

Doctoral Thesis

**Executive Functioning and Self-Management in Adolescents with Type 1  
Diabetes**

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## **Abstract**

### **Background**

Deterioration in Type 1 diabetes self-management and glycaemic control has been identified during adolescence, at a time when individuals begin to adopt greater responsibility for their diabetes care. Emerging literature has started to explore the association between executive function and self-management in adolescents with Type 1 diabetes. However, this literature is limited by the variability in the age ranges investigated and an over-reliance upon parent-report measures.

### **Aims**

This research study explored whether adolescent executive function and responsibility for diabetes care are associated with self-management and glycaemic control. The study also explored if executive function and responsibility for diabetes care are associated.

### **Method**

A cross-sectional design was adopted. Participants were aged 11-18 years with a diagnosis of Type 1 diabetes ( $n = 67$ ) and accompanying parents/caregivers ( $n = 41$ ). All participants completed self-report questionnaires measuring adolescent executive function, diabetes self-management and responsibility for diabetes care. HbA1c values provided a measure of glycaemic control.

**Results**

Better adolescent executive function was associated with better diabetes self-management, but not glycaemic control. Metacognitive components of executive function were identified as the strongest predictor of self-management. Adolescent responsibility for diabetes care did not predict self-management or glycaemic control. No association was found between responsibility for diabetes care and executive function. Adolescent-completed and parent-completed measures were positively associated. Adolescents reported better executive function and elevated responsibility for diabetes care than their parents/caregivers.

**Conclusion**

The results suggest that executive functioning abilities are important to consider when addressing adolescents' diabetes self-management. Metacognitive aspects of executive function were suggested to be of greater importance for adolescents in achieving effective self-management than behavioural components. The absence of a relationship between executive functioning, responsibility for diabetes care and glycaemic control suggests that other factors may be involved in predicting this outcome. Theoretical and clinical implications of these findings are discussed.

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## CHAPTER ONE

### 1. Introduction

#### 1.1 General Overview

Adolescence is recognised as a potentially challenging period of development, during which individuals navigate their way to adulthood – developing their independence, building a sense of identity and forming social and intimate relationships (Christie & Viner, 2005; Taylor, Gibson, & Franck, 2008). This already challenging transitional period can be exacerbated by chronic illness (Dovey-Pearce & Christie, 2013), which can interfere with the biopsychosocial developmental processes associated with adolescence (Yeo & Sawyer, 2005).

Type 1 diabetes is one of the most common chronic health conditions diagnosed amongst young people and affects approximately 1/700-1000 children in the UK (Dovey-Pearce & Christie, 2013). Successful management of Type 1 diabetes and achieving glycaemic control is vital for individuals with the condition to maintain their physical health, reduce health complications and achieve an optimal quality of life for the longest duration possible (Taddeo, Egedy & Frappier, 2008). Effective management of Type 1 diabetes is complex and requires individuals to adopt a multi-faceted treatment regimen (McNally, Rohan, Shroff-Pendley, Delamater, & Drotar, 2010). For adolescents, this means learning to effectively manage their diabetes in the context of a period of significant biopsychosocial development (Christie & Viner, 2005).

Research has identified that the management of diabetes and glycaemic control appears to significantly deteriorate during adolescence (Johnson et al., 1992; Rausch et al., 2012; Taddeo et al., 2008), at a time when individuals are starting to



develop autonomy and adopt greater responsibility for their diabetes care (Nardi et al., 2008).

Biological, psychological and social components have been identified as contributing factors to diabetes self-management in adolescence (Delamater, 2009). Further exploration of these could help aid understanding of the observed deterioration in self-management within this population. The biopsychosocial factors include: hormonal changes associated with puberty (Dovey-Pearce & Christie, 2013; Frank, 2005), the developing cognitive abilities of the individual (Eilander et al., 2015), mental health difficulties (Whittemore, Jaser, Guo, & Grey, 2010), family conflict (Anderson et al., 2002) and social acceptance and peer support (Delamater, 2009). Furthermore, it is interesting that the transition of responsibility, which occurs during adolescence (Nardi et al., 2008), coincides with the observed deterioration in self-management and glycaemic control. Research has demonstrated that responsibility for diabetes care is associated with self-management amongst this population (Helgeson, Reynold, Siminierio, Escobar, & Becker, 2008), however the precise nature of this association remains unclear.

