaks and troughs and ups and downs and relentless late nights. You are a true hero. I would also like to thank my parents for being my ray of Irish sunshine (a rare thing!), and my good friend Jennifer Bolton for always encouraging me and proof-reading my work.

Definitions and Abbreviations

BCTs: Behaviour Change Techniques

BCW: Behaviour Change Wheel

CLAHRC: Collaboration for Leadership in Applied Health Research and Care

COM-B: Capability-Opportunity-Motivation Model of Behaviour

DSN: Diabetes specialist Nurse

HbA1c: Glycated haemoglobin

HCP: Healthcare Professional

NHS: National Health Service – UK

NICE: National Institute for Health and Clinical Excellence

NIHR: National Institute of Health Research

NPT: Normalization Process Theory

PAID: Problem Areas In Diabetes Scale

SM: self-management

TDF: Theoretical Domains Framework

T1D: Type 1 diabetes

Chapter 1 Introduction

1.1 Overview

This thesis has a dual focus in that it is concerned with the process and experiences of individuals with Type 1 diabetes (T1D) incorporating an insulin pump and also with finding a way to support the associated self-management (SM) needs of this process by implementing a web-based SM tool. The focus of this thesis has arisen because national audits have consistently indicated that people with T1D are experiencing poor health outcomes and literature has identified that utilising a new health technology can improve health outcomes yet incorporation is also likely to require a process of adaptation and increased complexity. Understanding this process of SM could equip us to support and facilitate people with T1D *through* this process to achieve better health outcomes. Social Cognitive Theory underpins this body of work which considers the SM needs of people with T1D incorporating an insulin pump. A social network approach to SM is proposed as a way to garner and mobilise SM support. Behaviour Change Theory by means of the Behaviour Change Wheel (BCW), Theoretical Domains Framework (TDF) and identification of Behaviour Change Techniques (BCTs) was utilised to allow for identification of the mechanisms of most importance in a SM support tool for people with T1D incorporating an insulin pump, and the best means to access such a tool. This social network approach is novel in both T1D and utilisation of a new health technology, and is important to explore because strategies to improve outcomes for people with T1D have previously tended to take a one-dimensional approach which focuses on purely biomedical outcomes, education or individual motivations. This work proposes a more inclusive and comprehensive approach to supporting people with a long-term-condition such as T1D and a complex health technology to self-manage. The social network approach proposes considering the person within their wider context and influences, and how these can or do feed back into the ability to self-manage.

This thesis aimed to address the following research questions;

- What is the process of incorporating an insulin pump into the everyday lives of people with T1D?
- Are there strategies which are likely to lead to an insulin pump being embedded and strategies that are not?
- What are the elements that help and hinder incorporation?
- What are the behaviour change characteristics and strategies required to support SM using a web-based tool for people with T1D and an insulin pump?

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- What are the specific behavioural change characteristics and mechanisms that impact on implementing a web-based SM support tool into NHS practice?
- In what ways does GENIE need to be adapted or implemented to support people with T1D and an insulin pump?
- What are the practical and emotional means of support required upon initiation of insulin pump therapy, and how do these needs change over time?
- How can a social network intervention, such as GENIE, support this process of incorporation?

The aim of this chapter is to provide a summary of the relevant background literature which led to the development of the work within this PhD. The chapter will present a summary of the health policy around SM of a long-term-condition such as T1D, followed by an overview of T1D, and the associated biomedical and psychosocial experiences of this condition. T1D is presented as an example of both a long-term condition with complex SM needs which causes a great deal of distress and burden on the individual with the condition, and a long-term-condition which has severe associated complications and costs to the health service. The place of insulin pump therapy in supporting the management of T1D is discussed, as well as the support currently provided to integrate insulin pump therapy. The current NHS approach for SM support for people with T1D is outlined, followed by explorations of potential new ways and approaches to improve the quality of SM support received by people with T1D utilizing insulin pump therapy.

1.2 Self-management

“Self-management” includes the skills, knowledge, confidence and expertise people use to manage their long-term condition(s), and enablement of people to make choices and decisions about how to manage their day-to-day life and long-term-condition(s). This can include access to relevant information, achieving self-confidence to undertake SM tasks and practises, altering behaviour to self-manage better (either by undertaking particular behaviours more frequently or by reducing behaviours that impinge on SM), and acquiring technical skills to undertake SM. Provision of support to self-manage has been shown to be effective in preventing complications and the need to go into hospital, as well as making a significant contribution to health outcomes including substituting for formal care and improving quality of life (Wanless 2004; Department of Health 2005, 2010; De Silva 2011; Reeves et al. 2014). Long-term condition SM has become an increasingly important paradigm in healthcare delivery and its promotion is now an enduring feature of health care policy (Wanless 2004; Department of Health 2005, 2010, 2015), not least because of its perceived financial benefits related to reductions in service use (Phillips 2013). Effective SM support of long-term conditions is a key aspiration for improving health outcomes,

mental health and well-being and the appropriate utilisation of services for those living with long-term-conditions (Chapple and Rogers 1999; Wanless 2004; Department of Health 2005).

While it is widely acknowledged that good SM is an essential part of enabling people with a long-term-condition to lead better and longer lives, there has been a lack of operationalisation of the provision of support to enable people to self-manage. This has impacted significantly on the approach, development, theory, analysis and focus of this PhD work. Earlier scoping work within this PhD found that while there are desires, aspirations and forward planning of patient choice and SM of long-term-conditions at a macro and meso level (both NHS England at a national level and Clinical Commissioning Groups - CCGs - on a local level), the patient voice is not actually considered or prioritised in real terms (Reidy et al. 2016). Observations of CCG meetings and interviews with commissioners revealed that the focus and priorities were not aligned with individual or collective patient needs, but were instead on financial incentives (Reidy et al. 2016). These were directly linked to measuring biomedical outcomes in long-term conditions such as diabetes.

An orientation towards objective, measurable, biomedical incentives in managing long-term conditions in the NHS (such as payment by results of lowering blood test results) has been known to have an impact on how health service resources are then dedicated to SM support (Rogers et al. 2015). However, SM support services which are able to account for individual needs or provide tailored information as well as considering the environment in which a person is located have been found to be particularly effective improving health outcomes and are well-received (Kennedy et al. 2003; Lancaster and Stead 2005; De Silva 2011). Overlooking the individual needs and where they are situated grossly undermines how individuals are able to either change behaviour or self-manage on a day-to-day basis, both realistically and relatively. In light of this, it seems that an intervention to support people with a long-term condition to self-manage must then bypass the macro and meso level and go straight to the individual. The development of this PhD research was heavily influenced by this finding, and it was decided that the focus of SM support was with consideration of the person's engagement (or lack thereof) with their surroundings, utilising a more system-wide approach.

1.3 Type 1 diabetes

An example of a long-term-condition with complex SM needs is T1D. T1D comes under the umbrella term of "diabetes", which has an estimated prevalence (for adults) worldwide of 425 million (International Diabetes Federation 2015) and there are an estimated 4.7 million people living with diabetes in the UK (Atkinson et al. 2014; Diabetes UK 2019). More specifically, the most

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recent figures suggest that the unpreventable autoimmune condition T1D accounts for about 8% of all people with diabetes (Diabetes UK 2019), although the incidence and prevalence of T1D vary substantially between countries (Atkinson et al. 2014). T1D develops when the body's immune system attacks and destroys the cells that produce insulin. As a result, the body is unable to produce vital insulin, which leads to increased blood glucose levels that, if left untreated, cause serious life-threatening damage to all organ systems in the body.

With a growing population (Diabetes UK 2019), combined with significant potential for both short-term (e.g. hypoglycaemia, ketoacidosis), and long-term complications (e.g. coronary heart disease, blindness, amputation) (Diabetes UK 2011/12; Hex et al. 2012; Health and Social Care Information Centre 2012a) there are subsequent acute short and long-term impacts on health service delivery, capacity and costs. Hex and colleagues (Hex et al. 2012; Diabetes UK 2019) estimated that £1 million of the National Health Service (NHS) budget in the UK is spent on diabetes every hour, totalling around £10 billion per annum which is 10% of the entire annual budget. The total UK cost associated with diabetes is predicted to rise to £39.8 billion (17% of total health expenditure) by 2035/2036. In addition, diabetes as a whole accounts for 15% of deaths per year (Hex et al. 2012), 7% of the national medication budget, and the occupation of 15% of hospital beds at any one time (Diabetes UK 2011/12; Health and Social Care Information Centre 2012a; Kent & Medway Public Health Observatory 2014), and these rates are growing (Hex et al. 2012). Diabetes also contributes significantly to mortality, with one third of those diagnosed with diabetes in England and Wales being more likely to die earlier than their counterparts without diabetes (Kent & Medway Public Health Observatory 2014). Diabetes in the UK is an increasingly urgent public health issue which requires appropriate knowledge, skills, support and resource to enable people living with diabetes to manage their condition as well as possible (Phillips 2016).

1.4 Treatment and management of Type 1 diabetes

Treatment of T1D consists of demanding SM requirements including; taking tablets and/or insulin therapy (injections or insulin pumps), self-monitoring of blood glucose, good dietary control and exercise, understanding carbohydrate counting, insulin ratios and insulin resistance, in addition to understanding food content (glycaemic index and fat levels), and both hormonal and physical impacts on glucose levels (Campbell et al. 2018; Chatterjee et al. 2018). SM practices involve a spectrum of activities to meet these requirements such as taking specific prescribed medications, regular health checks, foot care, retinopathy screening and awareness of healthy eating and physical activities (in relation to the above) (Nefs et al. 2012).

Good health practice of those diagnosed with T1D is characterised by the need to regulate blood glucose levels, which are subject to extreme fluctuations if not regulated. The aim of blood glucose regulation is to prevent hyperglycaemia and avoid hypoglycaemia. Hyper and hypoglycaemia relate to the level of glucose in the blood. Hypoglycaemia is characterised by arterial glucose levels falling below the physiological range, thereby limiting blood-to-brain flow to brain glucose metabolism, and ultimately the necessary metabolic fuel for the brain (Cryer et al. 2003). On the other hand, chronically raised blood glucose levels (hyperglycaemia) are also known to be associated with a wide range of serious diabetes related complications such as cardiovascular disease, diabetic retinopathy, nerve damage and kidney disease (The Diabetes Control and Complications Trial Research Group 1993). Treatment for blood glucose regulation comprises insulin therapy (multiple insulin injections or an insulin pump) along with the aforementioned demanding, multicomponent regimen including blood glucose monitoring, dietary control and understanding as well as keeping fit in general (Aathira and Jain 2014). Blood glucose regulation is measured clinically through glycated haemoglobin (HbA1c) which identifies the average blood glucose levels over a period of approximately 3 months. This is often the main (although not the only) clinical outcome measure used in consultations with people with diabetes (Agiostatidou et al. 2017). An inability to fulfil demands to regulate blood glucose effectively can lead to diabetic ketoacidosis (characterised by a shortage of insulin and metabolic acidosis), coma, and death if untreated (Johnson et al. 1992; Kitabchi et al. 2009). Unsurprisingly then, improved glycaemic control delays the onset and progression of such complications (Weinger and Beverly 2010; NHS Digital 2019).

Diabetes carries with it consistently suboptimal health outcomes, yet with improvements in glycaemic control the onset and progression of complications are delayed (Weinger and Beverly 2010) and so effective strategies in SM to meet these burdensome demands are necessary. However, living with diabetes and managing glucose levels is a complex and often difficult task, and so support is needed to enable people to be able to SM as effectively as possible. Having diabetes can negatively impact on psychological wellbeing (Johnson et al. 2013a) and quality of life (Speight et al. 2012). To add to this complexity, poor psychological wellbeing can have significant impacts on glycaemic control, which in turn increases the risk of diabetes-related complications, increased healthcare costs and lost productivity (Diabetes UK 2008; The emotional and psychological support working group of NHS Diabetes and Diabetes UK 2010; Jones et al. 2015; Diabetes UK 2016; Joensen et al. 2018; Prahalad et al. 2018).

1.4.1 Technologies in diabetes insulin delivery: Continuous subcutaneous insulin infusion

Technological developments have occurred with the aim of supporting people with diabetes to manage the condition better. One example of this is a method of insulin therapy which is more physiologically representative of a fully functional pancreas (gradual drip-feeding rather than surges of insulin at particular points during the day), and so potentially enabling improvements in care. This development is called continuous subcutaneous insulin infusion (or an insulin pump), also known as insulin pump therapy. Insulin pumps are electronic devices which drip feed rapid-acting insulin into the user throughout the day, via a fine cannula implanted in the subcutaneous tissue. The user then self-administers, as required, extra shots of insulin to match their intake of glucose (carbohydrates). At this time the main, and more traditional method of insulin therapy, globally, is multiple daily insulin injections (Wilmot et al. 2014) but both multiple daily injections and insulin pump therapy are posited as options for insulin management for people with T1D (American Diabetes Association 2017). 15.6% of people with T1D in England are using insulin pumps (NHS Digital 2018a), although this figure is known to be less than much of Europe and the USA (Miller et al. 2015; Bohn et al. 2016; Sherr et al. 2016).

Insulin pumps, developed in 1963 (Kadish 1964) (see **Figure 1**), was not considered a viable means for management of T1D for many years, although explorations were undertaken to improve the technology (Pickup and Keen 2002) (See **Figure 2**). In recent years insulin pump technology has improved considerably (Pickup and Keen 2002) (See **Figure 3** and **Figure 4**). The uptake of insulin pumps grew in the UK in 2008 after NICE guidelines provided recommendations for its use following a growth in clinical evidence around benefits of the technology (National Institute for Health and Clinical Excellence 2008). Benefits of insulin pump therapy include more closely resembling physiological insulin delivery, as well as being shown to yield particular benefits over multiple daily injections which include reducing; HbA1c levels (especially when baseline levels are high - >8.5%), cardiovascular mortality, hypoglycaemia, the fear of recurrent severe hypoglycaemia, and improving quality of life (Linkeschova et al. 2002; Weissberg-Benchell et al. 2003; Misso et al. 2010; Monami et al. 2010; Pickup 2012b; Pickup 2012a; Steineck et al. 2015). Insulin pump have also been reported to offer the person wearing it greater flexibility in undertaking day-to-day activities, greater autonomy, improved sleep and improved socialisation (Low et al. 2005; Barnard et al. 2007; Pickup 2012a; Alsaleh et al. 2014), as well as improving quality of life as an indirect result of decreasing the rate of severe hypoglycaemia (Low et al. 2005; Pickup 2012a). In addition, health economics analysis has shown that insulin pump therapy is cost effective (Roze et al. 2005; Elías et al. 2016). However, there are gaps in the knowledge regarding the factors that may promote or inhibit the adoption and embedding of insulin pump therapy as a

SM strategy for T1D and there are huge inconsistencies in the provision or option of insulin pumps as a method of insulin therapy nationally (NHS Digital 2018c).

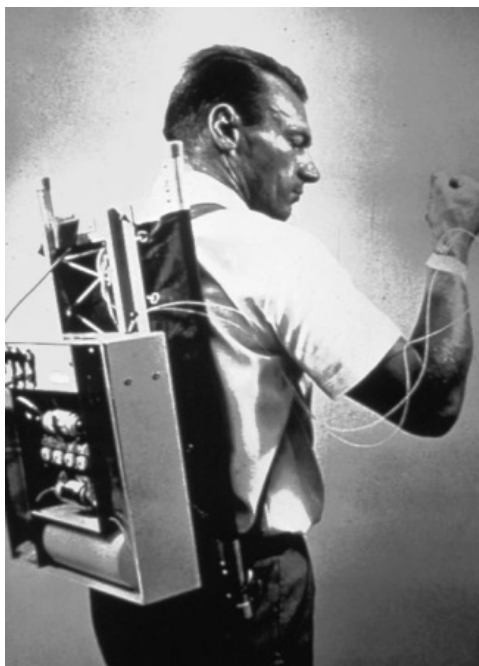


Figure 1: Dr. Arnold Kadish with the first insulin pump, 1963



Figure 2: The “wearable” insulin pump, 1983



Figure 3: Present day pump

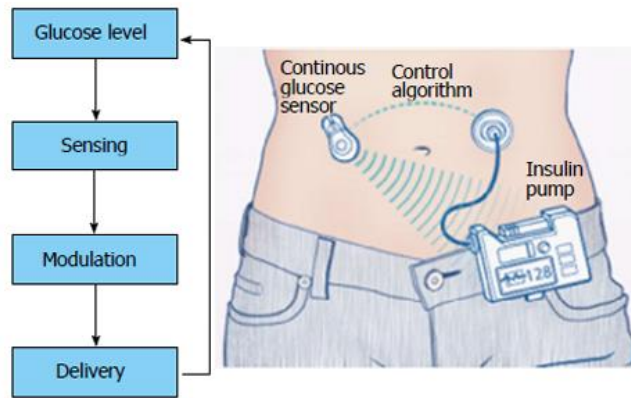


Figure 4: Next stage of pumps – integrating glucose monitoring and delivering insulin using algorithms

While NICE guidelines limit the eligibility of people with T1D to take up insulin pump generally, variation across uptake in clinics nationally range from almost 50% to less than 5% (NHS Digital 2018c), suggesting that guidelines are not being applied consistently. It has been reported that 15.6% of people in England are using insulin pumps, but women more so than men (61.4% vs 38.6%), and increasing levels of social deprivation correspond with less use of pumps (NHS Digital 2018c). There is limited knowledge on why this may be the case, although it has been found that HCPs can be gatekeepers to insulin pumps and select those for insulin pump therapy that they presume will possess particular personal and psychological attributes that might result in their making optimal use of the technology. However, these HCPs conveyed that these beliefs were challenged after witnessing new users of insulin pumps flourish with the new technology after being randomly allocated within a randomised clinical trial.

This approach to pump therapy selection is apparently not unusual. The European Association for the Study of Diabetes and the American Diabetes Association’s declaration of who an insulin pump may be a suitable treatment option for hints to a bias and strategic patient selection:

“people with Type 1 diabetes who are motivated to improve glycemic control following a trial of multiple daily insulin injection therapy and who can show the level of self-care required for adherence” (Heinemann et al. 2015, p. 717).

Motivation is often cited in official guidelines for insulin pump therapy for considering the suitability of a person for pump therapy (Scheiner et al. 2009; Morrison and Weston 2013; Heinemann et al. 2015) with no accompanying outline of how motivation is to be assessed, and whether that simply refers to “patient choice” or person-centred-care. In addition, there is no exploration of how judgement is made that patients have the capability to “show the level of self-care required for adherence”. The national pump audit (NHS Digital 2018c) has stipulated that the variation of insulin pump uptake between diabetes clinics in England and Wales, and the

disproportionate representation of women and those from more socially privileged backgrounds, suggests that there is a lack of equitable access to this technology, that more people should be considered for insulin pump therapy, and that these disproportions need to be investigated. There appears to be declamation of professional dominance and biomedical models of care and making decisions for people with T1D, rather than offering true choice of insulin therapy, accompanied with tools to support people to self-manage with a new, complex treatment option. There also seems to be an expectation that people will or will not be able to integrate an insulin pump, rather than considering that there is a process of incorporation of pump therapy and that there may be mechanisms of support for this process.

1.5 The current NHS approach for self-management support for people with diabetes

Much of the focus of care of people with diabetes in the UK is in relation to reducing the risk and progression of costly complications. National guidelines have been put in place which have been designed to monitor, help manage diabetes and reduce the risk of these complications, and are often focused on both Type 1 and Type 2 diabetes, rather than the conditions individually. Many of these guidelines refer to screening for complications or pre-requisites for complications, yet these are often not delivered successfully. One such guideline is screening for diabetic retinopathy (National Institute for health and Care Excellence (NICE) 2015) and one fifth of those who are eligible do not use the UK wide retinopathy screening service (Orton et al. 2013). Graham-Rowe et al.'s systematic review on barriers and enablers to this screening attendance (Graham-Rowe et al. 2018) identified the following theoretical domains as mediating factors: 'environmental context and resources' (e.g. accessibility of screening, time constraints, scheduling appointment issues, waiting times); 'social influences' (e.g. trust in HCP advice or HCP recommendation to attend, language barriers, level of support or encouragement from personal community, stigma); 'knowledge' (e.g. perception of risk or awareness of difference between eye screening and eye test); 'memory, attention, and decision processes' (e.g. lack of symptoms, competing health problems, forgetting); 'beliefs about consequences' (e.g. perceived necessity of screening, short-term adverse effects of screening); and 'emotions' (e.g. fear or anxiety of results or procedure, feelings of guilt).

The NHS also logs eight annual NICE-recommended care process checks and yet a recent national audit reported that only 42% of people with T1D received all eight of these (NHS Digital 2019). In addition, only 30% are achieving clinical HbA1c targets (<58mmol/mol) and less than 19% of people with T1D are reaching the combined key clinical treatment targets for HbA1c, blood

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pressure and cholesterol (NHS Digital 2019). Similarly, a recent national audit in the UK has also reported that only 4.3% of people with T1D receive the current “gold standard” of SM support offered by the NHS – “structured diabetes education” within the first year of diagnosis (when considered most timely) (Diabetes UK 2015a; NHS Digital 2018b). The structured diabetes education programme specifically for people with T1D is called Dose Adjustment For Normal Eating (DAFNE), although local versions of this kind of programme/SM support are delivered throughout the UK. It has been designed with the goal of improving the knowledge of people with T1D to count carbohydrates and match this to their personal insulin requirements (also known as ratios of insulin to carbohydrates). However, the uptake has not been as hoped (Harris et al. 2017), and also has not addressed other SM needs of people living with T1D. Studies have explored and identified some specific barriers for non-attendance at structured education, which include expectations that these programmes will not be useful (Horigan et al. 2017), lack of cultural sensitivity of the programmes offered (Harris et al. 2017) and participants not being able to attend for logistical, medical or financial reasons (Horigan et al. 2017).

The Diabetes Attitudes, Wishes and Needs: Second Study (DAWN2) was a cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. DAWN2 assessed psychosocial issues and health-care provision of people with diabetes, their family members and HCPs. They found that while 73% of people with diabetes received regular biomedical assessments (such as HbA1c), only 32% reported being asked by HCPs about being anxious or depressed. They also found that only 24% reported that their healthcare team asked them how diabetes impacted on their life (Nicolucci et al. 2013).

It is evident that efforts within the NHS aimed to enable people to manage T1D diabetes better are not meeting the SM needs of people living with this condition, and in addition there is a distinct lack of provision of SM support or understanding of SM needs provided to people who are also using an insulin pump (Groat et al. 2017). When there is a focus on SM of people on insulin pump therapy it is often related to measurement testing and knowledge (e.g. blood glucose testing, carbohydrate counting) (Bode et al. 2002; Groat et al. 2017) or use in inpatient settings (Bhatt and Reynolds 2015; Partridge et al. 2015; Umpierrez and Klonoff 2018) rather than other important factors relating to adjusting to the complexity of a new technology. There appears to be a gap in the knowledge around the SM needs of people incorporating pump therapy, rather than the current focus of biomedical outcomes and HCP prioritised targets. It is apparent that with the importance of SM on biomedical and psychosocial outcomes, alternative efforts to understand these needs and find a way to support them is necessary to improve quality in care.

1.6 New ways of approaching self-management support for people with diabetes

People with T1D and incorporating a new health technology have a mammoth task to manage their diabetes and need to have knowledge, self-efficacy, support and resources and the opportunity to be able to manage their condition. There is good evidence to suggest that there is an unmet need in the management of diabetes, which could unlock opportunities to provide more informed and appropriate support. It is likely that novel ways need to be considered to address this translational gap between the need for and the provision of more appropriate and effective SM support. The Diabetes UK “Future of Diabetes” Report (Diabetes UK 2017) highlighted six areas of priority to make it easier for people to live with diabetes, these being:

- 1). More support for emotional and psychological health;
- 2). Better access to HCPs who understand diabetes;
- 3). Better access to technology and treatments;
- 4). Widely available information and education;
- 5). More support and understanding at work and school; and
- 6). Hope for the future.

Over the past decade, knowledge has grown substantially with respect to the emotional and social difficulties that people with diabetes may encounter and it has been recognised that people with diabetes require more support for emotional and psychological health in order to SM well (The emotional and psychological support working group of NHS Diabetes and Diabetes UK 2010; Diabetes UK 2017). There is a resultant drive from policy makers for prioritising SM support (NHS England 2017) and increased momentum from NHS England and diabetes voluntary organisations to consider the emotional wellbeing of people with diabetes (Diabetes UK 2018; Lloyd et al. 2018; Hendrieckx et al. 2019), especially when complex new health technologies, such as insulin pump therapy, are introduced.

Emotional and psychosocial considerations of people with T1D include that a diagnosis of diabetes is associated with a 20% increased prevalence of anxiety (Smith et al. 2013b), a high degree of emotional distress and lower wellbeing than the general population (Handley et al. 2016; Holmes-Truscott et al. 2016; Fenwick et al. 2018). Some diabetes-specific anxiety presentations include; injection-related anxieties or needle phobia (Orenius et al. 2018), fear of hypoglycaemia and avoidance of hypoglycaemia (leading to maintenance of high blood glucose levels in an effort to

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avoid the risk of hypoglycaemia) (Gonder-Frederick 2013; Shepard et al. 2014; Nefs and Pouwer 2018), and fear of complications (Snoek et al. 2000), all of which may lead to avoidance or inability to self-manage effectively. Eating disorders are also associated with diabetes, especially in regards to intentional omission of insulin (Pinhas-Hamiel and Levy-Shraga 2013). Therefore, effective SM of diabetes requires attention to the behavioural, psychological, environmental and social aspects of this enduring condition (Nefs et al. 2012) and the willingness and ability for people with diabetes to engage with the treatments and care that are most suitable to their needs.

SM support which undertakes a holistic approach can indirectly impact on the emotional and physical wellbeing of people with T1D, for example physical activity is known to improve well-being, physical fitness and strength, while also reducing cardiovascular risk factors and insulin requirements (Chimen et al. 2012). However, particular activities can impact on glycaemic control both positively and negatively (McCarthy et al. 2017) so, ideally, sign-posting or engagement in activities would be combined with more support, tools and/or knowledge about the impact of such activities on managing diabetes. A study by Shaw et al. (Shaw et al. 2006) found that social capital influenced SM capabilities and suggested that HCPs' understanding of the context of social support of their patients is key to improving health – e.g. that HCPs would be able to support patients more if they understood who their patients turned to for SM help and where and how they access information about their diabetes. They considered the environment in which people with diabetes were located, and how this impacts on their health outcomes. They proposed that social and material resources and nearby access to these are also relevant to the capacity and ability to support SM in people living with diabetes. Perceived support has also been found to have a distinct impact on psychological adjustment and diabetes-related distress (Karlsen and Bru 2014), while self-efficacy can mediate some forms of negative engagements with network members (Schokker et al. 2011). Enlightenment of this information could then enable HCPs to better tailor the support that they wish to provide. However, considering that those living with diabetes spend such a small amount of their time with HCPs (3 hours a year, on average) compared with the amount of time dedicated to SM activities (8,757 hours a year) (Department of Health 2007); and that 40-80% of medical information provided in health consultations is forgotten immediately (Kessels 2003), it is clear that alternative access to means of self-managing (support, information and resources) could complement the support provided by HCPs and allow people to further address issues not dealt with in traditional settings (Allen et al. 2016).

NHS England has committed to rolling-out social prescribing in recognition of the contribution of activities and support to the mental and physical health of the population (NHS England 2019b), although a better understanding of the function of social support is needed (Strom and Egede

2012) as well as specificity of how and in what way particular elements (or members) of social support impact on the management of diabetes, especially in relation to incorporating health technologies (Reblin and Uchino 2008). Wiebe et al. (Wiebe et al. 2016) examined the social context of managing diabetes and declared social relationships from many sources (formal, informal, family, HCPs etc.) as a central element in diabetes management. These relationships lead to positive outcomes when they are affectionate, collaborative and invited by the person living with diabetes, while involvement characterised by conflict, judgement, intrusiveness and social control were associated with negative diabetes outcomes. In their meta-synthesis of the relationship between diabetes and depression, Gask et al. (Gask et al. 2011) also found relationships served as both the buffer and cause of difficulties with diabetes SM. Wiebe et al. suggested that people with diabetes might benefit from learning to communicate to others what is and is not helpful for SM, focusing on relational work and engaging their social support network to have enable access to the resources they need, when they need them. They suggest the use of interventions which effectively utilise or consider the social context rather than solely focusing on the individual.

There have been rapid developments and adoption of new technologies for SM of long-term-conditions in healthcare over the past decade, which brings opportunities for the health and care system (Gretton and Honeyman 2016). For example, digital health interventions designed to support SM have been found to; improve the ability to self-manage, substitute and compliment formal care reduce levels of diabetes related distress and produce substantial savings in traditional health service utilisation through enhancing and diversifying support received, and improve access to diabetes SM and behavioural support (Reeves et al. 2014; Kennedy et al. 2016; Murray et al. 2017; Li et al. 2018) and have also been found to be cost effective. The use of web-based access to mechanisms of support and information has grown alongside rapid advances in mobile technologies, combining traditional medical approaches to care with online interactions. HCPs are increasingly using e-health methods such as email, skype consultations and web-based interventions to engage with patients (Kaufman and Khurana 2016; NHS England 2016a; Morris et al. 2017) in order to provide more accessible and flexible support, while reducing healthcare costs (Elbert et al. 2014). A way to navigate personalised and supportive resources for both medical outcomes and wider wellbeing online might provide a novel approach to managing the varying and personal support needs of people with diabetes who are integrating a new health technology.

1.7 Summary

T1D is a long-term condition that is accompanied by a distinct risk of severe complications, a high rate of health service utilisation and an increased risk of mortality, and being such it takes up a

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significant proportion of the NHS budget. However, complications and mortality can often be avoided, reduced or delayed with improved SM. However, managing diabetes requires a complex treatment regimen. T1D carries with it a climate of uncertainty (about future complications and hope for new technology), strain (burdened with SM) and undulating requirements for complex knowledge, support and resource. People with T1D often struggle to achieve the targets which will, statistically, lower their long- and short-term health risks.

Managing diabetes creates illness burden and high rates of distress, yet there is a lack of appropriate and effective SM support provided, and a lack of opportunity to explore personalised agendas in engagements with the health service. New technologies have been developed to help people to deliver insulin therapy and to self-manage but these come with additional challenges in terms of the process of incorporation and SM practises. A new technology can bring hope but introducing a new and complex technology into someone's life (such as an insulin pump) can mean that new illness work is required, and a need to support the incorporation of this new technology and work. Measures currently undertaken by the NHS to support management of a long-term-condition such as T1D do not appear to be providing the breadth and depth of support needed for people managing a complex treatment regimen over an enduring period, and so alternative and innovative means to support SM are required. However, we need to understand the process of and specific SM needs of people with T1D incorporating an insulin pump.

This introduction leads onto how theoretical underpinnings have influenced the development, approach and analysis of this PhD work (Chapter 2). These theoretical underpinnings complement the complex SM requirements of T1D and complexities of incorporating a new health technology, and the lack of support to SM currently provided by the health service, while proposing novel approaches to address these needs. This is followed by Chapter 1 which describes the methodological approaches of the work that has been undertaken and the rationale of these approaches. This thesis has been prepared in alternative thesis format, whereby three papers constitute the core of the thesis. In addition to this is an autoethnography of the author before the presentation of the three papers, to provide some personal context. Usually the reflective piece comes at the end of the thesis, but as the author's journey as a user-researcher was set at the beginning of the PhD work, this has been presented before the three papers (in Chapter 1) to provide an upfront acknowledgement of the context for this research. The autoethnography outlines the personal context of this research (Chapter 1), followed by the three papers which compromise the core of this research (Chapter 1, Chapter 1 and Chapter 1), and then the discussion chapter which outlines the key findings of the three papers, discusses the findings as a whole, explores the implications of the work, describes the limitations of the work and offers proposals for future research (Chapter 1).

Chapter 2 Theoretical underpinnings

Traditionally, the way a health care system deals with people living with a long-term condition is largely centred around a biomedical approach, which is at odds with SM and providing appropriate support for SM. Biomedical approaches to illness management were developed and deployed in response to acute illness, not chronic illness, and do not tend to be receptive to the treatment, management and all-encompassing nature of an illness over time (Wade and Halligan 2004). The traditional biomedical approach does not prepare people with a long-term-condition to manage their illness day-to-day, yet this is where the vast majority of illness work occurs, and so much needs to change in the way of supporting people to improve their health and wellbeing. However, theory offers the opportunity to consider well-thought out alternative ways to support people to manage their health using evidence-based research. It also allows testing of the validity and replicability of approaches to illness management to determine whether these alternative approaches are effective with various populations and settings. This chapter explores theoretical explanations for behaviour change in health, in relation to what impacts on behaviour towards SM practices, and how this applies to people with T1D incorporating an insulin pump, and also explores theory in Implementation Science to inform the development of an intervention to support SM for people with T1D and an insulin pump.

2.1 Theoretical explanations for behaviour change in health

2.1.1 The Common-Sense Model of Self-Regulation

In attempting to understand illness related behaviour, and in this instance; achieving the balance between good SM of T1D while incorporating a complex new technology, the Common-Sense Model (CSM) offers evidence that patients' cognitions (thoughts about illness) and emotional reactions combine to form what can be described as a 'personal model' of the illness that subsequently drives behaviour relating to self-management (Lawson et al. 2007; Leventhal et al. 2016). CSM attempts to deconstruct 'lay' beliefs about illness and the dimensions of how we think about illness (Skinner et al. 2002). CSM, also referred to as the Personal Model, the Illness Representations Model, the Self-Regulatory Model, or Leventhal's Model, amongst others, considers what enables someone to make sense of their illness and guide their coping actions (Hale et al. 2007). The concept is that these cognitive representations which a person holds about their illness may underlie individual differences in illness-related behaviours. For instance, we know that when there is a belief that a disease is not chronic, when it is in fact chronic, such as

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with Arthritis or diabetes, there are consequences for morbidity and mortality (Cameron and Moss-Morris 2010).

The CSM can be broken down into five key components; Identity (of the condition and its symptoms), Cause (the perceived cause of the condition), Time-line (i.e. acute, chronic or cyclical), Consequences (perceptions on the outcome of the condition and its impact physically and socially), and Curability/controllability (the degree to which the individual has any control in the condition). This model of self-regulation purports that an individual with an illness continually monitors what is happening, and modifies their behaviour based on a reflection of the five key components above in order to guide their coping actions in order to obtain particular goals. If the illness beliefs are erroneous (e.g. in relation to chronicity), then the self-care choices a person makes are likely to be suboptimal with a concomitant consequence for their illness. More specifically, perceptions of illness have been shown to have a significant impact on medical and psychological outcomes in young people with diabetes (Edgar & Skinner, 2003). In this regard, it has been shown that beliefs about the consequences, feelings of personal control and impact of the condition, along with a more chronic time-line and a lack of confidence in professional care and treatment effectiveness, have an effect on self-care, glycaemic control, depression and non-attendance at clinics (Olsen and Sutton 1998; Edgar and Skinner 2003; Lawson et al. 2004; Lawson et al. 2007; Lawson et al. 2008; McSharry et al. 2011; Wisting et al. 2019). Broadbent et al. (Broadbent et al. 2006) found significant associations from the Brief-Illness Perception questionnaire (which has been widely used to measure perceptions about illness) with personal control, treatment and personal identity scored items, and a marked significance in terms of increased personal control lowering mean HbA1c levels. When cross-referenced with illness-perceptions, there have also been significant findings of decreased adherence to exercise, lack of sufficient insulin use, higher HbA1c levels and inability to self-manage (Skinner et al. 2005; Balfe 2009).

The starting point for looking at the process of self-management of people living with T1D and an insulin pump was from the perspective of the CSM, due to past (unpublished) research undertaken by the author on the factors which influence glycaemic control of young adults with T1D. The CSM has proven to be especially beneficial in providing a framework to guide interventions or a screening tool for identifying patients who may be less able to SM with the aim of signposting to interventions to improve illness perceptions (Jonker et al. 2018). However, as development of a protocol for this PhD work moved forward it became apparent that focusing on illness perceptions could limit the scope of this work. CSM interventions which do exist to improve illness perceptions do tend to grant positive results, yet these interventions provide a relatively static intervention which do not consider the context of the participant and so are likely

to benefit a particular, or narrow patient population. The interventions were inclined to focus on talking therapies rather than fostering and renegotiating potential outlets of support which already exist (Petrie et al. 2002; Broadbent et al. 2009; Keogh et al. 2011). As the protocol was being developed it became apparent that there would be a need for consideration of the whole context of people living with T1D. For example, while interventions developed using the CSM do tend to acknowledge the importance of spouse involvement or social support in general, they do not fully recognise or aim to address or harness the importance that network members play in self-management practises.

In addition, Kwasnicka and colleagues (Kwasnicka et al. 2016) performed a complex and thorough examination of theoretical explanations for maintenance of behaviour change in health and a range of themes to support explanations for SM practises. These explanations included; ; 1) Maintenance motives – having at least one sustained motive to continue behaviour, 2) Self-regulation – the ability to successfully monitor and regulate newly adopted behaviour, and have effective strategies to overcome barriers, 3) Resources – plentiful psychological and physical resources to draw on such as mindfulness, relaxation methods, sports facilities or health products, 4) Habits – practices which have become habitual and supported by automatic responses to cues, and 5) Environmental and Social influences – a supportive environment and social support. This review implicated the importance of the situation of the individual who is making choices about their behaviour towards SM practices, but also considers the resources that they have available (psychologically, such as self-efficacy for self-regulation, and physically such as access to relevant information and tools), and also the environment around them and the social support available. They note that motivation and habitual behaviours are likely to dominate decisions in health behaviours and prolonged health behaviours, especially when resources are limited. However, a positive disruption to these habits, and an opportunity to explore and develop new ones are likely to support positive and prolonged behaviour change. A positive disruption of habits due to an increased selection of opportunities and resources to support SM could also be referred to as improved “choice architecture” (Thaler and Sunstein 2008). This improved “choice architecture” can promote behaviour change by increasing freedom of choice. Kwasnicka et al.’s review implicates guidance for “providing individuals with resources that are needed to successfully maintain a new health behaviour” (Kwasnicka et al. 2016, p.292) which suggests that a more system-wide approach needs to be considered in order to support improvements in SM of long-term-conditions.

While illness perceptions offer identification of particular (and important) elements of difficulty in living with a long-term-condition such as diabetes, it does not quite meet the needs of providing an intervention to support SM for a wide range of people, especially those from wider

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socioeconomic backgrounds and/or those with very specific technology-related needs. Other approaches (described within this Chapter) appear to have the potential to provide a more flexible and personal model of SM support.

2.1.2 Social Cognitive Theory

A Social cognitive theory approach takes a broader view on health, behaviour change and SM than the traditional biomedical approaches. Social cognitive theory is concerned with: the knowledge of health risks and perceived benefits of particular health practices; the perceived self-efficacy (i.e. the control one feels one has over their own health habits); expectations about the outcomes which are considered alongside and influenced by the costs and benefits for different health practices; the goals people set for themselves and; the potential and actual plans and strategies for realizing these goals as well as; perceived facilitators and social and structural impediments to performing such behaviours. Social cognitive theory, which was developed by Bandura, focuses on triadic reciprocity between 1) Behaviour 2) Personal and cognitive factors and 3) the Environment (Smith et al. 2019). In terms of SM of a long-term-condition; Social cognitive theory purports that social influence and the dynamic and reciprocal interactions between the individual, the environment and behaviour, underpins behaviour change. Social cognitive theory considers the unique way individuals' acquire and maintain behaviours while also taking into account interactions with the wider social environment.

Conversely, while biomedical approaches dominate health service delivery with a presumption that patients are passive receivers of treatment (Wade and Halligan 2004), the way a health system deals with people with a long-term-condition can alter their sense of efficacy in ways that support or undermine efforts to self-manage their condition (Bandura 1992). For example, early research on the importance of self-efficacy on SM by O'Leary et al. found that a program which increased people with arthritis' perceived efficacy over their ability to exercise control over their condition resulted in greater reductions in pain and joint inflammation (O'Leary et al. 1988), slower biological progression of their condition, and reduced health service utilisation (by 43% over four years).

Further, environmental and social factors affect opportunities offered to individuals to undertake certain behaviours. These structures also affect the incentives to perform behaviours in a given context. Opportunities and incentives coincide to impact on the effort required for behaviour (or a SM practice, for example), and support that is (or is not) provided can also impact on the capacity to perform and/or maintain behaviour through facility of encouragement, help or information. Social modelling, or modelling behaviour on others actions, also affects behaviour,

options and emotional states by providing opportunity for vicarious learning of knowledge and skills and also confidence (Bandura 1986). Modelling is more likely to be influential through observation of people who are considered trustworthy (Bandura 1986). Knowledge is widely considered a precursor for SM, and is often the focus in NHS SM support interventions for people with diabetes through “structured education” courses. The premise is that if an individual does not have the knowledge of particular and specific actions and practices that are required to improve health then they do not have the capacity for necessary actions to be taken. For example, with diabetes; if a person does not know how many carbohydrates are in their food then they are not able to match their insulin accordingly, and so not able to make the necessary changes to the level of glucose in their body when they consume food. If people lack awareness of this crucial knowledge then there is little reason why they would endure changing health behaviours, especially if these suggested health behaviours are deemed useless or not applying to them. Social cognitive theory considers knowledge to be important, however, other factors also impact on and influence particular behaviours. An individual may understand that carbohydrates determine how much insulin is required to combat increasing glucose levels, and that higher glucose levels damage the body, for example, yet they may need confidence about what to do, the skills needed to do it (through practice or modelling to embed behaviour) or the ability to undertake these tasks accurately and appropriately. Self-efficacy factors in these decisions and can entail regulating motivation, thought processes, emotional states and actions or changing environmental conditions.

Self-efficacy is important because without the belief in the ability to produce desired outcomes there is little incentive to try (Bandura 1998). Attainment of goals requires a range of factors including skills and also self-belief in the ability to undertake tasks in particular contexts. This belief also impacts on acquisition of knowledge and regulation of motivation such as determining goals, commitment to such goals and expected outcomes of the goals (expectations) (Bandura 1986). This belief can then impact on how much energy or resource someone will expend on a particular goal, and how this perseverance impacts on their wellbeing and stress i.e. self-doubt can overrule skills. Experiences and consequential outcomes can impact on building self-efficacy – a reciprocal feedback loop. Successes can build a robust belief in confidence and ability, but failure or difficulty which is unresolved can result in reduction in belief, although this is lessened when tasks are practiced and confidence to undertake them has been gained. Over confidence can also be as a result of many past successes and result in less balanced judgement of abilities.

Building of self-efficacy does not only have to occur by means of personal experiences but can be through social support, or “collective efficacy”. Social support seems to benefit health, as shown in Berkman and Syme’s (Berkman and Syme 1979) prospective study on 4,700 adults which found

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that over nine years a greater degree of social support resulted in a significantly lower likelihood of dying during those years. Individuals who had few contacts with friends and relatives had higher rates of mortality than those with many contacts. Social support can also provide a protective factor for those already with a health condition such as heart disease, with a reduced risk of additional heart attacks and premature deaths for those with better social support (Barth et al. 2010). Vicarious experiences can also contribute to increasing self-efficacy and can raise one's belief that they too can succeed. Modelling on others' actions can help people to engage in activities and enabled imagined futures or outcomes, and can provide a standard against which to judge one's own actions. They can also teach techniques and skills, knowledge and social cues. In this respect social cognitive theory can offer an important new paradigm in health care intervention development. Social cognitive theory offers new opportunities to explore innovative, impactful ways to support people to self-manage by engaging the context in which the person resides and considering the triadic interaction between cognitions, the environment and behaviour.

Social cognitive theory pays particular attention to expectancies, incentives and social cognitions of the individual (Bandura 1986), and how these all interact with one another e.g. if I change my diet I could improve my health and feel more confident, but I do not have the money to pay for the means to do this or access to resources in my local community. In this instance goals are interlinked with motivational mechanisms and responsive to the environmental and social context. Recent social cognitive interventions have focused on the gap between intention and behaviour, in the hope of increasing the likelihood that intentions would be translated into behaviour. This could be in the form of planning, goal setting or increased opportunity. Skår et al. (Skår et al. 2008) found that 20-40% of people do not make implementation intentions when they are asked to, and so interventions would likely benefit from elements of planning, goal setting or increased opportunity. This approach may enable increased likelihood of intentions to be fulfilled. Examples of such strategies in an intervention include encouraging people to choose from several options to help them self-manage, utilising goal setting, complimented by encouraging participants to monitor progress through record keeping. For example, van Nimwegen and colleagues used these strategies to encourage a long term increase in participation in activity among people living with Parkinson's (van Nimwegen et al. 2011).

Social cognitive theory has been found to predict self-care behaviours of older adults with Type 2 diabetes (Borhaninejad et al. 2017), while social cognitive theory based interventions have been successful in health promotion, for example, promotion of physical activity among people in early stages of Type 2 diabetes diagnosis (Shamizadeh et al. 2019). Furthermore, interventions designed to consider collective efficacy and alter the social environment and the individual's

transactions within it have been successful in facilitating psychological adjustment, aiding recovery from traumatic experiences, and even extending life for individuals with serious chronic disease (Cohen et al. 2000; Cohen 2004) and so consideration of the individual in their whole context combined with supporting them to feel confident in SM through techniques such as goal setting could provide a powerful and effective means to support SM. Social cognitive theory has thus influenced the approach taken in this thesis towards supporting behaviour change through a SM support intervention which considers the SM practices of people with T1D incorporating an insulin pump through focusing on the needs and context of the individual concerned and their personal preferences and resources.

2.1.3 A Social Network Approach to self-management

A Social Network Approach is underpinned by social cognitive theory but takes this a step further – focusing on the relational work (the interpersonal engagement and interactions between network members) within a network of social support and how a person relates to this network and the emergent properties leading to SM. There are evident failings in attempts to enable people with T1D to attain glycaemic targets designed to prevent serious health complications (only 30% of people with T1D are achieving recommended glycaemic targets) (NHS Digital 2019) yet current methods to support people to improve glycaemic control have not proven to be fruitful. A Social Network Approach, could provide a means to support SM that is more useful and more sustainable in practice through considering the individual's interactions with their wider social network and resources in terms of navigation, negotiation and collective efficacy (Vassilev et al. 2014). Members of an individual's social support network (network members) are sources of a range of collective support which encompass emotional, practical and illness related 'work' (Vassilev et al. 2010), and this support demonstrates the role of collective efficacy (Band et al. 2019). Network members can be HCPs, family, friends, colleagues, community groups, objects (e.g. a bicycle), pets, spiritual groups etc. and have been associated with how individuals are able to self-manage (Kennedy et al. 2016; Vassilev et al. 2016).

Rather than provide a potentially one-dimensional focus on individual SM, a social network approach focuses on available and underused collective support, and on behaviour change at a cognitive level. Social networks and good social support can have positive effects such as: 1) promotion of SM, 2) development of fewer psychosocial problems and 3) creation of a buffering effect during stressful situations (Rosland et al. 2008; Schiotz et al. 2012; Joensen et al. 2013; Joensen et al. 2018). Increased social involvement is linked to greater SM capacity and potentially lower formal health care costs, especially when this involvement is from a diverse set of network members, i.e. health professionals, close family as well as casual acquaintances, friends and

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groups (Rogers et al. 2011; Rogers et al. 2014). Social support networks can provide a means of mobilising, mediating and accessing support for health and well-being (Holt-Lunstad et al. 2017; Holt-Lunstad 2018). Even when focused on HCPs, rather than directly with patients, social networks have even been found to improve the rate of recovery after strokes (Hand 2019) where being part of a network of clinical expertise outside of the clinicians own clinic or hospital allows a widening of boundaries and both contribution and access to new knowledge.

The social network approach considers the individual in the context of the support and resources in their vicinity or personal network, who or what they access to support them self-manage and in what ways they utilise this support to self-manage. For example, social network members have been known to contribute in different ways to support SM. This can include “illness work” such as; medication regiment work, taking and interpreting biomedical measurements, understanding symptoms, making appointments etc., or “Everyday work” which can include housekeeping, child rearing, shopping, personal care etc., or “Emotional work”, which includes providing comfort when worried or anxious, companionship or support for well-being. In addition, contributions from new connections and reconfiguration of existing members (engaging in a new way), can result in an increase in social capital and improve access to resources and/or voluntary and community groups and organisations (Blickem et al. 2013; Portillo et al. 2015).

In terms of SM support for people with T1D and incorporating a complex new technology, autonomy support from network members in the personal community of the individual may contribute to better glycaemic control by ameliorating the effects of diabetes distress (Mohn et al. 2015). Interventions that reduce diabetes distress and enhance the autonomy supportiveness of informal supporters may be effective approaches to improving glycaemic control (Lee et al. 2018), while also prioritising the heightened need for personalised support when incorporating something new, unfamiliar and complex, such as an insulin pump. Autonomy support from network members enables people to feel in control and supported, while providing a perception of choice around SM practices. Meaningful choice that reflects the person’s values and interests and creates an environment which is supportive and receptive. Providing a way for people to build on and increase the capacity of their personal support network is a novel, and potentially powerful way to approach SM. Disruption of current patterns of SM but within the capacity of the individual, and personalised and tailored to their needs, with the necessary support to access and consider new approaches to self-manage could provide an innovative way to address the current translational gaps in NHS England’s desire to provide SM support but with the current apparent inability to do this, at least consistently. However, developing an appropriate intervention is potentially useful but implementing it effectively concerns another field all-together. Theory is important in developing interventions, but delivering an intervention in practice must also be

theory driven to increase chances of success (Craig et al. 2008). Implementation Science offers the opportunity to consider and close the gap between evidence-based interventions and implementation of such interventions – the translational gap.

2.2 Theory in Implementation Science

Sir David Cooksey's extensive review of health research funding highlighted the strength of research in the UK, but also identified the barriers to effective translation of research into health outcomes (Cooksey 2006). While there have been some significant successes translating this research into practice, the consensus was that the UK has failed to maximise the impact of its research. The consultation brought to light a number of concerns with the current arrangements for public funding of health research, including translations of ideas from research into new approaches and developments of new products, and implementing these ideas into practice, i.e. the translation of health research into improvements. The review identified that the NHS is under pressure to deliver service targets, and payments by results potentially impact on implementing research into the NHS. This is something identified in earlier PhD scoping work examining the process of commissioning of SM support (Reidy et al. 2016). Implementation Science utilizes strategies to adopt and integrate evidence-based health interventions within and across different settings (Eccles et al. 2009; Damschroder 2019). Improvement Science then enables us to begin to address the challenges we face in improving the health care provided and received by the nation. Improvement Science provides understanding of the key variables in implementation of evidence-based interventions, how quality and cost of services is or is not improved as a result, and what processes do and do not work within and across health systems (Damschroder et al. 2009; Lloyd et al. 2013; Kennedy et al. 2014).

The Health Foundation recently examined the uptake of innovations and improvements in the health service and provided recommendations to support uptake (Horton et al. 2018). They proposed that interventions often need adapting to fit in with different contexts, and that co-design with users (such as HCPs delivering interventions and people utilising the intervention for health benefits) is much more likely to ensure successful implementation of innovations. Adopters often make adaptations to interventions, which they deem necessary for implementation and innovators should utilize theoretical approaches in order to describe innovations in ways that allow adaptations for these new contexts – as part of a toolkit. Use of theory supports adoption by providing consistency and replicability of an intervention itself and the implementation processes. Real world testing of innovations is also key before spreading them, working out the mechanisms of practices, processes and pathways to an innovation. As a result, this PhD work incorporated Implementation Science and Improvement Science to; 1) Consider what the SM

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needs of people with T1D who are using an insulin pump are, 2) Identify the necessary contents of a health intervention to support SM 3) Ascertain what strategies are needed to implement this health intervention into practice and 4) Establish whether the proposed tool is acceptable for people with T1D using a pump.

2.2.1 Implementation considerations

Complex interventions, or rather interventions which are known to have several components, are increasingly being used in the health service to improve health outcomes (Craig et al. 2008, 2013), however implementation of innovations into practice is a complex process. The Medical Research Council propose that “Complex interventions may work best if tailored to local circumstances rather than being completely standardised” (Craig et al. 2013, p. 588) implicating the importance of adaptable interventions which are sensitive to the local context. They also declare the importance of providing detailed descriptions of the intervention at hand to ensure replicability, synthesis of evidence and implementation in other localities. This increases the chance of interventions being replicated, sustained and measured for success. Considering how an intervention is applied and sustained in a local context requires a process of feasibility testing. Feasibility testing enables the intervention to be tested in a particular context and adapted before being piloted prior to implementation. Feasibility and piloting needs not be a scaled intervention, but provides an opportunity to examine key uncertainties identified during development and acceptability of the intervention with the target population.

2.2.2 Identifying the content of and strategies for implementation of a self-management intervention

There are many implementation theories, frameworks and models to assist understanding of the processes of implementation of a health intervention (Nilsen 2015). Normalization Process Theory (NPT) was initially thought the most appropriate theoretical Implementation model for this PhD work as a highly tested means to consider implementation of health innovations in a wide variety of health settings (Bracher et al. 2019). NPT is an applied theoretical model designed to explore how and to what extent interventions have become routinely embedded in health care practice (normalization) (May and Finch 2009). It has utility for sensitizing the research to the reaction, incorporation or rejection of an intervention. NPT sensitises the analysis of implementation according to four processes; ‘Coherence’ how much the intervention makes sense to stakeholders, ‘Cognitive participation’ the commitment and collective engagement of stakeholders for the success of the intervention, ‘Collective action’ the facilitators and barriers which determine how much relational work is required for implementation and embedding of an

intervention, ‘Reflexive monitoring’ the continuous appraisal process which feeds back into the intervention to refine and appraise the intervention in order for it to become “normalised” (May and Finch 2009; Macfarlane and O’Reilly-de Brun 2012; Lloyd et al. 2013; Ong et al. 2014).

Initially this research intended to use NPT to assist coding of transcripts of interviews examining the feasibility of a SM intervention and to give insights into how the proposed intervention works in practice, the acceptability and uptake of the intervention and how this intervention impacted on care. However, it became apparent that there would need to be a change of focus, with a thorough exploration of the mechanisms of importance for a SM intervention when incorporating a new health technology (Stage 2), rather than a focus on feasibility. While acceptability and usefulness of a social network SM intervention was explored (Stage 3), the intervention was still under development through these Stages and so needed a theoretical approach that would instead focus much more heavily on the mechanisms of the intervention, rather than presuming the intervention was ready for testing (feasibility or pilot stage). NPT provides particular strengths in identifying and analysing prospective applications of interventions into practice, or retrospectively to explore social and organisational activities that have supported or hindered implementation (May et al. 2018), yet in this instance a theoretical focus which would support the identification of components of importance in developing an effective intervention was chosen. The Behaviour Change Wheel (BCW) was selected due to both its synchronicity with social cognitive theory and focus on the context in which a behaviour occurs (or does not occur), the reflective processes that are involved in behaviour change and its provision of a clear and direct strategy to bring about change (Michie et al. 2008; Michie et al. 2011; Cane et al. 2012; Michie et al. 2014) (see **Figure 5**).

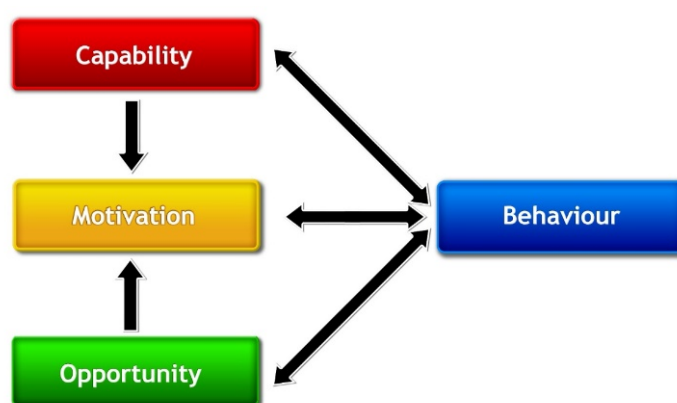


Figure 5: The Capability, Opportunity, Motivation – Behaviour Model (COM-B), the central cog of the Behaviour Change Wheel (Michie et al., 2011)

2.2.2.1 The Behaviour Change Wheel

The BCW came about when Michie et al. synthesised 19 frameworks of behaviour change interventions to create an overarching framework to provide a clear all-encompassing model of behaviour (See **Figure 6**) (Michie et al. 2011). This synthesis allowed for association of theoretical constructs with successful behaviour change in a variety of health settings. The BCW is an overarching framework which has the advantage of being a middle range theory that could be applied at an individual, group or environmental level.

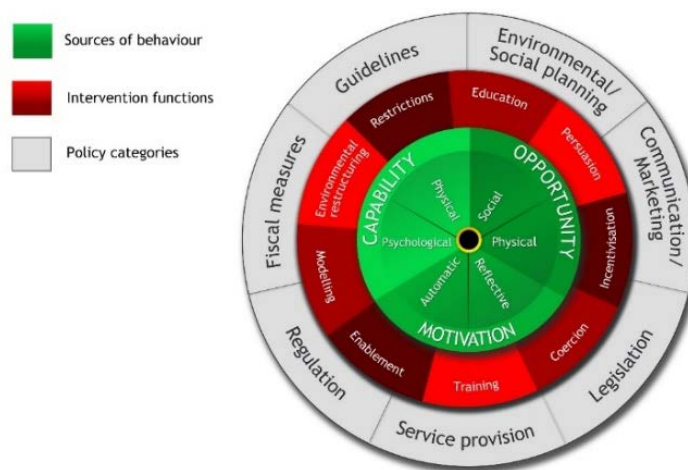


Figure 6. Determining the potential mechanisms of action of an intervention using the Behaviour Change Wheel

The centre of the BCW consists of the Capability, Motivation and Opportunity model (COM-B) which aids understanding of barriers and facilitators of behaviour in context. The central cog of the BCW consists of the Capability, Opportunity, Motivation – Behaviour (COM-B) components (See **Figure 5**). This is based on the premise that in order to initiate behaviour change there is a need to; maximise physical or psychological “Capability” to regulate behaviour (i.e. develop relevant skills), increase or decrease automatic or reflective “Motivation” to engage in desired/undesired behaviour, and target the physical or social “Opportunity” to support behaviour change. The COM-B offers understanding of barriers and enablers of behaviour. The BCW framework then allows systematic identification of intervention functions to address the behavioural targets for intervention. For example, if lack of knowledge (“psychological capability”) prevents SM then “education” would be targeted in the intervention design to address this. Applying the COM-B model helps formulate a “behavioural diagnosis” for a problem, and results in behavioural targets to address in intervention design (See **Figure 7**). The matrix offers guidance for selecting intervention functions that are more likely to address the behavioural targets that have been identified.

