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Author(s)	Hynes, Lisa
Publication Date	2015-09-24
Item record	http://hdl.handle.net/10379/5447

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**Using mixed methods to develop and test a theory of clinic attendance behaviour among
young adults with type 1 diabetes**

Thesis submitted for the Degree of Doctor of Philosophy

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Submitted September 2015

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Declaration

I declare that this thesis has not been submitted as an exercise at this or any other university.

I declare that this thesis is entirely my own work.

Signed: _____

Lisa Hynes

Statement of contribution

The candidate was responsible for the design, data collection, analysis and write-up of each of the three studies conducted in this research. The supervisory team, Graduate Research Committee, and local experts advised and provided support in conducting the research.

Funding

This work is funded by a Doctoral Research Scholarship from the College of Arts, Social Science and Celtic Studies in the National University of Ireland, Galway.

Acknowledgements

I have many people to be grateful to after the last four years. Firstly I would like to thank my primary supervisor, Dr Molly Byrne for her guidance, support and kindness from the first time I spoke to her about doing a PhD. I would also like to thank my co-supervisor, Dr Sean Dinneen for his energy and dedication to both research and clinical practice. I was very lucky to have a group of experts on my Graduate Research Committee, Dr Brian McGuire, Dr Máire O'Donnell and Dr Dympna Casey, who contributed hugely to this work. Thank you all!

I would like to say a special thanks to the members of staff in the diabetes day centre in University Hospital Galway for allowing me to become part of their team over the last four years. In particular, thanks to Mary Clare O'Hara, my PhD buddy, mentor and friend.

I have been supported and encouraged by every member of staff and by my fellow PhD students here in NUI, Galway to become the researcher and person I am. Thanks to everyone but a special mention has to be made for Deirdre, Teresa, Jenny, Corinna, Kristin, Ronan & Charlotte. It's been some four years!

For constant love, interest, patience and dinners, thanks to my family, my mom Claire and dad Sean, and my brothers, Mark and Barry. To my BFF's, Aoife, Hannah and Chloe, thanks for going on cheap holidays with me and keeping my life fun!

Finally, I would like to thank the young people and service providers who took part in this research and provided so much more than data.

Abstract

Background Clinic non-attendance among young adults with type 1 diabetes has been widely reported in previous research. Research suggests that regular attendance at diabetes clinics may be particularly important for young adults due to the challenges and risks associated with life as a young adult with type 1 diabetes. Therefore, interventions to improve clinic attendance among young adults with type 1 diabetes are needed. However, due to a lack of research focusing on clinic attendance behaviour, research is needed to develop a theoretical basis for future behaviour change interventions.

Aim The aim of this research is to develop and test a theory of clinic attendance among young adults with type 1 diabetes. This theory will provide a basis for future interventions targeting clinic attendance behaviour in this population.

Methods Following the guidelines of the UK Medical Research Council Framework for developing complex interventions, three studies were conducted in this research to address the three steps in the development phase of this framework. In study 1 a systematic review was conducted to identify the evidence base related to barriers and facilitators to clinic attendance among young adults with type 1 diabetes. A qualitative study involving young adults with type 1 diabetes and diabetes service providers, was conducted in study 2 to develop a theory of clinic attendance. Grounded theory was the method used to guide the approach to data collection and analysis, and theory development. In study 3, the theory of clinic attendance produced by the findings of study 1 and study 2, was tested. Young adults were recruited online and through diabetes clinics in the Republic of Ireland to complete a questionnaire. Structural Equation Modelling and moderation analyses were used to analyse the data.

Findings In study 1, a total of 12 studies (8 quantitative and 4 qualitative) were identified in the systematic review and analysed in a narrative synthesis. Clinic and young adult-related factors, such as difficulties communicating with the clinic and negative perceptions regarding the value of attendance, acted as barriers to adult diabetes clinic attendance in this study. In study 2, opportunities for contact between young adults and service providers facilitated the development of collaborative relationships, resulting in the engagement of young adults with the diabetes clinic. Regular clinic attendance behaviour was established or maintained in this study as a result of good relationships between young adults and service providers due to the increased value of attendance and a reduction in the impact of factors such as distress on attendance. According to the findings of study 3, collaborative relationships between young adults and service providers predicted attendance rates and informal contact, for example by telephone, and the engagement of young adults. The demographic variables gender and treatment modality, but not clinic or young-adult related variables, contributed to the prediction of clinic attendance behaviour in this study. Opportunities for contact between young adults and service providers, and the engagement of young adults, did not predict clinic attendance behaviour.

Conclusion The findings of this research contribute to insights in relation to clinic attendance behaviour and highlight modifiable factors related to clinic attendance. Clinic attendance behaviour comprises attendance at scheduled appointments, and informal contact between appointments to seek support and to cancel and reschedule unsuitable appointments. Interventions designed to improve relationships between young adults and service providers, and remove existing barriers to relationship development may be most effective in improving clinic attendance behaviour. Targets for future interventions may include improving continuity of care during transition and in adult diabetes clinics or supporting effective consultations using patient-centred approaches.

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List of Abbreviations

ADA	American Diabetes Association
DAFNE	Dose Adjustment For Normal Eating
DCCT	Diabetes Control and Complications Trial
HbA1c	Haemoglobin A1c
MAR	Missing At Random
MCAR	Missing Completely At Random
MDII	Multiple Daily Insulin Injections
MNAR	Missing Not At Random
MRC	Medical Research Council
NICE	National Institute for Health and Care Excellence
PRISMA	Preferred Reporting Items for Systematic-Reviews and Meta-Analyses
SEM	Structural Equation Modelling
SEP	Structured Education Programme
SMBG	Self-Monitoring of Blood Glucose

1. Introduction: The problem of clinic non-attendance among young adults with type 1 diabetes

1.1 Chapter overview

In this chapter the background to this research will be described. An introduction to important aspects of the study will be presented, such as information related to type 1 diabetes, self-management of type 1 diabetes, the implications of living with type 1 diabetes for young adults, and the relevance of these factors in relation to diabetes clinic attendance. The rationale for the current research will then be made, with the outline for this thesis.

1.2 Type 1 diabetes

Type 1 diabetes is an auto-immune disease which results in the destruction of the insulin-producing beta cells in the pancreas (Daneman, 2006). People with type 1 diabetes self-administer insulin daily, by injection or insulin pump, to maintain a level of control of blood glucose levels, known as glycaemic control. Self-management of type 1 diabetes aims to reduce mortality, acute and chronic diabetes-related complications, and maximise quality of life (Chiang, Kirkman, Laffel, & Peters, 2014). Acute complications associated with type 1 diabetes include hypoglycaemia, meaning severely low blood glucose levels, and chronic complications include retinopathy and nephropathy, which effect vision and kidney function (Daneman, 2006).

Type 1 diabetes is one of the most prevalent chronic conditions of childhood, along with asthma and cystic fibrosis (Torpy, 2010). Although type 1 diabetes accounts for 5-10% of all cases of diabetes, the prevalence of this condition is increasing, particularly among children under five years (Daneman, 2006; C. Patterson et al., 2014). The cause of type 1 diabetes is unknown, but there is likely to be a strong genetic component (Daneman, 2006; C. Patterson et al., 2014).

There are important psychological, social and developmental implications of living with type 1 diabetes which affect the quality of life and self-management of people with type 1 diabetes. Physical and psychological co-morbidities are common among people with type 1 diabetes e.g. coeliac (Holmes, 2002) or thyroid disease (Umpierrez et al., 2003), disordered eating or insulin omission (J. M. Jones, Lawson, Daneman, Olmsted, & Rodin, 2000) and, anxiety and depression (Kovacs, Goldston, Obrosky, & Bonar, 1997). Among people diagnosed with type 1 diabetes, twice as many deaths were reported in a study of 10 European countries in comparison to the general population of the same age and gender (C. Patterson et al., 2009).

Due to the high rates of diagnosis during childhood and adolescence (Daneman, 2006), every life stage may be affected by a diagnosis with type 1 diabetes (Chiang et al., 2014). For example, parents and young children may struggle to coordinate the administration of insulin and eating, or to manage insulin at school. During adolescence, diabetes related conflict in the family, and issues surrounding identity development and being 'normal' are common. Young adults must learn to interact with the health system, and engage in self-management in complex social and professional contexts. Adults with type 1 diabetes must navigate the stresses and demands of adult life including raising a family and working (B. J. Anderson & Wolpert, 2004; Chiang et al., 2014; NICE, 2004).

1.3 Diabetes self-management

Diabetes self-management comprises six broad areas: carbohydrate counting and awareness, insulin dose adjustment, self-monitoring of blood glucose, managing hypoglycaemia, managing equipment and injection sites, and accessing health care (Grant et al., 2013). The specific behaviours within the broad areas of self-management include reading food labels, adjusting quick-acting insulin according to the carbohydrate content of

food, self-monitoring of blood glucose (SMBG) before a meal or after a hypoglycaemia, and attending diabetes clinic appointments (Grant et al., 2013). Therefore, diabetes self-management involves complex daily tasks and more occasional tasks like attending diabetes clinic appointments. Self-management tasks such as SMBG and attending clinic appointments require equipment, time, planning, and skills such as communicating with service providers and implementing recommendations.

Over the last 10-15 years, diabetes self-management has progressed from being a strict, standardised regime to being more flexible and personalised (Nathan, 2014). Advances in insulin production, medical devices, mobile technology, and structured education programmes (SEP) for diabetes have resulted in the potential for people with type 1 diabetes to achieve glycaemic control while maximising and maintaining their quality of life (Barnard et al., 2014; Chiang et al., 2014; Grant et al., 2013).

Glycaemic control is assessed based on the physiological marker of diabetes control, haemoglobin A1c (HbA1c). Values for HbA1c that are at or below 7% in the United States (Chiang et al., 2014) and 7.5% in the United Kingdom (NICE, 2004) indicate optimal glycaemic control. Existing research related to adherence to diabetes self-management and glycaemic control illustrate that the work required of the individual to achieve glycaemic control and a good quality of life is considerable and challenging (Davies, 2004). Adherence to self-management was second lowest among people with diabetes in comparison to other chronic conditions, at 68% (DiMatteo, 2004). Among people with type 1 diabetes in the UK, 28% of measurements for glycaemic control were $\leq 7.5\%$ (National Health Service, 2011). However among young people aged between 16 and 24 years, 33% had considerably elevated measurements (National Health Service, 2011). As age increases, glycaemic control tended to improve suggesting that additional investment is needed to support young adults with type 1 diabetes (National Health Service, 2011).

Clinic attendance behaviour is the focus of this research and an integral area within diabetes self-management. Diabetes clinic attendance is a core self-management behaviour, associated with better diabetes-related outcomes (Dyer, Lloyd, Lancashire, Bain, & Barnett, 1998; Grant et al., 2013). The purpose of diabetes clinic attendance is for the prevention or early detection of diabetes-related complications, enabling timely intervention (DCCT, 1993). The clinic purpose is achieved by screening for signs of chronic complications, reviewing blood glucose results, evaluating glycaemic control based on HbA1c, reinforcing optimal self-management, and addressing service user's problems or questions. Diabetes self-management education and support from diabetes service providers, including goal-setting and reassurance, are recommended as part of the measures to achieve this aim (Chiang et al., 2014). According to guidelines from the American Diabetes Association (ADA), adults with type 1 diabetes are recommended to attend four diabetes clinic appointments annually (Chiang et al., 2014). A systematic review of characteristics of optimal service delivery for young people with type 1 diabetes reported that 3 to 4 visits per year was associated with lower HbA1c (Hatherly, Overland, Smith, Taylor, & Johnston, 2009). According to Dyer et al., (1998) improvements in glycaemic control were experienced by people who attended 75% or more of their diabetes clinic appointments per year.

1.4 Emerging adulthood and risk for young adults with type 1 diabetes

The life stage from age 18 to 30 years consists of two phases: emerging adulthood (18-25 years) and young adulthood (25-30 years) (Arnett, 2000). This period is characterised by change and development, but also by risks and challenges. Young adults experiment and adapt in crucial aspects of their adult lives such as romantic relationships, financial independence, education and career development. However, many of the risky behaviours associated with the teenage years, such as risky sexual behaviour, and drug and alcohol use

and abuse, have been found to reach their highest levels during emerging adulthood (Arnett, 2000).

The period from age 18-25 has been relabelled emerging adulthood due to the changes which have occurred to traditional roles and trajectories of life during this time. Some of the major changes relate to extended periods in higher education, and time spent travelling and living abroad. As a result, young people are living at home longer, less financially independent, and commit later to long-term relationships and starting a family (Arnett, 2000).

The framework provided by emerging adulthood (Arnett, 2000) has become an important framework for understanding the challenges and opportunities of working with young adults with type 1 diabetes (Hanna, 2012). The term transition describes many of the activities of life as a young adult, influencing the challenges and distractions faced by this population. Young adults with type 1 diabetes experience transition from paediatric to adult diabetes clinics (Sheehan, While, & Coyne, 2015), secondary or high school to higher education or employment, home to rented accommodation (Weissberg-Benchell, Wolpert, & Anderson, 2007), relying on the support of family and childhood friends to greater independence and new relationships (Allen, Channon, Lowes, Atwell, & Lane, 2011; Sparud-Lundin, Ohrn, & Danielson, 2010), and from an adolescent to adult identity (Luyckx et al., 2008).

Young adults with type 1 diabetes experience the same changes and challenges as their peers without type 1 diabetes. In addition, they must engage in a labour-intensive routine of daily self-management behaviours and adapt to life as an adult with a chronic health condition (Garvey & Wolpert, 2011). The same recommendations related to health behaviours such as diet, exercise, smoking and alcohol consumption apply to young adults

with type 1 diabetes as apply to young adults without the condition. However, skills, resources, support, and confidence are required to maintain self-management in the context of young adulthood. For example, although guidelines for alcohol intake are the same regardless of type 1 diabetes, young adults with the condition must take additional measures including eating some carbohydrate before going to sleep and monitoring for hypoglycaemia the following morning (P. Lee, Greenfield, & Campbell, 2009).

Previous research suggests that diabetes and quality of life related variables suffer as adolescents with type 1 diabetes become independent from parents, move out of home, attend university or enter the workplace (Weissberg-Benchell et al., 2007). Non-attendance at adult diabetes clinics (Pacaud et al., 2005; Eiser et al., 2013), declining or static glycaemic control (Garvey & Wolpert, 2011), and psychological morbidities like disordered eating or insulin omission for weight loss (Goebel-Fabbri et al., 2008) by young adults with type 1 diabetes have been widely reported. Physical, cognitive, emotional, and social development continues into the mid to late twenties (B. J. Casey, Getz, & Galvan, 2008; Dovey-Pearce & Christie, 2013; K.M. Hanna, 2012; Luyckx et al., 2008). Currently gaps exist in knowledge regarding the developmental trajectory into young adulthood, although evidence is gradually emerging. For example, family conflict and low scores on a measure of positive self-concept in mid to late adolescence were found to predict persistently poor glycaemic control during emerging adulthood (Luyckx & Seiffge-Krenke, 2009). Many variables have been associated with self-management among young adults with type 1 diabetes including self efficacy (Glasgow et al., 1999), amount and quality of communication with diabetes care providers (Sacco et al., 2004), and diabetes related distress and resilience (Yi et al., 2008). However the mechanisms through which these variables impact self-management, particularly clinic attendance is not clear due to a lack of research with this population, and research utilising longitudinal or experimental designs.

1.5 Transition from paediatric to adult diabetes services

In health service terms, transition is the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults as they grow up learning to live with type 1 diabetes (Dovey-Pearce & Christie, 2013). A central activity of the transition process is the move from a paediatric to adult diabetes clinic. Great variability has been found across young adult's transition experiences and the destinations of transition, including transition clinics, young adult diabetes clinics, adult diabetes clinics or general adult clinics (Holmes-Walker, Llewellyn, & Farrell, 2007; Lane et al., 2007; Sheehan et al., 2015).

As well as moving from one clinic to another, health care transitions may be taking place for young adults in relation to taking over responsibility from parents for being in contact with the diabetes clinic and organising attendance at the clinic, getting blood tests, collecting diabetes supplies such as glucose test strips, meeting service providers alone, dealing with a difficult consultation or test results, and managing day to day self-management with less input from parents or guardians (B. J. Anderson & Wolpert, 2004; Dovey-Pearce & Christie, 2013; Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005b; K. M. Hanna et al., 2013; Weissberg-Benchell et al., 2007; S. J. Wilson & Greenhaigh, 1999).

Transition may be seen as the gateway for problems related to clinic attendance behaviour in adult diabetes clinics. According to the findings of a recent systematic review, all studies which measured clinic attendance reported lower rates of attendance after transition to adult diabetes clinics in comparison to paediatric clinic attendance rates (Sheehan et al., 2015). Negative transition experiences and non-attendance at adult diabetes clinics may be associated with inadequate preparation of young adults before leaving a paediatric clinic (Scott, Vallis, Charette, Murray, & Latta, 2005), and a lack of

communication or collaboration between paediatric and adult diabetes teams (Kipps et al., 2002; Scott et al., 2005; Van Wallegem, MacDonald, & Dean, 2011).

Differences exist in the priorities and approach of paediatric diabetes clinics in comparison to adult clinics. The focus of paediatric diabetes care is the daily management of diabetes within the context of the family. This tends to be a more personal approach with greater familiarity, or continuity of care, between service users, their families, and service providers (Allen et al., 2011; Lancaster et al., 2010). Young adults have reported negative attitudes towards the orientation of adult diabetes clinic in comparison to paediatric clinics (Dovey-Pearce et al., 2005b) and service providers described inadequate support for young adults to adapt to changes in expectations for self-management, reduced access to care, and a new diabetes team (Brierley, Eiser, Johnson, Young, & Heller, 2012). Although a strong emphasis has been placed on improving the design and evaluation of transition services for young adults, high quality research to date has been limited (Sheehan et al., 2015).

1.6 Exploring determinants of self-management and clinic attendance behaviour

Complex interactions appear to occur between the developmental context and lifestyles of young adults, self-management, clinic attendance behaviour, and psychosocial and diabetes outcomes (Eiser et al., 2013; K.M. Hanna, 2012; Peters, Laffel, & American Diabetes Association transitions working group, 2011; Silverstein et al., 2005). For example, in a qualitative study investigating the factors which motivated non-adherence among young adults with type 1 diabetes, efforts to mislead service providers and difficulties communicating with staff regarding treatment were reported. This study demonstrates the interconnections between daily self-management, young adult's perceptions regarding their self-management, and interactions with diabetes clinics (Pyatak, Florindez, & Weigensberg, 2013).

According to Hanna (2012) empirical findings related to young adults are ‘few and fragmented’, despite the importance of this transitional period for long-term psychosocial and diabetes outcomes. Research to date has not isolated one single factor which consistently accounts for adherence to recommended diabetes self-management (Pyatak et al., 2013). Important emotional, cognitive, and behavioural factors associated with young adulthood have been found to interfere with self-management and may be important for understanding determinants of clinic attendance behaviour. Evidence is growing in relation to the impact of psychological, social and developmental variables, such as diabetes-related distress, diabetes-related perceptions, social support, identity development, and self-regulatory abilities on the adjustment of young adults with type 1 diabetes.

1.6.1 Diabetes-related distress

Psychological symptoms are prevalent among people with type 1 diabetes (Blanz, Rensch-Riemann, Fritz-Sigmund, & Schmidt, 1993; J. M. Jones et al., 2000; Kovacs et al., 1997). In addition to the impact of psychological symptoms on wellbeing, there are also serious diabetes-related implications because of the association between psychological morbidity and diabetes management problems (Hislop, Fegan, Schlaeppli, Duck, & Yeap, 2008; Peters et al., 2011). Recent research suggests that a large number of people with type 1 diabetes who do not have serious psychological diagnoses, may be experiencing sub-clinical diabetes-related distress (Balfe, Doyle, et al., 2013). Research to date suggests that diabetes-related distress may have a greater impact on glycaemic control than disorders such as depression (Gonzalez, Fisher, & Polonsky, 2011).

Diabetes distress relates to the emotional burden, stressors and frustration that stem from managing type 1 diabetes (L. Fisher, Hessler, Polonsky, & Mullan, 2012). Among young adults distress is caused by the effort, successes and failures, of balancing diabetes self-

management with everyday life (B. J. Anderson & Wolpert, 2004; Weissberg-Benchell et al., 2007). According to the findings of a qualitative study of the perspectives of young adults with type 1 diabetes, opportunities to talk to service providers about frustrations and difficulties related to diabetes, and access to support from peers with type 1 diabetes can moderate the impact of diabetes-related distress (Balfe, Doyle, et al., 2013). The potential role of clinic attendance behaviour to manage diabetes-related to distress is emphasised by this study.

1.6.2 Diabetes-related perceptions

Illness beliefs or perceptions influence coping behaviours, which influence health outcomes (Leventhal et al., 2012). Previous research has found that illness perceptions are modifiable and interventions to understand and change the illness perceptions held by people with chronic conditions can improve self-management behaviour, psychosocial and health outcomes (Harvey & Lawson, 2009; McAndrew et al., 2008). Among children and young people with type 1 diabetes, illness perceptions, including perceived consequences of diabetes and the control they believed they had over diabetes, influenced adherence to self-management behaviours such as SMBG (Harvey & Lawson, 2009; McGrady, Peugh, & Hood, 2014; Skinner, Hampson, & Fife-Schaw, 2002).

Illness perceptions related to type 1 diabetes have also been found to predict clinic attendance behaviour. People with type 1 diabetes who were not regularly attending their diabetes clinic held more negative beliefs related to the control they had over their diabetes, perceived consequences, and the perceived predictability and variability of the condition (Lawson, Bundy, Lyne, & Harvey, 2004). For example negative beliefs regarding the ability of diabetes treatment or diabetes clinics to produce desired outcomes were associated with clinic non-attendance. In another study, more positive diabetes-related beliefs were associated

with effective coping strategies such as seeking support and positive reinterpretation of their concerns, satisfaction with the diabetes clinic and regular clinic attendance (Lawson, Lyne, Bundy, & Harvey, 2007). Although further research is required to determine the direction of influence between diabetes-related perceptions and clinic attendance behaviour, the modifiability of illness perceptions makes them potential targets for interventions related to clinic attendance behaviour.

1.6.3 Social support

A large body of research exists, in general and in diabetes research, in relation to family functioning and social support in childhood and adolescence. General and diabetes-specific support for adolescents with type 1 diabetes is complicated and much research relates to the optimal balance between parenting and supporting diabetes management (B. J. Anderson & Wolpert, 2004; Kathleen M. Hanna, Juarez, Lenss, & Guthrie, 2003). The legacy of support from parents or guardians can also be complicated (Allen et al., 2011). For example, people diagnosed with type 1 diabetes during childhood or adolescence whose parents were very involved in supporting self-management, and gathering and providing information, described a negative impact on their ability to seek and understand diabetes-related information as adults (Rankin, Heller, & Lawton, 2011a). However access to and use of social support has received much less attention among young adults with type 1 diabetes in comparison to children and adolescents (Sparud-Lundin et al., 2010).

Perceptions and availability of social support is likely to be important for this group but may also be undergoing considerable change. The findings of one study emphasised the importance of diabetes-related support from service providers as young adults' access to diabetes-related support may be reduced, for example, if they have moved away from home (Allen et al., 2011; Balfe, Brugha, et al., 2013; Karlsson, Arman, & Wikblad, 2008). As

young adults adapt to more responsibility for self-management, they may be less inclined to share difficulties or concerns with parents, as they strive for a balance between autonomy and alliance (Sparud-Lundin et al., 2010). Young adults described the importance of self-reliance as they moved towards autonomy in self-management. However, encouragement from parents and acceptance from friends were also important for daily self-management (Karlsson et al., 2008). The assumption inherent in current health service delivery is that as young adults transition to adult services they will also transition to self-management which is completely independent. However, this policy and practice within diabetes services does not reflect the interdependence of the lives of young adults, and may be important for understanding and influencing clinic attendance behaviour (Allen et al., 2011).

1.6.4 Identity development

Identity development is one of the core developmental tasks of emerging adulthood (Arnett, 2000; Weissberg-Benchell et al., 2007). Identity development requires a process of exploration which may be disrupted by intrusions into daily life from the demands of type 1 diabetes (Seiffge-Krenke, 2001). In a study assessing a model of the influence of identity and coping on diabetes-related problems, it was found that a strong sense of identity was associated with less psychosocial and diabetes-related problems, and more adequate coping strategies (Luyckx et al., 2008).

Although identity development was found to be similar among participants with and without type 1 diabetes, the findings suggest that diabetes services designed with an understanding of the developmental needs of young adults are necessary. Considering the influential position of diabetes services in the lives of young adults with type 1 diabetes, the clinic has the potential to build the capacity of young adults to cope with type 1 diabetes, minimising the risk of serious problems with self-management or clinic non-attendance.

Young adults' sense of identity orient them towards more adaptive coping strategies (Luyckx et al., 2008). Existing services which have been described as inadequate for the complex needs of young adults may be undermining their potential to reach developmental milestones which are relevant to diabetes management.

1.6.5 Self-regulation

Successfully engaging in diabetes self-management requires complex self-regulation by adolescents and young adults with type 1 diabetes (K. K. Hood, Peterson, Rohan, & Drotar, 2009). Self-regulation is defined as the ability to control one's behaviours, emotions and cognitions to accomplish goals (Tangney, Baumeister, & Boone, 2004). Adolescents and young adults can experience difficulties with self-regulation because their capacity for coordinating emotions, cognitions and behaviours is still developing (Blakemore & Choudhury, 2006; B. J. Casey et al., 2008). A study of emerging adults with type 1 diabetes also found that greater impulse control, a sub-category of self-regulation, predicted better self-management. This relationship was partially mediated by diabetes-specific self-efficacy (Stupiansky, Hanna, Slaven, Weaver, & Fortenberry, 2013). Individual self-regulatory abilities as well as daily fluctuations in self-regulation, due to competing demands, were both found to predict adherence to self-management in a sample of older adolescents (Berg et al., 2014). The findings of self-regulation research highlight the importance of understanding individual and environmental influences on adherence to self-management among young people. A better insight into the factors related to daily self-management by young adults may inform strategies to support optimal self-management and enable interactions in diabetes clinics to be tailored to individual young adults.

There is a lack of research focusing on this age group to date, resulting in poor understanding of the trajectory of development from adolescence to young adulthood. In

addition, clinic attendance behaviour is rarely the focus of research and so is not well understood. Therefore determinants of diabetes self-management and the components of effective diabetes service delivery and support strategies are not clear (B. J. Anderson & Wolpert, 2004; Garvey & Wolpert, 2011; Peters et al., 2011).

1.7 Clinic attendance behaviour: Barriers, facilitators and consequences

Non-attendance at hospital-based clinics for the management of chronic conditions is a widespread problem (Gucciardi, DeMelo, Offenheim, & Stewart, 2008; Paterson, Charlton, & Richard, 2010). However the long-term impact of diabetes clinic non-attendance may be more serious due to the importance of clinic attendance to prevent or treat diabetes-related complications (Lawson, Lyne, & Harvey, 2005).

Clinic non-attendance reduces the efficiency of health services by resulting in under-utilisation of equipment and personnel (Murdock, Rogers, Lindsay, & Tham, 2002), reducing the number of appointments available (Martin, Perfect, & Mantle, 2005; Weinger, McMurrich, Yi, Lin, & Rodriguez, 2005), contributing to long periods without support between appointments (Balfe, Brugha, et al., 2013), and adds to cost, for example through additional correspondence with service users (Murdock et al., 2002; Weinger et al., 2005). Service providers try to account for non-attendance at outpatient clinics to avoid the inefficiencies created (Murdock et al., 2002). This can mean that some clinics are very large if more people attend than were expected based on previous attendance rates, resulting in short, impersonal consultations which are of little value to service users or providers (Balfe, Brugha, et al., 2013; Brierley et al., 2012). Therefore non-attendance can produce negative consequences which shape the delivery of services and the experiences of service users, potentially contributing to further non-attendance.

Psychosocial variables such as family conflict and openness (Jacobson et al., 1997), environmental variables like socioeconomic status (Jacobson et al., 1997), individual's diabetes-related beliefs (Lawson et al., 2004), younger age, shorter duration of diabetes (Dyer et al., 1998), dissatisfaction with diabetes services, and logistic factors like getting time off work (Lawson et al., 2005) have been associated with non-attendance at diabetes clinics. According to the findings of a systematic review including studies related to clinics for a range of chronic conditions, such as diabetes, dermatology, post-natal services, cardiac services and asthma, personal factors, clinic factors, and health system factors were found to be associated with non-attendance (Paterson et al., 2010). The type of treatment an individual was prescribed, high Body Mass Index, depression and anxiety, forgetfulness, a lack of health system accessibility, administrative issues, and the relationship between service providers and service users were found to contribute to clinic non-attendance (Paterson et al., 2010).

Rates of non-attendance at diabetes clinics have been estimated to be between 10 and 15% among adults with type 1 diabetes (Dyer et al., 1998; Peveler, Davies, Mayou, Fairburn, & Mann, 1993) and between 20 and 50% among young adults (Kipps et al., 2002). Among young adults, clinic attendance behaviour can be low or variable around the period of transition to an adult diabetes clinic, and across the years of emerging adulthood (Kipps et al., 2002; Perry, Steinbeck, Dunbabin, & Lowe, 2010; Sheehan et al., 2015; Sparud-Lundin, Öhrn, Danielson, & Forsander, 2008). One fifth of young adults in a study of wellbeing and functional outcomes, reported only attending the diabetes clinic in times of crisis and 15% only attended their general practitioner (Northam, Lin, Finch, Werther, & Cameron, 2010). The risks and burden associated with type 1 diabetes during young adulthood mean that the higher non-attendance rate among young adults is a serious problem that requires investigation.

During this time of movement, change and development the diabetes clinic has the potential to provide a reliable source of support, information and reassurance as young adults move from dependence to independence across life domains (Allen et al., 2011; K.M. Hanna, 2012). Habits and routines established at a young age or soon after diagnosis have been found to persist into adulthood, emphasising the importance of regular contact with service providers becoming a consistent and valued routine for young people with type 1 diabetes (Weissberg-Benchell et al., 2007; Wysocki, Hough, Ward, & et al., 1992). Delivering a service which meets the needs of young adults with type 1 diabetes is extremely challenging (Brierley et al., 2012; R. Casey et al., 2012; Garvey & Wolpert, 2011). Challenges are present at the levels of young adults and their environment, service providers, and the health system (Snow & Fulop, 2012). Thus, many factors must be considered to understand the barriers and facilitators to clinic attendance behaviour, and the role of the diabetes clinic, and to facilitate the design of effective approaches to behaviour change and service improvements.

Clinic attendance is rarely the focus of self-management or health services-related research, despite the importance of attendance at specialist diabetes clinics, and the problem of clinic non-attendance experienced locally and reported internationally. Previous research reported that forgetting appointments was the most common reason reported by service users for non-attendance at health service appointments. Therefore, intervention research commonly addressed non-attendance at outpatient clinics or in general practice settings by focusing on service user behaviour, for example by sending written, telephone, text, or e-mail reminders (Filippidou, Lingwood, & Mirza, 2014; Guy et al., 2011; Lim & Varkey, 2004; Macharia, Leon, Rowe, Stephenson, & Haynes, 1992). Significant improvements in clinic attendance rates have been reported using reminder systems. However much of the research targeting non-attendance is not recent and the interventions in previous research took place in a wide range of settings, including general practice and a range of hospital-based outpatient

clinics. There is a lack of intervention research related to clinic attendance behaviour among young adults with type 1 diabetes.

1.8 Developing interventions to target clinic attendance behaviour

In summary, attending routine scheduled appointments at hospital-based diabetes clinics is integral to the management of type 1 diabetes. Disengagement from diabetes services is common among young adults with type 1 diabetes. Gaps in existing research exist in relation to determinants of clinic attendance and non-attendance in this population. A basis for interventions to address clinic non-attendance among young adults with type 1 diabetes is needed.

The UK Medical Research Council (MRC) framework (Figure 1.1), first proposed in 2000 (Campbell et al., 2000) provides guidance for designing and implementing interventions which are appropriate for complex health service settings (Craig et al., 2008). Some of the greatest challenges which have emerged in health behaviour change research have included an inadequate understanding of mechanisms of change underlying effective interventions, selecting appropriate outcomes and measurement techniques, and pre-empting issues related to local contexts (Craig et al., 2008; Rowlands, Sims, & Kerry, 2005). The MRC framework facilitates the development, piloting, evaluation and implementation of interventions by identifying strategies to avoid these issues.

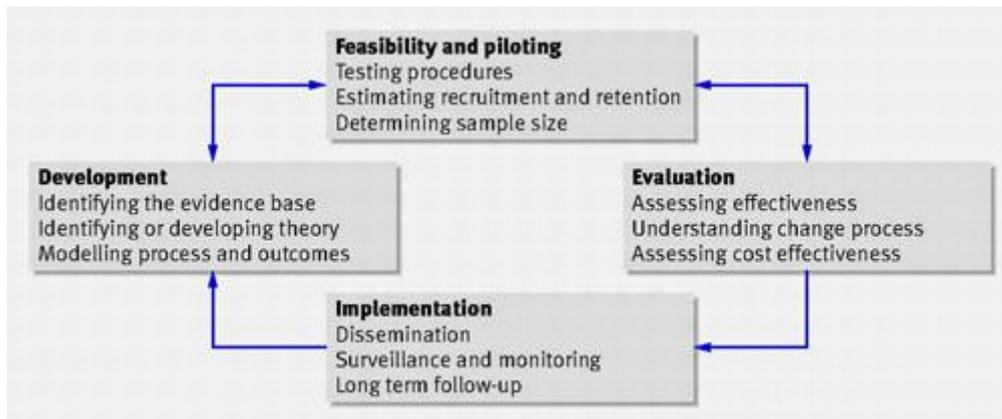


Figure 1.1 Medical Research Council framework for the development and evaluation of complex interventions to improve health (Craig et al., 2008).

Theories of behaviour provide explanations regarding the processes which are occurring, and facilitate an understanding of complex situations (Davidoff, Dixon-Woods, Leviton, & Michie, 2015). The use of theories, and explicit description of their use, is necessary to facilitate the design of interventions to change behaviour (Craig et al., 2008; Davidoff et al., 2015; Eiser et al., 2013). Although many theories of behaviour exist, there is a lack of theory-based research across health-related fields to date, making it difficult or impossible to know what mechanisms underlie behaviour or behaviour change (Craig et al., 2008; Michie & Prestwich, 2010; Michie, van Stralen, & West, 2011). Therefore, studies exist in isolation and the progression of knowledge and techniques of behaviour change has been limited (Michie & Johnston, 2012).

Having a theoretical basis for an intervention has been found to influence efficacy (Dombrowski et al., 2012; Taylor, Conner, & Lawton, 2012). A lack of specific behavioural theories defining and explaining diabetes-related behaviours precludes the development of effective interventions (Ayling, Brierley, Johnson, Heller, & Eiser, 2014; Michie & Johnston, 2012). Clinic attendance is an integral aspect of diabetes self-management and a priority of service delivery for young adults (Garvey & Wolpert, 2011; Grant et al., 2013). However, the

behaviour of clinic attendance has been neglected from a psychological perspective (Paterson et al., 2010). Without an in-depth theoretical understanding of this behaviour, the mechanisms governing clinic attendance are unknown, and improvements to services may be uninformed, or misguided, resulting in a waste of resources and potentially even harm (Davidoff et al., 2015).

1.9 Overall aim

The overall aim of this research was to develop and test a theory of clinic attendance behaviour among young adults with type 1 diabetes. The research question for each study conducted in this research and the corresponding papers are outlined below.

1.9.1 Research questions and thesis outline

- Study 1: What are the barriers and facilitators associated with clinic attendance among young adults with type 1 diabetes? (Paper 1)
 - Hynes, L., Byrne, M., Dinneen, S.F., McGuire, B. E., O'Donnell, M., & Mc Sharry, J. (2014). Barriers and facilitators associated with hospital clinic attendance among young adults with type 1 diabetes: a systematic review. *Pediatric Diabetes*. DOI: 10.1111/pedi.12198
- Study 2: What is involved in clinic attendance among young adults with type 1 diabetes, and what are the most important determinants of this behaviour? (Paper 2)
 - Hynes, L., Byrne, M., Casey, D., Dinneen, S.F., O'Hara, M.C. (2015). 'It makes a difference, coming here': A qualitative exploration of clinic attendance among young adults with type 1 diabetes. *British Journal of Health Psychology*. DOI: 10.1111/bjhp.12145

- Study 3: What are the relationships between the factors associated with clinic attendance behaviour among young adults with type 1 diabetes and what is the mechanism by which they influence clinic attendance behaviour? (Paper 3)
 - Hynes, L., Byrne, M., Conway, R., Dinneen, S.F., Canavan, R., Clarke, H., Hoashi, S., McDermott, J., McGurk, C., O’Shea, D., & Smith, D. (Submitted to Health Psychology) Testing a theory of clinic attendance among young adults with type 1 diabetes.

The methodology used to conduct this research is outlined in detail in the next chapter. A general discussion of the findings of the three studies, the limitations of the studies, and implications for future research and practice is presented in the final chapter of this thesis.

2. Methodology

2.1 Chapter overview

The aim of this chapter is to outline the overall design of this research. The aims of each study within the research will be presented. A description of the methods used to address the aim of each study will be provided with a discussion of the background and justification for their use. Finally, the ethical issues associated with this study will also be addressed in this chapter.

2.2 Aims and objectives of this research

The primary aim of this research was to develop a theory of clinic attendance behaviour among young adults with type 1 diabetes to provide a theoretical basis for the development of future interventions to address clinic non-attendance in this population. Qualitative and quantitative methods were used to develop the theory by integrating data from existing literature with the perspectives and experiences of the key stakeholders in relation to the topic of clinic attendance behaviour.

2.3 Overview of study design

A qualitatively led, exploratory mixed methods design, guided by the epistemology of pragmatism, was used in this research (Creswell & Plano Clark, 2007). In order to deal with important research questions in complex settings, health services and social science researchers increasingly adopt a mixed methods approach, involving both qualitative and quantitative methodologies (Dures, Rumsey, Morris, & Gleeson, 2010; Yardley & Bishop, 2015). Traditionally qualitative and quantitative methods have been utilised separately due to the long-standing belief that their underpinning epistemologies are incompatible and their findings incomparable (Burke Johnson & Onwuegbuzie, 2004). The epistemology of

pragmatism has emerged as a popular alternative to the positivist epistemological perspective associated with quantitative research methods, and the constructivist perspective associated with qualitative methods (Burke Johnson & Onwuegbuzie, 2004; Yardley & Bishop, 2015). Rather than labelling the knowledge produced in research guided by pragmatism as entirely objective or subjective, it is intended to have valuable external consequences (Yardley & Bishop, 2007). According to the philosophy of pragmatism, both qualitative and quantitative methods are means of knowledge generation which are best adopted based on their match with the goals of a study. Therefore, within mixed methods research guided by pragmatism, qualitative and quantitative methods are seen as ‘distinct but commensurate’ (Yardley & Bishop, 2015). By approaching mixed methods research in this way, the assumptions which guide the design, execution and evaluation of research are attended to, maintaining the integrity of both approaches and ensuring the quality of the overall study and reliability of results (Morse, 2003; Yardley, 2001).

The mixed methods design adopted in this study addressed the three steps (Identify the evidence-base; identify or develop a theory; model processes and outcomes) in the development phase of the UK Medical Research Council (MRC) Framework for the development and evaluation of complex interventions (Craig et al., 2008). A mixed methods approach was used due to the lack of relevant research, and the complexity of clinic attendance behaviour and the context of diabetes clinics. As a result, a mixed methods design, underpinned by the philosophy of pragmatism which is characterised by a responsiveness to complex research questions and settings, was deemed to be the most appropriate approach (Denscombe, 2008; Dures et al., 2010).

In this research clinic attendance behaviour was interrogated in depth through the use of qualitative and quantitative methods and by integrating the findings of each study

(Barbour, 1999; Moran-Ellis, 2006). An overview of this research and the points of integration are presented in Figure 2.1.

Study 1: Identify the evidence base

Study 2: Develop theory

Systematic review and narrative synthesis of barriers and facilitators to clinic attendance

Semi-structured interviews collected and analysed using grounded theory



Integration of methods and data

- Findings of study 1 and study 2 were integrated to form a comprehensive picture of clinic attendance behaviour
- Quantitative data collection tool was designed based on the qualitative findings of study 1 and study 2



Study 3: Modelling process and outcomes

Online and hospital-based questionnaire testing the theory of clinic attendance among young adults with type 1 diabetes



Integration of data

- Theory of clinic attendance produced in study 1 and study 2 was further developed based on the quantitative findings of study 3
- Insight into the quantitative findings of study 3 gained through the qualitative findings

Figure 2.1 Mixed methods research design including the points of integration of the qualitative and quantitative studies

In this research, a systematic review was conducted in study 1 to identify the evidence-base related to barriers and facilitators associated with clinic attendance among young adults with type 1 diabetes. As a theory did not already exist, a qualitative study based on grounded theory was conducted in study 2. The theory of clinic attendance was produced following the integration of the findings from study 1 and study 2. Finally, based on the findings of the previous two studies a questionnaire was constructed to measure the variables within the theory, and the theory of clinic attendance was tested in an international sample of young adults with type 1 diabetes. The quantitative findings of study 3 were further interrogated and understood by integration with the findings of study 1 and study 2. The approach to integration throughout this project was primarily at the level of data, although data also drove method in the case of the design and materials used in study 3.

2.4 Study 1 – Identifying the evidence base

2.4.1 Aims and objectives of study 1

The aim of study 1 was to identify and synthesise the existing evidence related to the factors which act as barriers or facilitators to clinic attendance behaviour among young adults with type 1 diabetes. According to the MRC guidance (Craig et al., 2008), complex interventions should be developed systematically using the best available evidence. Therefore, a systematic review was conducted in study 1 as a relevant review was not available.

2.4.2 Approach to study 1

An explicit and systematic process was used in this study to obtain all relevant published and unpublished literature, to appraise the quality of the existing evidence and to produce a comprehensive and reliable synthesis of the evidence (Garg, Hackam, & Tonelli, 2008; J. P. T. Higgins & Green, 2011; Oxman, Cook, & Guyatt, 1994). Narrative synthesis, as opposed to meta-analysis, was used to analyse the data extracted from the studies included in the systematic review. Meta-analysis of the data was not possible as a small number of studies which differed in terms of quality and research designs were identified in this review.

2.4.3 Procedure

2.4.3.1 Search strategy

Electronic databases, EBSCO CINAHL, MEDLINE, PsycINFO, and OVID EMBASE were searched from database start to July 2013. These databases were selected as they were relevant to the topic of this review and commonly used in similar reviews. The search terms were selected based on a scoping search. Potential search terms, such as ‘emerging adult’, ‘age 18-25’, ‘default’ and ‘loss to follow-up’, were selected from relevant studies and their utility for returning studies related to the research question was tested. The search terms ‘Diabetes’, ‘young adult’, ‘adolescent’, ‘attendance’, ‘non-attendance’, and ‘missed appointment’ were selected for the final search strategy. The search term, ‘Diabetes’, was accompanied with all combinations of the population and clinic attendance-related terms. A full sample search strategy for the EBSCO MEDLINE database is shown in Appendix A.

A grey literature search strategy was also implemented to gather unpublished sources of information such as theses or conference abstracts. A grey literature search was performed to avoid a positive skew in the findings due to publication bias (Garg et al., 2008; J. P. T. Higgins & Green, 2011). Three diabetes research networks (Australian Society for Psychological Research into Diabetes, Behavioural Research in Diabetes Group, and

Psychosocial Aspects of Diabetes group) were contacted by email. Members were asked to provide any relevant information in the form of conference proceedings, abstracts, theses or primary research. Reference lists of relevant studies were also searched for additional studies.

2.4.3.2 Study selection

Studies published in English were included if potential barriers and facilitators to clinic attendance were assessed among young adults aged 15 – 30 (inclusive) with Type 1 diabetes. The age range of 15-30 years was chosen due to varying definitions of young adults across the relevant research. However, the setting of each study had to be an adult diabetes clinic. Studies were excluded if the study population did not have Type 1 diabetes, information relating to participants aged 15 – 30 could not be extracted from the data, if adult diabetes clinic attendance was not an outcome variable, if it was a review or discussion paper, or if the study was not available as a full text.

All studies identified were transferred to an Endnote database to be assessed for inclusion. Following the removal of duplicates, studies were excluded in step 1 if there was evidence in the title that they were not relevant. In step 2, studies were excluded if they were deemed ineligible following examination of the abstract. Full texts were read in step 3 in order to produce the final group of studies to be included in the review. Any uncertainty regarding the inclusion of a study was discussed with the supervisory team and agreement was reached. Authors were contacted when the full text of articles could not be accessed online. In most cases contact details could not be found or no longer worked, or no response was received.

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) Statement, presented in paper 1 (pg. 67) of this thesis, guided the reporting of the inclusion and exclusion of studies in this systematic review. The PRISMA checklist and flowchart

facilitated transparency surrounding the decision-making processes in this study (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

2.4.3.3 Data extraction

A preliminary synthesis was conducted by tabulating the relevant data into separate data extraction tables for quantitative and qualitative studies. The following data were extracted: author, publication year, location & setting, sample characteristics (including size, gender and, mean age at time of study, at diagnosis and at transition if given), measure of clinic attendance, barriers to clinic attendance, facilitators of clinic attendance, overall findings and indicators of study quality. Textual descriptions and information regarding study quality were also included in the data extraction tables presented in paper 1 (p. 60) of this thesis.

2.4.3.4 Quality assessment

The quality of the studies in this review was assessed to avoid or minimise the impact of a study that was not rigorously conducted on the findings and conclusions of this review (Hróbjartsson, Boutron, Turner, Altman, & Moher, 2013). The quality of each study in this review depended on whether its design, conduct, analysis and presentation were appropriate to answer the research question (J. P. Higgins et al., 2011).

Quality assessments of the quantitative studies included in this review were conducted using predefined categories specified in the critical appraisal skills programme (CASP) checklist (Critical Appraisal Skills Programme (CASP), 2013). A tool which was developed based on existing literature and employed in published research informed the quality assessment of the qualitative studies reviewed (Bogosian, Moss-Morris, & Hadwin, 2010; Elliott, Fischer, & Rennie, 1999). Copies of the quality appraisal tools used in this study are

included in Appendix B and C. Minor adaptations were applied to both tools to increase their relevance to this review.

Due to the limited number of studies identified as being relevant for this review, the findings of the quality assessment did not result in studies being excluded. This approach was based on the recommendations of previous researchers and the Cochrane Collaboration. Based on these recommendations, details related to the quality appraisal were provided under the headings assessed to allow readers to determine the weight that should be assigned to each study included in the review. Using this approach, the role of each study in answering the research question was prioritised over the methodological issues identified (Gough, 2007; Hannes, 2011; J. P. Higgins et al., 2011).

2.4.3.5 Data synthesis

A narrative synthesis was conducted in this study, using words and text to summarise and explain the findings of the individual studies included (Popay et al., 2006). The synthesis of quantitative studies was informed by guidance in the conduct of narrative synthesis in systematic reviews compiled by Popay *et al.* (2006). The findings of the qualitative studies reviewed were analysed using the method for thematic analysis of qualitative research in systematic reviews described by Thomas & Harden (Thomas & Harden, 2008). This approach to the analysis of data from a systematic review enabled important evidence to be produced under conditions in which meta-analysis was not possible.

In this study, descriptive codes were assigned to units of meaning in the results section of each study. Codes were then organised into categories of factors which were related to clinic attendance. These categories were entered into synthesis tables for quantitative and qualitative studies and similarities and differences across studies were

identified. Synthesis findings from both study types were integrated at this stage due to the agreement in terms of the themes which had emerged.

2.5 Study 2 – Developing theory

2.5.1 Aims and objectives of study 2

The aim of study 2 was to address the second step in the development phase of the MRC framework by developing a theory of clinic attendance behaviour among young adults with type 1 diabetes. The qualitative methodology called grounded theory was used to build the theory based on interviews with young adults with type 1 diabetes and service providers regularly working with them.

2.5.2 Approach to study 2

Grounded theory was selected as the most appropriate methodology to address the research question. Grounded theory was selected because it produces a theory of basic psychosocial processes (Starks & Brown Trinidad, 2007; Payne, 2007; Cutcliffe, 2005) which moves beyond description to an understanding of the process by which a phenomenon occurs (Corbin & Strauss, 2008).

The core aspects of grounded theory used in this study were the method of sampling, known as theoretical sampling, and the main analysis technique, known as constant comparison. The theory was developed in this study by remaining grounded in the data and this grounding was facilitated by theoretical sampling and constant comparison (Cooney, 2011; Glaser & Strauss, 1967).

Grounded theory has developed along three independent paths since it was proposed in the late sixties: Glaserian grounded theory (Glaser & Strauss, 1967), Straussian grounded theory (Strauss & Corbin, 1998) and Constructivist grounded theory (Charmaz, 2006).

Straussian grounded theory was selected as the most appropriate approach to this study because of the comprehensive yet flexible guidelines for use, acknowledgement of the impact of context on the emerging theory, and the fit with the philosophical approach of pragmatism guiding this mixed methods study. The chosen methodology will be referred to as grounded theory from this point on.

2.5.3 Procedure

2.5.3.1 Participants

Young adults with type 1 diabetes and service providers were recruited through a hospital-based diabetes clinic. Existing qualitative research has tended to focus on service users or providers separately. Both groups were sampled in this study to obtain the perspectives of service users and service providers and gain an appreciation of the complexity of the factors which may be contributing to clinic attendance behaviour. All participants were provided with participant information and consent forms. The participant information and consent forms for young adults and service providers can be found in Appendix D and E. Participant information and consent forms for parents of adolescents aged under 18 and the information and assent forms for their child can be found in Appendix F, G and H. Ethical approval for this study was sought and obtained from University Hospital Galway Research Ethics Committee.

2.5.3.2. Setting

The setting was a busy hospital diabetes service which served nearly 800 adults, including 137 young adults, with type 1 diabetes (Cotter et al., 2014). The clinic was located on the campus of a large regional hospital providing paediatric and adult inpatient and outpatient services to a catchment area of approximately one million people in the west of

Ireland (Galway and Roscommon University Hospitals Group, 2012). This service held a monthly young adult diabetes clinic which was staffed by an experienced team with minimal involvement of junior doctors. However, the clinic was under considerable pressure to maintain the integrity of the young adult diabetes clinic, and young adults were often seen by unfamiliar service providers, or had missed appointments rescheduled to general adult clinics. Young adults received between one and four appointments per year, depending on their glycaemic control and any other serious issues they were dealing with. Service users received letters regarding upcoming clinic appointments and text reminders were sent just before appointments. Young adults had access to a doctor, diabetes specialist nurse, dietician, and eye and foot specialists in the clinic. Psychological support was available but the waiting list was very long and referrals tended to be a last resort. Intensive insulin treatment using Multiple Daily Insulin Injections (MDII) or insulin pumps, and carbohydrate counting, were the main approaches to diabetes treatment. The DAFNE (Dose Adjustment For Normal Eating) Structured Education Programme (Dinneen et al., 2009) was offered four times per year in the clinic. A transition support plan was in place between the young adult diabetes clinic and the paediatric diabetes clinic in the same hospital, facilitated by a diabetes specialist nurse who worked in both settings.

2.5.3.3 Recruitment

Participants were recruited purposively at first with the aim of recruiting a diverse sample in terms of the information which was available following a recent audit of the clinic, which was gender, age, years since diagnosis and pattern of attendance over two years (R. Casey et al., 2012). Simultaneous analysis of the data collected from purposively recruited young adults provided the basis for subsequent sampling, known as theoretical sampling. The concepts which emerged during the analysis of the data guided theoretical sampling. The aim of theoretical sampling was to enable further investigation into the questions raised by data

collection and analysis, for example by seeking to clarify the points made by previous participants (Corbin & Strauss, 2008; Glaser & Strauss, 1967).

A member of the clinic staff not directly involved in service provision assisted in the sampling process by extracting descriptive data related to all young adults associated with the clinic. Young adults were then contacted by post about taking part in an interview. Service providers were sampled through the paediatric and adult diabetes clinics to represent each of the professions regularly working with young adults, and included doctors, nurses, and allied health professionals. All of the service providers regularly working with young adults in this setting were recruited in this study. Therefore the recruitment of service providers was not based on theoretical sampling.

2.5.3.4 Sample size

Based on the grounded theory approach used in this study, the aim of recruitment was to achieve comprehensive descriptions of the categories of the theory rather than to recruit a representative sample. Therefore, the required sample size could not be stated in advance of this study (Starks & Brown Trinidad, 2007). Theoretical sampling continued in this grounded theory study until saturation was achieved, meaning that data collection no longer resulted in the identification of new concepts, and the categories of the theory made sense and were comprehensive (Corbin & Strauss, 2008; Creswell, 2007; J. C. Hood, 2007; Strauss & Corbin, 1994).

Determining whether the sample was adequate also depended on the quality of the data, the scope of the study, time and resources, the nature of the topic and the depth and quality of information obtained from each participant (Morse, 2000; Morse & Singleton, 2001). Previous recommendations related to sample size in grounded theory research have varied from 20-30 participants (Morse, 1995) to 30-50 participants (Stern, 2007). Therefore,

the criteria provided by Morse (2000; 2001) were used to ensure the sample size was adequate in this study. Immersion in the data during data collection and analysis and documentation of this process facilitated the decision-making process in this study (Bryant & Charmaz, 2007; Corbin & Strauss, 2008; Morse, 1995). The final sample size in this study was 29 participants, including 21 young adults and seven service providers.

2.5.3.5 Data generation and analysis

Based on the grounded theory method, the theory was developed through data collection and analysis, which proceeded simultaneously (J. C. Hood, 2007; Hunter, Murphy, Grealish, Casey, & Keady, 2011a; Walker & Myrick, 2006). Semi-structured interviews were conducted between February 2012 and February 2014. This approach was used because semi-structured interviews provided an appealing balance between structure and flexibility (Cooney, 2008; Holloway & Fulbrook, 2001). The aim of this study to develop a theory of clinic attendance behaviour was already specified. As a result, unstructured interviews would not have been appropriate. Individual interviews were chosen as opposed to focus groups because of the exploratory nature of the study. The dynamic created in a focus group may have taken from the in-depth understanding of clinic attendance behaviour that was the aim of this study.

All participants were given the option of being interviewed in person in the outpatient diabetes centre, the university, in their office or home, or over the phone and the full range of options were chosen across the sample. Interviews varied in length from 30 minutes to 2 hours and 20 minutes. Separate interview guides for young adults and service providers, outlined in paper 2 of this thesis (pg. 87), were used to explore attendance at the diabetes clinic. Interviews were recorded and transcribed verbatim. QSR NVIVO 10 was used to facilitate the organisation, management and analysis of the data.

Open, axial and selective coding techniques were used to analyse the data (Corbin & Strauss, 2008).

The primary analytical approach was constant comparison, facilitated by field notes and memos. Field notes were kept describing observations made during data collection, ranging from information about the participant, issues related to the interview guide, and early analytic insights (Corbin & Strauss, 2008; Patton, 2007). For example, following the second interview, the researcher wrote a field note describing personal concerns about asking a question which was an element of the interview guide but may have made the participant repeat themselves. However, the researcher noted that asking each question in the interview guide often resulted in surprising responses from participants. This field note, describing an observation just after an interview was important as it facilitated the improvement of the researcher's interview technique and highlighted the importance of allowing participants to tell their story without the researcher making premature assumptions. Memos consisting of conceptual rather than descriptive responses to data collection and analysis, were written to document ideas and relationships to facilitate the process of theory development (Corbin & Strauss, 2008; Lempert, 2007; Patton, 2007). An example of a memo made during this study is included in Appendix I.

In this study, constant comparison was the process through which codes, concepts and categories were created, broken down and rebuilt (Corbin & Strauss, 2008). A key process during constant comparison was the identification of similarities and differences in the data which facilitated the development of explanations of what was going on in the data (Hunter et al., 2011a). Possible explanations for the trends which were emerging in the data were developed and questioned repeatedly in this study. Memo writing, exploring data which had already been collected and collecting more data enabled these explanations to be tested and verified, or modified (Cooney, 2010; Reichertz, 2007).

Once the data were transcribed, open coding took place to organise the raw data into concepts, using codes which were chosen for their ability to represent the ideas in the data (Corbin et al., 2008). With each new transcript patterns began to emerge so that existing codes were integrated to become concepts. Properties, or characteristics, of the emerging concepts were noted, added to and altered as data collection and analysis proceeded (Corbin & Strauss, 2008).

Axial coding began as the concepts grew and developed enough to be reduced and combined into categories according to their shared properties. Dimensions were attached to the properties of each category, describing the range and variation within the data.

The theory was specified during selective coding by developing and questioning potential hypotheses regarding the interconnections within the theory. This process was facilitated using an organising framework called 'the paradigm' (Corbin & Strauss, 2008). At this stage there was a growing body of participant accounts, field notes and memos. Thus, diagrams and organising schemes were used as recommended (Cooney, 2008; Corbin & Strauss, 2008). The paradigm facilitated the organisation of the categories within the emerging theory under the headings: conditions (causal, contextual and intervening), strategy, and consequences (Creswell, 2007). An example of the use of the paradigm is included in Appendix J.

Following the analysis of the interviews of purposively sampled participants (six young adults and eight service providers), subsequent participants were theoretically sampled based on the likelihood that they would contribute to the explanation of clinic attendance (Corbin & Strauss, 2008). Theoretical sampling was implemented in two ways; interview guide modification and recruitment of young adults with particular characteristics or profiles. For example, two adolescents were recruited through the paediatric diabetes clinic in the

same hospital. This decision was based on the emergence of important concepts in the first group of interviews, such as relationships with service providers in paediatric diabetes clinics.

Once the theory of clinic attendance started to emerge from the data, a central question became clear, and guided additional theoretical sampling. The central question was: *what leads to the development of collaborative relationships between young adults and service providers for some young adults and not for others, and how do these relationships relate to engagement with the adult diabetes clinic (contact other than attendance at scheduled appointments) and regular clinic attendance?* Based on this question, more young adults were theoretically sampled, with the help of a member of the diabetes clinic team, who had different attendance patterns (regular or irregular), different levels of familiarity to service providers (familiar or unfamiliar), different levels of contact outside of scheduled appointments (appointments only; appointments and contact by email, telephone or drop in), different levels of commitment to self-management, and emotional well-being.

A core category was chosen which represented the central concept in the process being studied. Theoretical sampling in order to explore the dynamics emerging from the data facilitated the identification of the core category (Creswell, 2007; McCann & Clark, 2003; Strauss, 1987). Based on guidance for conducting grounded theory, the core category was abstract, appeared frequently in the data, explained and linked the other categories, and emerged from the data without being forced. The theoretical sampling strategy involving the recruitment of participants likely to provide relevant insight, and the modification of the interview guide, facilitated the exploration for and emergence of the core category. Candidates for the core category were also entered into the paradigm, the organising framework used in this study. Therefore, this tool encouraged commitment to important categories in the emerging theory and to question the possible directions and mechanisms of the relationships between the categories, particularly with the core category.

In this study, as data collection and analysis progressed the researcher became more immersed in the data, more familiar with the young adults and service providers who were being interviewed, and the health care and social contexts within which they lived, worked and self-managed. The approach to theory development, while managing the influence of these experiences and of any preconceptions, known as theoretical sensitivity, was facilitated by engaging in reflection while writing memos and field notes, and during supervisory meetings (Bryant & Charmaz, 2007; Corbin & Strauss, 2008; Glaser & Strauss, 1967). The process of questioning and comparing the data was enhanced by theoretical sensitivity as part of the grounded theory approach (Corbin & Strauss, 2008).

The step in grounded theory studies from description to explanation required engagement with existing literature in order to further understand the definitions and operationalisation of the concepts and categories which made up the theory (Corbin & Strauss, 2008). The process of refining the theory through theoretical sampling, constant comparison and engagement with the literature continued until the clarity, logic and explanatory power of the theory were satisfactory and there was sufficient evidence that data saturation had been reached. That is, the categories were well described, variation was present in relation to the concepts, and new concepts were no longer emerging (Corbin & Strauss, 2008; Creswell, 2007; J. C. Hood, 2007; Strauss & Corbin, 1994).

2.5.3.6 Rigour

Rigorous application of the method was the main safeguard for developing a theory of good quality (Cooney, 2011) because the characteristics of grounded theory actually enhance rigour, namely theoretical sampling and constant comparison (J. R. Cutcliffe, 2000). The methods used in this study to ensure and demonstrate rigour were based on the criteria of credibility, auditability and fittingness (Beck, 1993; Cooney, 2011). In this study the

credibility of the theory was demonstrated by the richness of the description of the study in this section and in paper 2 of this thesis. The evidence of the decision-making process provided, including the example of a memo included in Appendix I, demonstrates auditability in this study. Finally, the detailed information regarding the study setting provided in this section facilitates fittingness by enabling readers to assess the meaning of the findings of this study in other similar settings.

2.6 Study 3 – Modelling processes and outcomes

2.6.1 Aims and objectives of study 3

The aim of the third and final study in this project was to use statistical modelling to test a model based on the theory of clinic attendance behaviour among young adults with type 1 diabetes, addressing the final step in the development phase of the MRC framework (Craig et al., 2008). This model was developed based on the integration of the findings of study 1 and study 2. The findings of this study will inform further development of the theory of clinic attendance.

2.6.2 Approach to study 3

In this study a cross sectional, questionnaire-based design was used to test the theory of clinic attendance by comparing the structure of the theory of clinic attendance with data collected from an international sample of young adults. This process of modelling the factors which predicted clinic attendance behaviour was conducted to identify the relationships between the components of the model and the most important variables which should be targeted in future interventions.

Modelling was used in this study to gather important information about the design of interventions and methods of evaluation (Craig et al., 2008). However, the step of modelling

processes and outcomes has been described less in previous research in comparison to step one (identifying the evidence base) or two (identifying or developing theory) in the development phase of the MRC framework. The purpose of modelling in previous studies has been to develop an understanding of a proposed intervention and its possible effects (Paul, Smith, Whitford, O'Kelly, & O'Dowd, 2007) with the overall aim of maximising the chances of a successful trial that will add to knowledge and improve outcomes (Rowlands et al., 2005). A small number of examples exist of studies in which interventions were modelled before pilot testing (Eldridge et al., 2005; Hardeman et al., 2005; Paul et al., 2007; Rowlands et al., 2005). Methods for modelling processes and outcomes to design interventions have included statistical modelling (Hardeman et al., 2005), desk-based studies, for example reviewing and discussing evidence from epidemiology and behavioural science (Hardeman et al., 2005), and building a cost-effectiveness model (Eldridge et al., 2005).

2.6.2.1 Research questions

Based on the theory of clinic attendance behaviour models were specified and tested using structural equation modelling (SEM), Moderation analyses were also conducted to answer the research questions. The research questions in this study were:

1. Does the core pathway, from opportunities for contact to clinic attendance, described in the theory of clinic attendance predict clinic attendance behaviour (attendance rate, missed appointment rate or informal contact)?
2. Does this core pathway still predict clinic attendance behaviour when controlling for demographic variables, hassles and values associated with clinic attendance, and young adults' diabetes-related perceptions and behaviours?

3. Do relationships between young adults and services providers, or the engagement of young adults, moderate the pathways between clinic and young adult related factors, and clinic attendance behaviour?

2.6.3 Measures

The questionnaire tool (Appendix K) used in this study was designed to assess the components of the theory of clinic attendance. Demographic variables were assessed, including age, gender, living situation, and employment status. Diabetes-related information, including number of years since diagnosis with type 1 diabetes and current treatment modality for diabetes, was also collected. Opportunities for contact with service providers outside routine scheduled appointments, such as attending a structured education programme, were investigated using four questions developed for this study based on the findings of study 2.

The primary outcome in this study was clinic attendance behaviour, assessed using three measures: attendance rate (Dyer et al., 1998), missed appointment rate (Schectman, Schorling, & Voss, 2008), and informal attendance. The choice of measures for clinic attendance behaviour was based on a review of approaches used in previous literature and insights into clinic attendance behaviour gained in study 2.

Attendance rates in this study were based on the number of diabetes clinic appointments attended by participants, out of those scheduled for them, over two years. According to previous research clinic attendance behaviour is more complicated than attendance or non-attendance (Snow & Fulop, 2012). For example contact with the diabetes clinic outside appointments (Balfe, Brugha, et al., 2013), and cancelling and rescheduling unsuitable appointments (Weinger et al., 2005) may also be important. Therefore, missed appointment rates were calculated based on the appointments missed and not rescheduled, of

those scheduled for participants over two years. The possible range for this variable was from -100 to 100 because participants may have rescheduled more than they missed, missed more than they rescheduled, or may not have missed or rescheduled any appointments. In addition, informal contact was measured in this study by asking young adults to estimate how many times in the previous two years they had been in contact with the diabetes clinic by telephone, e-mail, text message, or by calling in to the clinic without an appointment.

The remaining elements within the theory of clinic attendance were assessed using validated measures, and are summarised below.

Relationships between young adults and service providers. The Working Alliance Inventory- Revised Short Form (WAI-SR; Hatcher & Gillaspay, 2006) was used to measure participants' perceptions of their relationships with at least one service provider in the diabetes clinic. Participants rated their experiences with services providers on a 5-point likert scale, ranging from *seldom* to *always*. Internal reliability of the WAI-SR is excellent, ranging from .94-.95 (Hatcher & Gillaspay, 2006). In the present sample, similar internal reliability was found ($\alpha = .94$).

Engagement of young adults with the diabetes clinic. The Diabetes Empowerment Scale-Short Form (DES-SF; Anderson, Fitzgerald, Gruppen, Funnell, & Oh, 2003) was used as a measure of the engagement of young adults with their diabetes clinic. The DES-SF is an 8-item measure of diabetes-related psychosocial self-efficacy. Participants rated their beliefs on a 5-point likert scale, ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The DES-SF has very good internal reliability ($\alpha = 0.84$; Anderson, Funnell, Nwankwo, Gillard, Fitzgerald, & Oh, 2001). Cronbach's alpha of 0.79 in the present sample was lower but still acceptable (Kline, 1999; Field, 2010).

2.6.3.1 Young adult's diabetes-related perceptions and behaviours

Diabetes self-care behaviours. A newly developed and validated measure, the Questionnaire to Assess Diabetes Self-Care Behaviours (D. Cooke, personal communication, May 13, 2014) was used in this study. In the present study, four subscales were adopted out of the 10 subscales which emerged in the development of the scale; monitoring (7 items), weight (3 items), illness management (3 items), and carbohydrate counting and testing (6 items). Responses to the weight and illness management subscales were on a 5-point likert scale, ranging from *never* to *always*. The response ‘This does not apply to me’ was also available for these two subscales. Participants responded to the remaining items on the 5-point *never* to *always* subscale, with the exception of an item on the monitoring subscale related to frequency of blood glucose self-monitoring for which responses ranged from 0 to 7 or more. Since some items (i.e. on the weight and illness management subscales) will not apply to all participants, an average score was obtained for each participant for each of the four subscales and used in all analyses. Subscale totals were used in this study as it is not recommended to create a single total score for diabetes self-care (Toobert, Hampson, & Glasgow, 2000). Cronbach’s alpha for the weight, illness management, monitoring and carbohydrate counting subscales were 0.85, 0.58, 0.87 and 0.39 respectively.

Autonomy for diabetes self-care. The Treatment Self-Regulation Questionnaire (TSRQ; Williams, Freedman & Deci, 1996) is a measure of autonomous self-regulation of health-related behaviours. The TSRQ consists of two subscales; autonomous regulation and controlled regulation. Participants were asked to rate the reasons for engaging in insulin administration and blood glucose self-monitoring on a 7-point likert scale, ranging from 1 (*not at all true*) to 7 (*very true*). The two subscales can be combined into the Relative Autonomy Index. In this study, participants responded to 8 items assessing the degree of autonomous self-regulation in relation to the stem ‘I take my medication for diabetes and check my blood glucose because...’. In previous studies excellent internal consistency was

reported for the autonomous ($\alpha = 0.81$) and controlled ($\alpha = 0.84$) subscales (Williams, Freedman & Deci, 1996) and the Relative Autonomy Index ($\alpha = .80$) (Lam & Gurland, 2008). Internal reliability for the Relative Autonomy Index in the present sample was .78.

Diabetes-related perceptions. The Brief Illness Perceptions Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) was used to measure participants' cognitive and emotional representations of their diabetes. The BIPQ consists of nine items which summarise each subscale of the Illness Perceptions Questionnaire-Revised (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). Items one to eight assess the dimensions consequences, timeline, personal control, treatment control, identity, concern, understanding and emotional responses. Each item is responded to on a likert scale, ranging from 0 to 10. Items one to eight can be combined to produce an overall score representing the degree to which diabetes is perceived as threatening or benign (The Brief Illness Questionnaire Scoring Instructions). This overall score has not been widely used in previous research, but has shown good internal reliability of .72 in a previous study (Storheim & Garratt, 2013). In the present study, the overall perceived threat score had a Cronbach's alpha of 0.69.

Distress related to type 1 diabetes. The Type 1-Diabetes Distress Scale (T1DDS; W. Polonsky, personal communication, December 12, 2014) was used to measure diabetes-related distress. The T1DDS is a 28-item measure. Participants rated the degree to which 28 feelings were a problem for them over the previous month on a 6-point likert scale, ranging from 1 (*not a problem*) to 6 (*a very serious problem*). This scale is new and so has not been widely used. In the present sample, the internal reliability was excellent ($\alpha = 0.94$).

Impulse control. The Brief Self-Control Scale (Tangney, Baumeister, & Boone, 2004) was used to measure participants' self-control in the face of competing emotions and contexts with a higher score reflecting better self-control. This 13-item scale is measured on a 5-point

likert scale, ranging from 1 (*not at all*) to 5 (*very much*). In a previous study among teenagers with type 1 diabetes, Cronbach's alpha was 0.83 (Berg et al., 2014), indicating excellent internal reliability. In the present sample, Cronbach's alpha was 0.81.

Social support. The modified Medical Outcomes Study Social Support Survey (mMOS-SS; Moser, Stuck, Silliman, Ganz, & Clough-Gorr, 2012) and the satisfaction subscale of the Social Support Questionnaire (SSQ; Sarason, Sarason, Shearin, & Pierce, 1987) were used to assess participants access to and satisfaction with everyday social support. The mMOS-SS consists of two subscales; instrumental/tangible support and emotional support. A total score can be computed with higher scores representing greater social support. Responses to this eight item scale are on a 5-point likert scale, ranging from *none of the time* to *all of the time*. In one study, the internal reliability of the mMOS-SS ranged from 0.88 to 0.93 (Moser et al., 2012). In the present sample, Cronbach's alpha was 0.88. The satisfaction scale adopted from the SSQ consists of three items related to satisfaction with support from family, friends, and a boyfriend or girlfriend. Participants were asked to rate their satisfaction with the support they had from each source on a 6-point likert scale, ranging from *very dissatisfied* to *very satisfied*. A "not applicable" option was also included. Excellent internal reliability ($\alpha = 0.93$) has been reported for this subscale in previous research (Siegert, Patten, & Walkey, 1987). In the present sample, a poor Cronbach's alpha of 0.36 was obtained.