	Intervention functions									
	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	Environmental restructuring	Modelling	Enablement	
Physical capability										
Psychological capability										
Physical opportunity										
Social opportunity										
Automatic motivation										
Reflective motivation										

Figure 7. Intervention function mapping matrix

2.2.2.2 The Theoretical Domains Framework (TDF)

The Theoretical Domains Framework (TDF) was utilized to provide a more comprehensive behavioural analysis than using individual theories or the BCW alone (Cane et al. 2012; Michie et al. 2014). The TDF compounds 84 constructs from multiple psychological theories (motivational, action, and organizational theories) and consists of 14 domains of theoretical constructs (Michie et al. 2005; Cane et al. 2012; Atkins et al. 2017). The TDF provides a useful framework for understanding the barriers and factors influencing specific behaviours (Cane et al. 2012; Curtis et al. 2015; Phillips et al. 2015). It provides detailed analysis of the potentially modifiable factors linked with the BCW (the COM-B components in the central cog of the wheel) to target in an intervention. In this instance the BCW and TDF (See **Figure 8**) provided a guiding framework for the tailoring and development of an online social network SM support intervention.

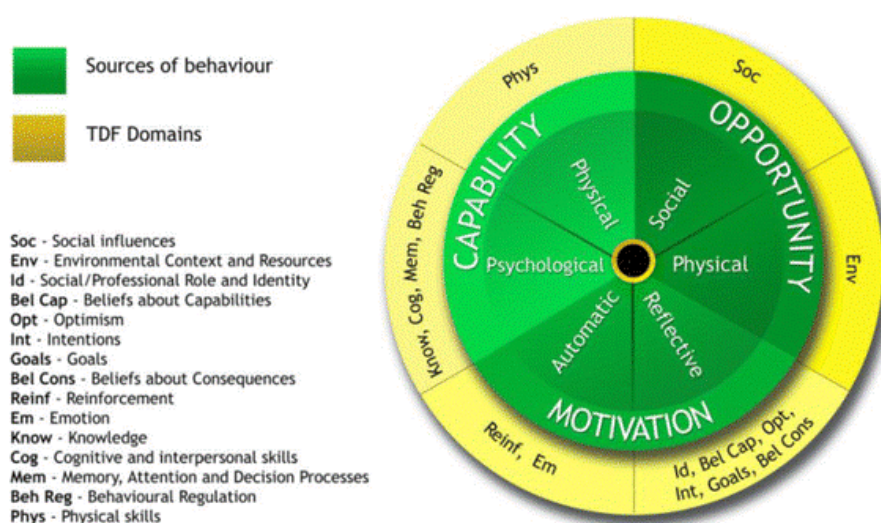


Figure 8. The 14 domains of the Theoretical Domains Framework structured according to the COM-B model

2.2.2.3 Behaviour Change Techniques

Behaviour Change Techniques (BCT) represent strategies that can be applied in interventions intervention development as active components of an intervention (such as with the BCW and TDF above). They are the components and actions of the intervention which are applied to daily life to help an individual change their behaviour in order to improve their health – this can be within the intervention of in applying the intervention in a context. Examples of which include; problem solving, instruction on how to perform a behaviour, restructuring the environment (social or physical), goal setting, focusing on past success etc. BCTs are regarded as active components of behaviour change, and are an agreed and standardised method of describing the context of interventions to assist in the observability, measurability and replicability of an intervention. The COM-B model is complimented by Michie et al.'s taxonomy of BCTs (BCT Taxonomy v1) (Michie et al. 2013) (See Appendix A). This taxonomy of 93 BCTs which are compiled into 16 groupings provides a standardised method of classifying the content of an intervention. The grouping are; 1) Goals and planning, 2) Feedback and monitoring, 3) Social support, 4) Shaping knowledge, 5) Natural consequences, 6) Comparisons of behaviour, 7) Associations, 8) Repetition and substitution, 9) Comparison of outcomes, 10) Reward and threat, 11) Regulation, 12) Antecedents, 13) Identity, 14) Scheduled consequences, 15) Self-belief, 16) Covert learning. These groupings have been distinguished in addressing potentially important areas of Capability, Opportunity and/or Motivation (Michie et al. 2011; Michie et al. 2014). A distinction can them be made between the content needs of the intervention and the way in which the intervention is delivered (the context). The BCT Taxonomy (v1) was used in this work to determine specific techniques within the proposed SM intervention for both the context of the intervention, and the strategies for implementation using a widely used and replicable format.

2.3 Summary

Use of theory can be a catalyst for implementation of effective and sustainable interventions in health through access to generalized and applicable knowledge (Damschroder 2019). This knowledge allows reliable translation of the evidence base into routine practice in order to incite the most benefit for people using the health service, which is of particular importance in this work striving to develop a means to support SM that is evidence-based and innovative, yet with a central and decisive focus on the evidence-based needs of the end user.

Utilising social cognitive theory and a social network approach has prioritised looking at the individual and the context in which they are situated, their motivations, as well as the setting in which the proposed intervention to support SM will be provided. This provides a unique and

inclusive approach to address SM in a way which has been overlooked traditionally. Social cognitive theory focuses on the bi-directional behavioural influences and impacts of the reciprocity between personal and cognitive factors, environment and behaviour, providing areas to consider and focus on. The social network approach focuses on the relational work of social networks, examining how the network around the individual can provide a resource for SM, and a framework to offer a pragmatic and flexible intervention which is responsive to individual needs, preferences and circumstance. This provides both a pragmatic approach to developing and implementing an intervention and also one which can be evaluated, replicated and sustained.

The use of theory driven intervention development here signifies areas of key importance to informing either developing, adapting or implementing an intervention into practice – in terms of behavioural reflective needs and contextual factors for implementation, and a key process to follow. The use of the BCW, TDF and BCTs sensitises the research to future intervention needs and considerations across different localities. This approach has allowed for an evidence-based, theory driven framework to determine the needs and requirements of an intervention in practice, both in terms of content and deliverables (context). In this instance it has allowed for identification of an intervention (called GENIE – described further in Chapter 1) and assessment of what needs to be added to the intervention or adapted or considered for the purpose of implementation to support people with T1D and an insulin pump to self-manage. These have been described in the findings and discussion within Chapter 1. Utilisation of theory is an important means by which to consider and incorporate the development or identification of evidence-based innovations (Damschroder 2019). Use of well-developed theory has allowed for assessment and understanding of the diverse contexts of implementation, appropriate adaptation of the innovation and opportunities to develop the execution of implementation strategies which are tailored to the context in which the innovation is to be situated and sustained over time.

Chapter 3 Methodology

3.1 Introduction

This research is orientated to systematically studying and understanding the lived experience of people with T1D who are incorporating a new technology as well as their SM needs over the process of incorporation and ultimately informs the adaptation and implementation of a tool which can more realistically and practically aid improvements for SM. GENIE is an existing SM intervention which was developed using a social network approach and is a tool which has been implemented with long-term conditions, although not yet specifically in T1D or in terms of incorporation of a new health technology. The network approach in combination with individual factors offers a more complete and comprehensive lens in which to consider the opportunity and ability to self-manage. This research explores the SM needs of this population and the potential of implementing a social network intervention such as GENIE to support people with T1D incorporate a new health technology.

This thesis has been prepared in alternative thesis format, whereby three papers constitute the core of the thesis. In combination with the papers, this chapter provides a rationale for the methods used, the purpose of which was to address the research questions of this work (see below). The findings and specific methods used are reported within the three papers.

1. What is the process of incorporating an insulin pump into the everyday lives of people with T1D?
2. Are there strategies which are likely to lead to an insulin pump being embedded and strategies that are not?
3. What are the elements that help and hinder incorporation?
4. What are the behaviour change characteristics and strategies required to support SM using a web-based tool for people with T1D and an insulin pump?
5. What are the specific behavioural change characteristics and mechanisms that impact on implementing a web-based SM support tool into NHS practice?
6. In what ways does GENIE need to be adapted or implemented to support people with T1D and an insulin pump?
7. What are the practical and emotional means of support required upon initiation of insulin pump therapy, and how do these needs change over time?
8. How can a social network intervention, such as GENIE, support this process of incorporation?

Chapter 3

Methods used were: A systematic review combined with a mixed-method approach using qualitative (semi-structured interviews, focus groups) and quantitative (questionnaires, glycaemic outcomes, activity uptake and social network mapping) was used for the three papers; using separate approaches and data sources to better illuminate the overall phenomena of incorporation of insulin pumps in T1D. The stages of the research were:

Stage 1) a systematic review and critical interpretative synthesis of the literature, to critically examine what is already known about the lived experience of insulin pump therapy and to provide an up-to-date overview and understanding (addressing Research questions 1, 2 and 3),

Stage 2) Focus groups with insulin pump users and specialist health care professionals (HCPs), to evaluate the perspectives and experiences of people with T1D using an insulin pump and specialist HCPs to examine the barriers and enablers to incorporating and self-managing an insulin pump and determine what behaviour change characteristics and strategies are required to identify the contents of and strategies for implementation of a complex health intervention (addressing Research questions 4, 5 and 6),

Stage 3) a mixed-methods study utilising longitudinal semi-structured interviews, social network mapping (using concentric circles) and resource elicitation (activity uptake) using a social network tool (GENIE), validated self-administered questionnaires (PAID, CLARKE) and glycaemic outcomes (HbA1c) from baseline, 3 and 6 months on from insulin pump initiation to explore and locate participant's expectations and experiences of pump therapy and the support and resources required through these time-points, and to examine the acceptability of the GENIE tool (addressing Research questions 7 and 8).

A summary of how these three papers connect and inform each other are demonstrated in **Figure 9** below.

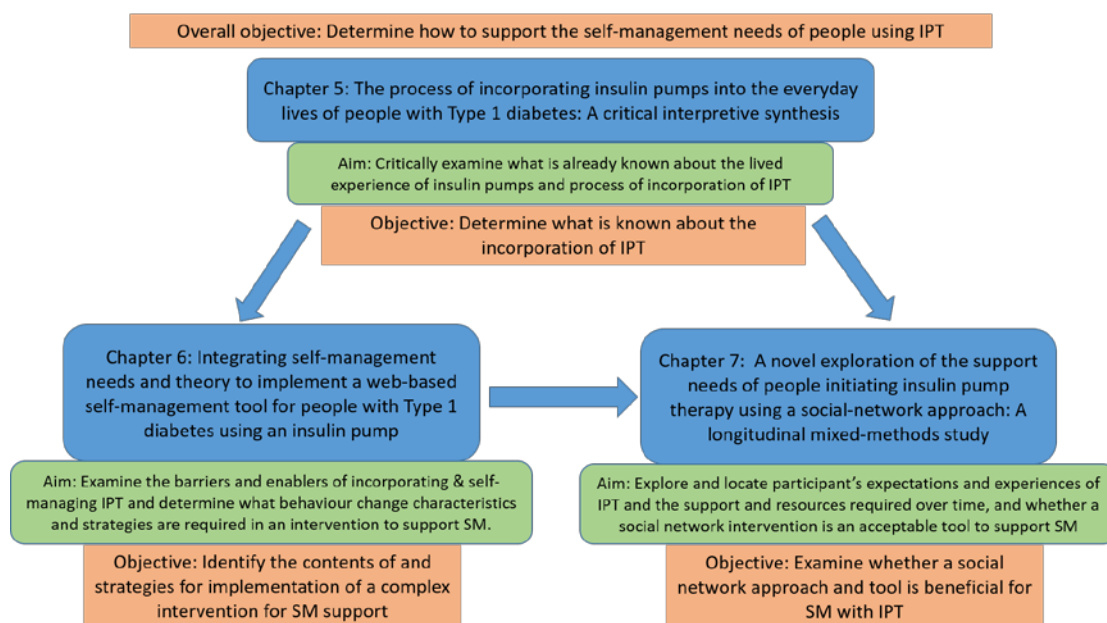


Figure 9. Model showing the inter-relationships between the papers that constitute the core of the thesis

The research questions, aims and objectives for each stage of the research will be discussed in more detail in this chapter. In addition, the decision to use the different methodological approaches will be outlined, including the rationale for the methods that were used. This chapter will offer detailed discussion of the methods and methodologies used in each of the empirical papers, general methodological considerations that were common across each of the studies and reflections of undertaking the research.

3.2 Stage one: The process of incorporating insulin pumps into the everyday lives of people with Type 1 diabetes: A critical interpretive synthesis

Stage 1 of the PhD involved a systematic review and critical interpretive synthesis (CIS) to build on earlier reviews and critically examine what is already known about the lived experience of insulin pumps and provide a current and in-depth exploration of user experience, and those integrally involved in or impacting on this experience (i.e. parents/caregivers/health care professionals (HCPs)). The aim was to offer enhanced understanding of mechanisms that shape the incorporation, adaptation, and use of pump therapy into the everyday lives of people living with diabetes, and establish what support and resources are needed to enable this. This paper was published in *Health Expectations* (Reidy et al. 2018) in February 2018.

3.2.1 Research questions

1. What are the factors that help and hinder incorporation?
2. What strategies are likely to lead to the insulin pump being embedded, and what are not?
3. What resources and support do people with T1D use to incorporate an insulin pump into their everyday lives?

3.2.2 Objectives

1. Illuminate the range of data regarding what we know about the experience and influence of incorporating, adaptation to and use of an insulin pump in order to understand the process of incorporation and subsequent SM needs.
2. Consolidate and critically evaluate research that examines the experience of living with pump therapy in order to determine the factors which may enable someone to incorporate a pump into their everyday lives.
3. Explore potential ways patients can navigate incorporating an insulin pump into their lives, be it socially, psychologically, practically or by tapping into potential resources (physical/psychological/social), and what the role of others are in this navigation.

3.2.3 Rationale for chosen methods

CIS is an exploratory method of reviewing the literature focused on generation of theory, rather than hypothesis testing, where relevance takes priority over quality in decisions about inclusion and various techniques can be utilised in synthesising findings (Dixon-Woods et al. 2006). The methods of CIS were used to identify domains from the literature that are key to successfully incorporating insulin pump therapy.

Like many areas of healthcare provision, the literature on integration of technology for people with T1D is large, diverse and complex, including empirical work using both qualitative and quantitative methods as well as policy documentation. Integration, or process of integration into everyday life, has not been consistently defined or explained across the field (O’Kane et al. 2015). There is substantial adjunct literature including those which examine the effects of insulin pump therapy on everyday life, perceptions of psychosocial factors of the insulin pump, experiences of using an insulin pump, and comparison of metabolic and psychological parameters of using an insulin pump. It was felt that traditional systematic searches may exclude some important work included in the grey literature, and that a more inclusive and organic process may be more effective, and fit better with the emergent and exploratory nature of the review questions. This included searching electronic databases; websites; and reference chaining.

A review of the area was considered of most benefit if it were to produce a “mid-range” theoretical account of the evidence and existing theory that is neither so abstract that it lacks empirical accountability nor so specific that its explanatory scope is limited. The aim was therefore less defined and more exploratory. A CIS allowed for a pragmatic exploration of the range of data available and to understand the factors which enable someone to incorporate an insulin pump into their everyday life. CIS also allowed modification of the research question in response to the findings, the question being “a compass rather than an anchor” (Eakin and Mykhalovskiy 2003) which was particularly helpful in consideration of this stage as a scoping stage to consider what was already known about the process of incorporating an insulin pump to inform the next steps of how to support someone to incorporate this new technology. The review had three stages: 1. Systematic search, 2. Critical appraisal and 3. Synthesis, which allowed for a structured process of literature searching and collation, followed by a process of critical evaluation and synthesis of the findings (presented in Chapter 1).

3.3 Collaborations:

Relationships were established with the following NHS trusts on the south coast that host insulin pump services, for the purposes of recruitment of insulin pump users and HCPs for Stages 2 and 3 of this research.

- Hampshire Hospital Foundation Trust Royal Hampshire County Hospital, Winchester) Stage 2 and 3)
- University Hospital Southampton NHS Foundation Trust (Southampton General Hospital, Southampton) (Stage 2 (patients only) and Stage 3)
- The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust (Royal Bournemouth Hospital, Bournemouth) (Stage 2 and 3)
- Portsmouth Hospitals NHS Trust (Queen Alexandra Hospital, Portsmouth) (Stage 2 and 3)
- Western Sussex Hospitals NHS trust (St Richard's Hospital, Chichester) (Stage 2)
- Torbay and South Devon NHS Foundation Trust (Torbay Hospital) (Stage 2)

These relationships were established in various ways. Southampton General Hospital insulin pump clinic were directly contacted enquiring as to whether they would be interested in being a site to implement GENIE with some of their new pump users. A follow-up meeting established what the GENIE tool was and the objectives for study (Stage 2 and 3). Snowball sampling was utilised whereby Southampton General Hospital HCPs identified colleagues to approach in Royal Bournemouth Hospital and Royal Hampshire County Hospital. Purposeful sampling was utilised in the following Trusts; the Queen Alexandra Hospital – where a known contact in the diabetes clinic

was emailed, and who then signposted to HCPs in the insulin pump clinic at that site; St Richard's Hospital where their lead Consultant was contacted via publically available email address and a meeting arranged whereby the purpose and objectives of the study were explained. Opportunity sampling was applied to Torbay Hospital whereby a senior colleague at The Health Foundation introduced the author to the lead Consultant at the diabetes clinic who was interested in taking part.

3.4 Stage 2: Integrating self-management needs and theory to implement a web-based self-management tool for people with Type 1 diabetes using an insulin pump

Stage 2 utilised focus groups with insulin pump users and HCPs to examine problems and challenges of SM using insulin pumps and utilised the BCW, and TDF to inform an appropriate intervention. Themes were identified to inform the requirements of an intervention to support SM of people with T1D utilizing pump therapy. BCT techniques were identified to address these issues, which then enabled intervention characteristics and strategies to be formed for an intervention to support people to incorporate the device. This paper is currently “under review” at the Journal of Medical Internet Research (JMIR) (Reidy et al. Under review) (as of 9th April 2019).

3.4.1 Research questions

1. What strategies, resources and social support do pump users need and use from the point of initiation of insulin pump therapy and do these needs change over time?
2. In what ways does a social network intervention need to be adapted or implemented in order for it to meet the SM needs of insulin pump users?
3. Does a social networking tool fit in with the priorities of insulin pump clinicians?

3.4.2 Objectives

1. Engage with pump users to identify what and how strategies, resources and social support have been accessed from the point of initiation of pump therapy, and why they chose these resources.
2. Identify how pump users think a social network tool can be appropriately and effectively adapted and implemented for people living with a pump.
3. Explore the factors which would impact on whether and how a social networking tool can be implemented with people with T1D and in practice.

3.4.3 Rationale

3.4.3.1 Focus groups with people living with diabetes

Focus groups with pump users provided the opportunity to explore the range of views and perspectives of the support required and resources used by current pump users, retrospectively, from pump initiation to their current point of use. Focus groups also allowed for exploration of the potential of a social network SM tool to adapt the tool to their specific needs.

Focus groups were used as the group dynamics that they afford facilitated discussion. This discussion provide a context for participants to explore their ideas, beliefs and values (Barbour 2007) around the process of incorporation and how a SM support tool may help, and how, and the associated outcomes of importance. Focus groups are excellent for generating debate and identifying areas of consensus and disagreement (Finch 2003). Their interactive nature can facilitate discussion, debate and possibly disagreement between participants (Green 2009). Utilising this interview method can enable exposure to the interaction between participants and any reflections they make through the discussion. This is advantageous as it provides insights into how knowledge relating to experiences and practises of SM are produced and reproduced.

In order to provide sufficient (although not exhaustive) information on the needs of pump users, and congruent with other similar health studies using this method, where samples often range from 12–40 participants over three to six focus groups (Tammaru et al. 2010; Cooke and Thackray 2012; Dasgupta et al. 2013; Carolan et al. 2015), it was decided that four focus groups of three to eight individuals would need to be conducted using a number of open-ended questions. This number of focus groups was chosen as likely to stimulate enhanced disclosure and a supportive environment which stimulates shared perceptions, elaborated accounts and clarification of experiences (Wilkinson 1998). Participants in the focus groups held an advisory capacity for the adaption of a social network intervention according to the needs of pump users and T1D specialist HCPs.

Participants were purposively sampled from participating NHS insulin pump clinics localities in consideration of different social groups (parents/non-parents, different ages, length of diabetes diagnosis etc.) to determine SM needs and experiences with an insulin pump and to inform the development of a social network intervention to ensure any intervention would be fit for purpose, and developed appropriately according to the needs of a variety of pump users and within the context of secondary care.

3.4.3.2 Focus groups with HCPs

Focus groups with HCPs allowed for exploration of how a social network tool could fit into NHS practice. Focus groups were undertaken at regular monthly staff meetings within NHS insulin pump clinics in n=5 secondary care settings, meaning that no additional effort was required from the HCPs in order to participate. This was designed to maximise recruitment from busy insulin pump clinics. Focus groups were deemed as the best way to explore this topic with insulin pump clinicians; the group environment was considered a strength for discussion of implementing a social network tool into practice. The focus group offered an opportunity for individual HCPs to respond to and build on others' comments, and brainstorm ideas. Insulin pump clinics were purposively sampled from the wider region to reflect differing levels of deprivation and population density within areas across the region.

3.4.4 Recruitment and sampling

The source of participants who were current pump users was via posters (Advert: Appendix C) through diabetes community groups (both offline and online, such as Diabetes UK local groups and peer-support groups such as 'Sugar Buddies' and 'Insulin Synonymous'), through Twitter and in Specialist NHS pump clinics. Participant information sheets (Appendix D) were sent to interested parties and invited to request any further information or have questions answered directly by the researcher.

HCPs were recruited through main contacts with insulin pump services via email and distributed through main point of contacts through their teams, and face-to-face invites. A letter of invitation (Appendix E) and Participant information sheets (Appendix F) was provided.

Opportunistic sampling for recruitment of current pump users was difficult over summertime where getting a group of people in one location at a mutually convenient time was problematic. Recruitment improved in early autumn (September) and with the support from local clinics telling their patients about the focus groups they were much easier to arrange.

Purposive sampling of HCPs worked well in some clinics where they had regular team meetings and were happy for the author to come along, but for other clinics which were more disorganised and experiencing staff sickness and annual leave it was much more difficult to arrange. As a result once clinic's Consultant arranged an interview with the author as an alternative option and the researcher had to be persistent, consistent and flexible for other clinics.

3.4.5 Identification of a potential social network Intervention


Stage 2 of this research identified the characteristics and BCTs required for an intervention to support SM of a person with T1D incorporating insulin pump therapy. Table 8, Table 9, outline the mechanisms and requirements of such an intervention and Table 10 determines the potentially active ingredients of potentially suitable intervention named GENIE (Reflective processes) and consideration of the delivery/implementation of this potentially suitable intervention (Strategy processes). Here a background is provided pertaining to the identified intervention and what adaptations were made prior to implementation with people initiating pump therapy in Stage 3 of this research.

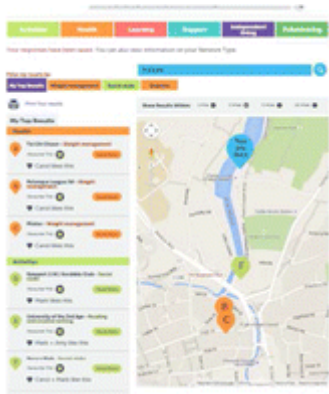
3.4.5.1 Generating Engagement In Network Involvement (GENIE), a web-based self-management intervention

In their appraisal of social network theory and analysis applied to public health, Valente and Pitts (Valente and Pitts 2017) declare that social networks may have a crucial part to play in health behaviours, and should be considered and integrated when designing interventions. These recommendations compliment the social network approach and access to personalised resources provided through GENIE; which offers the mapping of social support and a gateway to further support (Kennedy et al. 2016). Generating Engagement In Network Involvement (GENIE) is a web-based SM tool that has been developed based on the role that social networks play in SM and the need for a system-wide approach in health management (Rogers et al. 2011; Blakeman et al. 2014; Reeves et al. 2014; Koetsenruijter et al. 2015). GENIE was developed using a multi-level network approach to person centred SM support in response to findings that social involvement with a wider variety of people and groups supports personal SM, emotional and physical well-being (Fiori et al. 2006; Vassilev et al. 2011; Vassilev et al. 2016). GENIE offers engagement with and introduction to social change. GENIE was designed to have direct user impact through diversifying and improving support networks. It aims to do this by: 1) raising awareness of a persons' support network in order to reflect on what is currently provided to them, and to what personal effect; 2) explore the capacity and feasibility of opportunities to navigate their network support (and to re-negotiate existing relationships and roles); 3) to introduce access to resources (both online and offline); 4) to increase social capital through change in network structure; and 5) to incite improvements in wellbeing and quality of life. The tool works through the mapping and reflection of personal network membership and sign-posting to local resources of support which the participant chooses and values (Vassilev et al. 2015; Vassilev et al. 2019) (See **Table 1**). It is a social network tool that helps patients map their social network and makes best use of their existing contacts and add new ones where needed. This is influenced by Pahl and Spencer's (Pahl

and Spencer 2004) appraisal on personal communities, which affirms how individuals are embedded in complex relational work within personal communities, and that diverse relationships can substitute and facilitate the social environment which ultimately impacts on lived experience and health.

Table 1: GENIE elements (taken from Kennedy et al. 2016)

Elements	Details	Theory of how it works
Filter questions	The process starts with questions to provide details of the user’s context. This includes postcode; gender; age and health condition.	<ul style="list-style-type: none"> • Providing filter questions allows tailoring of suggestions and helps to reduce choice at the preference stage.
Concentric circles: Stage 1 	<p>Social network members (family, friends, groups, professionals) are represented and mapped, depending on subjective importance, onto three concentric circles. Details of relationship and frequency of contact are recorded.</p> <ul style="list-style-type: none"> • Support work can be: illness-related (taking medications and measurements, understanding symptoms, making appointments); everyday (housekeeping, child rearing, support for diet and exercise, shopping, personal care); or emotional (comforting when worried or anxious, well-being, companionship). 	<ul style="list-style-type: none"> • To explore everyday relationships and how network members contribute to support • To note change over time • To provide a visual image to enable engagement • To help people become conscious and reflexive of contributions made by others to self-management support (SMS) • As starting point for a discussion about how to extend existing support, access support from new sources, or change existing practice.

Elements	Details	Theory of how it works
<p>Typologies: Stage 1</p>	<p>Feedback and a summary is provided on network types:</p> <p>Diverse - family, friends, and community groups with <i>regular frequent contact</i>;</p> <p>Friend and/or family centred – mainly friends and/or family members with <i>regular contact and support</i>;</p> <p>Friend and/or family contact - some mostly friends and/or family members with <i>limited or patchy support</i>;</p> <p>Isolated or professional contacts only</p>	<ul style="list-style-type: none"> • To help people become conscious and reflexive of network structure and availability of SMS • Act as a prompt for healthcare professionals and others to take action where there are obviously fragile networks
<p>Preferences: Stages 2,3,4</p> 	<p>The user co-produces and owns the network map.</p> <p>Choices are tailored using a series of questions and based on preference and enjoyment rather than on health-based need. For example, the facilitator prompts by asking:</p> <p>“Are there things you used to do that you don’t do anymore? What stopped you from continuing to do these things?”</p> <p>This gives clues about how to</p>	<ul style="list-style-type: none"> • Non-intrusive methods are more effective than highly directive approaches which often fail because they do not deal with existing relationships to negotiate time and space for new activities (intimidating to attempt by oneself) or needing help with transport • The user is made a capable and willing to reciprocate participant • To reduce choice and complexities arising from

Elements	Details	Theory of how it works
	<p>identify the most relevant type of support, the likely barriers they may encounter, and how to encourage them to restart these activities.</p> <p>Network members are selected as potential buddies to accompany them to new activities.</p> <p>Asked to select the three activities or resources they are most interested in and agree to try them out. The locations of the activities are displayed on a Google-based map.</p>	<p>information overload counterproductive for learning, social engagement and social support particularly where there is poor health literacy.</p>
<p>Links to Voluntary and Community Organisations (VCOs): Stages 2,3,4</p>	<p>The preference questions link to community resources in a pre-created database.</p> <p>Categories in the database include: activities and hobbies, health, learning, support, independent living and volunteering</p>	<ul style="list-style-type: none"> • Diverse networks which include VCOs enhance health and well-being through providing access to new acquaintances for advice, support and links to resources are often missing where there is reliance on strong family ties. • Support from VCOs is non-clinical. • Specific benefits for people who are isolated.

A social network intervention builds on the foundation that diverse social networks, connectivity, and good social support promote SM through acquisition and dispersion of illness-work and

mobilisation of resources, with resulting improvements in physical and mental well-being (Gallant 2003; Wysocki and Greco 2006; Rosland et al. 2008; Schiotz et al. 2012; Joensen et al. 2013; Reeves et al. 2014). As well as the theoretical and pragmatic importance of social network members, there is a distinct importance of autonomy and control in providing SM support on the terms of the person living with the long-term-condition (Chapple and Rogers 1999; Kennedy et al. 2016). With this in mind, GENIE focuses on the needs of the user, the relational work within the network and also strategies for linking people to personalised wider resources through engaging social networks and local support online.

A trial of an earlier version GENIE demonstrated improved patient outcomes such as quality of life, engagement and health outcomes (Blakeman et al. 2014), in addition to health service use reduction and cost-savings (Reeves et al. 2014). GENIE was designed to have direct user impact through diversifying and improving support networks and was implemented amongst an isolated population of people living with Type 2 diabetes from 2014-2015 (Kennedy et al. 2016). The GENIE intervention involves mapping and visualization of an individual's social network, preference elicitation and links to network members, links to activities and both local and web-based resources. A social network intervention offers an alternative opportunity to address health and social needs in an increasingly resource-stretched NHS. Kennedy et al. found that the opportunity to engage in SM by means of their own personal needs and requirements enabled participants to increase their capacity and confidence for managing their illness (Kennedy et al. 2016).

3.4.5.1.1 Concentric circles

The concentric circles element of GENIE raises awareness of the user's support network, encouraging reflection of what is currently provided to them, and to what personal effect, enabling unique exposure and opportunities to navigate network support (and to re-negotiate existing relationships and roles). It consists of completion of an egocentric social network map by the participant (See **Figure 10**). The participant is asked who or what (including services, groups and objects) helps them self-manage and in what way. These contributions are labelled as network members and are categorised (Family member, Friend, Group, Health professional or Other) and then specified further e.g. Spouse. The participant is asked how frequently they interact with this network member (daily, at least once a week, at least once a month, less often) and places the network member within one of the three circles – the outer most circle representing a network member that they value (or are "important"), the next circle representing "more important" for SM and the inner most circle "very important", allowing for representation of diverse contacts in overlapping and varied roles (Pahl and Spencer 2004). In earlier studies rich data offered network characteristics that described the role of network members and how they

related to engagement in condition management (Rogers et al. 2011; Vassilev et al. 2013) and so are deemed valuable in explaining the processes involved in the role of network members in SM support. Typologies of these network members have been built into GENIE and are attributed as demonstrated in **Table 1** according to; count of network members, type of network member (variety) and frequency of contact.

Kennedy et al. (Kennedy et al. 2016) found that the visualisation of the participant's network enabled people to mobilise support in their networks and engage in new activities, especially in relation to making people aware of and linking to already available local resources.

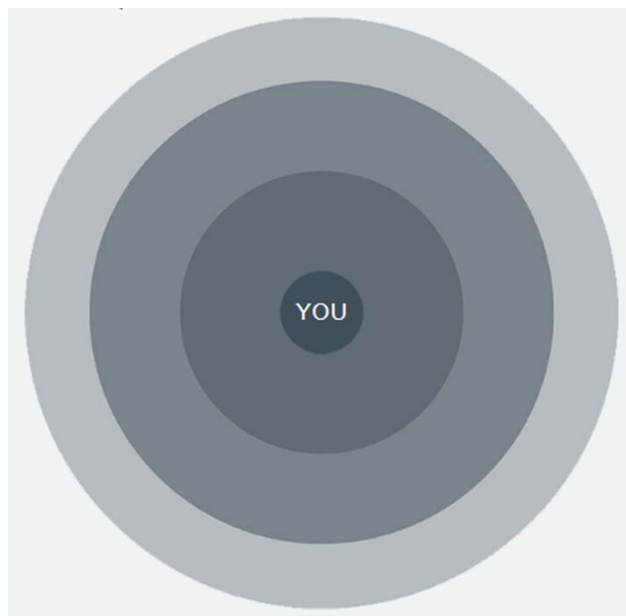


Figure 10. Concentric circles

3.4.5.1.2 Facilitation of GENIE

The facilitation process that accompanies GENIE is considered a fundamental and key component for the process of reflection of social network composition and linking to preferred activities (Kennedy et al. 2016). The facilitator guides the user through creating a visual map of the current support network, supporting the user to conceptualise themselves in a personal network of support and explore relational dynamics, then guiding the user through the 13 preference questions, supporting them to focus on their interests and needs, and then facilitating discussions around prioritising and accessing the preferred local and online resources. In Kennedy et al.'s (Kennedy et al. 2016) implementation of GENIE local Health Trainers and Care Navigators took on the role of Facilitator, and it was thought that lay facilitators could provide more enabling, encouraging and accessible support and facilitation than more formal healthcare professionals (Kennedy et al. 2016; Band et al. 2019). The perceived lack of status of the facilitator, as a 'lay'

role, assisted engagement and constructive discussion. The facilitation process fostered trust, enabling the facilitator to move the participant forwards (or nudging) with respect to thinking about how to build on, or strengthen, their existing social network, increasing participant focus, motivation and more honest, detailed responses (Kennedy et al. 2016).

3.4.6 Identified adaptations and considerations of implementing GENIE

3.4.6.1 A linked database

A facilitated social network tool such as GENIE depends on the quality of the activities and resources within the database within the tool. This element relies on both the local knowledge of the Facilitator (or the author in this instance), and also on the pre-created database on the tool itself. GENIE holds a database of local and online resources categorised as health-related information, activities relating to exercise (e.g. swimming, walking groups), weight loss groups, volunteering, education, hobbies etc. This database requires upkeep and quality input, which has the potential to create either extra workload and/or extra cost to recruit someone into a role to populate it and to maintain it. In this instance the author populated GENIE with T1D- and pump-specific resources identified through Stage 2 (See Chapter 1 findings) – which were identified within the focus groups, either directly (e.g. specific websites for T1D and exercise) or requested (e.g. “are there any local diabetes peer-support groups?”). This was a resource heavy activity that required updating every one-two months to ensure that resources were still relevant and current. This initial output and upkeep or workload would need to be taken into account in any feasibility testing for further implementation of such a tool. Further, at times there were a lack of suitable resources locally, which could lead to disappointing outputs from the tool, especially when one area had the identified resources and another neighbouring area did not, however, this does offer the opportunity to identify where there are gaps in local resources.

3.4.6.2 Training and recruitment of facilitators

Facilitation plays an important role and this comes with restrictions in recruitment; specifically in terms of the role to be undertaken in a lay capacity, rather than a professional healthcare worker (Kennedy et al. 2016). While this presents lower staff costs to support the intervention this does require either linking into current lay roles (Health Trainers, volunteers, support workers, care navigators), or having to create new roles, with added burden of set-up and sustainability. This would impact on how and where an intervention such as this could be implemented. Facilitation also means that this intervention is best introduced on a one-to-one basis rather than remotely.

Currently GENIE Facilitators receive a half day training, which the author has received, and which provides a background to a social network approach, demonstration of the tool, exercises to practice the tool and support to build the database. This can be resource intensive but enables Facilitators the confidence to deliver facilitation of the tool and ask questions and access support to deliver GENIE from the central GENIE team within the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Wessex team who developed the tool. The author took on the role of Facilitator in this research and had access to this support to query any technical issues with the tool (such as which browsers to use).

3.5 Stage 3: A novel exploration of the support needs of people initiating insulin pump therapy using a social-network approach: A longitudinal mixed-methods study

Stage 3 consisted of longitudinal qualitative semi-structured interviews, clinical outcomes which included validated questionnaires (PAID (Polonsky et al. 1995), CLARKE) and HbA1c from baseline, 3 and 6 months on from pump therapy initiation. Prior to introducing an intervention into wider clinical services, clinical effectiveness recommends exploring the acceptability on a smaller proportion of the patient population in order to understand the benefits prior to feasibility or full scale implementation, and so this tool was implemented with n=16 people who were just starting to use a new technology (an insulin pump) as opposed to a wider audience. Thematic analysis was used with sequential, time-ordered matrices along with assessment of the GENIE outcomes (uptake of activities and number, frequency and value of network members from baseline, 3 months and 6 months on) and change in survey responses and glycaemic outcomes (HbA1c). This phase aimed to establish what practical and emotional means of support are required upon initiation of pump therapy and to determine whether and how needs change over time using a social-network intervention, and whether this kind of intervention was acceptable and improved SM through uptake of activities and new or renegotiated network members. This paper was published in Diabetic Medicine in October 2019 (Reidy et al. 2019a).

3.5.1 Research questions

1. What support and resources do people with an insulin pump desire and utilize in the first six months of insulin pump therapy?
2. How do the needs of pump users change over time and/or in crisis from the point of initiation?

3. As an improvement tool, does a social network tool such as GENIE support SM for people living with an insulin pump, and if so, how?

3.5.2 Objectives

1. Use Genie to map the social network members, objects and resource utilisation of people starting on insulin pump therapy and follow-up them for six months to explore their support needs over this time.
2. Examine whether and how the needs of pump users change over time and whether this varies in times of struggle or crisis (i.e. sickness, changing batteries, attaching the pump to the body, Diabetic ketoacidosis, hospitalisation).
3. Explore whether and how pump users find benefit in mapping their social support and being facilitated to a means to connect with new resources

3.5.3 Recruitment and sampling

For Stage 3, the sole source of participants was through liaising with insulin pump Specialist services and clinicians on the South Coast of England. Initially, prior to study commencement, presentations were made to clinicians working within these clinics outlining the study details and eligibility criteria. Routes to recruitment were flexible so that potential participants could be invited through letters or invited directly through clinicians. For those who are not due in clinic, a member of the clinical care team sent off the invitation to participate in the study by post. R&D approvals were granted from all respective NHS trusts.

For Stage 3 all potential participants who expressed an interest in the study were given a Participant information sheets (Appendix G) consent form (Appendix H), advert (Appendix I) and invitation letter (Appendix J) on the day they began insulin pump therapy; they then either took these away and contacted the author directly, or alternatively provided their contact details for the author to contact them and arrange taking part. Potential participants who provided their contact details were then contacted by telephone at least 72 hours later; during this initial telephone correspondence an outline of the study was provided again and screening to ensure participants met the inclusion criteria. Any questions arising about the research or the procedure were also addressed during this initial telephone contact. In this same conversation, for those that were willing to participate, an arrangement was made for a research meeting with the author. These were organised at a time and place most convenient to the participant.

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Purposeful sampling worked relatively well for Stage 3 with a convenient natural variety amongst pump starters, and with a high response and participation rate from those approached in clinic (80%). However, participation did depend on the introduction by the clinic HCP. On all occasions but one 100% of patients were recruited in this way. The one unsuccessful attempt consisted of five people starting on pump. None of the HCPs remembered that the researcher was coming to the clinic (after being invited weeks beforehand) and the main clinic contact was off sick. This resulted in a difficult introduction to the potential participants as there was confusion as to what the research was. The Dietician running the session then vaguely (and unenthusiastically) introduced the researcher as a “postgraduate student doing some research”. This did not appear to be a fruitful or encouraging introduction. The usual format was for the author to give a short description on what the study was after being introduced by the main clinic contact. On this occasion it evident that the potential participants were wary and were more concerned with the complicated new technology that they had just been introduced to. One person asked to take part but the rest were, understandably, more focused on their pump. This made the author ensure that from that point on the timing and introduction were more carefully considered and delivered.

3.5.4 Rationale

3.5.4.1 Use of mixed-methods and theoretical positioning

Mixed methods research can be considered that which utilises methodologies of both quantitative and qualitative methods. Use of mixed methods are increasingly being used in health science research, often justified due to the intricate complexities associated within health services and users of health services, and chosen as a pragmatic approach to data collection (Chen 2006; O’Cathain et al. 2007; O’Cathain et al. 2010). However, use of mixed methods is often not discussed in terms of its origins (O’Cathain 2009), and yet traditionally there are distinct tensions between these methods which originate from conflicting epistemological and ontological ideologies, values and processes (Greene et al. 1989; Greene 2006; O’Cathain 2009). Such tensions arise from qualitative methods thought to be sat within a constructive paradigm, and quantitative methods connected to a post-positivism paradigm. However, the research undertaken in this thesis has utilised a more pragmatic approach to data collection, but in terms of pragmatism as its own paradigm that sits between constructivism and post-positivism, as proposed by Morgan as a philosophical system for research (Morgan 2014). This paradigm focuses on not only the *how* to undertake research (as is often a focus in pragmatic research methods), but also the *why* research should be undertaken in a particular way and not another. This purpose gives research an avenue to pursue goals and an approach to meet these goals. In this way

pragmatism is not merely a methodology (Hall 2013). It comes from the position that results cannot be determined before they are experienced, and so methods which are intuitive and responsive to pursuing a goal (or a research question) are more likely to advance our knowledge and understanding (Dewey 2008). Mixed-methods were used here to understand beliefs and actions (or outcomes) of participants, and determine meaningful questions to support SM, using methods which would be most appropriate to answer these questions, i.e. that the experiences of participants and articulation of these experiences provide in-depth explanations of behaviour, and that quantifiable outcomes demonstrate some of these behaviours, and changes in behaviour, over time, but are explained and comprehended through qualitative accounts.

However, as well as methodology providing tensions, there are also concerns over the lack of integration between findings from qualitative and quantitative methods used within studies (O’Cathain et al. 2010), as well as the lack of prominence of qualitative research in mixed-methods studies (Pope and Mays 1995; O’Cathain et al. 2007) limiting the impact of knowledge the research is likely to generate. In order to address these concerns, qualitative methods actually featured prominently in the data collection, and data was assessed using parallel constructs and then using a convergent design to compare the results (Wisdom and Creswell 2013). Findings were examined as to whether quantitative and qualitative findings were agreeable with each other (convergence), whether there were any discrepancies (discrepancy or dissonance), whether the two types of methods complimented each other (did the qualitative responses add depth to the quantitative findings, (complimentary) and participants (and data) were followed and compared (and triangulated) using a matrix of quantitative findings and qualitative responses to offer more in-depth comprehension about the mechanisms of change for participants over time, from incorporation of an insulin pump, and use of the GENIE intervention (Chen 2006; O’Cathain et al. 2010). Where quantitative findings were elaborated on in qualitative interviews, these were referred to within the manuscript (Chapter 1).

3.5.4.2 Semi-structured interviews

Semi-structured interviews are designed to offer the opportunity for a verbal interchange of conversation with the aim of encouraging exploration of a specific topics using a list of predetermined open-ended questions to prompt the exploration of the issue at hand. These interviews can provide an informal exchange which allows for feedback into the study at hand (Potter and Hepburn 2005). The semi-structured interviews provided a dynamic method which enabled exploration of participants’ experiences, needs, values and perspectives and an opportunity to explore what is unknown (Kvale 1994). In this instance the open ended nature of these questions also provided opportunity for exploration of interesting themes as they emerged

in the course of the interview. Thus it was anticipated that this method would give the researcher freedom to probe the interviewee to elaborate or to follow a new line of inquiry, which may be introduced by the respondent's answers. In this instance the semi-structured interviews explored the experience of incorporating insulin pump therapy over time, the related social network engagement and SM management needs. The use of semi-structured interviews allowed for further elaboration of the meaning and contribution of relationships within an individual's network, as well as the nature of the context and content of the illness work that they undertake, taking into account the support that is available in the entire configuration of social support. 1:1 interviews are a dynamic method which enabled participants to reconstruct their experiences and needs with the interviewee (Baker 1997). The method also enabled the interviewer to explore with the interviewee their understandings and perspectives of what they need and what they have experienced and are experiencing and anticipating, as well as explore, how the interviewee came to these comprehensions.

Overall, the interview method and consequential thematic analysis offered the opportunity to explore the wide range of views and perspectives of the process of incorporation and support needs. The semi-structured nature of the interviews offered the opportunity to explore, in depth, the opinions, values and beliefs of the interviewee (Silverman 2005) and then consider the common themes across the participants.

3.5.4.3 Questionnaires

Self-administered paper-and-pencil questionnaires used were The Problem Areas In Diabetes (PAID) scale (Appendix K) and the CLARKE hypoglycaemia awareness survey (Appendix L). These scales are self-administered and widely used reliable and verifiable scales in diabetes (Welch et al. 1997; Snoek et al. 2000; Geddes et al. 2007) and were already routinely collected in the clinics selected. The PAID scale is a 20-item survey utilising 5-point Likert scales and was developed to measure emotional distress in people with diabetes (Polonsky et al. 1995). The total score from the 20 questions is multiplied by 1.25 to generate a total score out of 100. A higher score reflects greater emotional distress. A total scores of ≥ 40 suggests severe diabetes distress (Snoek et al. 2011), while individual items that are scored 3 or 4 suggest moderate to severe distress for that particular element of diabetes management and the scale suggests this being discussed during clinical consultation (Snoek et al. 2012). The CLARKE is a measure of awareness of hypoglycaemia and is comprised of eight questions regarding the participant's exposure to episodes of moderate and severe hypoglycaemia (Clarke et al. 1995). A score of ≥ 4 suggests impaired awareness of hypoglycaemia.

3.6 Ethical approval:

Prior to commencement, the author compiled the study protocol and documentation in preparation for review by an NHS Research Ethics Committee; specific details for each study are outlined below.

Stage 1 did not require ethical approval. Ethical approval for Stage 2 was obtained from the University of Southampton (ERGO 26208) on 27th June 2017 for pump users the HCP focus groups (and interview) and Stage 3 acquired REC approval from the North of Scotland Research Ethics Committee on 12th September 2017 and HRA approval (REF: IRAS project ID: 213320, REC reference: 17/MS/0089) on 21st September 2017 following proportionate review.

In addition, six NHS Research and Development departments granted approval for the studies: Hampshire Hospitals NHS Foundation Trust, Portsmouth Hospitals NHS Trust, The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust, Torbay and South Devon NHS Foundation Trust, University Hospital Southampton NHS Foundation Trust, and Western Sussex Hospitals NHS Foundation Trust.

Stage 3 was adopted on to the CRN Portfolio (CPMS ID 35962) and therefore received Clinical Research Network support.

3.6.1 Ethical considerations

The main ethical issue of this research was that the topics broached in the focus groups, interviews or GENIE intervention, could have been of a sensitive nature for some participants. For example, questions exploring participant's experience of living or working with diabetes or specifically with a pump which may have raised participant's awareness of issues they had previously not acknowledged or raised upsetting scenarios. This issue was addressed by ensuring all participants were given the opportunity to view the topics to be discussed before consenting to taking part (information sheets where the topic was openly explained) as well as the opportunity to opt out. It is important to note that the upsetting questions cannot always be predicted because they are often dependent on the personal biographies and experiences of each individual participant, which was not known prior to conducting the research activity (interview, focus group). However, every effort was made to support participants during participation. Time was given and space if participants ever did seem more emotionally affected by questions and asked if they would like to have a break. There was also the opportunity to move onto a different point or question, stop the focus group or interview, and/or have a break, whichever was

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preferable. Participants were informed of this at the beginning of every research participation and the researcher was sensitive to the potential of these needs and opportunities throughout.

All patient participants were provided with contact details of the insulin pump team /or named Diabetes Specialist Nurse at their NHS Clinic, who could support them and offer appropriate on-wards referrals, and of organisations that could offer further psychological support, such as; steps to well-being, Mind, Samaritans, and condition specific Diabetes UK, who also have a helpline. There was no need for any signposting or referral but the information was there in case it was required.

A further potential burden to all participants was their time. To minimise this the participants were offered alternative times and convenient locations for focus groups and interviews and the researcher was very flexible, with participation often occurring in the evenings. For interviews there was the opportunity for face-to-face or telephone interviews to minimise travel and time burden and increase opportunity and convenience for participants (or potential participants) to take part. The inconvenience and opportunity cost associated with participation in qualitative research is often underestimated (Richards and Schwartz 2002). In order to compensate people for their time and to thank participants for participating in the research, each patient participant was given a £10 Amazon voucher on completion of a focus group or interview. Refreshments were also provided during focus groups and interviews to ensure that participants felt comfortable, appreciated and valued for the time they have given up to take part in the research.

Chapter 4 Autoethnography of a user-researcher

4.1 Introduction

This chapter is dedicated to the unavoidable elements of subjectivity from an author who is both the researcher and the researched (a person with T1D, who has a pump). It references the lay knowledge and personal experience of the researcher and how this is interlinked with the PhD work and journey. After deciding on a PhD which focuses on the process of incorporating a new health technology such as an insulin pump in T1D, I decided to attempt to acquire one myself. My local Clinical Commissioning Group had just recently decided that people with T1D would now be looked after in primary care rather than secondary care, unless they had “complex needs” or an insulin pump. This created angst about being looked after in primary care – where my GP did not adequately understand T1D enough to provide any support or advice and so a move to a pump seemed timely. This was especially timely while going through a time of change: training for a marathon. Marathon training made management of T1D much more difficult, yet had a positive impact on my general health, strength and weight. NICE guidelines suggest that patients only move onto insulin pumps when attempts to manage on multiple daily injections have failed (National Institute for Health and Clinical Excellence 2008), rather than as a customary option, which was off-putting. However, it seemed evident that a new approach was needed to manage concerning fluctuations in my blood glucose levels (raising very high during intense exercise due to glucagon release). So I convinced myself that not only would I then be able to understand an element of what the participants in my studies would experience, it would also meet some of my own management needs. I was in a unique position. I managed to get referred to the pump clinic who agreed that my exercise concerns enabled me to meet the criteria. At that point I decided to capture what happened when I did get this device that I had not previously wanted to wear on my body 24/7.

Firstly, ethnography, “the study of the people”, is a process of immersion which utilises an observational approach to data collection. Data collection and analysis is often from a variety of sources, such as documents, interviews, field notes, diaries and memos (Jones and Smith 2017). The process is thought to move beyond exploration of beliefs and attitudes to include actions and behaviour. We can never be sure that what people say they do is what they really do and methods such as diaries and observations can offer a unique insight into the continual process and reflection of thoughts and actions. Ethnography aims to understand the symbolic world in which we live and grasp the meanings we draw on to make sense of experience. Further, autoethnography focuses on the individual account, allowing for a personal narrative and

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reflexive account of a researcher undertaking a process or experience. Autoethnography is a vehicle for critical consciousness from both a user and researcher (McIlveen 2008).

Autoethnography means the researcher is both a life participant and observer (Alexander et al. 2015); the researcher is both the researcher and the researched (Muncey 2005).

Autoethnography reflects a desire to balance technical and professional expertise with value considerations, and connects “the practices of social science with the living of life” (Ellis 1999).

However, there can be concerns that autoethnography is too subjective and not ‘scientific’ enough for publication in academia, yet it offers a layer of in-depth experience that is unique, meaningful and, potentially, invaluable (Boncori 2018). It is this very uniqueness that is key.

Utilising auto-ethnography does not suggest that the author wishes to generalise the narrative, but instead offers an account from a scientist which is doused in personal perspective and reflection. In this instance an autoethnographical approach can offer a unique perspective and expression of a health experience and integration of technology, parallel to others, informing the researcher of this complex process while reflecting on how this shared experience impacts on their own approach as a researcher.

Social scientists and healthcare professionals have expressed their health experiences of cancer, epilepsy, depression and anxiety, and diabetes, amongst others, through autoethnography (Sealy 2012; Campbell 2015; Scarfe and Marlow 2015; Greenhalgh 2017; Lucherini 2017). Their accounts provide a unique insight into their experiences, with an analytical eye combining, reflecting on and exposing their own processes, emotions and actions. Lucherini (Lucherini 2017), a geographer usefully describes interviewing others with T1D while going through a process of self-reflection of his own diagnosis. He discusses the process of considering his own methods and coping mechanisms while enquiring about those of his participants, and how this impacted on interviews and their analysis. For Lucherini the process of research was some form of reflective and learning experience about the self. In addition, he expresses that in order to attempt to create a sense of rapport some over-talking and over-sharing of his own experience did sometimes occur.

Autoethnography can offer an opportunity to express, comprehend and be honest with these personal experiences and processes before embarking on understanding others.

Here an autoethnography will enable a comparison of personal accounts of my incorporation of an insulin pump over time, and capture the process of decision making, troubleshooting and exploration of priorities, and will elicit how these were all enacted in the process of incorporation.

4.2 Methods

4.2.1 Design

Mixed methods were used to collate autoethnographical data which included; audio diaries, artefacts, field notes, clinical outcomes and routinely collected surveys (The Problem Areas In Diabetes scale and the CLARKE hypoglycaemia awareness survey). Muncey (Muncey 2005; Muncey 2010) suggests utilising varied and creative methods, including artefacts in order to conjure up feelings and thoughts.

Chang (Chang 2016) suggest that authors of an autoethnography ask five key questions:

1. Does the autoethnography use authentic and trustworthy data?
2. Does the autoethnography follow a reliable research process and show the process clearly?
3. Does the autoethnography follow ethical steps to protect the rights of self and others presented and implicated in the autoethnography?
4. Does the autoethnography analyse and interpret the sociocultural meaning of the author's personal experiences?
5. Does the autoethnography attempt to make a scholarly contribution with its conclusion and engagement of the existing literature?

These questions were used to guide data collection and analysis. In order to address the question of authentic and trustworthy data various sources were cross-referenced (Chang 2016), including an audio diary method over time, so as not to rely on memory, along with field notes when there was no access to a dictaphone, photographs and clinical outcomes to triangulate my data sources. Audio diaries were completed when they met the following criteria: convenient to record, access was possible, when a new challenge arose, or for reflection or something which either affected or influenced a decision or outcome. Surveys used were The Problem Areas In Diabetes (PAID) scale and the CLARKE hypoglycaemia awareness survey. These are self-administered and widely used, reliable scales (Polonsky et al. 1995; Lancaster and Stead 2005; Geddes et al. 2007). The PAID scale was developed to measure emotional distress in people with diabetes, while the CLARKE is a measure of awareness of hypoglycaemia.

Triangulation of a variety of data sources was utilised and laid out in the order of the findings in order to follow a reliable research process, followed by a discussion of these findings. No close network members were revealed or indicated, in order to protect the rights of others who may have otherwise been implicated in this process of incorporation. In addition, attempts have been

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made to provide an in-depth analysis and interpretation of the personal experiences presented here.

4.2.2 Analysis

Interviews were audio-recorded and transcribed verbatim. Triangulation of data interviews utilised self-observation, self-reflection, self-analysis and artefact collection in order to collate rich, authentic and trustworthy data (Chang 2016). After distancing myself from the experience I analysed the collective data and reflected on the experience and process of my own insulin pump incorporation. I also considered how this had an impact on my data collection and analysis throughout the PhD process.

The PAID scale is a 20-item survey utilising 5-point Likert scales, Scores range from 0-100, where a higher score reflects greater emotional distress. The CLARKE scale and is comprised of eight questions. A score of four or more suggests impaired awareness of hypoglycaemia. These were completed at baseline and then at 2 and 3 years on. Changes in glycaemic control were also recorded using the HbA1c blood test taken routinely in clinic.

4.3 Findings

Video diaries were undertaken between 25th September 2015 – 15th November 2016, while clinical outcomes were available from September 2015 – September 2018. N= 36 audio diary entries were created, ranging from 00:13 – 09:59 minutes long (Mean = 03:14). The majority of recordings took place on Wednesdays (n=13, 36%), followed by Tuesdays (n=9, 25%), and Fridays (n=6, 17%).

4.3.1 Clinical data and surveys

Baseline mean HbA1c was 70mmol/mol, which only began to show a decline from 2 years on (60 mmol/mol) and then even more so at 3 years on (51 mmol/mol). The mean PAID score decreased from 22 at baseline to 14 at 2 years on and 15 at 3 years on. Hypoglycaemia awareness was maintained (

Table 2).

Table 2: Clinical outcomes over time

	Baseline	6 months	1 year	2 years	3 years
HbA1c (mmol/mol)	70	69	70	60	51
PAID	22	No data	No data	14	15
CLARKE	Aware	No data	No data	Aware	Aware

4.3.2 Diary entries

Diary entries explored frustrations, queries and new illness work that came up from the initiation of pump therapy up until 14 months afterwards. Excerpts of diary entries are presented below. These entries were selected as an example of particular elements of difficulty throughout incorporation and also demonstrate how these difficulties change over time (full diary entries in Appendix M);

Entry 1 – 25.09.15 - 00:54 - Friday

Packing to go to Canada. Trying to find places to put it [the pump] on my body. Keeps ripping out of body (3rd/4th time). [Sound distressed]. Trying different clothes on. Finding it hard to place the cable as it is quite long. I might be too long. Maybe that is useful? I don't want it to be too short either. Note to self: refer back to this. I've had a nightmare trying to sort out my prescription – I was given the wrong insertion set – it had no tube, but I managed to speak to Roche who delivered them – they were very helpful, and managed to get the stuff to me but it was very stressful. I didn't think it would come in time before I go away to Canada. Thought I'd have to go back to multiple daily injections because I couldn't rely on the pump. Annoyingly Roche had my old address even though I asked for the items to be posted to my work address. [Sigh] I have to sign for it. I have no idea how long this supply will last. Or how easy it will be to request more.

Entry 2 – 25.09.15 - 01:10 - Friday

Pump has just ripped out again. It's bleeding. [Sounds tired and distressed]. Turns out packing with a pump is very difficult. [Sigh].

Entry 3 – 14.10.15 - 08:57 - Wednesday

I am getting ready for work and changing the infusion set. It's difficult to remember when 3 days have gone by and it's time to change infusion set. I need to find a system to work it out, and not from memory. Do I need a calendar to tick it off? I think I need to look on a forum to see what other people do. I also need to change the tubing. I somehow managed to get the tubing, infusion set and cartridge all out of sync. I am [my life is] not in a regular pattern so the insulin cartridge is not being used in a regular way. It takes quite a long time to change the infusion set, so it's not that convenient when you are trying to hurry and make a move. It hurts to peel the very sticky sticker off. I think the sticker is amazing and it's really discrete, it sticks really well but it's bloody hard to get off. I keep forgetting which way round to put it so I clip it on weird - backwards. I'm finding it difficult to fit into my clothes easily. I am in a transitional period where I am in between houses and I'm finding it hard to store everything. Also I don't really have time to sew pockets into my clothes and I'm not even sure where the pockets should go, half my stuff is in storage. It's a lot to think about. When my stuff is out of storage and my housing is more stable hopefully I can think of ways to put pockets and stuff in my clothes.

Entry 5 – 21.10.15 - Wednesday

I want to report my experience from last night. I was at a pub quiz last night. When at the quiz, I had to give myself insulin for pizza that I was about to eat, so I got my pump remote out and was administering some insulin and one of the pub quiz masters shouted out not to use my phone. I was a bit surprised and didn't know what she was talking about and my housemate shouted out that I had diabetes and it was my pump. At this point I hadn't even clocked on as quickly as she had, but then I realised that my pump remote looks like a mobile, and it was embarrassing as the other quiz master had seen me before my housemate shouted out and jokingly said that I couldn't use my phone but everyone was looking, and I explained and then they seemed embarrassed and didn't know what to do. I realised it looked like a mobile phone and a couple of people have mentioned it but I guess that makes it more discreet but on this occasion I did feel like a bit of a doofus. Otherwise it was a great night!

Entry 10 – 25.11.15 – during the day - Wednesday

Just changing the cartridge on my pump. It's the middle of the working day so it's awkward – I realised I have to because I have less than 20 units left in it as I've still got dinner and boxing later so I'll need to change it. The annoying thing is that I am wearing a dress so I have to take different bits out at a time, and because it takes such a long time to pull the plunger back so it's quite annoying. I happen to have popped home so am doing it now because it beeped and told me my insulin cartridge is low but otherwise I would be in the office. I know I should think ahead but sometimes that is hard to do and you have the conundrum that the cartridges are quite small, but you don't want them to be bigger because you don't want the pump to be bigger but it does mean you have to change the cartridge more regularly.

Entry 15 20.12.15 - 14:45 - Sunday

I have just realised that I have had my pump off for 2 hours. It's a Sunday. I have been wondering around my home. I have been out for the last 5 consecutive days. I am not sure what impact that will have but the positive thing is I can fix it quite easily and quickly so it shouldn't be too detrimental. Going out it has been difficult to put the pump in tight-ish fitting clothes. The Holster has been useful, although the Velcro on it keeps ripping my tights. However, tight fitting dresses actually hold the pump rather well. I have two holsters – one is quite bulky but the other one flattens the pump and fits nicely into my leg on my inner thigh. It's more expensive though but is by Accu-chek [pump company]– from their website – and it's quite soft so I quite like that. I am feeling the need to get a sewing machine so I can sew pockets into my clothes. The one that hangs off your bra isn't ideal because it pops off your bra all the time, and you can see if something is hanging on your bra, and trousers are difficult. I still haven't found a way around most of these things but I am getting better at putting the pump on my body in tactful positions. People still seem interested in and intrigued by the pump and I am finding it easy to tell people about the pump and I am finding it easier to explain to people about the pump than injections, which is nice. I am finding that the cartridges don't last very long though, maybe a few days. I get two packs of 5 every time I get a prescription, so I would like them to last a bit longer, especially as the more I am exercising the more insulin I am using, so that's annoying. But, in terms of mastering the increased basal while I'm exercising, I am getting pretty good at that; 150-160% increased basal seems to have quite a good outcome. My BGs are now relatively normal after exercising, so I am finding that kind of amazing really. But I have had such high BGs [blood glucose readings] recently. I woke up with a BG of 19 yesterday, I think because I ate food when I came back from being out and forgot to give myself insulin for it. That's just a general issue though, and it's my fault, not a pump-specific issue. Actually, I do keep doing this – I have a shower and get my breakfast and I administer my insulin before I've reattached my pump, and then I realise and I reattached it and then the pump remote isn't going off what my BGs are, and I am just guessing how much to correct my high blood sugar by. Also, the pump remote is slow and time-consuming, and when you're injecting you know the insulin is actually going in, rather than having to remember that it is or isn't attached. I am not sure if that's a common problem or if it is just me being a complete dimwit. I just need to sort my shit out really.

Entry 18 23.12.15 - 14:12 - Wednesday

I realised I am running low on prescriptions so trying to log on to online prescription ordering – I have 4 insulin cartridges left as they only last a few days each and it'll be closed over Christmas and I'll be away. I feel like I am really on the edge of it – when I order I don't get a supply that lasts me long enough. I seem to be frequently ordering them. I order them once a month. I can't order my test strips or insulin – which were both last requested on 27th November, yet I am not allowed to order them again until 25th December, but they only last that length of time, and bearing in mind they are closed a lot over Christmas – I am away and they won't be open much so I will have a very

small window to order them. I can't actually order my insulin, which I need to live, until Christmas day, and they will not actually be open, so it won't be a case that I will have to just wait 48 hours as it will be longer than that. I'm not sure what to do. I couldn't have ordered them sooner as the system won't let me. [Sigh].

Entry 21 13.01.16 - 23:05 - Wednesday

Update for over Christmas. Where to start? Off the top of my head; It was quite difficult because I was eating at different times of day and lots of random meals and no regular routine, so it was difficult to keep on top of managing diabetes and I had a cold and now I seem to have another one so it was difficult managing diabetes. Sleeping was difficult. People were offering food all the time and I was constantly having to give myself insulin, which was easier on a pump but it was difficult putting in my infusion set. Sometimes it was painful putting in my infusion set or sometimes it did not seem to work. I was in Ireland last weekend I brought enough infusion sets with me, to last about 12 days. I had to use them all within a couple of days because none of them seemed to work – not sure if it was my skin or the package – my pump kept saying that it was blocked – which was really annoying – I had a really high BG most of the time because my pump wouldn't work. I kept changing everything all the time but nothing seemed to work. I used 3 or 4 infusions into my skin and I moved it to different sites but it would still say it's blocked and nothing seemed to work. The thing is when I got back to the UK, I did try the same pack and I didn't have a problem since. Actually I did change that and I accidentally ripped that out because it was in my pocket – the clip I usually use to clip onto my bra snapped – it kept on unclipping itself is now it's snapped so it doesn't clip onto anything. I have only had it for a few months and it's already broken. I am now using the band that goes around my thigh but it's either too tight or too loose and falls down my thigh. So not ideal at the moment. The band is also quite thin so feels a bit strange round my waist, but I have one on like that now in bed. But it's been really uncomfortable recently. The wire is quite long and is easy to pull out. I am finding it hard to sleep comfortably, I think it's because I am a restless sleeper so I don't sleep in one position. So the pump stopped working, it's difficult to keep track of my varying diet. If you don't have a routine it's all difficult. With it not working it's difficult running because I can't increase my basal. It has been very frustrating.

Entry 23 19.02.16 11:07 Friday

I wanted to do some entries about the more intimate aspects of having a pump – I have read some blogs about this – when I spoke to some of the girls at the insulin pump conference at the local hospital, before I went on the pump, they were discussing how some pumps are more discrete for sexual encounters – ones in which the tubing isn't attached to you. My experience before when I had a boyfriend when I first had the pump, up until a few months ago, was that he was fine about it. It did get in the way and you have to remember to unclip it. And you have to remember to clip it back on after, especially if you might

want to revisit any intimate moments. So it's hard to know when to put it back on or not. And you get the cord yanked. I since met someone else and hadn't mentioned on our dates that I had T1D, and then when we were going to be more intimate I didn't know what to say or how to say it. When I had injections, although if having dinner it's easier to go for dinner and give yourself some insulin on "Your old mobile phone" whereas you'd have to slip off to the toilets to inject yourself, but when it comes to sex, you don't have your pen out. You won't be able to check your BG levels – not knowing if you'll be having a hypo or high with a dry mouth, but with the pump you can't avoid talking about it. I'm not into one night stands it must be so awkward, "this thing that's attached to me is an insulin pump", it would be so awkward. It's probably easier when you're dating someone but the problem is when you're dating someone you're getting to know them and intending on having some form of prolonged relationship with them and they then assess you "do I want to carry on dating this person who has this chronic condition", or this weird thing they don't understand. The guy I am dating is Spanish, and there is probably some translation issues, or lost in translation issues actually, on an ongoing basis anyway. This was difficult to bring up. You don't know what to say and will they understand it? Even if they're English will they understand it? I didn't mention it until we were pretty much taking our clothes off. Luckily I'd had talked about my research in T1D. I tried to unclip it smoothly. He seemed okay about it. It doesn't mean he was. Luckily it's quite discrete. It's hard. You feel so different. So robotic. The next time I had the band around my waist and I had to unclip it and slip it over my head, in a non-crazy way, and a graceful way and I think I did it alright. I don't know if people care about it. I don't know if guys do care about it. Maybe it's harder for guys with diabetes. The woman may be thinking further ahead, possibly, and may be more likely to think of "breeding" potential [laughs]. I've heard another person with diabetes, who is a man, wonder if girls think about carrying that "defect" on. I just thought I'd make a log of these things, and how I deal with it. I would suggest that the less of a big deal you make it, and the smoother you can unclip it etc. the less they will think about it as a big deal. Another thing, strangely, guys are really interested in the technology wondering about the mechanics of the machinery, and less scary overall than injections!

Entry 24 11.04.16 - 14:09 - Monday

I'm about to go and give a presentation and I am very nervous, and I think my BGs are going high as a result – the usual anxiety induced high BG. I'm worried about whether my pump is going to fall off or beep or something. And it's [the talk] on diabetes, so that's interesting. I want to eat something, but I don't want my BG levels fluctuating because if I eat now, it's in 50 minutes time, so I'll need to do something with my BGs but I'd rather they stay as stable as possible and introducing food doesn't help that.

Entry 29 27.04.16 - 16:15- Wednesday

My pump malfunctioned when I was in a training session and made a loud beeping noise, it was really embarrassing. Still malfunctioning. Awkward.

Entry 30 07.05.16 16:59

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I just took my infusion set off and it was bleeding. I just wanted to make a note of that.

Entry 34 05.10.16 11:55 Wednesday

I can't find any of the straps that attach the pump to my body – the one I did like is stretched so now it falls down my body. You need to have a number of them because obviously they are very close to your body so need washing regularly. So now I am having to change my outfit and try and find something that has pockets as I can't find any more straps or the rest are in the wash, but I have hardly any items of clothing with pockets, and then it bulges out of the pocket. Practical issue.

4.3.3 Artefacts



Figure 11: Ripped infusion set out in the gym changing rooms, 15.06.16

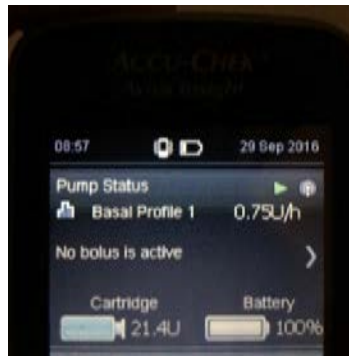


Figure 12: Still forgetting to charge the pump remote, and running low on insulin, 29.09.16

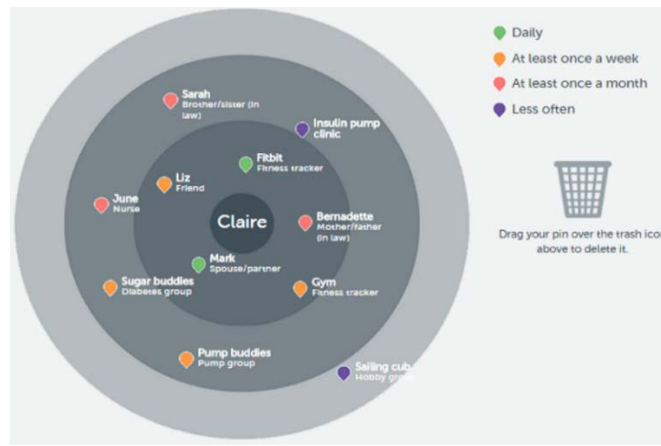


Figure 13. January 2018 -Concentric circles completed before recruitment of participants

Summary of field notes (in date order September 2015 – January 2018)

Overview:

Over the time I was integrating the pump I went to Toronto (a few days later), moved house and began my PhD.

Key barriers/considerations:

- How and what to order items from the pharma company
- What comes from the pharma company and what comes from the pharmacist?
- When to order
 - o Have done this last minute on numerous occasions, ran out unexpectedly
 - o Took time to adapt to pump and how quick resources run down (new work)
 - o How long it might last for and how quick delivery would be + where to deliver to
- How to wear the pump (out/hidden)
- Where to place the pump
- Body issues and new identity (robot?)
- How to insert the infusion kit, and rip out the old one
- How/when to tell people about the pump
- Security at airport and government buildings etc. – do I need a letter? Apologetic? Assertive?
- Buying products – various products – which size to get? What kind of clothes do they go under? How? Where best to place them? How much to pay? Where is best to buy products? Where to buy products in the UK? Does the pump stay put? Sew own pockets into clothes?
- Remembering to put the pump back on
- Holidays:
 - o In Bulgaria – pulled out pump on the beach – was 30+ mins walk away from my equipment, and hadn't brought spares to the beach. The question is; when to bring spares? It's easy to say "always" but this isn't always practical. Plus, another consideration is tan lines – with the pump on. I hadn't thought of this, previously.
 - o Yanking it out – reaching for something whilst holding the pump... and a small bag = can't fit spares + insulin pen. Have to prioritise.
 - o Keep cool pouches – needed to carry spare insulin cartridges around
 - o Glastonbury – need to think this through, and how much to bring.
 - o Fridge? Will I have access to a fridge? Medical tent? Will they have spares if something happens?
- I may have more highs and lows but I feel more in control of them – they (especially hypos) usually occur because I am testing my BG levels more with the pump and feel more able to correct high BG levels.
- Potential Participants in clinic seem much more interested in taking part in the study when I say I have T1D and a pump too. They sit up, listen more and ask me questions, then seem to consider my slides more carefully.

*BG = blood glucose levels

4.3.4 Field notes

Diary entries revealed unexpected frustrations and new situations that had to be overcome. The recordings over time revealed where new attempts were made to deal with problems that had arisen or were pondered. Many of these issues were resolved (increasing basal rate, new pump accessories) but also demonstrated bodily and life changes which impacted on former resolutions (change in muscle or exercise regimen requiring different approach to insulin needs, and failed pump accessories) and attempts at dealing with other perceptions of the pump in intimate relationships, the workplace (pump beeping during training) and personal life (pump being confused for a mobile phone during a pub quiz). The diaries also recorded fears (pump disturbing presentations) and revealing a new robot status in potential new relationships.

There was an evident process of incorporation and period of adjustment. There was a great deal of personal responsibility and sometimes disappointment expressed and it is evident that the independent nature of diabetes was prominent throughout. There was a distinct lack of referral to others (except for the pump clinic) in my support network, which may have otherwise supported me to troubleshoot, although there was reference to talking to others with an insulin pump and seeking support online, which helped with troubleshooting. I did not have a close partner at the time but since do and they have now entered into the central part of concentric circles (**Figure 13**). They feature profoundly in my management now and I would imagine I would have referred to them during this process of incorporation. However, the circles represented who I turned to for SM support at the time and allowed me to reflect on this for the first time. It has been useful to reflect on the experience of the new device as a single person at the point of initiation, and now with a significant other to support me and I felt I could personally comprehend the narratives of both single and partnered participants.

Less diary entries were made over time, suggesting that I had less to report and had overcome many issues, however, field notes refer to the burden of new experiences and consequential new illness work when incorporating a new health technology. Whenever I came across a new experience (Glastonbury festival – lack of access and requirements to over-supply equipment “just-in-case”) the pump brought new illness work and concerns, but I became less emotionally concerned and considered these as practical issues to be solved, rather than fearing this new work. Incorporating a new technology evidently became something which impacted, tweaked or enhanced many parts of my everyday life. I had to reconsider relationships, identity, and SM practices (especially exercise).

4.4 Discussion

Autoethnography here has been particularly useful for me as a researcher in considering the perspective of people who have taken part in my PhD research. I have been in a unique and advantageous position to be able to have a deeper comprehension of the process of incorporating a new health technology in T1D, and more as a user-researcher than I could have as a researcher alone. This has felt particularly pertinent for the third phase of research – implementing GENIE with people who are new to insulin pumps and exploring the process of incorporation and what support and resources were required during the process. I wanted to know how I would deal with these new situations, how I would feel, who/what I would rely on, how I sought help and who I trusted, and why. It also allowed me to reflect on how this might impact on my encounters with participants.

However, being a user-researcher has not been straight forward or advantageous in every way. Lucherini (Lucherini 2017) discussed over-sharing or over-talking in order to attempt to create rapport when interviewing peers with T1D. What does this mean for the research and what impact on the outcomes does it have? Being mindful of one's own process from the off-point can help to walk the tight line between the researcher and the researched, but it is a line that is difficult to avoid. There were guidelines for what the audio diaries in this instance would consist of, although sometimes these diaries also played a cathartic role for frustrations or confusion over myself, the "system" (prescriptions, ordering) or the physical pump. However, in order to avoid self-indulgence, recordings were kept to-the-point and an account was only given when I felt compelled, rather than undertaking an arduous day-by-day task. Attempts were made to structure audio diaries recordings (what their purpose was and what to report) and to reflect on my own process before interviewing participants in order to deal with some of this likely need for catharsis.

There were similarities of experiences between my own account and those of participants, in many ways, although I did not explore intimate encounters with participants, which could have been invasive, but potentially enlightening. I evidently had my own concerns and experiences in this matter, which gave another layer of the complex process of introducing a very visible new health technology. I felt able to give a more intimate, or expressive account here because I knew that I would be the only one to listen to recordings; no one else would ever hear my tired, sleepy, angry, upset, or fed-up voice. When participants gave their accounts at times I felt there was potentially a great deal more there than they recalled to me, especially if it touched on an emotive subject; "I just get on with it", "It's been tough", "I wanted to give it up", "I thought I couldn't do it", "I nearly gave it [the pump] back". These were stated quite calmly by participants,

but there was more than I could ever uncover in an interview, even when we seemed to have a strong rapport. Considerations of my own experience allowed me to consider that there was likely more here than I would realistically uncover from participants, and allowed me to ask further open questions if it seemed appropriate.

Considering the process of this incorporation and how it affected me enabled me to provide examples of travel, pump accessories, exercise adjustments and identity to participants when I was recruiting them to participate through the clinic. I was able to express some of my own experiences to potential participants when I was attending pump starts within the study sites to recruit participants for Stage 3 of this PhD research, which may have enhanced rapport or approachability with potential participants.

In terms of my own ability to self-manage my diabetes; my improved glycaemic control status and enduring efforts to “engage” in my condition is still not up to scratch according to NICE standards. This is even in consideration of my apparent knowledge of T1D and receipt of structured education. Updated NICE guidelines (2015) suggest healthcare professionals should “support” adults with T1D to aim for a HbA1c level of <48mmol/mol “to minimise the risk of long-term vascular complications” (The National Institute for Health and Care Excellence (NICE) 2016), while The Association of British Clinical Diabetologists (ABCD) divulge that the latest evidence suggests that >6 blood glucose tests a day are required by most people with diabetes in order to achieve a HbA1c of <58mmol/mol (The Association of British Clinical Diabetologists (ABCD) 2016). NICE suggest that I am not meeting their target, and that perhaps my healthcare professionals should “support” me better. It would seem that this target has been unobtainable by many with the latest National Diabetes Audit (2017-18) reporting that only 30% of people with T1D are achieving recommended glycaemic targets of <58mmol/mol (NHS Digital 2019) (note, this is even higher than the desired NICE target, which is not reported on by diabetes secondary care). Nordwall et al. (Nordwall et al. 2015) suggest that a target HbA1c <60mmol/mol would not only be more realistic but also provides relative protection from key diabetes complications. What this does mean is that most people with T1D are not even close to meeting national targets for their diabetes, that the process of SM is not simple, that SM support likely needs rethinking, and that there is space for an innovative approach to consider what target is actually realistic and will protect people with diabetes from experiencing diabetes-related health complications.

4.4.1 Limitations

There could be concerns over the blurred relationship between the researcher and the researched here in terms of reliability and validity (Borbasi 1994), although this has been

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considered with a triangulation of evidence sources, alongside consideration and valuation of the wider status that the user-researcher offers: a unique awareness of the phenomenon being studied, both the history of diabetes and care, and lived experience of these.

4.4.2 Conclusion

I have approached this PhD research with measure and consideration of the implications of my relationship with the condition I am focusing on, and feel my own personal experiences have given me more insight than I could ever have hoped to have had otherwise. This has not come without sacrifice and work, and constant reflection, and even complication, although I am confident that it has been beneficial. It has driven me on when I have felt fatigued or frustrated, and some subjectivity has indeed been inescapable (Lucherini 2017), and so it has been important to be aware of my own relationship with the research throughout. This has been made easier through frequent reflection with my supervisors, my partners, my friends and colleagues. The autoethnography allowed me to reflect on my own experience, both at the time of adaptation and incorporation, and also in relation to the experiences of participants' accounts within the empirical findings. Careful consideration of the most appropriate methodology in answering the research questions and aims have enabled this PhD work to be objective with an enhancement of some subjectivity, kept in check with reflection, supervision, and peer-review throughout.

Chapter 5 Paper 1: The process of incorporating insulin pumps into the everyday lives of people with Type 1 diabetes – a critical interpretive synthesis

5.1 Abstract

Background

Insulin pump therapy is a technological advancement that has been developed to help people manage Type 1 diabetes (T1D). However, ways of managing diabetes requiring the implementation of health technologies brings new complexities and a need to understand the factors which enable people with T1D to incorporate a novel device. This new comprehension could provide an exemplar for people with long-term-conditions to incorporate new technologies more generally.

Objective

To determine what influences the incorporation, adaptation and use of insulin pump therapy into the everyday lives of people living with diabetes.

Design

Critical interpretive synthesis (CIS) using systematic searches undertaken in seven electronic databases of literature, published 2008 onwards.

Results

A total of 4,998 titles were identified, 274 abstracts reviewed, 39 full articles retrieved and 22 papers selected for analysis. Three themes emerged which were of relevance to the introduction and use of insulin pump therapy; Tensions between expectations and experiences in adoption and early adaptation; Negotiation of responsibility and accessing support; Reflexivity, active experimentation and feedback.

Conclusions

This CIS builds on earlier reviews on lived experiences of insulin pump therapy. Novel insights are offered through examination of the experiences of pump users from children through to adults, their families and health care professionals. Expectations of what the device can do to improve SM impacts on the early stages of adoption as the reality of the technology requires substantial

thought and action. Areas for intervention to improve insulin pump incorporation include establishing who is responsible for management tasks of the device and enabling navigation to further means of support and resources.

5.2 Introduction

Over 4 million people live with diabetes in the UK, and Type 1 diabetes (T1D) accounts for about 10% of that population (Diabetes UK 2011/12). Continuous subcutaneous insulin infusion - insulin pump therapy, is a technological advancement used to support people with T1D manage their diabetes optimally. It is associated with psychosocial benefits (quality of life) (Hoogma et al. 2006a; Hoogma et al. 2006b; Barnard and Skinner 2007; Kerr et al. 2008; Hilliard et al. 2009; Muller-Godeffroy et al. 2009; Lynch et al. 2010; Misso et al. 2010; Yi-Frazier et al. 2010; Clark et al. 2011; Alsaleh et al. 2012; Cropper et al. 2012; Salehi et al. 2014; Bonfanti et al. 2016; Ghazanfar et al. 2016) and improved biomedical outcomes (Bode et al. 1996; Pickup et al. 2002; Weissberg-Benchell et al. 2003; McMahon et al. 2005; Silverstein et al. 2005; Hoogma et al. 2006a; Alcolado et al. 2008; Bruttomesso et al. 2008; Jakisch et al. 2008; Kerr et al. 2008; National Institute for Health and Clinical Excellence 2008; Nicolucci et al. 2008; Pickup and Sutton 2008; Riveline et al. 2008; Chellamuthu et al. 2009; Dissanayake et al. 2009; Pankowska et al. 2009; Gane et al. 2010; Kesavadev et al. 2010; Misso et al. 2010; Clark et al. 2011; Cook et al. 2012; Cropper et al. 2012; de Bock et al. 2012; Pickup 2012b; Shanmugasundaram et al. 2012; Carreira et al. 2013; Johnson et al. 2013b; Bonfanti et al. 2016; Quiros et al. 2016). Historically, new ways of managing diabetes through implementing new health innovations have brought new complexities, and is of particular relevance to insulin pump therapy which is more technologically advanced than previous modes of insulin delivery. Understanding the impact of these advancements is an important avenue for exploration in providing a model of how people incorporate new and complex health tools which ostensibly provide much needed flexibility and choice in how people living with a long-term condition(s) can self-manage. The purpose of this review is to analyse existing literature about the processes of adoption, adaptation, and embedding of a new physical health innovation (insulin pump therapy) in the lives of people with T1D and the resources and support that enable this.

Box 1.

Insulin pumps are electronic devices, about the size of a pager, which drip feed rapid-acting insulin via a fine cannula implanted into subcutaneous tissue, continually throughout the day (called a basal dose)(Pickup and Keen 2002). This device must, therefore, be worn constantly. The user then self-administers, as required, extra shots of insulin (called bolus doses) to match their intake of glucose (carbohydrates) throughout the day. These extra doses of insulin can be much more specific (and minute) at delivering insulin than traditional insulin injections. This apparatus also integrates what is called a “bolus calculator/advisor/wizard”, which recommend an appropriate (and usually personalised) insulin dose to the user.

Optimal self-care practices of people living with T1D constitutes a demanding and multifaceted regimen (Aathira and Jain 2014) including monitoring and controlling blood glucose levels, which are subject to extreme fluctuations, and risk of complications (Johnson et al. 1992; The Diabetes Control and Complications Trial Research Group 1993; Kitabchi et al. 2009). Whilst Multiple Daily Insulin injections remain the main delivery method of insulin therapy globally (Wilmot et al. 2014), both multiple daily injections and insulin pump therapy are recommended (Pickup and Keen 2002; National Institute for Health and Clinical Excellence 2008; American Diabetes Association 2017). However, the focus of insulin delivery is shifting towards the latter as a method considered more physiologically representative of a fully functioning pancreas (Mecklenburg et al. 1982; McAdams and Rizvi 2016). Insulin pump therapy has been shown to yield particular benefits

Box 2

“The [NICE] guidance states that Continuous Subcutaneous Insulin Infusion or ‘insulin pump’ therapy is recommended as a treatment option for adults and children 12 years and over with Type 1 diabetes mellitus if:

- attempts to reach target haemoglobin A1c (HbA1c) levels with multiple daily injections result in the person having ‘disabling hypoglycaemia’, or
- HbA1c levels have remained high (69mmol (8.5%) or above) with multiple daily injections (including using long-acting insulin analogues if appropriate) despite the person and/or their carer carefully trying to manage their diabetes

Insulin pump therapy is not recommended as treatment for people with Type 2 diabetes mellitus.”(NHS Digital 2017)

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over multiple daily injections (Low et al. 2005; Barnard and Skinner 2007; National Institute for Health and Clinical Excellence 2008; Pickup 2012b; Alsaleh et al. 2014), for example, lower cardiovascular mortality (Steineck et al. 2015), higher treatment satisfaction (Hussain et al. 2017) and improved glucose control (Pickup and Keen 2002). In 2008, the National Institute for Health and Clinical Excellence (NICE) recommended insulin pump therapy for people with T1D whose glucose levels were not well controlled by multiple daily injections (National Institute for Health and Clinical Excellence 2008). This has been estimated to apply to 15-20% of adults living with T1D in the UK (Pickup 2006), compared to 6% currently utilising pump therapy (Diabetes UK and JDRF 2013).

Two reviews of pump therapy in 2003 and 2009 found that while pump therapy improves glycaemic control, few studies have robustly assessed psychosocial aspects of using insulin pumps (Weissberg-Benchell et al. 2003; Pankowska et al. 2009). The latter is likely to be pertinent to assess given that insulin pump therapy requirements are likely to constitute an added burden for people, particularly in the initial stages of adoption (Weissberg-Benchell et al. 2003). A review by Barnard et al. in 2007 (Barnard et al. 2007) established that studies which do measure psychosocial aspects of insulin pump therapy were characterised by; variable methodology and psychosocial constructs, small sample sizes, a focus on one particular patient group, or were dated (the devices have since become smaller, more accurate and more widespread). Whilst understanding psychosocial outcomes is relevant to assessing the impact of pump therapy on wellbeing (Weissberg-Benchell et al. 2003; Pankowska et al. 2009) it is important to explore the factors that may promote or inhibit its adoption and embedding as a SM strategy for T1D. Thus, exploration of existing evidence is needed in order to illuminate the processes and outcomes by which insulin pump therapy becomes part of the management of diabetes.

This review is designed to build on earlier reviews by providing a current and in-depth exploration of user experience, and those integrally involved in or impacting on this experience (i.e. parents/caregivers/health care professionals (HCPs)). The aim is to offer enhanced understanding of mechanisms that shape the incorporation, adaptation, and use of pump therapy into the everyday lives of people living with diabetes, and establish what support and resources are needed to enable this.

5.3 Methods

5.3.1 Study design

Critical interpretative synthesis (CIS) was used to identify domains from the literature that are key to successfully incorporating insulin pump therapy. CIS is an exploratory method of reviewing literature, focused on prioritising generation of theory in synthesising findings. CIS allowed us to pragmatically explore the range of data, and understand factors which may enable someone to incorporate an insulin pump into their everyday lives. The review had three stages: 1. Systematic search, 2. Critical appraisal and 3. Synthesis.

5.3.2 Identifying relevant studies

A search strategy was developed incorporating the three main research aims; T1D (population); pump therapy (intervention); and terms relating to the psychosocial outcomes of the studies searched, using the PICOS model (**Table 3**). Different combinations of terms for each component were searched for (including relevant acronyms and truncations), in order to maximise capture of relevant literature (Noblit and Hare 1988). A systematic search of studies reporting users of pumps/HCP or significant other experiences of living with an insulin pump was conducted using a range of databases: AMED; CINAHL; EMBASE; MEDLINE; PsycINFO; Cochrane database; Web of Science. An academic librarian and three other researchers (AR, MB and MCP) provided feedback on development of the search strategy and its results.

Table 3: Search strategy key terms

Number	Term	OR/AND
S1	"insulin pump" "continuous subcutaneous insulin infusion" "CSII" "closed-loop glucose control" "Open-loop glucose control"	OR
S2	Habituation* Psychophysiology* Adaptation* "Quality of Life" "Normalisation" "Normalization" Incorporat* Integrat* Impact* Perception* Experience* Opinion* Attitude* "Social-support" Cope* Coping* Burden* "living with" "psychosocial" Psychol* "Social-functioning"	OR
S3	S1, S2	AND
S4	S3	Limited to English

5.3.3 Study selection and appraisal

Inclusion/exclusion (

Table 4) and eligibility criteria (

Table 5) were established using the PICOS approach. Initially, search criteria did not exclude studies based on publication date; however, early searches indicated that the (most recent) changes to NICE guidelines (2008) (National Institute for Health and Clinical Excellence 2008) considerably widened pump uptake, and consequently technological advancement and research

of this device. We, therefore, restricted our inclusion criteria to studies published 2008 onwards. However, some of the included papers were retrospective, and involved interviewing people who had been using pump therapy for 5+ years. These papers were included on the basis that they provided useful background and contextual information, and some of the barriers and facilitators to adoption and embedding of insulin pump therapy remain relevant. Although quantitative evidence was also reviewed, these papers were not included in the final analysis because they did not sufficiently explore lived experiences of insulin pump therapy.

Table 4: Selection criteria determined using the PICOS model

Selection criteria	Inclusion	Exclusion
Population	People with Type 1 or Type 2 diabetes People who have an insulin pump People who are considering using insulin pump therapy Research from the perspective of health care professionals/carers/relatives	Non-routine use of insulin pump therapy (such as use specifically in pregnancy or in hospitals)
Intervention(s)	Routine use of insulin pump therapy	No focus/data on experience of living with the pump Purely biomedical focus on the insulin pump Research focused on continuous glucose monitoring (CGM)
Comparison(s)	[none]	[none]
Outcome(s)	[none]	[none]
Study design(s)	Research protocols Qualitative Observational Methodological (including development work) Review	Purely quantitative RCT (& feasibility trials)
Publication type(s)	Peer reviewed original research article or review Databases and registers of on-going studies	Patent Commentary Editorial
Publication year(s)	>2008	

Language(s)	English
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Table 5: Eligibility criteria for literature identified in the search

Inclusion	<p>Studies examining some form of psychosocial aspect of living with pump therapy</p> <p>Peer-reviewed original research or review</p> <p>Studies published from 2008 to March 2017</p> <p>Research using qualitative or mixed methods, as well as literature reviews, review papers, reports, conference papers.</p> <p>Papers examining routine use of the pump</p>
Exclusion	<p>Abstracts that do not have a full-text article available</p> <p>Papers not written in English</p> <p>Papers with a purely bio-medical or quantitative focus</p>

Duplicate papers were removed before screening (Figure 14). Titles and abstracts were screened by CR, and a second reviewer from the team (split between MB, AR, AK, and IV). Disagreements about inclusion were resolved at the title screen stage by third review (IV) and through discussion between CR, AK and AR at the abstract stage. 39 full text articles were reviewed by both CR and AR, and one further article was identified through screening the reference lists of the full-text articles. After exclusions, quality appraisal was performed by CR and AR using guidance from Dixon-Woods et al. Included papers were deemed as mostly good quality based on this guidance, except for two which were included because of theoretical relevance (Moher et al. 2009). The final literature search was run in March 2017.

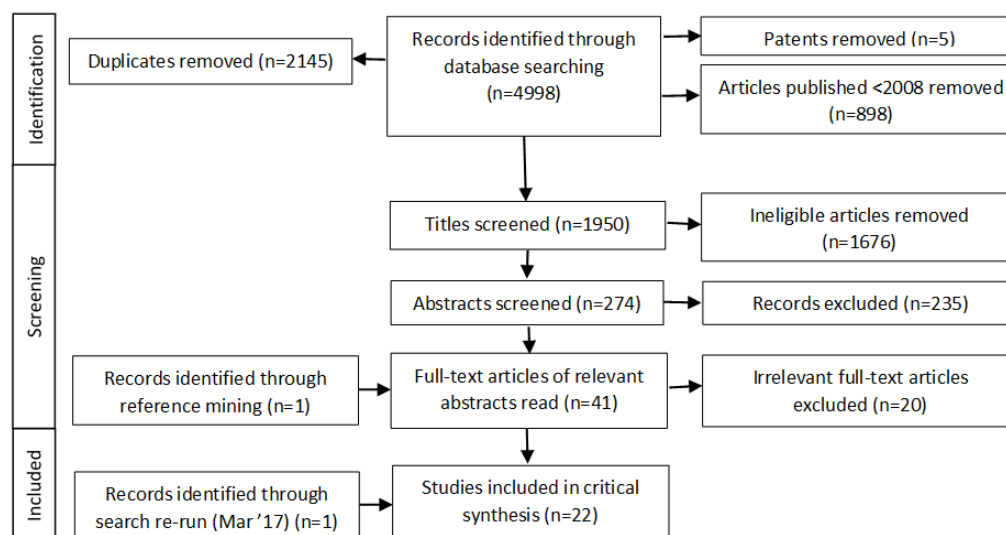


Figure 14. PRISMA flow diagram of identified articles

5.3.4 Data extraction and synthesis

Key information was extracted from papers using a data extraction form including a) background information about each paper b) key findings and themes identified by authors, c) references by authors in terms of implications and/or suggestions for improvement for incorporation of the device d) critical interpretations by reviewers of key themes for insulin pump therapy incorporation and e) how/whether social-support was defined/discussed. The data in the review constituted the main themes reported in each of the individual studies (Thomas and Harden 2008). Each paper was analysed in consideration of themes identified, after which the papers were systematically compared. CR reviewed full papers, and review findings were then discussed and refined with AR and IV in an iterative process. Where more than one paper contributed to a single theme, identifying numbers from the studies were noted at the end of each theme. This enabled relationships across the studies to be identified and provided the basis for a broader explanatory framework.

5.4 Results

22 studies were identified which described the experiences of pump therapy from the perspectives of children/adolescents/young adult pump users (9), (Participants n=251), adult pump users (8), (Participants n=143), HCPs (4), (Participants n=61) and/or parents of pump users (7), (Participants n=266). 18 of the papers were qualitative, and four used mixed-methods. Contextual data from each of the papers are presented in **Error! Reference source not found..**

Table 6: Contextual information about the included studies

Author(s), year, country	Aim	Study design*	Perspective	Sample**	Major findings
Wilson (2008), UK	To gain the pump user's perspective of using a pump with the objective of exploring communicative process with HCPs + how and why people self-manage their condition.	Descrip, Tel-ints	Pump user	N=25, Age: 18-80, Sex: 12M, 13F	If not pump-trained, Diabetes centres provided poor communication and lack of support for intensive diabetes self-management. Some pump users did not attend these clinics, instead communicating with alternative sources for support and information. Individuals were motivated to continue insulin pump therapy, despite barriers from HCPs.
Everett et al. (2010), UK	To determine the barriers of achieving better glycaemic control.	Descrip, FGs	Pump user	N=17, Mean Age: 44±13.3	Barriers were: Expectations of increased hypoglycaemia; anticipated restrictions to lifestyle; mistrust of HbA1c results; and the hard work associated with good glycaemic control. However, participants were eager to continue learning while HCPs need to learn from pump user experience. Hypo fear needs to be addressed early on in pump therapy pathway.
Todres et al. (2010), UK	To provide in-depth insight into the changes that may be experienced by people with diabetes embarking on insulin pump therapy.	Descrip, F2F ints	Pump user	N=4, Age range: 21-51, Sex: 2M, 2F	Switching from multiple daily injections to insulin pump therapy provides challenges in the short term but over a longer period there are significant improvements in quality of life for users. There is a change in the relationship between the pump user and HCP where successful implementation arises from a more collaborative relationship.
Hayes et al. (2011), UK	To examine why people with T1D choose to discontinue insulin pump	Descrip, F2F ints	Pump user	N=5, Sex: 2M, 3F	Main themes: the challenges of wearing the pump; the inconvenience of it; lack of control over the pump, body and health; and comparing expectations versus reality.

therapy.					
Olinder et al. (2001a), Sweden	To gain insight into and generate theoretical knowledge about the processes involved when insulin pump-treated adolescents take or miss taking their bolus doses.	Descrip, F2F ints	Pump user, parent, HCP	N=12, Age: 12-19, Mean Age: 14.4, Sex: 5M, 7F + N=4 parents + 1 DSN	'Lost focus' was identified as the main reason for missed bolus doses: forgetting to bolus post meal; distraction at mealtimes; the perceived impact of taking the bolus is too high (when around others/when fatigued with diabetes). Strategy involves agreements between adolescents and their parents about bolus reminders.
Olinder et al. (2011b), Sweden	To discover the specific reasons why bolus doses are missed and what strategies exist to avoid this, from the adolescents' point of view.	Descrip, F2F ints	Pump user	N=12, Age: 12-19, Mean Age: 14.4, Sex: 5M, 7F	Responsibility in the context of taking or missing bolus doses emerged as the core category. There is a need to clarify the responsibility for SM in continuous negotiations between adolescents and parents to avoid missed doses. HCPs can facilitate and encourage these negotiations.
Alsaleh et al. (2012), (USA, UK, Sweden	To identify studies that explore the experiences of children/young people and their parents on the transition from injections to insulin pump therapy, in the context of their daily life.	Sys lit search	Pump user, parent	Various	Six studies identified. People with diabetes learned about insulin pump therapy either formally from HCPs or informally from a friend/online. Advantages: improved diabetes control; a positive impact on the quality of life from greater flexibility in lifestyles. Disadvantages: pump visibility; physical restrictions; day-to-day management. All participants preferred pump therapy to multiple daily injections, but there is a scarcity of psychosocial data; further research is needed.
Alsaleh et al. (2013), UK	To determine the views and experiences of parents and children regarding the training and services they	Experi, F2F ints	Pump user, parent	N=34, Age: 5-17, Sex: 25M 17F, + N=38 parents	The insulin pump therapy programme provided was appreciated by the majority of families, and provided children and their parents with support for easier transition from multiple daily injections to pump therapy.

					received at a London teaching hospital, when the child commenced insulin pump therapy, and to inform future services.
Garmo et al. (2013), Sweden	To describe experiences of the impact of insulin pump therapy in adults with T1D after > 5 years' use of an insulin pump.	Descrip, F2F ints	Pump user	N=16, Age: 29-65, Median age: 55, Sex: 6M, 10F	The overarching theme revealed that insulin pump therapy was experienced as both a shackle and a lifeline. Six sub-themes emerged: subjected vs. empowered; dependent vs. autonomous; vulnerable vs. strengthened; routinized vs. flexible; burdened vs. relieved; and stigmatized vs. normalized.
Tullman (2013), USA	To explore the individual experiences of female, adolescents with T1D wearing an insulin pump.	Descrip, F2F ints	Pump user	N=12, Age: 12-28, Sex: 12F	Key positive themes: Increased flexibility; increased perceived control over diabetes; higher level of self-esteem. Key negative themes: increased awareness of own body; a constant struggle to maintain health; increased concern of body weight and relationship with food; lack of societal awareness of T1D and the pump. Also reports of general impact/change in intimate and peer relationships, although not necessarily negative.
IAlsaleh et al. (2014), UK	To examine the impact of switching from multiple daily injections to insulin pump therapy on glycaemic control and daily lives of children/young people and their families.	Descrip, F2F ints	Pump user, parent	N=34, Age: 5-17, Sex: 25M, 17F*** + N=38 parents	Key positive themes: Significantly improved blood glucose values after 6 months (8.2% vs 7.6%). Sustained over 3 years; insulin pump therapy generally preferred over multiple daily injections; better general well-being; feeling more in control of diabetes and live; more "normal" life. Parents described more healthy attitudes towards food; improved sleep patterns; more relaxed lifestyles; higher

					energy levels. Key negative theme: Most difficulty reported at the commencement of use.
Barnard et al. (2014), UK	To explore the experiences of adolescents with T1D and their parents taking part in an overnight closed loop study at home, using qualitative and quantitative research methods.	Experi, F2F ints	Pump user, parent	N=15, Age: 12-18, Mean age: 15.6±2.1, Sex: 9M, 6F + N=13 parents	Key positive themes: reassurance/peace of mind; confidence; "time off" from diabetes demands; safety; improved diabetes control. Key negative themes: difficulties with calibration, alarms, and size of the devices. Closed loop insulin delivery represents cutting-edge technology in the treatment of T1DM. Results indicate that psychological and physical benefits outweighed practical challenges.
Forsner et al. (2014), Sweden	To determine parents' experiences of caring for a child less than two years old who had T1D and was being treated with insulin pump therapy.	Descrip, Longit, F2F ints	Parent	N=6 parents, Age:25-40	Parents of infants with diabetes are in great need of support in order to manage the disease and pump technology. The fear of losing control and the lack of relief lead to social isolation. Educating someone close to the family could be a valuable intervention.
Saarinen et al. (2014), Sweden	To describe how people with T1D experience the transition from multiple daily injections to insulin pump therapy.	Descrip, FGs	Pump user	N=11, Age: 25-74, Mean age: 46, Sex: 6M, 5F	Key positive themes: Greater freedom and flexibility, particularly with meals; improved BG control. Those around users reacted with curiosity. Some pump users felt compelled to tell others that they had diabetes because the pump could be seen or heard. Coping with pump therapy in daily life was easier and more comfortable than expected. However, having to constantly be prepared for technical failure was cumbersome. Transition to insulin pump therapy may be liberating, but also imply a sense of the diabetes made visible.

Barnard et al. (2015), UK	To explore the psychosocial experiences of closed-loop technology and to compare ratings of closed- and open-loop technology for adults with T1D taking part in a randomized crossover study.	Experi, F2F ints	Pump user	N=24, Age: Mean 43±12, Sex: 13M, 11F	Closed-loop therapy can free participants from the demands of self-management. Key negative themes: technical difficulties; 'connectivity', which it is hoped will improve. Key positive themes: improved blood glucose control; reassurance/reduced worry; improved overnight control leading to improved daily functioning and diabetes control; improved sleep. Key negative themes: technical difficulties; intrusiveness of alarms; size of equipment. Participants recommend closed-loop technology.
Hood and Duke (2015), USA	To investigate the multidimensional meaning of living with an insulin pump while facing the challenges of life as an emerging adult.	Experi, F2F ints	Pump user	N=9, Age: 19-24, Mean age: 20.9, Sex: 3M, 6F	T1D is like the process of learning tightrope walking; learning to live with diabetes unfolds over time and requires the walker to return to the wire after inevitable falls, trying to achieve a balance. Four themes represent the essence of the day-to-day experiences of these emerging adults: seeking control, becoming responsible, staying connected, and accepting me.
O'Kane et al. (2015), UK/Canada/USA	To examine how T1D devices are adopted, carried, and used.	Descrip, F2F ints, DS, GMU	Pump user	N=41, Age:23-65, Sex: 10M, 31F	Negative themes: adoption of devices; carrying devices; use of devices in front of others. Difficulties Include interactions with; family, friends, colleagues, romantic partners, people while travelling, + strangers. Non-routine events led to uncharacteristic hiding of diabetes/technology in uncertain social situations vs showing off the technology in social situations where there was something to gain. Wide variation in "Normal use" in familiar public situations such as routine work lives and personal lives. In public there

					is variation on whether pump users care what strangers think.
Rankin et al. (2015), UK	To understand the impact on parents who care for young children using insulin pumps; to help interpret psychological outcomes reported in quantitative research; and to inform provision of support to future parents.	Descrip, F2F ints	Parent	N=19, Age: 34-44, Mean age: 40.1±3.7, Sex: 6M, 13F	Positive themes: no injections, fewer restrictions on child especially in relation to eating, better family life and glycaemic control. Negative themes: Additional and unanticipated work to manage their child's diabetes using a pump. Parents felt they would benefit from being made aware of the additional work involved, and also from education and support to address concerns. Better measures to evaluate parents' concerns were also raised.
Ferrari et al. (2016), Australia	To better understand the complexities of the lived experience of children and how this may differ across multiple daily injections and insulin pump treatment regimens	Descrip, Longit, F2F ints	Pump user	N=17, Age: 7-15, Mean age: 11.8±2.4, Sex: 7M, 10F	Illness phase and treatment regimen shaped how bodily cues were interpreted. Insulin pump therapy allowed children to listen to and trust their bodily cues rather than override. Shame was a barrier to support engagement. Different internalised and externalised views of T1D emerged. Overall, children were insightful experts of their own experiences.
Lawton et al. (2016), UK	To explore health professionals' views about insulin pump therapy and the types of individuals they thought would gain greatest clinical benefit from using this treatment.	Descrip, F2F ints	HCP	N=18, DSN:12, Diet:6, Prac: 5-29	HCPs perceived insulin pump therapy as offering better insulin therapy to some individuals. However, HCPs felt that pump therapy is more technically complex than multiple daily injections, and so, selected individuals based on whether potential users possessed attributes to enable optimal use of the technology. However HCPs assumptions had been challenged by working on the REPOSE trial by observing individuals making effective use of insulin pump therapy who they would not have recommended.

Shulman et al. (2016), Canada	To understand why pumps have been broadly adopted in order to inform optimal practice and the development of strategies to deal with pressures to adopt new technologies into practice.	Descrip, F2F ints	HCP	N=16, Sex: 8M, 8F, Phys:16, Prac: 2.5-45	Key themes: pump therapy may fall short of expectations of improved glycaemic control; although insulin pump therapy deemed as limited in terms of this outcome, HCPs also saw where it had value both for the users and for themselves. Pumps status as a new technologies, which were seen to have current, or to promise future, benefits.
Perry et al. (2017), Australia	To examine the support context for people with diabetes using insulin pump therapy from the HCP perspective, as well as contextual influences for HCPs and people with diabetes.	Descrip, Tel-ints	HCP	N=26, Sex, DNE: 12, Diet: 3, Phys: 8, GP: 3	Key themes: difficulties, disconnections, and disarray. Reports of shortages of HCP pump therapy expertise in practice + disconnected and disarrayed service structures and processes. Needs for consistent and coordinated care for people with an insulin pump, and the infrastructure to facilitate this was highlighted.

From the data analysis, three themes of relevance emerged: *Tensions between expectations and experiences in adoption and early adaptation; Negotiating responsibility and accessing support from health care professionals and wider networks; and, Reflexivity, active experimentation, and feedback.*

5.4.1 Tensions between expectations and experiences in adoption and early adaptation

Polarisation between expectations and experiences of users in learning to live with the technology was reported as common in the early stages of adoption. Prominent in the narratives was the device allowing for “increased flexibility” but accompanied by descriptions of ongoing disruption in daily activities, and needs for adjustment when initiating this type of insulin therapy (Garmo et al. 2013; Tullman 2013; Rankin et al. 2015).

There were differences in people's initial expectations. Where some saw the pump as a panacea for insulin delivery, others simply saw the device as a tool which incrementally improved existing efforts at diabetes-related daily management by making subtle but useful adjustments.

“In the way, simple. Really I think it is in the way and the fact that it didn't meet up to the expectations that I perhaps thought it would in overall control” (Female who discontinued insulin pump therapy). (Hayes et al. 2011)

“I have a very stationary job but I am fairly active at the weekends and then I can sometimes adjust to a temporary basal rate, or change the programme. I have a basal programme that is lower.” (Female, aged 52 years) (Garmo et al. 2013)

This initial expectation (and potential contradiction) was seen as important to address by all parties (users/parents/HCPs) (Hayes et al. 2011; Garmo et al. 2013; Tullman 2013; Forsner et al. 2014; Rankin et al. 2015; Shulman et al. 2016) and perceptions of what the pump could do shaped subsequent expectations of the amount and nature of work required to master living with this new device (Wilson 2008; Olinder et al. 2011a; Rankin et al. 2015; Lawton et al. 2016). Reasons given by people with T1D for wanting to move to insulin pump therapy from multiple daily injections included pursuit of greater stability and control over blood sugar levels, and desire for a more flexible lifestyle (Alsaleh et al. 2012; Saarinen et al. 2014; Hood and Duke 2015). Most users indicated that the new equipment made self-management easier in terms of work required to balance glucose levels, enabling them greater flexibility in, for example; when/where/how they chose to eat; and undertaking spontaneous activities (Olinder et al. 2011a; Alsaleh et al. 2012; Garmo et al. 2013; Tullman 2013; Forsner et al. 2014; Saarinen et al. 2014; Rankin et al. 2015; Lawton et al. 2016; Shulman et al. 2016; Ferrari et al. 2018).

“It just gets better and better; the transition from syringes to pump was painless. I think it is much easier to have the pump than all those syringes.” (Male, aged 25 years)(Saarinen et al. 2014)

By comparison, multiple daily injections was described by some as an insensitive approach to physiologically imitating insulin production, with inability to adjust levels of insulin in the body for up to 24 hours;

“The pump allows me to obtain tight control of my blood glucose by administering very small amounts of insulin...which cannot be done with insulin injections...this prevents me having to have a higher basal rate...which leads to more hypos because it is too much insulin for me.” (Gender unknown, aged 25 years) (Wilson 2008)

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However, improved self-management and ‘flexibility’ sat in tension with increased expectations to learn new “work”; new skills and adopt new practices associated with a more complex piece of technology (Everett et al. 2010; Hayes et al. 2011; Alsaleh et al. 2012; Alsaleh et al. 2013; Garmo et al. 2013; Alsaleh et al. 2014; Forsner et al. 2014; Saarinen et al. 2014; Barnard et al. 2015; Hood and Duke 2015; Rankin et al. 2015). Parents reported “putting their life on hold” (Alsaleh et al. 2014) while integrating the new tool into management of their child’s diabetes. Acquiring new skills relating to use and monitoring of the device was seen as tedious, challenging (Alsaleh et al. 2012; Rankin et al. 2015) and burdensome with respect to the complexity and frequency of some tasks (Barnard et al. 2015; Rankin et al. 2015).

Considering where and how to wear this contraption on the body also illuminated constraints to ‘flexibility’, while a potential dissonance seemed to occur between expectations that insulin management is automatic and simplified with the reality of the new machine requiring substantial thought and action. Feelings of vulnerability were also described when there was an overwhelming need to prepare for potential failures in this new apparatus (Hayes et al. 2011; Garmo et al. 2013; Barnard et al. 2014b). This was often reported as illness-burden, particularly in studies representing the views of adults and parents, and during the early stages of adoption (Hayes et al. 2011; Garmo et al. 2013; Alsaleh et al. 2014; Barnard et al. 2014b; Forsner et al. 2014; Saarinen et al. 2014; Barnard et al. 2015).

In addition to new work, the device also introduced new inflexibilities. Typical daily experiences of insulin pump therapy were described in dichotomised terms as representing both a shackle and lifeline (Garmo et al. 2013). For many, the pump was experienced as constraining because it interfered with day-to-day life, due to the increased visibility necessitating further work to discretely attach this piece of equipment to the body, and/or the status attributed to a permanent appendage to be worn 24/7 (Hayes et al. 2011; Garmo et al. 2013; Tullman 2013; Alsaleh et al. 2014; Forsner et al. 2014; Saarinen et al. 2014; Barnard et al. 2015; Hood and Duke 2015; O’Kane et al. 2015). Physical restrictions were also imposed, which were caused by the bulky nature of the tool and its connecting tubes and alarms.

“As a woman, I like tight skirts and dresses, I can’t wear that anymore. I have to choose clothes based on the pump.” (Female 43 years) (Saarinen et al. 2014)

Women expressed more concern than men about body image and social acceptance in terms of the visibility and concealment of the pump (Hayes et al. 2011; Saarinen et al. 2014; O’Kane et al. 2015). Parents were less concerned about practicalities of wearing the device, and more with the reliance and safety of the technology (Alsaleh et al. 2012; Alsaleh et al. 2013; Alsaleh et al. 2014; Barnard et al. 2014b; Forsner et al. 2014). These disadvantages illuminate discrepancies between

expectations and realities of introducing a new health contraption, and a variety of experiences and perspectives on its adoption. Different demands in daily activities, and in user's preferences and priorities, mean that everyday contexts in which the device may be accommodated is variable, and that there are a range of 'trade-offs' between the limitations and advantages of pump therapy.

There were descriptions of persistent aloneness in trying to be "normal", and trying to hide the equipment from others to achieve this. Many users of an insulin pump expressed feelings of being different from peers, yet wanting to be and feel "normal" (Olinder et al. 2011b; Garmo et al. 2013; Tullman 2013; Barnard et al. 2015; Hood and Duke 2015; O'Kane et al. 2015; Shulman et al. 2016).

"When you take it out [the pump] you feel like you're exposing something about yourself for people to, sort of, either, sort of, judge that it's good or bad, in a way, and then I more, sort of, fear someone's reaction." (Female, age unknown) (O'Kane et al. 2015)

Living with diabetes was described as a constant struggle, and the process of self-management as isolating and lonely (Hood and Duke 2015), especially when there was a potential for prying or judgement from others (Everett et al. 2010; Todres et al. 2010; Olinder et al. 2011b; Alsaleh et al. 2013; Tullman 2013; Saarinen et al. 2014; Hood and Duke 2015; O'Kane et al. 2015; Shulman et al. 2016). Intimate relations were also discussed with reference to the inevitable awkwardness in explaining the device to a sexual partner, or the contraption getting in the way (Hayes et al. 2011; Garmo et al. 2013; Tullman 2013; Saarinen et al. 2014; O'Kane et al. 2015). While most users expressed being open to others some preferred not to expose their diabetes diagnosis or means of insulin delivery to strangers (Todres et al. 2010; Hayes et al. 2011; Olinder et al. 2011b; Garmo et al. 2013; Tullman 2013; Saarinen et al. 2014; Hood and Duke 2015; O'Kane et al. 2015; Ferrari et al. 2018). However, contemporary popular interest in innovation was thought to assist in explaining the condition to others, by using the apparatus (a relatively familiar looking object) as opposed to injections (Garmo et al. 2013; Tullman 2013; Alsaleh et al. 2014; Saarinen et al. 2014; Hood and Duke 2015; Rankin et al. 2015).

5.4.2 Negotiating responsibility and accessing support from health care professionals and wider networks

This second theme highlights the ensuing need for emotional and practical assistance, and understanding of who is responsible for the management tasks relating to the pump, during the initial phase of adoption.

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How individuals incorporate the device and undertake activities relies, to an extent, on external influences, encompassing a range of social and healthcare support-related relationships. Users of insulin pump therapy articulated how social-support provided additional assistance, and how a network of support enabled the work of self-management to be shared out (Olinder et al. 2011a; Tullman 2013; Rankin et al. 2015; Ferrari et al. 2018). HCPs also echoed the importance of ongoing multifaceted, holistic, and tailored expertise in facilitating pump therapy use (Shulman et al. 2016; Perry et al. 2017). However, not all social interactions were viewed as beneficial to self-management.

In the main, facilitation and encouragement from family members and HCPs in adapting to and understanding the mechanisms of the device were considered helpful by those living with this tool (Everett et al. 2010; Todres et al. 2010). Mastering insulin pump therapy, from the user's point of view, was described as easier when there was trust and assistance from HCPs which was tailored and holistic (Garmo et al. 2013; Hood and Duke 2015).

“I don't want my blood sugars to be high all the time or low all the time...But when [the HCP] adjusts stuff without looking at what's actually going on or listening, it's just kind of pointless.” (Sex unknown, young adult, exact age unknown) (Hood and Duke 2015)

The complexity of the equipment could make users feel vulnerable in terms of needing backing to programme and manage its more advanced features (Garmo et al. 2013; Saarinen et al. 2014). Complex tasks included understanding how insulin is administered, and sharing practical tips for discrete/un-invasive placement on the body (from other users or HCPs). Advocated assistance included provision of psychological support in clinics and play therapy for younger children. Aids to assist with subcutaneous cannula insertion, simplifying the process and easing pain, or testing a saline pump to experience how it feels to be attached to the device before implementation were also advised (Alsaleh et al. 2013), as well as more information and interaction to set up the machine (Saarinen et al. 2014; Perry et al. 2017; Ferrari et al. 2018). However, too much information at initiation could be unhelpful. Not seeking or having any ongoing support or information about the equipment proved to be detrimental to incorporation (Hayes et al. 2011; Perry et al. 2017; Ferrari et al. 2018).