2.6.3.2 Hassles and value associated with clinic attendance

Patient-centeredness of the diabetes clinic. The modified Health Care Climate Questionnaire (mHCCQ; Williams, McGregor, King, Nelson, & Glasgow, 2005) was used to assess the extent to which diabetes clinics were perceived as autonomy supportive by participants. This 6-item measure is a modified version of a 15 item measure (Williams, Grow, Freedman, Ryan, & Deci, 1996) with a 7-point likert scale, ranging from 1 (*strongly*

disagree) to 7 (*strongly agree*). A higher score reflects higher perceived autonomy support from the diabetes clinic. Excellent internal reliability ($\alpha = 0.91$) has been reported in previous research using the mHCCQ (Williams et al., 2005). In the current study, Cronbach's alpha was 0.95.

Satisfaction with the diabetes clinic. Two subscales were adopted in this study from the Satisfaction With Outpatients Services (SWOPS; Keegan & McGee, 2003) Questionnaire. The registration satisfaction subscale asks participants to rate six elements of the registration process in their diabetes clinic (registration, attitude of clerical staff, privacy, quality of waiting area, waiting time and refreshment facilities) using a 5-point likert scale, ranging from *poor* to *excellent*. Cronbach's alpha of 0.84 was reported. In the current study, Cronbach's alpha was 0.85. The overall satisfaction subscale was also adopted for this study. This subscale asks participants to rate overall satisfaction with their treatment at the clinic, satisfaction with medical care, nursing care and the running of the clinic. Participants were asked to respond on a 5-point likert scale ranging from *very dissatisfied* to *very satisfied*. In the original validation study, Cronbach's alpha was 0.84, and 0.89 in the present study.

2.6.4 Sample size

The adequacy of the sample size in this study was determined based on the complexity of the models specified and tested and the ratio of participants to parameters in each model. A simple path model was specified and tested in this study to minimise the information demand during statistical modelling (Kaplan, 2001; Muthén & Muthén, 2002). Adequate parameter to sample size ratios of between 5:1 and 10:1 were maintained throughout the process of model respecification and testing in this study (Kline, 2005).

2.6.5 Participants

Young adults aged between 18 and 30 years (inclusive) were sampled. The upper limit of 30 was chosen to maintain consistency with study 1 and study 2, but the lower age of 18 was chosen, rather than 15, to avoid ethical issues related to online recruitment of adolescents under 18. No additional exclusion criteria were applied to maximise the likelihood of recruiting a representative sample of young adults with type 1 diabetes.

The recruitment strategy in this study aimed to ensure that a sufficient sample size was achieved and that young adults with the full range of clinic attendance profiles may participate. Clinic-based and online recruitment strategies were used. Participants were sampled through diabetes clinics in the Republic of Ireland, and diabetes-related websites and social networks. The theory of clinic attendance was developed based on the integration of the findings of study 1 and study 2. As a result, the theory comprised qualitative data collected from young adults with type 1 diabetes and service providers, and the qualitative and quantitative evidence collected and synthesised from 12 international studies. Therefore, the theory should have been generalizable to the diabetes clinic experiences of young adults with type 1 diabetes and the recruitment of international participants was appropriate.

Contact was made with seven adult diabetes clinics in the Republic of Ireland. Young adult diabetes clinics operated in three of the seven clinics. In the other four clinics, young adults attended general adult diabetes clinics. The clinics were in a variety of settings across the midlands and east of Ireland, in small to large towns catering to large catchment areas.

Online recruitment sites included the websites of diabetes-related organisations and publications (such as Diabetes Ireland, and the Juvenile Diabetes Research Federation UK), and social media platforms (such as facebook and twitter). A range of websites and platforms were identified and contacted to maximise the representativeness of the sample recruited. When recruiting through social media, a network of connections related to the research topic

was necessary. Therefore contact was made with prominent social media users who organised groups or were active in sharing content. Private Facebook groups of young adults with diabetes, such as groups of university students, were identified and contacted.

2.6.6 Procedure

Participants recruited in diabetes clinics were either contacted in person by the researcher or by a member of their diabetes team while attending the diabetes clinic. Participants recruited online were contacted through posts on diabetes-related websites or social media.

The questionnaire was pilot tested with seven young adults who were involved in a related project and changes were made based on feedback. The feedback related to the length of the questionnaire, the suitability of some questions to young adults with type 1 diabetes, and suggestions for additional response options in the section of demographic questions. All participants were provided with detailed study information, and completed consent forms (Appendix L). Young adults recruited in hospitals completed paper questionnaires. Those who participated online completed an identical questionnaire accessed through a website created for the study (<https://yourdiabetesclinic.wordpress.com>). The questionnaires took approximately 30 minutes to complete. Ethical approval for this study was obtained from the Research Ethics Committee of the National University of Ireland, Galway and three of the hospital-based clinics where participants were recruited.

2.6.7 Data screening

2.6.7.1 Multivariate normality

Multivariate outliers were identified using the test for Mahalanobis Distance (D^2) (Field, 2009) because data which are multivariate normally distributed is a core assumption

of SEM (Kaplan, 2001). Cases with unusual combinations of values on more than one variable, such as extreme low and high values, were considered to be multivariate outliers. In this study, four multivariate outliers were identified based on values for Mahalanobis Distance (D^2). Extreme low and high values were found when the data for each of the four participants were screened. All four cases were removed from the dataset.

2.6.7.2 Missing data

A full dataset without missing data was necessary to conduct SEM (Kaplan, 2001). Some missing data were observed in the dataset in this study. Little's MCAR Test was conducted to determine whether the data were Missing Completely At Random (MCAR) or Missing At Random (MAR), as opposed to Missing Not At Random (MNAR) (Scheffer, 2002). A non-significant chi-square statistic indicated that the data were MCAR or MAR, and that measures, such Estimation Maximisation (EM), could be taken to address it (Allison, 2003). By using EM to deal with the missing data in this study, all of the available quantitative data were used to estimate the values each participant would have entered (Allison, 2003). In this study, EM was used as the data were found to be MAR and the percentage of missing data was less than 30% (S. V. Owen et al., 2007; Peugh & Enders, 2004).

2.6.8 Statistical analysis

Structural Equation Modelling (SEM) was chosen as the most appropriate statistical method for addressing the aims of this study, which were to model processes and outcomes related to the theory of clinic attendance. The findings of study 2 indicated that central variables within the theory may play moderating roles between other variables and the outcome of clinic attendance. Therefore, moderation analyses were also conducted to further model the relationships within the theory. Using SEM, several models representing the

hypothesised relationships within the central pathway in the theory of clinic attendance were tested by evaluating the predictive ability of each model and their fit to the data (Kline, 2005; Kaplan, 2001). SEM was conducted in AMOS 20 (Arbuckle, 2011) and moderation analyses were conducted using the programme Interaction v.1.7 (Soper, 2011).

The major benefit of SEM over other approaches, such as regression, was the flexibility with which models could be built, for example the models could have been simple or very complex, bidirectional relations could have been included, and more than one ‘indicator’ or measure of an independent or dependent variable may have been used (Byrne, 2010). Although causal conclusions could not be made using SEM, pre-specified causal models were built and their consistency with the data was evaluated (Byrne, 2010). Therefore, SEM was a suitable method for this theory development study (Byrne, 2010).

Using SEM in this study, the aim was to produce a model of clinic attendance behaviour that was substantively meaningful and statistically well-fitting (Byrne, 2010). However researchers have been criticised for being overly concerned with model fitting, at the expense of the substantive meaning of the models being tested (Kaplan, 2001; Nachtigall, Kroehne, Funke, & Steyer, 2003). A focus on the predictive ability of the structural equation model and the development of the underlying theory in this study maintained the focus on learning valuable information related to the phenomenon under investigation (Kaplan, 2001).

Parameters were added one at a time in this study, depending on problematic associations found between some variables and based on pathways suggested by the theory of clinic attendance (Byrne, 2010). Bidirectional arrows indicating a covariance between two variables were added to account for correlations between the outcome measures. In addition, direct pathways were added between a central variable and two of the clinic attendance measures when the indirect pathways hypothesised by the theory were not significant.

2.6.8.1 Assessing model fit

Based on guidance produced by Byrne (2010) and Kline (2005), the goodness-of-fit between models specified using AMOS software and the observed data (i.e. the model fit) was evaluated using a range of criteria drawn from the available indices. The primary indicator of model fit used in this study was the chi-square statistic (a non-significant chi-square statistic suggested good model fit). The chi-square statistic has been found to be sensitive to sample size when the sample is greater than 200, and is based on the assumption that the model fits perfectly in the population, which would never be expected (Byrne, 2010). Therefore researchers have developed a range of goodness-of-fit indices used to complement and expand upon the chi-square statistic.

The fit between the specified model and the data were assessed using the absolute fit (Q) index (ratio between chi-square and the associated degrees of freedom), and Root Mean Square Error of Approximation (RMSEA) with 90% confidence intervals (90% CI). The comparative fit was assessed using the Comparative Fit Index (CFI) and the Tucker-Lewis Index (TLI). Rigorous thresholds were applied based on existing literature: Q ; <5 was good, <3 was excellent, RMSEA; $<.1$ was good, $<.05$ was excellent, CFI; $>.9$ was good, $>.95$ was excellent, TLI; $>.9$ was excellent (Byrne, 2010; Hu & Bentler, 1999). The Akaike Information Criteria (AIC) were used to compare the fit of two competing models. The lower AIC value depicts the preferred model (Byrne, 2010).

2.7 Ethical considerations

A framework for evaluating the ethics of health research with human participants based on major ethical codes, declarations and other relevant documents guided ethical considerations in this research (Emmanuel, Wendler, & Grady, 2000). The seven requirements according to this framework are as follows:

- **Value** must be added in terms of improvements in health or knowledge as a result of the research.
- The research must be **scientifically valid** by applying rigorous methodological standards.
- **Fair participant selection** must guide recruitment based on scientific objectives and consideration of potential risks and benefits in order to avoid disproportionate distribution of either among vulnerable or privileged groups.
- A **favourable risk-benefit ratio** in terms of the risks and benefits to participants as well as society must be present.
- The research must be subject to ethical **review by independent persons** with the power to approve, amend or terminate it.
- Participation in the research must be **informed and voluntary**.
- **Respect** must be shown to participants by protecting their privacy, having the opportunity to withdraw, and monitoring their wellbeing.

Although the framework compiled by Emmanuel et al., (2000) related more closely with clinical research, it was important that this research, which may be seen as posing significantly less harm to participants, was approached with the same objective and person-centred standards. Participants were recruited in study 2 and study 3, including adolescents aged between 16 and 18 in study 2. Ethical approval was sought and obtained for data collection in study 2 and study 3 of this project from the relevant Research Ethics Committees. The primary ethical concerns raised by these two studies related to informed consent, confidentiality and anonymity, fair participant selection, favourable risk-benefit ratio and respect for participants. The following section will outline how each of these ethical concerns was addressed in this research. The consent and assent forms and participant information sheets for study 2 and study 3 are included in Appendices D, E, F, G, H and L.

2.7.1 Informed consent

The purpose of procedures for obtaining informed consent in this research was to ensure that it was truly the decision of the individual to take part in the research or not, and that the research was in line with the individual's values, interests and preferences (World Medical Association, 1997). As well as providing accurate information related to the purpose, methods, risks and benefits of participation, it was necessary to ensure that participants understood the information provided (Applebaum, Lidz, & Meisel, 1987).

Among adolescents aged 16-18 recruited in study 2, a process of informed consent from parents or guardians as well as informed assent from the participant themselves was followed (Brody, Scherer, Annett, & Pearson-Bish, 2003; Broome, 1999). Issues associated with recruiting adolescents aged 16-18, such as developmental issues, the imbalance of power, history of health care interactions and health status, were considered (Broome, 1999).

As a population with a chronic condition, members of the target population for this research may have been contacted and recruited for numerous studies. This may have affected the willingness of young people to take part in the research in a negative or positive manner. This consideration applied to the sample as a whole including service providers. In cases where the research was based in a single setting, as in study 2, or participants were recruited through their diabetes clinic, as in study 3, the importance of informed and voluntary consent, and adequate time to make a decision, were central to facilitate potential participants to choose, independently, to take part in research which was of interest to them.

Information related to each study in this research and to informed consent was clear, provided in more than one form (e.g. written and oral) and age-appropriate. A dynamic consent procedure was followed during study 2 whereby consent was renegotiated at the point of initial contact, recruitment and interview with participants (J. Cutcliffe &

Ramcharan, 2002). This ‘process consent’, in conjunction with the traditional consent procedure described above, ensured that participants were aware of and had the opportunity to withdraw once the research had commenced and without providing an explanation. This procedure was time-limited however as participants could not withdraw their accounts once the research had been presented or published. Participants were made aware of this in the consent form (J. Cutcliffe & Ramcharan, 2002). Potential participants in study 3 were provided with detailed information about the study, what their participation would involve, how their data would be treated, and that their participation was voluntary and they could withdraw at any time until the point when their questionnaire was completed and submitted.

In study 3, the experience of completing a questionnaire related to diabetes self-management, distress related to diabetes, and participant’s beliefs about their diabetes may have caused some distress. It was estimated that the distress caused by completing the questionnaires included in this study would be low. The content of the questionnaire was clearly outlined in the study information which potential participants read before providing informed consent. Distress may have been minimised when participants were aware of the content of the questionnaire.

2.7.2 Fair participant selection & respect for participants

Criteria to ensure fair participant selection and respect for research participants were closely linked in this research. The priority in this research was to collect the views and experiences of a representative sample of young adults with type 1 diabetes. Therefore, the exclusion criteria applied in this research were broad. Young adults with co-morbid physical or psychological diagnoses were not excluded from this research (Weijer & Miller, 2004). Respect was shown to participants in this research by providing detailed and accurate information regarding each study, recruiting individuals only following the receipt of the

informed consent of participants, implementing and maintaining procedures for anonymity and confidentiality, and providing participants with a report of the findings of the study in a timely manner (Emmanuel et al., 2000).

2.6.3 Confidentiality & anonymity

The process of data collection and procedures for securely managing the data of each individual was of particular importance in this research. Challenges to confidentiality were encountered in this research, for example, the small sample sizes and level of description used in study 2 (Rinaldi Carpenter, 2006). Confidentiality was enhanced in study 2, by using digital recording equipment so that sound files could be saved to password protected computers. Confidentiality and anonymity were maintained in study 2 and study 3 by storing the transcripts and questionnaires in a secure location and by using anonymised documents for storing participant information (Emmanuel et al., 2000). Discomfort or distress may have been minimised or avoided when participants were confident in the knowledge that the information they provided could not be associated with them should they feel embarrassed or worried about their responses.

2.8 Summary of this chapter

This chapter provided an overview of the study design and details of the methodological approach of each study. The use of mixed methods in this study is demonstrated by the influence of study 1 and study 2 in relation to the planning of study 3. The aim of the three studies described in this chapter were to identify the relevant evidence base, develop a theory and model processes related to the behaviour of interest, addressing the three steps within the development phase of the MRC framework for developing complex interventions. A systematic review and narrative synthesis, ground theory study and questionnaire-based study, using qualitative and quantitative methods were conducted to

address the study aims. The main ethical considerations related to informed consent, confidentiality and anonymity, fair participant selection, favourable risk-benefit ratio and respect for participants. Measures to address these ethical issues included the provision of detailed participant information and sharing the findings of completed studies with participants.

3. Study 1: Barriers and facilitators associated with attendance at hospital diabetes clinics among young adults (15-30) with Type 1 diabetes mellitus: A systematic review

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Abstract

Regular clinical attendance is recommended to facilitate self-management of diabetes. Poor attendance is common among young adults with Type 1 diabetes mellitus (DM). This systematic review aimed to produce a narrative synthesis of the evidence regarding factors which promote or impede regular attendance at adult diabetes clinics among young adults (15-30 years) with Type 1 DM. Studies reporting facilitators and barriers to clinic attendance were identified by searching four electronic databases, checking reference lists and contacting diabetes research networks. A total of 12 studies (eight quantitative and four qualitative) met the inclusion criteria. Young adult's experiences transitioning from paediatric to adult diabetes care can influence attendance at the adult clinic positively if there is a comprehensive transition programme in place, or negatively if the two clinics do not communicate and provide adequate support. Post transition, relationship development and perceptions of the value of attending the clinic are important for regular attendance. Controlled research is required to better understand decisions to attend or not attend outpatient services among people with chronic conditions. Service delivery must be sensitive to the developmental

characteristics of young adults and tailored support may be required by young adults at greatest risk of non-attendance.

Keywords: clinic attendance; young adults; type 1 diabetes mellitus; transition.

3.1 Introduction

The competing distractions of young adulthood, such as attending university or moving away from home, often interfere with the requirements of successful diabetes management, including the establishment and maintenance of consistent contact with the adult diabetes service (Garvey & Wolpert, 2011; Nakhla, Daneman, To, Paradis, & Guttmann, 2009). It is recommended that adults with Type 1 diabetes attend between two and four medical appointments annually (American Diabetes Association, 2000). Achievement of this recommendation is particularly important among young adults. Yet considerable variation in attendance rates is regularly reported, for example attendance across four clinics, 2 years after transition to adult care varied from 29 to 71% in one study (Kipps et al., 2002). Currently, service provision may not reflect an understanding of the complex needs of this group (Bowen, Henske, & Potter, 2010; Garvey & Wolpert, 2011; P. Owen & Beskine, 2008).

Clinic attendance is important during this developmental stage as behaviours which are commonly associated with young adults may expose individuals with Type 1 diabetes to a greater risk of harm (K.M. Hanna, 2012). Despite the increased risk, rates of smoking and alcohol consumption are roughly equivalent among young adults with and without Type 1 diabetes (Peters et al., 2011). The demands of work or college, changes in levels of physical activity, varying motivation for self-care and differing dietary patterns have also been reported as barriers to self-care among young adults (Peters et al., 2011). Thus, in addition to the fundamental considerations of diabetes care, the adult diabetes clinic has an important

role to play in risk minimisation, and providing education and support which is developmentally appropriate (Garvey & Wolpert, 2011).

A minority of adolescents aged 13-19 maintain glycaemic control in line with the ADA-recommended level of <7.5% (M. Rewers et al., 2009). Even fewer young adults aged 20 or older achieve the recommended level of $\leq 7\%$ (Daneman, 2006; Wood et al., 2013). A complex association exists between glycaemic control and clinic attendance rates. However, due to the competing demands and developmental challenges of young adulthood, experts have recommended that the establishment and maintenance of regular clinic attendance be considered the main aim of care during young adulthood (Garvey & Wolpert, 2011).

3.1.1 Review aim

The aim of this systematic review was to synthesise the findings of a range of studies investigating barriers and facilitators to clinic attendance among young adults (15-30 years) with Type 1 diabetes. It was not possible to conduct a meta-analysis on the studies reviewed. Therefore a narrative synthesis was the most appropriate method of analysis. Both quantitative measures of clinical data and qualitative explorations of the views and experiences of young adults and health care staff were included to facilitate a comprehensive understanding of clinic attendance among young adults with Type 1 diabetes (Gough, Oliver, & Thomas, 2012).

3.2 Methods

3.2.1 Search strategy

Electronic databases, EBSCO CINAHL, MEDLINE, PsycINFO, and OVID EMBASE were searched from database start to July 2013. The search term, 'Diabetes', was accompanied with all combinations of the terms 'young adult' or 'adolescent', and

‘attendance’, ‘non-attendance’ or ‘missed appointment’. A full sample search strategy for the EBSCO MEDLINE database is shown in the supporting information (Appendix A).

Three diabetes research networks (Australian Society for Psychological Research into Diabetes, Behavioural Research in Diabetes Group, and Psychosocial Aspects of Diabetes group) were contacted by email. Members were asked to provide any relevant information in the form of conference proceedings, abstracts, theses or primary research. Reference lists of relevant studies were also searched for additional studies.

3.2.2 Study selection

Studies published in English were included if potential barriers and facilitators to clinic attendance were assessed among young adults aged 15 – 30 (inclusive) with Type 1 diabetes. The age range of 15-30 years was chosen due to varying definitions of young adults across the relevant research. Studies were excluded if the study population did not have Type 1 diabetes, information relating to participants aged 15 – 30 could not be extracted from the data, if clinic attendance was not an outcome variable, if it was a review or discussion paper, or if the study was not available as a full text.

Three reviewers (L.H., M.B., and J.Mc S.) selected search terms based on initial scoping searches of the relevant literature. All studies identified were transferred to an Endnote database to be assessed for inclusion. Following the removal of duplicates, studies were excluded in step 1 if there was evidence in the title that they were not diabetes related. In step 2, studies were excluded if they were deemed ineligible following examination of the abstract. Full texts were read in full in step 3 in order to produce the final group of studies included.

3.2.3 Data extraction

A preliminary synthesis was conducted by tabulating the relevant data into separate data extraction tables for quantitative and qualitative studies. The following data were extracted: author, publication year, location & setting, sample characteristics (including size, gender and, mean age at time of study, at diagnosis and at transition if given), measure of clinic attendance, barriers to clinic attendance, facilitators of clinic attendance, overall findings and indicators of study quality. Textual descriptions and information regarding study quality were also included in the data extraction tables.

3.2.4 Quality assessment

Quality assessments of quantitative studies were conducted using predefined categories specified in the critical appraisal skills programme (CASP) checklist (Critical Appraisal Skills Programme (CASP), 2013) (Appendix B). A tool which was developed based on existing literature and employed in published research informed the quality assessment of the qualitative studies reviewed (Bogosian et al., 2010; Elliott et al., 1999) (Appendix C). Minor adaptations were applied to both tools to increase their relevance to this review. Due to the limited number of studies identified as being relevant to the review, the findings of the quality assessment did not result in studies being excluded. Table 3.1a and Table 3.1b show the data extracted from all studies and the methodological issues which emerged. The contribution of each study to the findings of this review can be seen in Table 3.2 enabling the reader to assess the strength of the evidence.

Table 3.1a.

Characteristics of quantitative studies included

Reference	Country	Design	Sample size (% male) Mean age of sample (SD)	Focus on clinic attendance	Quality
Cadario <i>et al.</i> , 2008	Italy	Retrospective cohort study	62 (54.8%) 19 years (2.8)	-% of attendance at regular visits -Delay in attending adult clinic (transition delay)	Sample may not be representative; small number of potential variables considered.
Kipps <i>et al.</i> , 2002	United Kingdom	Retrospective cohort study	229 (50%) 22 years (range: 18.2 – 26.5)	-% regularly attending a clinic (regularly defined as at least every six months) -Decline in clinic attendance since transition	No major quality issues identified
Perry <i>et al.</i> , 2010	Australia	Retrospective cohort study	239 (52.3%) Regional – 23.1 years	Planned and unplanned hospital	Influences of additional variables

			(2.7) City – 21.4 years (2.0) Capital – 23.7 years (3.0)	contacts	were not accounted for.
Sparud-Lundin <i>et al.</i> , 2008	Sweden	Retrospective, longitudinal study	104 (51%) 18-24 years	Diabetes care utilization in adult clinic and in comparison to rates in paediatric clinic	No major quality issues identified
Vanelli <i>et al.</i> , 2004	Italy	Retrospective, longitudinal study	73 (58.9%) 26.5 years (2.6)	Clinic attendance records	Lacking details of transition prior to transition programme; absence of control group.
Van Wallegghem <i>et al.</i> , 2008 Van Wallegghem <i>et al.</i> , 2011	Canada	Non-randomised intervention evaluation	248 (not specified) Group 1 – 18 years Group 2 – 19-25 years	Clinic attendance records and patient survey	Suitability of control group; basic data presented; lack of analysis of effectiveness of intervention elements.

Wilson <i>et al.</i> , 1999	United Kingdom	Cross-sectional	Not specified 16 – 25 year olds eligible	Clinic attendance records	Basic design; findings unclear due to the absence of data.
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Table 3.1b.

Characteristics of qualitative studies included

Reference	Country	Design	Sample size (% male) Mean age of sample (SD)	Focus on clinic attendance	Quality
Brierley <i>et al.</i> , 2012	United Kingdom	Semi-structured interviews with health care staff	14 (57.1%) Not specified	Explore views of staff regarding current service provision and working with young adults (aged 16-21)	No major quality issues identified
Olsen <i>et al.</i> , 1998	United Kingdom	Interviews & focus groups with young adults	21 (N/S) 17-19 years	Loss to follow up following transition	Methodology not specified; lack of participant details.
Scott <i>et al.</i> , 2005	Canada	Survey to inform telephone interviews with young adults	Survey 75 (58.7%) 20.2 years (2.5)	Barriers & facilitators to clinic attendance	Lack of details about interviewees; qualitative methodology not

			Interviews		specified.
			19 (N/S)		
			N/S		
Snow <i>et al.</i> , 2012	United Kingdom	Semi-structured interviews with young adults	19 (47.4%) 18 – 25 years	- Clinic attendance records -Meaning of clinic attendance	No major quality issues identified

3.2.5 Data synthesis

The synthesis of quantitative studies was informed by guidance in the conduct of narrative synthesis in systematic reviews compiled by Popay *et al.* (Popay *et al.*, 2006). The findings of the qualitative studies reviewed were analysed using the method for thematic analysis of qualitative research in systematic reviews described by Thomas & Harden (Thomas & Harden, 2008). Descriptive codes were assigned to units of meaning in the results section of each study. Codes were then organised into categories of factors which were related to clinic attendance. These categories were entered into synthesis tables for quantitative and qualitative studies and similarities and differences across studies were identified. Synthesis findings from both study types were integrated at this stage due to the agreement in terms of the themes which had emerged.

3.3 Results

Figure 3.1 shows the process of inclusion of studies. Database searches identified 1766 citations, with 1030 remaining after the removal of duplicates. Screening of titles and abstracts resulted in 129 potentially eligible studies. Of these, 15 were excluded as the full text was unavailable. Full text versions of the remaining 114 were examined in detail. Of these, 12 peer-reviewed journal articles met the inclusion criteria (Brierley *et al.*, 2012; Cadario *et al.*, 2009; Kipps *et al.*, 2002; Olsen & Sutton, 1998; Perry *et al.*, 2010; Scott *et al.*, 2005; Snow & Fulop, 2012; Sparud-Lundin *et al.*, 2008; Van Wallegghem, MacDonald, & Dean, 2008; Van Wallegghem *et al.*, 2011; Vanelli *et al.*, 2004; S. J. Wilson & Greenhaigh, 1999). Of those included, four were identified through inspection of reference lists (Olsen & Sutton, 1998; Sparud-Lundin *et al.*, 2008; Van Wallegghem *et al.*, 2008; S. J. Wilson & Greenhaigh, 1999) and one through correspondence (Van Wallegghem *et al.*, 2011). Van Wallegghem *et al.* produced two reports evaluating their patient navigator project, both of

which are included in this review (Van Walleggem et al., 2008, 2011). The same data is reported in both articles, thus results synthesised in this review will refer to the more recent of the two reports (Van Walleggem et al., 2011).

Quantitative research methods were employed in eight (Table 3.1a) and qualitative methods in four (Table 3.1b) of the studies included. Transition from paediatric to adult diabetes care was the primary focus of eight of the studies reviewed (Cadario et al., 2009; Kipps et al., 2002; Olsen & Sutton, 1998; Scott et al., 2005; Sparud-Lundin et al., 2008; Van Walleggem et al., 2008, 2011; Vanelli et al., 2004), while the other four were based exclusively in adult or young adult diabetes services (Brierley et al., 2012; Perry et al., 2010; Snow & Fulop, 2012; S. J. Wilson & Greenhaigh, 1999). Barriers and facilitators to clinic attendance are summarised in Table 3.2 and discussed in the following section under the themes of support and continuity of care during transition from paediatric to adult diabetes services, and relationship development, perceived value of clinic attendance, and communication within the adult diabetes service.

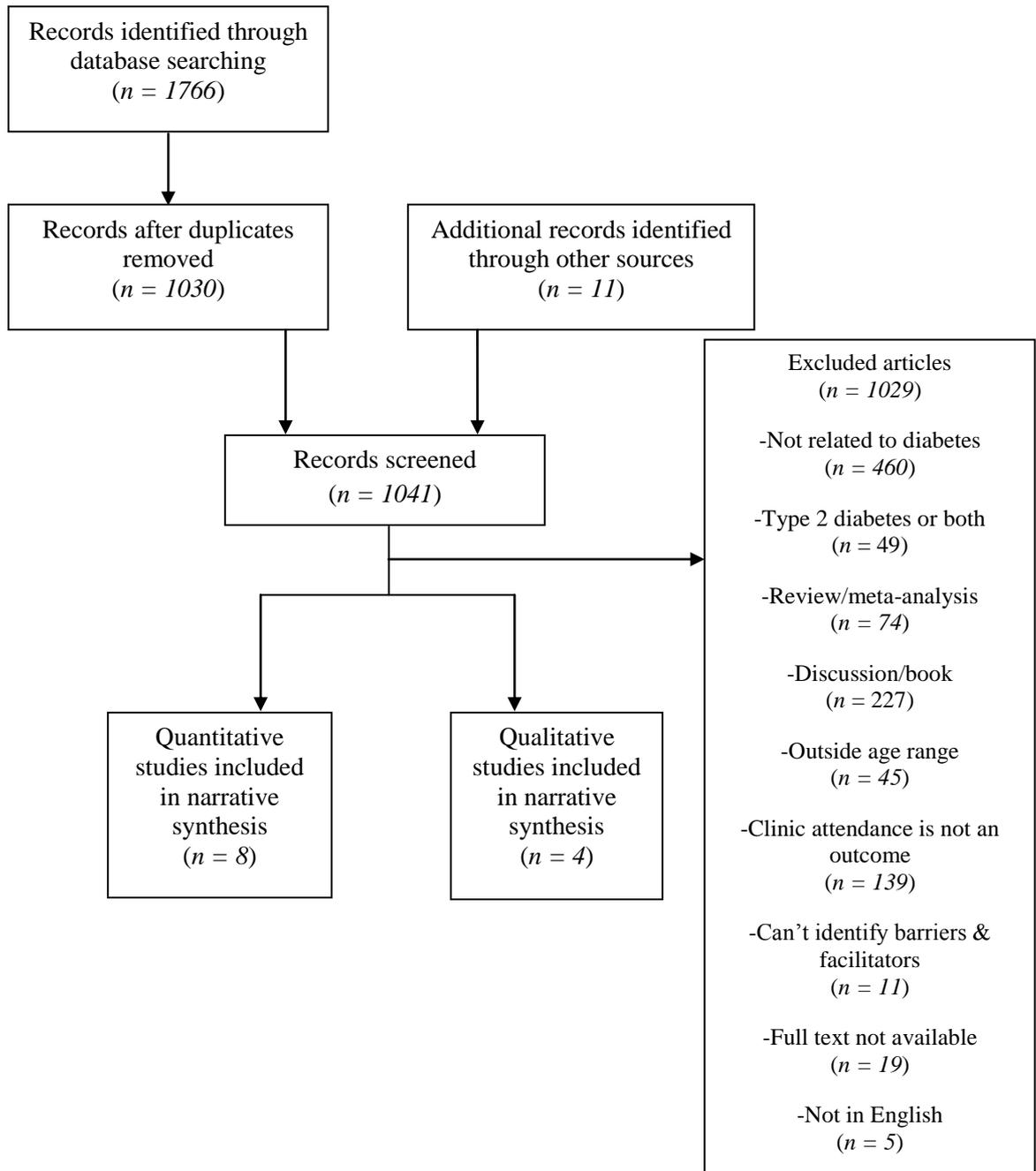


Figure 3.1. Flow chart of studies screened, excluded (with reasons) and included in the review.

Table 3.2.

Summary of facilitators and barriers to clinic attendance

Setting	Facilitators	Studies	Barriers	Studies
Transition	Transition programme	Kipps <i>et al.</i> , 2002 ; Cadario <i>et al.</i> , 2008 ; Vanelli <i>et al.</i> , 2004;	Lack of collaboration between paediatric and adult clinics	Kipps <i>et al.</i> , 2002; Cadario <i>et al.</i> , 2008; Vanelli <i>et al.</i> , 2004;
	-Continuity of care -Involvement of young adults	Olsen <i>et al.</i> , 1998	-Inadequate communication between services -Unprepared young adults	Scott <i>et al.</i> , 2005; Brierley <i>et al.</i> , 2012; Olsen <i>et al.</i> , 1998
	Support and information during transition	Kipps <i>et al.</i> , 2002; Sparud-Lundin <i>et al.</i> , 2008; Cadario <i>et al.</i> , 2008; Vanelli <i>et al.</i> , 2004;	Unsupported transition	Kipps <i>et al.</i> , 2002; Olsen <i>et al.</i> , 1998; Cadario <i>et al.</i> , 2008;
	-Written and oral information	Olsen <i>et al.</i> , 1998	-Negative emotional impact	Scott <i>et al.</i> , 2005; Snow <i>et al.</i> , 2012; Van Walleggem <i>et al.</i> ,
	-Familiar staff		-Lack of time to adapt	2011

-Role of parents

Adult diabetes clinic	Continuity of staff in adult clinic -Familiarity	Wilson <i>et al.</i> , 1999; Vanelli <i>et al.</i> , 2004; Scott <i>et al.</i> , 2005; Brierley <i>et al.</i> , 2012	Challenges to relationship development -Time constraints -Perceptions held by staff & young adults	Scott <i>et al.</i> , 2005; Brierley <i>et al.</i> , 2012; Snow <i>et al.</i> , 2012
	Valued clinic characteristics and resources	Vanelli <i>et al.</i> , 2004; Scott <i>et al.</i> , 2005; Brierley <i>et al.</i> , 2012 ; Snow <i>et al.</i> , 2012	Low perceived value of attendance	Snow <i>et al.</i> , 2012 ;Van Wallegghem <i>et al.</i> , 2011
	Clear procedure for appointment making & breaking	Wilson <i>et al.</i> , 1999	Difficulties communicating with service Conflicting schedules	Olsen <i>et al.</i> , 1998; Wilson <i>et al.</i> , 1999; Snow <i>et al.</i> , 2012; Van Wallegghem <i>et al.</i> , 2011 Olsen <i>et al.</i> , 1998; Scott <i>et al.</i> , 2005; Snow <i>et al.</i> , 2012

3.3.1 Transition programmes facilitate attendance through continuity of care

Improvements in rates of attendance at the adult diabetes clinic were reported in the four studies in which formal protocols were implemented, guiding the transition of young adults from paediatric to adult diabetes services (Cadario et al., 2009; Kipps et al., 2002; Van Wallegghem et al., 2011; Vanelli et al., 2004). By holding clinics to introduce staff from the adult diabetes clinic to young adults preparing for transition, a sense of continuity of care was created. An active role by young adults in the transition process was associated with attendance at the adult diabetes clinic (Vanelli et al., 2004).

In six studies, however, attendance at the adult clinic was hindered by a lack of collaboration between paediatric and adult diabetes services according to young adults and health care staff (Brierley et al., 2012; Cadario et al., 2009; Kipps et al., 2002; Scott et al., 2005; Van Wallegghem et al., 2011; Vanelli et al., 2004). The lack of collaboration created barriers through the loss of valuable patient information (Brierley et al., 2012), and heightened the impact of being faced with a move into an unfamiliar service (Brierley et al., 2012; Cadario et al., 2009; Kipps et al., 2002; Scott et al., 2005; Vanelli et al., 2004). Continuity of care was also compromised when the experience of young adults in the adult clinic was in stark contrast to the norm in the paediatric clinic. Disparity between paediatric and adult services, such as reduced access to specialist care (Perry et al., 2010) and a shift to patient responsibility for appointment scheduling (S. J. Wilson & Greenhaigh, 1999) had a negative impact on satisfaction and perceived value of clinic attendance (Van Wallegghem et al., 2011).

3.3.2 Complex model of support needed to facilitate attendance

Multiple sources of support and information to aid transition facilitated attendance at the adult diabetes clinic according to the findings of four studies (Cadario et al., 2009; Kipps

et al., 2002; Van Wallegghem et al., 2011; Vanelli et al., 2004). For example, the transition intervention evaluated by Van Wallegghem *et al.* comprised a website, bimonthly newsletter, drop-in evenings and educational events (Van Wallegghem et al., 2011). Attendance post transition in the intervention group was higher (89.1% medical appointments attended in the adult diabetes clinic) than attendance in the standard transition group (59.4% medical appointments attended in adult diabetes clinic).

Young adults in five studies who did not receive adequate support and information during transition were less likely to attend the adult clinic regularly or at all (Cadario et al., 2009; Kipps et al., 2002; Olsen & Sutton, 1998; Scott et al., 2005; Van Wallegghem et al., 2011). A lack of support and poor awareness of the emotional needs of young adults among staff resulted in negative emotions and dissatisfaction (Brierley et al., 2012; Olsen & Sutton, 1998; Scott et al., 2005). Some young adults interviewed felt abandoned and uncertain (Olsen & Sutton, 1998; Scott et al., 2005; Van Wallegghem et al., 2011), were out of contact with, or unaware of specialist services and of the need to reconnect and regularly attend an adult diabetes clinic (Scott et al., 2005).

In one study, health care staff reported a greater problem with non-attendance across the young adult period as opposed to non-attendance after transition (Brierley et al., 2012). Staff attributed this in part to a lack of support for young adults to adapt to the new service. Attendance rates among young adults aged 19-25, who had transitioned to the adult diabetes clinic without the support of a transition programme improved from 60% to 73% following the introduction of multiple sources of support and communication between young adults and health care staff, such as educational events (Van Wallegghem et al., 2011).

Young adults found they 'just got out of the rhythm' when they started going to the adult diabetes clinic (Olsen & Sutton, 1998). A period of non-attendance during the young

adult period was reported by participants and attributed to a sense of denial when diabetes seemed too much to handle (Snow & Fulop, 2012). In the more recent version of the study by Van Wallegghem et al. (Van Wallegghem et al., 2011), evaluating the Maestro patient navigator, a survey of the experiences of patients found that almost half of those surveyed (n = 35) did not receive medical care for a period of more than 1 year. The most common reason reported for reconnecting with the adult diabetes service was fear of complications. Young adults described realising the need to commit to their own self-care (Van Wallegghem et al., 2011).

Changes to supervision of clinic attendance by parents may play a role in the decrease in clinic attendance in adult diabetes clinics in comparison to paediatric clinics (Sparud-Lundin et al., 2008) and the declining attendance rates frequently reported following the first year in the adult diabetes clinic (Kipps et al., 2002; Perry et al., 2010; Sparud-Lundin et al., 2008). Although parents may no longer attend the adult diabetes clinic, a routine of regular attendance supervised by parents in the paediatric diabetes clinic facilitated the maintenance of regular attendance in the adult diabetes clinic (Snow & Fulop, 2012) while poor attendance at the paediatric diabetes clinic was associated with loss to follow up during the transition process (S. J. Wilson & Greenhaigh, 1999).

3.3.3 Continuity of Care enables relationship development in the adult diabetes clinic

Within the adult diabetes clinic young adults in four studies preferred consultations with familiar health care staff (Brierley et al., 2012; Scott et al., 2005; Vanelli et al., 2004; S. J. Wilson & Greenhaigh, 1999). Health care staff reported that due to time constraints and challenges establishing continuity of care they made generalisations and judgements in

relation to young adults which undermined relationship development within the clinic (Brierley et al., 2012).

Fear or perception of being ‘told off’ or judged by health care professionals for unsatisfactory glycaemic control was a barrier to clinic attendance in three studies (Brierley et al., 2012; Scott et al., 2005; Snow & Fulop, 2012). Young adults felt health care staff did not take the time to understand the struggle they experienced to achieve glycaemic control (Snow & Fulop, 2012).

3.3.4 Perceived value influences clinic attendance

Privacy, confidentiality, and short waiting times may have facilitated the consistent rate of clinic attendance reported in the study by Vanelli *et al* (Vanelli et al., 2004). Short waiting times (Scott et al., 2005), appointment reminders and timely test results (Snow & Fulop, 2012) were among recommendations made by young adults for improving adult diabetes services. Valued benefits which may positively influence the decision of young adults to attend the diabetes clinic included practical information regarding a broad range of topics, and emotional support and reassurance ideally delivered by peers or mentors with diabetes (Brierley et al., 2012; Scott et al., 2005; Snow & Fulop, 2012).

3.3.5 Clear procedures and efficient communication are important for regular attendance

Difficulties communicating with the clinic regarding the scheduling of appointments were reported in four studies (Olsen & Sutton, 1998; Snow & Fulop, 2012; Van Wallegem et al., 2011; S. J. Wilson & Greenhaigh, 1999). In addition, young adults in three studies struggled to attend appointments due to conflicting clinic and work schedules (Olsen & Sutton, 1998; Scott et al., 2005; Snow & Fulop, 2012). Young adults who perceived a lack of

value in relation to clinic attendance and difficulties securing time off work may decide against attendance at future clinic appointments (Snow & Fulop, 2012). In order to facilitate clinic attendance among young adults in one clinic, evening appointments were introduced, staff ensured young adults arranged the next appointment before leaving the clinic each visit, and the clinic administration rescheduled missed appointments to avoid placing the onus on young adults to make contact (S. J. Wilson & Greenhaigh, 1999).

3.4 Discussion

To the best of our knowledge, this is the first systematic review to synthesise the evidence related to clinic attendance among young adults aged 15 – 30 years, with Type 1 diabetes. The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement was used to guide the reporting of key methodological information (Moher et al., 2009). According to previous longitudinal research, many young adults with Type 1 diabetes experience poor clinical and psychiatric outcomes (Bryden, Dunger, Mayou, Peveler, & Neil, 2003). Regular attendance rates at the adult diabetes clinic have been associated with improvements in HbA1c (Dyer et al., 1998) which equates to a reduction in risk of complications related to diabetes (Holmes-Walker et al., 2007). Regular specialist care following transition to the adult diabetes clinic and a phone support service resulted in fewer costly hospital admissions with diabetic ketoacidosis, a serious condition resulting from hyperglycemia (Holmes-Walker et al., 2007). Young adults receive positive input by attending clinic appointments which is vital during the period when long term self-care behaviours become habits (Wolpert & Anderson, 2001d).

In this review, clinic attendance rates were associated with continuity of care, supportive and organisational characteristics of services, and issues related to administration and communication between young adults and diabetes services, during transition and within

adult care. The review findings make an important contribution to both practice and research by highlighting modifiable factors related to clinic attendance.

3.4.1 Review results and previous research

3.4.1.1 Importance of continuity of care

Outpatient services routinely strive to achieve continuity of care (Haggerty et al., 2003). Continuity during transition is of equal importance according to the positive associations reported in this review between continuity during transition and attendance at adult diabetes clinics. Regardless of the presence of a transition programme, contact between young adults and adult diabetes services in order to maximise clinic attendance appears to be inadequate. This gap is illustrated by the fact that a wide range of durations of transition were reported across studies in this review (Cadario et al., 2009; Sparud-Lundin et al., 2008; Vanelli et al., 2004). For example, some young adults attended the adult diabetes clinic in the same month as their final visit to the paediatric diabetes clinic, while others had yet to attend the adult diabetes clinic three to four years later (Sparud-Lundin et al., 2008).

Attendance among young adults declined from two years pre transition to the adult diabetes clinic to two years post transition in one study (Kipps et al., 2002). This decline in attendance among young adults is regularly reported indicating that factors which distinguish attendance at the paediatric from the adult diabetes clinic strongly influence clinic attendance. Following transition, continuity within adult diabetes services is important to young adults (Scott et al., 2005). Meeting a different member of staff at each visit makes it very difficult to obtain value from the clinic visit and leads young adults to question future attendance (Greene, 2009). In practice, the presence of trainee doctors (Greene, 2009), time constraints (Brierley et al., 2012) and fully booked clinics (Mason, 1992) hinder continuity in the adult diabetes clinic. In addition a lack of guidance in relation to the implementation of continuity

within services for the management of chronic illness has been reported (Haggerty et al., 2003).

3.4.1.2 Provision of support to young adults

The findings of this review indicate that support may take a number of forms and come from a number of sources. This is reflected in existing research which describes models of support provision including negotiated telephone support (Howells et al., 2002), patient navigator programme (Van Walleggem et al., 2011), diabetes personal trainers (Nansel et al., 2009), collaborative university diabetes clinics (Newton & Nelson, 2008) and cognitive behavioural group training (Van der Ven et al., 2005) to improve glycaemic control and diabetes related outcomes in the short and long term. Professionals, peers, family members and other non-professionals have taken part in diabetes research as support providers. Positive outcomes have resulted from novel supportive interventions.

3.4.1.3 Age-appropriate schedules & procedures

Irregular patterns of clinic attendance may be attributed in part to difficulties in clinic administration and communication with young adults, based on the findings of this review. Attendance research to date has neglected the role of health services in the problem of non-attendance (Paterson et al., 2010). Young adults with Type 1 diabetes cannot be described simply as attenders or non-attenders (Snow & Fulop, 2012). Factors such as unsatisfactory clinic experiences (Greene, 2009) or perceived barriers to attendance such as inflexible appointment schedules (Snow & Fulop, 2012) cause young adults to consider whether or not to attend prior to each scheduled appointment. In this review, recommendations for modifications to existing services included flexible appointment schedules (Snow & Fulop, 2012), evening clinics (S. J. Wilson & Greenhaigh, 1999), clear and user-friendly appointment making and breaking procedures (Snow & Fulop, 2012; Van Walleggem et al.,

2011; S. J. Wilson & Greenhaigh, 1999), communication with diabetes services facilitated by familiar members of clinic staff (Brierley et al., 2012) and appointment reminders (Scott et al., 2005; Snow & Fulop, 2012).

3.4.2 Implications for research and practice

Due to varying definitions of young adults across the relevant research, studies were included in this review with samples of young adults aged 15-30 years. Nonetheless, the developmental stage which is influential across this population is emerging adulthood. Emerging adulthood (18-25 years) is a period of development which is distinct from adolescence and young adulthood due to marked differences in demographic profiles, self-classification, identity development, risk behaviours and family relationships (Arnett, 2000).

Guidelines for the recommended care of 'emerging adults' were produced by the American Diabetes Association in 2011 (Peters et al., 2011). Although this developmental distinction is over a decade old, translation of the needs of this population into research and practice has been slow. Perry *et al.* concluded that delivering a service which is compatible with the priorities and lifestyles of young adults may be effective in solving the problem of non-attendance during the young adult period (Perry et al., 2010).

Despite the importance of clinic attendance in the context of diabetes self management, it is rarely the focus of research. The limitation of the evidence upon which this review is based highlights the fact that future research must progress in terms of design and measurement. For example, information related to patient factors which may be relevant to clinic attendance, such as insurance coverage, socio-economic status, ethnicity and culture, was not provided in the studies reviewed. Improvements in the types and quality of studies conducted will facilitate a better understanding of the variables which influence clinic attendance and the development of complex interventions to improve clinic attendance.

3.4.3 Limitations of review

As a result of the high number of cross sectional research studies, evaluations and audits of care in this area, it was not possible to conduct a statistical meta-analysis and conclusions from this review are limited. Populations studied were often limited to a single, hospital based clinics which impacts the ability to generalise findings. Convenience samples, retrospective methods and basic designs were adopted in several studies reviewed. In a number of cases group differences were presented in the form of percentages without the inclusion of information related to the statistical significance of these differences. Relevant evidence may also have been neglected due to the exclusion of studies not printed in English.

Reviews aiming to synthesise evidence prioritise the fit between the findings of the combined studies above the procedures of individual studies (Gough et al., 2012). Agreement across the studies reviewed, illustrated by the appearance of the review themes across multiple studies, indicates that good fit was found in this synthesis.

The inclusion and exclusion of studies based on the criteria dictated by the review question was not straightforward. This was due to the fact that clinic attendance was often not the primary outcome or researchers did not clearly outline the relationships between the variables measured and clinic attendance. Therefore, all data relevant to clinic attendance were extracted. Barriers and facilitators were then inferred resulting in the review findings.

3.4.4 Conclusion

Existing research does not adequately address the complexity of clinic attendance and non-attendance among young adults with Type 1 diabetes. Similar issues exist related to transition from paediatric to adult care and attendance at adult clinics for other conditions such as cystic fibrosis and asthma (Bloom et al., 2012). A combination of factors associated

with the developmental characteristics of young adults with inadequate models of service provision is likely to contribute to clinic non-attendance in this population (Perry et al., 2010). There are features of clinic organisation which appear to be linked to attendance, such as establishing contact between young adults and health care staff during transition and mechanisms of appointment making and breaking, which may be readily amenable to change. Clarification is needed in relation to the relative contributions of variables such as transition experience, duration of diabetes and family relationships to decisions to attend the adult diabetes clinic.

4. Study 2: ‘It makes a difference, coming here’: A qualitative exploration of clinic attendance among young adults with type 1 diabetes.

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Objective: Young adulthood is a time of significant challenges and risks for people with type 1 diabetes. Poor outpatient clinic attendance is common among young adults with type 1 diabetes. The aim of this qualitative study was to develop a theory explaining attendance at a hospital-based diabetes clinic.

Design: Using a grounded theory methodology, data were collected through semi-structured qualitative interviews.

Method: Twenty nine people (21 young adults with type 1 diabetes and 8 service providers) from one hospital-based diabetes clinic were interviewed. Interviews were audio-recorded, transcribed and analysed according to grounded theory methodology.

Results: *Relationships between young adults and service providers* is the core category of this theory. Collaborative relationships between young adults and service providers increased the perceived value of attendance and reduced the vulnerability of young adults to the barriers within the existing service, such as meeting unfamiliar service providers. Relationships between young adults and service providers were developed following opportunities for contact (e.g. structured education programme or crisis of diabetes), and facilitated

engagement with the service and further attendance. Barriers to clinic attendance included young adults' negative perceptions of their diabetes self-management and a lack of value associated with attending.

Conclusion: The diabetes clinic was described as an important and valued resource by young adults and service providers. Collaborative relationships between young adults and service providers enhanced service provision in this study. According to the results of this study, clinic attendance may be improved by increasing opportunities for relationship development between service providers and young adults.

Keywords: clinic attendance; young adults; type 1 diabetes; transition.

4.1 Introduction

Type 1 diabetes is an auto-immune disease which requires people diagnosed with the condition to undertake a labour intensive routine of self-management (Daneman, 2006). Self-management, including insulin dose adjustment and managing low blood glucose levels, aims to achieve glycaemic control to avoid the onset of the complications associated with type 1 diabetes, such as problems with eyesight, while enabling the individual to maintain their quality of life (Chiang et al., 2014; Grant et al., 2013).

Young adults, during the period known as emerging adulthood (18-25 years) (Arnett, 2000), have unique needs and face different challenges in comparison to other age groups (Balfe, Brugha, et al., 2013; Garvey & Wolpert, 2011). The implications of living with type 1 diabetes for young adults and the service providers working with them, are reflected in growing evidence demonstrating poor physiological (Petitti et al., 2009; The National Health Service Information Centre, 2011), psychological (Hislop et al., 2008; Johnson, Elliott, Scott, Heller, & Eiser, 2014) and behavioural (Goebel-Fabbri et al., 2008; Morris et al., 1997;

Sparud-Lundin et al., 2008) outcomes. Therefore, researchers and service providers have called for a new treatment paradigm to inform service delivery for young adults with type 1 diabetes (Balfe, Brugha, et al., 2013; Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005a; Garvey & Wolpert, 2011). Important characteristics of a new paradigm may include continuity of care, provision of age-appropriate information, and support to overcome barriers to the active involvement of young adults in their care (Dovey-Pearce et al., 2005a).

Attendance at specialist hospital-based diabetes clinics is important among adults with type 1 diabetes, to access the medical checks and education associated with good diabetes-related outcomes and quality of life (Peters et al., 2011). In the context of transitions from paediatric to adult diabetes services, home to independent living and school to work or university, young adults are at risk of disengagement from healthcare (Peters et al., 2011). Adverse short term (e.g. diabetic coma) and long term (e.g. complications of the eyes or kidneys) outcomes have been associated with irregular attendance or non-attendance by young people at diabetes clinics (A. Rewers et al., 2002). Regular contact between specialist diabetes care providers and young adults with type 1 diabetes has been identified as a priority of service delivery (Garvey & Wolpert, 2011).

Despite the importance of attendance at specialist diabetes clinics, clinic attendance is rarely the focus of research. A recent systematic review reported a lack of high quality intervention studies addressing non-attendance among young adults with type 1 diabetes (L. Hynes et al., 2014). Qualitative accounts further emphasise the importance of understanding and managing young adult's experiences in adult diabetes services. For example, in one study, a shift was reported from a personal, family-centred approach in the paediatric setting to a focus on individuals' physiological outcomes in the adult setting. This contributed to negative perceptions among young adults regarding access to staff and information (Rankin, Heller, & Lawton, 2011b).

A lack of specific and relevant theory may account for the low level of adoption of theory for designing interventions in diabetes research to date, according to the findings of a recent review (Ayling et al., 2014). The UK Medical Research Council guidelines for the development and evaluation of complex interventions emphasise the importance of a good theoretical understanding of any behaviour and the specific mechanisms involved, in advance of developing interventions to address it (Craig et al., 2008; Eiser et al., 2013). The aim of this study was to develop a theory explaining attendance at a specialist outpatient clinic for young adults with type 1 diabetes.

4.2 Method

Grounded theory was chosen as this research focused on clinic attendance, a poorly understood topic, which is influenced by multiple factors related to young adults, service providers and diabetes services (Bluff, 2005; Corbin & Strauss, 2008). Grounded theory has evolved since its introduction by Glaser and Strauss (Glaser & Strauss, 1967), including the approach developed by Strauss and Corbin (Corbin & Strauss, 2008; Strauss & Corbin, 1998) adopted in this study. This approach is associated with flexibility to the demands of the research environment and specific research question, offers guidance and tools to support analysis, and is aligned with the philosophy of pragmatism (Corbin & Strauss, 2008). Ethical approval was obtained from Galway University Hospital Research Ethics Committee. The study design is illustrated in Figure 4.1.

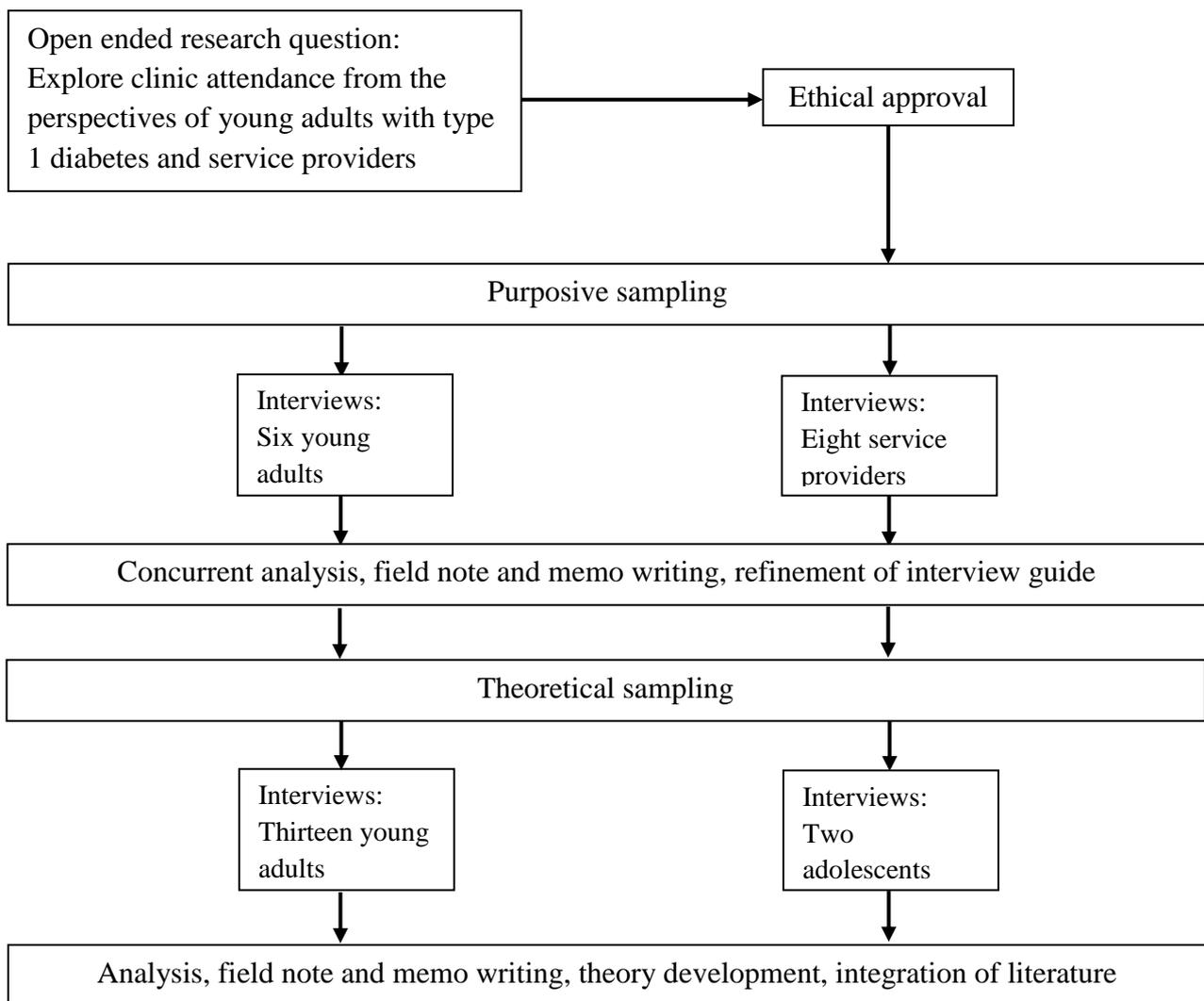


Figure 4.1 Study design-adapted from Protudjer, Dumontet, and McGavock (2014)

4.2.1 Participants

Young adults with type 1 diabetes and service providers were recruited in order to represent the core diabetes clinic stakeholders. The setting was a hospital diabetes service which served nearly 800 adults, including 137 young adults, with type 1 diabetes (Cotter et al., 2014). Information related to young adult participants is summarised in Table 4.1. This information is not provided for the service providers who took part to preserve their anonymity.

Table 4.1

Demographic Information for Adolescent and Young Adult Participants

Group	Gender	Age	Duration of diabetes (Years)	Attendance over 2 years	Diabetes Treatment	Completed SEP
Young adult 1	Male	22	10	<50%	MDII	Yes
2	Male	23	7	50-75%	MDII	No
3	Male	21	19	50-75%	Pump	No
4	Female	24	5	<50%	MDII	Yes
5	Female	22	17	>75%	MDII	No
6	Female	26	9	50-75%	MDII	Yes
7	Female	20	10	>75%	MDII	No
8	Female	23	5	>75%	MDII	Yes
9	Male	20	7	>75%	MDII	No
10	Male	22	5	<50%	MDII	No
11	Female	23	13	50-75%	MDII	No
12	Female	22	9	>75%	MDII	Yes
13	Female	24	10	50-75%	MDII	Yes
14	Female	25	7	<50%	MDII	Yes
15	Female	26	8	>75%	MDII	Yes
16	Male	28	7	>75%	MDII	No
17	Female	25	10	<50%	MDII	Yes

18	Male	22	6	<50%	MDII	Yes
19	Male	21	11	<50%	MDII	No
Adolescent 1	Male	16	10	N/A	Pump	N/A
2	Female	16	1	N/A	MDII	N/A

MDII – Multiple Daily Insulin Injections; Pump – Insulin pump therapy; SEP – Structured Education Programme

Participants were recruited purposively at first with the aim of recruiting a diverse sample in terms of the information which was available following a recent audit of the clinic, which was gender, age, years since diagnosis and pattern of attendance over two years. A member of the clinic staff not directly involved in service provision assisted in the sampling process by extracting descriptive data related to all young adults associated with the clinic (Table 4.1). Young adults were then contacted by post about taking part in an interview. Service providers were sampled through the paediatric and adult diabetes clinics to represent each of the professions regularly working with young adults, and included doctors, nurses, and allied health professionals.

4.2.2 Data generation and analysis

Semi-structured interviews were conducted between February 2012 and February 2014. All participants were given the option of being interviewed in person in the outpatient diabetes centre, the university, in their office or home, or over the phone. Separate interview guides for young adults (Table 4.2a) and service providers (Table 4.2b) were used to explore attendance at the diabetes clinic. Interviews were recorded and transcribed verbatim. QSR NVIVO 10 was used to facilitate the organisation, management and analysis of the data.

Table 4.2a

Young adult interview guide

-
- Can you tell me a bit about yourself?
 - What is it like for you to have type 1 diabetes?
 - What do you think about the adult diabetes services available to you?
 - Tell me about a typical day at the adult diabetes clinic.
 - Can you tell me about the paediatric diabetes clinic?
 - What do you think is the purpose of attending the diabetes clinic?
 - What kinds of reasons have you had for missing appointments?
 - What would you like to change about the health services for type 1 diabetes?
-

Table 4.2b

Service provider interview guide

-
- Can you tell me about your job?
 - What do think are the major issues facing young adults with type 1 diabetes?
 - What do you think are the major issues you face working with young adults with type 1 diabetes?
 - Can you describe a typical afternoon in the adult diabetes clinic/paediatric diabetes clinic?
 - What do you think about clinic non-attendance?
 - How is the running of the clinic affected by clinic non-attendance?
 - What would you like to change about the diabetes clinic?
-

Open, axial and selective coding techniques were used to analyse the data (Corbin & Strauss, 2008). The primary analytical approach was constant comparison, facilitated by field notes and memos, as outlined in Figure 4.1. Once the data were transcribed, open coding took place to organise the raw data into concepts, using codes which were chosen for their ability to represent the ideas in the data (Corbin et al., 2008). With each new transcript patterns began to emerge so that existing codes were integrated to become concepts. Axial coding began as the concepts grew and developed enough to be reduced and combined into categories according to their shared properties. The theory was specified during selective coding by developing and questioning potential hypotheses regarding the interconnections within the theory.

Following the analysis of the interviews of purposively sampled participants (six young adults and eight service providers), subsequent participants were theoretically sampled based on the likelihood that they would contribute to the explanation of clinic attendance (Corbin & Strauss, 2008). For example, two adolescents were recruited through the paediatric diabetes clinic in the same hospital. This decision was based on the emergence of important concepts in the first group of interviews, such as relationships with service providers in paediatric diabetes clinics. The interview guide was modified to facilitate the checking of emerging concepts, as part of the theoretical sampling approach.

Once the theory of clinic attendance started to emerge from the data, a central question became clear, and guided additional theoretical sampling. The central question was: *what leads to the development of collaborative relationships between young adults and service providers for some young adults and not for others, and how do these relationships relate to engagement with the adult diabetes clinic (contact other than attendance at scheduled appointments) and regular clinic attendance?* A core category was chosen which represented the central concept in the process being studied. Theoretical sampling in order to

explore the dynamics emerging from the data facilitated the identification of the core category (Creswell, 2007; McCann & Clark, 2003; Strauss, 1987).

The process of refining the theory continued until the clarity, logic and explanatory power of the theory were satisfactory and there was sufficient evidence that data saturation had been reached. That is, the categories were well described, variation was present in relation to the concepts, and new concepts were no longer emerging (Corbin & Strauss, 2008; Creswell, 2007; J. C. Hood, 2007; Strauss & Corbin, 1994). The methods used in this study to ensure and demonstrate rigour were based on the criteria of credibility, auditability and fittingness (Beck, 1993; Cooney, 2011), and are outlined in Table 4.3.

Table 4.3

Methods for ensuring and demonstrating rigour

Criteria	Credibility:	Auditability:	Fittingness:
Definition	Richness of the description of the research topic	Evidence of the decision making process	Meaning for other individuals in similar situations
Evidence	-Comprehensive description of method used -Modification of interview guide to clarify and check emerging concepts -Provision of quotes to support findings -Checking theory with	-Use of memos to record and reflect on beliefs, assumptions, and processes of decision-making, analysis and theory development -Use of theoretical sampling	-Provision of information related to the study context

4.3 Results

A total of 29 interviews (21 young adults and 8 service providers) were conducted. The title of this paper, ‘It makes a difference, coming here’, captures the perception which emerged from the perspectives of young adults and service providers, that the diabetes clinic was an important resource for young adults with type 1 diabetes. A trend emerged in the data suggesting that major events such as attending a structured education programme, brought young adults into contact with the service in a way that changed their level of engagement with the clinic, and potentially their attendance. Further exploration of this dynamic resulted in the emergence of the core category in this study, ‘relationships between young adults and service providers’. The theory of clinic attendance outlined in Figure 4.2, presents barriers and facilitators associated with diabetes clinic attendance, and the process through which relationships play a central role. Whilst we are aware that clinic attendance is complex and is influenced by a wide range of determinants, for clarity we have attempted in this theory to identify the *main* variables and describe their relationships to clinic attendance.

4.3.1 Clinic attendance behaviours

The issue of clinic attendance differed from the perspectives of service providers and young adults in this study. According to the service providers, attendance is a huge problem in the clinic.

For most young adults, they definitely DNA (Did Not Attend) at least two clinics a year. So there’s four months where they’re, not on their own, but they’re not going to be seen by us.

Service providers were familiar with the overcrowded clinics and the lists of young adults who 'did not attend'. Whereas many young adults believed that they rarely missed an appointment, even when this was not the case, because they considered those that they missed to have been cancelled and rescheduled.

I don't think I've ever missed one of the appointments. That's probably a lie. I don't actually know.

Young adult 1, male, age 22, <50% attendance

Clinic attendance behaviour, in reality, comprised contact between young adults and service providers, including e-mail or telephone contact, as well as attendance at scheduled appointments.

I suppose it depends on whether or not you have a contact; if you have a diabetic nurse that you could call. If I didn't have (my nurse) I probably would want to be going more regularly.

Young adult 14, female, age 25, <50% attendance

However, service providers described the challenge they faced, in the context of limited resources in terms of staff and time, to provide a tailored service addressing the particular needs of each young adult and to maintain the important, yet burdensome contact with young adults outside appointments.

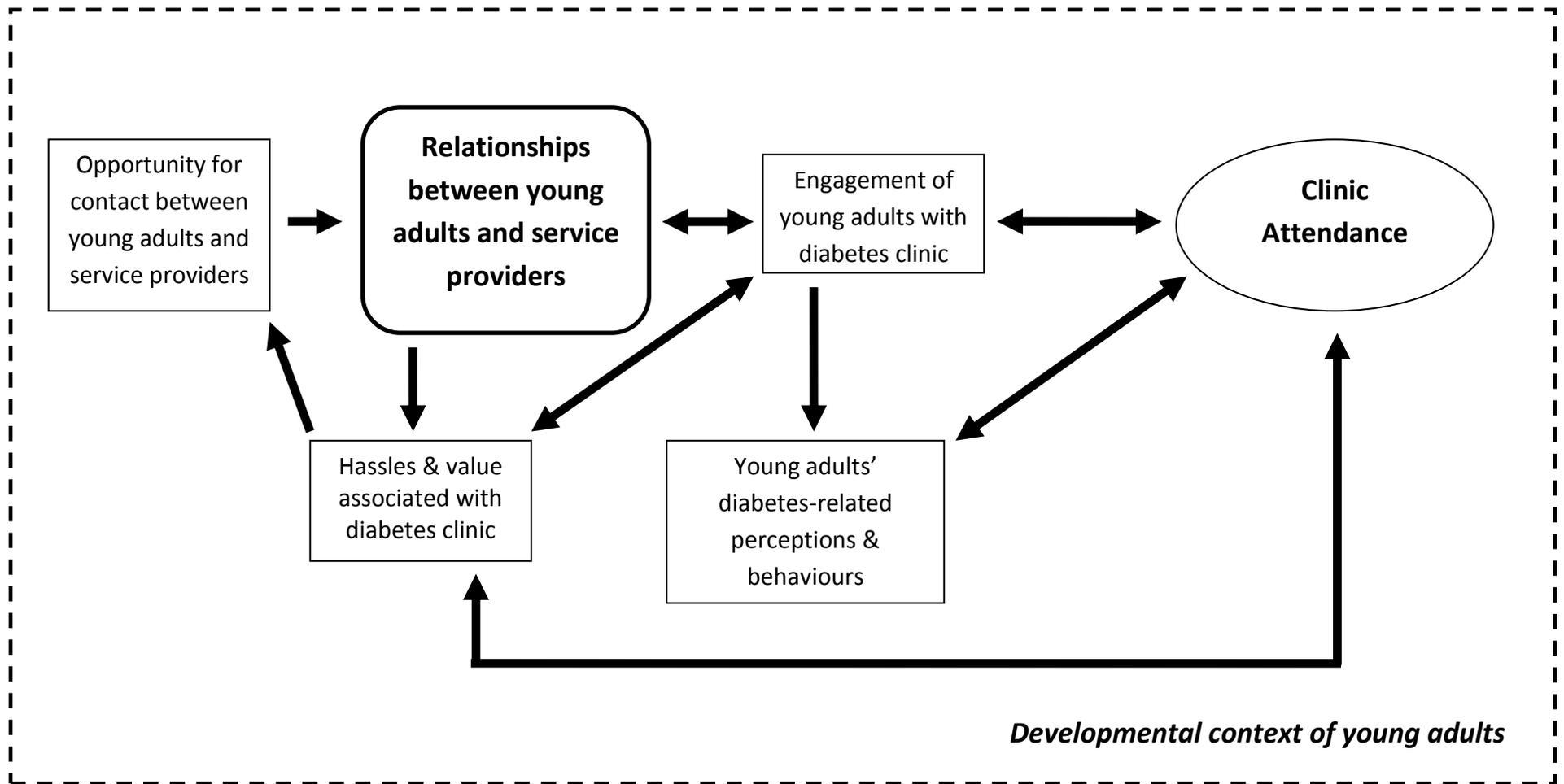


Figure 4.2. Theory of clinic attendance among young adults with type 1 diabetes

You have to make time to read an e-mail that you weren't banking on. That could take 15 minutes to go through and discuss with the nurse and then you might need to find another 5, 10 minutes to e-mail the person back.

Service provider 6

If they've not met me before it can be difficult to find out what they need to know.

Service provider 6

The description by one young woman encapsulated clinic attendance behaviour among the young adults interviewed in this study; 'I'll always go, but I don't go to them all.' (Young adult 17, female, age 25, <50% attendance). This illustrates that perceptions of the importance of clinic attendance among young adults may not be reflected in their rate of attendance at routine scheduled appointments.

4.3.2 Young adults' developmental context, and diabetes-related perceptions and behaviours

Young adults' diabetes-related perceptions and behaviours represented in Figure 4.2 include perceptions of diabetes, diabetes self-management, and distress related to diabetes. These diabetes-related perceptions and behaviours were in constant interplay each other, within the developmental context of young adults (Figure 4.2). For example, self-management was vulnerable to the unpredictability and variability of life as a young adult in terms of the competing demands of work, study and social life.

When I went into college I think as most people do, diabetes became the last thing on my mind, I didn't care, I didn't want to know about it.

Young adult 6, female, age 26, 50-75% attendance

Young adult with diabetes say, from tomorrow on I'm going to do A, B and C. And for 3 days they will and you will always get the e-mail for the first 2 weeks off them. Then, slowly you won't get an e-mail for a fortnight.