Assistance and information from others in a non-clinical setting was identified as relevant. Insulin pump users described wanting to learn about the device and find ways to fit it into their lives through learning from peers (i.e. people who actually have experience of living with T1D) (Everett et al. 2010; Hood and Duke 2015).

“We’re like, ‘How’s your blood sugar?’... “We’ll joke about it [blood sugar levels]. It’s...reassuring, that other people are going through it too, you know. So you don’t feel as weird...You feel kind of normal.” (Female, young adult, exact age unknown) (Hood and Duke 2015)

Interactions with peers offered the prospect of support, shared learnings, and practical solutions for day-to-day problems (Wilson 2008; Everett et al. 2010; Alsaleh et al. 2012; Tullman 2013; Hood and Duke 2015). Connecting with others through face-to-face contact or through blogs was considered valuable (Hood and Duke 2015). Similarly, meeting other families was valued (Alsaleh et al. 2013), where parents with some shared responsibility for managing this machine also reported on the initial burden (Alsaleh et al. 2012; Alsaleh et al. 2014; Forsner et al. 2014). Valued elements of meeting others included; sharing the training experience, meeting others in the same situation, and a relaxed atmosphere which facilitated troubleshooting.

However, accessing aid, whether from peers, family members or HCPs was influenced by the level of responsibility taken, or desired, from the user.

“It’s starting to hit me now . . . I don’t realize that the diabetes is damaging [my body] ... It [having the pump] was just kind of a wake-up call... is my responsibility ... not my mom’s.” (Female, young adult, exact age unknown) (Hood and Duke 2015)

The level of responsibility is also seen to vary between age groups, from younger children needing more intensive parental assistance to adults wanting to feel a full sense of control over their diabetes, and incremental changes in desired responsibility in between (Everett et al. 2010; Todres et al. 2010; Hayes et al. 2011; Olinder et al. 2011a; Olinder et al. 2011b; Garmo et al. 2013; Tullman 2013; Forsner et al. 2014; Hood and Duke 2015).

There are also times when the need for support varies (e.g. in times of sickness). The establishment of distribution and transfer of responsibility from parents to children, adolescents and young adults was discussed. Parents often hold most of the responsibility of diabetes management for children, which is gradually handed over, to varying effect (Olinder et al. 2011a; Olinder et al. 2011b; Alsaleh et al. 2013; Tullman 2013; Alsaleh et al. 2014; Hood and Duke 2015; Ferrari et al. 2018).

“But now, in the autumn she missed a little bit again [of insulin doses]. Then I realized that it’s not possible to leave the responsibility to her so much, because it didn’t work, she forgot doses and such.” (Mother) (Olinder et al. 2011a)

A hindrance to this transfer of responsibility could be parental fear of the ability of the child to self-manage, and so the parent may be reluctant to surrender responsibility. Parents were quoted as desiring education and assistance themselves (Olinder et al. 2011a; Forsner et al. 2014).

5.4.3 Reflexivity, active experimentation and feedback

This theme focuses on challenges faced by new pump users, and the process of the integration and normalisation of the device. The term 'reflexivity' here refers to how experiences that interrupt what is normalised and/or habitual for individuals are encountered and understood consciously (i.e. reflexively), and the implications that this has for how people then act and incorporate the new apparatus into their everyday lives.

Normalisation of this piece of equipment as a new practice is a process of gradual acceptance and assimilation. Some respondents described how the device felt like a tattoo, an appendage, or an extension of self after the initial period of getting to grips with the new contraption, requiring a journey of reflection, active experimentation and feedback (Tullman 2013; Forsner et al. 2014; Hood and Duke 2015; O'Kane et al. 2015).

“I was self-conscious about [the pump] at first... I was like, ‘Ugh, people will see it’ [the pump] ... But [going to diabetes camp] really got me out of my shell... It’s like telling someone I got a new tattoo... It’s [the pump] just a part of me.” (Male, young adult, exact age unknown) (Hood and Duke 2015)

Adoption was predicted on a demand that the user trust the machine to perform its functions safely (Todres et al. 2010; Hayes et al. 2011; Tullman 2013; Barnard et al. 2014b). As well as adjusting to the initial complexities, fear that the apparatus would do something that the user does not want it to, or not wanting to give up control suggests psychological adjustments alongside other practical adjustments.

“At night I can’t help think that if the buttons pressed or ... even in the day if you knock it [the pump] or something goes in or too much, you haven’t got full control over what you are putting in your body really so that was part of it as well’ (Female who discontinued insulin pump therapy) (Hayes et al. 2011)

Over time, the initial stress and vulnerability created by dependence on a machine gave way to feelings of autonomy when the technology was mastered (Hayes et al. 2011; Alsaleh et al. 2013; Garmo et al. 2013; Barnard et al. 2014b; Forsner et al. 2014; Saarinen et al. 2014; Barnard et al. 2015; Hood and Duke 2015; Shulman et al. 2016).

“You have to be a bit knowledgeable as well and you have to learn about the pump yourself very carefully... It’s a case of having the courage to try the different functions of the pump, so you know what to do if something goes wrong.” (Female, aged 54 years) (Garmo et al. 2013)

Users of pump therapy reported the need for a period of adjustment to feel comfortable with being attached to a machine 24 hours a day (Everett et al. 2010; Todres et al. 2010; Hayes et al. 2011; Olinder et al. 2011a; Olinder et al. 2011b; Garmo et al. 2013; Tullman 2013; Saarinen et al. 2014; Hood and Duke 2015; O’Kane et al. 2015).

The visibility of the device created a sense of heightened awareness of one’s body and as a result a greater need for assistance to adapt and find ways to comfortably situate the machine at the point of introduction (Alsaleh et al. 2013; Tullman 2013; Alsaleh et al. 2014; Saarinen et al. 2014). Through technical control of the apparatus, and resulting stabilised blood glucose levels, greater personal control was realised (Todres et al. 2010; Saarinen et al. 2014). A common depiction of incorporation involved the need to gain motivation and confidence to adapt it (Wilson 2008; Todres et al. 2010; Garmo et al. 2013; Alsaleh et al. 2014; Forsner et al. 2014; Saarinen et al. 2014; Hood and Duke 2015; Lawton et al. 2016). For example, a parent of a young child using insulin pump therapy commented on how longer term benefits were predicated on performing necessary work during the adoption phase;

“You take care of it [diabetes] yourself. It’s freedom with responsibility. That demands courage.” (Parent) (Forsner et al. 2014)

5.5 Discussion

This review suggests a period of adjustment and experience that emerges over time, and a process of incorporation that changes from the point of anticipation (pre-insulin pump therapy) through to adoption. This process is accompanied by having to navigate and be responsive to a range of contingent bodily sensations and technological demands that were unexpected at the outset. There is an initial liminality associated with use of the pump as a foreign object, and upon introduction users feel that they are on the edge of something new. People living with diabetes who adopt pump therapy do so with existing experiential knowledge of their condition; as such the process of adjustment necessary to embed this technology into everyday life includes integration of new knowledge about management combined with their existing understandings.

Initial expectations shape both the type and amount of work the person subsequently puts in to adopting and integrating the device into his/her daily life. Negotiation of responsibility and access

to personalised information, support, and resources can affect how well s/he is able to incorporate pump therapy. What follows is a need to engage in active experimentation, in which the user reflects on his/her experience and feeds that back into use of the appliance, adapting it to his/her needs. This can also be facilitated through negotiation of the assistance available to him/her (e.g. shared experiences of other users of insulin pump therapy, feedback from HCPs). The more the new pump user becomes accustomed to the tool, its physical presence, and the greater the degree of aid available to him/herself and his/her families/significant others, the easier it can be incorporated.

This review suggests a qualitative difference between using multiple daily injections and insulin pump therapy which centres on experiencing metabolic improvements, but also to feelings of ease, personal control and confidence in using and habituating to more complex technology. The apparatus evokes feelings of technological advancement and flexibility, and so high expectations of the device's potential are engendered. The previous method of insulin delivery required needles, a very physical but singular interaction, whereas this machine is integrated into the body 24/7. This process can make users much more aware of their body image and appearance. Additionally, using insulin pump therapy introduces new types of work, the completion and normalisation of which requires acquiring new skills and renegotiating relations within personal communities.

The review also suggests that if a new user of insulin pump therapy has no access to additional support or resources, then their ability to incorporate the new appliance will be hindered. It has been found that effective diabetes medical care and self-management is enriched by improving access to specialist and ongoing diabetes HCPs (Funnell et al. 2008; Casey et al. 2011; Diabetes UK 2015b). However, HCPs providing care for patients with diabetes do not currently receive postgraduate training for the relief or assessment of educational, medical, emotional or psychological aspects of diabetes (Byrne et al. 2017). Other means to supplement this support are therefore vital. Many aspects of self-management are more achievable through working with others, by allowing knowledge, skills and resources to be pooled (Bandura 1998, 2000).

The, very recent (post-March 2017), Relative Effectiveness of Pumps Over multiple daily injections and Structured Education (REPOSE) trial (Heller et al. 2017), compared insulin pump therapy with multiple daily injections, with findings that resonate with this current review including pump expectations not being met but experiencing; increased discretion, flexibility, and spontaneity (especially with food or exercise). The report, however, focused on improvements in diabetes self-management due to structured education and ongoing support. Studies considered here indicate that there is a potentially stressful element in introducing a new and complex technology into

someone's life. The role of others in accessing assistance could be a future avenue to explore. What we do know is that social networks and good social support are associated with better functioning, fewer psychosocial problems, and improved self-management in people with diabetes in general (Kyngas 2000; Karlsson et al. 2008). Social networks can provide emotional and/or practical aid as well as facilitating a means to mobilise, negotiate, mediate, and access further means of assistance (Vassilev et al. 2011; Blickem et al. 2013; Hempler et al. 2016; Kennedy et al. 2016). A supportive social network is known to have a "buffering" effect in situations eliciting stress (such as the introduction of a complex new technology) (Cohen and Wills 1985; Miller and DiMatteo 2013), but the impact of social-networks amongst people living with insulin pump therapy is not well, or reliably, documented (Ritholz et al. 2007). When insulin pump therapy is first introduced, the level of responsibility taken for pump management is as much as the user is willing to accept, and this varies. The desire for responsibility of self-management is thought to increase from childhood through to adulthood, and negotiation with caregivers is required to share out tasks. The findings in this synthesis not only resonate with and compliment research on social-networks in long-term-conditions (outlined above), but also with studies examining shared responsibility between adolescents with T1D and their caregivers (Ingerski et al. 2010; Vesco et al. 2010). While motivation to take responsibility for self-management is important, (Casey et al. 2011; Barnard et al. 2014a) motivation is not all that is required, as people living with T1D may, for example, feel fatigued. Sharing responsibility for the work of managing the condition can enable better self-management and improved health outcomes through sharing the illness and insulin pump related burden associated with the complexity, frequency and relentless nature of some self-management tasks (Helgeson et al. 2008; Barnard et al. 2014a). This is where a link to support and resources could prove crucial.

5.5.1 Implications

These findings identify the types of beliefs that influence the adoption and diffusion of technologies. In terms of an insulin pump, barriers to incorporation for the person with diabetes include the tension between the expectations of the device and the actual experience. For improved integration early conversations are needed from HCPs about the likely period of disruption, potential pump users have not been familiarised with the work that is going to be carried out and they need time, resources and information to overcome this. HCPs and manufacturers of pumps need to be realistic with potential users so that they can anticipate this work. Frank conversations about the limitations of the apparatus are necessary. People with diabetes need to be given the opportunity to build confidence about using this new appliance, and negotiations between children/adolescents and their parents must be undertaken. Being

prepared for the time required to work the contraption into their lives, as well as sensitivity to the inevitable variability between users could set realistic expectations. Harrison et al. (Harrison et al. 2014) described how perceived assistance from HCPs or peers formed an important aspect of patient satisfaction and should be considered for future interventions. In examining the social network that pump users have access to, and enabling them to tap into further (and ongoing) means of support and resources, users of insulin pump therapy could incorporate the apparatus more successfully.

5.5.2 Limitations

A number of limitations must be acknowledged with respect to the present review. Firstly, the findings of the synthesis reflect the background and experiences of the reviewers, and as such are subjective. We acknowledge that the findings could have been different if conducted by a different set of researchers, however, steps have been taken in line with guidance (Dixon-Woods et al. 2006) to ensure transparency in reporting on analytic processes which informed our analyses. Secondly, the papers included in the review incorporated a variety of methods, meaning that data quality was variable. The authors were sensitive to the quality of the methodology and did bear this in mind throughout the data analysis, and no concerns were raised with respect to the veracity of reporting or integrity of findings.

Thirdly, while men and women were, roughly, equally represented as participants in the papers reviewed (where these were reported) (44% vs 56%), it appears that men were relatively underrepresented in the quotes given in the papers (15% vs 45% - with the remaining 40% of quotes being non-gender specific). Therefore, quotes offered in this synthesis of papers could potentially offer a pump adoption experience that is skewed towards female users. One possible contributor to this gender imbalance could be that more women expressed fears and concerns relating to body image and social acceptance than male participants.

Fourthly, reporting on demographic composition of study samples was not consistent across the papers reviewed. For example, not all studies disclosed the mean/median age (Wilson 2008; Todres et al. 2010; Hayes et al. 2011; Tullman 2013; Forsner et al. 2014; O’Kane et al. 2015; Lawton et al. 2016; Shulman et al. 2016; Perry et al. 2017) or range (Everett et al. 2010; Hayes et al. 2011; Barnard et al. 2015) of their participants. For those that did, the range was from 5-80, and of HCPs the range of years in practice was 2.5-45. The papers included a range of ages (children, adolescents, young adults, adults) and perspective (users of insulin pumps, parents, HCPs), which offered an array of insights. However, saturation was not reached for any demographic group or perspective. Future studies may therefore look to explore comparatively

the experiences of sub-groups within the population of insulin pump adoptees and their families/significant others.

5.5.3 Conclusion

This review makes several original contributions to the knowledge base relating to experiences of pump users adoption and use; (1) investigation of recent studies not included in previous reviews of insulin pump device adoption (2) synthesis of lived experiences of users of various ages, in greater depth; (3) synthesis of perspectives from parents and HCPs. To our knowledge, this review also represents the first to explore, qualitatively and pragmatically, the process of incorporating a new technology, worn 24/7, in a long-term condition.

Chapter 6 Paper 2: Integrating self-management needs and theory to implement a web-based self-management tool for people with Type 1 diabetes using an insulin pump

6.1 Abstract

Background

Type 1 diabetes (T1D) is an autoimmune disease requiring intensive self-management (SM). An insulin pump (a new health technology) is designed to better support personal T1D management but at the same time exacerbates the complexity and requirements of SM. Research shows that people with diabetes are likely to benefit from navigating and connecting to local means of social-support and resources from online interventions which offer flexible, innovative and accessible SM. However, questions remain as to which behaviour change mechanisms within such resources benefit patients most and how to foster engagement with and endorsement of SM interventions from both patients and healthcare professionals (HCPs).

Objective

The aim of this study was to evaluate the perspectives and experiences of people with T1D using an insulin pump and specialist HCPs pertaining to a web-based social network (SN) intervention to support SM and determine what behaviour change characteristics and strategies are required.

Methods

Focus groups with insulin pump users (N=19) and specialist HCPs (N=20) in 6 NHS Trusts across the South of England examined the barriers and enablers to incorporating and self-managing an insulin pump. Analysis was undertaken using the Behaviour Change Wheel and Theoretical Domains Framework followed by a taxonomy of Behaviour Change Techniques (BCTs) to identify the contents of and strategies for implementation of a complex health intervention.

Results

Four themes represent the SM perspectives and experiences of stakeholders: (1). A desire for access to tailored and appropriate resources and information - the support and information required for successful SM is situational, contextual and varies according to time and life

circumstances and so needs to be tailored and appropriate; (2). Specific social-support preferences - taking away isolation, providing shared learnings and practical tips, but limitations included the fear of judgement from others and self-pity from peers; (3). The environmental context: Capacity and knowledge of pump clinic HCPs - HCPs acknowledge patient's need for holistic support but lack confidence in providing it; and (4). Professional responsibility: "Risks and dangers" – HCPs are bombarded with "risks and dangers" around SM support for patients and question whether it fits into their role. BCTs were identified to address these issues.

Conclusion

The use of a behavioural theory and a validated implementation framework provided a comprehensive approach for systematically identifying barriers to and enablers of self-managing T1D with an insulin pump. A web-based SN intervention appears to offer additional forms of SM support while complimenting NHS services. However in order for intervention implementation, HCP apprehensions about responsibility when signposting to outside agencies or support would need to be addressed, and opportunistic features added where pump users could actively engage with other people living with T1D.

6.2 Background

In the UK, approximately 400,000 people are currently living with Type 1 diabetes (T1D) of which both the prevalence and healthcare costs of managing are increasing (Foster et al. 2019; Patterson et al. 2019). Improved blood glucose levels is viewed as a primary goal of self-management (SM) efforts because it delays the onset and progression of diabetes-related complications (stroke, heart disease, neuropathy). However only 30% of people with T1D are achieving recommended glycaemic targets and attainment of these targets are complex. There is recognition of the need for more tailored interventions to enhance the opportunity to improve blood glucose levels (McBrien et al. 2016). Theoretically founded web-based interventions in particular are seen to offer the opportunity to support flexible, innovative, and accessible self-management to address this growing crisis (El-Gayar et al. 2013).

Treatment of T1D consists of demanding SM requirements including; insulin therapy (multiple daily injections - or insulin pumps), self-monitoring of blood glucose, and comprehensive understanding of nutritional, hormonal and physical impacts on glycaemia (Campbell et al. 2018; Chatterjee et al. 2018). Multiple daily injections is the most common insulin therapy method but interest and uptake in insulin pumps have risen over the past 20 years and predictions suggest this will continue due to growing global interest and evidence to support their use (Umpierrez and Klonoff 2018). The DAWN2 study found that outcomes are better for people with diabetes when

they have greater access to diabetes SM education and positive social support (Nicolucci et al. 2016). A recent review suggested that interventions to improve these aspects are necessary and require more flexible and personal SM support for those using these devices (Reidy et al. 2018). This review highlighted how the process of incorporating an insulin pump often changes treatment expectations and experiences and comprises a distinct, and potentially difficult, process of learning, exploration and adaptation. People with T1D initiating a new health technology need to self-manage but they need appropriate options to do so and web-based interventions have unlocked potential in this regard.

Technology can play a key role in bringing diabetes care to the individual (Prahalad et al. 2018). Interest in web-based SM interventions has increased over the last decade (Wantland et al. 2004; Prahalad et al. 2018) not least because web-based elements (or e-health) offer opportunities to take pressure off the NHS while supporting flexible and accessible SM (El-Gayar et al. 2013). Additionally, interventions which take into account the individual's social context in behaviour change are relevant in improving health outcomes (Hood et al. 2015). It is well recognized that poor psychological wellbeing can have a significant impact on glycaemic control, which in turn increases the risk of diabetes-related complications, increased healthcare costs and lost productivity (Diabetes UK 2008; The emotional and psychological support working group of NHS Diabetes and Diabetes UK 2010; Jones et al. 2015; Diabetes UK 2016; Joensen et al. 2018; Prahalad et al. 2018). A web-based social support network approach to SM could provide an avenue to improved psychological wellbeing and blood glucose levels. Social networks and good social support have been shown to promote diabetes SM and assist in physical and mental wellbeing (Gallant 2003; Wysocki and Greco 2006; Rosland et al. 2008; Schiotz et al. 2012; Joensen et al. 2013; Reeves et al. 2014; Allen et al. 2016).

Blakeman et al.'s trial of an earlier version of the Generating Engagement in Networks Involvement (GENIE) social-network intervention demonstrated improved quality of life, engagement in healthcare and health outcomes (Blakeman et al. 2014). GENIE is a tool that helps participants map their personal community of support and make best use of existing contacts and add new ones where needed, as well as signposting (and providing a nudge) to personalised resources in their locality and has been presented elsewhere (Kennedy et al. 2016). In spite of this, little progress has been made in implementing and spreading psychosocial or social-support interventions into clinical practice to improve SM (Funnell 2006; Barnard et al. 2012; Gonzalez et al. 2016; Reddy et al. 2016; Chatterjee et al. 2018). There are challenges in the implementation, sustainability and accessibility of these interventions in local contexts and to relevant stakeholders (patients and healthcare professionals- HCPs) (Campbell et al. 2007). Consideration of the mechanisms of success are often missing (Pilkington et al. 2017). Mulvaney et al.'s review

Chapter 6

of diabetes mobile intervention design (Mulvaney et al. 2011) found that there was often little consideration for what SM barriers were addressed or the likely motivation for potential users. They suggested tailoring health intervention content and/or design to stakeholder characteristics in order to improve patient engagement and outcomes.

The Medical Research Council have identified the importance of utilising theory and incremental stepped approaches when developing behaviour change interventions (Craig et al. 2008). In this instance the Behaviour Change Wheel (BCW) was selected and accompanied by the Theoretical Domains Framework (TDF) due to their focus on the context (the physical setting) in which a behaviour occurs, the reflective processes that are involved in behaviour change and provision of a clear and direct strategy to bring about change (Michie et al. 2011; Michie et al. 2014; Murphy et al. 2017). The evidence base for digital SM interventions in long-term-conditions may be able to progress more effectively if we focus not only on measured outcomes but also document and examine the dimensions and processes of interventions most important to stakeholders.

6.2.1 Aim

This paper provides a comprehensive needs identification of the specific insulin pump SM needs and perspectives of people with T1D, and HCPs working in T1D pump clinics. This will identify recommendations to optimise an intervention to improve SM of an insulin pump from the point of pump therapy initiation. These recommendations will be considered in reference to an innovative approach to SM; using a web-based social-support networking intervention.

6.3 Methods

6.3.1 Study design

Focus groups offer the opportunity to explore the range of views and perspectives of the support required and resources used by current pump users, from pump initiation to current point of use. Focus groups can stimulate enhanced disclosure and a supportive environment which incites elaborated accounts and clarification of experiences (Wilkinson 1998). Focus groups with HCPs allowed for exploration of how an online SM support tool could fit into NHS practice. The group environment was considered a strength for discussions of implementation and offered an opportunity for individual HCPs to respond to and build on colleague's comments and brainstorm ideas.

6.3.2 Setting

A total of n=11 Focus groups and one interview in the south of England were carried out between July 2017 and January 2018. The focus groups took place within six NHS Trusts which represented varying levels of deprivation and population density across the region. Six focus groups were with insulin pump users (n=19) (see **Table 7**), and five focus groups and one interview with diabetes specialist HCPs (n=20). We held one focus group per clinic (except one where we also undertook an interview). Conversations lasted 40–72 min (average=56.33 min) with patients and 27-44 min (average=37.6 min) with HCPs.

Table 7. Participant demographics

	(%) UNLESS OTHERWISE STATED
Age (Mean, SD, range)	38.53 (9.91), range 20-53
Sex (Female)	52.6
Ethnicity (White British)	84
Income (average UK = £26,500)	
Lower than average	42.1
Average	31.6
Higher than average	26.3
Education level (Degree level or above)	63.2
Time since diagnosis (Mean, SD, range)	21.95 years (SD=12.77), 3-41 years
Time since pump start (Mean, SD, range)	5.94 years (SD=5.98), 0.5-19 years
Diabetes-related complications^a	47.4
Been in hospital > 3 times^b for hypoglycaemia or DKA^c	10.5
Healthcare professionals	(n=) unless otherwise stated
Role	
Diabetes Specialist Dietician (%)	5 (25%)
Diabetes Specialist Nurse (%)	7 (35%)
Diabetes Consultant (%)	7 (35%)
Diabetes Assistant Practitioner (%)	1 (5%)
Sex (% Female)	75%
Age (% , range)	70% aged 45-54
Ethnicity (White British)	80%
Time in diabetes clinical practice (Mean, SD, range)	13.69 years (8.22), 2 months – 27 years
Time working with pumps (Mean, SD, range)	8.74 years (5.98), 2 months – 24 years
Time working in current diabetes clinic (Mean, SD, range)	10.11 years (7.62), 2 months - 25 years

^aEye damage; Background retinopathy/Eye damage/Treated retinopathy/Nerve damage (neuropathy)/Other complications

^bOver the last 3 years

^cDKA = Diabetic ketoacidosis

6.3.3 Population sample

Key stakeholders (insulin pump users and HCPs) were invited to take part in focus groups in their locality to help determine what they need to support SM when utilising an insulin pump to manage T1D.

6.3.4 Patient and healthcare professional recruitment

Eligible patient participants were 18–65 years old, had been diagnosed with T1D for > one year, and had an insulin pump for > six months. Participants who had lived with a pump for less time were excluded to focus on the experiences of overcoming, and reflection of, the initial period of adjustment. Diagnosis of diabetes < one year were also excluded so as not to obscure experiences of incorporating a new technology with those of a new diagnosis. Participants were invited to take part through social media, posters in local pump clinics, through local diabetes-charities and peer-support groups.

All HCPs in insulin pump clinics working directly with patients were eligible to participate in the study and were invited to attend focus groups through direct contact with the clinic.

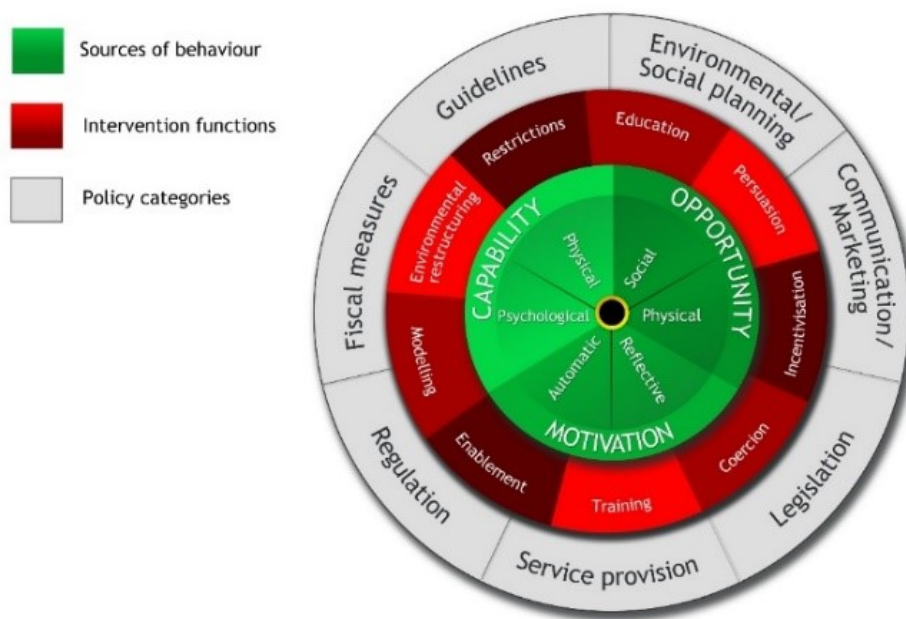


Figure 15. Determining the potential mechanisms of action of an intervention using the Behaviour Change Wheel

Which intervention functions should be used?

Sources of behaviour	Intervention functions									
	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	Environmental restructuring	Modelling	Enablement	
Physical capability					■				■	
Psychological capability	■				■				■	
Physical opportunity						■	■		■	
Social opportunity						■	■		■	
Automatic motivation		■	■	■			■	■	■	
Reflective motivation	■	■	■	■						

Figure 16. Intervention function mapping matrix

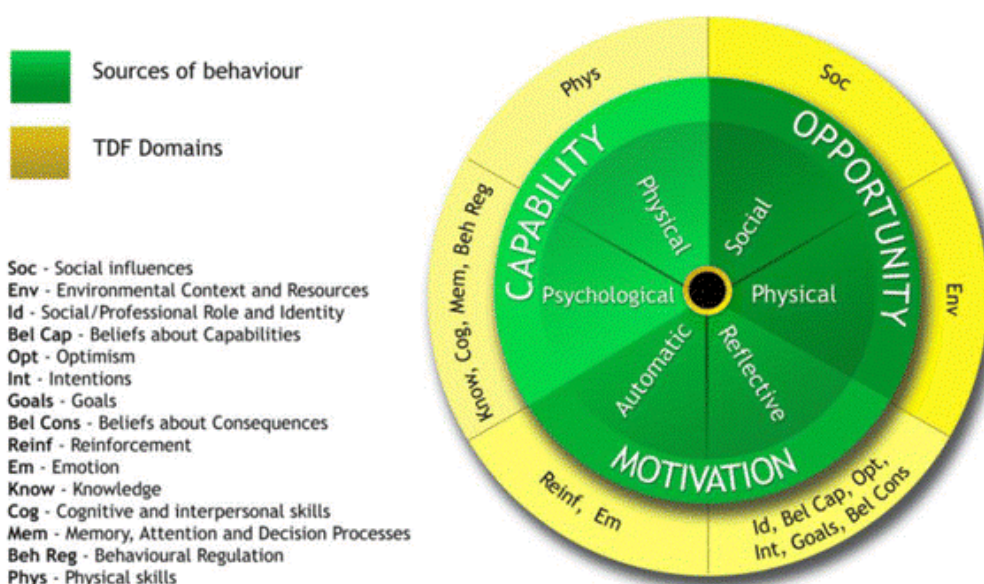


Figure 17. The 14 domains of the Theoretical Domains Framework structured according to the COM-B model

6.3.5 Theory

The Behaviour Change Wheel (BCW) (Michie et al. 2011) is an overarching framework from a synthesis of behaviour change interventions providing a clear all-encompassing model of behaviour change. This synthesis integrates theoretical constructs leading to successful behaviour change in a variety of health settings. The central cog of the BCW consists of the Capability, Opportunity, Motivation – Behaviour (COM-B) components (See **Figure 15**). This is based on the premise that in order to initiate behaviour change there is a need to; maximise physical or

psychological “Capability” to regulate behaviour (i.e. develop relevant skills), increase or decrease automatic or reflective “Motivation” to engage in desired/undesired behaviour, and target the physical or social “Opportunity” to support behaviour change. The COM-B offers understanding of barriers and enablers of behaviour and underscores the potentially modifiable factors for an intervention to target. The BCW links the COM-B model results with intervention functions (See **Figure 16**). We also utilized the Theoretical Domains Framework TDF (Cane et al. 2012; Michie et al. 2014) (See **Figure 17**) to provide specific and comprehensive behavioural domains to target in the intervention. Using the BCW and the TDF in this way has been recommended elsewhere (Cane et al. 2012; Michie et al. 2014; Curtis et al. 2015). The TDF compounds 84 constructs from multiple psychological theories (motivational, action, and organizational theories) into 14 domains (Michie et al. 2005; Cane et al. 2012; Atkins et al. 2017). For example, if lack of knowledge prevents SM this would be coded as “psychological capability” in COM-B, and then more specifically “Knowledge” using the TDF and the intervention function mapping of the BCW might suggest an intervention function of “education”.

A taxonomy of behaviour change techniques (BCTs) (Michie et al. 2013) then enables specification of techniques describing the active components of the intervention in order to tailor and optimise a social-network intervention. Focus group interview topic guides for both patients and HCPs were developed in consideration of the components of the COM-B model (Michie et al. 2011) and TDF (Cane et al. 2012) to ensure participants had the opportunity to explore each element (e.g. physical opportunity to self-manage).

6.3.6 Behavioural Analysis

Behavioural analysis using the BCW and TDF and complimentary taxonomies of BCTs, comprised of three stages to systematically determine the necessary mechanisms of action for supporting SM and developing a suitable intervention (See Figure 18).

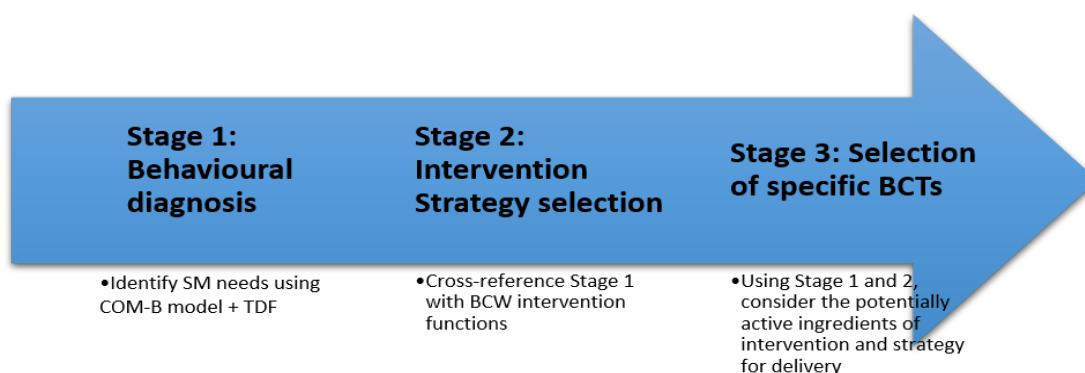


Figure 18. Determining potential mechanisms of action of an intervention using the Behaviour Change Wheel

Stage 1. Behavioural diagnosis: The first stage identifies barriers and enablers from the focus groups using the COM-B model as a framework (Stage 1a) (**Figure 15**), broken down into physical or psychological capability, reflective or automatic motivation and social or physical opportunity. Then by using the TDF alongside the COM-B model to provide a more comprehensive behavioural analysis (Stage 1b) (**Figure 17**).

All focus group interviews were transcribed verbatim. A deductive approach to analysis was used for the initial analysis using the theoretical framework provided by the COM-B Model and the TDF (Hsieh and Shannon 2005). The data were further analysed inductively to identify themes within COM-B and TDF sub-components (Braun and Clarke 2006). The author (CR) identified overarching themes within each COM-B component to summarise quotes representing similar underlying ideas. Data and quotes were selected from the transcripts to illustrate each subtheme and are presented by theme rather than theoretical sub-component for conceptual accessibility.

Stage 2. Intervention Strategy selection: The second stage cross-references the behavioural diagnosis (the relevant COM-B and TDF components identified in Stage 1a and 1b) with the BCW 'intervention functions' (Education; Persuasion; Incentivisation; Coercion; Training; Restriction; Environmental restructuring; Modelling; Enablement) (See **Figure 15**).

We used the Intervention mapping matrix outlined in the BCW (**Figure 16**) to establish which intervention functions would be most pertinent in targeting the SM support required.

Stage 3. Selection of specific Behaviour Change Techniques: Stage 3 specifies the BCTs needed for the intervention (components of the intervention such as goal-setting, restructuring the social environment, framing/reframing etc.) (Michie et al. 2013) according to the findings of Stage 1 and 2. This allowed us to determine the necessary mechanisms of action for a social support networking tool. A distinction will be made regarding the potentially active ingredients of an intervention (Reflective) and the components and delivery of the intervention (in consideration of the context/setting) (Strategic).

6.4 Results

6.4.1 Behavioural analysis

6.4.1.1 Stage 1. Behavioural diagnosis:

We determined the SM needs and perspectives for this group of patients and HCPs in order to identify recommendations to optimise a web-based SM support intervention (See Table 8 and Table 9 for a breakdown). Four key themes were identified:

1. *Desire for access to tailored and appropriate resources and information*
2. *Specific Social-support preferences*
3. *The environmental context: Capacity and knowledge of pump clinic HCPs*
4. *Professional responsibility: "Risks and dangers"*

1. Desire for access to tailored and appropriate resources and information

It was acknowledged that at the initiation of pump therapy the pump can be complicated and difficult to master. Patient's reported a desire for holistic support and flexible, convenient access to information and resources as well as access to the latest scientific research, but only at the right time for them (as and when). Web-based support was particularly salient due to ease of access. This kind of support, information and resource was desired in times of heightened difficulty and situational change including; pregnancy, bereavement, health-complications, new job, new working hours, new insulin or glucose measuring method, and experience of "burnout". People's time was also limited and so resources had to be used wisely, both in terms of attending clinics and accessing assistance. All of the pump user focus groups included substantive discussions about access to tailored and advanced fitness-related information. Fitness activities alongside others living with T1D or advice from others about exercise was hoped to take away some of the anxieties about experiencing (or preparing for) low (or high) blood glucose levels during exercise;

I don't know if any of you have heard of the website Runsweet or Ex-carbs or anything like that?...All of the rest of the Type 1 diabetes management was fine for me, but exercise was my big issue...Anyway, Ex-carbs is a website that helps you to come up with a good way to begin exercising.

(Dan, pump user)

In addition relevant information was needed that was specific to Type 1 diabetes, and/or insulin pumps, rather than more generally for any type of diabetes;

"It would be nice to have access to a website that gives you information about diets and Type 1 diabetes. I go to [diabetes charity], but it's not up-to-date. It's for Type 2.

(Katherine, pump user)

Access to other holistic pursuits were cited as important owing to participant's desire for enjoyable activities for promotion of positive mental health and/or finding that these activities also required some navigation in terms of the impact on their glycaemic control;

“I’ve never been really sporty...I also do get a little bit annoyed that every time anyone [in diabetes groups] does talk about any kind of social interactions, other than “meet-ups”, it’s always revolved around sports. I would love to see, or even run, some more diabetic-friendly groups that are, for example, theatre based. The pressure of being on stage is likely to cause hypos or have a high so you need a group which understands that, you know?”

(Stephanie, pump user)

2. Specific social-support preferences

Social support was fundamental to most insulin pump users. Flexible and open contact with the clinic was valued, although this did depend on personal experiences with HCPs, but support from peers was equally valued. Being amongst other people with T1D, both on and offline provided a wealth of otherwise unseen yet vital information for day-to-day life such as practical tips and provision of assistance (faulty equipment, where to place the pump on the body). This need varied according to circumstance; T1D specific support groups, especially if just diagnosed, were desired and diabetes-specific fitness groups were valued for the opportunity to determine how best to exercise without glucose levels going too high or low or how/where to carry to extensive equipment. Meeting peers was associated with taking away some of the isolation of living with a hidden condition;

[I would like] social things like groups that you can meet people who are in a similar situation to you...because you can’t just walk down the street and ask “are you on a pump?”

(Mark, pump user)

But actually I had no idea that diabetes-- I remember thinking this condition was incredibly rare, because I never knew anyone else with it.

(Jenny, pump user)

Access to peer-support was cited as important in sharing stories, troubleshooting, sharing illness-burden and speaking to people who understand this “invisible” condition. Some desired online support, others face-to-face contact, and it was common to desire both. While face-to-face interactions were important, online access allowed people to conveniently “dip in” or “lurk” at a safe distance. In addition, participants expressed wanting to be of assistance themselves, a support of mutual (reciprocal) benefit. However, apprehensions were raised about how you select

people who are likely to be in the same situation as you. Identities start to be focused on the fact that they are pump users;

Personally, I find having a one-on-one conversation with someone and asking questions... as wonderful as the nurses are, and the clinic nurses are fantastic, but having someone who uses a pump every single day- It was really positive being in a group setting and having conversations amongst ourselves...You could say “what do you do while you're asleep?” “Do you ever get over having something strapped to you?” Just basic questions.

(Harry, pump user)

I guess more links... I had some like issues with it [the pump] sticking on--and no one's ever told me about what kind of tapes that I can use to keep it on or stuff like that, or even nice covers for your pump, just like nice things that are easier to find through that [social-network intervention] rather than having to go through Amazon.

(Lauren, pump user)

There were distinct barriers to speaking to others with T1D, such as a lack of confidence, especially when there is a perceived risk of peer-judgement or competition;

Because if you are nervous of -- If you don't have the best control or you have been through a bit of a rough patch, or you don't really know-you know-It must be daunting to meet other people so I think you have to be in the right kind of place to want to—

(Jenny, pump user)

3. The environmental context: Capacity and knowledge of pump clinic HCPs

Many HCPs were positively encouraging of the psychosocial needs of patients and recognised that social and peer-support were valuable for patients;

Yes, so, it is useful. It's very positive. The good thing I like about it is the opportunity to meet other people, network and do other things outside of diabetes, and for them to feel as normal as possible, but they are normal. You know what I mean?

(DSN 5, HCP)

HCPs were enthusiastic about supporting their patients to self-manage, especially in terms of patient's need for holistic support and resources, but lacked confidence in addressing the psychosocial needs of patients themselves;

I think it's a question of whether we think we're skilled. I think it's more a part of taking history but it realms into the psychological support, psychology support territory and whether as nurses and dietitians and clinicians, we think we would have the skills to deliver that. I think it's something which if it was something very, do tick box; A, B and C, this is something which we don't do in our routine clinical basis...but a lot of the care is focused towards the more technical and medical and other supportive aspects.

(Consultant 4, HCP)

However, some HCPs voiced a lack of value for psychosocial support, or SM support where it was not seen as part of their clinical remit;

So, realistically...resources that are available are something that you kind of say--, "oh look I know I've got my little 'talking change' thing and my "little thing in there for somebody who" and "that's a resource that I can make available", but, I don't say, "Would you like to talk to a psychology person--?" to everybody that comes in...and I suppose that a lot of it is that if it's not broken what's to fix?

(Consultant 6, HCP)

Most clinicians were interested in innovative ways for patients to access other support. They were especially enthusiastic about their patient's needs with an appreciation of the benefits of engagement with other people with T1D, especially others with a pump for shared learnings and experiences. Some clinicians considered potential facilitation of access to social-support interventions in structured education sessions while others considered approaches to such support via signposting through their clinic, rather than access within. However, HCPs were concerned about competing priorities and the consequential lack of time/capacity in clinic to engage in SM support or to include a facilitated online intervention;

...I think the CCG fund the pumps but we don't have an awful lot of funding for the team that supports the pump service, so whilst we had small numbers we could incorporate it into our service level agreement but as the pump service has grown we're struggling to offer the support we would like to offer. The feedback we're getting is our pump

patients love our service and want more of it but actually we can't really give them anymore because we're not funded to.

(Dietician 4, HCP)

4. Professional responsibility: "Risks and dangers"

Some HCPs were evidentially concerned about the risk and dangers of signposting or onwards referral to an online SM support tool, and held fears that such signposting to a non-clinical environment could have negative consequences in terms of their professional responsibility;

Yes, or, accuracy of...Or the potential dangers of peer-to-peer advice regarding immediate clinical matters. I think that's my opinion at the moment. Sharing it in a controlled way with the, you know, organizations that are available to have them. In terms of peer-to-peer advice, what if someone gives them the wrong advice? Maliciously, for instance.

(Consultant 7, HCP)

Or "creating problems for problems sake" by offering SM support services within a clinical setting;

My first thought about this, is it bringing up things that we actually don't need to bring up, I would think that. I know we do want to make sure that everybody is well supported and has access to that support. At the same time, if somebody's absolutely fine...We don't want to be making them feel that there is something wrong when there isn't... What you don't want to be doing is creating problems. For problems sake.

(Dietician 3, HCP)

However, pump users referred to unhelpful experiences of HCPs blocking access to information, resources or medical equipment. Patients demonstrated understanding of risk, but also the need to make decisions themselves;

Going back to that idea of online groups, I understand that you would want to have a warning to say, "this is not NHS, this is not moderated. This is just a group that is publicly available and we're not recommending or making any sort of judgment". I'm fine with the warning but ideally would want to still have a link to it...I understand the caution but one of my pet peeves is when healthcare professionals make a choice for me [agreement in room] and say I'm not going to bother to give you the bigger picture and the different options because I think this one is best for you.

(Hugh, pump user)

HCPS considered a social-network intervention especially useful for patients who are young adults going through transition or those experiencing loneliness. However, patients felt that they themselves would benefit from further support, no matter their circumstances, but according to when they needed it, and on their own terms.

Table 8: Matrix of links between COM-B model, TDF domains, intervention functions and BCT for pump users

Behavioural diagnosis using COM-B – barriers and enablers (Stage 1a)	TDF v2 domains linking to COM-B components (Stage 1b)	Potential Intervention functions (Stage 2)	Suggested Behaviour Change techniques (using the 93 BCT taxonomy v2) (Stage 3)
Psychological capability	<p><i>2. Skills:</i> (Skills development) The pump can be complicated and difficult to master.</p> <p><i>1. Knowledge:</i> (Knowledge of task environment) Need to know where to access services or information.</p> <p><i>1. Knowledge:</i> (Knowledge about condition) Want to improve comprehension of impact of exercise on SM.</p> <p><i>10. Memory attention and decision processes:</i> (Decision making) Want help to make choices about SM.</p>	Education Enablement	<p>1.2 Problem solving</p> <p>3.2 Social support (practical)</p> <p>4.1 Instruction on how to perform a behaviour</p> <p>12.1 Restructuring the physical environment</p> <p>12.2 Restructuring the social environment</p>
Physical capability	<p><i>2. Skills:</i> (Practice/skills development) Access to practical tips –how to use the pump’s advanced features and where to place pump on body etc.</p>	Training Enablement	<p>3.2 Social support (practical)</p> <p>4.1 Instruction on how to perform a behaviour</p> <p>12.1 Restructuring the physical environment</p> <p>12.2 Restructuring the social environment</p>
Reflective motivation	<p><i>3. Social role and identity:</i> (Identity) SM support must be relevant/specific.</p> <p><i>8. Intentions:</i> (Stability of intentions) Determined to make pump “work”.</p> <p><i>11. Environmental context and resources:</i> (Resources/material resources) SM tool must be credible.</p> <p><i>11. Environmental context and resources:</i> (Organisational culture/climate) Bombarded with “risks and dangers”.</p>	Education Persuasion	<p>1.1 Goal setting (behaviour)</p> <p>1.2 Problem solving</p> <p>2.2 Feedback on behaviour</p> <p>6.3 Information about others’ approval</p> <p>9.1 Credible source</p> <p>9.3 Comparative imagining of future outcomes</p>

	<p><i>4. Beliefs about capabilities: (Beliefs)</i> Difficult to manage a complex condition, but belief that the right information delivered in the right way can make it work.</p> <p><i>6. Beliefs about consequences: (Characteristics of outcome)</i> Understanding that not being able to SM will lead to health complications, but also thinking about it all the time won't help either.</p> <p><i>9. Goals: (Goals (autonomous/controlled))</i> Want to self-manage well and in a way that suits personal circumstances.</p>		<p>11.2 Reduce negative emotions</p> <p>11.3 Conserving mental resources</p> <p>15.3 Focus on past success</p> <p>13.2 Framing/reframing</p>
Automatic motivation	<p><i>10. Memory attention and decision processes: (Cognitive overload/tiredness)</i> Never "having a break" from diabetes.</p> <p><i>13. Emotion: (Burn-out)</i> Feeling burnt out and not able to SM.</p> <p><i>13. Emotion: (Negative affect)</i> Overwhelmed by diabetes so not wanting or able to engage in SM.</p> <p><i>11. Environmental context and resources: (Barriers)</i> Not knowing anyone else with T1D.</p> <p><i>11. Environmental context and resources: (Barriers)</i> only having access to people who have very negative experiences of diabetes/ not wanting to speak to others.</p> <p><i>13. Emotion: (Negative affect)</i> Feeling alone/isolated.</p>	<p>Persuasion</p> <p>Environmental-restructuring</p> <p>Modelling</p> <p>Enablement</p>	<p>1.1 Goal setting (behaviour)</p> <p>1.2 Problem solving</p> <p>3.1 Social support (unspecified)</p> <p>3.2 Social support (practical)</p> <p>3.3 Social support (emotional)</p> <p>9.3 Comparative imagining of future outcomes</p> <p>11.2 Reduce negative emotions</p> <p>11.3 Conserving mental resources</p> <p>12.1 Restructuring the physical environment</p> <p>12.2 Restructuring the social environment</p> <p>13.2 Framing/reframing</p>
Physical opportunity	<p><i>11. Environmental context and resources: (Barriers)</i> Lack of time to attend or access clinic or other resources of SM.</p> <p><i>11. Environmental context and resources: (Resources/material resources)</i> Not having access to practical tips and information.</p> <p><i>11. Environmental context and resources: (Barriers)</i> Opportunity to form groups.</p> <p><i>11. Environmental context and resources: (Barriers)</i> Desire to access</p>	<p>Environmental-restructuring</p> <p>Enablement</p>	<p>1.1 Goal setting (behaviour)</p> <p>1.2 Problem solving</p> <p>3.1 Social support (unspecified)</p> <p>3.2 Social support (practical)</p> <p>3.3 Social support (emotional)</p> <p>7.1 Prompts/cues</p> <p>12.1 Restructuring the physical environment</p>

	<p>social support but no physical access/opportunity to access.</p> <p><i>11. Environmental context and resources:</i> (Resources/material resources) SM support not local</p> <p><i>11. Environmental context and resources:</i> (Organisational culture) HCPs withholding choice</p> <p><i>3. Social/professional role and Identity:</i> (Organisational commitment) Organisational restrictions on peer-support services</p> <p><i>11. Environmental context and Resources:</i> (Barriers) Physical characteristics of pump</p> <p><i>3. Social/professional role and Identity:</i> (HCP-patient relationship/communication) HCPs not being accessible</p>		
Social opportunity	<p><i>12. Social influences:</i> (Social pressure) Fear of judgement from others</p> <p><i>12. Social influences:</i> (Alienation) Fear of disclosure/exposure</p> <p><i>12. Social influences:</i> (Social pressure) Stigma of the condition from others</p> <p><i>3. Social/professional role and Identity:</i> (Professional role) HCPs as gatekeepers</p> <p><i>12. Social influences:</i> (Social support) Pump users desire social support</p>	<p>Environmental-restructuring</p> <p>Enablement</p>	<p>3.1 Social support (unspecified)</p> <p>3.2 Social support (practical)</p> <p>3.3 Social support (emotional)</p> <p>12.1 Restructuring the physical environment</p> <p>12.2 Restructuring the social environment</p>

Table 9: Matrix of links between COM-B model, TDF domains, intervention functions and BCTs for HCPs

Behavioural diagnosis using COM-B – barriers and enablers (Stage 2a)	TDF v2 domains linking to COM-B components (Stage 2b)	Potential Intervention functions (Stage 3)	Behaviour Change techniques (using the 93 BCT taxonomy v2) (Stage 4)
Psychological capability	4. <i>Beliefs about capabilities:</i> (Self-confidence and perceived competence) Important to know how, and to be confident in using the self-management intervention and how to address psychosocial needs of patients	Education Training	4.1 Instruction on how to perform a behaviour 6.1 Demonstration of the behaviour 8.1 Behavioural practice/rehearsal 15.1 Verbal persuasion about Capability
Physical capability	2. <i>Physical skills:</i> (Skills development) Need training to facilitate self-management tool	Training Enablement	1.2 Problem solving 4.1 Instruction on how to perform a behaviour 6.1 Demonstration of the behaviour 8.1 Behavioural practice/rehearsal
Reflective motivation	11. <i>Environmental context and Resources:</i> (Facilitator) Social support is relevant for patient group 11. <i>Environmental context and Resources:</i> (Organisational culture/climate) Fits in with clinic 9. <i>Goals:</i> (Goal priority) Other/competing priorities in clinic 5. <i>Optimism:</i> (Pessimism) “Is there room for indulgence in the NHS?” 6. <i>Beliefs about consequences:</i> (Outcome expectancies) Potential for peers to “give bad advice”, “What you don't want to be doing is creating problems for problems sake.” 3. <i>Social/professional role and Identity:</i> (Professional boundaries) Bombarded with “risks and dangers”, and professional responsibility 3. <i>Social/professional role and Identity:</i> (Professional role) Is it (SM) even our role? Refer onwards for psychosocial support	Coercion Education Persuasion Incentivisation	1.1 Goal setting (behaviour) 1.4 Action planning 1.5 Review behaviour goal(s) 1.8 Behavioural contract 1.9 Commitment 4.4 Behavioural experiments 5.1 Information about health consequences 5.5 Information about social and environmental consequences 6.2 Social comparison 6.3 Information about others’ approval 7.1 Prompts/cues 8.1 Behavioural practice/Rehearsal 9.1 Credible source 9.3 Comparative imagining of future outcomes 13.2 Framing/reframing 13.3 Incompatible beliefs
Automatic	13. <i>Emotion:</i> (Positive affect) Like Genie	Enablement	12.1 Restructuring the

motivation	and have seen how much patents benefit from peer and other holistic support <i>13. Emotion: (Negative affect) Fear backlash/responsibility</i>	Environmental-restructuring Modelling (for other clinics)	physical environment 12.2 Restructuring the social Environment 13.3 Incompatible beliefs
Physical opportunity	<i>11. Environmental context and Resources: (Barrier) Lack of time to undertake/facilitate further SM support in clinic</i> <i>11. Environmental context and Resources: (Resources/material resources) Lack of capacity in clinic</i> <i>11. Environmental context and Resources: (Person x environment interaction) Patient time restraints</i> <i>11. Environmental context and Resources: (Facilitators) Using leaflets to advertise SM intervention</i> <i>11. Environmental context and Resources: (Organisational culture/climate) Lack of holistic support provision</i> <i>11. Environmental context and Resources: (Facilitator) But clinic want to be flexible</i> <i>11. Environmental context and Resources: (Barriers) “The lost tribe” (patients clinics can’t reach)</i> <i>11. Environmental context and Resources: (Facilitator) Clinics want to offer more direct access to SM support/peer-support</i>	Enablement Environmental-restructuring	1.2 Problem solving 3.1 Social support (unspecified) 12.1 Restructuring the physical environment 12.2 Restructuring the social Environment
Social opportunity	<i>12. Social influences: (Social support) Clinicians stress that their patients often want to speak to other patients</i>	Enablement Environmental-restructuring	12.1 Restructuring the physical environment 12.2 Restructuring the social environment

6.4.1.2 Stage 2. Intervention Strategy selection:

Intervention functions for pump users

Capability: Psychological capabilities were identified in the behavioural diagnosis and using the Intervention mapping matrix (Figure 16). The following intervention functions were identified; Enablement (a means to increase capability or reduce barriers to SM through encouragement, practical and emotional support, and access to support and opportunities) and Education (increasing knowledge or understanding including structured education, access to appropriate information and instructions for performing pump tasks). Physical capability SM barriers and

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enablers pinpointed to intervention functions of Training (imparting physical skills in relation to pump technicalities) and Enablement (as described above).

Motivation: Motivational factors of SM that were related to reflective reasoning (conscious intentions, decisions and plans to SM) led to intervention functions of Education (as described above). Where there were reflective motivational barriers preventing SM due to support not being seen as relevant or an intervention being credible, then intervention functions such as Persuasion through communication to introduce positive feelings to stimulate action, or assurance of credibility through research were selected. Where a social-network intervention enables management of self-driven priorities to attend SM this increases the likelihood that users will be willing to commit time to, and that the time they commit is well spent and valued. Appropriate intervention functions for automatic motivation to SM (emotional responses, desires and habits) included Persuasion, Environmental-restructuring (changing the physical or social context), Modelling (providing an example for people to emulate/aspire to), and Enablement.

Opportunity: Social and physical opportunity to access both emotional and practical support, especially in relation to the specificities and mechanics of a new health technology were identified in the behavioural diagnosis and could be addressed by a SM support web-based intervention. These needs were described in terms of unconventional and flexible ways to self-manage, such as 24/7 access and online sources of education, peer-support and information). However, access to any support or resources had to be on their terms, in line with personal needs and life-demands, especially in response to concerns over uninvited sharing of self-management strategies from others. This linked with the intervention functions of Enablement and Environmental-restructuring (providing access to support, information and opportunities). Enablement intervention functions were identified to address physical opportunity barriers such as lack of time to attend or access the clinic or other resources in relation to sourcing support that is physically closer to the individual.

Intervention functions For HCPs

Capability: HCPs say they believe in prioritising the wider well-being of their patients and want to support SM, but while they are clear about the medical outcomes they must focus on in their professional role, the remit of SM support they should provide is not clear to them. HCPs voice concern over their lack of confidence, ability or desire to offer SM support. This is where strategic Intervention functions of Training, Enablement and Education benefit; to instruct HCPs how to facilitate signposting to an intervention, enable behavioural practice and provide verbal persuasion about capabilities as well as educating about the importance of SM support.

Motivation: When it came to Reflective motivational factors it is evident that buy-in is needed.

Coercion (changing conscious evaluations of the social-network approach to SM), Education (increasing knowledge or understanding of the importance of social support for their patients), Persuasion (using communication to stimulate action) and Incentivisation (creating expectation of reward – that patients will benefit from access to SM support) were deemed as appropriate intervention functions, while Enablement, Environmental-restructuring and Modelling (comparisons with other clinics) were identified for Automatic motivational factors.

Opportunity: Both physical and social opportunity pinpointed to Enablement and Environmental-restructuring (provision of physical opportunities and socially acceptable environments to provide SM support) as necessary intervention functions (See Table 10).

Table 10: Identified BCTs of intervention (Reflective or strategy processes)

Identified needs (BCTs)	Social-network intervention ingredients
Reflective processes	
1.1 Goal setting (behaviour)	Agreement to attend a preferred activity identified in intervention.
1.2 Problem solving	Social network tool maps their social support network and examines whether the participant would like this to change at all. Intervention also enquires about their personal needs and preferences and then offers opportunities in their local community to address these needs. A discussion is then undertaken about how to access these, and barriers + facilitators.
1.4 Action planning	Steps would need to be taken to support each clinic to implement, to identify pathways.
1.5 Review behaviour goals	Clinic would need to be reviewed to identify whether further support needs to implement intervention would be required
2.2 Feedback on behaviour	Facilitator follows participant up. Discuss and inform them of how their circles have changed, and what activities have been taken-up.
3.1 Social support (unspecified)	Genie facilitates discussion around who offers them social support in relation to their condition and allows facilitation/gives information about further personalised social support i.e. peer-support groups, and ask who may help them participate in chosen activities.
3.2 Social support (practical)	Discuss the practical support required, received and desired from the participant and facilitate discussion over whether any changes are required, and how to undertake these changes, or social network members who can help them physically access groups.