Service provider 7

Distress related to diabetes quickly followed periods of sub-optimal self-management according to some young adults. Dissatisfaction among young adults with the perceived quality of their self-management was described by some young adults as a motivator, and by others as a significant barrier, to clinic attendance.

I should be going to the clinics, but the fear that I have is that they're (service providers) going to turn around and go well you've the signs of diabetes eye disease or your kidney function isn't as good as it should be; that's what terrifies me.

Young adult 7, female, age 22, <50% attendance

4.3.3 Young adults' relationships with service providers, engagement and clinic attendance

The core category of the theory of clinic attendance is relationships between young adults and service providers (Figure 4.2). Relationships between young adults and service providers were characterised by familiarity and collaboration and involved the discussion of problems, negotiation of routines for self-management, and goal-setting. These activities resulted in mutual understanding and a sense of accountability.

I couldn't explain what was happening (to blood glucose levels). So I kept a food and glucose diary and then we (young adult and nurse) were able to figure it out.

Young adult 14, female, age 25, <50% attendance

It's all about coming to agreements with young people. I usually try and ask them what's good for them, how much do they feel they could do? And we usually try and come to agreement.

Service provider 8

When you're having a bad time your HbA1c (measure of diabetes control), you don't feel like you're getting given out to (being reprimanded). I mean, they (service providers) understand that people aren't going to be perfect all the time, and basically they help you as much as they possibly can.

Young adult 6, female, age 26, <50% attendance

According to this theory of clinic attendance, the existence of collaborative relationships fostered the engagement of young adults with the diabetes clinic (Figure 4.2), increasing the likelihood of regular clinic attendance. Young adults had the motivation and confidence to engage after experiencing the support available from the clinic.

When you're educated then you're confident and you know you have the clinic there, and you know going into your doctor what you're talking about, you feel better and that whatever problem is happening, we'll sort it between all of us.

Young adult 4, female, age 24, <50% attendance

Engagement may or may not result in regular attendance but may establish a routine of contact between young adults and service providers. Indicators of engagement among young adults included seeking out, and participating with, the support available from service providers, or bringing problems or questions to the clinic.

I'd know them in there (adult diabetes clinic), that I could e-mail them and stuff but I think when I didn't know them (before SEP), I didn't know what the story was, I didn't want to be bothering them, they're really busy.

Young adult 4, female, age 24, <50% attendance

4.3.4 Characteristics of the diabetes clinic and opportunities for relationship development

Due to the hassles and value associated with the diabetes clinic (Figure 4.2), previous clinic attendance was not sufficient to result in the establishment or maintenance of a pattern of regular clinic attendance, without a good relationship between young adults and service providers. Access to personalised support was increased among young adults who had a relationship with the service providers resulting in enhanced perceptions regarding the hassle and value of clinic attendance. However, clinic-related hassles, including long waiting times at appointments and meeting unfamiliar service providers, negatively impacted participants' perceptions of the clinic, and potentially their decision to attend appointments.

I always see a different doctor and I don't like that part. They're kind of learning through me, they don't know me.

Young adult 15, female, age 26, >75% attendance

Clinic-related hassles such as short, impersonal consultations also acted as barriers to relationship development in this study.

You don't always have the time to address their (young adult's) issues. Sometimes you can't because the problems are complex, but you're conscious of the fact that time is ticking and you need to tell this person a certain amount of information.

Service provider 6

It's a little bit chaotic at times. They'd be going through the chart and they'd be jumping up and dealing with something else.

Young adult 16, male, age 28, >75% attendance

Therefore, relationships developed through opportunities for contact (Figure 4.2) between young adults and service providers which occurred outside scheduled appointments, such as attending a structured education programme or being admitted to hospital following an acute complication of diabetes.

I got to know them (service providers) when I was in hospital, they were coming to see me every two days or so. But I think that if I had just to go straight in (to the adult diabetes clinic) I definitely wouldn't have had as good a relationship with them.

Young adult 13, female, age 24, 50-75% attendance

The only place we have to see are they alright is when we bring them into DAFNE (Structured Education Programme). But that's the only place we have for that (relationship development), not the clinic, definitely not.

Service provider 7

4.3.5 Interactions between relationships, engagement and young adults' perceptions

Engagement with the clinic influenced young adults' decisions to attend appointments or maintain contact with the clinic, despite risk factors for clinic non-attendance, such as distress related to diabetes and perceived hassle of clinic attendance. Engagement influenced young adults' perceptions of clinic-related hassle resulting in more satisfying clinic

experiences. Meeting service providers at appointments with whom young adults had a relationship reinforced their engagement with the clinic, indicating that a reciprocal relationship existed between relationships and engagement. In addition, engagement positively influenced young adults' diabetes-related perceptions and behaviours, preventing a cycle of inadequate self-management, distress and non-attendance from developing.

If you were having a tough time with your bloods they'll schedule times to ring you over a few weeks and they'll keep in contact with you until you have it under control again, which is great like, so you always have somebody there.

Young adult 6, female, age 26, 50-75% attendance

Bringing them (adolescents and young adults) back to the clinic and linking them up with the diabetes nurse specialist who will often see them or have telephone contact with them seems to bring them back on board.

Service provider 1

Young adults who did not have a good relationship with service providers and who struggled with their self-management and feelings of anxiety were more likely to avoid attending appointments or seeking support. As a result, there was an increased risk that non-attendance would become a pattern. For example, one young woman reported missing appointments following a period of time when self-management was not prioritised with a plan to 'try and be better for the next one (clinic appointment) (Young adult 12, female, age 22, >75% attendance). The following quote from a young woman who was struggling to deal with her diabetes and was not familiar with the service providers illustrates that knowing that support is available from the clinic doesn't necessarily result in young adults actually seeking support.

I can always pick up the phone and call the hospital, like that's what they're there for and I need to realise that's what they're there for. Even if I know I promised weeks and months ago that I would ring them.

Young adult 7, female, age 20, >75% attendance

4.3.6 Summary of findings

Willingness to attend depended on the distress related to diabetes experienced by many young adults, their perceptions of hassle and value related to the diabetes clinic, and whether or not they had a relationship with the service providers. Once a relationship existed, experiences with supportive and understanding service providers made young adults more likely to attend the diabetes clinic despite feelings of distress, due to the knowledge and confidence they had that they would benefit from attending. For example, one young woman emphasised that the value she gained from attending the clinic transcended any worry regarding poor test results or negative responses from the service providers.

Well I know I haven't been doing ok in the last while but it (attending the diabetes clinic) kind of, it kind of sets up a plan, how to fix it.

Young adult 12, female, age 22, >75% attendance

Therefore, the existence of relationships between young adults and service providers and engagement of young adults with the clinic appeared to buffer the impact of barriers and increase clinic attendance.

4.4 Discussion

The aim of this study was to develop a theory explaining clinic attendance behaviour among young adults with type 1 diabetes from the perspectives of young adults with the

condition, and service providers. This theory provides a basis for future research and practice related to developing services for young adults with type 1 diabetes.

4.4.1 Collaborative relationships maintain clinic attendance by fostering engagement

The findings of this study suggest that opportunities for contact between young adults and service providers lead to relationship development and the engagement of young adults with the diabetes clinic. The value of clinic attendance is enhanced among young adults who are engaged with the clinic and regular clinic attendance becomes more likely. The impact of the hassles of attendance, like meeting unfamiliar staff, and of young adult variables, like distress, on clinic attendance behaviour, are diminished by the positive effects of relationships and engagement.

According to existing literature, collaborative relationships between service users and providers form the foundation of ‘patient-centred’ or empowerment-based approaches to diabetes care (R. M. Anderson & Funnell, 2010). Studies of ‘working alliances’ between service users and providers suggest that the accountability, trust and emotional bond which characterise collaborative relationships in healthcare settings, play a direct role in the treatment and outcomes of chronic conditions such as diabetes, cancer and heart disease (Fuertes et al., 2007).

The significance of young adults developing a relationship with service providers may be related to the importance of having access to service providers for diabetes-related support, at a time of transition in relation to other sources of support, such as parents (Allen et al., 2011; K.M. Hanna, 2012; G. C. Williams, Freedman, Z.R., & Deci, E.L., 1998). The extent to which service providers are perceived as ‘autonomy supportive’, for example acknowledging feelings and offering choices, has been found in previous research to be

associated with significant improvements in glycaemic control, by increasing autonomous motivation and perceived competence (G. C. Williams, Freedman, Z.R., & Deci, E.L., 1998). The development of autonomous motivation for self-management is thought to contribute to long term persistence and adherence among people with diabetes (G. C. Williams, Freedman, Z.R., & Deci, E.L., 1998). This association between collaborative relationships and self-management may explain the link found in this study between relationships, engagement of young adults and the ongoing maintenance of clinic attendance.

4.4.2 Supporting the engagement of young adults with the diabetes clinic

According to the findings of this study, the existing model of diabetes services for young adults based on routine clinic appointments, does not support the process of relationship development between service providers and young adults. Contacts which supported relationship development and through which support was often delivered, seemed to happen outside routine scheduled appointments in this study (e.g. support through e-mail). A similar 'relationship shift' was reported by participants in a qualitative study, following completion of an intensive, week-long diabetes self-management programme (Murphy, Casey, Dinneen, Lawton, & Brown, 2011).

However, maintaining contact outside appointments presented a serious challenge for service providers in terms of time and resource management. The importance of relationship development demonstrated by this study emphasises the need to integrate the provision of ongoing support for self-management within routine service provision. By continuing to deliver diabetes services to young adults using existing models, high rates of clinic non-attendance are likely to persist, as the findings of this study suggest that young adults actively respond only after experiencing collaboration with, and support from, service providers.

According to the American Diabetes Association Standards for Diabetes Education (R. M. Anderson & Funnell, 2007), diabetes self-management support (including goal-setting and follow-up reminders) is necessary to sustain behaviour change in conjunction with diabetes self-management education. The formation of long-term relationships between diabetes service users and providers may be facilitated by implementing a combined approach of education and support. The use of a collaborative or empowerment-based approach in consultations has been found to actually increase efficiency by ensuring that recommendations and information provided to service users were relevant and realistic (Levinson, Gorawara-Bhat, & Lamb, 2000).

4.4.3 Distress and non-attendance

Distress was likely to persist or increase for young adults in this study who struggled consistently with their self-management. Diabetes-related distress refers to the worries, concerns and fears experienced by people with diabetes (L. Fisher, Gonzalez, & Polonsky, 2014). Diabetes-related distress may be more prevalent than depression or anxiety, and result in more problems for people with type 1 diabetes in terms of emotional well-being, diabetes self-management and glycaemic control (Gonzalez et al., 2011). Research regarding access to mental health services has found that as distress increases, individuals can become less likely to seek help (C. J. Wilson, Bushnell, & Caputi, 2011). Strategies for re-engaging people following long periods of non-attendance at diabetes clinics are likely to be most effective by explicitly prioritising the management of distress rather than focusing on diabetes care alone.

Considering the competing demands of emerging adulthood, it may be unrealistic to expect unwavering commitment by young adults to independent diabetes self-management (Peters et al., 2011). This study suggests that a focus among diabetes service providers on developing relationships with young adults may support their engagement with the clinic,

establishing or maintaining regular attendance, despite challenges such as experiencing diabetes-related distress.

4.4.4 Implications for practice

This study suggests that diabetes services should prioritise the development of relationships between service providers and young adults. Routine encounters could be utilised as opportunities for relationship development. For example, service providers from adult diabetes clinics could attend adolescent or transition clinics (Crowley, Wolfe, Lock, & McKee, 2011). Diabetes self-management support may be delivered in conjunction with education (Chaney et al., 2012), using novel methods such as websites, smart phone apps, and phone calls (Howells et al., 2002; Nordfeldt, Angarne-Lindberg, Nordwall, Ekberg, & Bertero, 2013; Sacco, Morrison, & Malone, 2004; Whittmore, Grey, Lindemann, Ambrosino, & Jaser, 2010), or in settings such as a university-based health services (Wdowik, Kendall, Harris, & Keim, 2000). Methods for delivering or facilitating consultations like agenda-setting tools and group consultations may be efficient methods of introducing an empowerment-based approach to appointments (R. M. Anderson & Funnell, 2010; Funnell & Anderson, 2004).

4.4.5 Implications for research

This theory of clinic attendance is currently being tested in a quantitative study involving an international sample of 18 to 30 year olds with type 1 diabetes to assess its explanatory power and transferability to other health service settings. Theories developed using grounded theory are developed to a level of generality that enables them to be used to explain a phenomenon by transferring it to other similar settings (Cooney, 2011; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Morse & Singleton, 2001). Therefore, this theory may be useful in explaining clinic attendance among children and older adults, and in outpatient or

general practice settings catering to people with different conditions. Future research should employ longitudinal and experimental designs to understand the relationships between the components of this theory and the causal mechanisms leading to regular clinic attendance. Understanding the relative contributions of the components of this theory will identify the most important modifiable factors which should be targeted in future research and service planning to improve clinic attendance.

4.4.6 Limitations

This study has a number of limitations. Interviews were conducted only once with each participant preventing the checking of the researchers interpretations with the participant who provided the account. Data were collected from only one setting. Future research may seek to conduct multiple interviews with participants and integrate data from a number of hospital-based diabetes clinics or from other sources such as policy documents or relevant online forums.

4.4.7 Conclusion

Diabetes-related outcomes have not reflected the improvements in technologies for the treatment of type 1 diabetes (Aschner, Horton, Leiter, Munro, & Skyler, 2010; Johnson et al., 2014). Successful treatment of chronic conditions depends on human behaviour, as well as cognitive and environmental factors (B. E. Fisher, Thorpe, McEvoy DeVellis, & DeVellis, 2007). However, it has been suggested that approaches to care have been ‘psychologically naive’ to date (Von Korff, Glasgow, & Sharpe, 2002). To be successful, future services must be informed by psychological theories of behaviour. Evidence from our theory of clinic attendance, and from existing literature, suggests that support from familiar service providers is important for the translation of diabetes-related knowledge and skills into behaviour, and for establishing and maintaining regular clinic attendance. Procedures are needed which

minimise threats to clinic attendance, and embed the process of relationship development at the centre of this theory of clinic attendance, within the approach to service provision for young adults with type 1 diabetes.

5. Paper 3: Testing a theory of clinic attendance behaviour among young adults with type 1 diabetes

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Objective The aim of this study was to test a theory of clinic attendance, developed in previous studies, in an international sample of young adults with type 1 diabetes.

Methods Young adults ($n = 154$), with type 1 diabetes and aged between 18 and 30, completed a questionnaire which was compiled based on the theory of clinic attendance. Structural Equation Modelling and moderation analyses were used to analyse the data.

Results In line with the theory of clinic attendance, good relationships between young adults and service providers predicted higher levels of engagement ($B = .174, p < .001, \beta = .383$), informal contact with the diabetes clinic (e.g. by telephone) ($B = .197, p < .001, \beta = .321$), and attendance rates among young adults ($B = .463, p = .001, \beta = .212$). The model in which gender and treatment modality were controlled for provided the best fit to the data.

Satisfaction with the clinic was important in relation to clinic attendance among young adults who were less engaged but only predicted clinic attendance among young adults who had a good relationship with service providers.

Conclusion Interventions to improve clinic attendance behaviour should prioritise the development of relationships between young adults and service providers. Addressing issues related to relationship development will benefit young adults and service providers. Future intervention research based on our theory of clinic attendance will provide further insights into the role of the diabetes clinic in supporting young adults' self-management.

5.1 Introduction

Type 1 diabetes is an autoimmune condition affecting the production of insulin (Daneman, 2006) and is one of the most prevalent chronic conditions of childhood, along with asthma and cystic fibrosis (Torpy, 2010). The prevalence of this condition is increasing, particularly among children under five years (Daneman, 2006; C. Patterson et al., 2014). People with type 1 diabetes carry out a demanding routine of daily self-management to maintain a level of control of blood glucose levels, known as glycaemic control. Attendance at hospital-based diabetes clinics is a core self-management behaviour for people with type 1 diabetes. Diabetes clinics provide people with type 1 diabetes with access to information, support for self-management and screening tests for the complications associated with type 1 diabetes, such as eye problems (Grant et al., 2013; Harvey & Lawson, 2009).

Young adults face unique challenges adjusting to life with type 1 diabetes (Davies, 2004; Garvey & Wolpert, 2011), often reflected in poor psychosocial and diabetes-related outcomes (Barnard, Peyrot, & Holt, 2012; Garvey & Wolpert, 2011). Therefore, the diabetes clinic may be a particularly important resource for this population. However, levels of engagement with important clinic services for diabetes management can be low or inconsistent during the period of young adulthood due to high rates of clinic non-attendance in this group (Kipps et al., 2002; Perry et al., 2010; Sheehan et al., 2015; Sparud-Lundin et al., 2008). Interventions are required to improve clinic attendance behaviour among young adults. However, a lack of research exists to inform the development of effective interventions (Ayling et al., 2014).

Following the guidance of the UK Medical Research Council Framework for the development of complex interventions (Craig et al., 2008), we developed a theory of clinic attendance due to the need for a theoretical basis to inform future behaviour change interventions (Davidoff et al., 2015). Our theory of clinic attendance, outlined in figure 5.1, is based on the findings of a systematic review (L. Hynes et al., 2014) and qualitative study (L. Hynes, Byrne, M., Casey, D., Dinneen, S.F., & O'Hara, M.C., 2015).

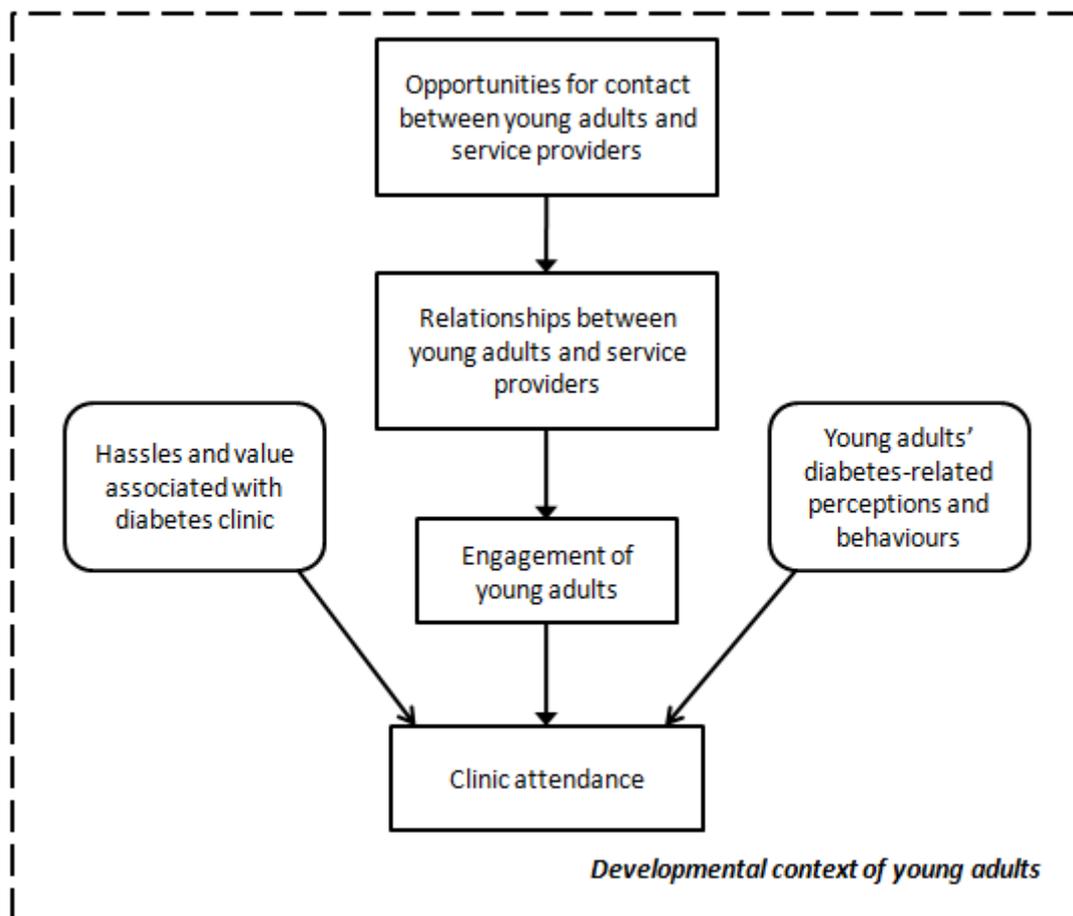


Figure 5.1. Model of Theory of clinic attendance among young adults with type 1 diabetes

According to the core pathway within our theory of clinic attendance behaviour (L. Hynes, Byrne, M., Casey, D., Dinneen, S.F., & O'Hara, M.C., 2015), the existence of a good relationship between young adults and service providers, developed through opportunities for contact outside clinic appointments, fosters the engagement of young adults with the diabetes clinic. Clinic attendance behaviour is established or maintained among young adults who have a relationship with their diabetes team and have become engaged with the clinic. For young adults with a relationship with a service provider, the value of clinic attendance increases and the impact of the hassles which can be associated with the diabetes clinic (such as long waiting times) occur less or are less detrimental to clinic-related perceptions. Finally, the impact of the busy and unpredictable life of a young adult and any negative diabetes-

related perceptions and emotions are less likely to negatively influence clinic attendance behaviour. The support and value experienced by young adults who have developed a relationship with their team and have become engaged with the clinic encourages attendance despite these barriers.

This study aimed to test the theory of clinic attendance to gain an understanding of the most important predictors of clinic attendance behaviour among young adults with type 1 diabetes (Craig et al., 2008; Rowlands et al., 2005). The research questions in this study were: 1. Does the core pathway, from opportunities for contact to clinic attendance, described in the theory of clinic attendance predict clinic attendance behaviour; 2. Does this core pathway predict clinic attendance behaviour when controlling for demographic variables, hassles and values associated with clinic attendance, and young adults' diabetes-related perceptions and behaviours; and 3. Do relationships between young adults and services providers, or the engagement of young adults, moderate the pathways between clinic and young adult related factors, and clinic attendance behaviour?

5.2 Method

5.2.1 Participants

A total of 183 young adults (18-30 years) with type 1 diabetes were recruited through diabetes clinics in the Republic of Ireland, or through diabetes-related websites or social networks.

5.2.2 Procedure

Participants recruited in diabetes clinics were either contacted in person by the researcher (LH) or by a member of their diabetes team while attending their diabetes clinic. Participants recruited online were contacted through posts on diabetes-related websites (such

as Diabetes Ireland, and the Juvenile Diabetes Research Foundation UK) or social media (such as Facebook and Twitter).

The questionnaire was pilot tested with seven young adults who are involved in a related project and changes were made based on feedback. All participants were provided with detailed study information and completed consent forms. Young adults recruited in hospitals completed paper questionnaires. Those who participated online completed an identical questionnaire accessed through a website created for the study (<https://yourdiabetesclinic.wordpress.com>). Ethical approval for this study was obtained from the Research Ethics Committee of the National University of Ireland, Galway and three of the hospital-based clinics where participants were recruited.

5.2.3 Measures

The questionnaire tool was designed to assess the components of the theory of clinic attendance (Figure 5.1). Demographic variables were assessed, including age, gender, living situation, and employment status. Diabetes-related information included number of years since diagnosis with type 1 diabetes and current treatment modality for diabetes. With the exceptions of the variables *opportunities for contact between young adults and service providers* and *clinic attendance behaviour*, the variables in the theory of clinic attendance were assessed using validated measures, and are summarised below and in Table 5.1.

5.2.3.1 The core pathway

Opportunities for contact with service providers outside routine scheduled appointments, such as attending a structured education programme, were investigated using four questions developed for this study based on the qualitative study previously conducted by this group.

Relationships between young adults and service providers. The Working Alliance Inventory- Revised Short Form (WAI-SR; Hatcher & Gillaspay, 2006) was used to measure participants' perceptions of their relationships with at least one service provider in the diabetes clinic.

Engagement of young adults with the diabetes clinic. The Diabetes Empowerment Scale-Short Form (DES-SF; Anderson, Fitzgerald, Gruppen, Funnell, & Oh, 2003) was used as a measure of the engagement of young adults with their diabetes clinic.

The primary outcome in this study was *clinic attendance behaviour*, assessed using three measures: attendance rate (Dyer et al., 1998), missed appointment rate (Schechtman et al., 2008), and informal contact. Attendance rates in this study were based on the number of diabetes clinic appointments attended by participants, out of those scheduled for them, over two years. Missed appointment rates were calculated based on the appointments missed and not rescheduled, of those scheduled for participants over two years. The possible range for this variable was from -100 to 100. Negative scores indicated that more appointments were rescheduled than were missed and positive scores indicated that more appointments were missed than rescheduled. Participants with a score of zero reported that they had not missed or rescheduled any appointments. Informal contact was measured in this study by asking young adults to estimate how many times in the previous two years they had been in contact with the diabetes clinic by telephone, e-mail, text message, or by calling in to the clinic without an appointment.

5.2.3.2 Young adults' diabetes-related perceptions and behaviours

In this study, young adult's diabetes-related perceptions and behaviours were assessed using measures of diabetes self-care behaviours, autonomy for diabetes self-care, diabetes-related perceptions, distress related to type 1 diabetes, impulse control, and social support.

The measures used to assess this component of the theory of clinic attendance were the Questionnaire to Assess Diabetes Self-Care Behaviours (D. Cooke, personal communication, May 13, 2014), the Treatment Self-Regulation Questionnaire (TSRQ; Williams, Freedman & Deci, 1996), the Brief Illness Perceptions Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) , the Type 1-Diabetes Distress Scale (T1DDS; W. Polonsky, personal communication, December 12, 2014), the Brief Self-Control Scale (BSCS; Tangney, Baumeister, & Boone, 2004), the modified Medical Outcomes Study Social Support Survey (mMOS-SS; Moser, Stuck, Silliman, Ganz, & Clough-Gorr, 2012) and the satisfaction subscale of the Social Support Questionnaire (SSQ; Sarason, Sarason, Shearin, & Pierce, 1987).

5.2.3.3 Hassles and value associated with clinic attendance

Hassles and value associated with clinic attendance were assessed using measures of the patient-centeredness of the diabetes clinic and satisfaction with the diabetes clinic. The modified Health Care Climate Questionnaire (mHCCQ; Williams, McGregor, King, Nelson, & Glasgow, 2005) and two subscales (registration satisfaction and overall satisfaction) from the Satisfaction With Outpatients Services (SWOPS; Keegan & McGee, 2003) Questionnaire were adopted in this study.

Table 5.1

Measures used to assess the constructs in the theory of clinic attendance

Theoretical construct	Measure	Cronbach's alpha (α) (previous research)	Sample item and response options
Relationships between young adults and service providers	WAI-SR (12 items)	$\alpha = .94$ (.94-.95)	5-point likert scale, ranging from <i>seldom</i> to <i>always</i>
Engagement of young adults	DES-SF (8 items)	$\alpha = .79$ (.84)	5-point likert scale, ranging from 1 (<i>strongly disagree</i>) to 5 (<i>strongly agree</i>)
Young adults' diabetes-related perceptions and behaviours	Diabetes Self-Care Behaviours: - Monitoring (7 items) - Weight (3 items) - Illness management (3 items) - Carbohydrate counting and testing (6 items)	$\alpha = .87$ $\alpha = .85$ $\alpha = .58^a$ $\alpha = .39^a$	5-point likert scale, ranging from <i>never</i> to <i>always</i>
	TSRQ (8 items)	$\alpha = .78$ (.80)	7-point likert scale, ranging from 1 (<i>not at all true</i>) to 7 (<i>very true</i>)
	BIPQ (8 items)	$\alpha = .69$ (.72)	Likert scale, ranging from 0 to 10, related to each question
	T1DDS (28 items)	$\alpha = .94$	6-point likert scale, ranging from 1 (<i>not a problem</i>)

	BSCS (13 items)	$\alpha = .81 (.83)$	to 6 (<i>a very serious problem</i>) 5-point likert scale, ranging from 1 (<i>not at all</i>) to 5 (<i>very much</i>)
	mMOS-SS (8 items)	$\alpha = .88 (.88 - .93)$	5-point likert scale, ranging from <i>none of the time</i> to <i>all of the time</i>
	SSQ – Satisfaction subscale (3 items)	$\alpha = .36^a (.93)$	6-point likert scale, ranging from <i>very dissatisfied</i> to <i>very satisfied</i>
Hassles and value associated with clinic attendance	mHCCQ (6 items)	$\alpha = .95 (.91)$	7-point likert scale, ranging from 1 (<i>strongly disagree</i>) to 7 (<i>strongly agree</i>)
	SWOPS		
	Registration satisfaction subscale (6 items)	$\alpha = .85 (.84)$	5-point likert scale, ranging from <i>poor</i> to <i>excellent</i>
	Overall satisfaction subscale (4 items)	$\alpha = .89 (.84)$	5-point likert scale ranging from <i>very dissatisfied</i> to <i>very satisfied</i>

Note. DES = Diabetes Empowerment Scale-Short Form; WAI-SR = Working Alliance Inventory-Revised Short Form; TSRQ = Treatment Self-Regulation Questionnaire; BIPQ = Brief Illness Perceptions Questionnaire; T1DDS = Type 1 Diabetes Distress Scale; BSCS = Brief Self Report Scale; mMOS-SSS = modified Medical Outcomes Study-Social Support Survey; HCCQ = Health Care Climate Questionnaire

^aRemoved from analyses due to low reliability in the current sample.

5.2.4 Statistical analysis

Research questions one and two, which related to the predictive ability of the theory of clinic attendance, were addressed using structural equation modelling (SEM). Using SEM, several path models representing the hypothesised relationships within the theory of clinic attendance (Figure 5.1) were specified and their fit to the data was evaluated (Kline, 2005; Kaplan, 2001). SEM was conducted in AMOS 20 (Arbuckle, 2011). The final research question, which related to the moderating influences of relationships and engagement in the theory of clinic attendance, was addressed using moderation analyses, conducted using the programme Interaction v.1.7 (Soper, 2013).

To evaluate model fit the following indices were inspected: chi-square index (smaller values and non-significant p -value indicate better fit), absolute difference (Q ; <5 is good, <3 is excellent), Root Mean Square Error of Approximation (RMSEA; $< .1$ is good, $<.05$ is excellent), Comparative Fit Index (CFI; $>.9$ is good, $>.95$ is excellent), Tucker-Lewis Index (TLI; $>.9$ is excellent) and Akaike Information Criteria (AIC; smaller values indicate better fit) (Byrne, 2010; Hu & Bentler, 1999).

5.3 Results

The questionnaire was fully completed by 158 young adults. However, four cases identified as multivariate outliers were removed from the dataset, resulting in a final sample for analysis of 154 participants. Participant characteristics are summarised in table 5.2. The means and standard deviations for the theory of clinic attendance variables are presented in Table 5.3.

Table 5.2

Characteristics of participants (n = 154)

Variable	<i>M</i> (SD)
Age in years	23.43 (3.76)
Duration of type 1 diabetes in years	10.65 (6.36)
Variable	<i>N</i> (%)
Female	107 (69.5)
Treatment modality	
Multiple Daily Insulin Injections	87 (56.9)
Insulin pump	47 (30.7)
Other	19 (12.4)
Existence of co-morbidity	
Yes	50 (32.7)
No	102 (66.7)
Prefer not to say	1 (0.6)
Clinic type	
Young adult diabetes clinic	53 (34.4)
Adult diabetes clinic	95 (61.7)
Other	6 (3.9)
Attended Structured Education	
Yes	64 (41.6)
No	85 (55.2)
Not sure	5 (3.2)

Table 5.3

Means and standard deviations for theory of clinic attendance variables (n = 154)

Categories	Variable	Range ^a Possible (Actual)	<i>M</i>	<i>SD</i>	
Core pathway	Opportunities for contact	0 – 4 (0 – 4)	1.51	1.25	
	Relationships (WAI-SR)	12 – 60 (12 – 60)	39.55	11.27	
	Engagement with diabetes (DES-SF)	8 – 40 (15 – 40)	29.45	5.12	
	Clinic attendance behaviour:				
	Attendance Rate (%)	0 – 100 (0 – 100)	86.21	24.59	
	Missed appointment Rate ^b (%)	-100 – 100 (-100 – 100)	65.03	30.39	
	Informal Contact	Unlimited (0 – 50)	5.63	6.93	
Young adults' diabetes-related perceptions & behaviours	Autonomous motivation (TSRQ)	0 – 9 (0 – 9)	4.66	1.47	
	Perceived threat (BIPQ)	0 – 80 (16 – 62)	40.52	9.54	
	Diabetes distress (T1DDS)	28 – 168 (31 – 156)	77.27	26.99	
	Diabetes Self-Care Behaviours:				
	Monitoring subscale	1 – 5.29 (1 – 5.29)	4.03	0.96	
	Weight subscale	0 – 5 (0 – 5)	2.66	1.15	
	Self-Control (BSCS)	13 – 65 (19 – 63)	39.28	8.22	
	Social Support (mMOS- SSS)	8 – 40 (10 – 40)	29.26	6.52	

Hassles & value associated with diabetes clinic	Clinic autonomy support (mHCCQ)	6 – 42 (7 – 42)	29.57	9.41
	SWOPS			
	Registration satisfaction subscale	6 – 30 (7 – 30)	19.03	5.09
	Overall satisfaction subscale	4 – 20 (6 – 20)	15.97	3.35

Note. DES = Diabetes Empowerment Scale-Short Form; WAI-SR = Working Alliance

Inventory-Revised Short Form; TSRQ = Treatment Self-Regulation Questionnaire; BIPQ = Brief Illness Perceptions Questionnaire; T1DDS = Type 1 Diabetes Distress Scale; BSCS = Brief Self Report Scale; mMOS-SSS = modified Medical Outcomes Study-Social Support Survey; HCCQ = Health Care Climate Questionnaire

^aHigher scores indicate more of each construct

^b $n = 149$

5.3.1 Clinic attendance behaviour

In this study, 64.9% ($n = 100$) of participants reported attending 100% of their scheduled clinic appointments over the previous two years. Only 3.2% ($n = 5$) reported not attending any scheduled appointment in that time.

In terms of the number of appointments rescheduled by participants over two years, 27.3% ($n = 42$) rescheduled one appointment and 18.2% ($n = 34$) rescheduled between two and seven appointments. Although 39.6% of participants missed 1 to 10 appointments over two years, only 20.8% ($n = 31$) missed more appointments than they attended. By rescheduling missed appointments, 27.5% ($n = 41$) of participants attended more appointments than they missed.

Informal contact by e-mail, telephone, text messaging, or calling in to the clinic was reported by 81.2% ($n = 125$) of the participants in this study. Informal contact by telephone was the most common form of contact reported in this study (74.7%), followed by e-mail (24.7%), and calling into the clinic without an appointment (18.2%).

5.3.2 Testing the theory of clinic attendance

Research question 1: Does the core pathway, from *opportunities for contact between young adults and service providers to clinic attendance*, described in the theory of clinic attendance predict clinic attendance behaviour (*attendance rate, missed appointment rate or informal contact*)?

The initial model was not a good fit for the data; $\chi^2_{(10)} = 83.622$, $p < .001$, $Q = 8.36$, CFI = .174, TLI = -.735, RMSEA = .219 (90% CI = .177 - .264), AIC = 117.622. However, some support for the model was found as *relationships between young adults and service*

providers significantly predicted *engagement by young adults with the diabetes clinic* ($B = .174, p < .001, \beta = .383$).

Covariances were added to account for correlations between *attendance rate* and *missed appointment rate* ($r = -.529, p < .001$), and *attendance rate* and *informal contact* ($r = .197, p < .014$). Direct pathways were specified between *relationships between young adults and service providers*, *attendance rate* ($r = .162, p < .045$) and *informal contact* ($r = .294, p < .001$).

As summarised in Table 5.4, the resulting SEM model showed a significantly improved fit to the data; $\chi^2_{(6)} = 10.231, p = .115, Q = 1.71, CFI = .953, TLI = .834, RMSEA = .068$ (90% CI = .000 - .137), AIC = 52.231. *Relationships between young adults and service providers* continued to predict the *engagement of young adults with the clinic* ($B = .174, p < .001, \beta = .383$). In addition *relationships between young adults and service providers* predicted *informal contact* ($B = .191, p < .001, \beta = .310$) and *attendance rate* ($B = .448, p = .002, \beta = .205$).

Table 5.4

Goodness of fit values for models addressing research question 1

Model	χ^2	df	<i>p</i>	<i>Q</i>	RMSEA	90% CI	TLI	CFI	AIC Model
(A)	83.622	10	.000	8.362	.219	.177, .264	-.735	.174	117.622
(B)	10.231	6	.115	1.705	.068	.000, .137	.834	.953	52.231

Note. Model (A) = Initial model representing the core pathway within the theory of clinic attendance (B) = Best fitting model representing the core pathway within the theory of clinic attendance. Model df = degrees of freedom; *Q* = Absolute fit; RMSEA = root mean square error of approximation; 90% CI = 90% Confidence Intervals. TLI = Tucker-Lewis Index; CFI = Comparative Fit Index; AIC = Akaike Information Criteria; $\Delta \chi^2$ = chi square difference test.

Research question 2: Does this core pathway still predict clinic attendance behaviour when controlling for demographic variables, *hassles and value associated with clinic attendance*, and *young adult's diabetes-related perceptions and behaviours*?

Separate models were specified to test the predictive ability of the core pathway in the theory of clinic attendance while controlling for demographic variables and the variables assessed in this study to represent the hassles and value associated with clinic attendance and young adult's diabetes-related perceptions and behaviours. Only variables which were associated with clinic attendance behaviour were included in the models. A table of Pearson correlations between the variables is included in Appendix M.

The model which showed the best fit for the data in relation to research question 2 was the model in which the influence of the demographic variables associated with clinic attendance behaviour, gender and treatment modality, were controlled for. Young adults using insulin pumps ($M = 8.40$, $SD = 9.06$) made significantly more informal contacts ($p = .002$) with the diabetes clinic in comparison to those using multiple daily insulin injections ($M = 4.09$, $SD = 5.08$). Women were in contact informally with their diabetes clinic significantly more often than men ($p = .002$). Women made an average of 6.57 ($SD = 7.65$) informal contacts over two years, compared to 3.49 ($SD = 4.27$) by men.

This final model was an excellent fit for the data; $\chi^2_{(13)} = 16.076$, $p = .245$, $Q = 1.24$, CFI = .970, TLI = .916, RMSEA = .039 (90% CI = .000 - .094), AIC = 78.076. In this model, *relationships between young adults and service providers* predicted the *engagement of young adults with the diabetes clinic* ($B = .174$, $p < .001$, $\beta = .383$), *informal contact* ($B = .197$, $p < .001$, $\beta = .321$) and *attendance rate* ($B = .463$, $p = .001$, $\beta = .212$). The final model is depicted in Figure 5.2, including the standardised estimates for the significant pathways.

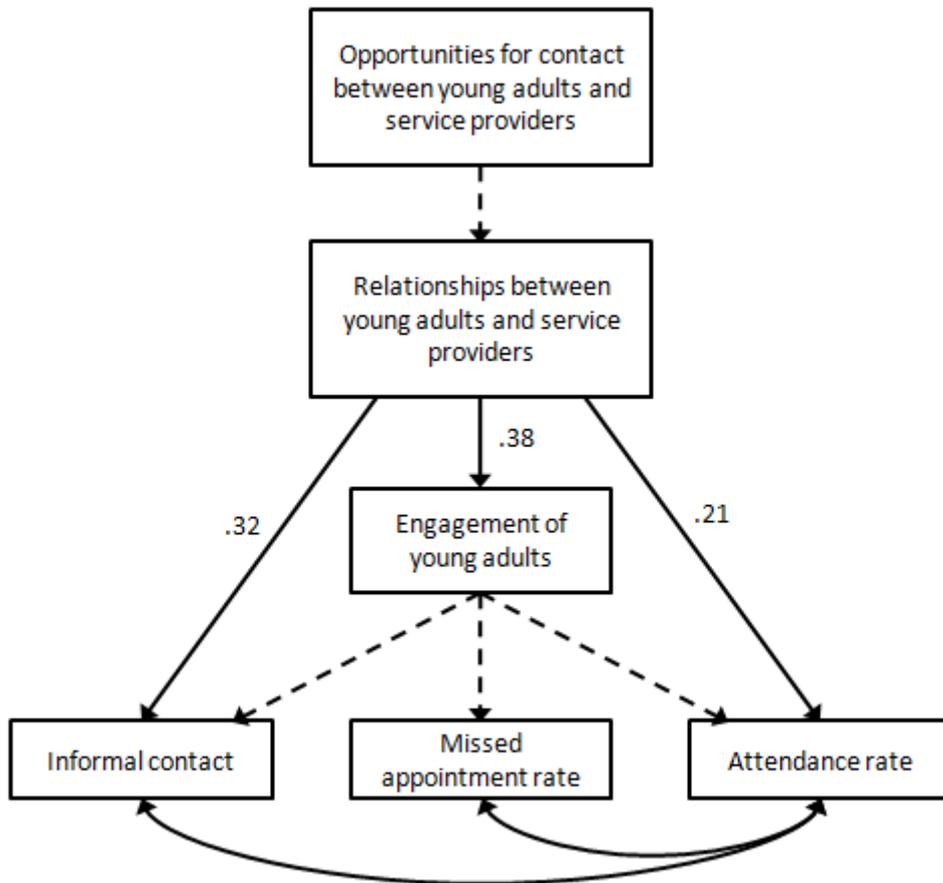


Figure 5.2. Final Structural Equation Model of the core pathway in the theory of clinic attendance among young adults with type 1 diabetes. The demographic variables and error terms were not included in the figure for clarity. The dashed lines signify non-significant pathways. All standardised estimates were significant at the $p \leq .001$ level.

5.3.3 Moderation analyses

Relationships between young adults and service providers moderated the relationship between the *registration satisfaction* and *informal contact* ($\text{Adj } R^2 = 9\%$, $F_{(3, 150)} = 6.26$, $p < .001$, $B = .02$, $SE = .009$, $\beta = .384$, $p = .042$), *overall satisfaction with the clinic* and *informal contact* ($\text{Adj } R^2 = 10.99\%$, $F_{(3, 150)} = 7.30$, $p < .001$, $B = .03$, $SE = .01$, $\beta = .389$, $p = .018$), and *overall satisfaction with the clinic* and *missed appointment rate* ($\text{Adj } R^2 = 4\%$, $F_{(3, 145)} = 3.07$, $p = .029$, $B = -.012$, $SE = .059$, $\beta = .348$, $p = .050$).

Young adults with better relationships with service providers, and higher levels of satisfaction with the clinic, reported most informal contact. Those with poorer relationships with service providers reported least informal contact but also high levels of satisfaction. Little change occurred in terms of the missed appointment rate, regardless of overall satisfaction, among young adults with better relationships with service providers. Whereas, young adults with poorer relationships were more likely to miss appointments, even as overall satisfaction increased.

Finally, the *engagement of young adults with the diabetes clinic* was found to moderate the relationship between *satisfaction with registration* and *attendance rate* ($\text{Adj } R^2 = 4\%$, $F_{(3, 150)} = 3.07$, $p = .029$, $B = -.22$, $SE = .077$, $\beta = .348$, $p = .004$). Among young adults high in engagement, attendance rate did not seem to depend on satisfaction with clinic factors such as waiting times, while less engaged young adults were more likely to attend if they also rate satisfaction with the clinic registration process highly. Moderation graphs are presented in Appendix N.

5.4 Discussion

The aim of this study was to further develop and test our theory of clinic attendance, developed in previous studies, among an international sample of young adults with type 1 diabetes. The primary research question was whether relationships between young adults and service providers, developed as a result of opportunities for contact outside scheduled appointments, predicted clinic attendance behaviour by increasing the engagement of young adults with the diabetes clinic. The findings of this study provided some support for the predictive ability of the theory of clinic attendance.

5.4.1 Clinic attendance behaviour is associated with collaborative relationships

Relationships with service providers significantly predicted young adults' level of engagement and clinic attendance behaviour (attendance rate & informal contact) in this study. Experiencing opportunities for relationship development, like attending a Structured Education Programme, did not predict relationships in this study. This may be accounted for by issues with the approach to measuring 'opportunities for contact' in this study.

When controlling for gender and treatment modality using SEM, the fit between the theory of clinic attendance and the data was best, indicating that these demographic variables played a role in predicting clinic attendance behaviour. Young women and individuals using insulin pumps, made significantly more informal contacts with the diabetes clinic. The influence of relationships between young adults and service providers in the models tested in this study persisted whether or not clinic or young adult-related variables, including diabetes self-care, were controlled for.

Moderation analyses demonstrated the importance of relationships with service providers and engagement among young adults, for clinic attendance behaviour, irrespective of young adult's satisfaction with the clinic. In line with previous research (Balfe, Brugha, et al., 2013; Jenkinson, Coulter, Bruster, Richards, & Chandola, 2002; B. Williams, Coyle, &

Healy, 1998), despite self-reported satisfaction with the clinic, young adults without a relationship with the diabetes team were at greater risk of missing appointments in comparison to young adults with better relationships with service providers. Young adults who were less engaged and had lower levels of satisfaction with the diabetes clinic were at greater risk of non-attendance compared to young adults with higher levels of engagement. Therefore, satisfaction with services should not be assumed to be a sufficient indicator of the adequacy of diabetes clinics to meet the needs of young adults.

The findings of this study show that interventions to improve service delivery and clinic attendance behaviour among young adults should prioritise measures to improve relationships between young adults and service providers. Future interventions to improve clinic attendance behaviour should be designed to reduce barriers to relationship development, such as low continuity of care (Allen et al., 2012), and support collaborative diabetes management, for example by utilising patient-centred consultation tools (Zoffmann & Kirkevold, 2012).

5.4.2 Engagement in diabetes management depends on familiarity

The engagement of young adults with diabetes self-management was predicted by relationships with service providers in this study. This finding confirms the importance of familiarity for the engagement of young adults and service providers in diabetes management, reported in previous research (Greene, 2009). However, service providers have reported that they are often not familiar enough with young adults to be able to provide advice that is personal and responsive (Balfe, Brugha, et al., 2013; Brierley et al., 2012).

It was hypothesised in this study that relationships with service providers would predict young adults' clinic attendance behaviour indirectly, through engagement. However, young adults' level of engagement did not predict clinic attendance behaviour in this study,

and a direct association was found between participants' relationships with service providers and their rates of clinic attendance and informal contact. Engaged and committed service users and providers are conceptualised as the two walls in the house of care model for delivering better services for people with long-term conditions (Coulter, Roberts, & Dixon, 2013). Many terms and descriptions exist referring to the ethos, orientation and behaviour of engagement, active involvement and empowerment. Greater understanding of what engagement means and entails for people with diabetes and diabetes service providers is necessary before it can be realised in practice.

5.4.3 Clinic attendance behaviour among young adults

The findings of this study illustrate the complexity of clinic attendance behaviour, providing important information for service delivery and intervention development. For example, the mean attendance rate was high in this study, with participants attending 86% of their scheduled appointments over two years. However, 58% of participants in this study attended fewer than 3-4 annual appointments and this level of attendance has been associated with better glycaemic control (Hatherly et al., 2009). In addition, 82% of young adults made informal contact by telephone, text message, e-mail, or calling into the clinic, at least once in the previous two years. However, informal contact by telephone or e-mail is often not integrated within models of service delivery and has been described as a significant resource burden by service providers (Balfe, Brugha, et al., 2013; Brierley et al., 2012; L. Hynes, Byrne, M., Casey, D., Dinneen, S.F., & O'Hara, M.C., 2015). This burden on service providers may be reduced, and access to support for young adults may be improved, by acknowledging the importance of informal communication, such as email, as an intrinsic component of service delivery.

5.4.4 Limitations

Due to missing data and challenges recruiting large numbers of young adults a small to medium sized sample was included in the analysis. Adequate parameter to sample size ratios were maintained throughout the process of model respecification and testing (Kline, 2005). However, caution is advised when interpreting the results of SEM with small to medium sized samples (Kline, 2005).

Data related to clinic attendance behaviour were gathered through self-report in this study as opposed to assessing attendance through participants' hospital records. However, attendance rates reported in this study were similar to those reported in research in which hospital records were used to assess attendance (Johnson et al., 2014).

This study is cross sectional and so conclusions cannot be made regarding causal mechanisms or the direction of causality in relation to clinic attendance behaviour. For example, it is acknowledged that more frequent attendance by young adults may contribute to better relationships with service providers, as opposed to good relationships influencing attendance behaviour, as hypothesised in this study. Nonetheless, the findings of this study provide a basis and rationale for future intervention research.

5.4.5 Implications for research and practice

The findings of this study are in line with international guidelines for diabetes service delivery which is patient-centred (Chiang et al., 2014; NICE, 2004; Nicolucci et al., 2013). However, the implementation of patient-centred care has been challenging in practice and mixed evidence exists for the impact of patient-centred practices on health outcomes (Mead & Bower, 2002). The findings of this study, which suggest that prioritising the improvement of relationships between young adults and service providers may provide a basis for successfully implementing patient-centred diabetes services, should be tested in future interventions research

Future research using longitudinal designs is necessary to understand the development and maintenance of relationships with service providers, and the mechanisms through which relationships influence clinic attendance behaviour and other psychological, diabetes-related and health service outcomes. Additional research is needed to clarify the definition of engagement with diabetes clinics. There is a need for reliable measurement tools to be developed to assess the development of relationships, engagement with diabetes clinics and clinic attendance behaviour.

5.4.6 Conclusion

Regular clinic attendance among young adults and engaging young adults in diabetes management are priorities of service delivery during young adulthood (B. J. Anderson & Wolpert, 2004; Garvey & Wolpert, 2011). According to the findings of this study, interventions which address clinic non-attendance by improving relationships between young adults and service providers will contribute to the achievement of these service delivery priorities. The clinic attendance behaviour of young adults may be better understood, facilitating service planning and development, if services ensure that hospital records reflect attendance behaviour. Prioritising relationship development in diabetes clinics may have wide reaching implications for service users and providers, and for improving clinic attendance behaviour. Interventions targeting relationships between young adults and service providers are necessary to test the theory of clinic attendance and further develop knowledge in relation to clinic attendance behaviour.

6. General discussion

6.1 Chapter overview

This chapter will present a summary of the overall findings of this research and evaluate the contribution made by this research to understanding clinic attendance behaviour among young adults with type 1 diabetes. The theory of clinic attendance will be discussed in relation to existing literature and approaches to designing interventions targeting clinic attendance behaviour will be presented. The implications of the findings for future research and practice will be described. The limitations of each study will be described and approaches to addressing these limitations will be suggested. Finally, this chapter will end with concluding remarks.

6.2 Summary of the overall findings of this research

- According to this research, the developmental context of young adults presents distractions from diabetes and self-management and impacts the emotional wellbeing of young adults. These contextual factors can negatively influence decisions to attend the diabetes clinic, particularly among young adult without a good relationship with a service provider.
- Clinic-related factors, such as long waiting times, create barriers to clinic attendance behaviour, by hindering relationship development or reducing young adults' perceptions of the value of clinic attendance.
- Collaborative relationships between young adults and service providers predict clinic attendance behaviour among young adults, and may support wellbeing and self-management.
- Engagement is the active role with the diabetes clinic taken by young adults who have experienced a collaborative relationship with service providers. Positive, supportive

experiences in the diabetes clinic are necessary to influence clinic attendance behaviour. The relationship of engagement with clinic attendance behaviour is not clear.

- Clinic attendance behaviour among young adults with type 1 diabetes involves attendance at scheduled appointments, informal contact outside scheduled appointments, and communication regarding appointments such as cancelling and rescheduling unsuitable appointments:
- Barriers to relationship development such as a lack of continuity of care, and the discretionary nature of informal contact provide evidence that existing diabetes services do not adequately fit the requirements of service provision for type 1 diabetes, or for young adults. Addressing this poor fit would benefit young adults with type 1 diabetes and service providers. The removal of organisational and interpersonal barriers within diabetes clinics may facilitate a shift to patient-centred or empowerment-based diabetes services, and consistent clinic attendance behaviour.

6.3 Contribution of this research

The importance of relationships between young adults and service providers has been described in previous studies (Holmes-Walker et al., 2007; Wolpert & Anderson, 2001d). However, due to a lack of research on clinic attendance behaviour, the influence of relationships on attendance had not previously been investigated in depth. In addition, previous research linked relationships between young adults and service providers with improved diabetes-related outcomes, but the mechanism by which ongoing collaboration with the diabetes clinic would result in improved self-management and outcomes remained unclear. The findings of this research suggest causal pathways between collaborative relationships in diabetes clinics and improved outcomes among young adults. The central role of the diabetes clinic in supporting diabetes management during young adulthood is

highlighted by the findings of this research, suggesting that future investment in interventions focusing on service delivery is warranted.

6.4 Collaboration addresses the unique needs of young adults with type 1 diabetes

The findings of this research indicate that prioritising relationship development will facilitate service providers' awareness of, and ability to address, the unique needs of young adults. Addressing the complex issues and concerns of young adults is challenging for service providers. A lack of time, skills and confidence has been associated with neglect by service providers of the psychosocial issues faced by young adults (Brierley et al., 2012; Freed & Hudson, 2006). However, in this study, relationships between young adults and service providers predicted better clinic attendance rates and more informal contact by young adults. Clinic attendance behaviour was predicted by relationships in this study, even while factors such as the perceived threat associated with diabetes were controlled for.

There is a perception that young adults are not motivated to improve their health or avoid future complications related to diabetes (B. J. Anderson & Wolpert, 2004; Pyatak et al., 2013; Weissberg-Benchell et al., 2007). However, the findings of this research show that it is possible to engage young adults with diabetes management. Young adults are more future-oriented, in terms of their cognitive abilities, in comparison to adolescents (Moilanen, 2006). Therefore they are capable of planning and preparing for events in the near and far future, and their ability to engage with the diabetes clinic and with diabetes self-management should not be assumed or under-estimated.

Type 1 diabetes is a burdensome condition to live with. Therefore, consideration of and support for the psychosocial needs of people with diabetes is regularly and widely called for. Access to routine psychosocial support remains contentious and far from routine (Barnard et al., 2012; L. Fisher et al., 2014; A. Jones, Vallis, & Pouwer, 2015; Nicolucci et

al., 2013). Associations between non-adherence to self-management and clinic non-attendance due to fear of judgement from service providers indicate that young adults most in need of regular screening and support may be unlikely to attend (Snow & Fulop, 2012).

Interventions which focus on relationship development to improve clinic attendance behaviour have the potential to address psychosocial difficulties faced by young adults, such as diabetes-related distress. Considering the high prevalence of diabetes-related distress and its implications for diabetes self-management, supporting self-management and clinic attendance despite distress is an important role for diabetes clinics (Balfe, Doyle, et al., 2013). The findings of this research suggest that the joint aims of supporting diabetes self-management and reducing diabetes-related distress may be possible through the implementation of clinic attendance behaviour interventions which focus on relationship development.

6.5 The role of transition in clinic attendance behaviour

Clinic non-attendance was associated with poor relationships between young adults and service providers in this study. Inadequate continuity of care during transition from a paediatric diabetes clinic and in the adult diabetes setting was a prominent barrier to the development of relationships in adult diabetes clinics. The findings of this research contribute to existing evidence that successful transition is associated with continuity of care and is necessary for attendance at adult clinics (Allen et al., 2012; Forbes et al., 2001; Sheehan et al., 2015). There is some evidence supporting transition programmes for improving clinic attendance among young adults with type 1 diabetes. However, there is still evidence that some young adults experience long periods before attending an adult diabetes clinic after leaving the paediatric clinic, and of declining rates of attendance across the young adult period (Kipps et al., 2002; Sparud-Lundin et al., 2008).

Understanding and improving clinic attendance among young adults must account for the impact of paediatric and transition experiences. The first appointments attended by young adults in the adult setting may influence their perceptions of the adult diabetes clinic. Times of transition provide opportunities for behaviour change and habit development (B. J. Anderson & Wolpert, 2004; Weissberg-Benchell et al., 2007; Wysocki et al., 1992). Therefore, the transition from paediatric to adult diabetes clinics may be an ideal time for interventions targeting self-management, including clinic attendance behaviour.

6.6 Diabetes service benefits associated with collaboration

This study suggests that future interventions should prioritise relationship development between young adults and service providers to reduce clinic non-attendance and the inefficiencies created by non-attendance. For example, clinic non-attendance creates uncertainty among service providers regarding the size of each clinic from day to day. This uncertainty has implications for the planning and running of each clinic and contributes to low continuity of care and disconnection during consultations (Balfe, Brugha, et al., 2013).

According to previous research, service providers rely on assumptions and generalisations to determine the needs and preferences of service users due to time constraints, low continuity of care and the biomedical focus of diabetes clinics (Balfe, Brugha, et al., 2013; Brierley et al., 2012; Graugaard, Holgersen, Eide, & Finset, 2005; Hall, Stein, Roter, & Rieser, 1999). Service providers can be frustrated by a lack of insight into the motivations of young adults and describe concern regarding their ability to engage with complex issues (Brierley et al., 2012; Pyatak et al., 2013). Barriers to clinic attendance reported in this study, such as time constraints during consultations and low continuity of care, negatively impact the experiences of service providers as well as young adults. Quality of care is associated with the wellbeing of service providers (Health Services Executive,

2015; Paparella, 2015; Wallace, Lemaire, & Ghali, 2009). Therefore future interventions to address clinic attendance behaviour may also benefit quality of care through improving the wellbeing of service providers. The need to rely on assumptions to guide interactions may be avoided by implementing mechanisms for the development of collaborative healthcare relationships.

Existing inequalities for young adults in accessing support from service providers emerged in this study when it was found that young adults who had experienced a major event, like a hospitalisation, were more likely to have developed a collaborative relationship with a service provider. Existing services are often forced to prioritise people who are at greatest risk of diabetes-related complications (Balfe, Brugha, et al., 2013). However, this may be at the expense of the quality of care provided to other young adults. As reported in this research, and in previous studies, young adults may become vulnerable to non-attendance if the value of attendance is overtaken by the barriers to attendance (Balfe, Brugha, et al., 2013; Scott et al., 2005; Snow & Fulop, 2012). Therefore, young adults may not receive the support they need to cope with and manage their diabetes until a problem arises.

The findings indicate that establishing and maintaining clinic attendance behaviour is a process which begins with familiarity between young adults and service providers. Adherence to diabetes self-management naturally fluctuates with the demands of daily life, emotions, and motivations (Paterson, 2004; Paterson, Russell, & Thorne, 2001). Therefore, clinic attendance behaviour interventions which focus on relationship development may need to be based on a model of long term contact, and accessible and flexible support. As a result, the primary and secondary outcomes of clinic attendance behaviour interventions which focus on relationship development will need to be carefully chosen, reflecting the causal mechanism suggested by this research and outcomes of importance to young adults and service providers.

6.7 A patient-centred model for intervention development

The formation of long-term relationships between diabetes service users and providers may be facilitated by integrating the provision of ongoing support for self-management within routine service provision. The use of a collaborative or empowerment-based approach in consultations has been associated with greater efficiency, improved communication and better psychosocial and diabetes-related outcomes (R. M. Anderson & Funnell, 2010; Husted, Esbensen, Hommel, Thorsteinsson, & Zoffmann, 2014; Levinson et al., 2000; G. C. Williams, Freedman, & Deci, 1998; Zoffmann & Kirkevold, 2012).

Empowerment is a patient-centred approach to diabetes management characterised by collaboration between service users and providers. Empowerment means that people with diabetes are supported to make informed decisions which are in line with their own goals and values. In addition, a core characteristic of the empowerment approach is the acknowledgment by service users and providers that self-management is the responsibility of the person with diabetes (R. M. Anderson & Funnell, 2010; Funnell & Anderson, 2004). Empowerment is associated with improved psychosocial, diabetes-related and health service outcomes by ensuring that service users are facilitated, through the provision of information and support, to work towards the goals that are important to them (R. M. Anderson & Funnell, 2007, 2010; Zoffmann & Kirkevold, 2012). However, it was reported in a large international study that most people with diabetes are not actively engaged by their healthcare providers to take control of their condition (Nicolucci et al., 2013).

The purpose of diabetes clinic attendance is for prevention, early detection and intervention in relation to diabetes-related complications (DCCT, 1993). To achieve this aim, regular clinic attendance is required among people with diabetes regardless of their health status and pattern of self-management. However, service provision for diabetes continues to

be guided by a system with an acute illness bias in which resources are often diverted to emergency management (Anderson & Funnell, 2010; Balfe et al., 2013). Despite persistent growth in the numbers of people diagnosed with chronic conditions and the increased life expectancies of people with chronic conditions, the provision of care which is long term and collaborative has not progressed to meet the demand (E. H. Wagner et al., 2001).

‘Working alliance’, the concept used to represent relationships between service users and providers in this research, is a dimension of patient-centred models of service delivery (Y. Y. Lee & Lin, 2010). Therefore, the patient-centred model may be a useful model for future interventions targeting clinic attendance behaviour. There is a lack of research testing patient-centred or empowerment-based approaches to diabetes service delivery for young adults. However, the importance of strong relationships with service providers has been described (B. J. Anderson & Wolpert, 2004; Balfe, Brugha, et al., 2013; Holmes-Walker et al., 2007; Ritholz et al., 2014). According to the findings of this research, the impact of a patient-centred model of care on clinic attendance behaviour is through the influence of relationship development.

The patient-centred model of service delivery comprises the following dimensions: a biopsychosocial perspective, actively seeking the service user’s point of view, sharing power and responsibility, acknowledging the service user as an individual with a unique history, and working alliance (Y. Y. Lee & Lin, 2010; Mead & Bower, 2000; Zandbelt, Smets, Oort, Godfried, & de Haes, 2006). Patient-centred or empowerment-based approaches to diabetes service delivery have been associated with behaviour change and improved outcomes (Glasgow et al., 2004; G. C. Williams et al., 1998; Wolpert & Anderson, 2001a). However the evidence for the utility of patient-centred approaches to health service delivery is inconsistent (Mead & Bower, 2002).

Patient-centred care is often described as a tendency or style as opposed to a guiding model for service delivery, influencing the design, ethos and delivery of health services. Issues with the conceptualisation of patient-centred care may have resulted in conflicts between interventions and intervention contexts, reflected in the findings of many patient-centred intervention studies. In previous research, factors have been identified, at the level of diabetes service, service user, service provider and consultation, which influence the delivery of patient-centred care (Y. Y. Lee & Lin, 2010; Mead & Bower, 2000; van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003).

For example, in two separate randomised controlled trials of patient-centred interventions, service providers struggled to integrate attention to the wellbeing of service users with diabetes management due to personal attitudes and financial and organisational constraints (Kinmonth, Woodcock, Griffin, Spiegel, & Campbell, 1998; Russell, Thille, Hogg, & Lemelin, 2008; Woodcock, Kinmonth, Campbell, Griffin, & Spiegel, 1999). Similarly, in the 'Talking Diabetes' intervention, service providers were trained in patient-centred consultation skills for working with children and adolescents with type 1 diabetes, and their parents (Robling et al., 2012). Improved communication skills were found among service providers who received the training but were not maintained. Children in the intervention group were more able to cope with diabetes. Parents reported that children were a lot more positive about attending appointments and that they experienced greater continuity of care following the intervention. However, no improvement in HbA1c was found.

There are significant constraints on the implementation of a patient-centred model of service delivery which may be attributed in part to constraints on the development of relationships between service users and providers, including busy clinics and inadequate support for service providers (R. M. Anderson & Funnell, 2010; Russell et al., 2008). The findings of this research suggest that collaborative relationships, which are based on

familiarity, have an important influence on interactions between service users and providers, making relationships a pre-requisite for patient-centred service delivery rather than a dimension of the patient-centred care model. The flexibility in consultations, support for the autonomy of service users, and shared decision-making which characterise patient-centred consultations, require a foundation of familiarity and continuity of care. Inadequate investment in the conditions necessary for patient-centred service delivery, such as the existence of relationships between young adults and service providers, may have contributed to the inconsistent evidence related to patient-centred health services and the challenges reported by service providers to commit to a patient-centred model.

The main finding of this research relates to the central role of collaborative relationships between young adults and service providers in determining clinic attendance behaviour. Despite the barriers to communication and relationship development regularly described in diabetes clinics (e.g. Snow et al., 2012), existing research shows that collaboration within consultations can be facilitated and can result in improved outcomes.

In a theory-based intervention developed using participatory methods, nurses, adolescents (Husted et al., 2014) and adults (Zoffmann & Kirkevold, 2012; Zoffmann & Lauritzen, 2006) with type 1 diabetes were facilitated to overcome barriers to shared decision-making during diabetes clinic appointments. Based on a philosophy of empowerment, reflection sheets were used during consultations to highlight the difficulties the service user was facing and enabled shared insights, productive problem-solving relationships and the resolution of conflicts which had acted as barriers to engagement with self-management, including clinic attendance. This intervention demonstrated that it is possible to support service users and providers to collaborate within the context of busy hospital clinics, resulting in improvements to the quality of services, the experiences of service users and providers, and outcomes including clinic attendance and glycaemic control.

A large and growing body of literature exists surrounding patient-centred service delivery, empowerment-based approaches to diabetes management, and the active involvement or engagement of service users. The findings of this research place these health service concepts within a single framework by suggesting the relationships and pathways between the components of a patient-centred model of care and clinic attendance behaviour. The need for change at multiple levels within diabetes services using complex intervention designs is emphasised by this research.

6.8 Understanding clinic attendance behaviour

Previous research did not reflect the complexity of clinic non-attendance (Paterson et al., 2010). This study makes a contribution to the literature by assessing a greater range of determinants of clinic attendance behaviour, using qualitative and quantitative methods. In previous research, little attention to service related or psychological determinants of clinic attendance behaviour had been assessed. For example, although forgetting was the most common reason for non-attendance in previous research, it was not a common cause of non-attendance in this research. Non-attendance for logistical reasons did occur but young adults who valued diabetes clinic appointments organised the time to attend many of their scheduled appointments, or rescheduled appointments as necessary. Therefore, researchers and service providers had a restricted understanding of clinic attendance behaviour due to the limitations of existing evidence, resulting in barriers to designing effective interventions to address clinic non-attendance. The mixed methods approach used in this research was appropriate due to the limitations of the available evidence.

The findings of this research indicate that diabetes service providers may need to broaden their approach to understanding and measuring clinic attendance to include attendance rates and contact with diabetes clinics by young adults. By not accurately

monitoring the type and amount of contact, for example by telephone, email, calling in to the clinic, or scheduled appointments, between young adults and service providers, much of the work undertaken by service providers, and the approaches to care which work best, go unrecognised.

Collaborative relationships and engagement may improve aspects of clinic attendance behaviour. Missed appointments can still occur, but are more likely to be rescheduled or supplemented by informal contact for support or problem-solving. Therefore, efforts to improve clinic attendance behaviour, such as ensuring young adults develop collaborative relationships with service providers, may need to consider outcomes like informal contact by telephone with diabetes clinics, as well as attendance rates, to evaluate the efficacy of interventions. In addition, this study and previous studies show that channels of communication with diabetes clinics can be poor, making it difficult for young adults to communicate regarding appointments, resulting in negative attitudes towards clinics and long gaps between appointments. Removing barriers to clinic attendance, such as barriers to communication for cancelling and rescheduling appointments should also be considered in future intervention development.

Informal contact is often not a formal aspect of diabetes service. Therefore, informal contact can be burdensome for service providers, and is not available to all young adults. Informal contact by young adults, such as communication by telephone, e-mail or by calling in to the clinic without an appointment, is facilitated by collaborative relationships with service providers. Familiarity is necessary for informal contact to be possible, and enables young adults to gain support and information between appointments. Similar to the findings of previous research, informal contact is often not a recognised aspect of diabetes services. Therefore, informal contact can be burdensome for service providers, and is not available to all young adults (Balfe, Brugha, et al., 2013). However, communication with service

providers has been associated with better glycaemic control (Hatherly et al., 2009) and is a central aspect of diabetes service delivery for supporting self-management among young adults (Pyatak et al., 2013), reducing diabetes-related distress (Balfe, Doyle, et al., 2013) and providing a source of support as young adults supports systems are also in transition (Allen et al., 2011).

Complete clinic attendance information will facilitate the development of diabetes services and equitable and efficient use of resources, thereby aligning the model of diabetes service delivery with the reality of service delivery. Decisions regarding changes to service delivery should be made following consultation with young adults and service providers to maximise the effectiveness of new approaches (Johnson et al., 2014).

6.9 Implications for research

The purpose of this research was to provide a basis for future intervention research targeting clinic attendance behaviour. Based on the findings of this research, future interventions should be designed to improve relationships between young adults and service providers and increase regular clinic attendance. Relationships may be improved, according to this research, by reducing the barriers to relationship development, such as low continuity of care, and supporting service providers and young adults to engage in collaborative diabetes management.

Reducing barriers to relationship development may be achieved by redesigning diabetes clinics to ensure young adults meet the same service providers, or at least one key service provider, as often as possible (e.g. Holmes-Walker et al., 2007). In addition, future interventions may reduce barriers to relationship development by implementing different consultation models which prevent short and impersonal consultations. For example, the impact of group consultations or consultations attended by more than one service provider,

such as a nurse and a doctor, on relationship development could be tested in future interventions.

Previous research indicates that service providers and service users struggle to engage in collaborative management of chronic conditions (Hall et al., 1999). Knowledge, skills, expectations, and familiarity are some of the factors influencing the quality of collaboration in health service settings, which could be targeted in future interventions (R. M. Anderson & Funnell, 2010). For example, an intervention involving the use of patient-centred consultation tools (e.g. Zoffmann et al, 2012) provides an explicit framework for consultations, including non-judgemental discussion of issues and support for self-management such as goal setting. As a result, both service users and providers are equally involved and informed regarding the aims and objectives of each consultation and of ongoing diabetes management. According to the findings of this research, interventions designed to reduce barriers to relationship development or to support collaborative diabetes management will improve clinic attendance behaviour by increasing the value of clinic attendance and encouraging attendance despite the competing demands and concerns experienced by young adults.

Research surrounding self-management and clinic attendance behaviour has focused on determinants related to service users only, neglecting the role of health service contexts, and the relationship between service users and providers (Osterberg & Blaschke, 2005; Paterson et al., 2010). This study has contributed knowledge related to young adults and clinic-related determinants of clinic attendance behaviour, and to broadening the description of clinic attendance behaviour itself. Additional clinic attendance research is needed to verify and further investigate the determinants of clinic attendance identified in this study. Previous research has reported that enhancing the compatibility of diabetes services with the lifestyles of young adults may help to address the problem of clinic non-attendance (Perry et al., 2010). The findings of this research suggest that interventions prioritising relationship development

facilitate service providers to address the unique needs of young adults. Further research is needed to test this finding regarding the potential role of diabetes clinics for supporting young adults.

In addition, research using longitudinal and experimental designs is necessary to understand the impact of service delivery models and relationship-focused interventions on clinic attendance behaviour. According to this research, the outcomes of interventions targeting clinic attendance behaviour among young adults with type 1 diabetes should be carefully chosen. Biomedical outcomes are most commonly selected in diabetes research (Davies, 2004). However, as clinic attendance and engagement with diabetes management are priorities of service delivery during young adulthood, interventions targeting these behavioural outcomes are warranted. Future longitudinal research may demonstrate relationships between collaborative relationships, self-management by young adults and glycaemic control.