3.3 Social support (emotional)	Discuss the emotional support required, received and desired from the participant and facilitate discussion over whether any changes are required, and how to undertake these changes, or social network members who can help them emotionally access groups.
4.1 Instruction on how to perform a behaviour	If a person wants to attend a course or education session then Genie can facilitate access to this, or if a person wants to learn from peers then Genie can point them in the direction of a peer support group.
7.1 Prompts/cues	Genie consists of concentric circles, which prompt the participant to prioritise certain social network members over others. Genie then asks thirteen preference questions to prompt the user as to their preferred activities to support their SM. Participants are then followed up by facilitators 2 weeks later.
9.3 Comparative imagining of future outcomes	Prompt the person/clinic to imagine and compare likely or possible outcomes following attending versus not attending particular groups, or activities that they used to take part in.
11.2 Reduce negative emotions	Facilitator advises on using members of the current social support network to reduce anxiety about attending groups etc.
11.3 Conserving mental resources	Facilitator advises on utilising social support network, or access peer-support groups etc. to share the burden of diabetes or to trouble-shoot with
12.1 Restructuring the physical environment	Enabling access to groups and information that can help them SM
11.2 Reduce negative emotions	Facilitator advises on using members of the current social support network to reduce anxiety about attending groups etc.
11.3 Conserving mental resources	Facilitator advises on utilising social support network, or access peer-support groups etc. to share the burden of diabetes or to trouble-shoot with
12.1 Restructuring the physical environment	Enabling access to groups and information that can help them SM
12.2 Restructuring the social environment	Enabling access and restructuring to groups and information and support that can help them SM
13.2 Framing/reframing	Facilitator to reassure participant that it is okay to ask for help or support from others re: SM, and that other support can offer practical tips rather than personal assumptions
15.3 Focus on past success	Facilitator enquires what activities they used to do, and whether network members can assist their attendance at activities they are interested in.
Strategy processes	
1.8 Behavioural contract	Clinic would need to sign contract to identify what they expect from intervention and what support they require.

1.9 Commitment	Clinic would need to make SM support a priority and normalised within the clinic setting, and be committed to offering SM support.
4.1 Instruction on how to perform a behaviour	Facilitators of GENIE receive training in how to deliver GENIE. The tool comes with a training programme.
4.4 Behavioural experiments	Pilot study intervention with clinics to demonstrate intervention benefits in this patient group/context
6.1 Demonstration of the behaviour	Facilitators of GENIE receive training in how to deliver GENIE. The tool comes with a training programme.
6.3 Information about others' approval	Share experiences from other clinics/areas which are using the tool.
8.1 Behavioural practice/rehearsal	Facilitators of GENIE receive training in how to deliver GENIE. The tool comes with a training programme.
9.1 Credible source	Buy in from each area it is applied is important for implementation. Participants (and HCPs) are assured that Genie has risen out of former research and everything that is put on Genie is checked.
9.3 Comparative imagining of future outcomes	Prompt the person/clinic to imagine and compare likely or possible outcomes following attending versus not attending particular groups, or activities that they used to take part in.
12.1 Restructuring the physical environment	Enabling access to SM support and information that can help patients SM
12.2 Restructuring the social environment	Enabling physical access to groups and information and support that can help patients SM
13.2 Framing/reframing	Suggest that SM support might increase clinic time available rather than decrease clinic time. SM support can have clinic benefits after intervention.
13.3 Incompatible beliefs	Draw attention to HCP/clinic's restriction to providing SM support and their self and national (NHS England, wider clinic) identification and remit as encouraging SM support and its evidence based strengths.

6.4.1.3 Stage 3. Selection of specific Behaviour Change Techniques:

The specific BCTs needed for the intervention were identified according to the behavioural analysis and intervention strategy selection in Stage 1 and 2 and on the basis of a facilitated web-based social-network intervention - GENIE (See **Table 8** and **Table 9**). A distinction was made regarding the potentially active ingredients of an intervention (Reflective processes) and the delivery of the intervention (context/setting) (Strategy processes) (See **Table 10**). The more 'Reflective' BCTs would need to be contained within the social-network tool but the 'Strategic' processes would need to be integrated to the intervention implementation plan. This approach to

intervention development addresses the requirements of both insulin pump users with T1D and professionals working in an insulin pump clinic. It addresses their varying needs and expectations, and how a web-based intervention for enabling SM support can attend to these.

6.5 Discussion

This study provides a model for supporting people using new health technologies such as an insulin pump. It puts the most important needs at the forefront, providing evidence of the active components required in a translational web-based intervention. The physicality of the pump impacts on the users' experience of SM and the technicalities in using an advanced new technology exacerbates SM needs. The specificity of the insulin pump changes people's priorities because it impacts on their day-to-day experiences and identity. Pump therapy means that users have a renewed need for HCPs, akin to diagnosis of diabetes, but this need subsides. The pump requires access to a particular network of people for specific troubleshooting needs.

We identified that a long-term-condition such as diabetes requires an array of SM approaches and ability to master these. Utilising a new health technology requires specific skills, understanding, confidence, motivation and opportunity. The behavioural analysis used in this study signposted the necessary components of an intervention to support SM. There lies a potential conflict for the person living with T1D where "good" management takes considerable effort, and this can create a friction between freedom and clinical targets of blood glucose control, or the opportunity for tighter control without sacrificing freedom. The question arises as to whether this extra attention will actually improve the quality and length of life. The current SM options offered might incite questions over whether life will be less or more enjoyable if they take part in them, for example; using 5 days of annual leave to attend an NHS structured-education class, not knowing whether this education class will actually be useful. There is a trade-off to be made. If we want to intervene then we must consider these factors. We found that ultimate behaviour change in SM of diabetes and use of a health technology requires support and resources which is personal/specific to the individual and varies according to time and life circumstances. Specific social-support can take away some of the work of SM, and also the isolation, providing shared learnings and practical tips, but limitations include fear of judgement from others and exposure to off-putting self-pity from peers.

In addition, we found that an intervention would be more successfully implemented if there were opportunities to access SM support and motivation from pump users by access to relevant disease/technology-specific resources and interests. For example, social opportunity needs to be addressed when HCPs do not entrust pump users to make their own choices or access non-clinical

resources, or lack psychological capability and/or physical opportunity; with HCPs even if willing, often not having the confidence or capacity in their clinic to amend or enhance their routine or psychosocial care and question whether and where SM fits into their role. Recommendations provided here in delivering training to HCPs to facilitate signposting to holistic SM support, enabling behavioural practice and providing verbal persuasion about capabilities as well as educating about the importance of SM echo those given in the DAWN2 study (Holt et al. 2016; Byrne et al. 2017). Guidelines within the intervention could give assurances to HCPs about what they are signposting to. However, some HCPs “if it isn’t broke don’t fix it” attitude highlighted that while NHS England are pushing for more SM support, this is not reaching or convincing to all clinicians on the ground. Fisher et al. (Fisher et al. 2017) suggest a clear 3 step framework for diabetes HCPs to support behaviour change. The first step requires clinicians to shift their mind-set, moving from a hierarchal model to a more collaborative model, reorienting from information-giving to nuances of patient-driven needs.

HCPs can be seen as gatekeepers or blocking of the provision of SM support necessary to manage a complex condition like diabetes. There was little doubt amongst HCPs, even those with general concerns, that particular groups of patients would greatly benefit from being signposted to further support that the clinic did not provide. However, the discrepancies show contrasting beliefs between patients and HCPs, where patients themselves considered this access beneficial in a variety of ways, especially in terms of managing fitness activities, general practical advice or emotional support. Credibility and likelihood of the effectiveness of an intervention is important for both users and those who guard access (clinicians), particularly in order for clinicians to offer patients the opportunity to participate. Priorities vary depending on perspective, and understanding them both at this stage can inform intervention design and how to determine and ensure credibility.

The social-network intervention proposed here (GENIE) is structured around facilitating networks and collective, tailored forms of support through the building of dedicated resources in a database. Whether targeted at particular groups or long-term conditions as a whole, a web-based social-network tool can accommodate multiple SM needs. However, limitations are evident where access to resources are only as good as the resources that are already in place locally. A social-network intervention such as this would also benefit people through addressing the identified need to register collective interests and initiate peer-support. For example, having the facility for people to “register their interests” in attending or creating groups in their local area, potentially viewing others in their local area (via the intervention platform) who have shared interests to initiate or take part in peer-support.

The behavioural assessment of people with diabetes and HCPs draws parallels with past research. For example, Mulvaney et al.'s review (Mulvaney et al. 2011) that SM interventions in diabetes should integrate technology compounded with human contact for clinical support, as well as motivation and support to change behaviour to SM (e.g. goal setting and problem solving). In addition, the American Diabetes Association (Beck et al. 2017) encourages behavioural elements such as problem solving, decision-making and access to e-health tools as vital to support SM. A focussed social-network intervention with integral guided facilitation in place is likely to be sensitive to these needs, combined with participant follow-up from the Facilitator. A Facilitator also has the potential to provide a favourable supportive element to personalised goals in light of findings that provision of human support was advantageous in other eHealth interventions (Mohr et al. 2011).

People who are empowered and skilled to self-manage their diabetes have improved health outcomes (Chatterjee et al. 2018), so appropriate and tailored access, as opposed to a one-size-fits-all model is likely to support improved SM. HCPs needs to accept patient priorities and means of information and advocacy (Mazanderani et al. 2013) rather than blocking its use, while understanding the importance of experiential evidence. Some noted factors of success in web-based interventions and acceptability have been the focus of psychosocial experiences, the availability outside of clinic hours, based on up-to-date evidence-based guidance, and access to both peer-generated and professional advice. However, understanding the barriers preventing HCPs from supporting SM are fundamental too. This comprehensive behavioural analysis provides a complete feedback loop for a web-based intervention, which is better equipped to facilitate ongoing SM, considering the needs and strategies for both sets of stakeholders and determine how, when and why SM support interventions can be best utilised.

6.5.1 Strengths and Limitations

The use of focus groups in this study allows in-depth discussion and understandings of collective experiences of SM and of patient and HCP views that would be impossible to explore using quantitative methods, while the use of the BCW and TDF driven interview scripts provides a well-tested, evidence based guidance and framework. For example, it has been noted that the automatic in addition to the reflective process of motivation to enact behaviour on the part of healthcare professionals is often overlooked and are important to enhance behavioural approaches to implementation (Potthoff et al. 2019). The use of theory driven intervention development signifies areas of key importance to intervention implementation – both behavioural and reflective needs and contextual factors for implementation, and a key process to follow. It sensitises the research to future intervention needs and considerations across different localities.

The recruitment of pump users from various clinics and the involvement of clinics in different settings was an important element of the expected variability between local health systems. Recruitment of patients included a variation of ages and sex, education attainment and parenthood, while clinicians represented a good and balanced spectrum of the kinds of professionals working in insulin pump clinics. However, limitations to the study were that patients recruited were likely to be those who are more “engaged” in diabetes management to want to come along to a diabetes-related focus group, be willing to discuss some personal elements of their health and be willing to sit amongst a group of peers with the same condition in their own time.

6.5.2 Future Research and Conclusions

Technology is a means to deal with diabetes and opens up new ways to manage the condition, but the condition ultimately drives it. It takes time to master and support, skills and information to do this is crucial. People with T1D have an esoteric knowledge, which makes them a select group, with a uniqueness of knowledge that does not necessarily equate with any other group. This challenges professional dominance and creates an invisible barrier where HCPs hold much medical knowledge and are unsure of what and when to share this with their patients. HCPs can be gatekeepers to improving SM or to facilitating access to SM support. They are limited by time constraints and fear of professional responsibility. However, a web-based tool which is person-based, appropriate, accessible and adaptive to local needs in hand with a strategic (and theoretically informed) approach can be a powerful tool for SM support which can vastly enhance support already provided by HCPs without compromising stakeholders concerns. This paper is timely in that it coincides with The NHS Long Term Plan from NHS England in January 2019 that promises to expand the provision of digital SM support tools (NHS England 2019a). In addition, there is a recent drive for integration of psychosocial support into routine diabetes care (19, 22) and this study provides an initial engagement into the factors that would impact on how psychosocial support is taken up with HCPs and the priorities for patients. The next phase of development is to integrate these findings into strategic intervention implementation criteria for supporting people to SM with a new technology like an insulin pump.

Chapter 7 Paper 3: A novel exploration of the support needs of people initiating insulin pump therapy using a social-network approach: A longitudinal mixed-methods study

7.1 Abstract

Aims:

Few diabetes interventions approach improving health and well-being through social networks, yet social networks provide a potentially powerful means of mobilising, mediating and accessing support and resources. We aimed to establish what practical and emotional means of support are required upon initiation of insulin pump therapy and how needs change over time using GENIE, a social network intervention.

Methods:

The longitudinal design used semi-structured interviews, surveys (PAID, CLARKE) and HbA1c from pump initiation, three and six months on. Interviews used GENIE to capture participants' expectations and experiences of pump therapy and associated support and resources. Thematic analysis was used with sequential, time-ordered matrices.

Results:

Sixteen adults undertook 47 interviews. A total of 94 activities were acquired while tally, frequency and value of network members increased over time. The novelty of pump therapy impacted on participants self-management needs. Key themes included: 1. The independent nature of managing diabetes, 2. Overcoming the challenges and illness-burden of a pump, 3. The need for responsive and tailored emotional and practical support, and 4. Useful resources when incorporating pump therapy. GENIE was thought to be novel and beneficial.

Conclusions:

A social network approach determined what resources and support people with diabetes require when incorporating a new health technology. Visualisation of support networks using concentric circles enabled people to consider and mobilise support and engage in new activities as their

needs changed. The novelty of pump therapy creates new illness work but mobilisation of personally valued flexible, tailored support can improve the process of adaptation.

7.2 Background

There is a drive from policy makers for prioritising self-management support in long-term-conditions (NHS England 2017) and increased momentum from NHS England and diabetes voluntary organisations to consider the emotional wellbeing of people with diabetes when promoting self-management support (Diabetes UK 2018; Lloyd et al. 2018). The need for self-management support is heightened when new health technologies, such as insulin pump therapy in Type 1 diabetes, are introduced, requiring renewed knowledge, confidence and resources (Reidy et al. 2018). However, few diabetes support interventions explore or address improving self-management abilities or engagement with health services together with social support networks, yet for people with long-term conditions, social networks can provide an important means of mobilising, mediating and accessing support for health and well-being (Holt-Lunstad 2018).

The World Health Organization now lists “social support networks” as a determinant of health (World Health Organization). Network members located in the personal community of a person with a long-term condition are sources of emotional, practical and illness-related ‘work’ (Vassilev et al. 2011) and have been associated with improving self-management (Kennedy et al. 2016; Vassilev et al. 2016). Personal communities of social support can range from members who are healthcare professionals, family, friends, community groups, objects [e.g. a bicycle], or even pets, which have been known to provide emotional support (Brooks et al. 2018), especially when these relationships are diverse (including “weak ties”) (Vassilev et al. 2016). For example, network members can be distributors of health literacy (Edwards et al. 2015). As such, interventions which seek to enhance an individual’s personal community of social support, and access to wider resources and local support are likely to compliment self-management strategies (Seeman 1996).

Kennedy et al. (Kennedy et al. 2016) implemented a web-based social support and networking tool named Generating Engagement in Networks Involvement (GENIE) with an isolated population of people with diabetes. The tool mapped and reflected personal network members and signposted to local sources of support. This resulted in increasing participant’s capacity and confidence for managing their diabetes. Bandura’s Social Cognitive Theory (SCT), which focuses on social influence and the dynamic and reciprocal interactions between the individual, the environment and behaviour, underpins this approach. SCT considers the unique way individuals’ acquire and maintain behaviours while also taking into account interactions with the wider social

environment (Bandura 1998), while the need for a responsive network when managing a long-term condition has been illustrated in the recent development of a scale to measure collective-efficacy (CENS) (Band et al. 2019). Measurement of collective-efficacy can be a unique predictor of loneliness or an indicator of a network with the potential to provide responsive support and resource.

There is growing interest in the part network members can play in self-management of diabetes through sustaining learned self-management practices or day-to-day life (Rintala et al. 2013; Rankin et al. 2014) and the impact that diabetes-related technology has on close network members (Barnard et al. 2016). In addition, The World Diabetes Day theme for 2018-2019 is 'Family and diabetes' to promote the role of family members in self-management (The Lancet et al. 2018). Wiebe et al. (Wiebe et al. 2016) evaluated the social context of managing diabetes, exploring how social relationships are a central element in diabetes management. They suggest use of interventions which focus on the relational work involved in social relationships, and engagement of networks to enable access to resources as and when needed. Even when focused on healthcare professionals, social networks have been thought to improve the rate of recovery after strokes (Hand 2019) where being part of a network of extended clinical expertise allows a widening of boundaries and both contribution and access to new knowledge. In terms of implementation, Kennedy et al. found that GENIE both enhanced support for people to self-manage and was acceptable and implementable in a UK setting when delivered through lay health workers in the community (Kennedy et al. 2016). However, there is a lack of research exploring the range and value of network members involved in self-management of Type 1 diabetes, or of network members and resources of value when integrating a new health technology.

Here we explore the support and resource needs of people with Type 1 diabetes incorporating pump therapy over the initial 6 month period through GENIE. We considered the mechanisms through which participants valued this support and resource and how these needs shifted over time, and whether the intervention was deemed acceptable.

7.3 Methods

7.3.1 Design


Mixed-methods consisted; longitudinal interviews combined with questionnaires, HbA1c and GENIE intervention outcomes (mapping of network members onto concentric circles and activity uptake) (See Table 11). Following informed written consent, participants took part in a semi-structured interview shortly after pump initiation (Baseline), 3 months (T2) and 6 months later

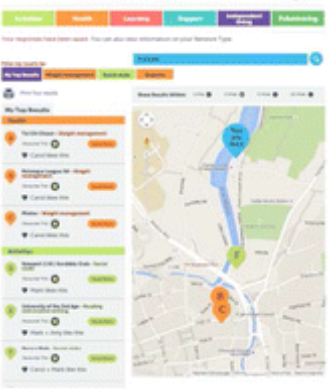
(T3). This involved working through GENIE (Table 11) (with an adapted database populated with Type 1 diabetes and insulin-pump-specific resources, local activities and services), followed by reflective questions about GENIE. The semi-structured interviews provided a dynamic method which enabled exploration of participants experiences, needs, values and perspectives. The interviews initially explored the individuals and groups that contribute to the participant's personal network, how these network members contribute to self-management (at each time point), and further elaboration of the meaning and contribution of relationships within this network. The interviews also explored the nature of the context and content of the illness work that network members undertake in terms of supporting integration of pump therapy as well as their interest in social activities. The preferred activities that arose from GENIE were discussed and ways and means in which the participant may access these new activities. All interviews were digitally recorded and transcribed verbatim for analysis. The quantitative outcomes captured an overview of changes while incorporating the device, while the qualitative responses provided more depth about the nuances of these relationships and lived experiences.

Ethical approval for this study was granted by the National Research Ethics Service (Reference 17/NS/0089).

Table 11: GENIE elements (taken from Kennedy et al. 2016)

Elements	Details	Theory of how it works
Filter questions	The process starts with questions to provide details of the user's context. This includes postcode; gender; age and health condition.	<ul style="list-style-type: none"> • Providing filter questions allows tailoring of suggestions and helps to reduce choice at the preference stage.
Concentric circles: Stage 1	Social network members (family, friends, groups, professionals) are represented and mapped, depending on subjective importance, onto three concentric circles. Details of relationship and frequency of contact are recorded.	<ul style="list-style-type: none"> • To explore everyday relationships and how network members contribute to support • To note change over time • To provide a visual image to enable engagement • To help people become conscious and reflexive of

Elements	Details	Theory of how it works
	<ul style="list-style-type: none"> Support work can be: illness-related (taking medications and measurements, understanding symptoms, making appointments); everyday (housekeeping, child rearing, support for diet and exercise, shopping, personal care); or emotional (comforting when worried or anxious, well-being, companionship). 	<p>contributions made by others to self-management support (SMS)</p> <ul style="list-style-type: none"> As starting point for a discussion about how to extend existing support, access support from new sources, or change existing practice.
<p>Typologies: Stage 1</p>	<p>Feedback and a summary is provided on network types:</p> <p>Diverse - family, friends, and community groups with <i>regular frequent contact</i>;</p> <p>Friend and/or family centred – mainly friends and/or family members with <i>regular contact and support</i>;</p> <p>Friend and/or family contact - some mostly friends and/or family members with <i>limited or patchy support</i>;</p> <p>Isolated or professional contacts only</p>	<ul style="list-style-type: none"> To help people become conscious and reflexive of network structure and availability of SMS Act as a prompt for healthcare professionals and others to take action where there are obviously fragile networks
<p>Preferences: Stages 2,3,4</p>	<p>The user co-produces and owns the network map.</p> <p>Choices are tailored using a series of questions and based on</p>	<ul style="list-style-type: none"> Non-intrusive methods are more effective than highly directive approaches which often fail because they do not deal with existing relationships to negotiate time and space for new

Elements	Details	Theory of how it works
	<p>preference and enjoyment rather than on health-based need. For example, the facilitator prompts by asking:</p>	<p>activities (intimidating to attempt by oneself) or needing help with transport</p> <ul style="list-style-type: none"> • The user is made a capable and willing to reciprocate participant
	<p>“Are there things you used to do that you don’t do anymore? What stopped you from continuing to do these things?”</p>	<ul style="list-style-type: none"> • To reduce choice and complexities arising from information overload counterproductive for learning, social engagement and social support particularly where there is poor health literacy.
	<p>This gives clues about how to identify the most relevant type of support, the likely barriers they may encounter, and how to encourage them to restart these activities.</p>	
	<p>Network members are selected as potential buddies to accompany them to new activities.</p>	
	<p>Asked to select the three activities or resources they are most interested in and agree to try them out. The locations of the activities are displayed on a Google-based map.</p>	
<p>Links to Voluntary and Community Organisations (VCOs): Stages 2,3,4</p>	<p>The preference questions link to community resources in a pre-created database.</p>	<ul style="list-style-type: none"> • Diverse networks which include VCOs enhance health and well-being through providing access to new acquaintances for

Elements	Details	Theory of how it works
	Categories in the database include: activities and hobbies, health, learning, support, independent living and volunteering	<p>advice, support and links to resources are often missing where there is reliance on strong family ties.</p> <ul style="list-style-type: none"> • Support from VCOs is non-clinical. • Specific benefits for people who are isolated.

7.3.2 Setting

The study took place between January 2018 and September 2018 in insulin pump clinics over three NHS Trusts in the South of England. Forty-three interviews were conducted face-to-face and four via telephone.

7.3.3 Population sample

Purposive sampling was used by each clinic to search their clinic database for potential participants who met the inclusion criteria; individuals who had been diagnosed with Type 1 diabetes for >6months aged >16 years and due to initiate insulin pump therapy. A recruitment pack including the study Participant Information Sheet (which outlined the study and the topics which would be covered in the interview) and invitation letter was sent in the post or given by a clinician during a clinic visit. Participants were purposefully sampled to ensure a range of ages, marital status, sex and employment status to reflect differing perspectives.

7.3.4 Data analysis

The widely used, reliable scales (Polonsky et al. 1995; Geddes et al. 2007) routinely collected in the clinics selected were self-administered. The Problem Areas In Diabetes (PAID) scale was developed to measure emotional distress in people with diabetes and has 20-items which utilises a 5-point Likert scale (range 0-100), where higher scores reflect greater emotional distress. The CLARKE survey is an eight-item measure of hypoglycaemia awareness. A score of four or more suggests lack of hypoglycaemia awareness. The PAID, CLARKE and HbA1C results were collected by the clinic at Baseline and T3. The differences in HbA1c and PAID between baseline and T3 were compared using Wilcoxon signed-rank tests.

Participants completed concentric circles of network members and preference questions for activities on the GENIE database at Baseline, T2 and T3. Changes in the number of network members, frequency of contact (days per year) and value of contact (on a scale of 1-3, 3 being most valuable) of each network member were collated and compared over 6 months. Uptake in activities, and the type of activities were also recorded. Statistical data were analysed using IBM SPSS, V25.

Longitudinal qualitative interview data were subject to trajectory analysis, which focuses on changes over time utilising sequential, time-ordered matrices (Grossoehme and Lipstein 2016) combined with thematic analysis. Thematic analysis was guided by Braun and Clarke's (Braun and Clarke 2006) well-established five-step framework. The first step required familiarization with the data through multiple readings, followed by the second step whereby an initial list of ideas about what is in the data was generated and initial codes were collated from the data. The third step is where themes begin to emerge, where we refocused and refined the analysis of the initial ideas and codes, at the broader level of themes. The themes were explored and reviewed for refinement in the fourth step, which included comparing and contrasting the similarities and difference between themes, interviews and contexts. Step five was where the themes were finally defined and named.

7.4 Results:

We conducted 47 interviews with 16 participants. Purposeful sampling worked relatively well in this instance with opportune natural variety amongst pump starters, and with a high response and participation rate from those approached in clinic (80%). However, one participant (P8) was lost to follow-up at T3. Participants had a mean age of 38 years, mean diagnosis of 27 years and 11 (69%) were female (see **Table 12** and Supplementary File 1 for individual characteristics). Participant baseline characteristics are presented in. A Wilcoxon signed-rank test indicated that the average HbA1c of participants was lower at 6 months than at baseline (average rank of 8.5 vs. average rank of 1.5) and that the observed difference between both measurements was significant ($p=0.001$). The Wilcoxon signed-rank test also indicated that PAID scores were lower at 6 months than baseline (average rank of 9.1 vs average rank of 4.0) and that the observed difference was significant ($p=0.001$) (**Table 13**). There was no statistically significant improvement of hypoglycaemia awareness. However, hypoglycaemia awareness improved from 75% of participants to 81% due to one person regaining hypoglycaemia awareness.

Table 12: Baseline sociodemographic properties of participants (n=16)

INSULIN PUMP USERS	% (N=) UNLESS OTHERWISE STATED
Age (Mean, SD, range)	37.63 (15.62), 21-65
Sex (Female)	68.8 (11)
Ethnicity (White British)	87.5 (14)
Income (average UK = £26,500)	
Lower than average	56.3 (9)
Average	25 (4)
Higher than average	18.8 (3)
Marital status	
Never married or formed a civil partnership	43.8 (7)
Married or in a civil partnership	43.8 (7)
Divorced	12.5 (2)
Work situation %	
In paid full time work (full or part-time)	56.3 (9)
Retired from paid work	12.5 (2)
In full time education or training	25 (4)
Long-term sick/disabled	6.3 (1)
Education level (Degree level or above)	43.8 (7)
Time since diagnosis (Mean, SD, range)	27.06 years (12.81), 11-45 years
Diabetes-related complications ^a	50 (8)
Ever been in hospital for hypo or Diabetic Ketoacidosis?	56.3 (9)

^a Eye damage; Background retinopathy/Treated retinopathy/Neuropathy/Cardiovascular disease/Other complications

Table 13: Participant clinical outcomes

Participant	HBA1C BASELINE MMOL/MOL (%)	HBA1C T3 MMOL/MOL (%)	HBA1C CHANGE	PAID BASELINE	PAID T3	PAID CHANGE
1	59 (7.5)	46 (6.4)	-13 (-1.1)	1	5	+4
2	72 (8.7)	70 (8.6)	-2 (-0.1)	17	6	-11
3	68 (8.4)	60 (7.6)	-8 (-0.8)	11	5	-6
4	68 (8.4)	65 (8.1)	-3 (-0.3)	50	35	-15
5	51 (6.8)	53 (7.0)	+2 (+0.2)	30	10	-20
6	67 (8.3)	60 (7.6)	-7 (-0.7)	6	4	-2
7	98 (11.1)	75 (9.0)	-23 (-2.1)	38	5	-33
8	85 (9.9)	81 (9.6)	-4 (-0.3)	59	16	-43
9	60 (7.6)	53 (7.0)	-7 (-0.6)	22	8	-14
10	80 (9.5)			46	51	+5
11	64 (8.0)	60 (7.6)	-4 (-0.4)	11	13	+2
12	62 (7.8)	57 (7.4)	-5 (0.4)	9	6	-3
13	86 (10.0)	74 (8.9)	-12 (-1.1)	14	13	-1
14	56 (7.3)	49 (6.6)	-7 (-0.7)	69	33	-36
15	68 (8.4)	60 (7.6)	-8 (-0.8)	10	8	-2
16	68 (8.4)	63 (7.9)	-5 (-0.5)	30	16	-14
AVERAGE /TOTAL	68.74 (8.4) ±13	61.73 (7.8) ±10	-7.01 ^a (-0.6)	26.75 ±20	14.30 ±14	-12.45 ^b

^a P= <0.001^b p= <0.005

7.4.1 GENIE concentric circles

The number, frequency of contact and value of network members increased over time from baseline to T3 (**Table 14**). The majority of network members at each time point were family members (41%) followed by friends (15%) and HCPs (15%). Unsurprisingly, HCPs had a relatively low frequency of contact compared to their (high) value (**Table 14****Error! Reference source not found.**). The most commonly cited healthcare professionals were pump therapy clinicians (See

Supplementary File 2) and while there was a significant decline in frequency of contact (which includes face-to-face contact, emails, texts and phone calls) over 6 months ($p=0.006$), the value of these clinicians did not change significantly ($p=0.361$) (**Figure 19**).

Table 14: Changes in numbers, frequency of contact and value of network members

	Count of network members			Frequency of contact (collective days per year)			Value of contact		
	Baseline	T2	T3	Baseline	T2	T3	Baseline	T2	T3
HCP	24	23	19	520	380	52	52	52	43
Family members	64	57	64	12021	12177	12049	155	163	153
Friends	24	26	27	2020	1763	2164	44	47	55
Pets	6	9	8	1877	3285	2607	12	20	18
Fitness activities	12	16	19	624	1025	1534	24	37	46
Groups	6	12	14	497	1082	825	10	23	23
Health technology	5	10	10	1150	2984	2984	13	26	26
Social media	3	4	4	469	521	521	6	7	7
Colleagues	6	6	8	1524	1524	1901	11	11	13
Object	3	3	4	742	734	1099	7	7	10
Education	3	2	3	20	8	373	3	2	4
Other	2	3	3	369	373	20	4	7	5
Total	158	171	183	21833	25856	26129	341	402	403
Mean (SD) per participant	10.20 ±3.29		12.20 ±3.75 ^a	1354.73 ±790.99		1747 ±933.29 ^b	22.13 ±1.83		26.73 ±9.92 ^c

^a $P=0.017$

^b $P=0.018$

^c $P=0.033$

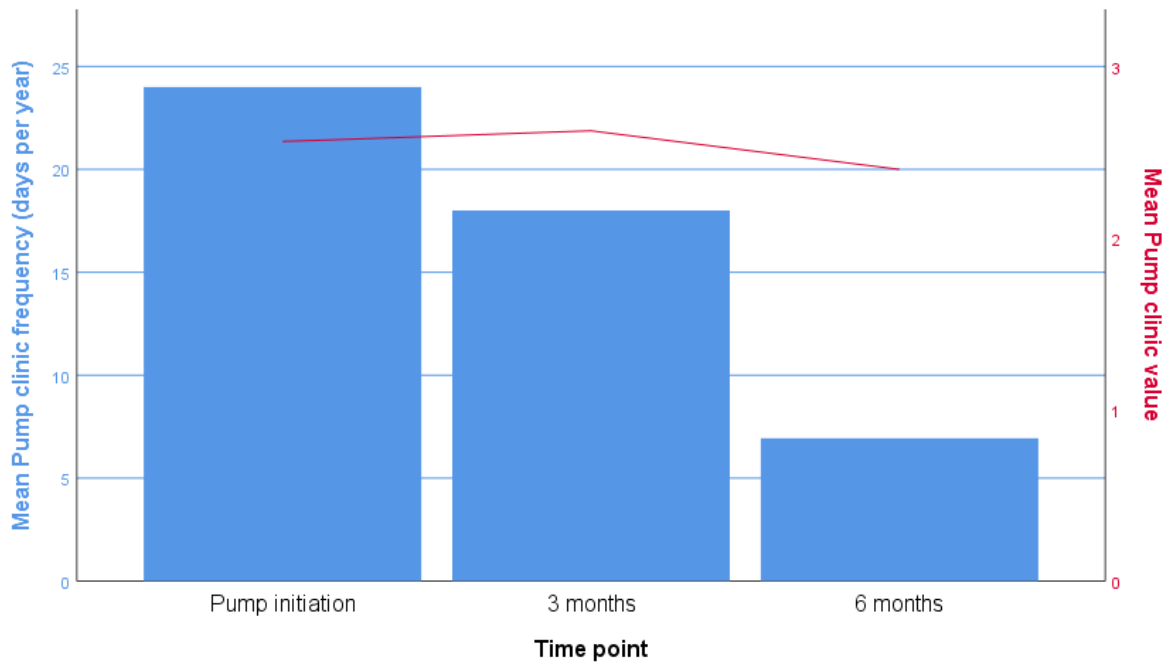


Figure 19. The frequency of engagement with the pump clinic over time vs value of the pump clinic

Some participants experienced a decline in partner contact and value over time where two participants broke up from long-term relationships (**Figure 20**). However, contact with family members remained relatively stable. Most described more contact with mothers than fathers, and while partners were the network member most frequently communicated with, mothers were valued nearly equally (**Figure 20**). In addition, while children were often seen more frequently than a sibling(s), a particular sibling was especially valued. These relationships were

discussed in more detail in the qualitative interviews.

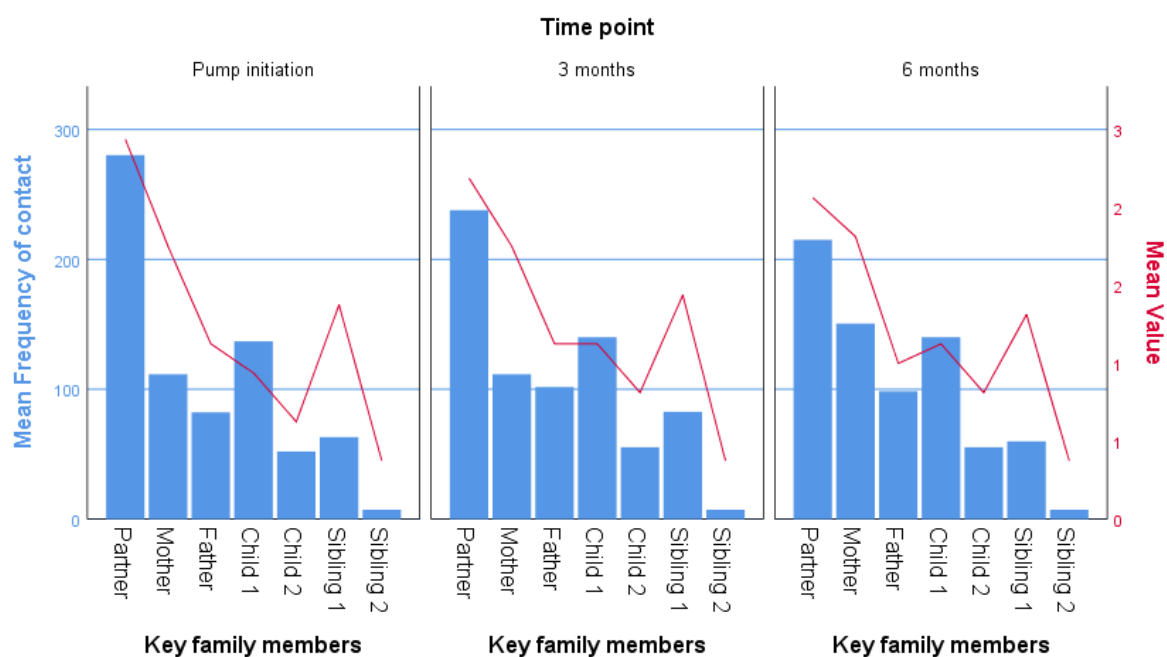


Figure 20. Frequency and value of contact with key family members over time

7.4.2 GENIE preference elicitation

The preference elicitation encouraged engagement and uptake of a range of activities and resources, whereby a total of 94 new activities were undertaken (and a Mean of 5.88 per participant) (see Table 15). Participants had a particular interest in online support, resources or social media (with 50 reported activities undertaken). Participants were also keen to undertake exercise and a total of 24 exercise-related activities were reported. These interests were explored in more detail in the qualitative interviews.

Table 15: Participant uptake of activities

Types of engagement		Total
Online or telephone support/ social media	Diabetes information websites	10
	Peer-support group (online)	8
	Pump accessories website or blog	8
	Video blogs/instructions	6
	Blogs	5
	Online health forum	2
	Twitter	3
	Googling carb content	1
	Total	50
Health	Walking	7
	Yoga/Pilates	5
	Ice skating / Snowboarding	2
	Team sports	2
	Running	2
	Swimming	2
	Cycling	2
	General exercise/gym classes	2
	Total	24
Activities/ groups	Volunteering	3
	Sewing / Baking	2
	History group	1
	Book club	1
	Men in Shed's	1
	Total	8
Other	Carbs & Cals app	4
	Fitbit	2
	Flash Glucose Monitor	2
	Total	8
Learning	Recipes	3
	Diabetes book	1
	Total	4
Total		94

7.4.3 Semi-structured interviews

The matrix table (**Table 16**) demonstrates the progression of needs over time. This process captured substantial life changes and disruption during this period. Four key themes were identified and Supplementary File 3 presents some of the quotes which elaborate on the themes identified:

1. The independent nature of managing diabetes
2. Overcoming the challenges and illness-burden of the pump
3. The need for responsive and tailored emotional and practical support
4. Useful resources when incorporating pump therapy

Table 16: Time ordered matrix of themes

Themes	Time 1	Time 2	Time 3
The independent nature of managing diabetes	Establishing independence and feelings of self-efficacy and responsibility heavily featured at baseline discussions	Occasional mention of independence.	Some mention of independence but more comfortable discussing and reflecting on the support others provide or impact others have on self-management.
Overcoming the challenges and illness-burden of the pump	Excited, dubious, wondering how they will place it on their body and other practical concerns.	Describe “new lease of life”. More lived experiences and cyborg identify. More advanced features being used. Describe taking on difficulties. Easier to tell people than MDI. Pumps = new illness work. Some problems. Huge array of in-depth descriptions of experiential pump experiences.	More routine. More reflective about how pump has helped them. More descriptive of how and why went on pump. Solutions of consolations to pump issues. Discuss what is resolved and what is still left to be resolved. Some say that the pump has helped them to be more interested in Type 1 diabetes Self-management.
The need for responsive and tailored emotional and practical support	Partners most referred to followed by mothers who were seen less but provided highly valued support. Initial impressions of pump clinic. Describe past negative experiences. Most GPs not deemed helpful.	Changes in support. Tested relationships. Shifts (in circles) where has had the opportunity to reflect. Experiences of calling clinic. Tried and tested support. Bad GP experiences – especially re: prescriptions. Very happy with pump clinic.	Remember additional people/weak ties who help. Most important support discussed. Comments from colleagues/family members that they are more relaxed now. Changes consolidated (less shifts in circles). Happy with clinic
Useful resources when incorporating	Peers: Not much experience of this as	Peer-support: Discussed much more	Peer-support: Used a lot for tips.

pump therapy	yet for most but distinct support described by others. Resources: Not many resources at this point except YouTube for some. Describe interests or barriers to activities.	and in-depth. Some bad experiences. Otherwise peer-support added to circles. Resources: Trying out different support – especially emergency and practical support (accessories and resources – manual/online info). Describe what helped and tried and tested approaches (YouTube, peer-support). Describe increase in activities.	Resources: Still discussing struggles with positioning on the body. Like downloaded results. New activities taken up. Libre. Future tech.
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1. The independent nature of managing diabetes

Many participants articulated how they have to manage diabetes for and by themselves. Baseline discussions featured this topic quite heavily compared to T2 and T3, likely because it was the start of conversations about what support and resource is required or desired for self-management.

Participants expressed the centrality of independence and responsibility in their self-management, such as the constant personal calculations of carbohydrates, exertion, current and future bolus', hormones, stress levels and potential dawn phenomenon on blood glucose levels. However there were many discussions around how this effort was frequently undermined by the sheer lack of understanding of the lived experience, or passing of judgement on self-management from others (family members, friends, colleagues, strangers or clinicians). There was a narrative of unwillingness to ask others for help, as if admitting defeat, or perceived lack of capability of others to help (often from experience).

Most participants described either trying to be “positive” and “not think/talk too much about bad things”, or not thinking too much about potential complications, Considering who provides support to self-manage, and how, did seem like a novel task and evidently not something that had been considered before by most.

2. Overcoming the challenges and illness-burden of the pump

Most participants spoke of barriers they faced acquiring a pump, yet persevering and continuing to assert their wishes. Numerous participants described wanting better control over their glucose levels and that a pump may unlock opportunities for this to be realised. Some participants expressed less confidence acquiring a pump and were encouraged or inspired by partners or family members, or friends who already had the device. Where participants did not assert themselves close network members supported them to persevere.

The pump was described as relatively easy to use and logical but requiring new practices to learn and much trial and error initially. At baseline, a third of participants observed and expected that the pump would take time to accommodate and would require experimentation. There were some expressions of fear of consequences for getting it wrong. Other expectations included discomfort around having something attached 24/7, but also optimism about a new tool to help self-management. There was discussion around the associated extra consumables needed, especially from female participants. The physicality of the pump created discussions about how participants were beginning to deal with the size, noise and accessories required and the new found or increased illness-work required to place it on their body. However, some baseline discussions involved feelings of invigoration in relation to diabetes; like a positive disruption to self-management of this enduring condition.

Pump therapy initiation was described by all at T2 as a learning process of challenges and overcoming these, such as where to put the device. T2 also brought challenges to original expectations, including surprise at sleeping being “okay”. There were incidents of inconvenient alarms, batteries failing suddenly, the remote being slow, clunky or even failing, forgetting to change cannulas regularly, and the increased workload changing equipment regularly. Most participants described feelings of even more invigoration towards their diabetes self-management practices, such as dealing with diabetes all over again but with more tools and revitalised interest. Participants expressed appreciation for access to more advanced features than injections (multi-wave, extended bolus, reduced/increased basal). The device even gave way to an appealing new “robot” identity.

At T3 nearly all participants were still fine-tuning, but described how trial and error increased their knowledge and confidence and helped them come to terms with not having a perfect solution. Family members or partner suggestions were valued here. “Tightening up” or mastering long-acting insulin requirements, and “honing in” on more specific problems (exercise, particular foods, varying working patterns) were also discussed. Life events (e.g. moving home) had an impact for some being able to incorporate pump therapy as they would have liked, and grasp all

the new technological options offered. Any matters encountered were resolved through speaking to their clinic, manufacturer helpline or via peer-support. All participants said they were really pleased with the pump, even though it required extra work.

3. The need for responsive and tailored emotional and practical support

Network members that influenced self-management and the ability to incorporate pump therapy included family members, pets, friends, colleagues, employers, groups and healthcare professionals. Life experiences sometimes disrupted support networks and consequent diabetes care.

Where people had long-term partners they were cited as the closest sources of support within a personal community. They were often described as being central to emotional and practical support but there were also some conflicting reports of criticism and lack of understanding about diabetes in general. Some partners attended pump initiation and clinic appointments, providing another ear to remember the complex information, and would seek out further support on behalf of their loved ones. This was especially helpful with the extra work required by the pump (more blood-glucose checking, more information to retain, more appointments). They also provided or supplemented support where the participant had to provide support to others e.g. children and older parents. As time went on partners were especially valuable when participants were sick or needed extra support. Over time some participants reflected that their partners had been on this journey of adaptation too. Single participants relied more heavily on close friends and close family members, and expressed concerns over their safety concerning hypoglycaemia, especially at night.

Mothers were often described as calming, encouraging, and supportive although sometimes anxious or judgemental. Sometimes mothers were considered more helpful than partners for emotional support and diabetes management. In some cases the roles had reversed where parents now knew much less about diabetes-related experiences or regimen, and so could provide less technical and practical support than before. Fathers were generally deemed “less helpful” than mothers, usually due to providing less communication and emotional support and less interaction with diabetes management growing up, but not by all. Sometimes fathers were described as a calming presence and sometimes offering humour.

If participants had any family members who had diabetes as well it was apparent that they provided support or understanding that only others with diabetes could offer. Other important network members included children, nieces/nephews, grandparents, and siblings. Some

participants turned to their close siblings or children for emotional support. For one participant who was single and retired, her children were her main source of support. Family members often provided consistent and reliable support. Over half of participants had pets and most described their pets at baseline as highly valued network members. Some added their pet in later after reflecting on what/who is in their personal support network.

Friends were valued for taking part in activities and for offering non-judgemental or emotional support. There was no expressed expectations for friends to understand diabetes intricately but some participants did talk about valued friends treating them “like normal” rather than those who “do not understand diabetes”. Support or flexibility in the work place or whilst in education was valued, e.g. when undertaking night-shifts, or during hypoglycaemia. Colleagues being interested, and looking out for those starting pump therapy or supporting them if needed during hypoglycaemia were appreciated. Work colleagues could be in a position to be helpful “weak ties”. However, there were also reports of managers or colleagues being unhelpful, rude or obstructive.

There were extensive and in-depth discussions about support from clinicians, especially at pump clinics. At initiation pump therapy clinicians were considered important but with a need to create trust and reliable support. Group education sessions were appreciated by most participants, but with a request for one-to-one sessions to address more intimate issues. At baseline the clinic held the key to understanding discrete and important features of the pump. New pump users relied on the expertise and chosen delivery of that integral expertise. This did not appear to in conflict with independent self-management but complimentary when non-judgemental, supportive, consistent and accessible. This created positive engagements and collaborative relationships enabling participants to integrate pump therapy into their lives gradually, and in ways that were not fully captured by most former clinicians. Most participants did not consider their GP as a self-management network member, yet 100% put their pump clinic. However, a couple of participants spoke of important relationships with their GP or Practise nurse who had created highly valued sustainable and trusting relationships and responsive emotional support.

At T2 many participants discussed issues acquiring essential pump prescription items. The clinic became especially important when there were experiences of general healthcare professionals not understanding Type 1 diabetes. Participants also expressed appreciation at the clinic having honest and potentially difficult conversations with them. The current clinic was described as “more friendly”, with former clinics disparaging and “less supportive”. Most participants spoke about speaking to the clinic for practical tips since pump initiation and the value of these opportunities.

At T3 participants shared experiences of reaching out for help. If participants had not contacted the clinic they usually had a list of items to discuss and troubleshoot at follow-up appointments. Clinics were now opportunities for troubleshooting rather than “having to go” or for “being judged”. They were utilised well and the resources available in clinic were appreciated.

4. Useful resources when incorporating pump therapy

Many participants wanted more information about developments in diabetes technology or self-management tips. Information and support were sought and desired from a variety of sources including; the pump manual, manufacturer helpline, social media and apps. Social media use included social networking sites (namely Facebook, Twitter, Instagram), blogs, video-blogs (YouTube), and diabetes websites. Social media was prominent in baseline discussions and continued throughout and it became apparent that social media provided convenient access to information and peer-support. Peers were deemed useful for practical and emotional support by many (both online and offline) and were integral to their support networks due to the uniqueness of knowledge (about diabetes) held by peers. Most mentioned being a lurker rather than an active participator but appreciated reading other’s comments, especially when they did not know others with Type 1 diabetes. Video blogs helped relieve anxiety by visualising complex new pump tasks. A few participants conveyed how being on pump therapy felt more like being part of a community, where peers seemed more accessible. However not all peer communication on social media was deemed useful with potential exposure to negative self-management practices or unwarranted advice.

The pump manual assisted with troubleshooting at T2 for many and access to this comprehensive information reduced the need for additional contact with the clinic. The helpline heavily featured in follow-up interviews. Participants expressed assurance knowing there was an emergency point of contact, and as time moved on where half contacted the helpline, were further reassured to know it was also reliable and useful.

At T2 and T3 new activities had commenced and participants spoke of activities they had undertaken as a result of GENIE. Participants mentioned engaging with various health, exercise or carbohydrate counting apps. Exercise in general was deemed important, with walking and yoga or Pilates particularly of interest, although undertaking personally chosen activities in general were referred to as supporting both physical and mental health and reducing insulin requirements through keeping active. An example of this is one participant who joined “Men in Shed’s” which provided the opportunity to get back into recreational

work as an electrician which he was forced to stop professionally due to heart problems. He felt this not only improved his mental health but his physical health too. However, barriers to undertaking activities for participants, either old or new, included provoking anxiety about meeting new people, groups not catering to diabetes-specific needs (for weight loss or exercise) or feeling unable to do an activity previously enjoyed, although these were also a drive to take up interests again.

7.4.4 Reflections on the social network intervention

GENIE prompted conversations about various elements of living with Type 1 diabetes and a pump, personal interests and what support was present, or not. All participants identified personalised activities through GENIE. GENIE also enabled participants to reflect on and express what they desire to help them manage, and why.

7.4.4.1 Concentric circles

All participants enjoyed engaging with the concentric circles activity due to having a novel visual image of their support, and the reflective nature of the task. Most participants reported the usefulness of visual reflection of their support network leading to re-evaluation of current network members and reconsideration of support received, and identification of further sources of support. The reflective space within GENIE enabled novel reflection and illumination of the mechanisms in which network members do or do not support or engage in self-management tasks when integrating a complex new technology. Identified mechanisms included: modelling of behaviour (e.g. peer-learning, sharing of practical tips); persuasion (e.g. network members encouraging pump therapy or self-management techniques); providing information, support, or even criticism and social pressure; and engagement with more diverse activities and connections.

7.4.4.2 Preference elicitation

Participants' mostly described how GENIE offered specific and tailored preferences and an element of safety in searching for online or local groups and activities. However, some participants said that they did not want to be directed to resources and did not feel the need to be encouraged to do any activities, preferring instead to take up activities on their own. On the other hand, some of these participants did express specific reasons for not taking up activities, such as lacking a companion to attend activities or lack of confidence attending groups alone.

Modifications were also suggested including; making GENIE available as an App, more explanations about particular activity options and network interactions; adding clarity to what the preference entails rather than being over generic, and offering more language options.

7.4.4.3 Delivering GENIE

Some participants suggested accessing GENIE within the clinic setting, offering the opportunity to reflect on their diabetes self-management and preferred activities in a focused clinic rather than busy day-to-day life. Other suggestions included access via local diabetes groups for convenience, or having a drop-in space during clinic.

7.5 Discussion

At the centre of a diagnosis of Type 1 diabetes is the individual living with diabetes. Participants were keen to establish their own levels of responsibility and capabilities to manage their diabetes, but there was also evidence of engaging with the network of people, objects and resources around them to support self-management during adaptation to a new health technology. This study offered the opportunity to explore the network and resources around people in the process of incorporating a pump from the point of initiation up to 6 months on. This exploration utilised a social network tool, GENIE, to offer personalised, tailored opportunities and signposting to further support and resource. Using concentric circles within GENIE, this cohort demonstrated a rich range of network members of varying types, numbers, frequency and value.

Participants expressed an initial liminality when introduced to pump therapy, which required an increased need for practical and emotional support and reassurance. As time went on participants' confidence grew to trial new methods to integrate, relate to and wear the pump. Qualitative results highlight the complexity and nuances of social relationships. Partners and mothers were frequently highlighted as sources of integral support. This occurred even when these network members also created sources of anxiety or judgement. Pump therapy was also a source of new anxiety for network members but as time went on this anxiety decreased.

Participants who had been diagnosed in childhood discovered a new imbalance of expertise and experience in the management of diabetes between parent and (now adult) child. Where parents could no longer provide technical or practical support or knowledge they provided vital and valued emotional support.

It was not expected that all healthcare professionals (e.g. GPs, pharmacists) would know a lot about Type 1 diabetes, but language did matter; participants expected to be spoken to with some respect of their capabilities. This could be the difference between clinicians being a viable option to turn to for support or any form of collaborative relationship. While frequency of contact with clinicians decreased over 6 months, other sources of support, resource and activities were gained. There appears to be a return on investment for the non-judgemental, accessible self-management support and education given by pump clinics. Specialist clinic support at the outset provided

reassurance and skills, which enabled participants to self-manage more confidently. However, these clinics do not seem to represent the majority of diabetes clinics where there are concerns around the effectiveness and appropriateness of communication methods and approaches in the delivery of diabetes healthcare (Lloyd et al. 2018). It has been noted that interactions with healthcare professionals can elicit distress when they do not acknowledge limitations to managing Type 1 diabetes and (unintentionally) disempower patients to self-manage through unrealistic expectations (Snow et al. 2013). Recent research also shows that clinicians do not feel confident, or familiar in approaching or delivering psychosocial support to meet the needs of people with diabetes (Byrne et al. 2017). These clinics represent a model of good practice for the delivery of structured education and healthcare. Accessing support on their own terms was important for participants and any contact with clinicians was carefully selected, preferring to manage on their own where possible. Participants' demonstrated determination and capability to self-manage but were keen to collaborate with engaged clinicians to address concerns.

Users expressed a desire to access GENIE conveniently and in an accessible setting (such as a drop in service in clinic or in local groups). Kennedy et al. (Kennedy et al. 2016) found that those in lay roles provided the best fit for facilitation of GENIE, and so implementation may benefit from utilising peers as volunteer Facilitators (or 'peer support workers'). Peer facilitation offers a combination of informational, instrumental and emotional support, whilst bridging the gap where healthcare professionals are not equipped to approach or deal with day-to-day self-management tasks and requirements (Funnell 2010). With training and support, peers can potentially, and economically, bridge this gap utilising established communication and behavioural strategies (e.g. preference elicitation, goal setting) (Funnell 2010). For example, Small et al. (Small et al. 2013) found that telephone self-management support interventions that were delivered by lay and peer support workers significantly improved HbA1c level and self-management behaviours.

This study captures this unique process of changing needs over time and an avenue to respond to these changing needs. Providing an opening to help people with diabetes navigate their social network and means to personalised support and resources as and when they needed through GENIE appears to have supported identification of new ways to support self-management and more smoothly incorporate a new health technology. In addition, facilitation to personally tailored activities was not only acceptable to participants, it also provided opportunity and social restructuring to open up new opportunities. The use of a social network intervention offered a positive disruption to self-management through novel considerations of network members and how they impact on self-management. In addition, the pump offered positive disruption through offering something new to approach self-management with. Suddenly there was a reason or a potential to try new techniques (e.g. variable night-time background insulin for dawn

phenomenon). However, there are distinct technicalities to consider with the pump that created increased illness-work and burden for new pump users. People with Type 1 diabetes are “super users”; experts in their own diabetes, and so in reality it is then a case of tapping into tailored support when it is deemed necessary.

7.5.1 Limitations

An increase in social network size should not be viewed as an end in itself, but the means to support people to achieve other recovery goals. It is worth noting that while the tool does not intervene directly with maladaptive networks or network members it does incite change within the individual through engagement with the Facilitator and renegotiation of existing network members but also through an increase in network and variety where there is a potential for further sources of support outside of the relationships in existence before engaging in the tool. In addition, while peer-support and social media featured strongly here, it is not desired by all, and there are concerns over how and when social media is used by people to self-manage (Reidy et al. 2019b). It is worth pointing out that while purposive sampling sought a diverse range of participants, women do represent the vast majority of participants in this study (69% vs 31%). However, while the male voice is not as well explored here, there is a national (UK) disparity between men and women in uptake of pumps more generally (61% vs 39%) (NHS Digital 2018c). In addition, while reductions in HbA1c levels were achieved and some improved awareness of hypoglycaemia, we cannot know whether this is a direct result from engaging with this social network intervention, or whether this would have occurred regardless. Rather, this study provides rich descriptions of the complex and conflicting process that occurs when integrating a new health technology to manage a long-term condition and a potential means to support navigation of self-management support.

7.5.2 Conclusion

Utilising a social network intervention like GENIE provided the opportunity to explore the specific needs of people with Type 1 diabetes who are utilising a new health technology. However, access to such an intervention must also be a choice and not a one-size fits all model. Whether confident or actively seeking more support, there was value in offering people the unique opportunity to reflect on the current status of their support network and to consider what options they may wish to employ in future. In this instance social networks offered varying and rich opportunities for support which amalgamated over time and in response to life events and changes in circumstances. It would be valuable to widen the scope of this tool to target other people with diabetes, especially those experiencing any form of isolation, new health practises (diagnoses,

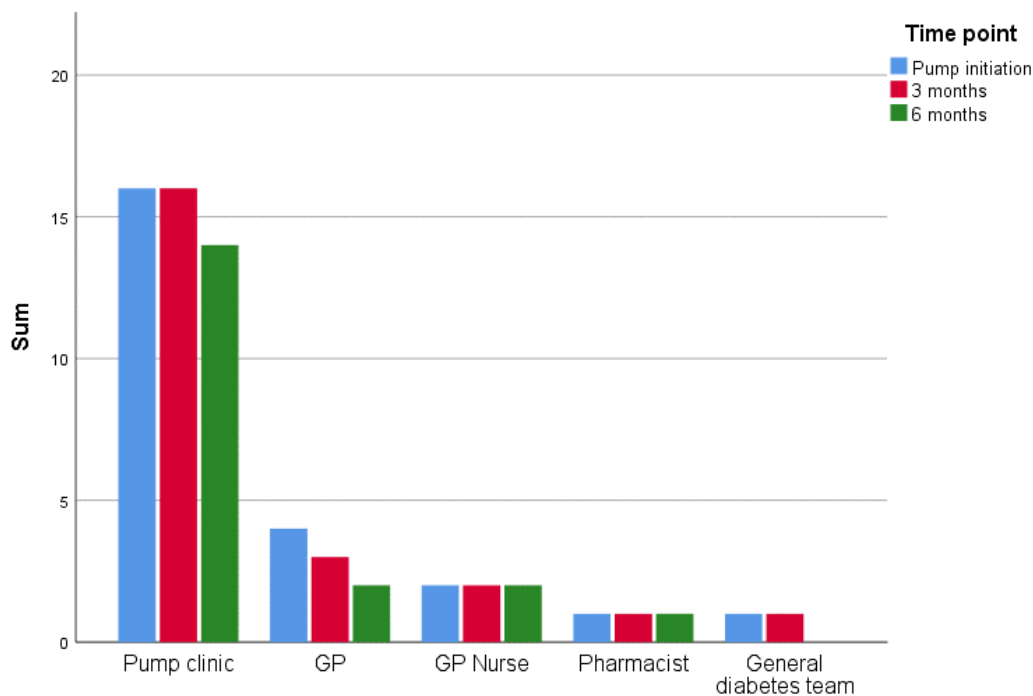
new health technology) or going through any form of transition. While this tool was deemed acceptable and enlightening, more work needs to be done to consider implementation and whether the improvements experienced by participants in this study can be demonstrated on a larger scale.