In this study, the theory of clinic attendance was developed based on data gathered from young adults and service providers. However, the theory was tested with a sample of young adults only. Service providers would be required to play an integral role in a diabetes clinic which prioritises relationship development and may also benefit from this approach. Therefore, the impact of clinic attendance behaviour interventions targeting relationship development on service providers should also be explored in future research.

Further research using the theory of clinic attendance, in conjunction with a patient-centred model of service delivery, such as the House of Care model for delivering services for people with chronic conditions (Coulter et al., 2013) should be conducted. The findings of this study indicate that additional research is needed to understand the development of collaborative relationships, and the relationship between the engagement of young adults with

diabetes management and clinic attendance behaviour. Addressing these issues of definition and measurement may be important for designing interventions to improve clinic attendance. Similar issues related to clinic attendance behaviours among young adults with chronic conditions such as cystic fibrosis or asthma may also occur. Therefore future research may assess the predictive ability of the theory in different health service settings.

The complexity of clinic attendance behaviour, illustrated in this study, also requires further investigation. Based on input from service providers and young adults, clinic attendance behaviour and the important aspects of this behaviour in relation to diabetes self-management and outcomes, should be defined and reliable measurement tools developed for use in research and practice.

This study emphasises the need to employ theories of behaviour to support the careful examination of behaviours and to understand the causal chain between emotions, cognitions, environmental variables, and individual and medical outcomes. It is widely reported that changing self-management behaviours to improve glycaemic control is very challenging for individuals with type 1 diabetes, health care professionals and researchers (Davies, 2004). Understanding and targeting behavioural outcomes, such as engagement and clinic attendance behaviour, fall within the remit of health psychology (Michie & Johnston, 2012). To achieve the quality of life and biomedical aims which are important to service providers and people with type 1 diabetes, health psychology can contribute by developing and evaluating interventions with an understanding of the causal mechanisms between behavioural determinants, behaviours and health outcomes (Michie & Johnston, 2012). Implementing patient-centred models of service delivery is a promising approach to improving clinic attendance behaviour. However adopting this approach requires changes to the organisation of services and the approach of service providers. This has implications for the design and management of diabetes services and the training of service providers.

Considerable evidence for the efficacy of a patient-centred approach to diabetes service delivery is necessary to warrant this investment. Therefore, health psychology research in this area may contribute to the evidence for implementing the kinds of complex interventions required for addressing clinic attendance behaviour.

6.10 Implications for practice

Diabetes services should prioritise relationship development with young adults with type 1 diabetes to improve clinic attendance behaviour. Collaborative relationships have the potential to improve clinic experiences and diabetes outcomes for young adults, working conditions for service providers, and the quality and efficiency of service provision. The ‘House of Care’ model for delivering services to people with chronic conditions (Coulter et al., 2013) gives equal weight and prominence to the participation of service users and providers in the management of chronic conditions, like type 1 diabetes. A culture change in the approach and expectations of service users and providers may be required for patient-centred models of diabetes service delivery to produce outcomes such as improved clinic attendance behaviour (R. M. Anderson & Funnell, 2010).

The findings of this research suggest a number of organisational changes which may facilitate improvements in clinic attendance behaviour. Organisational barriers have been associated with clinic non-attendance in this research and in previous studies (Snow & Fulop, 2012; Van Wallegem et al., 2011). For example, low continuity of care, long waiting times and short, impersonal consultations are factors often associated with clinic non-attendance among young adults which may be addressed within diabetes services. Gaps in training and support available to service providers working with people with chronic conditions are also associated with clinic non-attendance (Brierley et al., 2012). Implementing and maintaining patient-centred practices has been found to be a serious challenge for service providers in

previous research (Russell et al., 2008; Woodcock et al., 1999). Changes to diabetes service provision should include access to training related to communication, shared decision-making and problem solving, and ongoing support for service providers should be integrated within diabetes services (Brierley et al., 2012; Wolpert & Anderson, 2001a; Zoffmann & Kirkevold, 2012). Measures within diabetes services to support and manage the resource burden of patient-centred practices may include allotting time for informal contact for diabetes self-management support, fostering communication within the multi-disciplinary team, using technology and social media, identifying care coordinators, and using consultation or pre-consultation tools for planning and communication (R. M. Anderson & Funnell, 2010; Brierley et al., 2012; E.H. Wagner, 2000; Wolpert & Anderson, 2001a).

6.11 Strengths and limitations

This study has a number of strengths and limitations. In this section, the effect of the exploratory nature of the study and issues related to the use of the methods chosen for each study will be discussed in terms of the strengths and limitations of the overall research. Factors which were omitted from this study but should be considered in future research will also be described.

In study 1 a systematic review and narrative synthesis of studies related to clinic attendance behaviour among young adults was conducted. The findings of systematic reviews are only as reliable as the studies included in the review (Garg et al., 2008). Methodological issues existed across the studies in this review. However each study met the inclusion criteria and contributed to answering the review question. It was not possible to complete a meta-analysis. Therefore a narrative synthesis was conducted. Narrative synthesis is a relatively new approach to synthesising the findings of systematic reviews. Due to the heterogeneity of studies suitable for narrative synthesis, and the descriptive nature of the findings involved,

prescriptive guidelines do not exist for narrative synthesis (Popay et al., 2006). Despite measures to enhance transparency and reporting associated with narrative synthesis, this may be a more subjective process than meta-analysis. Therefore, caution should be used in interpreting the findings and applying them to future studies. The findings of this review were not intended to inform intervention development but served the purpose of identifying gaps in the literature related to the review topic and provided an overview of existing knowledge.

In study 2, one interview only was conducted with each participant and the setting for the study was one diabetes clinic. Grounded theory studies can involve more than one interview per participant to facilitate the checking of emerging concepts through pursuing specific questioning with participants (Hunter, Murphy, Grealish, Casey, & Keady, 2011b). In this case, rich and detailed data were gathered from each participant, and additional insight into the data that were already gathered was obtained in subsequent interviews, through the technique of theoretical sampling. In addition, more than one diabetes clinic may have been included in the study, enabling similar but different contexts to have been compared and similarities and differences accounted for in the findings. In this study, saturation was reached through data collection in one clinic. For practical reasons related to time limits on the overall research, participants were not recruited from other clinics. However, future research should be conducted in different settings to further develop the theory of clinic attendance. Finally, data can be gathered in grounded theory studies from sources other than interviews or focus groups, for example, relevant online forums, magazines or policy documents (Corbin & Strauss, 2008). Interview data was gathered in study 2 in this case and was deemed to be adequate to answer the research question. As clinic attendance research progresses, qualitative research with more specific aims may take a different approach to data collection.

In study 3, the limitations related to the sample size, the use of self-report to collect clinic attendance data, and the cross-sectional design. Structural equation modelling is a large sample statistical technique (Muthén & Muthén, 2002). However, obtaining large samples is a significant challenge in social science research (Nachtigall et al., 2003). An adequate sample size was obtained in this study ($n = 154$), with acceptable participant to parameter ratios maintained throughout the process of specifying and testing models based on the theory of clinic attendance behaviour (Kline, 2005). A larger sample may have resulted in more reliable conclusions in this study (Muthén & Muthén, 2002). In addition, variables which did not predict clinic attendance in this study but were hypothesised to, such as young adults' diabetes-related perceptions and behaviour, may have played a greater role if the sample size had been larger.

A larger sample size may also have facilitated the use of SEM to its full potential, for example by including the measurement of latent variables or unobserved variables (Byrne, 2010). Only one indicator of each component within the theory of clinic attendance was assessed in this study. However it is possible to include components of a theory as an unobserved variable in structural equation models, and assess that variable using more than one relevant measure, or indicator. More information regarding each variable could have been gained using this approach. The model used to test the theory of clinic attendance was a relatively simple path model to minimise the information demand associated with a more complex model, as the participants to parameter ratio would not have been reliable (Kline, 2005).

In study 3, young adults were recruited online and through diabetes clinics in the Republic of Ireland. Online recruitment was an important addition to the study due to the difficulty associated with recruiting young adults with type 1 diabetes. This is a relatively small group who are likely to be living away from home and may even be working, travelling

or studying abroad. Young adults were also recruited from seven Irish diabetes clinics. In most cases, the researcher recruited these young adults through a single visit to each centre. Recruiting through fewer clinics but over more than one visit may have been a more productive approach to recruitment. This way, the service providers would have become more familiar with the researcher and the recruitment criteria of the study, and may have been in a better position to support the recruitment process. In addition the researcher would have been more comfortable with the running of each clinic and the best way to approach the service providers and young adults.

Additional measurement issues may have limited the findings of study 3. For example, the measurement of opportunities for contact was created for this study based on the findings of study 2 and may need additional work in future research. The measurement tools used to assess diabetes self-care behaviour and diabetes-related distress are newly developed measures. As a result there was no information available regarding the reliability or validity of these measures which were shared with the researcher through correspondence. However, both measures addressed significant gaps in the measurement tools available as they were specific to type 1 diabetes and were up to date. Previous measures of diabetes self-care behaviour and diabetes-related distress were either out of date or contained questions which would be associated with type 2 diabetes. The progression in treatment for type 1 diabetes in recent years and differences between the management of type 1 diabetes and type 2 diabetes made it essential that a recent, specific tool was used. Despite public perception that the two conditions overlap, type 1 diabetes and type 2 diabetes are not related and assumptions that they are similar are inaccurate and insensitive. Therefore the use of these new measures contributed to this study by providing additional sensitivity to the measurement of the variables and a better fit between the items and the experiences of the participants.

Unprompted positive feedback was received from young adults who took part in this study related to the content of the questionnaire.

Young adults in this study were asked to respond to a number of questions related to clinic attendance behaviour, such as the number of appointments that had been scheduled for them in the previous two years. The purpose of this approach was to gain as much information related to clinic attendance behaviour as possible so that calculations could then be made to represent the attendance rates, rates of informal contact, and missed appointment rates for each participant. This approach was taken based on insights into potential complexities related to clinic attendance behaviour which emerged from study 1 and 2. The attendance rates of the participants in this study are in line with the attendance rates in previous research in which hospital records were used to measure clinic attendance (Johnson et al., 2014). However, the level of bias associated with self-report, particularly since participants were asked to remember a range of figures, cannot be estimated. It was necessary to rely on self-report in this study due to the fact that hospital records could not be obtained for the participants recruited online. As described in this study, hospital records related to clinic attendance behaviour may not reflect attendance and contact by young adults accurately. Therefore, self-reported clinic attendance behaviour may provide important insight into young adult's perceptions of clinic attendance behaviour which are valuable to intervention developers.

It is acknowledged that the cross-sectional design used in this study is a limitation as causal conclusions related to the influence of clinic attendance behaviour cannot be made. Future research using longitudinal designs should be conducted to understand the causal relationships within the theory of clinic attendance. However, since SEM is based on pre-specified relationships and a theoretical understanding of a phenomenon, the consistency with the data of causal assumptions can be assessed using this statistical approach (Byrne, 2010).

Forms of informal contact assessed in study 3 included contacts by telephone, email, text message, and by calling into the clinic without an appointment. These methods of contact were chosen based on the findings of study 2. However, contact through social media or smart phone applications, such as whatsapp, has emerged as a popular trend, but was not assessed in this study. Future studies should consider communication through social media and mobile technology by diabetes clinics with young adults.

6.12 Conclusions

The complexity of clinic attendance behaviour was not reflected in previous research, delaying progress in understanding and addressing low levels of clinic attendance among young adults. Clinic attendance behaviour should be understood in terms of attendance at scheduled appointments and informal contact by young adults, such as by telephone. Relationships between young adults and service providers predicted better attendance rates and more informal contact by young adults in this research. In addition, relationships between young adults and service providers appeared to facilitate developmentally appropriate service delivery. Future interventions designed to improve relationships between young adults and service providers by removing existing barriers to relationship development and supporting collaborative diabetes management may be most effective in improving clinic attendance behaviour. The findings of this study support the position that during the period of young adulthood, the success of diabetes services should be measured in terms of the relationships developed with young adults in addition to their clinical outcomes (Funnell & Anderson, 2004).

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Appendix A. EBSCO Medline search strategy

OVID MEDLINE SEARCH STRATEGY

S1: Diabetes AND adolescen* AND attendance

Retrieved: 134 articles

S2: Diabetes AND adolescen* AND non-attendance

Retrieved: 11 articles

S3: Diabetes AND adolescen* AND missed appointment*

Retrieved: 6 articles

S4: Diabetes AND young adult* AND attendance

Retrieved: 45 articles

S5: Diabetes AND young adult* AND non-attendance

Retrieved: 5 articles

S6: Diabetes AND young adult* AND missed appointment*

Retrieved: 3 articles

Appendix B. Quality assessment tool for quantitative studies reviewed

Critical Appraisal Skills Programme – Questions to help you make sense of a cohort study

	Yes	Can't tell	No
1. Is the study relevant to the review?			
2. Have the aims of the study clearly focused on explaining attendance among 15-30 year olds? - In terms of...			
- Population studied?			
- The outcomes considered?			
3. Are the aims of the study clearly stated?			

	Yes	Can't tell	No
4. Is the choice of study method appropriate (e.g. for the claims being made due to the cross-sectional nature of studies included)?			

	Yes	Can't tell	No
5. Is the population studied appropriate?			
- Was the sample representative of its target population?			
- If applicable: was an appropriate control group used?			
- How representative was the sample? (Number of hospitals/clinics, self-selection, contact with non-attenders)			

	Yes	Can't tell	No
6. Is confounding and bias considered?			
- Have all possible explanations of the effects been considered?			

- Did the study achieve a good response rate?			
- Were rigorous processes used to develop the questions (piloted/validated measures)?			

	Yes	Can't tell	No
7. Was follow-up/period of measurement long enough to obtain a reliable measure of attendance?			
- Could the effect be temporary (of variables on attendance)?			
- Was follow-up sufficiently complete?			
- Was dose/response demonstrated? (Any comment on degree of association between a variable and attendance?)			

	Yes	Can't tell	No
8. Are tables/graphs adequately labelled & understandable?			
- Comment on author's choice and use of statistical methods, if employed?			
- Are the authors confident in the study design, power etc?			
- What are the findings of this piece of research?			

Appendix C: Quality assessment criteria for qualitative studies

Criteria	Definition	Notes
Report explicit scientific context and purpose	Is it specified where the study fitted within relevant literature, and the intended aims or questions of the study?	
Situating the sample	Did the researchers describe the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant?	
Appropriate methods	Are the methods and procedures used appropriate or responsive to the intended purposes or questions of the study?	

Sampling	Did the researchers provide adequate information regarding a) the sample, b) recruitment and c) the suitability of sampling for the methodology used?	
Specification of methods	Did authors report all procedures for gathering data, including specific questions posed to participants? Did authors specify ways they organized the data and methods of analysis?	
Clarity of presentation	Is the manuscript well organised and clearly written, with technical terms defined?	
Participant characteristics which may have been influential	Did authors consider characteristics such as duration of diabetes, treatment modality,	

	attendance patterns, glycaemic control, developmental issues, work/education status?	
Grounded in the data – inclusion of examples	Did authors make reference to and provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them?	
Providing credibility checks	Are credibility checks provided where relevant such as member checking, using multiple qualitative analysts, comparing 2 or more varied qualitative perspectives, reference to reflective practice, triangulation with external factors (e.g. outcome) or quantitative data?	

Coherence	Are understandings represented in a way that achieved coherence and integration while preserving nuances in the data?	
Appropriate discussion	Are the data and understandings derived from them discussed in terms of their contribution to theory, content, method and/or practical domains, with limitations acknowledged?	

Appendix D: Participant information and consent form (Young adults)



Improving outcomes for young adults with type 1 diabetes

Participant Information Sheet

Research Team:

Lisa Hynes (*PhD candidate in Psychology & Health*)

Dr Molly Byrne (*School of Psychology, NUI, Galway, academic supervisor*)

Dr Sean Dinneen (*Young Adult Diabetes Service, UHG, clinical supervisor*)

Please take your time to read this information form about the study before you decide whether or not you want to take part.

This form will tell you:

- Why the study is being done and what you need to know about it
- What you will be asked to do if you decide to take part

Study title – *What are the barriers and facilitators to attending diabetes clinic appointments?*

It is important you understand why this study is being done and what you will be asked to do. Please take your time reading this form and do not hesitate to contact me if you have any questions or queries. Contact details can be found at the end of this form.

Why is this study being done?

There can be ups and downs in life with type 1 diabetes. Day-to-day activities must be managed differently for people with diabetes, so at a time when life is busy enough, the years from secondary school to the age of 30 can really challenge young adults with diabetes and the health care staff who work with them.

This study is being done to talk about the views and experiences of the people using and working in the young adult diabetes clinic in University Hospital, Galway.

Do I have to take part?

It is your decision to take part in this study or not. You can decide not to take part or you can withdraw from the study at any time and without giving a reason. Your decision will be private, and will not be discussed with anyone.

What does taking part involve?

If you decide to take part in this study, you will be invited to be interviewed by the researcher in the diabetes outpatient clinic in UHG, over the telephone or at another location of your choice, such as your home. This interview will last about 30 minutes to one hour and will

involve the researcher asking you some questions about your life, what it is like to have diabetes, your opinions about going to the young adult diabetes clinic and dealing with doctors, nurses and dieticians. You will only be asked to talk about things you are comfortable with. These interviews will be recorded using a tape recorder.

What are the possible benefits of taking part?

Taking part in this study may give you a chance to express your opinions as a young adult with type 1 diabetes. By expressing your opinions, you are providing information that this research team will study to develop ideas which may improve services and resources for young adults with type 1 diabetes.

What are the possible risks of taking part?

The most important thing is that you understand what this study is about and are sure that you are happy to take part if that is what you decide. We would like to assure you that we are available to answer any questions and provide information if it is appropriate.

Things may come up in the interview that cause you distress. If that happens we urge you to contact the research team and support can be provided for you through the diabetes service.

What happens at the end of the study?

The information we get from the participants in this study will be put together and examined. A summary of the findings of the study will be made available to all participants. The results of this study may be published but you will not be identified in any way.

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the secretary of Dr Shaun O’Keeffe, chairperson of the University Hospital, Galway Research Ethics Committee.

Phone: 091 775022 E-mail: Colette.collins@hse.ie

Will my information be confidential?

All information collected about you during the course of this research will be kept strictly confidential and will not be shared with anyone else. The information will be stored securely and in a way that protects your identity.

We would like to thank you for taking the time to read this information, and to remind you that we are happy to answer any questions you may have. Also, remember you are free to decline to take part in this study or to change your mind at any time without consequences or questions. Please hold on to this information form.

Contact details:

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NUI Galway
OÉ Gaillimh



Galway University Hospitals
Ospidéal na h-Ollscoile Gaillimh
UNIVERSITY HOSPITAL GALWAY
MERLIN PARK UNIVERSITY HOSPITAL

Consent form

Thank you for reading the information sheet about this study. If you are happy to be interviewed and for this information about you to be recorded, typed and analysed then, please complete and sign the form below. Thank you!

Please write your initials in the boxes below if you agree with each statement:

1. I have read the Participant Information Sheet and have been given a copy to keep. I have been given an opportunity to ask questions about the project and I understand why this study is being conducted.	
2. I understand that my participation is voluntary that I am free to withdraw my consent at any time without necessarily giving a reason and without my medical treatment or legal rights being affected.	
3. I understand that if I withdraw consent at any time that the data I have already provided will be maintained unless I specifically request that it is deleted.	
4. I am willing to participate in either one-to-one interviews or interviews carried out over the telephone where the interviews will be tape recorded.	
5. I understand that all information I give will be stored securely and will not be used or released in such a way that I could be identified.	
6. I agree that the information gathered about me can be used for future research.	
7. I agree that my interview data can be linked to basic information held on the hospital's Electronic Patient Record such as gender, date of birth, HbA _{1c} results, clinic attendance and length of time since diagnosis with type 1 diabetes.	

..... / /

Name of Participant (CAPITALS) Signature

Date

E-mail: _____ **Phone:** _____

(So that I can be in contact to organise your interview)

Appendix E: Participant information and consent form (Service providers)



NUI Galway
OÉ Gaillimh



Galway University Hospitals
Ospidéal na h-Ollscoile Gaillimh
UNIVERSITY HOSPITAL GALWAY
MERLIN PARK UNIVERSITY HOSPITAL

School of Psychology, National University of Ireland, Galway

& Endocrinology and Diabetes Centre, University Hospital Galway.

Galway Managing Diabetes Together Study

Participant Information and Consent Form

Research Team:

Lisa Hynes (*PhD candidate in Psychology & Health*)

Dr Molly Byrne (*School of Psychology, NUI, Galway, academic supervisor*)

Dr Sean Dinneen (*Young Adult Diabetes Service, UHG, clinical supervisor*)

Please take your time to read this information form about the study before you decide whether or not you want to take part.

This form will tell you:

- Why the study is being done
- What you will be asked to do if you decide to take part.

Study title - Living with Type 1 Diabetes: The views of young adults & health care staff.

It is important you understand why this study is being done and what you will be asked to do. Please take your time reading this form and do not hesitate to contact me if you have any questions or queries. Contact details can be found at the end of this form.

Why is this study being done?

There can be ups and downs in life with type 1 diabetes. Day-to-day activities which must be managed differently for people with diabetes, so at a time when life is busy enough, the years from secondary school to the age of 30 can really challenge young adults with diabetes and the health care staff who work with them.

This study is being done to talk about the views and experiences of the people using and working in the Young Adult Diabetes Service in University Hospital, Galway.

Do I have to take part?

It is your decision to take part in this study or not. You can decide not to take part or you can withdraw from the study at any time and without giving a reason. Your decision will be private, and will not be discussed with anyone.

What does taking part involve?

If you decide to take part in this study, you will be invited to be interviewed by the researcher in the diabetes outpatient clinic in UHG, over the telephone or at another location of your choice, such as your home. This type of interview lasts about 30 minutes to one hour and will involve the researcher asking you some questions about your job, your experience working with young adults with diabetes and your opinions about the Young Adult Diabetes clinic. You will only be asked to talk about things you are comfortable with. These interviews will be recorded using a tape recorder.

What are the possible benefits of taking part?

Taking part in this study may give you a chance to express your opinions as a health care professional working with young adults with type 1 diabetes. By expressing your opinions, you are providing information that this research team will study to develop ideas which may improve services and resources for young adults with type 1 diabetes.

What are the possible risks of taking part?

The most important thing is that you understand what this study is about and are sure that you are happy to take part if that is what you decide. We would like to assure you that we are available to answer any questions and provide information if it is appropriate.

What happens at the end of the study?

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If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the secretary of Dr Shaun O’Keeffe, chairperson of the University Hospital, Galway Research Ethics Committee.

Phone: 091 775022

E-mail: Colette.collins@hse.ie

Will my information be confidential?

All information collected about you during the course of this research will be kept strictly confidential and will not be shared with anyone else. The information will be stored securely and in a way that protects your identity.

We would like to thank you for taking the time to read this information, and to remind you that we are happy to answer any questions you may have. Also, remember you are free to decline to take part in this study or to change your mind at any time without consequences or questions. Please hold on to this information form

Contact details:

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NUI Galway
OÉ Gaillimh



Galway University Hospitals
Ospidéal na h-Ollscoile Gaillimh
UNIVERSITY HOSPITAL GALWAY
MERLIN PARK UNIVERSITY HOSPITAL

Consent Form for Staff

Thank you for reading the Participant Information Sheet about this study. If you are happy to be interviewed and for this information about you to be recorded, typed and analysed then, please complete and sign the form as below.

Please initial the boxes below if you agree with each statement:

8. I have read the “Living with Type 1 Diabetes: The views of young adults & health care staff” Participant Information Sheet and have been given a copy to keep. I have been given an opportunity to ask questions about the project and I understand why this study is being conducted.	
9. I understand that my participation is voluntary that I am free to withdraw my consent at any time without giving a reason.	
10. I understand that if I withdraw consent at any time that the data I have already provided will be maintained unless I specifically request its deletion.	
11. I am willing to participate in either one-to-one interviews or interviews carried out over the telephone where the interviews will be tape recorded.	
12. I understand that all information I give will be stored securely and will not be used or released in such a way that I could be identified.	
13. I agree that the information gathered about me can be used for future research.	

..... /

Name of Participant (CAPITALS)

Signature

Date

Phone: **E-mail:**

(Please provide your contacts details so your interview can be arranged)

Appendix F: Participant information for adolescents under 18 years



NUI Galway
OÉ Gaillimh



Galway University Hospitals
Ospidéal na h-Ollscoile Gaillimh
UNIVERSITY HOSPITAL GALWAY
MERLIN PARK UNIVERSITY HOSPITAL

School of Psychology, National University of Ireland &

Endocrinology and Diabetes Centre, University Hospital Galway

Galway Managing Diabetes Together Study Information

Research Team:

Lisa Hynes (*PhD candidate in Psychology & Health*)

Dr Molly Byrne (*School of Psychology, NUI, Galway, academic supervisor*)

Dr Sean Dinneen (*Young Adult Diabetes Service, UHG, clinical supervisor*)

Please take your time to read this information form about the study before you decide whether or not you want to take part.

Study title - Living with Type 1 Diabetes: The views of young adults & health care staff.

It is important you understand why this study is being done and what you will be asked to do. Please take your time reading this form and do not hesitate to contact me if you have any questions or queries. Contact details can be found at the end of this form.

Why is this study being done?

There can be ups and downs in life with type 1 diabetes. So at a time when you are busy enough, the years from secondary school to the age of 30 can be a real challenge for young adults with diabetes and the health care staff who work with them.

This study is being done to talk about the views and experiences of the people using and working in the Young Adult Diabetes Service in University Hospital, Galway.

Do I have to take part?

It is your decision to take part in this study or not. You can decide not to take part or you can withdraw from the study at any time and without giving a reason. Your decision will be private, and will not be discussed with anyone.

What does taking part involve?

If you decide to take part in this study, you will be invited to be interviewed by the researcher in the National University of Ireland, Galway, the diabetes outpatient clinic in UHG, over the telephone or at another location of your choice, such as your home. This type of interview lasts about 30 minutes to one hour and will involve the researcher asking you some questions about your life, what it is like to have diabetes, your opinions about going to the Young Adult Diabetes clinic and dealing with doctors, nurses and dieticians. You will only be asked to talk about things you are comfortable with. These interviews will be recorded using a tape recorder.

What are the possible benefits of taking part?

Taking part in this study may give you a chance to express your opinions as a young adult with type 1 diabetes. By expressing your opinions, you are providing information that this research team will study to develop ideas which may improve services and resources for young adults with type 1 diabetes.

What are the possible risks of taking part?

The most important thing is that you understand what this study is about and are sure that you are happy to take part if that is what you decide. We would like to assure you that we are available to answer any questions and provide information if it is appropriate.

Things may come up in the interview that cause you distress. If that happens we urge you to contact the research team and support can be provided for you through the Young Adult Diabetes Service.

What happens at the end of the study?

The information we get from the participants in this study will be put together and examined. A summary of the findings of the study will be made available to all participants. The results of this study may be published but you will not be identified in any way.

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the secretary of Dr Shaun O’Keeffe, chairperson of the University Hospital, Galway Research Ethics Committee.

Phone: 091 775022

E-mail: Colette.collins@hse.ie

Will my information be anonymous?

All information collected about you during the course of this research will be kept strictly anonymous and your participation in the study will be private. The information will be stored securely and in a way that protects your identity.

Finally, it is your decision to take part in this study or not, but as you are younger than 18, your parent or guardian will also be asked to read this information and think about your decision with you.

If the researcher believes that you are in immediate danger because of something that was said in your interview, it is the law that this information must be passed on to someone who can help you, like the Gardaí.

We would like to thank you for taking the time to read this information, and to remind you that we are happy to answer any questions you may have. Also, remember you are free to decline to take part in this study or to change your mind at any time without consequences or questions. Please hold on to this information form

Contact details:

Lisa Hynes,
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St Anthony’s, NUI, Galway.
Phone – 086 1614812
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School of Psychology,
St Anthony’s, NUI, Galway.
Phone – 091 - 495182
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Appendix G: Participant information for parents of adolescents under 18 years



National University of Ireland, Galway

School of Psychology

Galway Managing Diabetes Together Study

Parent/guardian Information and Consent Form

Research Team:

Lisa Hynes (*PhD candidate in Psychology & Health*)

Dr Molly Byrne (*School of Psychology, NUI, Galway, academic supervisor*)

Dr Sean Dinneen (*Young Adult Diabetes Service, UHG, clinical supervisor*)

Please take your time to read this information form about the study before you talk to your child and decide whether or not they want to take part.

This form will tell you:

- Why the study is being done
- What your child will be asked to do if he or she decides to take part.

Study title - Living with Type 1 Diabetes: The views of young adults & health care staff.

It is important you understand why this study is being done and what your child will be asked to do. Please take your time reading this form and do not hesitate to contact me if you have any questions or queries. Contact details can be found at the end of this form.

Why is this study being done?

There can be ups and downs in life with type 1 diabetes. Day-to-day activities which must be managed differently for people with diabetes, so at a time when life is busy enough, the years from secondary school to the age of 30 can really challenge young adults with diabetes and the health care staff who work with them.

This study is being done to talk about the views and experiences of the people using and working in the Young Adult Diabetes Service in University Hospital, Galway.

Do I have to take part?

It is your child's decision to take part in this study or not. Together, you can decide not to take part or he or she can withdraw from the study at any time and without giving a reason. The decision will be private, and will not be discussed with anyone.

What does taking part involve?

If your child decided to take part in this study, he or she will be invited to be interviewed by the researcher in the diabetes outpatient clinic in UHG, over the telephone or at another location, such as your home. This type of interview lasts about 30 minutes to one hour and will involve the researcher asking some your child some questions about his or her life, what it is like to have diabetes, opinions about going to the Young Adult Diabetes clinic and dealing with doctors, nurses and dieticians. Your child will only be asked to talk about things they are comfortable with. These interviews will be recorded using a tape recorder.

What are the possible benefits of taking part?

Taking part in this study may give your child a chance to express his or her opinions as a young adult with type 1 diabetes. By expressing their opinions, your child is providing information that this research team will study to develop ideas which may improve services and resources for young adults with type 1 diabetes.

What are the possible risks of taking part?

The most important thing is that you understand what this study is about and are sure that you are happy for your child to take part if that is what you decide together. We would like to assure you that we are available to answer any questions and provide information if it is appropriate.

Things may come up in the interview that causes your child distress. If that happens we will urge him or her to contact the research team and support can be provided through the Young Adult Diabetes Service.

What happens at the end of the study?

The information we get from the participants in this study will be put together and examined. A summary of the findings of the study will be made available to all participants. The results of this study may be published but your child will not be identified in any way.

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the secretary of Dr Shaun O’Keeffe, chairperson of the University Hospital, Galway Research Ethics Committee.

Phone: 091 775022

E-mail: Colette.collins@hse.ie

Will my information be confidential?

All information collected about your child during the course of this research will be kept strictly confidential and will not be shared with anyone else. The information will be stored securely and in a way that protects your identity.

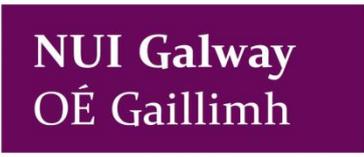
We would like to thank you for taking the time to read this information, and to remind you that we are happy to answer any questions you may have. Also, remember your child is free to decline to take part in this study or to change is or her mind at any time without consequences or questions. Please hold on to this information form

Contact details:

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Appendix H: Participant assent and parent consent form



Galway University Hospitals
Ospidéal na h-Ollscoile Gaillimh
 UNIVERSITY HOSPITAL GALWAY
 MERLIN PARK UNIVERSITY HOSPITAL

Parent Consent & Young Adult Assent form

Thank you for reading the Research Information Sheet about this study. If you are happy to be interviewed and for this information about you to be recorded, typed and analysed then, please complete and sign the form as below. Both participant and parent must read and sign this form, and return it to me in the stamped addressed envelope provided. Thank you!

Please initial the boxes below if you agree with each statement:

14. I have read the “Living with Type 1 Diabetes: The views of young adults & health care staff” Participant Information Sheet and have been given a copy to keep. I have been given an opportunity to ask questions about the project and I understand why this study is being conducted.	
15. I understand that my participation is voluntary that I am free to withdraw my consent at any time without necessarily giving a reason and without my medical treatment or legal rights being affected.	
16. I understand that if I withdraw consent at any time that the data I have already provided will be maintained unless I specifically request that it is deleted.	
17. I am willing to participate in either one-to-one interviews or interviews carried out over the telephone where the interviews will be tape recorded.	
18. I understand that all information I give will be stored securely and will not be used or released in such a way that I could be identified.	
19. I agree that the information gathered about me can be used for future research.	
20. I agree that my interview data can be linked to basic information held on the hospital’s Electronic Patient Record such as gender, date of birth, HbA _{1c} results, clinic attendance and length of time since diagnosis with type 1 diabetes.	

.....

___/___/___

Name of Participant (CAPITALS) Signature

Date

Appendix I: Example of a memo

The following passage is an example of a memo aiming to understand the role of informal contact between young adults and service providers in the diabetes clinic:

Casual contact is an important concept. It's not officially monitored so it's totally overlooked as a resource when in fact it is vital. Its purpose is instrumental and perceptual. Young adults get a lot out of just popping in or calling up with issues that can't wait until their next appointment or would otherwise be resolved by young adults themselves but without guidance and possibly incorrectly. But even more importantly, the knowledge that they have this relationship with staff and could access help in person or by phone or email anytime is hugely important and appreciated by young adults. This is the core of the potential for a 'supportive accountability' model to be appropriate here. But why do some young adults not take advantage of the opportunities for casual contact even though they all know it's there?

Appendix J: Example of use of the paradigm

Causal Conditions	Intervening Conditions	Strategy	Consequences	Core Category	Context
-Cause the Core Category	-Broad and specific situational factors that influence strategy	-Actions taken in response to the Core Category	-Outcomes from using Strategy	-All categories fit around this	-Broad and specific situational factors that influence strategy
Major events	Diabetes-related variables	Engagement	Attendance	Alliance	Clinic factors
<i>-DAFNE</i>					<i>-Continuity of care</i>
<i>-Transition</i>	<i>-Control</i>				<i>-Routine</i>
<i>-Starting insulin pump therapy</i>	<i>-Diagnosis story</i>				<i>-Services offered, like screening & support</i>
<i>-Experiencing serious lows and highs</i>	<i>-Learning through experience</i>				<i>-Communications</i>
	<i>-Transitions</i>				<i>-Intervals between appointments</i>

Perceptions of attendance

-Clinic functions

-Fear of deterioration

-It makes a difference

-Staff are always there

-Value

Wellbeing

-Acceptance and

adaptation

-Battle with yourself

Normal development

-Responsibility

-Age-related activities

-Independent or alone?

Support

-Staff

-Friends

-Family

-Diabetes Ireland

-Needs

-Authority

Appendix K: Questionnaire

Your Diabetes Clinic Study - Welcome!

Welcome to this questionnaire about your experience with type 1 diabetes, and health services for diabetes care. Thank you for agreeing to take part in this study.

Please provide the answer which is best for you, to each question. This is not a test. Please be as honest as you can when you are completing this questionnaire. Your responses will be confidential. Nobody from outside the research team will see them.

The first section asks for some information about you. This information will be stored separately and securely and you will be not asked to provide your name.

1. What age are you in years?

2. What is your gender?

Female

Male

3. What county do you live in?

4. What is your current living situation?

Living with parent(s) or guardian(s)

Living alone

Living with a friend(s)

Living with a spouse or partner

Living in college/university residence

Other (please specify)

5. What is the highest educational qualification that you have? Please tick one.

No qualifications

Completed secondary or high school

Diploma

Undergraduate degree

Postgraduate degree

Other (please specify)

6. What is your employment status?

In full time employment

In part time employment

Looking after house/family

Student

Student in part time employment

Unemployed

Other (please specify)

7. For how many years have you had type 1 diabetes? Please estimate if you are not sure.

8. What kind of treatment are you currently using for your type 1 diabetes? Please tick the option which applies to you right now.