Supplementary File 1: Participant baseline characteristics

Participant	Age	Sex	Diagnosis	Complications?	Pump	Income	Marital status	Children?	Work situation	Education level
P1	48	Male	40	Background retinopathy	Roche Accu-Chek Insight	Higher	Married or in a civil partnership	Yes	In paid work	Doctoral degree
P2	22	Female	17	Similar to Diabetic Amyotrophy	Roche Accu-Chek Insight	Lower	Never married or formed a civil partnership	No	In full time education	NVQ or equivalent
P3	21	Female	20	None reported	Roche Accu-Chek Insight	Lower	Never married or formed a civil partnership	No	In full time education	A-Levels or equivalent
P4	22	Female	17	Background retinopathy	Roche Accu-Chek Insight	Lower	Never married or formed a civil partnership	No	In full time education	Bachelor's degree or equivalent
P5	55	Female	44	None reported	Roche Accu-Chek Insight	Lower	Divorced	Yes	In paid work	Bachelor's degree or equivalent
P6	22	Female	12	None reported	Roche Accu-Chek Insight	Lower	Never married or formed a civil partnership	No	In paid work	Bachelor's degree or equivalent
P7	27	Male	20	None reported	Roche Accu-Chek Insight	Average	Never married or formed a civil partnership	Yes	In paid work	A-Levels or equivalent
P8	29	Female	26	Retinopathy	Roche Accu-Chek Insight	Lower	Married or in a civil partnership	Yes	In paid work	NVQ or equivalent
P9	52	Female	45	None reported	Roche Accu-Chek Combo	Higher	Married or in a civil partnership	No	In paid work	Bachelor's degree or equivalent
P10	23	Female	12	None reported	Roche Accu-Chek Insight	Lower	Never married or formed a civil partnership	No	In full time education	A-Levels or equivalent
P11	40	Male	34	Retinopathy	Roche	Average	Married or in	Yes	In paid	Bachelor's

		e		y	Accu-Chek Insight	e	a civil partnership		work	degree or equivalent
P12	65	Fem ale	27	None reported	Roche Accu-Chek Insight	Averag e	Divorced	Yes	Retired from paid work; Voluntary work	NVQ or equivalent
P13	55	Mal e	44	Retinopath y; Neuropath y; Nephropat hy; Cardiovasc ular disease	Roche Accu-Chek Combo	Lower	Married or in a civil partnership	Yes	Long-term sick/disabl ed	GCSEs or equivalent
P14	32	Fem ale	11	Neuropath y	Medtronic MiniMed™ 640G	Lower	Married or in a civil partnership	No	In paid work	Bachelor's degree or equivalent
P15	32	Mal e	20	Pre- proliferativ e retinopath y	Medtronic MiniMed™ 640G	Averag e	Never married or formed a civil partnership	No	In paid work	Doctoral degree
P16	57	Fem ale	44	None reported	Roche Accu-Chek Insight	Higher	Married or in a civil partnership	Yes	Retired from paid work; Voluntary work	GCSEs or equivalent

Supplementary image 2: Count of healthcare professionals by type



Supplementary file 3: Quotes from semi-structured interviews

Theme/sub-theme	Time	Quote
1. The independent nature of managing diabetes		
	T1	Interviewer: You normally wouldn't put them before the pump, put the diabetes clinic? P10: No, I don't think so because I'm quite independent with that... Yes, and it's not your first thought to be like, "I'm going to ring them again" or something like that. It's not your first thought. You think, "What can I do here right now?"
	T1	P13: Most of it is down to me and I've done it all myself, because nobody else knows how I feel. You can tell them and they go, "Yes, yes, yes. Put a plaster on it. It'll be okay." It doesn't work like that. Life is not like that and diabetes is certainly not like that. Even healthcare professionals, if you tell them how you're feeling, they don't really understand how you're feeling...They probably heard it a thousand times before, but they don't understand it.
	T1	P16: I think that's why you don't get people involved because they just wouldn't know. What's the point, they just don't get it, or they might half get it.
	T1	P12: Well. I tend to all on my own, to be honest. I've not really-- I just get on with it.
	T1	P12: I'm quite independent when it comes to most things. I have to be pretty desperate before I—yes.
	T2	P3: Hmm. It's difficult because something happens and he's like, why didn't you tell me. I've dealt with it my entire life on my own and it's

		difficult to say oh by the way.
	T2	P16: Well I'm not one that really shouts out I'm a type 1 diabetic. So, most people wouldn't know don't know. So, support, there isn't much and that is fine because nobody could know it as well as I do... That's right. So, as support goes there's really me because I support myself a lot in what I do so I'm the most important that's why I'm in the middle.
	T2	I: Healthcare professionals, what is their role in your life? P12: Nothing. I: Introducing you to the pump for example? P12: Oh, yes. Better tools for diabetes, but actual management of it nothing because I do that.
	T3	P13: I think diabetes can be such an individual type of condition anyway, we all know you need insulin to treat it but not everybody is the same and I think that's half the complication with having diabetes, no two people are the same.
2. Overcoming of the challenges and illness-burden of the pump		
2.1 Technicalities of the pump		
	T1	Researcher: How do you find solutions? P11: Observing the results and of course making some changes and seeing what happened after the changes.
	T1	P9: And I'm probably starting to use some of the functions that at the moment I don't know, what I don't know. I don't need to know what I don't know because I'm still getting used to the basics probably.
	T2	P5: I think there are a lot of things to learn to start off with, sort of scary things like fitting the catheter in is a completely different skill, isn't it? The first time I did it I was a bit gung-ho and it was fine, but the next time I did it I messed up loads of times and then the third time I got my daughter who is not medically trained but I said can you stand there while I do it please.
	T2	P1: It's still new enough that you are concentrating on it, still new enough that you are thinking about changing catheters and just do it slowly. That phase of making things happen rather than just using it.
	T2	P12: I've got the basics and I know how to do the basics, so at this point I feel I'm in control now. So, however, many classes we had to start with, let's say we had three. For the first two I was really on it and got it all and I think I must have slept through the third one because I really, or whether there was just so much information I switched off. I'm not sure what it was, whether I was having a bad day, but I was really panicky about the first time I had to change the battery, the first time I had to change the cartridge.
	T2	P10: It just feels like the last three months have been so intense, not that it wasn't the best time to start the pump, but I feel like from now on I can really concentrate on using the pump rather than, and using it properly, rather than being, oh I've got all this stuff to do and get into a proper routine now.
	T3	P4: Still a way to go but I'm happy. We need to tighten up my basal dose a bit, but we gave me a bit more in certain periods of the day because there was a trend of me going a bit high towards the end of the day. So, hoping that will fix that. I feel like my results have been better since our meeting as well so that's good.

	T3	P5: Yes. I think as I said to [DSN], I did find the start quite difficult. I was quite a slow starter in coming to grips with it. But I think the last three months has been really good and in fact the other day I was thinking, oh no I wouldn't be without it now. At the beginning I really didn't think I'd think that.
2.2 The physical pump		
	T1	P12: We did a dry run for a week. I hated it. I was like, "I can't do this". I hate this being stuck to my body. I hate this great lump I'm carrying around on the side of me. Three days in, we had to change the cannulas. Mine dropped out within the day, "Thank goodness" so I took the whole lot off."
	T1	P12: It's like "No, I've got to see this through because it's going to tighten my control. I've got to see it through".
	T1	P14: Sort of having a constant monitor, that's it isn't it? If they can, that's why it helps. It's supposed to, sort of, give you less ups and downs, ideally.
	T1	P5: The worst thing was when-- the alarm goes off at work, to say you only have 25 units left, and my colleague was saying "What is that noise? What is that odd—oh." ... And then a few days later there was this funny alarm that went off... and he went, "Is that you running out of medicine again?"
	T1	P5: My bag has got heavier rather than lighter.
	T1	P16: I think going to the toilet now is going to take a lot longer than what I used to be.
	T2	P1: Frustrating sluggishness, this is ten years out of date.
	P1	P1: So it went to 90% and I thought, OK, it is beginning to fall, that happened quite quickly. Then from 90% to stop was within hours, from almost literally nowhere.
	T2	P3: Yes, so you are always attached to it, so when I'm getting dressed do I hold it, do I put it on my bed, do I un-attach it completely?
	T2	P6: Sometimes I'll get up in the middle of the night to go to the toilet and I completely forget I'm attached to the pump and it just drags behind me and I'm like, oh pump!
	T2	P5: A little bit. I'm surprised how easy I found it just to have it when I'm sleeping and stuff.
	T2	P1: It's still new enough that you are concentrating on it, still new enough that you are thinking about changing catheters and just do it slowly. That phase of making things happen rather than just using it. The learning point that you realise that doesn't work either so.
	T2	P16: I was talking to somebody at the group today and they've given me a couple of tips, so I will take that on board. But, yes, at the moment in jeans you can pop it in your pocket, dresses and skirts are more difficult, but I have bought something which was way too big, but someone has given me a few tips on how I can cope with that, so I will try that.
	T2	P11: The only thing really is just a matter of sorting the pump itself placing it somewhere else, I need to find a firmer holder for it.
	T3	P6: I don't know just sort of I guess, even just little things like getting used to having it on me. I don't even notice it's there half the time. I did back in June on one occasion I'd taken it off, I think I'd had a shower, taken it off and then come back out and I forgot to put it back on...I think it's because

		I'm so used to it being there that I don't notice it's not there. I guess that's one not so good thing. But, yes, and just getting used to it.
	T3	P3: It is weird, you have this thing connected to you. Sometimes you forget it, you're on the bed and you get yanked backwards.
	T3	P12: I'm just so aware of it. Maybe I'll put a piece of tape over it. I don't know what the answer is to that. Pop it in your bra but that would still show.
	T3	P9: Well I'm only using my stomach, which I think long term I probably need to use more areas otherwise it's going to end up, it's already looking a bit.
	T3	P12: Just not having to have those injections, it's so much easier in public to get this out and pretend it's your phone rather than have to get your needle out.
2.3 The impact of the pump on daily life		
	T1	P10: But it's exciting and it adds something to you, like changes things up a bit... Just try something new. It's almost like starting a blank.
	T1	P2: I had a pudding. Instead of saying, "No, I'm not going to have a pudding because I'll have to have another injection." Now I'm like, "I'll have a pudding, just fiddle with the machine."
	T1	P16: Sometimes I would just do an injection but if it was difficult I wouldn't.
	T1	P3: It is a worry actually, isn't it? Because I don't know how-- I didn't really take any notice of how exercise affects me, but now I have to.
	T2	P7: It's been a lot easier to manage because sometimes, well before in the summer my blood was always sky high not giving a reading, but I've had a few high ones, but it seems to be a lot easier to correct it than having to just have three or four units or insulin injection every so often. It's just a lot easier to do it at the press of the finger.
	T2	P10: I found that it's making me do more research. I'm Googling how many carbs are in things instead of being like, oh I know that, because that was what it was ten years ago.
	T2	P10: I think it's like when you get a new phone you just want to play with it don't you. It's just like the same thing, it's just like a, oh I want to do this.
	T2	P4: It feels like dealing with diabetes all over again, it's a renewed interest in how to look after it and also feeling like I can actually improve this time where I felt I was steadily, what's the word when you are just? ...Plateau. When I just plateaued, when I'm at a steady level... It felt like that for ages and then now I'm keener and more positive about it.
	T2	P15: Very good. For every hour of the day the insulin is matched to me as much as possibly it can. Of course every day is different, and you are going to get ups and downs but it's far better. Even if things are going a bit higher or lower I can adjust that with the temporary basal rate which absolutely brilliant.
	T2	P9: Yes, I've got some sort of base rules now, like I drop the meal one 50% and then an hour or two before exercise I'll drop the basal by 50%, so quite big changes. Then if I go to aqua I take it off, I'm now confident it's not going to go, when I first went I was like oh my God no insulin for an hour I'll be shooting up, but actually the exercise seems to keep it just

		about.
	T2	P11: So, it's a big advantage of the pump. The other thing I would say that you can use the different options like delaying or extending your insulin according to what you eat. So I think it's a big advantage.
	T2	P6: Yes, definitely. I am part robot and I'm happy with that, I'm proud of it.
	T2	P9: When I go on a new yacht I always say at the beginning I've got diabetes and now I say I'm now the new improved version because I've got a turbocharge, I've got the pump and everything...
	T3	P2: It's been so much better. I had my meet up with [DSN] last week and I said I feel like a different person a bit. I'm not stabbing myself every day, it's not hurting, I used to dread it because you always have to get it out in front people and it always hurts. But I just feel so free with it and because my control is so much better I'm not having a hypo every day. So I sometimes will react like, oh, yes, I forgot I'm diabetic. Yes, its life changing, I would say it's actually life changing.
	T3	P4: It improves your confidence with diabetes I think and knowing you can make these small adjustments rather than, just having something that works a bit more like a pancreas I guess and making those small adjustments might actually change your results for a few weeks.
	T3	P6: It's a bit like routine because I like to go out every evening to feed the guinea pigs their fresh vegetables and top up all their food and their hay and stuff like that. So I guess it gives you a good routine and it was my trigger. "Okay, I'm feeding the guinea pigs. I need to do my-- before I have the pump, I need to do my long-lasting insulin." Yeah, it all just went in together.
	T3	P6: But I still to this day get days that I get in bed and I'm like oh I haven't done my long lasting, oh, yes, I don't have to do it. I can just go to bed, this is great!
Loving the pump	T3	P8: It's been brilliant. I enjoy it.
	T3	P3: Pretty good. I wouldn't go back, I do like it, I'm still getting used to it and getting all the carbs right, but I do like it.
	T3	P6: Overall, it's been good and as I keep saying to people I'd never go back. I'm not giving my pump back to anyone, I'm going to guard it with my life.
	T3	P16: I'm really pleased with it, I really, really am. It's good, it's really good. It's different, you've got so much more control. I know we've been through this, but I'm really, really pleased with it.
3. The requirement of responsive and tailored emotional and practical support		
3.1 Sources of support from family members		
Mothers	T1	P1: She does still worry. If I'm on the phone, "are you being okay is everything all right?" This [the pump] will worry her silly. This was worrying her silly on Saturday she was already saying "you'll be okay". Then "what will you do?", "You're going to test enough, won't you?"
	T1	P4: Yes, my mum wants us to have a long, healthy life because my grandad didn't. That kind of means that sometimes she's a bit stressy but she's still my biggest support system.
	T1	P6: I was quite excited when I could show her a really good day I'd had and I'd talked all about it. But other than that, I just—[pause]. I guess

		she's just always concerned for my health because I'm her daughter.
	T1	P10: My mum... She leaves it to me, but she'll just be there like, "Okay, what are you going to do about that?" We talk every day and stuff like that.
	T1	P16: Well I would have said my mum, but she's died, because she lived with it and understood a lot about it.
	T1	P3: My mum's been a good help. She doesn't know much about the pump but when I was younger she had full control, my dad is diabetic as well, so she's a bowl of knowledge that woman. Really good.
	T1	P3: My mum and dad were always there but obviously with this new equipment they don't know, my dad is diabetic, but he will always be on injections... mum is like, well I don't know anything about it I can't really offer you any advice. I think it's probably the nurses because they're there. [Boyfriend] tries but sometimes I get annoyed, I'm like, no, shut up, I don't want to talk about.
Closet network members	T1	P4: I think my mum is more the emotional one and my boyfriend is more like the day to day stuff... I just always -- if I get overwhelmed I would call my mum. It's just habit. He'll comfort me with things to do with uni and stuff because we're both feeling it. With my illness, my mum dealt with it first and she's just the person that I always went to.
	T1	P14: He's the one I moan to first. Mainly because we live together. He's the first person I see when I go home at night, and he tends to drive me to all my appointments and stuff...
	T1	P13: She wants to be able to do it, she wants to be able to understand it but she just- sometimes she just doesn't get her head around it.
	T3	P2: I would feel like I'm totally alone if they weren't there. I go to them for advice. [Boyfriend] comes to every appointment with me because he's so interested in it and he wants to help, and he likes to know what's going on because I'm not very good at remembering. So he's like, remember you've got to do that, and I'm like, oh yes cheers [Boyfriend]. If I didn't have them I don't know, I think I would struggle a lot more.
	T3	P4: [Boyfriend] has been really good recently as well. I went through a period where I was just randomly higher, and I tested it at dinner time and I was 5 or something and I was really lucky, and he said I know how stressed you've been, but he didn't want to talk to me about when I was stressed so he just talked to me about it afterwards. So it shows that he's paying attention... He knows it will freak me out more if I talk about it.
	T3	P9: I think maybe husband could come in a bit. Yes, I think I do mention things to him from time to time and he's always supportive. Yes, so maybe I think he needs to come in a bit... He's said to me he can notice that I'm more relaxed and it's taking less effort for me to keep things going.
The role of Fathers	T1	P10: My dad doesn't know I suffer mental health issues. My brother and my mum do.
Family members with T1D	T1	P6: But he [brother] was actually diagnosed with Type 1 on the 22nd of December last year-so we're really close... Before, I probably wouldn't have put him in. He probably would have just been, "He's one of my family members. He knows I've got it," kind of thing and that's that. But since he got it, we've been messaging a lot and he's obviously asking me a lot of questions and then vice versa, it's just nice to have someone to talk about things like that and I'm like, "Oh, have you heard about this?"

	T1	P6: I think at the moment, it's just nice to know that someone else who understands as much as me. I feel like, I can imagine that my family think they understand, but I don't really believe that they do. Because I think back to sort of like, I think, "If I didn't have it, would I really understand?" I don't think so
	T1	P5: He was the one who said "you really ought to try a pump, it's so good" ... he loves it, it's so fantastic... So that's really been a positive thing...so that was a big encouragement for me. He keeps on phoning up saying "how's it going?", and "is it good?"
Other family members	T1	P5: Okay. So if I put my youngest daughter first... She knows quite a lot about diabetes from living with me. Plus she is interested in medical things. She's fascinated with the pump... So when I had to change my infuser the first time, I was a bit anxious about it and so she said, "I'll come over and I'll help you." ... So that was quite good, it was like a bit of moral support.
	T1	P12: Well. I tend to all on my own, to be honest. I've not really-- I just get on with it. I suppose two of my children, who live locally, they're probably the ones –they're the ones that I've been discussing the pump with over the last week... I suppose they would be the most important in the support network for me...Over the last week, there has been some ups and downs because of the pump and that and yes they've been there and just listened to me rant on....and then we just come up with some pearls of wisdom or something, or some encouragement.
	T1	P11: I would say my daughter as well. She's obviously small...She's got some understanding and interest. I would put it in the way like positive that she's around and she's trying something to check my blood sugar or for example the pump, she likes to play around to understand how it works. It's the way that it's someone else who is around you and supports you. It's not actually diabetes treating but just psychological support. It's very good.
	T1	P12: I'd go through periods where I'm hypo in the night. Living on your own, that's- obviously, could be a concern...I'd say to them, "Do you understand I just get hypo in the night and there doesn't seem to be any rhyme or reason for it?" I don't expect them to say anything to do because they can't. Again, it's just sometimes getting it off my chest. Also, I suppose so that they know that "Okay, mum might be hypo in the night. Maybe I just give her a text in the morning, make sure that she's okay" ...Yes. They'd be able to say, "Well, she's been saying that she had something".
	T2	P12: Yes, they're quite, you know, want to know what it's all about and how it works, well not how it works but what it's all about and how's it going. Not so much now because we're about three months in, aren't we, so not so much now.
3.2 Pets		
	T1	P2: She's my baby. Obviously, if I'm having a high day where I'd rather might take her out for a walk and do a little bit of exercise where she keeps me because I go running with her... She's just my best friend.
	T2	P13: Probably a bit more active. Yes, certainly more active. It's another responsibility you have isn't it, but it's all part of looking after a dog, isn't it? All animals are like that.
	T3	P14: It was quite funny because she basically is my life, I love her to bits,

		but it wasn't until we spoke about it that time that I was like, actually, she's a proper – yeah, she just chills me out. And obviously my mood affects my diabetes anyway, but I wouldn't have thought about it – yeah, I just wouldn't have thought about it.
	T3	P4: That's what I like about being home I get more of a routine. Dogs actually improve life so much, dogs are really good for things like that...They make you get out of bed.
	T3	P16: They calm you down as well, when you feel a bit uptight you just give them a stroke and it's actually quite a stress-relieving thing to do, so if you have a bad day, stroke a dog and then you get a lot of hair because they're retrievers and they're fur making machines but -
3.4 Support outside of the home		
	T1	P6: Because I feel like if I needed to I could turn to her and talk to her about anything. And yes, she's good and she's been quite understanding at ice skating...it's quite funny actually because we'll be practicing something and I'll start to get maybe wobbly on my feet and she'll say, "Just take it easy. Go check your number." And I'll go, "Actually, yes, you might be right. Yes, I might be running a bit low," and so it's quite nice. She's just-- she doesn't make a big deal of my diabetes but she's aware of it.
	T1	P9: The friend that's recently been diagnosed with multiple sclerosis. Since she's been diagnosed, I think she knows that I know what it's like for her to deal with something and have good times and bad times. I feel now, I can also empathize with her. Actually, it's quite nice to talk to her because I would very gladly listen to how it's going with her...It doesn't go away and with her multiple sclerosis, obviously, she has to deal with it every day and she sometimes, I think, she has to put on a brave, like, "Oh yes, it's not too bad, I'm going okay."
	T1	P12: She's one of my oldest friends, I've known her since I was 16...We've both been there for each other, seen each other through divorces, and child-rearing years, and so- shared experiences... sometimes, all we want is to just be able to offload. We don't necessarily want somebody to sort our problems, unless it's something that we just don't know the way forward.
	T2	P14: She treats you like a normal person and I love that... sometimes I'm iffy about telling people straight away that I'm diabetic... sometimes I want to be treated like a normal person...it's almost like they want to be your carer...And you're like no I just want you to be my friend. That's what I absolutely adore about [Friend] because she knows but it's not her first thought about you.
Unhelpful friends	T1	P16: Yes there are friends, but they wouldn't have a clue. They know that blood sugar is high or low, but I don't think they really know... Yes, yes that's right, all you need to do is lose a couple of pounds...They are confused between type 2 and type 1, they don't know. If you lose some weight, you know.
Difficulties making new friends	T3	P15: I suppose the trouble is down in [Area], I didn't have many friends down there I suppose but I suppose that's a bit of a reason why I'm back up here. It's far easier for me to make friends when I already had friends; when I don't have them, it's extremely hard. When you go to university, everyone's in exactly the same situation so it's not a problem but when you're an adult, it doesn't work the same way.

Supportive colleagues	T3	P6: I hadn't really thought about how much they actually are looking out for me until recently. That lady has always been like, "are you OK?", and I hadn't really thought about it and it wasn't until this other colleague then was like, "you are drinking loads", and I thought actually they are quite aware and quite helpful, so in a way they are like a support to me. That's quite good... Even if I'm a bit strange that day they are just like, are you OK? I'm like, yes, it's just me, don't worry.
HCPs	T1	P4: My pump team, though, they're completely different. I love [Dietician]... Exactly, yes, that's what I had with my first ever diabetes nurse, but she was part of a pump clinic as well. She was like [Dietician], basically. She was so supportive and she'd always encourage you and be like, "The thing is, yes, you're going high, but you're correcting it really quickly," and things, or "You're testing so at least you know you're going high and that shows you're putting effort into." That's what you need to hear. You don't want to be told -- That's not going to encourage you... I don't know actually, they have been very helpful, so I'll put them.
	T1	Interviewer: Where would you put them, do you think? In terms of support, would you put them in the centre circle, as quite important in your own healthcare? P9: Yes, definitely, knowing that they're there and particularly the support of [Dietician] and others...she was there straight away, no panic. I'm sure, if I rang them up they would definitely be there... I'd be very confident, number one, they'd respond and number two, they give me good advice and so I'd probably put them quite close.
	T1	P9: They have the, obviously they have the professional expertise but I think the [Area] team also have a good way of making you feel confident and take ownership yourself. They're not too judgemental and they're very much let's find out-- give you the freedom to work out what's going to work for you. So give you the tools and then be there to support you and help you analyze how it's going with their professional--
	T2	P1: I've never called them [the clinic], I've pinged them a couple of emails and I actually sent them a picture of that Libre graph and said, what the hell is going on here? I said what's happening, is this ultra-slow release carbs kicking in at 9pm or is this that my 9pm rate is wrong? ... Between us we came up with a plan, so I said this is what I think might be OK are you OK with this? Good ... Share an image and it arrives on their desk, that's quite clever. So them being able to see that is useful because then they know what the hell you are talking about.
	T2	P2: I think DSN 8 and Dietician 8 with the texting as well it's very easy. It's good. You've got the manual. I think it's fine, I think I've got everything.
	T2	P3: Yes, if you leave messages they'll ring you back. I had to change this appointment, it was supposed to be a couple of weeks ago. I had a lecture and I couldn't miss it and they were really good.
	T2	P5: Well it's good because you know what it's like when it's your life you just go through every day, you don't reflect, it's very good. The last 14 days what do you think happened? Oh, yes. And what happened then? There's no judgement, it's about how would you manage this, so it gives you time for reflection and I think that's the most valuable thing.
	T3	Interviewer: Would you be more confident going to the pump clinic to ask? P11: I've got the feeling that probably they are a bit more experienced

		[than other HCPs]. Maybe they meet a variety of cases with diabetes? I don't know, it's hard to say, I can't really, but when you come and talk to them... I think the other thing is maybe when you meet the team there are usually the dietician and the nurse, so maybe together they can support you from different angles. Maybe that's why you feel more confident coming to them because if there are two of them and both of them give you some advice on different points of view... Yes, because they are kind of supporting each other that's why probably there are two of them.
	T3	P4: Mainly we were talking about the fact that I'm moving home so I need to get transferred to another hospital, so has been really helpful with all of that. She's written a letter to my GP, so they've got all the information about my pump, so I don't have to remember everything because a lot of the time people have just passed on without any information apparently and then it falls on them to remember everything accurately. Yes, so I'm glad she did that, so that was nice. She was positive. I had to fill out a questionnaire and she was trying to, because I was a bit disappointed that my HbA1c hadn't come down even more and she was just like keeping me motivated.
	T3	P3: I don't know actually because they aren't diabetic, are they, but yet they're knowledgeable, they know their stuff and I find them really helpful. The good ones they say, "I don't know what it's like to have diabetes, but this is known to help". (P2)
4. Useful resources when incorporating insulin pump therapy		
4.1 Access to information, social media, peer-support and diabetes technological advancements		
Pump manual	T3	P12: Especially when it's something new like the pump, you get two huge books with it and when my pump was playing up at night I tried going through these books and I was getting so frustrated and upset really because I need to have this sorted now. This can't wait 24 hours or even until morning really. So eventually I did give in and I did ring them.
	T1	P6: Just to know what else there is that maybe I could incorporate in what I'm doing and am I missing something or have I forgotten things because I've had it so long?
	T1	P13: I'd love to know what's going on, what's coming up... When I heard about all these weird and wonderful things going that were supposedly being tested like the Google eye contact lens, which I thought was a brilliant idea and the stem cells, insert them into your kidneys so they could work. I would really like to see more of that happening and all of the weird and wonderful things like that, and you think, "Yes, that'd be good".
	T1	P9: I'm always interested in research. Like with most people- what's coming next.
Need for carb counting	T1	P4: I went to the carb counting groups and things. I like refresher courses because I forget stuff.
Social media and peer-support	T1	P4: Yes, and it's just good to see people trying new things out... It's a big help but it's more just like the comfort of it more than anything, it's not like I'm turning to anyone in the group...because my sister definitely makes me feel isolated.
	T1	P14: It's nice to sort of read stuff —you can tend to search something and find the answer to something off of the post of someone else. It's quite handy.

T1	P12: Talking to somebody who's diabetic is such a help. When I first became diabetic, the nurse they sent me had all the textbook knowledge. It's like "Okay, that's helpful". I don't know why a different nurse came the next time and she said, "I shouldn't tell you this, but I'm diabetic". I said, "That's great". I could ask her all the things that had been going through my mind that I felt I couldn't ask anybody else because they really wouldn't understand what I was feeling. It was so helpful just to be able to talk to this nurse who was diabetic.
T1	P14: I'd quite like to do something with other diabetics that want to lose weight as well. It's so different trying to lose weight with Type 1 diabetes. I've had personal trainers in the past, and they don't get it at all. They're like, "Why are you having juice at this point?" "Well, because I have diabetes" "Yes, but that's going to make you put on weight. "Yes, but I need sugar." "No, you need to quit sugar." "Well, I can't quit sugar."
T2	P7: I'm going to say probably [Pump peer-support group] because it's 24/7, sort of thing. I'm often on there even if I'm not asking questions I just look through it and it's already been asked, so, it's a lot easier.
T2	P4 Maybe [Diabetes peer-support group] into the middle. I've been reading a lot more of their stuff on Facebook and it's quite nice that, well it's good to see people's positive stories because, oh well done, but then it's also good to see that everyone struggles with it on some days. Some days you just can't tell why something is going wrong and it's just irritating so it's not just me... I'm paying more attention to them recently.
T2	P3: I do value them definitely because of the support. The people are on there are all diabetic, they know what it's like, they know the issues that come about and how to solve a problem. That's what I like. People you can talk to who are diabetic and not that are just trained in diabetes. There is a difference between that.
T2	P6: I think it's partly because you have these group, because you start your pump with a group of people so straight away you start hearing about people's back stories and you think, yes, I've experienced that, and you start to think actually yes, you could benefit from speaking to similar people more and obviously because you are all learning a new thing. But I think all diabetics could gain from speaking to others, but I just think when you are on pen you just go to your clinic, get interrogated and then you leave. That was my experience anyway. So it was kind of like diabetes is just a background thing, it was the thing you had and maybe once or twice a non-diabetic person would be like, oh wow what are you doing, and be all interested, and you tell them all about it and that would be that.
T2	P6: I remember when I went to my carb counting that was quite exciting because I then again met more people and was like, oh this is exciting. But then there is no continue on from that, so you are like, oh, OK
T2	P10: That's the other thing as well, I find sometimes people go on these things looking for an answer, but every type 1 diabetic is different as well. Then you get people on it like, oh you said do this, and obviously it's the internet so everybody hides behind their keyboard don't they and start shouting at each other.
T2	P9: Yes, if they can say, yes, actually I did have this problem and I've found that this is really helpful, you might find it helpful. Rather than, oh this is happening, that's happening, I can't do anything, I'm doomed.

	T3	P5: Oh, yes, very useful because it means, well like I said about the people on the course, you get a wider, if you speak to somebody or go on a forum you'll find somebody has done that already. If you were going to Australia and didn't know what to do about your pump you go on there and there will be a lot of people, they will all have dealt with it probably in different ways, but you've got an idea of how they did it and then you decide the way you want to do it yourself.
	T3	P6: Like I said about the whole community thing because it's like you are not the only one and there are loads of other people and look at all these amazing things some people are doing; people do all this cycling and stuff and just, I don't know, I certainly haven't felt alone since I've been on the pump in a weird way.
	T3	P7: Well you go around asking questions and learn new things about it. Like at the conference they said to write all your basal rate is down. I'd never thought of that and I've done it now, but it's that simple what can really help quite a lot.
	T3	P4: Yes, because I use YouTube like when I had complications with the pump when I first got it I used You Tube, so I think it's good they've got lots of explanatory videos about how to set certain things up if I had any other complications. You know sometimes it does those electronic errors and things?
4.2 Activities and apps		
	T1	P3: I do like it. It's good for my mental health. I find if I don't exercise, I'm so, ugh, sluggish
	T1	P16: I love walking, I do know it's great, it's good for the diabetes not having so much insulin. So, I've thought at the moment that it's all beginning to fall into place.
	T2	P3: You do notice when you are not exercising. It helps control I think exercise as well. I don't know how but it does...Especially mentally as well, you feel low don't you when you haven't got the hormones going around.
	T3	P13: I have been down to the Men in Sheds... I: And would you like to do that? MP: Oh, God, yes. Well it was part of my work... So, yes, getting into something like that would be good...Take my mind off everything else... Yes, get into something else... when I told them that I was an electrician they went, oh! Ah! Their eyes lit up. Welcome, come on in. So I thought, OK.
Pump manufacturer helpline	T1	P12: And I think probably, at the moment, not that I've used it; would be [pump helpline]... Maybe they'll be in the outer one because they're just going to be now and then, aren't they?
	T2	P13: Yes, the [Pump manufacturer] Helpline... Because when something does go wrong they are there with an answer.
	T2	P12: Oh, everything. Thank goodness they are there. I don't like calling them, I guess that's because to me it feels as if I'm not coping with my own problem, but I'm very glad that they are there. It gives you some sort of feeling of safety in a way that they are there if you need them. But I do generally like to sort things out myself, however, maybe not with this... And they're so lovely, they're so helpful there. It's not as if they're, oh it's you again.

Reflections on the GENIE intervention		
Concentric circles		
	T1	P1: Concentric circles is quite good in terms of having a visual image of what is happening to you. That's quite reflective. That was quite fun.
	T1	P2: Very weird, because I didn't think I had that many people around me... But then going through it I'm like, "Oh yeah I see that person and can actually tell that person stuff." I realize that I do have quite a good network around me. So yeah, it was very weird, it feels like I've just opened up, everything...But yeah, it's very interesting to see, actually.
	T1	P5: It makes you realize, that actually it's quite a lot of people, it's not like you're relying on one person, but also, as you said, it's the reciprocity of it. They all ask me for help, pretty much. It's not just, like take, take, take.
	T1	P9: I think it's useful, but I'm trying to sort out who is actually supporting me. Actually what is helping me and why. It's not something I've actually tried to analyze like that...I think there's a lot more support out there probably online than I'm-- I think I could be getting a lot more support.
	T1	P11: It was actually giving some idea like, where actually you don't make me think like reflect on where do you work, who you have around, what kind of people, or groups who supports you. It can actually visualize and make you aware of, actually there are some people or some other opportunities to use.
	T2	P5: I did show it to everybody I think, and they were interested to see where they were. I think that might have made [daughter] think oh I'm a bit close perhaps I ought to move out a little bit. I think [daughter 2] went, oh I won't phone you every day then! It's really funny. That's not why I showed them, but I just thought they'd been genuinely interested to see it.
Preference elicitation		
	T1	P2: I think it's all helpful actually because it was really reassuring for me to know the way I perceive people around me and also with the stuff I like doing and guide me to where I can actually do that. To those needs/wants.
	T1	P5: I think it's a good idea because it gives an extra dimension, of trying to find things that might interest you, or might help you. You might google something, but you wouldn't necessarily go, you might say, specifically, where is there Pilates in [Area]. But, it's giving you the bigger picture, of what's available.
	T1	P10: The whole volunteering thing, I've never known where to start kind of thing. That's something I've always wanted to do. I've just never gotten round to it kind of thing. Whereas seeing it there on the screen, I'm like, yes. It's like "Oh." Physically having it standing in front of you is quite nice.
	T2	P6: In the past I was really wanting to join up with either a knitting group or a drama group. I was desperately searching the web trying to find somewhere, but I was kind of, I'm not sure I just want to leap into the unknown. Whereas this feels a bit more safe. It's not just some random people putting things on the Internet.
	T3	P7: It is helpful when obviously I was living in [Area] you could just click on it and see what all the groups were. You could click on the group and find out about the group, what time they are, where they are, even what age range normally go and everything.

	T3	P12: That might be something on there, a list of things that are out there that you could contact should you need to like your local diabetes centre, your local diabetic nurse, a local support group... Like signposting.
Delivering GENIE		
In clinic	T3	P3: I think in the clinics when you come and see everyone is probably if they go through that... I think you are thinking about it then, you are thinking about how you manage it whereas outside you think about here and now. In the clinic you are like what can I do... so if you have a high blood you just correct it and get on with it, whereas here you are like why was that high? When you are in the clinic you think what were you doing that day?
Through local groups	T3	P5: I think probably tapping into the group, so whatever the Diabetes UK local groups are, I think they'd be interested in that and then perhaps do a workshop and say this is the principle and then let people have the opportunity to have a go and log in themselves.
Drop-in to GENIE	T3	P5: And probably somewhere like the hospital if there was something like a drop-in and not just for pump clinics but to actually, so say for the diabetic clinic in wherever say well every, if you run every Tuesday then every second Tuesday so-and-so is going to come in, if you are interested in seeing this she will be there to ask questions. That kind of thing.

^A T1 - Baseline, ^B T2 - 3 months on, ^C T3 – 6 months on

Chapter 8 Discussion and conclusion

8.1 Chapter introduction

This thesis aimed to further understand the process of incorporating an insulin pump for people living with T1D, and propose a means to support them to manage during the course of incorporation and thereafter. The research presented in this thesis makes a novel contribution to a rapidly growing focus on the SM needs of people with T1D using new technologies and ways to support them to manage their diabetes better. It extends the understanding of the process of incorporating an intimate (worn 24/7) new health technology, the SM needs people with T1D have during this process, the mechanisms by which people need support to self-manage and how this changes over time. Finally, this thesis proposes a pragmatic, acceptable and novel way to support these SM needs in ways which complement and supplement health service provision, largely through utilising and renegotiating new and existing social network members in the community of the individual as well as voluntary and community organisations. This chapter will provide a summary of the key findings presented within the previous thesis chapters; these findings will then be discussed in the context of the previous literature. In addition, the implications of the findings at will be explored followed by the limitations of the body of work within this thesis and finally, scope for future research will be discussed.

8.2 Key findings

8.2.1 Paper 1: The process of incorporating insulin pumps into the everyday lives of people with Type 1 diabetes: A critical interpretive synthesis

The aim of Paper 1 was to critically examine and to understand what is already known about the lived experience of pump therapy. The systematic review and CIS identified a wealth of data of the process of incorporating an insulin pump in children, adolescents, young adults and adults with T1D; a total of 22 relevant published articles were uncovered which examined this process from the perspectives of people with T1D, parents and healthcare professionals. A number of key findings were identified with respect to the process of incorporation, specifically that while these devices represent technical progress and present many benefits, there are also complex issues to consider. For example, there is a potential encumbrance on self-care when balancing the demands of a technologically-advanced, intensified, regimen. There is, as a result, an initial liminality upon introduction to pump therapy, and a heightened bodily awareness. It became evident that there may be stark differences between expectations of what the technology is able

to do, and subsequent experiences of the technology. The technology can be overwhelming for the user but a process of negotiation of responsibility, and access to support from health care professionals, friends and family can be beneficial. It takes time, motivation and confidence for the technology to become a normal part of life. This was found to be made easier by a process of reflection, supported experimentation with the new technology and feedback with members of the users support network.

There is an initial liminality upon introduction to a complex new technology such as an insulin pump. The machine is a foreign object, and upon introduction users are on the edge of something new. People living with diabetes have an experiential knowledge of diabetes, but then have to go through a ritual to grasp new practices and the knowledge to understand it. If this is done in isolation then it is harder to move through to adaptation and incorporation. The more the user feels accustomed to it, and the more support they have to do this then the easier it can be incorporated. Initially the user wonders what the device is doing, and there is doubt about whether the machine, or the person (from the perspective of a significant other), is reliable. There is uncertainty. The previous technology required needles, a very physical interaction, whereas the pump is more integrated into the body. Understanding this can reduce expectations of a simple process to follow or straightforward set of rules to gain control over blood glucose levels. It is understood to be a difficult task which requires constant negotiations with insulin (Tullman 2013). A key concept from the review was the idea of being subjected to insulin pump therapy versus feelings of being empowered by it. There was a general feeling throughout the papers about the person with T1D being the operator, and being empowered by access to support and resources which enable them to have more capacity to take control of their disease, as well as the pump itself with its new possibilities.

The results of Paper 1 provides a backdrop of what the process is relating to incorporation of an insulin pump. With these key findings the rationale for Stage 2 was formed, providing the next stage for an intervention which could be used to support people with T1D to self-manage and incorporate this device.

8.2.2 Paper 2: Integrating self-management needs and theory to implement a web-based self-management tool for people with Type 1 diabetes using an insulin pump

The aim of Paper 2 was to provide a comprehensive needs assessment of people with T1D using an insulin pump and specialist HCPs to optimise a web-based social network intervention to support SM and determine what behaviour change characteristics and strategies are required.

The focus groups identified that insulin pump users were eager for access to flexible and varied resources according to their own need and not to be restricted by HCPs as to what they “should” and “shouldn’t” access. These resources and support should be situational, contextual and vary according to time and life circumstances of the individual concerned. Specific social-support preferences were outlined, which centred around taking away isolation and contact with others living with T1D for shared learnings and practical tips. It was common for aspirations to be voiced about providing a social network intervention which would allow registration of particular interests such as a local T1D specific running group to address unmet needs in how to exercise with T1D and with or without a pump. The environmental context was important, such as the capacity and knowledge of insulin pump clinic HCPs. HCPs were enthusiastic and interested in innovative ways for their patients to access holistic, emotional and practical support and were encouraging of additional ways to supplement NHS support of diabetes management, especially outside of clinic hours, however, HCPs expressed not having capacity in their clinic to amend their routine care. Professional responsibility in relation to perceived risks and dangers became apparent where social support was considered important in relation to reducing the burden of T1D, but concerns were raised by HCPs over the potential for peers to “give bad advice”. The use of behavioural theory provided a comprehensive framework to identify these key barriers and facilitators of managing T1D and to propose the elements within an intervention which would address them. A social network tool such as GENIE appeared to address some of the key desires and issues raised, offering the potential to provide SM support which compliments and addresses key SM needs which are not currently provided within the NHS. Areas for further consideration included HCP apprehensions over professional-responsibility (and fallout) when signposting to outside agencies or support and opportunistic features of a SM tool to include the ability to actively engage with other people living with diabetes.

The results of Paper 2 inform the key mechanisms of a potential intervention to support SM of T1D when incorporating an insulin pump and the key resources and information over the initial 6 months of incorporation.

8.2.3 Paper 3: A novel exploration of the support needs of people initiating insulin pump therapy using a social-network approach: A longitudinal mixed-methods study

The aim of Paper 3 was to establish what practical and emotional means of support are required upon initiation of insulin pump therapy and how needs change over time using GENIE, a social network intervention, and whether such an intervention was deemed useful.

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Implementation of GENIE at insulin pump initiation was shown to increase the number, frequency of contact and value of network members over time from baseline to 6 months. There were a total of n=94 new activities reported (a mean of 5.88 activity per participant). Concentric circles revealed a wide variety of network members including family members, pets, friends, colleagues, employers, groups and HCPs. Thinking about network support was described as a novel task. Many participants articulated how they have to manage diabetes for and by themselves, and try to “stay positive” and “not think about bad things”. They also described feeling undermined by others and an unwillingness to ask for help from others. However, interviews revealed the complexity and nuances of social relationships and pump incorporation experiences and four key themes were identified; 1) The independent nature of managing diabetes, 2) Overcoming the challenges and illness-burden of insulin pump therapy, 3) The need for responsive and tailored emotional and practical support, and 4) Useful resources when incorporating an insulin pump. There was a particular preference for partners and mothers for SM support, where partners provided both illness, everyday and emotional work and mother mostly emotional work. However, while partners were seen more frequently and offered more types of “work”, mothers were valued nearly equally, demonstrating the sustainability and value of these kinds of enduring relationships. While partners were the closest sources of support, single participants relied more heavily on close friends and other family members. Single participants were especially concerned over safety with hypoglycaemia, especially at night, and support from loved ones could be negative and critical. The majority of HCP type network members were insulin pump clinic HCPs, which received a relatively low frequency of contact vs value (low contact yet highly valued). Insulin pump therapy was described as a learning process with much negotiation. Over 6 months there was much trial, error, increased knowledge, growing confidence, practical solutions or coming to terms with not having a perfect resolution. Former HCPs were cited as unhelpful, judgemental, and critical, in contrast the current pump clinic were thought to appreciate participant capabilities with non-judgemental, consistent and easy to access support. There appears to be a return on investment for the non-judgemental, accessible SM support and education given by the pump clinic. Specialist clinic support at the onset provided reassurance and skills, which enabled participants to self-manage more confidently. In addition, participants wanted access to up-to-date developments in diabetes and technology. Information, support and tips were sought and desired from a variety of sources (manual, helpline, social media, apps), and peer-support which was desirable for practical and emotional support, providing a uniqueness of knowledge.

Most participants reported the usefulness of visual reflection of their support network leading to re-evaluation of network members and reconsideration of support received, and personalised

access to resources. Over the time of incorporation the levels of distress decreased, as did HbA1c (glycaemic control) and levels of hypoglycaemia awareness increased slightly.

8.3 General discussion

This PhD work sits within the ‘Engagement with self-directed support’ research and implementation theme of the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) in Wessex. The aims of the research group are to better understand the mechanisms that allow individuals to benefit from their social networks and links to community resources to support engagement with condition management; and in doing so, improving access to community resources. The projects within this theme are supported by a body of research that demonstrate the social context of long-term condition SM and more specifically, the role of others in shaping and supporting SM practices (Rogers et al. 2011; Vassilev et al. 2011; Vassilev et al. 2013; Reeves et al. 2014; Allen et al. 2016; Kennedy et al. 2016; Koetsenruijter et al. 2016; Vassilev et al. 2016; Allen et al. 2018; Walker et al. 2018; Band et al. 2019). This PhD research extends the work of the ‘Engagement with self-directed support’ research and implementation theme to support SM practices of people living with Type 1 diabetes and incorporating a new health technology, especially in terms of the role of social support networks and why traditional methods of SM support in T1D (“structured education”) (Campbell et al. 2018) might not be the only or most effective way to support SM. This work delves deeper by providing comprehension on the process of incorporation of an insulin pump, the distinct mechanisms of SM needs in the process of incorporation and the relational components and role of social support networks.

Work has been undertaken in this area from prominent authors such as Professor Julia Lawton, Dr David Rankin, Professor Katharine Barnard-Kelly, and Professor Fiona Campbell. Examples of this work include explorations of the impact of peers on diabetes SM (Rankin et al. 2014; Rankin et al. 2018) the role of HCPs as gatekeepers (Lawton et al. 2016) and need for appropriate training for HCPs to provide psychosocial and SM support (Campbell et al. 2018), as well as the hopes and expectations of new technology in managing diabetes and the impact of new technology on family members (Barnard et al. 2014b; Barnard et al. 2016; Garza et al. 2018). Further, parents experience of managing their child’s diabetes (Lawton et al. 2015a; Rankin et al. 2015; Lawton et al. 2018), parent’s support and information needs (Rankin et al. 2016), as well as communication needs between parents and caregivers of children and healthcare professionals (Lawton et al. 2015b; Campbell et al. 2018). This field of research in diabetes also explores the impact of

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emerging diabetes technologies on intimacy with partners and the complexities of these close relationships (Barnard et al. 2016; Garza et al. 2019). This thesis demonstrates an extension of the research which is already taking place around the impact, needs and support provided by particular network members by exploring how to harness appropriate SM support for people with T1D, especially those incorporating a complex new health technology. It also provides a different focus, bringing together this other dispersed research by considering how the individual within these personal communities engages with and negotiates support with and between their network members and resources, rather than viewing each relationship separately and essentially out of context of the whole network of support.

The findings outlined in this thesis demonstrate that potential benefits for quality of life of insulin pump therapy (such as increased flexibility, independence, and dietary freedom) can be outweighed by the additional burdens of pump therapy (including need for frequent monitoring of blood glucose, continual physical attachment to the device, and perceived restrictions to activities such as swimming and sexual intimacy). While some may view insulin pumps as the gold standard for optimal SM and opportunities in the future (closed loop systems more akin to a fully-functioning pancreas), there is more than meets the eye in terms of integration and adaptation. People with diabetes demonstrated motivation and desire to manage their diabetes themselves, and acquire capabilities to do so, but there was also evidence of engaging with the network of people, objects and resources around them to support SM during adaptation to a new health technology.

Further, there are consistent and complimentary findings from Paper 1, 2 and 3 which implicate the need for support, information and resource from a range of sources throughout new technology incorporation, and that this needs to be personalised to the individual. Paper 1 structured the process of incorporation, while Paper 2 identified the mechanisms for SM and incorporation according to motivational elements, capability to undertake tasks and practises and opportunity to do so, while offering specific intervention requirements to address these, while Paper 3 provided an in-depth exploration of this incorporation over time, the nuanced relational work that occurs and also examined whether GENIE was an acceptable method to offer SM support. This is an important finding clinically; SM of T1D is deemed crucial for preventing complications (Reddy et al. 2016), and yet the vast majority of people with T1D are attaining clinical outcomes which put them at high risk (NHS Digital 2019), as well as a distinct proportion of people with T1D suffering from diabetes distress and illness burden, which also affects these outcomes (Pallayova and Taheri 2014; Hessler et al. 2017; Powers et al. 2017) and yet is not being addressed (Wylie et al. 2019).

The main method of SM support provided through the NHS and other international health institutions has been utilisation of structured education programmes (Haas et al. 2012; National Institute for Health and Care Excellence 2015; Reddy et al. 2016), although these are not currently providing the SM support that they set out to . In addition, there is a process of “education” that usually occurs before and during the introduction to insulin pump therapy in order to support incorporation. However, reviewing the evidence for the process of incorporation suggests that this education does not mean the process is simple or easy (Reidy et al. 2018). Exploring the nuances of what the process is this seems especially pertinent when medical “advice” continues to be commonly provided by ‘expert’ doctors in didactic consultations to patients rather than through collaboration with patients and evaluation of patients’ personal needs and barriers. Traditionally, HCPs put people with diabetes in a passive position, offering a professional dominance, however, people with T1D have an esoteric knowledge which challenges professional dominance. HCPs can be gatekeepers or facilitators to improving SM and yet this PhD work demonstrates that the person with T1D benefits from a collaborative approach that supports them to be equipped to manage day-to-day.

GENIE offered a positive disruption to SM through novel considerations of network members and how they impacted on SM. The pump also offered positive disruption through providing a new approach to managing diabetes; suddenly there was a reason or a potential to try new techniques which could provide a particularly opportune time to introduce an intervention to support SM – when the participant is particularly motivated to make specific behavioural changes and take on new skills and knowledge. However, the machine created increased illness-work and burden for new insulin pump users which required increased practical and emotional support and reassurance.

Undertaking GENIE incited conversations about various elements of living with diabetes and this new machine, what they were and were not interested in and what support they did or did not have and what they wanted to help them manage, and why. The reflective and visual nature of the task helped understanding of the key relational components missing from former work in this area. GENIE enabled re-evaluation of current contacts, and reconsideration of how they support the individual.

8.3.1 Implications

This thesis and the papers within it have shown that a limited comprehension of important psychosocial factors in insulin therapy using insulin pump therapy restricts our insight into the factors that enable someone to successfully incorporate and integrate this more advanced

method of SM in T1D, both practically and psychosocially. Where these factors have been explored they have been explored in isolation and not consolidated to construct a whole picture of the lived experience and incorporation of this new technology. In general, most of the research focuses on the biomedical outcomes of moving from multiple daily injections to insulin pump therapy, or a superficial exploration of the lived experience using a crude measurement of Quality of Life, which also has no clear definition in itself (Hirose et al. 2012). This body of work offered the opportunity to explore the network and resources around people in the process of incorporating the device. It was evident that utilising a new health technology requires specific skills, understanding, confidence, motivation and opportunity. This work established that HCPs need to accept patient priorities and means of information and advocacy rather than blocking their access, and also appreciating the lived experiences of their patients. It was apparent that people with T1D turn to their assigned HCPs for appropriate information and support when they felt listened to, and when accessible. Reaching out for support is not taken lightly either – suggesting appropriate and sustainable health service utilisation when HCP support is considered useful. People would utilise their support networks for information and practical resource, such as attending appointments with loved ones to hold more valuable illness-related information, or consulting peers for practical tips for exercising and wearing the device. This is consistent with Vassilev et al.'s (Vassilev et al. 2014) findings within a meta-synthesis on the role of collective efficacy in the management of long-term conditions, that networks can enable and improve sustained SM practices, and help changes in behaviour to improve management.

This work adds to those studies that highlight the difficulties of the traditional method of HCPs using patient characteristics to predict clinical success with insulin pump therapy (Lawton et al. 2016), and as a result limiting opportunities for those patients to navigate incorporating a potentially important means to manage their diabetes. This work highlights that while a person with diabetes would ideally need to be engaged and motivated to take on the new tasks associated with a new health technology, they also need to be supported, have access to various resources and know who and where to ask for help and support. In addition, this support needs to be accessible and according to personal preference (online, in clinic, with peers etc.). Insulin pumps evidentially present as a more complex regimen to execute than multiple daily injections in consideration of the technical and diverse features, as well as the physical positioning and impact on diabetes-related identity. As well as the acknowledged need for comprehensive education and skills training to help ensure that individuals can use the technology to optimal effect (Lawton et al. 2016; Campbell et al. 2018), this PhD work has identified that utilisation and negotiation of personal social support networks and linking into resources to help self-manage in a way that fits with personal values are important factors in incorporation. Assessment of the

support surrounding patients and their families to help anticipate and mitigate the impact of the SM challenges could provide more comprehensive and effective support for both psychosocial and physical health outcomes, especially for those from more disadvantaged groups.

The future of insulin pumps appears to lie in closed-loop technology, also known as an artificial pancreas, where the user also wears a continuous glucose monitor (CGM) which feeds back into the insulin pump and makes corrections based on live fed information from the CGM with a sophisticated computer algorithm to manage dosing (Galderisi and Sherr 2018). The pump and its incorporation is an initial step towards this highly anticipated (and increasingly more realistic) further technological development. This PhD work is relevant for how people incorporate new technology, and is especially relevant considering where the technology is headed. The findings demonstrate that social network members and access to personalised and tailored resources which take into account the individual's social and environmental context have an important part to play in the integration, incorporation and adaptation of an advanced health technology in self-managing T1D.

8.3.2 Limitations and further research

Whilst the papers in this thesis have made an original contribution to the research literature, there are notable limitations. These have been discussed in the included papers and for clarity will only be briefly returned to here especially in consideration of wider limitations of the body of work as a whole, in view of setting the course for future research.

When examining qualitative results around SM and lived experience of a long-term-condition, and the general subjective focus of the work, it is important to take into account the idea of 'response shift bias.' Response shift relates to the self-evaluation of these experiences; it is essentially the tendency for people with chronic disease to express their lives with a long-term-condition more positively or be more accommodating towards or about their illness, despite the related hardships imposed on them (Schwartz et al. 2007). Participants here may have adapted their understanding of their lives based on a worse-case-scenario version of their health and that in contrast, taking into account the levels of positivity and negativity, a chronic illness-based quality of life standard. Their responses and reflections may represent this balance, and so responses may not be representative of the whole experience of incorporation of insulin pump therapy, and did not capture their needs at moments of crisis or grave concern. As a result, some needs at these crisis points will not have been accounted for or addressed within this research. Instead this research can be considered as a contribution to the needs of SM support on a day-to-day level and not all-encompassing or a one-size-fits-all model.

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However, most current research on T1D insulin therapy and integration of technology focuses on biomedical outcomes, such as HbA1c improvements comparing insulin pumps to traditional multiple daily injections, which ignores the evidence that people do not purely make decisions about adopting and using new health technologies based on objective benefits. This stresses the need for systematically studying and understanding people's subjective reactions to new technologies, especially technologies that are designed to support people to self-manage, and while the needs at crisis points have not necessarily been captured in full, this focus on the subjective and day-to-day needs presents a novel avenue and one which can contribute to wider psychosocial and/or biomedical health outcomes in a way that compliments current NHS care.

It should also be acknowledged that there was a limited time period of follow-up for people initiating insulin pump therapy in the 3rd stage of this PhD work, which was set to 6 months. It was understood that adaptation to a new technology in the context of a long-term-condition does not finish there, by any means, but the decision was made to focus on the most intensive period, and to capture this process in depth, however, adaptation keeps going and thus the implications for the work bears this important consideration in mind.

The Autoethnography highlighted a lack of exploration around intimate issues in this body of work, which were mentioned briefly in the systematic review (Reidy et al. 2018) but not addressed in focus groups or interviews with people with T1D. However, sexual health and intimacy in diabetes is something which has been highlighted as an area where there is a need for more support, understanding and resources (Barnard-Kelly et al. 2019a; Barnard-Kelly et al. 2019b). It was not in the scope of this work to focus on particular elements of intimacy, and rather on the process of incorporation as a whole, although future work would benefit from specifically and sensitively examining this overlook yet valuable element of living with T1D and wearing a new device 24/7.

While recruitment of insulin pump users and HCPs from a range of clinics in different settings represented variability between local health systems, it did create extra burden and work on the researcher and delays in terms of local R&D approvals, integrating the research concept in each clinic, recruitment and implementation. A flexible approach was undertaken within each context but this was costly on time. A relationship had to be maintained between each clinic and required much effort in the busy NHS clinics. Some clinics were more set up for research involvement than others and these did impact on the timescale of the studies. As a result some clinics had more opportunity to recruit and there was an imbalance of recruitment with n=15 of the n=16 participants in Stage 3 coming from two localities rather than all four. It should also be noted that the supportive clinics which recruited participants for Stage 3 do not seem to represent the

majority of diabetes clinics where there are national (and international) concerns around the effectiveness and appropriateness of communication methods and approaches in the delivery of diabetes healthcare (Snow et al. 2013; Byrne et al. 2017; Lloyd et al. 2018). However this work provided a model of good practice rather than simply focusing on what is not working. The research undertaken in Stage 2 (focus groups) helped to provide a balance with these best practice clinics whereby participants were from a variety of other clinics, not just those with appropriate and effective communication methods and approaches. This meant that key barriers for clinics to comprehend and engage in a more holistic and system-wide approach to SM support were identified and these perspectives were considered when developing and adapting the intervention for Stage 3.

The content of the intervention was also found to be as valuable as the setting where it takes place. For example, focus groups in Stage 2 identified a desire for easy access to GENIE in the form of an app, and access without a facilitator, which is currently particularly popular in SM support (Jimenez et al. 2019). A work around might involve an initial introduction to GENIE face-to-face and then access remotely via an app, although further work would need to test whether the app was still deemed as useful in this instance. Future work would also benefit from piloting GENIE in a range of clinics with these intervention elements in place to support quality improvement on a larger scale, with a focus on spreading successful sustained implementations across diverse settings.

With GENIE being acceptable to people with T1D incorporating a complex new technology, and ensuring quality improvement of SM support, future work should, therefore, focus on piloting and then trialling GENIE to see whether these effects can be scaled up and with more diverse and disadvantaged populations. NHS England's Long Term Plan (NHS England 2019a) proposes expanded provision of SM support tools for people with diabetes, as well as widening access to e-health. Fortunately, social prescribing is also part of this Long Term Plan and as a result Primary care networks, announced as part of the 2019 GP contract, will be funded to employ one social prescriber each from 2019 (Marmot 2008). A "social prescription" is a referral to an activity in the community, which are typically provided by the local voluntary and community sectors. This is known as social prescribing. The Plan states that nearly 1,000,000 people will qualify for referral to social prescribing schemes by 2023-24 (NHS England 2019a). Social prescribing has also attracted interest in North America (Gottlieb et al. 2017), Australia (Australian Government 2013), and Scandinavia (Jensen et al. 2017). However, the accompanying Implementation Plan suggest that further knowledge is needed to identify who is most likely to benefit from social prescribing and what interventions are most cost effective (Drinkwater et al. 2019). This Social Prescriber

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(who could be a community development worker, wellbeing coordinator, social prescribing coordinator) would hold detailed knowledge of local organisations, services and support.

The Long-Term-Plan and associated Implementation Process Plan proposes increases in the use of volunteering across local health and care services, as well as providing funding to facilitate this to support identification, integration and growth of volunteering networks, especially when these are targeted or benefitting areas of deprivation. In terms of facilitators for GENIE, volunteers could provide both an effective and sustainable workforce. Glazier et al.'s (Glazier et al. 2006) systematic review on interventions to improve diabetes self-care found that lay intervention facilitators, a focus on behaviour-related tasks, provision of feedback, a focus wider than diabetes and tailoring of an intervention were all key features in successful outcomes for socially disadvantaged populations.

Implementation may benefit from utilising 'peer support workers' as facilitators of GENIE based on the value provided through peer-support – especially face-to-face experiences, and past research. Studies have shown that peers as coaches are an acceptable and qualitatively beneficial intervention for both volunteers and participants (Joseph et al. 2001). Peer facilitation offers a combination of peer support but also informational, instrumental and emotional support, whilst providing a bridge between patients and the health care system (Funnell 2010). Peer-support can fill the gap where health care professionals are not equipped to deal with the personalised educational and/or behavioural and psychosocial support needed to manage Type 1 diabetes, whether that be through lack of time, priority, understanding or confidence on the part of the healthcare professional to address non-biomedical matters (Funnell 2010). With training and support in utilising established communication and behavioural strategies (e.g. preference elicitation, goal setting), peers could potentially provide cost-effective, pragmatic and beneficial facilitation. (Funnell 2010). For example, Small et al. (Small et al. 2013) found that telephone SM support interventions that were delivered by lay and peer support workers significantly improved HbA1c level and SM behaviours.. In addition, studies have shown that peers as coaches are an acceptable and qualitatively beneficial intervention for both volunteers and participants (Joseph et al. 2001). Interestingly, interventions that are delivered by community educators or lay people also appear to have the most positive effects on people with diabetes from socially disadvantaged populations (Glazier et al. 2006). Chapin et al. (Chapin et al. 2013) piloted a face-to-face peer support intervention which improved depression and quality of life for health and functioning. They also found that it was feasible to implement the intervention through peer-facilitators with minimal resources and technical assistance. Buman et al. (Buman et al. 2011) found that trained peers can also be successful in improving maintenance of physical activity, delivered through the community.

Peer facilitation of a web-based SM intervention could offer a combination of perceived or actual accessibility and relatability, while providing informational, instrumental and emotional support. However the mechanisms for which peer-facilitators may be effective in implementing a SM intervention are not yet known, which implicate the need for further research. The author proposes taking this research forward through exploring whether peer-facilitators are an effective and acceptable means to deliver a SM support intervention such as GENIE by undertaking a critical realist review of when peer-facilitation of interventions have been utilised in diabetes, who it has worked for, how it has been undertaken, and in what context. This could determine the potential for peer-facilitation of GENIE, the outcomes for participants and peer-facilitators, what settings would be best to implement peer-facilitators and the training needs of peer-facilitators. This review will inform future work developing peers as facilitators of the GENIE intervention in the form of a pilot feasibility RCT.

8.3.3 Conclusion

This thesis has made a novel contribution to the field through providing an in-depth exploration into a hidden and under-utilised approach to support people with T1D who are incorporating a health technology. SM and social support of people with diabetes has been explored on many occasions, although largely in respect to Type 2 diabetes and largely without consideration of a change in treatment (such as introduction of a new technology). This PhD work has illuminated the nuances and process of incorporation of a complex device. The SM needs and relationships required in this process have proven to be complex and multifaceted. Exploration of HCP views in contrast with patient views have provided a fuller and more useful context to consider the barriers and facilitators of an intervention which encourages and champions a system-wide approach to SM support than simply examining patient and HCP views in isolation. For example, HCPs express more “meso” concerns of in terms of striving for improvement in the quality of care in a context of fear of professional responsibility and lack of training and capability to provide psychosocial care of the people attending their service as patients. While patients express their individual needs and how their social support and access to resources impacts on their ability to self-manage. This research has provided the mechanisms of how these networks support SM, when they are considered supportive and why. Utilisation of social cognitive theory combined with a social network focus allows us to reflect on the nature of these relationships in a much broader way. In this instance taking a social network approach through the intervention GENIE has provided a catalyst or mechanism leading to change on a cognitive level for participants. GENIE enabled engagement in a wider range of activities, connection to more diverse and valued support networks, increase in social capital and novel reflection on the place that network

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members have in personal SM when integrating a complex new technology. Providing a gateway and an exemplar to help patients with long term conditions navigate a means to support and resources to (more) smoothly incorporate new technologies into their lives and could, ultimately, improve the quality of care received by people with a long-term-condition by means of appropriate SM support.

Appendix A Paper: Commissioning of self-management support for people with long-term conditions: an exploration of commissioning aspirations and processes

Authors: Claire Reidy, Anne Kennedy, Catherine Pope, Claire Ballinger, Ivo Vassilev, Anne Rogers

Abstract

Objectives: To explore how self-management support (SMS) is considered and conceptualised by Clinical Commissioning Groups (CCGs) and whether this is reflected in strategic planning and commissioning. SMS is an essential element of long-term condition management and CCGs are responsible for commissioning services that are coordinated, integrated and link into patient's everyday lives. This focus provides a good test and exemplar for how commissioners communicate with their local population to find out what they need.

Design: A multisite, quasi-ethnographic exploration of 9 CCGs.

Setting: National Health Service (NHS) CCGs in southern England, representing varied socioeconomic status, practice sizes and rural and urban areas.

Data collection/analysis: Content analysis of CCG forward plans for mention of SMS. Semi-structured interviews with commissioners (n=10) explored understanding of SMS and analysed thematically. The practice of commissioning explored through the observations of Service User Researchers (n=5) attending Governing Body meetings (n=10, 30 hours).

Results: Observations illuminate the relative absence of SMS and gateways to active engagement with patient and public voices. Content analysis of plans point to tensions between local aspirations and those identified by NHS England for empowering patients by enhancing SMS services ('person-centred', whole systems). Interview data highlight disparities in the process of translating the forward plans into practice. Commissioners reference SMS as a priority yet details of local initiatives are notably absent with austerity (cost-containment) and nationally measured biomedical outcomes taking precedence.

Conclusions: Commissioners conceptualise locally sensitive SMS as a means to improve health and reduce service use, but structural and financial constraints result in prioritisation of nationally driven outcome measures and payments relating to biomedical targets. Ultimately, there is little evidence of local needs driving SMS in CCGs. CCGs need to focus more on early strategic planning of lay involvement to provide an avenue for genuine engagement, so that support can be provided for communities and individuals in a way people will engage with.

Strengths and limitations of this study

- As a study taking place 14 months on from the establishment of Clinical Commissioning Groups (CCGs), it provides a snapshot of how these organisations commission SMS at a time of flux and change.
- This quasi-ethnographic approach uses data from a number of sources: documentary analysis, interviews and observation, which enhances the strength of the findings, (although it is relevant to note that some data were missing from some sites).
- Exploring the public-facing messages and descriptions that CCGs portray about self-management and aligning this with the experience of CCG Governing Body meetings which occur 'in public' allow for a novel demonstration of how the message that is given to the public plays out in practice.
- The work was undertaken in one region and therefore may have limitations in terms of typicality and representation of the full range of variation in all English CCGs.

Introduction

This study seeks to explore how self-management support (SMS) is being understood and made available to patients through local commissioning. In 2013, Clinical Commissioning Groups (CCGs) were created by the Health and Social Care Act 2012 (HSCA12) reforms that were intended to bring decision-making closer to the front line. SMS has been declared a priority as an essential element of integrated systems of support for long-term conditions (NHS Commissioning Board 2012; Coulter et al. 2013; Naylor et al. 2015) and a means of achieving cost-containment. SMS that involves the actions and activities of patients themselves has been linked to a health service agenda of more inclusive patient and public involvement (PPI) (Wanless 2002), an ethos which is also reflected in the new guidance of how CCGs should operate (NHS England; Coulter et al. 2013; NHS England 2015a). Thus, the extent of engagement and participation of patients and the public

in CCGs is a good indicator of the extent to which CCGs are progressing with a SMS agenda and makes it different from other areas of commissioning, because patient actions are a central element to the success of implementing local SMS strategies and interventions. The focus of the study reported here explores how SMS has been conceptualised by commissioners, how this commitment works through into practice (in terms of decisions made by CCG Governing Bodies and commissioners), and to what extent commissioning decisions are made through engagement with patients and the public (as a means to develop locally appropriate services).

SMS constitutes one of the top 10 priorities for transforming the healthcare system (Naylor et al. 2015). SMS is one means through which health and social care services can enable people to take 'better care' of themselves (Department of Health 2005) and encourages the assumption of responsibility by individuals for making decisions to optimise health and well-being. SMS traditionally involves increasing the capacity, confidence and efficacy of the individual to self-manage by providing a range of options. Self-management (SM) for long-term condition includes the actions and resources people use to meet physical, social, emotional and psychological needs, which affects: response to symptoms; effective working with health professionals and mobilisation of community resources. SMS has been viewed as necessary for; improving health outcomes, ensuring appropriate utilisation of services, increasing patient confidence, reducing anxiety, reducing unplanned admissions, improving medication and treatment adherence and reducing health systems cost (Stearns et al. 2000; Challis et al. 2010; Purdy 2010; Panagioti et al. 2014). The SMS schemes, which have been developed and implemented in the UK over the past 20 years, view the patient as the expert in their condition (e.g., The Expert Patients Programme) (Department of Health 2001) and the ethos of patient's voice and choice is evident in the development of recent provision, which has included: new technologies, patient information provision, skills training, support from health professionals and the promotion of the mobilisation of resources from personal support networks (Department of Health 2012c; Coulter et al. 2013; Kennedy et al. 2014; Marent et al. 2015; NHS England 2015a, b).

The commissioning process, integrated care and why SMS is a priority

To date, there has been little research attention paid specifically to the new commissioning arrangements for how the principles of SMS provision have been translated into practice by commissioning bodies, with previous research largely focusing on the organisation of commissioning arrangements and the attendant contracting and transactional processes (Checkland et al. 2013; Hughes et al. 2013; Porter et al. 2013; Shaw et al. 2013; Petsoulas et al. 2014; Wye et al. 2015). CCGs are scrutinised and monitored as commissioners of health provision

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in England, with the intention of extending their remit to jointly commission social care alongside local authorities under the governments' integrated care agenda. National Health Service (NHS) England, the national body who oversees the NHS budget, has celebrated the integrated care agenda as a 'person-centred', whole-system approach of collaborative working and aligning resources to help people self-manage more effectively at a time of fiscal restraint in the NHS (NHS England 2015a). Integrated care has been considered by NHS England as integral to the change and adaptation needed to meet the future challenges of a growing population living with long-term conditions with; patient led commissioning, increased choice and personalised care as central to this change (Department of Health 2005; NHS Finance 2009; Department of Health 2012a; Coulter et al. 2013; Foot et al. 2014; Panagioti et al. 2014). One of the means by which NHS England has championed integrated care is through creating Vanguard sites; healthcare providers chosen to support improvement and integration of services, with the aim of providing inspiration to the rest of the health and care system. Such sites are supported financially and practically through NHS England (NHS England 2015b). Integrated care for people with long-term conditions is intended as a focus of those responsible for commissioning services, and with it increasing attention has been placed on maximising the potential of SMS as a way to use NHS resources more efficiently while demand for healthcare is rising. The Wanless report into NHS resource requirements identified effective SMS as an essential part of the 'fully engaged' scenario, which it predicted would bring about the greatest gains in public health for the least cost and this has been reinforced in subsequent policymaking with regard to long-term condition management (Wanless 2002, 2004).

However, effective long-term condition management requires SMS that can be built into everyday life. This relies on considering the patient's social and cultural background as it is from this background that patients interpret and act on decisions about their treatment and recovery (Marent et al. 2015). Thus, CCGs are encouraged by NHS England to use the 'House of Care' model (Figure 1) (Coulter et al. 2013), which represents a move away from the traditional 'Medical' model of health service provision and focuses instead on the integration of service users' experiences and resources. This has been seen as a way of re-distributing burden on the health services by managing the gap between the supply of health services and the demand from patients ('demand management') (Chapple and Rogers 1999). However, a crude focus on 'demand management' can sit in tension with involving patients and the public as partners in care; a lack of sensitivity to how patients use information, what information they need and the mechanisms and support they personally require to enable them to look after themselves could lead to ineffective SMS interventions being implemented. Imison and Gregory (Imison and Gregory 2010) suggest that it would be unwise to solely focus on 'demand management' and rather this should be seen

as part of a wider strategy for maximising value from the NHS budget while focusing more on enabling patients to make informed decisions by maximising shared decision-making and utilising patient feedback measures. Effective SMS, therefore, requires listening to the patient voice, to avoid services being implemented that do not actually meet the needs of patients. Although, how much local commissioners are actually listening to the patient voice is unknown.

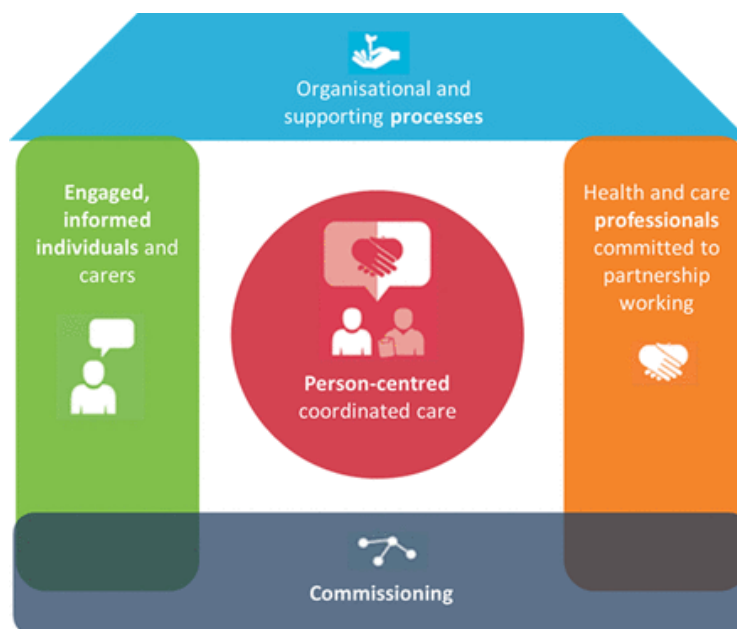


Figure 1: The House of Care Model (NHS England).

Engaging the patient and public voice: commissioning personalised care

The 'no decision about me without me' commitment from the government (Department of Health 2012c) is focused on shared decision-making, and pathways for patients and the public to influence commissioning decisions are a key part of the intended process. But, while PPI is seen as needing to be represented in policymaking and the operationalisation of SMS (Marent et al. 2015), it is unclear how this is perceived and acted on in the commissioning deliberations and decisions of CCGs. SMS relates directly to the need for services to be tailored to the patient and, thus, if decisions about such services are made without genuine collaboration with patients and the public, then services are likely to add to failed SMS services that have gone before them. In supporting people to participate in healthcare decisions, whether through partnerships with professionals or engaging with the commissioning process, CCGs need to provide access to information which can help their population make better decisions about their care.

One of the key goals of the reforms under the HSCA12 was to increase the public accountability of those responsible for commissioning care for patients (CCGs) (Department of Health 2012a, b; Checkland et al. 2013). NHS England published a guide for CCGs in December 2013, justifying planning for patients at a local level and requiring CCGs to develop a 2-year Operational plan and

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5-year Strategic plan (NHS England 2013a). However, our earlier work reviewing the plans of the (at that time) 211 CCGs in England indicated that 2 years down the line there were varying degrees of transparency in the work of CCGs (Reidy 2015), and that not all CCGs were providing their local populations with access to information that could help them make better decisions about their care. This work included regional disparities where some CCGs, largely in northern and more deprived parts of the country, provide less easy access to their forward plans in comparison to more affluent CCG localities with smaller populations.

Since SMS is so directly linked to the day-to-day lives of people, it is an example of commissioning decisions that most obviously require PPI input, so that support can be provided for communities and individuals in a way that people will engage with. Here, we explore commissioners' understanding and perception of local needs and SMS, as well as how they translated their understanding into actions and objectives that were commissionable alongside assuring local people that local services meet their needs. This study examines how this is played out in practice and the range of voices that are actually being involved in the development of NHS SMS services. As part of this study, we have used methodological innovation (Tierney et al. 2016) in working alongside and supporting patients and the public as Service User Researchers (SURs).

This study focuses on CCGs in the areas surrounding the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Wessex, the south coast of England. The NIHR CLAHRC Wessex is a research and implementation programme which runs over 5 years, with the aim of improving the health of the people of Wessex and the quality and cost-effectiveness of healthcare.

Methods

Study design

We conducted a multisite, quasi-ethnographic analysis of nine CCGs in the south of England (table 1) to explore the 'new' NHS structure of commissioning relating to the implementation of SMS services. The study was undertaken over 12 months from June 2014 to May 2015. Data collected within each phase are detailed in table 2. An overview of the study is shown in table 3.

Ethnography, and specifically direct observation, has been found to be particularly suited to uncovering the structural features of 'new wave' public policies, of which commissioning following the HSCA12 is one (Porter et al. 2013). Here, it allows for a comparison of the blueprint of the NHS with narrative accounts of SMS and patient engagement, and actual observations of decision-making and promotion of commissioner priorities to elicit how these priorities are

enacted in routine public-facing meetings. The study comprised case studies of the nine CCGs and had three phases: the collection and analysis of documents (official 2-year Operational and 5-year Strategic plans of CCGs—both plans were sought from all nine CCGs); semi-structured interviews with commissioners (commissioners from all nine CCGs were invited to participate) by one researcher (CR, EB, JE) and observations of CCG Governing Body meetings (which are held in public) by public and patient representatives (SURs) and researchers (CP, CA and CR). Phase I explored the aspirations and priorities of CCGs in commissioning SMS; phase II illuminated commissioners' conceptualisations of SMS initiatives, whereas phase III sought to elucidate how commissioning intentions for SMS play out in practice in a, supposedly, public setting.

Table 1: Demographics of CCGs in the south of England

CCG name	Population 2014* (Av† 266 525)	Practices (Av†=38)	Running cost allowance £m (1.66–21.75)	Revenue allocation 2013–2014 £000	IMD score‡,* (Av†=22.07)
CCG 1	270,070§	37¶	6.38¶	272,132	26.88§
CCG 2**	197,335¶	21¶	4.91¶	196,338	13.62¶
CCG 3	216,773¶	26¶	5.28¶	238,193	27.05§
CCG 4**	545,959§	54§	13.24¶	570,234	10.63¶
CCG 5**	140,473¶	18¶	3.49¶	193,410	23.09§
CCG 6	777,024§	103§	18.73§	896,682	16.38¶
CCG 7**	219,981¶	24¶	5.21¶	228,440	9.86¶
CCG 8**	209,101¶	30¶	5.06¶	210,343	15.87¶
CCG 9	218,525¶	22¶	5.22¶	206,440	10.75¶

*England range=2251–1 493 512.

†England average.

‡Index of Multiple Deprivation Score, 2015.

§Above average.

¶Below average.

**Vanguard site.

††England range=5.45–47.39.

CCG, clinical commissioning group.

Table 2: Phases of the study and data collected from nine CCGs in the south of England

Phase		Objectives	Main tasks	Data collected
1	Documents: to collect the 2-year Operational and 5-year Strategic plans of CCGs	To determine the accessibility, scale and value of SMS services in the priorities of commissioners	<ul style="list-style-type: none"> Explore the nature of public accessibility of the forward plans of CCGs, collecting the 2-year and 5-year plans via CCG websites Identify which CCGs have plans available and examine whether and to what extent they mention SM 	Publically available 2-year and 5-year plans (via the internet). Content analysis categorised CCGs as high, medium or low profile according to what extent their plans mention SM
2	Interviews: to explore commissioners' conceptualisation of SMS	To acquire an understanding of commissioners' opinions regarding SMS services	Recruit commissioners (through purposive sampling via face-to-face and email contact) to interview	Ten semi-structured interviews with commissioners (including Managers, Programme Directors, and GP and lay board members) from six CCGs and one local Strategic Clinical Network. Framework analysis identified the key elements and themes from participants' accounts
3	Observations: to determine what level of input and influence a lay perspective has on commissioning services	To work with patient and public representatives as Service User Researchers to determine what the forward plans and intentions of commissioners mean in practice. How do	Employ SURs (×5) following a formal application process via advertisements sent to voluntary, NIHR and University student organisations. SURs were to be selected with consideration of variety, in terms of: age, gender, health	Field notes and reflective diaries were collated by all researchers during and after the Governing Body meetings as well as debrief notes on their experiences. Governing Body meeting minutes were collected and collated, identifying items relevant to PPI and SMS.

		commissioners make sense of the plans and how is this translated to the public?	condition, carer status and experience (or lack of) of formal meetings. Facilitate SURs in developing research skills, involvement in project development, taking fieldnotes, debrief sessions, reflective diaries and gathering observations of CCG Governing Body meetings	These were consolidated with reflective diaries, debrief notes, field notes, the forward plans and interviews, in a workshop with SURs
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- CCG, clinical commissioning group; SM, self-management; SMS, self-management support; SURs, service user researchers.

Table 3: The process of exploring the transparency of NHS purse strings

Phase:	Phase I	Phase II	Phase III
Objective	<ul style="list-style-type: none"> • What is the NHS blueprint? 	<ul style="list-style-type: none"> • What is the plan of action and understanding of the blueprint? • How do commissioners' conceptualise SM support? 	<ul style="list-style-type: none"> • How do commissioners make sense of SMS in practice? • What evidence is there of CCGs engaging with the public voice in Governing Body public-facing meetings?
Method	Strategic and Operational plans	Interviews with Commissioners	Observations and fieldnotes

- CCG, clinical commissioning group; NHS, national health service; SM, self-management; SMS, self-management support.

Interview participants were sent an information and topic guide before interviews (online supplementary document 1), and written consent was obtained prior to the face-to-face interview. Interviews covered the following topics; commissioners' understanding of SMS, including how they prioritise SMS, whether there are any local drivers for this, how they make decisions about SMS and how their CCG currently supports SMS, as well as whether there are any SMS initiatives currently in development. Commissioners were also asked what changes they have seen in SMS, how they evaluate SMS services, how this feeds back into the commissioning process

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and what their preferred/desired outcomes for SMS services are. Interviews were audio-recorded, transcribed and anonymised. CCG Governing Body meeting observations involved collecting: field notes, reflective diaries and debrief notes, which were taken by the researchers present at these meetings.

Analysis

Operational and Strategic plans were collated and categorised according to the level and content of references to SM using content analysis (Krippendorff 2004). Interview transcripts and fieldnotes were read repeatedly for familiarisation and interview data were coded, using NVivo V.10, with a framework based on our research questions and from reading of relevant policy documents, to describe the data in a literal sense (Mason 2002). Inductive coding allowed us to capture unexpected themes. We examined emerging themes within each interview and compared commissioning practices across the nine CCG localities to identify variation and how SMS services are prioritised. Emerging analytical ideas were explored, discussed and refined in a cyclical process of data collection and analysis (Patton 2002; Green 2009). Finally, the presence of SM in the forward plans of CCGs was synthesised with the interview data alongside the published board meeting minutes, reflective diaries and meeting debrief sessions in collaboration with SURs in a workshop.

Results

Eight CCGs provided access to Strategic plans and seven CCGs provided access to Operational plans (table 4). The CCGs around the south coast were similar to CCGs nationally in terms of accessibility of future plans (Reidy 2015), although unlike some CCGs nationally, all of these CCGs provided access to at least one of their forward plans (Strategic or Operational). However, whereas CCGs 1 and 4 produced a combined Strategic and Operational plan together, CCGs 2 and 8 produced a joint Strategic plan, but produced no Operational plan and CCG 9 had no Strategic plan but did have an Operational plan. We conducted 10 interviews, lasting between 30 and 40 min, with commissioners from six of the nine CCGs plus one from the Wessex Strategic Clinical Network. Commissioners from all nine CCGs were invited to participate via email, reminder emails (x2) and telephone contact, but CCGs 7, 8 and 9 provided no response and no indication as to why they would not take part, despite reminder emails. Ten CCG Governing Body meetings were observed (a total of ~ 30 hours) from five CCGs. Observations at Governing Body meetings were limited to the capacity of the SURs and for CCGs 6, 7, 8 and 9, there was no local SUR availability. Experiences of SURs at CCG Governing Body meetings were collated into Good and Bad practice

recommendations (see online supplementary document 2). Of the nine CCG sites, five (CCGs 1, 2, 3, 4 and 5) had data taken from forward plans, interviews and observations, whereas the remaining had data taken from forward plans (except for CCG 6 which also had interview data). Data collection was limited where the CCGs did not respond to invitations to participate in interviews, and the limited capacity of SURs to observe Governing Body meetings.

Table 4: Data collected from CCGs in the south of England

	Phase I		Phase II	Phase III
CCG	Strategic plan available?	Operational plan available?	Interview? (N)	Board meeting? (N)
CCG 1	Joint Strategic and Operational plan	Joint Strategic and Operational plan	Yes (1)	Yes (3)
CCG 2*	Yes	No	Yes (1)	Yes (2)
CCG 3	Yes	Yes	Yes (1)	Yes (1)
CCG 4	Joint Strategic and Operational plan	Joint Strategic and Operational plan	Yes (2)	Yes (2)
CCG 5	Yes	Yes	Yes (2)	Yes (2)
CCG 6	Yes	Yes	Yes (2)	No
CCG 7	Yes	Yes	No†	No
CCG 8*	Yes	No	No†	No
CCG 9‡	No	Yes	No†	No
Strategic clinical network	NA	NA	Yes (1)	NA
Total	8	7	10	10

*CCGs 2 and 8 had a joint Strategic plan but no Operational plan.

†Commissioners from all nine CCGs were invited to participate via email, reminder emails (×2) and telephone contact.

‡CCG 9 had no Strategic plan but did have an Operational plan.
CCG, clinical commissioning group. NA, not applicable.

Observations of Governing Body meetings

Observations of publically held Governing Body meetings by SURs uncovered how meetings were presented to the public and exemplify the lack of capacity to engage patient and public voices and agendas (online supplementary document 3). These meetings were identified as public-facing meetings and signage at these meetings (online supplementary document 4) represented this as such. Such signs also stated that CCGs are: 'putting patients at the centre of everything we do', 'involve you in the planning and development of services; consult with you on our plans; involve you in decisions about your care; promote choice', as well as 'listening to your views and concerns'. Yet, there were no mention of SMS in the Governing Body meetings, no apparent way for patients and the public to engage with decision-making concerning SMS, and no signposting to other decision-making meetings. SURs also noted that lay members on the CCG Board did not seem to be very 'lay' in any respect and usually were represented by just one 'lay' person. These stark 'non-findings' meant that we were unable to do any form of analysis on SMS from the fieldnotes and diaries. At the workshop with SURs, following the Governing Body meeting observations, we reviewed findings from phases I and II. Combined findings allude to a disjunction between aspirations of commissioners and their operationalisation of SMS services. The analysis of the interviews thus focuses on why it is proving hard for commissioners to engage their local population in driving forward and embedding SMS.

To what extent do the CCG plans mention SMS?

A content analysis was undertaken to consider whether the Strategic and Operational plans of CCGs mention SMS (and related terms). SMS (and related terms) was mentioned on 200 different occasions and to varying degrees across the nine CCG's forward plans, ranging from 3 references to 66, with a mean of 25. CCGs were categorised according to whether their plans were regarded as high, medium or low profile (figure 2). The sites which have no affiliation to Vanguard site status are noted for having the lowest number of references to SM terms.

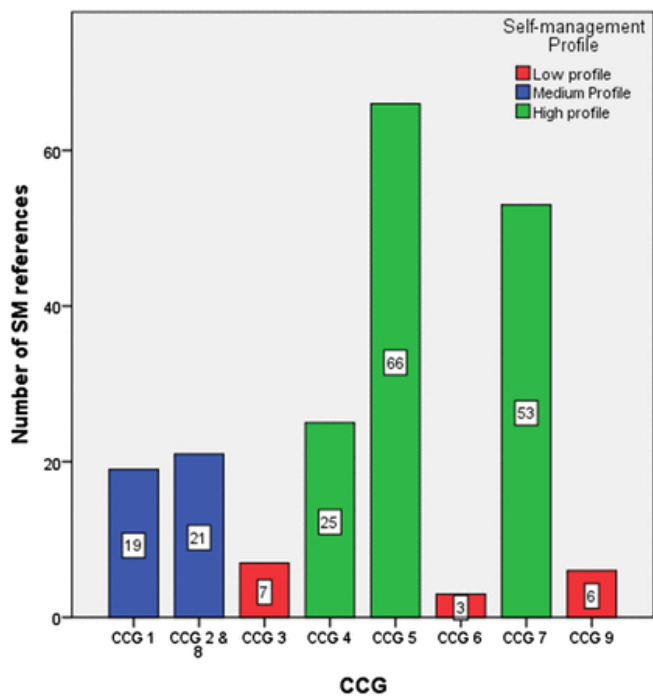


Figure 2: The number of references made to SMS terms in the, available, South of England CCG forward plans (Strategic, Operational or both).

Table 4: Data collected from CCGs in the south of England

CCG	Phase I		Phase II	Phase III
	Strategic plan available?	Operational plan available?	Interview? (N)	Board meeting? (N)
CCG 1	<i>Joint Strategic and Operational plan</i>	<i>Joint Strategic and Operational plan</i>	Yes (1)	Yes (3)
CCG 2*	Yes	No	Yes (1)	Yes (2)
CCG 3	Yes	Yes	Yes (1)	Yes (1)
CCG 4	<i>Joint Strategic and Operational plan</i>	<i>Joint Strategic and Operational plan</i>	Yes (2)	Yes (2)
CCG 5	Yes	Yes	Yes (2)	Yes (2)
CCG 6	Yes	Yes	Yes (2)	No
CCG 7	Yes	Yes	No†	No
CCG 8*	Yes	No	No†	No
CCG 9‡	No	Yes	No†	No
Strategic clinical network	NA	NA	Yes (1)	NA
Total	8	7	10	10

*CCGs 2 and 8 had a joint Strategic plan but no Operational plan.

†Commissioners from all nine CCGs were invited to participate via email, reminder emails (x2) and telephone contact.

‡CCG 9 had no Strategic plan but did have an Operational plan.

CCG, clinical commissioning group. NA, not applicable.

Three themes were identified from the semi-structured interviews with commissioners which are explored below: (1) SMS conceptualisation: a nationally driven agenda; (2) the problem of bringing in new knowledge about SMS into the commissioning process and (3) a lack of capacity to engage patient and public voices and agendas.

SMS conceptualisation: a nationally driven agenda

Targeting quality care with a focus on austerity (cost-containment) to maximise value from the NHS budget dominated commissioners' conceptualisation of SMS. Most commissioners used similar 'key' terms with reference to SMS, which were commensurate with a 'top-down' influence, and expressed as being hard to 'get right', suggesting that their understanding of SMS was not inherent, but came from a directive, rather than an individualised personal understanding. Commissioners' expressed understanding was framed by new measures advocated by NHS England such as the Patient Activation Measure (PAM) (Hibbard et al. 2004), which implies a formulaic simplified means of the evaluation of needs, motivations and abilities of people with long-term conditions, which they felt would fulfil the remit of a focus on SM;

If you were at Level 1 [of PAM], which would be the lowest, you'd probably maybe be in denial, not think it's your responsibility to manage your health at all and that you would probably expect your GP or secondary care or whoever to actually be dealing with all that stuff for you; it's not your responsibility at all. (Commissioner 5)

Some commissioners' explanations concerning SMS did not indicate that conceptualisation of SMS was acquired from knowledge of local needs of the CCG population. In providing explanations as to how SMS is introduced into the commissioning process, rather than locally driven initiatives, commissioners cite national incentives and refer to guidelines from NHS England (such as the Integrated Care agenda) and the National Institute for Health and Care Excellence (NICE), a public body of the Department of Health which provides national guidance and advice on good practice in healthcare. Although SMS is mentioned as a 'priority' for local commissioners, details of local initiatives were notable for their absence. On the face of things, priorities seem to vary between CCG localities but centralised influences, especially those amenable to performance management, are seemingly prioritised. Successes in the development of SMS services tended to be linked to financial incentives such as the Quality and Outcomes Framework (based on pay for performance and a known key motivator in health service provision) (Chew-Graham et al. 2013). In contrast, if outcome measures and payments for services were to refer to targets unrelated to SMS, this made it difficult, if not impossible, for healthcare professionals to implement and support;

Interviewer: When you're having clinical consultations with patients, to what extent is SM in your mind as you're working through the needs of that person that's sat in front of you?

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Respondent: I think you try to keep it there but you often feel that you've got tasks to get through. (Commissioner 3)

There was also a preference for using centrally prescribed evidence with the 'evidence' used by commissioners to validate their decisions seemingly derived centrally from NICE and NHS England. Logical pathways were prioritised by commissioners, and measures and outcomes which they felt were 'tangible', traditional and safe. Where evaluation of services were referred to, it was reported to be via formal biomedical measures, such as Commissioning for Quality and Innovation, admission rates, amputations and more recently, by the patient activation measure:

As an organisation, one of the key imperatives is to live within your financial means and...we've got our colleagues in Finance who are under tremendous pressure...there's a limited amount of money to be spent and obviously the opportunities for investing in something that might deliver in 10, 15 years is not as attractive to them, as can you do something that sort of changes the balance sheet by the end of this financial year!...I think inevitably, for the hard outcomes, you get drawn back to the national ones there...we may have an opinion on the appropriateness of those there but they are the ones that are measured and so we can't really, you know, move away from those.
(Commissioner 7)

The problem of bringing in new knowledge about SMS into the commissioning process

Most forward plans of CCGs rated as giving SMS 'high-profile' (Figure 2) declared what SMS services they intended to commission, for example; establishing integrated care teams across the CCG who will work closely with acute trusts to ensure care is delivered promptly in the community and support SMS through appropriate signposting and voluntary sector support, or interventions which use smartphone technology to revolutionise how people can interact with the healthcare system. One CCG was not just aspirational and had already commissioned SMS services, including the employment of a 'Support Group Development Officer' utilising a system-wide approach to service design. However, there appeared to be no clear pathway for how such initiatives are brought to the commissioners' table, how they are theorised to be effective ways to enable SM or how they actually come into fruition, other than the link to Vanguard site status (Table 1). Such sites have higher incentives for promoting SMS and have more resources to attain this goal.

Additionally, most commissioners acknowledged changes in orientation with a shift towards more patient involvement and empowerment, joint-decision-making and the 'expert patient', and moving away from traditional methods of healthcare;

I think there's a huge amount of change in terms of culture, so when I first started in the NHS it was very much basically you manage the patient's condition for them. I think that's completely changed, where a lot of the national guidance has said, 'Actually you've got expert patients, they know their condition, then actually support that patient, empower that patient to actually manage their condition themselves' and that just pays dividends...we have to go that way, because...there's not enough resource in terms of doing a hands-on approach for everyone. (Commissioner 15)

However, embedding new knowledge in the commissioning process was more problematic:

If I'm honest, I think it's one of those things we want to do and I'm worried that it will continue to be overshadowed and squeezed out by the demands to meet the insatiable desire for fix-it medicine. (Commissioner 3)

Similarly being able to embed patient-focused agendas and engagement in SMS could be problematic to incorporate into commissioning.

A lack of capacity to engage patient and public voices and agendas

Preliminary work preceding the in-depth interviews found that 90% of CCGs in England needed to be contacted to gain access to their forward plans (i.e., they were not easily, clearly or directly accessible via the website, or were incomplete early drafts or spreadsheets) (Reidy 2015), suggesting that public accountability and accessibility of plans were not being extensively enacted. This theme of accessibility was replicated in interviews with commissioners;

Interviewer: Are there any local drivers for SMS? Do you get approached by anyone in the community about self-management such as groups, the local cancer groups?

Respondent: Do we get approached? I don't think we get approached; we might approach them...So I think it's about us going to maybe a local charity or a local patient group or you know a local service provider. (Commissioner 13)

The capacity to engage varied between localities. Some areas acknowledged a significant shift towards working with the community and voluntary sector as being part of culture change and priorities moving towards SMS and engaging in their communities, and have developed

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programmes to help implement this change. But, there was a lack of clarity over how local drivers actually influence the commissioning of services. There is a mention of PPI, but a lack of detail as to how many members of the public and patients are involved, how they are represented in decision-making meetings and, overall, how they input into the decision-making process. While commissioners referred to the latter as drivers, evidence of actual involvement is not as apparent. It seems that rather than communities approaching the CCG with ideas, commissioners' approach selected groups in the communities at their discretion and avoid communicating with people more directly.

Discussion

The results of this study contribute to the current understandings of how commissioners see, represent and incorporate SMS into commissioning. For SMS to be an integral part of the 'fully engaged' scenario, and bring about the greatest gains in public health, services are required that can be adopted by patients. The documentary analysis allowed us to examine how national guidelines on SMS have been interpreted, and then by interviewing commissioners we were able to explore this further. Interviews illuminated how commissioners conceptualise these guidelines, which was found to be fashioned by official terminology and reinforced by group thinking and top-down national agendas. We went on to explore how commissioners' interpretations are then put into practice, and what happens when members of the public approach the only public-facing meeting available to them (CCG Governing Body meetings). In observing such meetings with SURs, it was clear that PPI in SMS decision-making was entirely absent at public-facing meetings. It was found that there were no discussions around a means to ensure SMS services are more personalised and person-centred. Overall, we found that while some CCGs do reference SMS in their plans, and mention that it is an important part of the culture change of the NHS, in practice it is difficult for them to buy into and operationalise SMS if this does not come from a top-down initiative (Vanguard, PAM, etc.). Thus, contrary to guidance and policy, CCGs are not implementing services that have come from the needs of the local population. By not offering obvious avenues for patients and the public to engage when they do approach public-facing meetings, it is not clear where a naive member of the public is to go to have their voice heard. In essence, the rates of long-term conditions and multi-comorbidities are increasing, and as a result, the need for SMS services are too, yet the public voice appears to be lacking in the commissioning of SMS. Where commissioners do want to focus on SMS, they simply do not have the capacity to create these opportunities in their day-to-day work if it does not tie into their traditional, nationally driven, financial incentives.

Effective SMS of long-term conditions is a key aspiration for improving health outcomes and appropriate utilisation of services for those living with long-term conditions. Marent et al. (Marent et al. 2015) suggest that including lay perspectives in decision-making could be one strategy to reorient health services towards changing demands in health service provision and patient expectations. However, our initial phases of exploration (Reidy 2015) found that CCG plans were often inaccessible and that there are regional variations, with less wealthy areas at risk of not being involved with the commissioning of their health services. In our current study, we have found that there is also variation about how much SMS is mentioned or prioritised in the forward plans, by individual commissioners and in Governing Body meetings. Some areas are clearly prioritising SMS in their key outcomes more than others and implementing a variety of SMS resources. Such sites are more often than not 'Vanguard sites'; those awarded with higher incentives and means to attain this goal. With financial drivers and structural limitations being noted by commissioners as the key drivers as to what actually gets commissioned in practice, and alluding to a commissioning process which is often fragmented, this increased financial incentive through Vanguard status appears to give an artificial advantage to the selected sites in implementing SMS.

Currently, CCGs are measured on their adherence to national directives and financial incentives, yet it is evident that effective SMS demands more than an order from NHS England. Commissioning decisions are made with reference to ticking the boxes of key biomedical outcome measures, which are often incongruent to measures which reflect improved SMS for patients (i.e., self-efficacy, shared decision-making, health-related quality of life and psychological well-being). Improved SM should improve biomedical outcomes and not the other way around. In essence, CCGs are performance-managed against centralised drivers, especially in terms of austerity. Procedural and biomedical markers (e.g., the percentage of patients who turn up to outpatient appointments), which can be directly linked to financial impacts on the service, are what gets measured, with a strong sense of lip service to national priorities which are hard to get into practice on the front line. If outcome measures and payments for services refer to targets unrelated to SMS, this makes it difficult, if not impossible, for healthcare professionals to implement support. Where SMS services are being actively commissioned these have been introduced through top-down (rather than locally driven) initiatives, that is, the Integrated Care agenda, national 'Vanguard' sites and, more recently, NHS England's promotion of the PAM (NHS England 2016b). Using PAM requires purchase of a licence by CCGs in order to use it to assess patients' engagement with their health. It is a way to measure the population's level of 'activation' regarding SM rather than an intervention to support SM, and it is also not a tool which

has been designed or developed through engagement with patients or the public. It is through a focus on formulaic evidence and minimal and poor PPI engagement that the formulation of SMS services have not, to date, progressed further.

Relevance of study with regard to wider literature/comparison with previous studies

Despite the rhetoric of ensuring services are designed around patients' needs, we found that patients and the public were not engaged in commissioning in meaningful ways and their voice was, almost entirely, absent. CCG Governing Body meetings are held in front of a public audience, but are not 'public meetings' in the sense of participation. Whilst CCG's propose to be more accountable to the public, Governing Body meetings remain the principle forum for direct public engagement, but provide few opportunities for CCGs to learn from the experiences of patients and the public. This resonates with Smith et al.'s (Smith et al. 2013a) study on commissioning high-quality care for people with long-term conditions, in primary care trusts, shortly before the restructuring of commissioning which found that commissioning meetings and workshops tended to be more of a 'ritual' rather than fulfilling the purpose and potential of such gatherings to involve people with specific interests to deliver outcomes. The results presented here also resonate with Checkland et al.'s (Checkland et al. 2013) exploration of accountability in the new CCGs, in so far as questions could be asked by the public at the beginning of board meetings, but not in response to matters raised during the meeting. While the CCG sites explored in Checkland's study expressed intentions to set up additional forums for patients and the public, such 'additional forums' were not made accessible to the SURs in the current study. So where else do CCGs expect to be held accountable? CCG board meetings are CCG's public-facing meetings, and their opportunity to interact with their public, and to be accountable, but with no known access to SMS decision-making meetings and subgroups, the standing of real transparency and accessibility to SMS decision-making in CCGs is questionable.

No research, to date, has investigated the perspectives of commissioners on their desired outcomes of SMS services (Boger et al. 2015), despite their key role in commissioning patient-focused SMS services. Efforts that feel more like a tick box exercise for accountability, rather than a genuine pursuit of the public and patient perspective, can be entirely fruitless, seeding a feeling of suspicion and distrust (Foot et al. 2014). Contrary to the prevailing one-size-fits-all model of lay involvement, which does not tailor to the needs of particular demographics, Armstrong et al. (Armstrong et al. 2013) have identified specific strategies to help ensure that patient involvement can realise its full potential. They recommend a participative approach, laid out beforehand in strategic planning with a clear agenda, although most CCGs do not currently have this capacity. This study adds to the literature around the importance of SMS and that for effective long-term

condition management, good SMS that people can build into everyday life is key, while providing evidence for the rarely sought, understood or known commissioner view on what SM is or how they actually involve the patient and public voice to inform their decisions. It highlights that without in-depth knowledge on the existing preferred outcomes of all stakeholders, there is a risk that support services for SM will be commissioned that have, potentially, limited impact on their target population (Boger et al. 2015).

Implications

CCGs charged with commissioning services for long-term conditions reflect the health policy priority of including and providing improved provision for SMS services. This study allows us to understand the gaps present in the commissioning of SMS services, and where CCGs can target to begin to achieve their ambitious 5-year plans. This can be described in terms of the ‘third translational gap’ (Gibson et al. 2012), considering the integration of healthcare as it occurs at the level of the individual patient within the wider context of their lives. A focus of work looking at implementation in community and domestic settings brings to the fore a commitment to working with patients and the public (Gibson et al. 2012). Understanding what the commissioning landscape currently holds for SMS offers an opportunity to target areas for improvement and implement meaningful strategies and innovations for improvement (Panagioti et al. 2014). These areas include improvements to the health service overall by improving patients' health and well-being (Challis et al. 2010; Kennedy et al. 2014) and at a system level (Stearns et al. 2000; Challis et al. 2010; Purdy 2010; Panagioti et al. 2014). As an outcome of all of these, there are reduced health systems costs (Stearns et al. 2000; Challis et al. 2010; Purdy 2010; Panagioti et al. 2014).

There are instances where commissioners are trying to fulfil this drive for openness, accessibility, transparency and patient feedback, but where SMS starts as a priority in CCG plans, it becomes less obvious in the day-to-day work of commissioners. Attending Governing Body meetings from the perspective of the people, the CCG is striving to serve left fundamental questions regarding how the CCG is actually listening to the patient voice. The ‘pressing’ focus, in reality, is on financially driven imperatives, meaning that putting SMS into practice becomes the hurdle at which most commissioners' fall.

This study highlights where CCG aspirations and operationalisation do not align, and draws attention to where intentions are not being put into practice—effective SMS which is developed from the bottom-up. While the culture of the NHS is moving away from a medical model to a more person-centred model, the desire for SMS cannot be met without a structure which allows the flexibility for adaption to local needs, so that changes can be incorporated to enable increased capacity to facilitate corporation. The imperative of patients' voice and choice has taken on

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reinforced authority in the light of failures in fundamental care (Department of Health 2013; NHS England 2013b) and is thus worthy of exploration in newly established organisations responsible for the commissioning of services. In relation to SMS, where patients and the public are co-producers and providers of the capacity to enact support, lay involvement in policymaking and commissioning has increased in salience. If CCGs are willing to collaborate and learn from the experiences of their patients, then they can set in motion the implementation of services which are able to effectively address the needs of the people using their services, turning guidance and policy into actual experience.

Appendix B BCT Taxonomy (v1): 93 hierarchically-clustered techniques

Page	Grouping and BCTs	Page	Grouping and BCTs	Page	Grouping and BCTs
1	1. Goals and planning	8	6. Comparison of behaviour	16	12. Antecedents
	1.1. Goal setting (behavior) 1.2. Problem solving 1.3. Goal setting (outcome) 1.4. Action planning 1.5. Review behavior goal(s) 1.6. Discrepancy between current behavior and goal 1.7. Review outcome goal(s)		6.1. Demonstration of the behavior 6.2. Social comparison 6.3. Information about others' approval		12.1. Restructuring the physical environment 12.2. Restructuring the social environment 12.3. Avoidance/reducing exposure to cues for the behavior 12.4. Distraction 12.5. Adding objects to the environment 12.6. Body changes
3	1.8. Behavioral contract 1.9. Commitment	9	7. Associations	17	13. Identity
	2. Feedback and monitoring		7.1. Prompts/cues 7.2. Cue signalling reward 7.3. Reduce prompts/cues 7.4. Remove access to the reward 7.5. Remove aversive stimulus 7.6. Satiation 7.7. Exposure 7.8. Associative learning		13.1. Identification of self as role model 13.2. Framing/reframing 13.3. Incompatible beliefs 13.4. Valued self-identify 13.5. Identity associated with changed behavior
	2.1. Monitoring of behavior by others without feedback 2.2. Feedback on behaviour 2.3. Self-monitoring of behaviour 2.4. Self-monitoring of outcome(s) of behaviour 2.5. Monitoring of outcome(s) of behavior without feedback	10	8. Repetition and substitution	18	14. Scheduled consequences
5	2.6. Biofeedback 2.7. Feedback on outcome(s) of behavior		8.1. Behavioral practice/rehearsal 8.2. Behavior substitution 8.3. Habit formation 8.4. Habit reversal 8.5. Overcorrection 8.6. Generalisation of target behavior 8.7. Graded tasks		14.1. Behavior cost 14.2. Punishment 14.3. Remove reward 14.4. Reward approximation 14.5. Rewarding completion 14.6. Situation-specific reward 14.7. Reward incompatible behavior 14.8. Reward alternative behavior 14.9. Reduce reward frequency 14.10. Remove punishment
6	3. Social support	11	9. Comparison of outcomes	19	15. Self-belief
	3.1. Social support (unspecified) 3.2. Social support (practical) 3.3. Social support (emotional)		9.1. Credible source 9.2. Pros and cons 9.3. Comparative imagining of future outcomes		15.1. Verbal persuasion about capability 15.2. Mental rehearsal of successful performance 15.3. Focus on past success 15.4. Self-talk
7	4. Shaping knowledge	12	10. Reward and threat	19	16. Covert learning
	4.1. Instruction on how to perform the behavior 4.2. Information about Antecedents 4.3. Re-attribution		10.1. Material incentive (behavior) 10.2. Material reward (behavior) 10.3. Non-specific reward 10.4. Social reward 10.5. Social incentive 10.6. Non-specific incentive 10.7. Self-incentive 10.8. Incentive (outcome) 10.9. Self-reward 10.10. Reward (outcome) 10.11. Future punishment		16.1. Imaginary punishment 16.2. Imaginary reward

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	4.4. Behavioral experiments	15		16.3. Vicarious consequences
	5. Natural consequences		11. Regulation	
	5.1. Information about health consequences		11.1. Pharmacological support	
	5.2. Salience of consequences		11.2. Reduce negative emotions	
	5.3. Information about social and environmental consequences		11.3. Conserving mental resources	
	5.4. Monitoring of emotional consequences		11.4. Paradoxical instructions	
	5.5. Anticipated regret			
	5.6. Information about emotional consequences			

Appendix C Patient Advert- Focus groups



CLAHRC Wessex
Collaboration for Leadership in Applied Health Research and Care

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NHS
*National Institute for
Health Research*

Do you have Type 1 diabetes and use an insulin pump?

We would like to find out what support and resources people use to help them incorporate an insulin pump

Are you;

- Aged 18-65
- Have Type 1 diabetes for at least 1 year
- Used an insulin pump for at least 6 months

We would like to invite you to take part in a Focus Group.
Focus Groups dates and times are below...

If you are interested in finding out more about this study please contact Claire Reidy at the University of Southampton
Email: c.m.reidy@soton.ac.uk Tel: 023 8059 7628

[DATE]
or
[DATE]
at
[LOCATION]

And to thank you for your time, you will be reimbursed with a
£10 Amazon voucher.

Appendix D Patient Participant Information Sheet - Focus groups

Participant Information Sheet – Focus groups

Study Title: The factors that support people to incorporate an insulin pump into their everyday lives

Researcher: Ms Claire Reidy **Ethics number:** 26208

Please read this information carefully before deciding to take part in this research. If you are happy to take part then you will be asked to sign a consent form.

What is the research about?

This project aims to understand what factors support people to incorporate an insulin pump into their everyday lives. This research is part of a PhD project by Ms Claire Reidy, Doctoral Research Fellow of the School of Health Sciences, of The University of Southampton. It will form part of a PhD thesis.

We believe that people with long term health conditions can cope better if they have support from family and friends and access to resources which are personalised to their own needs and wishes.

This study aims to explore what support and resources people living with a pump use, and whether this varies over time. The study also aims to adapt an online tool named GENIE for people living with an insulin pump.

The tool is called GENIE, and it can map what social support the user receives and enable access to further support, resources and information in their local area. Users are guided through the GENIE tool by a facilitator.

The facilitator asks the user questions about their friends, family and healthcare professionals and how often they see them. This is recorded using a diagram to demonstrate how important certain people are to the user. Pretend names for both the user and the family members can be used if preferred, but the information is not shared with anybody.

The Genie tool then asks questions about the user's preferred social activities related and unrelated to their diabetes. The user can just let the facilitator know what interests them

and what sort of information they would like or what activities they prefer. The tool then provides the user with a helpful overview of online and offline activities, resources and groups they can join or view on their own or with existing friends in their local area.

If you have had Type 1 diabetes for at least one year, have used an insulin pump for at least six months, and are aged between 18-65 then you will be invited to join the study. The study has been reviewed by the University of Southampton Ethics Committee. This is to make sure the study is both a safe and a useful study for local people using an insulin pump. If you decide to join in the study the researcher will invite you to take part in a Focus Group to discuss the support and resources you have used to help you incorporate the pump, and what you think needs to be on the GENIE tool for it to be helpful for other pump users. You will also have the opportunity to speak to the researcher by phone or email to discuss any questions you may have.

Why have I been invited?

You have been invited to join the study because you have Type 1 diabetes and you are using an insulin pump.

What will happen to me if I take part?

If after reading this information sheet you decide that you would like to take part, you will be given the opportunity to ask the researcher any questions you have (although you can ask questions even if you have not decided to take part!). Once you are happy to take part, you will be invited to a Focus Group and asked to sign a consent form.

The Focus Group will consist of a conversation with a small group of other insulin pump users to discuss the support and resources you have used to help you incorporate the pump, and whether this has varied over the time you have had the pump. As a group you will also be shown the GENIE tool and asked to advise on the kinds of services and resources that need to be on there for it to be helpful for pump users, as well as how you think it would be best delivered in the insulin pump service.

You will also be asked to answer a short questionnaire about yourself and your diabetes when you come to the Focus Group, which will take about 5 minutes. This is so that we can make sure we are speaking to a variety of pump users.

We would like to record the conversations you have in the Focus Group so that we can make sure we capture all the key points and adapt the tool in the best way possible.

The Focus Group should take no longer than 1 hour, though this time may vary depending on your responses.

Even if you agree to join this study you will still be free to withdraw your participation, although if you withdraw after taking part in the Focus Group then your conversations in

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the Focus Group will still be taken on board. However, these conversations will be anonymised, as standard.

Are there any benefits in my taking part?

It is hoped that your participation will help us to build a better understanding of the support that people using an insulin pump need and use, and where there are gaps in support of resources. Your participation may also help us to better understand how online and offline communities help people with diabetes them manage their condition. Your responses may therefore benefit others, and could inform future research and interventions.

By taking part, you may benefit from a raised awareness of the importance of your own personal networks. The reflective nature of the Focus Group may allow you to use this experience to make better use of your existing social network for self-management support as well as consider potential alternatives.

You will also have your time reimbursed with a £10 Amazon voucher and refreshments will be provided throughout the Focus Group.

Are there any risks involved?

We see no potential risk to focus groups Participants, beyond what would normally be expected in everyday life. However the Focus Group will include conversations about living with a pump, and the support you have needed, and we recognise that talking about your experiences might not always be comfortable. Some participants may feel upset when talking about their condition or about their support, and some people may find the activity intrusive or distressing. If so please do let the research facilitator know so that they can support you, if need be.

Should you feel upset, there is the opportunity to move onto a different question, take a break in the focus group, step out of the room, or terminate the focus group altogether.

Whilst it is not intended that the focus group should upset you, it would be helpful to identify someone, with the researcher, who would be supportive to you should you need them following participation.

Additionally, if feel you need to talk to someone after the interview you can phone the Samaritans group on 116 123 or the Diabetes UK Helpline on 0345 123 2399.

What happens when the research study stops?

Once the study has been completed the information obtained will be written up, anonymised and analysed, and the findings will be written up (as part of the requirement of the PhD). A summary of the study and its findings will be made available to those who

have participated. It is anticipated that the findings will be published in a relevant journal. You will not be identified in any report/publication that arises from this research.

Will my participation be confidential?

Although all participants are named during the Focus Group, (or you can chose to use another name), when the recording is written up all names will be anonymised and changed. The questionnaire that you are asked to fill in does not ask for your date of birth (only the year) or name, so that participants and members of their social network (including your health care professionals) cannot be identified. All research paperwork will only have anonymised details so that you cannot be identified. All research data will be stored on a secure database and will not include any personal details.

For data analysis, the anonymised research data will be shared within the research team at the University of Southampton. This data will not contain any personal details. This research project is being conducted in accordance with the Data Protection Act (1998) and the University of Southampton's research data management policy which is available at: <http://www.calender.soton.ac.uk/sectionIV/research-data-management.html>.

What happens if I change my mind?

You can withdraw from the study for any reason at any time without providing a reason; and your usual care will not be affected. If you withdraw from the study the research team will only retain the data collected up until the point you withdraw, and at this point it will have been anonymised.

This decision will not affect any services you or your relatives receive and will not affect your legal rights. You will need to inform the researcher of your intention to withdraw so that you are not contacted again in the future.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you are welcome to contact the independent University of Southampton Research Governance office.

Isla Morris

University of Southampton Research Integrity and Governance Manager

Rgoinfo@soton.ac.uk

023 80 595058

Alternatively you could contact the supervisor of this research project, Professor Anne Rogers, Professor of Health Systems Implementation (02380 596830, A.E.Rogers@soton.ac.uk)

Who is organising and funding the research?

The organisation financially supporting the research is The Health Foundation, and this is through the NIHR CLAHRC Wessex in the Faculty of Health Sciences at The University of Southampton. The research sponsor is the University of Southampton as this is where the doctorate will be registered.

Where can I get more information?

For further information about the study, please contact the PhD candidate, Claire Reidy via Email: c.m.reidy@soton.ac.uk or Telephone: (0)23 8059 7628

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Appendix E Letter of invitation Focus groups HCPs

Using a social networking tool (GENIE) to support people to incorporate an insulin pump into their everyday lives:

Study Invitation Letter

Dear,

This is a letter to invite you to take part in the above study. The study asks you to take part in an informal Focus Group, which can form part of a clinic team meeting. This is a research study designed to enable people with Type 1 diabetes and an insulin pump to access additional resources and support. You have been invited to take part in this study because you work in an NHS insulin pump service.

This research is part of a PhD project by Ms Claire Reidy, under the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) in Wessex, based at The University of Southampton.

I have enclosed an information sheet which explains the details of the study. I would be grateful if you could take the time to read this document before deciding whether to participate in this study.

If you would like to take part in the study, or have any questions please contact the lead researcher, Claire Reidy by email; c.m.reidy@soton.ac.uk or telephone; 02380 597628.

Yours sincerely,

Claire Reidy

Appendix F HCP Participant Information Sheet

Participant Information Sheet

Study Title: Using a social networking tool (GENIE) to support people to incorporate an insulin pump into their everyday lives

Researcher: Ms Claire Reidy **IRAS number:** 213320

Please read this information carefully before deciding to take part in this research. If you are happy to take part then you will be asked to sign a consent form.