Multiple Daily Insulin Injections

Insulin pump

Twice daily insulin

Basal/bolus insulin

Other (please specify)

9. Do you have any other physical or psychological diagnosis apart from type 1 diabetes?

Yes

No

I would prefer not to say

If yes, can you please specify?

10. What kind of clinic do you, or have you attended for your diabetes since you turned 18?

Young adult diabetes clinic

Adult diabetes clinic

Other

If other, please specify the type of clinic

[Have you answered each question on this page? Please try to answer every question, or as many as you can.](#)

Visiting the diabetes clinic

The next section asks you about the interactions you have with the diabetes clinic. Please provide the answer you think is correct, even if you are not sure.

11. How many times have you attended a scheduled appointment in the clinic in the last two years?

12. How many appointments were scheduled for you in the last two years?

13. How many scheduled appointments did you **not** attend in the last two years?

14. How many appointments did you reschedule in the last two years?

15. How many times have you called into the clinic unscheduled in the last two years?

16. How many times have you contacted the clinic by telephone in the last two years?

17. How many times have you contacted the clinic by email in the last two years?

18. How many times have you contacted the clinic by text message in the last two years?

Have you answered each question on this page? Please try to answer every question, or as many as you can. Remember your responses are anonymous and confidential!

Your experiences with the diabetes clinic

The following questions ask about your experiences with your diabetes clinic, and the hospital that your clinic is linked to, or part of.

19. Have you ever been admitted to the hospital overnight with a problem caused by your diabetes?

Yes

No

Not sure

20. Have you ever been admitted to the hospital overnight with a problem which affected your diabetes?

Yes

No

Not sure

21. Have you ever attended an education programme delivered in your diabetes clinic?

Yes

No

Not sure

If yes, what was the course called, and in what year did you attend the course?

22. Have you ever experienced something out of the ordinary, in relation to your diabetes, like a number of episodes of hypoglycemia, which meant you were in contact with the staff of the diabetes clinic more often than normal?

Yes

No

Not sure

If yes, please provide additional information, if you would like:

Members of staff in the diabetes clinic

The next section asks you to think about at least one member of staff that you meet in your diabetes clinic.

Below is a list of statements about experiences people might have with the staff in the diabetes clinic. Some items refer directly to a member of staff, with an underlined space. So, as you read the sentences, mentally insert the name of the member of staff in place of _____ in the text. Think about your experience in the diabetes clinic, and decide which category best describes your own experience. Please tick one option for each statement.

23. Think about your experience in the diabetes clinic, and decide which category best describes your experience.

	Seldom	Sometimes	Fairly often	Very often	Always
What I am doing in the diabetes clinic gives me new ways of looking at my diabetes.					
As a result of visits to the clinic, I am clearer as to how I might be able to change.					
___ and I collaborate on setting goals for my care.					
I believe ___ likes me.					
___ and I respect each other.					
___ and I are working towards mutually agreed upon goals.					
I feel that ___ appreciates me.					
_____ and I agree on what is important for me to work on.					
I feel _____ cares about me even when I do things that he/she does not approve of.					
I feel that the things I do in the diabetes clinic will help me to accomplish the changes that I want.					
_____ and I have established a good understanding of the kind of changes that would be good for me.					
I believe the way we (you and the staff in the diabetes clinic) are working with my diabetes is correct.					

Have you answered each question on this page? Please try to answer every question, or as many as you can.

Living with type 1 diabetes - 1. Diabetes self-care

Great, you have finished the first section of this questionnaire! Thank you!

The next 5 sections are about what it's like for you to live with type 1 diabetes. The sections are: Diabetes self-care; Managing diabetes; Thoughts about diabetes; Control over your behaviour; and Everyday support. Please continue to answer every question as best you can.

In this section you will be asked about how you manage your diabetes.

Please think about what you are doing at the moment. There may have been times in the past when your answers would have been different. We are interested in how you are looking after your diabetes now.

24. Self-care as part of your lifestyle - Monitoring blood glucose

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always	This does not apply to me
I check my blood glucose more regularly when I feel stressed						
I check my blood glucose more regularly if my weight starts to go up or down						
I adjust my insulin if my weight starts to go up or down						

25. When I am feeling very unwell, e.g. flu, infection...

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always	This does not apply to me
...I check my ketone levels whatever my blood glucose levels are						
...I check my ketone levels when my blood glucose is higher than normal						
...I adjust my insulin						

Living with type 1 diabetes - 1. Diabetes self-care

For the following questions, please think about what you have done over the last 2 weeks. If the last 2 weeks have not been typical for you, for example, you have been ill or on holiday, please think about the 2 weeks before that.

26. Checking and recording blood glucose levels

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always
I checked my blood glucose before meals					
I carried my blood glucose meter with me					
I check my blood glucose when I am physically active e.g. walking, gardening					
I wash my hands before checking my blood glucose					
I check my blood glucose before going to bed					
I check my blood glucose on waking to make sure my long-acting (background) insulin dose is right					

27. Please think about a time when your blood glucose was low

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always
I check my blood glucose if I think I am having a hypo					
I check my blood glucose soon after treating a hypo					

28. Counting carbohydrates – Over the last 2 weeks...

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always
I counted the carbohydrates I ate					

29. On average, over the last 2 weeks, how many times have you checked your blood glucose each day?

0	1	2	3	4	5	6	7 or more

Have you answered each question on this page? Please try to answer every question, or as many as you can.

Living with type 1 diabetes - 1. Diabetes self-care

30. To help me count carbohydrates...

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always
...I weighed food					
...I guessed					
...I read food labels					
...I used information leaflets, books, internet sources e.g. Google, smart phone applications etc.					
...I looked at the food on my plate					
...I looked at pictures of food portions					

31. Taking insulin – Over the last 2 weeks...

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always
I adjusted my quick-acting insulin according to the carbohydrates I was eating					
I took the right amount of quick-acting insulin for snacks that I ate					

32. Did you do anything to help you work out how much quick-acting insulin to take?

	Never	Rarely, about 25% of the time	Sometimes, about 50% of the time	Often, about 75% of the time	Always
Over the last 2 weeks, to help me work out how much quick-acting insulin to take, I used a pump/pump wizard/bolus calculator					

Have you answered each question on this page? Please try to answer every question, or as many as you can. There are no wrong answers. We are interested in your opinions and experiences.

Living with type 1 diabetes – 2. Managing your diabetes

There can be different reasons why people behave in healthy ways, for example taking medication, checking blood glucose, following a diet or exercising regularly. Please consider the following behaviours and indicate with a tick how true each of these reasons are for you.

33. I take my insulin and check my blood glucose because:

	Not at all true 1	2	3	Somewhat true 4	5	6	Very true 7
Other people would be mad at me if I didn't.							
I find it a personal challenge to do so.							
I personally believe that controlling my diabetes will improve my health.							
I would feel guilty if I didn't do what my doctor said.							
I want my doctor to think I'm a good patient.							
I would feel bad about myself if I didn't.							
It's exciting to try to keep my blood glucose in a healthy range.							
I don't want other people to be disappointed in me.							

Have you answered each question on this page? Please try to answer every question, or as many as you can.

Living with type 1 diabetes – 3. Thoughts about diabetes

You are about half way through the questionnaire! We very much appreciate you giving your time to do this.

This section asks you about how you feel about your diabetes, and the things that make it easier and more difficult to live with diabetes.

Please tick the option that gives the best answer for you to each statement.

34. In general, I believe that I:

	Strongly disagree	Somewhat disagree	Neutral	Somewhat agree	Strongly agree
...know what part(s) of taking care of my diabetes that I am dissatisfied with.					
...am able to turn my diabetes goals into a workable plan.					
...can try out different ways of overcoming barriers to my diabetes goals.					
...can find ways to feel better about having diabetes.					
...know the positive ways I cope with diabetes-related stress.					
...can ask for support for having and caring for my diabetes when I need it.					
...know what helps me stay motivated to care for my diabetes.					
...know enough about myself as a person to make diabetes care choices that are right for me.					

Have you answered each question on this page? Please try to answer every question, or as many as you can.

Living with type 1 diabetes – 3. Thoughts about diabetes

For the following questions, please tick the box below the number that best corresponds to your views.

35. How much does your diabetes affect your life?

No affect at all 0	1	2	3	4	5	6	7	8	9	Severely affects my life 10

36. How long do you think your diabetes will continue?

A very short time 0	1	2	3	4	5	6	7	8	9	Forever 10

37. How much control do you feel you have over your diabetes?

Absolutely no control 0	1	2	3	4	5	6	7	8	9	Extreme amount of control 10

38. How much do you think your treatment can help your diabetes?

Not at all 0	1	2	3	4	5	6	7	8	9	Extremely helpful 10

39. How much do you experience symptoms from your diabetes?

No symptoms at all 0	1	2	3	4	5	6	7	8	9	Many severe symptoms 10

Living with type 1 diabetes – 3. Thoughts about diabetes

40. How concerned are you about your diabetes?

Not at all concerned 0	1	2	3	4	5	6	7	8	9	Extremely concerned 10

41. How well do you feel you understand your diabetes?

Don't understand at all 0	1	2	3	4	5	6	7	8	9	Understand very clearly 10

42. How much does your diabetes affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

Not at all affected emotionally 0	1	2	3	4	5	6	7	8	9	Extremely affected emotionally 10

43. Please list in rank-order the three most important factors you believe cause your diabetes.

1.
2.
3.

Have you answered each question on this page? Please try to answer every question, or as many as you can, with the answer which is best for you.

Living with type 1 diabetes – 3. Thoughts about diabetes

This section asks you about some of the areas of having and managing diabetes that can cause problems. Living with type 1 diabetes can be tough. Listed below are a variety of distressing things that many people with type 1 diabetes experience. Thinking back over the past month, please indicate the degree to which each of the following may have been a problem for you by ticking the most appropriate option. For example, if you feel that a particular item was not a problem for you over the past month, you would tick under 'Not a problem'. If it was very tough for you over the past month, you might tick under 'A very serious problem'.

44. Thinking back over the past month, please indicate the degree to which each of the following may have been a problem for you by ticking the appropriate number.

	Not a problem 1	A slight problem 2	A moderate problem 3	A somewhat serious problem 4	A serious problem 5	A very serious problem 6
Feeling that I am not as skilled at managing diabetes as I should be.						
Feeling that I don't eat as carefully as I probably should.						
Feeling that I don't notice the warning signs of hypoglycemia as well as I used to.						
Feeling that people treat me differently when they find out I have diabetes.						
Feeling discouraged when I see high blood glucose numbers that I can't explain.						
Feeling that my family and friends make a bigger deal out of diabetes than they should.						
Feeling that I can't tell my diabetes doctor what is really on my mind.						
Feeling that I am not taking as much insulin as I should.						
Feeling that there is too much diabetes equipment and stuff I must always have with me.						
Feeling like I have to hide my diabetes from other people.						
Feeling that my friends and family worry more about hypoglycemia than I want them to.						

45. Please continue to think back over the past month, and indicate the degree to which each of the following may have been a problem for you by ticking the option that best describes how you feel.

	Not a problem 1	A slight problem 2	A moderate problem 3	A somewhat serious problem 4	A serious problem 5	A very serious problem 6
Feeling that I don't check my blood glucose level as often as I probably should.						
Feeling worried that I will develop serious long term complications, no matter how hard I try.						
Feeling that I don't get the help I really need from my diabetes doctor about managing diabetes.						
Feeling frightened that I could have a serious hypoglycaemic event when I'm asleep.						
Feeling that thoughts about food and eating control my life.						
Feeling that my friends or family treat me as if I were more fragile or sicker than I really am.						
Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.						
Feeling concerned that diabetes may make me less attractive to employers.						
Feeling that my friends or family act like "diabetes police" (bother me too much).						
Feeling that I've got to be perfect with my diabetes management.						

46. Please continue to think back over the past month, and indicate the degree to which each of the following may have been a problem for you by ticking the option that best describes how you feel.

	Not a problem 1	A slight problem 2	A moderate problem 3	A somewhat serious problem 4	A serious problem 5	A very serious problem 6
Feeling frightened that I could have a serious hypoglycaemic event while driving.						
Feeling that my eating is out of control.						
Feeling that people will think less of me if they knew I had diabetes.						
Feeling that no matter how hard I try with my diabetes, it will never be good enough.						
Feeling that my diabetes doctor doesn't know enough about diabetes and diabetes care.						
Feeling that I can't ever be safe from the possibility of a serious hypoglycaemic event.						
Feeling that I don't give my diabetes as much attention as I probably should.						

Have you answered each question on this page? Please try to answer every question, or as many as you can. You're doing great!

Living with type 1 diabetes – 4. Control over your behaviour

The following statements relate to the amount of self-control you have over your behaviour in general.

47. Using the scale from 1 to 5, please indicate by ticking below the appropriate number, how much each of the following statements reflects how you typically are.

	Not at all 1	2	3	4	Very much 5
I am good at resisting temptation.					
I have a hard time breaking bad habits.					
I am lazy.					
I say inappropriate things.					
I do certain things that are bad for me, if they are fun.					
I refuse things that are bad for me.					
I wish I had more self-discipline.					
People would say that I have iron self-discipline.					
Pleasure and fun sometimes keep me from getting work done.					
I have trouble concentrating.					
I am able to work effectively towards long-term goals.					
Sometimes I can't stop myself from doing something, even if I know it's wrong.					
I often act without thinking through all the alternatives.					

Have you answered each question on this page? Please try to answer every question, or as many as you can.

Living with type 1 diabetes – 5. Everyday support

The following questions ask about people in your environment who provide you with help or support. People sometimes look to others for companionship, assistance or other types of support. Please tick one option for each question.

48. If you needed it, how often is someone available...

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
to have a good time with?					
to help with daily tasks if you were sick?					
to help you if you were confined to bed?					
to love and make you feel wanted?					
to take you to the doctor if you need it?					
to turn to for suggestions about how to deal with a personal problem?					
to prepare your meals if you are unable to do it yourself?					
who understands your problems?					

49. Please rate how satisfied you are, in general, with the support you have from each of the three sources below.

	Very dissatisfied	Fairly dissatisfied	A little dissatisfied	A little satisfied	Fairly satisfied	Very satisfied	N/A
Your family							
Your friends							
Your boyfriend/ girlfriend							

Have you answered each question on this page? Please try to answer every question, or as many as you can. You're nearly finished!

Satisfaction with the diabetes clinic

This is the last section! Thanks again for your time.

In this section, you will be asked about your satisfaction with your diabetes clinic.

50. Please answer the questions below by ticking the response from 1 to 7 that best describes your views regarding your relationship with the diabetes clinic staff about your diabetes.

	Strongly disagree 1	Moderately disagree 2	Slightly disagree 3	Neutral 4	Slightly agree 5	Moderately agree 6	Strongly agree 7
I feel that I am provided with choices and options about my health by the diabetes clinic staff.							
I feel that the diabetes clinic staff understand how I see things with respect to my health.							
The diabetes clinic staff convey confidence in my ability to make changes regarding my health.							
The diabetes clinic staff encourage me to ask questions.							
The diabetes clinic staff listen to how I would like to do things regarding my health.							
The diabetes clinic staff try to understand how I see my health before suggesting any changes.							

Have you answered each question on this page? Please try to answer every question, or as many as you can.

Satisfaction with the diabetes clinic

The following questions will ask you to rate how satisfied you are with the practical things in your diabetes clinic, like how long you are waiting.

51. How would you rate the registration process when you arrive at the clinic for your appointment?

	Poor	Fair	Good	Very good	Excellent
The registration process (e.g. simple, quick etc.)					
Attitude of the administrative staff					
Privacy					
Quality of the waiting area					
Waiting time at the clinic					
Canteen or refreshment facilities					

52. Please rate each of the following elements of the diabetes clinic.

	Very poor	Poor	Average	Good	Very good
Overall, how good do you think the medical care is in the diabetes clinic?					
Overall, how good do you think the nursing care is in the diabetes clinic?					
Overall, how good do you think the running of the diabetes clinic is?					

53. Overall, how satisfied are you with the diabetes clinic?

Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied

Have you answered each question on this page? Please try to answer every question, or as many as you can.

You're finished! Thank you sincerely for giving your time to complete this questionnaire.

A summary of the findings of this study will be shared through our website, www.yourdiabetesclinic.wordpress.com in the near future.

Please do not hesitate to contact the researcher if you have any questions or comments after completing this questionnaire, or about this study.

Email: l.hynes2@nuigalway.ie

Is there anything you would like to add that you didn't get to say about your diabetes clinic in this questionnaire, or any comments about the questionnaire?

**Appendix L: Study 3 participant information (clinic and online) and consent forms
(clinic and online)**



School of Psychology, National University of Ireland, Galway

Understanding young adult's attendance at diabetes clinics

Research Team:

Lisa Hynes (*PhD candidate in Psychology & Health*)

Dr Molly Byrne (*Health Behaviour Change Research Group, School of Psychology, NUI, Galway, academic supervisor*)

Dr Sean Dinneen (*Endocrinologist, Young Adult Diabetes Clinic, University Hospital Galway, clinical supervisor*)

Please take your time to read this information form about the study before you decide whether or not you want to take part.

It is important you understand why this study is being done and what you will be asked to do. Please take your time reading this form and do not hesitate to contact me if you have any questions or queries. Contact details can be found at the end of this form.

Why is this study being done?

This study is going to improve our understanding of why young adults attend, or don't attend the diabetes clinic. We are not yet sure what exactly makes a good clinic or what can make young people miss appointments, or stop going to the clinic altogether. We need to know more about your views of the diabetes clinic to be able to make important changes and improvements.

Who can take part in this study?

Young adults with type 1 diabetes, aged between 18 and 30 years are invited to take part in this study.

Do I have to take part?

You do not have to take part in this study. The information in this form is intended to help you decide whether or not you would like to take part, but the decision is up to you. If you decide to take part and fill out the questionnaire, you are free to stop and leave the study, by not returning the questionnaire, at any point and without giving a reason.

What does taking part involve?

You will be asked to complete a questionnaire if you decide to take part in this study, which will take about 20 minutes to complete. Before you complete the questionnaire, please read and fill in the consent form which you will see at the beginning of the questionnaire. In the

questionnaire you will be asked to respond to questions regarding your diabetes, the things you do to take care of your diabetes, how you feel about having diabetes, how satisfied you are about the health service for diabetes care, and how often you go to appointments in the hospital.

What are the possible benefits of taking part?

Taking part in this study may give you a chance to share information about you as a young adult with type 1 diabetes, which this research team will study to develop ideas to improve services and resources for young adults with type 1 diabetes.

What are the possible risks of taking part?

The most important thing is that you understand what this study is about and are sure that you are happy to take part, if that is what you decide. We would like to assure you that we are available to answer any questions and provide information if we can.

Things may come up as you complete the questionnaire that cause you distress. If that happens to you, we urge you to contact us and we will assist you in accessing a support service.

What happens at the end of the study?

The information we get from the participants in this study will be put together and examined. At the end of this study we will send you a report describing what we find out. The results of this study may be published but you will not be identified in any way.

Will my information be anonymous?

The information you provide will be kept strictly anonymous and your participation in the study will be private. The information will be stored securely and in a way that protects your identity.

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact ethics@nuigalway.ie.

We would like to thank you for taking the time to read this information, and to remind you that we are happy to answer any questions you may have. Also, remember you are free to decline to take part in this study or to change your mind at any time without consequences or questions. Please hold on to a copy of this information form

Contact details:

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School of Psychology, National University of Ireland, Galway

Understanding young adult's attendance at diabetes clinics

Research Team:

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Things may come up as you complete the questionnaire that cause you distress. If that happens to you, we urge you to contact us and we will assist you in accessing a support service.

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The information we get from the participants in this study will be put together and examined. At the end of this study we will send you a report describing what we find out. The results of this study may be published but you will not be identified in any way.

Will my information be anonymous?

The information you provide will be kept strictly anonymous and your participation in the study will be private. The information will be stored securely and in a way that protects your identity.

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact ethics@nuigalway.ie.

We would like to thank you for taking the time to read this information, and to remind you that we are happy to answer any questions you may have. Also, remember you are free to decline to take part in this study or to change your mind at any time without consequences or questions. Please hold on to a copy of this information form

Contact details:

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Dr Molly Byrne
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AMBE, NUI, Galway.
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Consent form

Thank you for reading the information about this study! If you are happy to complete the questionnaire please complete the form below.

Please put an X in the boxes below if you agree with each statement:

21. I have read the “Understanding young adult’s attendance at diabetes clinics” participant information form.	
22. I understand that my participation in this study is voluntary.	
23. I understand that my data will be part of the data in this study once I submit my completed questionnaire.	
24. I understand that all information I give will be stored securely and will not be used or released in such a way that I could be identified.	

.....

___/___/___

Your name

Date



Consent form

Thank you for reading the information about this study, and for clicking on the link! If you are happy to complete the questionnaire please complete the form below.

Please put an X in the boxes below if you agree with each statement:

25. I have read the “Understanding young adult’s attendance at diabetes clinics” participant information form.	
26. I understand that my participation in this study is voluntary, that I am free to exit the questionnaire at any time, without having to give a reason.	
27. I understand that my data will be part of the data in this study unless I exit before I finish the questionnaire and submit my responses.	
28. I understand that all information I give will be stored securely and will not be used or released in such a way that I could be identified.	

Appendix M: Pearson correlations between the theory of clinic attendance variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
1 Age	1																		
2 Duration	.39 ^c	1																	
3 Missed Appointment Rate	.02	.08	1																
4 Attendance Rate	.01	-.08	-.53 ^c	1															
5 Informal Contact	-.00	-.06	-.06	.20 ^a	1														
6 Opportunities for Contact	.14	.32 ^c	.07	.00	.22 ^b	1													
7 DES-SF	.16 ^a	-.01	-.04	.05	.08	-.04	1												
8 WAI-SR	-.04	-.19 ^a	.05	.16 ^a	.29 ^c	.07	.38 ^c	1											
9 TSRQ	.13	.16	.08	-.07	-.12	.02	.22 ^b	-.14	1										
10 BIPQ	-.03	-.06	-.20 ^a	.07	.09	.18 ^a	-.47 ^c	-.23 ^b	-.36 ^c	1									
11 T1DDS	-.09	-.06	-.10	.02	.07	.04	-.55 ^c	-.29 ^c	-.34 ^c	.65 ^c	1								
12 Monitoring	.19 ^a	.05	-.15	.13	.12	.05	.43 ^c	.15	.21 ^b	-.07	-.22 ^b	1							
13 Weight	.07	-.00	.12	-.04	.12	.21 ^b	.20 ^a	-.00	.20 ^a	-.00	-.08	.44 ^c	1						
14 BSCS	.11	.06	.06	.01	-.06	-.06	.39 ^c	.09	.20 ^a	-.40 ^c	-.50 ^c	.34 ^c	.16 ^a	1					
15 mMOS-SSS	.07	.00	.05	.04	-.13	-.23 ^b	.41 ^c	.10	.25 ^b	-.44 ^c	-.40 ^c	.16	-.01	.35 ^c	1				
16 HCCQ	.03	-.11	.05	.15	.13	-.03	.35 ^c	.74 ^c	-.03	-.26 ^b	-.38 ^c	.05	-.06	.11	.25 ^b	1			
17 Process satisfaction	.01	-.02	.11	.05	.14	.09	.23 ^b	.48 ^c	.02	-.20 ^a	-.14	.04	-.04	.12	.26 ^b	.47 ^c	1		
18 Overall satisfaction	.05	-.05	.17 ^a	.02	.13	.02	.26 ^b	.67 ^c	.00	-.27 ^b	-.33 ^c	-.04	-.06	.08	.13	.82 ^c	.55 ^c	1	

Note. ^a = $p < .05$, ^b = $p < .01$, ^c = $p < .001$. DES = Diabetes Empowerment Scale-Short Form; WAI-SR = Working Alliance Inventory-Revised Short Form; TSRQ = Treatment Self-Regulation Questionnaire; BIPQ = Brief Illness Perceptions Questionnaire; T1DDS = Type 1 Diabetes

Distress Scale; BSCS = Brief Self Report Scale; mMOS-SSS = modified Medical Outcomes Study-Social Support Survey; HCCQ = Health Care Climate Questionnaire

Appendix N: Moderation graphs

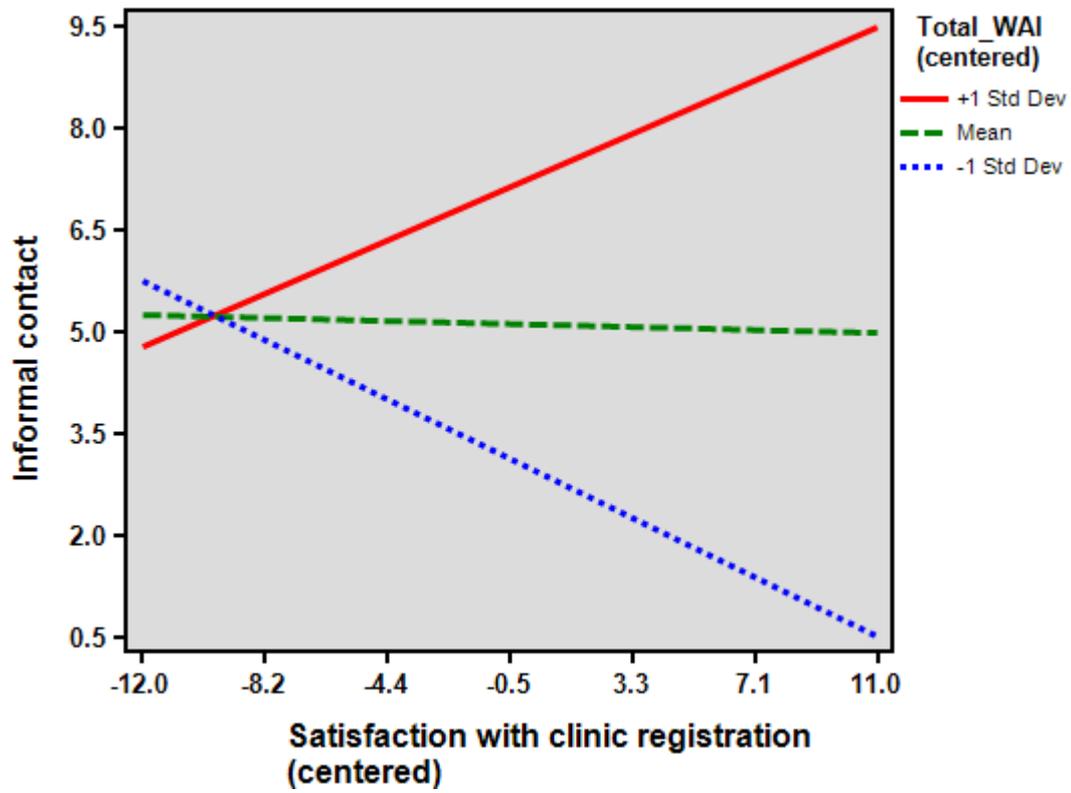


Figure 1. Graph of moderating effect of relationships between young adults and service providers between satisfaction with registration and informal contact.

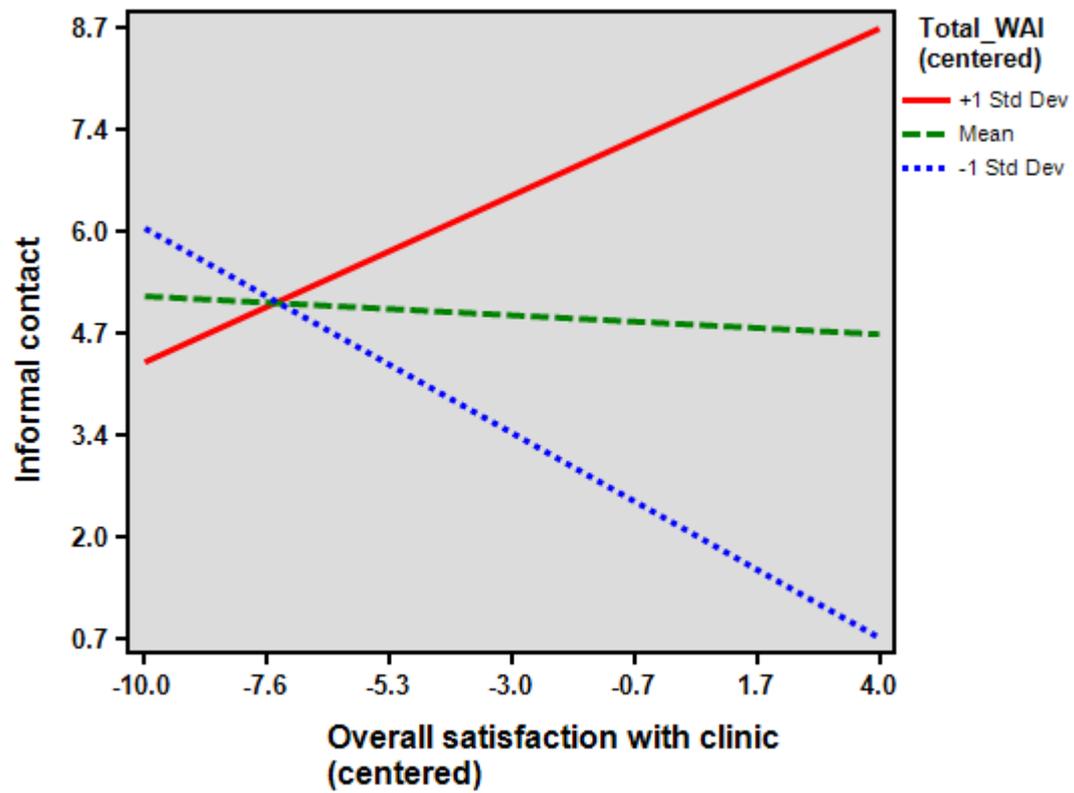


Figure 2. Graph of the moderating effect of relationships between young adults and service providers between overall satisfaction with the clinic and informal contact.

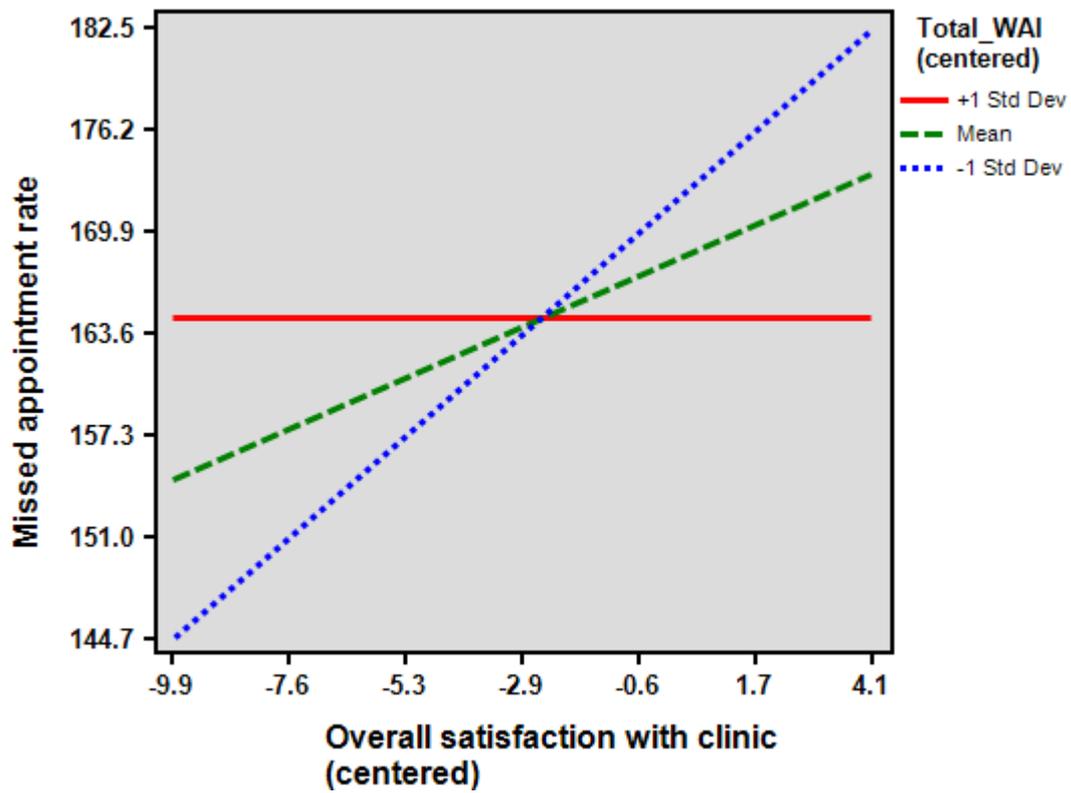


Figure 3. Graph of moderating effect of relationships between young adults and service providers between overall satisfaction with the clinic and missed appointment rate.

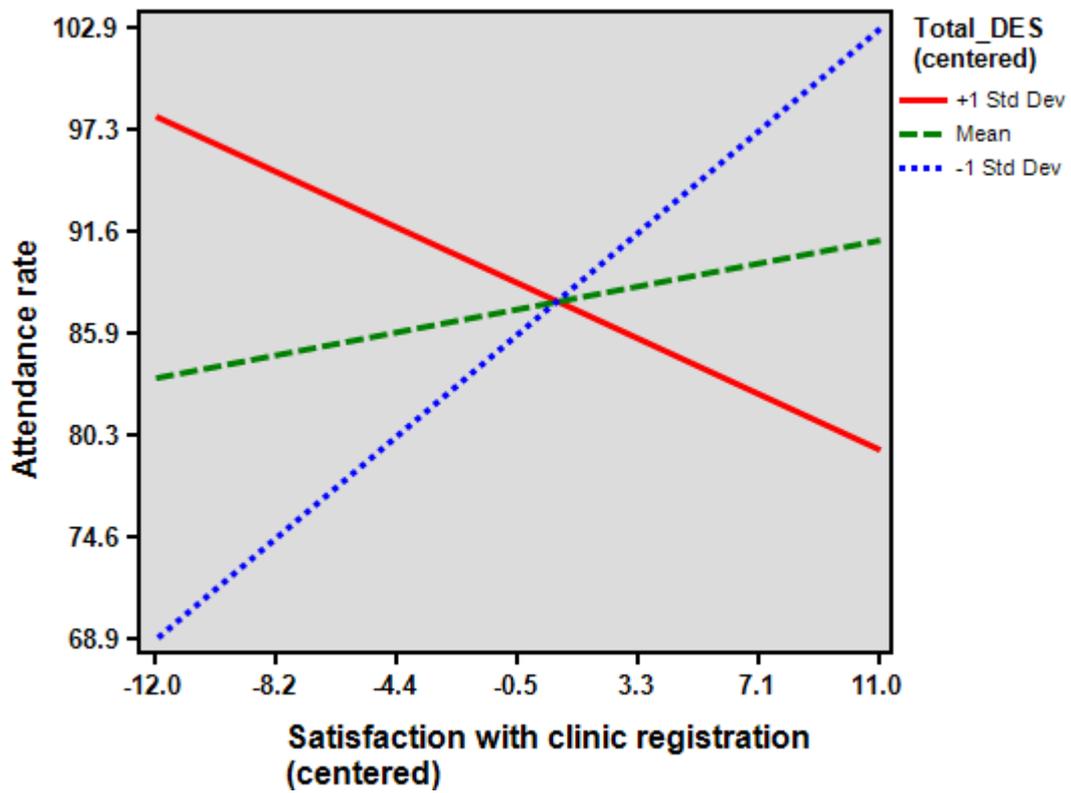


Figure 4. Graph of moderating effect of *engagement by young adults with the clinic* between *satisfaction with registration* and *attendance rate*.