What is the research about?

This project aims to understand what factors support people to incorporate an insulin pump into their everyday lives. This research is part of a PhD project by Ms Claire Reidy, Doctoral Research Fellow of the School of Health Sciences, of The University of Southampton. It will form part of a PhD thesis.

We believe that people with long term health conditions can cope better if they have support from family and friends and access to resources which are personalised to their own needs and wishes.

This study aims to adapt a social networking tool (named GENIE) for people living with an insulin pump, and see how it can best fit within an insulin pump service.

If you are working within an insulin pump service then you will be invited to join the study. The study has been reviewed by the Health Research Authority (HRA) and the University of Southampton Ethics Committee. This is to make sure the study is both a safe and a useful study. If you decide to join in the study the researcher will invite you to take part in an informal Focus Group, which can take place in your clinic team meeting to discuss and advise how this tool may best fit within your service. This will then allow the tool to be adapted appropriately and later implemented in a way that fits the needs and priorities of both insulin pump users and insulin pump health care professionals. You will also have the opportunity to speak to the researcher by phone or email to discuss any questions you may have.

The social networking tool, GENIE, can be accessed online. It maps what social support the user receives and enables access to further support, resources and information in their local area. Users are guided through the GENIE tool by a facilitator.

The facilitator asks the user questions about their friends, family and healthcare professionals and how often they see them. This is recorded using a diagram to demonstrate how important certain people are to the user. Pseudonyms for both the user and the network members can be used if preferred, but the information is not shared with anybody.

The GENIE tool then asks questions about the user's preferred social activities related and unrelated to their diabetes. The user can just let the facilitator know what interests them and what sort of information they would like or what activities they prefer. It then provides the user with a helpful overview of online and offline activities, resources and groups they can join or view on their own or with existing friends in their local area.

Why have I been invited?

You have been invited to join the study because you work within an NHS insulin pump service.

What will happen to me if I take part?

If after reading this information sheet you decide that you would like to take part, you will be given the opportunity to ask the researcher any questions you have (although you can ask questions even if you have not decided to take part!). Once you are happy to take part, you and your insulin pump team can arrange for the researcher to come to a clinic team meeting. At the beginning of this team meeting you will be asked to sign a consent form.

The Focus Group will be informal and consist of a conversation within your clinical team. It will introduce your team to the GENIE tool and guide you through it, as it would a user. You will then be asked to comment on the tool, in your professional capacity, and how you think it would be best delivered within your insulin pump service.

You will also be asked to answer a short questionnaire about yourself and your clinical practice, which will only take a few minutes to complete. This is so that we can make sure we are speaking to a variety of healthcare professionals.

We would like to record the conversations you have in the Focus Group so that we can make sure we capture all the key points and adapt the tool in the best way possible.

The Focus Group should take no longer than 45 minutes, though this time may vary depending on your responses.

Even if you agree to join this study you will still be free to withdraw your participation, although if you withdraw after taking part in the Focus Group then your conversations in the Focus Group will still be taken on board. However, these conversations will be anonymised, as standard.

Are there any benefits in my taking part?

It is hoped that your participation will help us to build a better understanding of how people with insulin pumps can access support that is personalised and enables them to better self-manage. Your participation may also help us to better understand how tools to help people self-manage can fit within secondary health care services. Your responses may therefore benefit others, and could inform future research and interventions.

Are there any risks involved?

We see no potential risk to focus groups Participants beyond what would normally be expected in everyday life.

What happens when the research study stops?

Once the study has been completed the information obtained will be written up, anonymised and analysed, and the findings will be written up (as part of the requirement of the PhD), and will inform the next stage of the PhD study – implementing the GENIE tool. A summary of the study and its findings will be made available to those who have participated. Please ask to be included in this dissemination by contacting the researcher or letting the researcher know during the focus group. It is anticipated that the findings from the PhD will be published in a relevant journal. You will not be identified in any report/publication that arises from this research.

Will my participation be confidential?

Although all participants are named during the focus group, (or you can chose to use another name), when the recording is written up all names and services will be anonymised and changed. The questionnaire that you are asked to fill in does not ask for your personal details, such as date of birth (only your age) or name so that participants cannot be identified. All research paperwork will only have anonymised details so that you cannot be identified. All research data will be stored on a secure database and will not include any personal details.

For data analysis, the anonymised research data will be shared within the research team at the University of Southampton. This data will not contain any personal details. This research project is being conducted in accordance with the Data Protection Act (1998) and the University of Southampton's research data management policy which is available at: <http://www.calender.soton.ac.uk/sectionIV/research-data-management.html>.

What happens if I change my mind?

You can withdraw from the study for any reason at any time without providing a reason. If you withdraw from the study only the data collected up until the point you withdraw will be retained, and at this point it will have been anonymised.

This decision will not affect your legal rights. You will need to inform the researcher of your intention to withdraw so that you are not contacted again in the future.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you are welcome to contact the independent University of Southampton Research Governance office.

University of Southampton Research Integrity and Governance Manager

Rgoinfo@soton.ac.uk

023 80 595058

Alternatively you could contact the supervisor of this research project, Professor Anne Rogers, Professor of Health Systems Implementation (02380 596830, A.E.Rogers@soton.ac.uk)

Who has reviewed the study?

The study has been reviewed by the North of Scotland (1) Research Ethics Committee.

Who is organising and funding the research?

The organisation financially supporting the research is The Health Foundation, and this is through the NIHR CLAHRC Wessex in the Faculty of Health Sciences at The University of Southampton. The research sponsor is the University of Southampton as this is where the doctorate will be registered.

Where can I get more information?

For further information about the study, please contact the PhD candidate, Claire Reidy via Email: c.m.reidy@soton.ac.uk or Telephone: (0)23 8059 7628

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Appendix G Intervention Participant Information Sheet

Participant Information Sheet

Study Title: Using a social networking tool (GENIE) to support people to incorporate an insulin pump into their everyday lives

Researcher: Ms Claire Reidy **IRAS number:** 213320

Please read this information carefully before deciding to take part in this research. If you are happy to take part then you will be asked to sign a consent form.

What is the research about?

This project aims to understand what factors support people to incorporate an insulin pump into their everyday lives. This research is part of a PhD project by Ms Claire Reidy, Doctoral Research Fellow of the School of Health Sciences, of The University of Southampton. It will form part of a PhD thesis.

We believe that people with long term health conditions can cope better if they have support from family and friends and access to resources which are personalised to their own needs and wishes.

This study aims to test an online tool that will help you access personalised support and resources so that you are better able to incorporate an insulin pump, and manage your diabetes.

The tool is called GENIE, and it can map your social groups and offer you more and varied social activities, information and resources. You will be guided through the GENIE tool by a facilitator (either someone within the insulin pump team, or the researcher), so you won't need to use the computer, or navigate the tool on your own, if you find this difficult.

The facilitator will ask you questions about your friends and family and how often you see them. This will be recorded using circles to demonstrate how important certain people are to you. If you feel this is too personal then you can use a pretend name for both you and your family members/friends.

The Genie tool then asks you questions about your preferred social activities relate to your diabetes and more generally. At this point you can just let the researcher know what interests you have and what sort of activities you prefer. The tool then provides you with a helpful overview and print out of activities, resources and groups you can join or view on your own or with existing friends in your local area, and how to reach them.

If you have had Type 1 diabetes for at least six months, are aged between 16-65, and are due to start using an insulin pump then you will be invited to join the study. If you chose to join the study you will have your usual care before, during and after your clinic visits, but if you chose to take part then you will be able to use the GENIE tool as well. The study has been reviewed by the Health Research Authority NHS Ethics committee. This is to make sure the study is both a safe and a useful study for local people using an insulin pump. If you decide to join in the study the researcher will see you when you are due to start your pump. You will also have the opportunity to speak to the researcher by phone or email to discuss any questions you may have.

Why have I been invited?

You have been invited to join the study because you have Type 1 diabetes and you are due to start using an insulin pump.

What will happen to me if I take part?

If after reading this information sheet you decide that you would like to take part, you will be given the opportunity to ask the clinical team, or the researcher any questions you have. Once you are happy to take part, you will be asked to sign a consent form. You can either send this in the self-addressed envelope provided or confirm you would like to take part by telephone or email to the researcher and then present the signed consent form when you next attend clinic.

You will still be offered all of your usual clinical care by the team at all times and you are still able to withdraw at any time. If you consent to join this study (also known as the GENIE study), this will be in addition to your usual care.

Your clinical team will book you in for your insulin pump initiation and you will meet with the researcher on the same day in clinic, or within the same week at a time and place of your choosing.

Use of the GENIE tool (or intervention) consists of a face-to-face interview and an exercise that involves mapping the people who are important to you on a diagram. This will be done with a facilitator (the researcher or a member of the clinical team) in a place that is convenient to you. The whole interview and exercise should take no longer than 1 hour, though this time may vary depending on your responses.

Visit 1 – Pump initiation

During this appointment you will be asked to complete a short questionnaire about yourself and your diabetes. This session should take no longer than 1 hour.

The facilitator (the researcher or a member of the clinical team) will ask you about how you use people or groups online and offline in your social networks to help you manage your condition and who you reach out to for support in different situations. This interview

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will be digitally recorded to enhance the accuracy of reporting your experiences with online and offline support. During this time we will look at which individuals and groups are important to you with regards to managing your condition; we will use a diagram called a concentric circle as an exercise to help you discuss the support that you have, and how you make decisions about who to go to for help in certain situations, such as a change in your condition, a flare up in your symptoms or a technical issue.

The Genie tool then asks you questions about your preferred social activities related and unrelated to your diabetes. You can just let the researcher know what interests you have and what sort of activities you prefer. The tool then provides you with a helpful overview of activities, resources and groups you can join or view on your own or with existing friends in your local area.

A date and appointment will be made for you to return in 3 months time. You will be sent a reminder letter nearer to this appointment and if you have a mobile phone, a text message. The appointment will take approximately 45 mins and will be held in your insulin pump clinic.

Visit 2 – 3 month follow up

The researcher will ask you to complete two questions and the questionnaires that you filled in during your pump start (Visit 1) as part of your routine care. You will also be asked whether you have joined any social groups or have become more active in your local community, and how your experience of the pump has been during the previous 3 months.

A date and appointment will be made for you to return in 3 months time. You will be sent a reminder letter nearer to this appointment and if you have a mobile phone, a text message. The appointment will take approximately 45 mins and will, again, be held in your insulin pump clinic.

Visit 3 – 6 month follow up

This visit will be very similar to Visit 2 – your 3 month follow-up. The researcher will ask you to complete two questions and the questionnaires that you filled in during your pump start (Visit 1) as part of your routine care. You will also be asked whether your activities or access to resources have changed in the last few months, and how your experience of the pump has been during the previous 3 months. You will also be asked to evaluate the GENIE tool and provide feedback so that we can make it better.

Are there any benefits in my taking part?

It is hoped that your participation will help us to build a better understanding of the support that people using an insulin pump need and use, and where there are gaps in support of resources. Your participation may also help us to better understand how online

and offline communities help people with diabetes them manage their condition. Your responses may therefore benefit others, and could inform future research and interventions.

By taking part, you may benefit through a raised awareness of the importance of your own personal networks. The reflective nature of the interview may allow you to use this experience to make better use of your existing social network for self-management support as well as consider potential alternatives.

You will also have the opportunity to use this tool in addition to the support already received from your insulin pump clinic. However, we understand that we are benefitting greatly from your participation and will reimburse you for your time with a £10 Amazon voucher for each stage of your participation (Visit 1, Visit 2 and Visit 3), and will provide refreshments during the interviews.

Are there any risks involved?

We see no potential risk to you. During the course of the study you will always be offered your usual care. However the tool does ask you about your social networks (friends, families, health care professionals), some people may find this intrusive, or distressing, if so please do let the research facilitator know so as they can support you, if need be.

Talking about your experiences might not always be comfortable. Some participants undertaking the interviews may feel upset when talking about their condition or about their support.

Should you feel upset, there is the opportunity to move onto a different question, take a break in the interview, or terminate the interview altogether.

Whilst it is not intended that the interview should upset you, it would be helpful to identify someone, with the researcher, who would be supportive to you should you need them following the interview.

Additionally, if feel you need to talk to someone after the interview you can phone the Samaritans group on 116 123 or the Diabetes UK Helpline on 0345 123 2399.

What happens when the research study stops?

Once the study has been completed the information obtained will be written up, anonymised and analysed, and the findings will be written up (as part of the requirement of the PhD). A summary of the study and its findings will be made available to those who have participated. In order to request this information you are asked to contact the researcher (Claire Reidy; contact details below) to request a summary, which will be emailed to you upon completion and write up. It is anticipated that the findings will be published in a relevant journal. You will not be identified in any report/publication that

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arises from this research. All your data will be anonymised and you will receive the usual care from your insulin pump team.

Will my participation be confidential?

Although all participants are linked to their data initially, the data will be anonymised so that participants and members of their social network cannot be identified. All clinical information we collect will be kept confidential by allocating you a unique study number. All research paperwork will only have your unique number and your initials on it so that you cannot be identified. All research data will be stored on a secure database and will not include any personal details.

In the GENIE tool we could use a Pseudonym (a pretend name) instead of your name, so as you cannot be identified, you can use pseudonyms for your friends and family if you wish.

For data analysis, the anonymised research data will be shared within the research team at the University of Southampton. This data will not contain any personal details, only the unique number. Your anonymised data will be stored on a password protected computer. This research project is being conducted in accordance with the Data Protection Act (1998) and the University of Southampton's research data management policy which is available at: <http://www.calender.soton.ac.uk/sectionIV/research-data-management.html>.

What happens if I change my mind?

You can withdraw from the study for any reason at any time without providing a reason; and your usual care will not be affected. If you withdraw from the study you can request to have all your research data destroyed. The research team will only retain the data collected up until the point you withdraw if it is because you lose capacity to consent, and at this point it will have been anonymised. If you have attended an interview and chose to withdraw either during or after the interview, you will still receive reimbursement of your time for that interview and prior involvement.

This decision will not affect any services you or your relatives receive and will not affect your legal rights. You will need to inform the researcher of your intention to withdraw so that you are not contacted again in the future.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you are welcome to contact the independent University of Southampton Research Governance office.

Research Integrity and Governance Manager, University of Southampton

Rginfo@soton.ac.uk

023 80 595058

Alternatively you could contact the supervisor of this research project, Professor Anne Rogers, Professor of Health Systems Implementation (02380 596830, A.E.Rogers@soton.ac.uk)

Who has reviewed the study?

The study has been reviewed by the North of Scotland (1) Research Ethics Committee.

Who is organising and funding the research?

The organisation financially supporting the research is The Health Foundation, and this is through the NIHR CLAHRC Wessex in the Faculty of Health Sciences at The University of Southampton. The research sponsor is the University of Southampton as this is where the doctorate will be registered.

Where can I get more information?

For further information about the study, please contact the PhD candidate, Claire Reidy via Email: c.m.reidy@soton.ac.uk or Telephone: (0)23 8059 7628

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Appendix H Intervention Consent Form

CONSENT FORM

Title of Project: Using a social networking tool (GENIE) to support people to incorporate an insulin pump into their everyday lives

Name of Researcher: Claire Reidy

IRAS number: 213320

Ethics reference:

Please initial all boxes if
you agree with the
statement

1. I confirm that I have read and understand the information sheet (Version 3, Phase 2, August 2017) 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 participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I agree to take part in this research project and agree for my data to be used for the purpose of this study. I understand that all my details will be kept confidential and my name will not appear on any reports or documents.
5. I agree to my Diabetes consultant being informed of my participation in the study and that my responses will remain anonymous.
6. I give permission to be contacted as part of the study to participate in a follow up interview in approximately 3 months and 6 months time.
7. I agree to be audio recorded during the 3 interviews in order for the interviews to be transcribed and analysed for research purposes only; the tapes will be stored securely in the University of Southampton, and destroyed post transcription.
8. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Appendix I Intervention Advert



CLAHRC Wessex
Collaboration for Leadership in Applied Health Research and Care

UNIVERSITY OF
Southampton

NHS
National Institute for
Health Research

**Do you have Type 1 diabetes
and are you going to start
using an insulin pump in the
next few months?**

We would like to help you access support and resources in your local area to help you incorporate the insulin pump.

This study will involve taking part in 3 interviews at your pump clinic; one when you start pump therapy, and then 3 and 6 months on from your pump start.

If you are interested in finding out more about this study please contact Claire Reidy at the University of Southampton

Email: c.m.reidy@soton.ac.uk

If you chose to take part, you will be reimbursed with a £10 Amazon voucher to thank you for your time

V1, June 2017, IRAS number: 213320



Appendix J Intervention Invitation letter

Using a social networking tool (GENIE) to support people to incorporate an insulin pump into their everyday lives:

Study Invitation Letter

Dear

This is a letter to invite you to take part in the above study. This research study aims to enable people with Type 1 diabetes to access resources and support that will help them incorporate an insulin pump. You have been invited to take part in this study because you have Type 1 diabetes and you will be starting on insulin pump therapy.

I have enclosed an information sheet and Summary of Participation, which explains the details of the study. I would be grateful if you could take the time to read these documents before deciding whether to participate.

If you would like to take part in the study, or if you have any questions please either let your insulin pump team or the lead researcher know. The lead researcher is Claire Reidy, E: c.m.reidy@soton.ac.uk T: 02380 597628.

If you do not wish to participate in the study please ignore this letter of invite. You do not have to participate in the study, and it will not affect the quality of care provided if you choose not to.

Yours sincerely,

Insulin Pump service, NHS Trust

Appendix K Problem Areas In Diabetes (PAID) Questionnaire

Problem Areas in Diabetes Questionnaire (PAID)

INSTRUCTIONS: Which of the following diabetes issues are currently problems for you?
Circle the number that gives the best answer for you. Please provide an answer for each question.

Name:	Date:
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	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
1. Not having clear and concrete goals for your diabetes care?	0	1	2	3	4
2. Feeling discouraged with your diabetes treatment plan?	0	1	2	3	4
3. Feeling scared when you think about living with diabetes?	0	1	2	3	4
4. Uncomfortable social situations related to your diabetes care (e.g. people telling you what to eat)?	0	1	2	3	4
5. Feelings of deprivation regarding food and meals?	0	1	2	3	4
6. Feeling depressed when you think about living with diabetes?	0	1	2	3	4
7. Not knowing if your mood or feelings are related to your diabetes?	0	1	2	3	4
8. Feeling overwhelmed by your diabetes?	0	1	2	3	4
9. Worrying about low blood sugar reactions?	0	1	2	3	4
10. Feeling angry when you think about living with diabetes?	0	1	2	3	4
11. Feeling constantly concerned about food and eating?	0	1	2	3	4
12. Worrying about the future and the possibility of serious complications?	0	1	2	3	4
13. Feelings of guilt or anxiety when you get off track with your diabetes management?	0	1	2	3	4
14. Not "accepting" your diabetes?	0	1	2	3	4
15. Feeling unsatisfied with your diabetes physician?	0	1	2	3	4
16. Feeling that diabetes is taking up too much of your mental and physical energy every day?	0	1	2	3	4
17. Feeling alone with your diabetes?	0	1	2	3	4
18. Feeling that your friends and family are not supportive of your diabetes management efforts?	0	1	2	3	4
19. Coping with complications of diabetes?	0	1	2	3	4
20. Feeling "burned out" by the constant effort needed to manage diabetes?	0	1	2	3	4

Appendix L CLARKE Hypoglycaemia Survey

Clarke Hypoglycaemia Survey

INSTRUCTIONS: Please tick only one option for each question

Name:

Date:

1. Tick the category that best describes you
 - I always have symptoms when my blood sugar is low
 - I sometimes have symptoms when my blood sugar is low
 - I no longer have symptoms when my blood sugar is low

2. Have you lost some of the symptoms that used to occur when your blood sugar was low?
 - Yes No

3. In the past 6 months, how often have you had moderate hypoglycaemic episodes, where you might feel confused, disorientated or lethargic and were unable to treat yourself?
 - Never Once or twice Every other month
 - Once a month More than once a month

4. In the past year, how often have you had severe hypoglycaemic episodes, where you were unconscious or had a seizure and needed glucagon or intravenous glucose?
 - Never 1 time 2-3 times
 - 4-5 times 6-7 times 8-9 times
 - 10-11 times 12 or more times

5. How often in the last month have you had readings less than 3.5 mmol/l with symptoms?
 - Never 1-3 times 1 time per week
 - 2-3 times per week 4-5 times per week Almost daily

6. How often in the last month have you had readings less than 3.5 mmol/l without any symptoms?
 - Never 1-3 times 1 time per week
 - 2-3 times per week 4-5 times per week Almost daily

7. How low does your blood sugar need to go before you feel symptoms?
 - 3.4 to 3.9 mmol/l 2.8 to 3.3 mmol/l
 - 2.2 to 2.7 mmol/l Less than 2.2 mmol/l

8. To what extent can you tell by your symptoms that your blood sugar is low?
 - Never Rarely Sometimes Often Always

Appendix M Autoethnography diary entries

Entry 1 – 25.09.15 - 00:54 - Friday

Packing to go to Canada. Trying to find places to put it [the pump] on my body. Keeps ripping out of body (3rd/4th time). [Sound distressed]. Trying different clothes on. Finding it hard to place the cable as it is quite long. I might be too long. Maybe that is useful? I don't want it to be too short either. Note to self: refer back to this. I've had a nightmare trying to sort out my prescription – I was given the wrong insertion set – it had no tube, but I managed to speak to Roche who delivered them – they were very helpful, and managed to get the stuff to me but it was very stressful. I didn't think it would come in time before I go away to Canada. Thought I'd have to go back to multiple daily injections because I couldn't rely on the pump. Annoyingly Roche had my old address even though I asked for the items to be posted to my work address. [Sigh] I have to sign for it. I have no idea how long this supply will last. Or how easy it will be to request more.

Entry 2 – 25.09.15 - 01:10 - Friday

Pump has just ripped out again. It's bleeding. [Sounds tired and distressed]. Turns out packing with a pump is very difficult. [Sigh].

Entry 3 – 14.10.15 - 08:57 - Wednesday

I am getting ready for work and changing the infusion set. It's difficult to remember when 3 days have gone by and it's time to change infusion set. I need to find a system to work it out, and not from memory. Do I need a calendar to tick it off? I think I need to look on a forum to see what other people do. I also need to change the tubing. I somehow managed to get the tubing, infusion set and cartridge all out of sync. I am [my life is] not in a regular pattern so the insulin cartridge is not being used in a regular way. It takes quite a long time to change the infusion set, so it's not that convenient when you are trying to hurry and make a move. It hurts to peel the very sticky sticker off. I think the sticker is amazing and it's really discrete, it sticks really well but it's bloody hard to get off. I keep forgetting which way round to put it so I clip it on weird - backwards. I'm finding it difficult to fit into my clothes easily. I am in a transitional period where I am in between houses and I'm finding it hard to store everything. Also I don't really have time to sew pockets into my clothes and I'm not even sure where the pockets should go, half my stuff is in storage. It's a lot to think about. When my stuff is out of storage and my housing is more stable hopefully I can think of ways to put pockets and stuff in my clothes.

Entry 4 – 18.10.15 - Saturday

I had some new issues – changing my infusion site [found it difficult to remember what the infusion site was called]. I need to do this every three days, but I'm told not to do it just before bed because if it stops working or doesn't work I won't know for a long time because I'll be asleep. So I replaced it this morning instead, but it took the third attempt for it to be successful because it wouldn't stick to my skin. This is unusual as they normally do stick. I was bleeding. It's a problem with the right hand side problem, so I had to move back to the left. I used two different boxes of infusion sets so they are different batches but it seems more about the side of the body – level to the belly button, towards the hip on right hand side – and it wouldn't stick but it is fine on left hand side. I am starting to notice little marks where the cannulas are going in. It often seeps or bleeds a little bit when I take them out. The infusion sets are tough to peel off and it usually hurts, but it's not too bad. I'm still finding it difficult to track the 3 days. Still working on how much to increase basal rates while I'm in the gym because I'm still having really high blood sugars afterwards after doing interval training. But the pump means I can check this and correct it much easier and much more specifically adjust and correct because I can give small units of insulin and also know how much insulin is on board. For example, if my BG is a little high before bed I would've to had to give myself 2 units of insulin or nothing, whereas now I can give 0.5 units instead, which is incredibly helpful. I'm impressed with that.

Entry 5 – 21.10.15 - Wednesday

I want to report my experience from last night. I was at a pub quiz last night. When at the quiz, I had to give myself insulin for pizza that I was about to eat, so I got my pump remote out and was administering some insulin and one of the pub quiz masters shouted out not to use my phone. I was a bit surprised and didn't know what she was talking about and my housemate shouted out that I had diabetes and it was my pump. At this point I hadn't even clocked on as quickly as she had, but then I realised that my pump remote looks like a mobile, and it was embarrassing as the other quiz master had seen me before my housemate shouted out and jokingly said that I couldn't use my phone but everyone was looking, and I explained and then they seemed embarrassed and didn't know what to do. I realised it looked like a mobile phone and a couple of people have mentioned it but I guess that makes it more discreet but on this occasion I did feel like a bit of a doofus. Otherwise it was a great night!

Entry 6 – 27.10.15 - 11:59 – Tuesday

I have been trying to work out if coffee is making my blood sugar high before lunch so was going to start giving myself insulin (for 10g of carbs) to see if that prevents it. However, I was putting a

note on my remote when trying to deliver insulin – saying that I was giving insulin for coffee, and the pump remote said there was an electronic error, so to hold the power button for 5 seconds to restart it. It is taking a long time to turn back on again, a few minutes. When it did turn back on again it had my grams of carbs still in there. I just wanted to record that this was an issue.

Entry 7 – 31.10.15 - 13:50 - Saturday

Just finished in the gym, increased basal rate to 130% while in the gym, which stopped just before I finished, ran 6k, BG was 8 point something, and so dealt with that and did BG after and it was 12. Not sure what to do to deal with this. I feel like I need to think more about this. I am wondering if my pump has to be in range for the temporary basal to continue working – is it still increasing my rate to 130% in that time or not? Was it working? Was it not functioning? But it didn't say it was a problem so I presume it's okay. I wonder what it would have been if I hadn't have increased it. I walked uphill, jogged and ran. I'm planning to keep trying to improve/perfect this.

Entry 8 – 03.11.15 - 10:08 - Tuesday

I was “playing around” with my pump yesterday and noticed that on 27th September there was no recording of how much insulin I had. I was in Toronto. I can't have not had any insulin that day. I know I changed the time but I was definitely in Toronto so it can't account for no recordings of insulin. Maybe the time difference has confused it.

I just got back from the Dermatologist – they gave me some emollient to try and get rid of the scab on my necrobiosis. Tacrolimus. This is based on a case study. I have to wait 3 months to see them again. They showed me the study. There a not many double blinded negative trials in this area because there aren't many dermatologists with an interest in diabetes so I don't have a clinician who would know about this as it's difficult to treat if they don't understand diabetes – the senior clinician I saw said that. There's a lack of specialist interest so not much research. Medical students came in and prodded it. It's nice to feel like someone is interested in your condition – it makes you feel like maybe something will be done. And when they say it is trying and testing that's okay and sounds reasonable. It's hard for my skin to heal, but he would be much more worried if I was older as it may ulcerate. I feel like I had a nice appointment because they spent a lot of time with me and seemed interested.

Entry 9 - 03.11.15 - 14:58 – Tuesday

Just tried to do my BG and my pump remote said “E57 electronic error, press and hold the power button for 30 seconds.” It's restarting. Took approx. 100 seconds to restart. It's so slow.

Entry 10 – 25.11.15 – during the day - Wednesday

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Just changing the cartridge on my pump. It's the middle of the working day so it's awkward – I realised I have to because I have less than 20 units left in it as I've still got dinner and boxing later so I'll need to change it. The annoying thing is that I am wearing a dress so I have to take different bits out at a time, and because it takes such a long time to pull the plunger back so it's quite annoying. I happen to have popped home so am doing it now because it beeped and told me my insulin cartridge is low but otherwise I would be in the office. I know I should think ahead but sometimes that is hard to do and you have the conundrum that the cartridges are quite small, but you don't want them to be bigger because you don't want the pump to be bigger but it does mean you have to change the cartridge more regularly.

Entry 11 – 01.12.15 - 00:41- Tuesday

Not long home. Bit stressed. I'm trying to finish a paper. I keep thinking I'm nearly finished but everything seems to be taking so long so it's hard to finish. I thought I'd be done by now so I agreed to take part in some diabetes research in London – they had an incentive of £80 and it was on BG meters. Pretty good incentive for a 2 ½ hour Focus Group. I was interested to see a focus group session about something to do with diabetes. Everyone was on insulin but half had Type 1 diabetes and half had Type 2 diabetes, and there were about 9 or 10 of us. The insulin users with Type 2 diabetes seemed to do at least one or two injections a day and wanted to carb count.

They kept saying the meters were for “busy people” – easier to access your results etc. I seemed to have a slightly different preference to most people, although I was younger so maybe this is why? But people kept wanting to talk about their experiences. It was obviously a pharma company who contacted this market research company to undertake these focus groups. They were obsessed about the kind of “concepts” people were interested in or not interested in. They described one meter in a few different ways and they were trying to find out what was the best way to describe it. They had a continuous glucose one which obviously everyone wanted this and participants kept saying “where can I sign up”, but these are expensive so it's not so easy to actually get these so it seemed like they were offering something unrealistic. One woman said one of the meters would “make it obvious that she had diabetes” and another woman said “why does it matter that you have diabetes, why would you be ashamed of that?”, and the first woman said “well I don't want people to know”. The one who didn't want people to know had Type 1 diabetes, the one that didn't mind had Type 2 diabetes, and she was really slim, but it was interesting. They were fighting both corners of whether people want to expose their diabetes or not, whatever type they had. They also spoke about not being able to get testing strips on the NHS but the market researcher didn't want to hear about those things. He did not want to know about the practicalities of the

meter, he wanted to know what we thought about how fast the meter was or that it does this and it has this feature. But people actually wanted to talk about how they felt and their experiences.

Entry 12 02.02.15 – 08:15 - Wednesday

BG was high this morning – 16. Something. I had a magnum last night but I did take the “apparently” appropriate amount of insulin, although I had an Ovaltine afterwards, so maybe that’s why it’s high but it keeps being high this week. I feel like I need to do a fasting test this week. I did change my infusion site but maybe it’s something to do with that. It’s confusing.

Entry 13 02.02.15 - 23:35 - Wednesday

I’ve just realised that for the past 3/4 hours I haven’t had my pump attached to me. I went boxing and came home and had a shower, took my insulin pump off and since then I’ve eaten dinner, eaten a magnum, put together some furniture (a galvanised TV stand), hung out with [housemate], but none of the insulin I have administered has gone into me. I guess I was trying to do too many things in a bit of a hurry. It’s now 21.5, I am surprised it’s not worse. I did have hot and sour soup though, which doesn’t have too many carbs in it. The weird thing was I put a new site on today, and putting them in is a bit painful and it is painful to take the old site out, the infusion set that is. I just thought I’d report that mishap.

Entry 14 02.12.15 - 23:38 - Wednesday

I just wanted to report that I felt ashamed at forgetting the pump for so long, and a bit worried at how useless I am. I am trying to figure out a way to clip it on to me, because I did have it in my sports bra wrapped up but now I have to find another way to put it on me now that I am wearing different clothes. Sometimes it’s tiring to think of all these things.

Entry 15 20.12.15 - 14:45 - Sunday

I have just realised that I have had my pump off for 2 hours. It’s a Sunday. I have been wondering around my home. I have been out for the last 5 consecutive days. I am not sure what impact that will have but the positive thing is I can fix it quite easily and quickly so it shouldn’t be too detrimental. Going out it has been difficult to put the pump in tight-ish fitting clothes. The Holster has been useful, although the Velcro on it keeps ripping my tights. However, tight fitting dresses actually hold the pump rather well. I have two holsters – one is quite bulky but the other one flattens the pump and fits nicely into my leg on my inner thigh. It’s more expensive though but is by Accu-chek – from their website – and it’s quite soft so I quite like that. I am feeling the need to get a sewing machine so I can sew pockets into my clothes. The one that hangs off your bra isn’t ideal because it pops off your bra all the time, and you can see if something is hanging on your

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bra, and trousers are difficult. I still haven't found a way around most of these things but I am getting better at putting the pump on my body in tactful positions. People still seem interested in and intrigued by the pump and I am finding it easy to tell people about the pump and I am finding it easier to explain to people about the pump than injections, which is nice. I am finding that the cartridges don't last very long though, maybe a few days. I get two packs of 5 every time I get a prescription, so I would like them to last a bit longer, especially as the more I am exercising the more insulin I am using, so that's annoying. But, in terms of mastering the increased basal while I'm exercising, I am getting pretty good at that; 150-160% increased basal seems to have quite a good outcome. My BGs are now relatively normal after exercising, so I am finding that kind of amazing really. But I have had such high BGs recently. I woke up with a BG of 19 yesterday, I think because I ate food when I came back from being out and forgot to give myself insulin for it. That's just a general issue though, and it's my fault, not a pump-specific issue. Actually, I do keep doing this – I have a shower and get my breakfast and I administer my insulin before I've reattached my pump, and then I realise and I reattached and then the pump isn't going off what my BGs are, and I am just guessing how much to correct my high blood sugar by. Also, the pump remote is slow and time-consuming, and when you're injecting you know the insulin is actually going in, rather than having to remember that it is or isn't attached. I am not sure if that's a common problem or if it; just me being a complete dimwit. I just need to sort my shit out really.

Entry 16 22.12.15 - 01.10 - Tuesday

I'm not feeling very well. I'm changing my infusion set – something which I've noticed as a problem a few times is when you change the part of the infusion set which connects the cannula to the pump [the tube and new insulin cartridge] that's a bit annoying because you have to take it apart, and the whole process is slow, it tells you to take your cartridge out and rewinds the piston rod, which is very slow, and usually at some point I get confused over whether I've taken the cartridge off the old infusion set or if it's the new one and because I change them at different points, and so I don't have a set routine. I would be interested in how often I actually change the tubing because I suspect I am keeping it on for longer than the supposed 6 days. Sometimes I've done the whole long process and then realise I've put the old tubing back on instead of the new one, and then you have to go through most of the long process again to correct this. However, I have realised that the new infusion set is more coiled as the old one has been stretched out more. It's a long annoying process. My housemate and I went to bed at the same time and she's probably been in bed for half an hour already while I've been dealing with all of this. Practical issues. Now I need to check, and maybe correct, my BG level on top of this. I note that I should probably make a note of all of these and work out ways to get around these problems, because

sometimes there are too many issues so I don't plan for or deal with any of them, whereas really I should focus on one at a time and deal with them bit-by-bit, so it's less overwhelming.

Entry 17 22.12.15 - 01:15 - Tuesday

Just did my BG which was 6.7 which was really nice so not a problem. I'm not well so it makes it harder to keep them down, but the illness is not pushing my BGs up too much which is good.

Entry 18 23.12.15 - 14:12 - Wednesday

I realised I am running low on prescriptions so trying to log on to online prescription ordering – I have 4 insulin cartridges left as they only last a few days each and it'll be closed over Christmas and I'll be away. I feel like I am really on the edge of it – when I order I don't get a supply that lasts me long enough. I seem to be frequently ordering them. I order them once a month. I can't order my test strips or insulin – which were both last requested on 27th November, yet I am not allowed to order them again until 25th December, but they only last that length of time, and bearing in mind they are closed a lot over Christmas – I am away and they won't be open much so I will have a very small window to order them. I can't actually order my insulin, which I need to live, until Christmas day, and they will not actually be open, so it won't be a case that I will have to just wait 48 hours as it will be longer than that. I'm not sure what to do. I couldn't have ordered them sooner as the system won't let me. [Sigh].

Entry 19 23.12.15 - 14:15 - Wednesday

I have a cold. [laughs] Right, methodological issue – my colleague burped in the background during my last transmission – practical issues – it was him drinking too much coke apparently [laughs] the practicalities of doing an autoethnographic study; you cannot just record anywhere.

Entry 20 08.01.16 - 18:09 - Friday

I am in Ireland. I went for a run, for 7km, I didn't take any increased basal as I was going to be in the middle of nowhere, and I carried 2 sugar tablets with me. I haven't eaten or drunk anything. I did take an adjustment dose before I went, but my BG is 20.5. So I definitely need an increased basal. An hour 15 before I went my BG was 19.1 (I don't know why). I had 3.1 bolus, and I went for a 7km run and now it's 20.5, 3 ½ hours later. I have now had a dose of 3.2. So the increased basal is helpful. I also still have a bit of a cold so that isn't helping.

Entry 21 13.01.16 - 23:05 - Wednesday

Update for over Christmas. Where to start? Off the top of my head; It was quite difficult because I was eating at different times of day and lots of random meals and no regular routine, so it was

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difficult to keep on top of managing diabetes and I had a cold and now I seem to have another one so it was difficult managing diabetes. Sleeping was difficult. People were offering food all the time and I was constantly having to give myself insulin, which was easier on a pump but it was difficult putting in my infusion set. Sometimes it was painful putting in my infusion set or sometimes it did not seem to work. I was in Ireland last weekend I brought enough infusion sets with me, to last about 12 days. I had to use them all within a couple of days because none of them seemed to work – not sure if it was my skin or the package – my pump kept saying that it was blocked – which was really annoying – I had a really high BG most of the time because my pump wouldn't work. I kept changing everything all the time but nothing seemed to work. I used 3 or 4 infusions into my skin and I moved it to different sites but it would still say it's blocked and nothing seemed to work. The thing is when I got back to the UK, I did try the same pack and I didn't have a problem since. Actually I did change that and I accidentally ripped that out because it was in my pocket – the clip I usually use to clip onto my bra snapped – it kept on unclipping itself is now it's snapped so it doesn't clip onto anything. I have only had it for a few months and it's already broken. I am now using the band that goes around my thigh but it's either too tight or too loose and falls down my thigh. So not ideal at the moment. The band is also quite thin so feels a bit strange round my waist, but I have one on like that now in bed. But it's been really uncomfortable recently. The wire is quite long and is easy to pull out. I am finding it hard to sleep comfortably, I think it's because I am a restless sleeper so I don't sleep in one position. So the pump stopped working, it's difficult to keep track of my varying diet. If you don't have a routine it's all difficult. With it not working it's difficult running because I can't increase my basal. It has been very frustrating.

Entry 22 19.02.15 - 10:57 - Friday

I have had a few issues – the insulin pump stopped working in Ireland – even though I changed everything it still had problems. It has been working since then. Maybe 3 or 4 times it has given me an error message on my pump remote, which has been annoying. Each time I put a new battery in it never says “100%” even though it's a brand new battery. Sometimes the battery goes down and then it goes up again. At the beginning when it starts to go down it goes down really quickly. I have been carrying spare batteries around with me. I'm anxious it will just stop. I worry when I am exercising, or going away just in case it depletes. Numerous people have commented on my remote thinking it is a phone, or a “very old phone” they would say. I've been finding it hard to place it on my clothes – it's getting a bit tiresome. I think I really want need sewing machine to sew things pockets into my clothes. Most days my clothes are dictated by the pump i.e. I am going to be walking a lot so I can't wear the holster around my leg. The other day I was walking around campus and it started falling down my leg – I had to adjust it on my upper thigh in the middle of

campus – I had to pull my skirt up and fix it – luckily it was quiet but it was embarrassing to have to fix it in public – I was praying that no one would come along and see my fiddling with this weird thing on my leg like “what the fuck is that?”. That was a bit embarrassing and I was feeling a bit up fed by then. I had the holster on really tight as well. Maybe because I have been running a lot my legs are a bit smaller so it’s not sticking on my leg as well, or maybe the stickiness of the Velcro is going? But the bra clip is broken so I need to get another one. But they are very expensive. I bought underwear too. One goes round my waist but my waist is quite small so it sits low and bounces about. Jeans might be okay but if you’re wearing tight jeans it bulges out on your hip. I am also at a new GP surgery which is a bit of a nightmare – trying to arrange an appointment to sort out my prescriptions. I finally managed to get a cancellation today. Fortunately because you get a letter from the pump clinic to say you need a significant amount of BG tests usually the surgery is quite amenable to that so once you’ve got your letter and you’ve convinced them – you are able to articulate yourself then they’ll give you more testing strips than you get otherwise, which is nice.

My exercise basal rate has changed – the fat and muscle distribution has changed – now I am having hypos instead of high BGs and now I am not giving myself any extra insulin for exercise and I come out perfect. Something has changed now that I am doing less running. My pump is amazing because I can adjust that so easily. I have cancelled an increased basal during the exercise where I would have been stuck with it if I’d have injected it in. Which is amazing.

I have had diabetes for 22 years and 8 months, since June 1993, and according to large scale trials I should have diabetic retinopathy by now. I should have had it a few years ago, but I hadn’t. I opened a letter today, which has revealed that I now do have background retinopathy (reads out letter). So either it was going to happen inevitably anyway or I’ve made it worse by doing all this exercise and making my BG levels high, or maybe it would have happened anyway. But now I have it. And I can’t un-have it. On the positive side I feel like my BG levels are better. I’m really intrigued about what my HbA1c levels are – considering the level of adjustment that I’ve had to do but I’m pretty certain that my HbA1c will improve from the pump, so hopefully I can ensure that my retinopathy does not get worse.

Entry 23 19.02.16 11:07 Friday

I wanted to do some entries about the more intimate aspects of having a pump – I have read some blogs about this – when I spoke to some of the girls at the insulin pump conference at the local hospital, before I went on the pump, they were discussing how some pumps are more discrete for sexual encounters – ones in which the tubing isn’t attached to you. My experience before when I had a boyfriend when I first had the pump, up until a few months ago, was that he was fine about

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it. It did get in the way and you have to remember to unclip it. And you have to remember to clip it back on after, especially if you might want to revisit any intimate moments. So it's hard to know when to put it back on or not. And you get the cord yanked. I since met someone else and hadn't mentioned on our dates that I had T1D, and then when we were going to be more intimate I didn't know what to say or how to say it. When I had injections, although if having dinner it's easier to go for dinner and give yourself some insulin on "Your old mobile phone" whereas you'd have to slip off to the toilets to inject yourself, but when it comes to sex, you don't have your pen out. You won't be able to check your BG levels – not knowing if you'll be having a hypo or high with a dry mouth, but with the pump you can't avoid talking about it. I'm not into one night stands it must be so awkward, "this thing that's attached to me is an insulin pump", it would be so awkward. It's probably easier when you're dating someone but the problem is when you're dating someone you're getting to know them and intending on having some form of prolonged relationship with them and they then assess you "do I want to carry on dating this person who has this chronic condition", or this weird thing they don't understand. The guy I am dating is Spanish, and there is probably some translation issues, or lost in translation issues actually, on an ongoing basis anyway. This was difficult to bring up. You don't know what to say and will they understand it? Even if they're English will they understand it? I didn't mention it until we were pretty much taking our clothes off. Luckily I'd had talked about my research in T1D. I tried to unclip it smoothly. He seemed okay about it. It doesn't mean he was. Luckily it's quite discrete. It's hard. You feel so different. So robotic. The next time I had the band around my waist and I had to unclip it and slip it over my head, in a non-crazy way, and a graceful way and I think I did it alright. I don't know if people care about it. I don't know if guys do care about it. Maybe it's harder for guys with diabetes. The woman may be thinking further ahead, possibly, and may be more likely to think of "breeding" potential [laughs]. I've heard another person with diabetes, who is a man, wonder if girls think about carrying that "defect" on. I just thought I'd make a log of these things, and how I deal with it. I would suggest that the less of a big deal you make it, and the smoother you can unclip it etc. the less they will think about it as a big deal. Another thing, strangely, guys are really interested in the technology wondering about the mechanics of the machinery, and less scary overall than injections!

Entry 24 11.04.16 - 14:09 - Monday

I'm about to go and give a presentation and I am very nervous, and I think my BGs are going high as a result – the usual anxiety induced high BG. I'm worried about whether my pump is going to fall off or beep or something. And it's on diabetes, so that's interesting. I want to eat something, but I don't want my BG levels fluctuating because if I eat now, it's in 50 minutes time, so I'll need

to do something with my BGs but I'd rather they stay as stable as possible and introducing food doesn't help that.

Entry 25 11.04.16 - 21:50 - Monday

I got into bed, and I've ripped my infusion set so it's stuck to me but the bit that the tube clips onto flipped up and the cannula has come out of my skin. I'm trying to take a photo – took it. Didn't hurt but it was a weird kind of yank. I always wonder if I've damaged the tube – how stretchy is the tube?

Reporting back from earlier – where I felt my BGs go up. Before the presentation I did my BG and it was 24, and afterwards it was 12, but interestingly my pump seems to have given me too much insulin, so I ate some crisps, then I went to the gym. I still have to do the fasting tests... one of my priorities for the next couple of weeks (NB I didn't do it). I need to find out when my next consultation is. I need to pick up my prescription because I don't have many left. With all of the prescription stuff I find I get completely out of sync, and it's hard to keep on top of it all. My HbA1c was a little bit better. My meter - I think I test when I know it's not right, rather than when I know it is right I don't because I feel fine. So when it feels fine I think "I don't need to do it" and when I do feel a bit high then I test it then. I don't have much time so I am being economical with testing, never mind ordering prescriptions more often. So I don't think it's an accurate record. I don't really want to test when I don't want to but I do test when I want my pump to give me the right insulin. BG readings are a crass reassurance – at dinner times or when you think you know what your BG is. Less likely to test when you know it's okay – unless you want to skew your results for that very reason?

I changed my infusion set a day early because I ripped that one out.

My skin is getting a little sensitive, and dry and I'm getting little dots around my stomach. I am not sure how bad that will get but I only had it put in in September, so how bad is it going to get?

I still prefer the pump to injections, even though it's a bit difficult describing it to new people. I've purposely not told people. Some people I find it's more okay to tell them, it's a bit of a novel thing – they're interested in the technology and it's kind of cool. It seems less scary than needles, but then I think I seem a bit more abnormal in a sense because I have a machine attached to me.

When I describe it people look a bit freaked out but when I show them the site it looks okay because it's quite small, especially if I take the tube out because otherwise it looks like I have some kind of drip attached to me. That's what it reminds me of, when I had a drip attached to me. It's just there all of the time, and you're trying to go to the toilet and it's just this drip that's following you around, and you can't do anything properly because you've got to be careful where the tube is

going and if you knock the drip over or pull the cannula out. But when I take it out then people see this little sticker on my stomach and it seems okay.

Entry 26 11.04.16 - 21:57 - Monday

In intimate relationships the pump can be quite interesting. So, originally, on the first date I told this person about the pump, and they seemed quite interested, but people forget about the pump when it gets to more intimate relations, and you get more close and your body becomes more exposed and then the pump is there and you have to try and swiftly remove it/untangle it, before it gets yanked or it gets pulled because it's strapped round your thigh, and you are taking your clothes off and you don't want to ruin the mood, and point out to the person "oh I know you're trying to be really intimate with me right now, but my weird robotic machine thing is attached to me via a tube" erm so that's something I haven't quite mastered yet. So, we'll see how that goes, but it's a bit embarrassing. But I think the infusion sticker bit is fine. That doesn't seem to be a problem. It's just the tube. The tube is the problem. The tube makes it much more evident that there is something there. It's hard to hide.

Entry 27 11.04.19 - 21:59 - Monday

The tube is still difficult to hide. I still need to get a sewing machine to sew things into my clothes. I find it difficult to put it places when I'm running. When I'm running I have to put it in a bag and put that into my sports bra, but sometimes this comes out and my arm catches in it or when I'm skipping it can come out or doing burpees so it comes out a lot and is embarrassing. I find it's a bit of a hazard. And it does come out of my bra more. And my stomach isn't ideal because I don't have many clothes that would also it to be on there – it's fine for while but it does feel like tights where they restrain you all day. I think my thighs have got smaller and the Velcro one comes undone or the other band slips down. I am still searching for a solution.

Entry 28 22.04.16 - 10:46 - Friday

Reflecting on the patient pump conference 2 days ago. It was really good to go. I was supposed to be invited to this group about the kind of pump you're on so you can meet others with your pump and I heard two guys talking about another group – an exercise group that they went to. The idea sounds interesting the ones coming up are specific to what pump you are on, so you talk about the nuances with your own pump with others on the same pump. But they went to an exercise specific group that I was supposed to be invited to before the conference – so exercise and having a pump. They were talking about exercise and the different kinds of exercise they do and the effects it has, and it sounds like they were carrying on a conversation they had before which makes me think they went to the group, and he was speaking about the exercise group. It was really interesting

overhearing other people talk about things, they were talking so normally about having a pump and issues with the pump, and the diabetes pump service team were standing proudly around. I didn't feel that I had the same experience as all of them. One woman said she'd had air bubbles in her pump and she sounded very dramatic about it. It sounded like it might have been a unique experience. She was very dramatic about it. I felt like we dealt with things differently. She sounded like she really panicked and almost had a heart attack – and it was very dramatic language she used, and I just thought, she had a completely different way of dealing with it than me. I don't know how that affects how we look after it but the way she handled it sounded very stressful. Does the pump add more stress to someone? Less good for quality of life? I think how you deal with a situation could be interplaying with how you deal with everything. It was interesting talking to others and nice to be able to talk to people in ways that mean something to you rather than doctors saying what the pros of the pump are. I never realised how amazing not doing injections would make me feel. It was that that really emotionally connected me to it. It was such a task. You never knew if it would be absorbed right. It's adjustable. It's like a friend that can give you some advice and let you exactly know how much insulin is in there. I can probably think about diabetes a little bit less, just a little bit less, with the pump, and actually that seems to make a lot of difference. Other people have a phone looking device, so a remote doesn't feel like a big deal, but no one has a syringe, or an injection so you can't normalise that so easily but the pump you can.

I was on a date the other day, and I had to run for a train, and my pump dropped from my thigh, and he asked if I was okay, and I grabbed it and he was distracted by the train and hasn't said anything but that wasn't ideal, the pump just falling off you and revealing itself, but at that stage it is easier to hide.

Entry 29 27.04.16 - 16:15- Wednesday

My pump malfunctioned when I was in a training session and made a loud beeping noise, it was really embarrassing. Still malfunctioning. Awkward.

Entry 30 07.05.16 16:59

I just took my infusion set off and it was bleeding. I just wanted to make a note of that.

Entry 31 09.08.16 09:57 Tuesday

My needs seem to have changed as I've not been working out as much – I have had to change my units and my ratio for carb to insulin ratio. And also I'm not increasing when I'm doing interval training. But I'm back into training again now so it may change again now. When it was warm the other day my infusion set fell off while I was running. It's like if it's warm it comes off easier – the

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week before I was having a lot of hypos although I was trying to eat more to replenish my glycogen store.

Entry 32 17.08.16 11:06 Wednesday

I just wanted to make a note that most times I take the infusion set out it bleeds, and it hurts too. My needs are still changing. I guess I don't have enough of a routine. I am training again now so it may change again.

Entry 33 04.10.16 15:53

Just been on the phone with the pump helpline – about technical difficulties I've been having – to keeps coming up with an error message 57 and it's happening very regularly – sometimes x2 a day. Also the battery seems to be depleting very suddenly = what it is saying on the screen of the pump doesn't match the situation with the remote. The battery charge keeps changing – it will be "full" and then dead or the opposite. I rang them this morning at 10:30, it said it went through to the American office, didn't get through. Rang again now and I got through to someone. They were really good and went through each part of the remote with me and went through what the error messages mean. It's a known error and they're currently developing it to make it better so they'll; send me a new remote but it may be an issue that still comes up. But what seems to help is charging it, and when it says it's fully charged leave it for another 10 seconds, so I'll try that. They're also sending a new battery. They also recommend charging it every night even if it doesn't look like it needs it, but that doesn't seem very convenient. She went through step-by-step which was really helpful but it keep turning off its very convenient. But it felt really supportive and helpful ringing the helpline. Although they've sent through an outdated notice, and to my old address – apparently they have two different systems (which isn't helpful...).

Entry 34 05.10.16 11:55 Wednesday

I can't find any of the straps that attach the pump to my body – the one I did like is stretched so now it falls done my body. You need to have a number of them because obviously they are very close to your body so need washing regularly. So now I am having to change my outfit and try and find something that has pockets as I can't find any more straps or the rest are in the wash, but I have hardly any items of clothing with pockets, and then it bulges out of the pocket. Practical issue.

Entry 35 19.10.16 19:28 Wednesday

Went to the gym, BG was high pre-gym, I gave some insulin – but less than I would normally - thought my run would make my BG levels increase but the walk home (45 minute walk) would

make BG levels decrease. My BG now is 15.5, and was 22.3 before. On my remote it says I've still got 2.64 units being processed. But that doesn't translate – each point will bring me down 3 – so now I've learnt not to think of it the same as correction doses, because it doesn't seem to work the same. I don't know why. I've "realised" that the thing that makes it different from just injections – although I know there is research on bolus advisors, whether and why they are good etc. – but I think an added bonus of a bolus advisor with your pump is that, "well it's obvious but that it knows exactly how much insulin you've got in you at the time, exactly." If I'd have injected myself with that insulin, I'd be sitting here thinking "I know how much I've given myself, I'm not sure the exact time I took it. But the pump remote tells you exactly what time you took it and exactly how much you took (without having to write it down). So you think I'll ride it out and see how it goes rather than giving more insulin right now or eating some sugar. That's why the pump has this "extra level of support, control, choice and options". You could calculate all that yourself but in practice that is really hard when – say I've been working and working later than I expect to, I rush to the gym, then I walked home, and now I am about to rush out again and I quickly showered and changed and doing my makeup. I'm in a hurry; I can't hold all of this information all of the time, I can't write it down all of the time, and I don't. I am not someone who does that very easily, I find it really unnatural to log/record all of my activities, and tiresome, burdensome. So I love that it's all on this meter. I just wanted to highlight that. I find it extra useful, I guess, than just being a bolus advisor. It has more information, and less work inputting. There's a record of every single bit of insulin that goes in my body, and that's really powerful information for me. And obviously we are all different and we can tweak it easier according to your own body because it's there. All of the information is there. In general we're terrible at guessing. Sometimes we're really good at guessing and we have a general feeling about something, and sometimes it's intangible what it is that we know is right or wrong, but I think this just kind of explains it all a bit more – why. It's so personal, it backs you up sometimes like now – it's 15.5 but my machine says I'm going to be okay, so I will leave my diabetes BG levels for a bit and see if they are okay. Maybe they won't be but it won't be my fault if I leave it now to play out. You have a physical visual memory of that.

Entry 36 15.11.16 - 12:26 - Tuesday

I have two points:

I went to London (South) last weekend (am) and I thought I brought all of my kit with me but it turns out I did not have a spare infusion set. I was changing my clothes, pulled my tights down and they caught on my infusion set that I had put in that day, and snapped it. I did have Novorapid (short-acting insulin) with me but I did not have Lantus (long-acting insulin), and I was staying the night. I spoke to my mother (who lives in North West London) who I was meeting for lunch, she

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said she would speak to my old family chemist and see if they could give her some Lantus. I had one needle with me that I would have alternated using the short-acting and then the long-acting insulin. I also spoke to 111 and asked if they could send a long acting prescription to a chemist that was nearby in South London, they said they would call back and get the duty doctor to do that. I also posted on Facebook on a site for people with pumps to ask if they knew anyone in London I could meet up with to get an infusion set from. They said there was a Facebook page that was called "Help I've forgot my T1D kit" and where people from round the country report when they've not got equipment and need it. I tried to join that group but it took 12 hours or 24 hours to actually get accepted so I couldn't post on it, but someone through this peer-support group on FB posted on it on my behalf and also posted it on Twitter (and they have a lot of followers). Someone responded to them and said they'd post on a London site for me. Some other girls said they would meet me at Waterloo and give me a couple of infusion sets. Then we got in contact with each other directly and arranged to meet up. So through someone with diabetes, through someone else with diabetes, through someone else with diabetes through someone else with diabetes that meant that I could meet up with them later on (early evening) and get an infusion kit. In the meantime I did meet my mum and she did manage to get long-acting insulin from our old family chemist, who said that if I could get the prescription sent directly to them they would be able to claim back for the insulin pens. So I was helped by social support networks and the resources I was able to tap into through social media and personal connections. My mum helped me out by speaking to the chemist, the chemist was very helpful and knew me and helped my mum, out and then these people I hardly know through my online connections, my "weak ties", helped me. So "it was incredible". People were incredibly helpful and I felt very lucky that I could get help within a few hours. I got everything I needed. Otherwise I would have had to cancel all my plans in London for the next two days and gone back to Southampton to get my kit. So feeling very grateful. I used 111 before (2 ½ years ago) and they were really unhelpful. I called them in the morning, first thing, on a Saturday and at 11pm that night still could not get hold of any insulin so went to A&E in Bath and waited over an hour with a BG level of over 30 to get one short-acting insulin pen. But this time they were flexible and helpful too and sent the prescription to my old family chemist.

My second point is that I have an insulin pump review tomorrow. I got a blood test last week so I rang my GP surgery two weeks ago and requested a blood test. They said the waiting time was 3 weeks. So tried to ring them all day to pick up a blood test form and prescription and when I told the receptionist I had been trying all day she said "oh I don't know why that is, we've had four receptionists on all day" and I thought, "well, well done, but I still couldn't get through so that's not very helpful." Anyway, they weren't very nice or helpful. I did manage to pick up a blood test form and went to the hospital and got the blood test done. I rung today asking for the results and

they said “yes we have your results but it says I can’t give you the results, you have to speak to a doctor.” I questioned this. I asked if there was any reason I can’t see my results. She said “no I am not clinically trained so I can’t give you your blood test results”. So I said “why is that?” and she said in case I, the patient, did not understand the results, so I have to speak to a doctor about it, and could I see a doctor at 16:10, and I said no because I had a meeting. I said that I was not happy not being able to see my results considering I am a patient who has had diabetes for over 23 years and I am a health researcher, I am pretty sure I can understand my results. But apparently the surgery does not trust me to have my own results of my own blood. I was told that “some people can’t read their results”, well, I can so give them to me. Apparently “these are safeguards so patients don’t read their own results”, well I am not sure what a patient would do with their own information but this surgery seem to think that patients can’t be trusted with their own results. I am not sure what they think the patients are going to do with those results. I found it incredibly unhelpful and I am not very happy about it. It seems patronising. I just wanted to report on that.

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