There is an emerging literature indicating that children with diabetes are vulnerable to developing neuropsychological difficulties (Bade-White & Obrzut, 2009), which highlights the importance of considering the interaction between the biological and neuropsychological components of Type 1 diabetes and the effects on its management. Research has started to consider specific aspects of adolescent cognitive development, such as executive function skills, and how these might relate to diabetes self-management in terms of an individual's capacity to plan, initiate and carry out self-management tasks (Duke & Harris, 2014). The literature regarding adolescent executive function and Type 1 diabetes, to date, is limited.

The healthcare guidance for the UK, highlights the importance of management of Type 1 diabetes from the delivery of diagnosis and outlines key priorities as to how individuals with Type 1 diabetes should be supported (National Institute for Clinical Health Excellence [NICE], 2015). Improving adherence rates to treatment and management of chronic illnesses has been the focus of a number of manifestations from policy makers, to improve the health of patients and avoid preventable fatalities, as well as to reduce wastage of resources and the financial costs involved (Holloway & van Dijk, 2011). In order to address difficulties with self-management, the nature of such difficulties, first need to be understood.

This study was designed to identify and explore the potential associations between adolescent executive function and diabetes self-management and glycaemic control, and between adolescent responsibility for diabetes care and diabetes self-management and glycaemic control. In addition, it aimed to begin to explore if adolescent executive function and responsibility for diabetes care are associated. Continuing exploratory research into these areas may contribute to the development of a better, more comprehensive understanding of the neurocognitive and psychosocial factors that may impact on this disease and its management. A greater understanding of the difficulties associated with achieving good self-management in adolescents with Type 1 diabetes may facilitate better-informed clinical practice. This could enable more individualised and targeted supports and guidance to be offered to adolescents with Type 1 diabetes, their parents, families and associated systems (such as schools and employers). This study hoped to take a step towards such an understanding.

## **1.2 Chapter Overview**

This chapter begins with an overview of Type 1 diabetes, its pathology and its prevalence in adolescents and an overview of the risks associated with poor diabetes management. The biological, cognitive, psychological and social aspects of Type 1 diabetes are described. The treatment and management of Type 1 diabetes is then described, identifying the developments in different regimens to improve the efficacy of the treatment and well-being of the individuals with diabetes. The chapter then moves on to consider diabetes and its management in the specific context of adolescence. Key factors to acknowledge when exploring self-management within this population are identified, including physical and biological development, the role of changing responsibility and the search for autonomy, the impact of psychological difficulties and social influences. Behavioural aspects of adolescence pertinent to diabetes self-management are noted, with acknowledgement to relevant theory of behaviour. The construct of executive function is described and discussed in relation to the self-management of diabetes in adolescents. A review of the relevant literature is presented and limitations of the research are identified. A rationale for the current research study is then presented. To conclude, the research hypotheses and research questions are outlined.

## **1.3 Type 1 Diabetes**

Chronic illnesses such as Type 1 diabetes, not only have a biological basis and a physical impact on the body, but also affect psychological and social aspects of an individual's life (Adal et al., 2015). Similarly, alongside its biological management, psychological and social factors have been identified as important aspects to consider in the management of Type 1 diabetes (Delamater, 2009). The biopsychosocial model provides a framework for acknowledging the different aspects of Type 1

diabetes and its management, as well as considering the development of individuals during the period of adolescence within multiple domains (Eilander et al., 2015), relevant to this research study. This section will address the biological, psychological and social aspects of Type 1 diabetes and its management in adolescence.

### **1.3.1 Pathology and prevalence of Type 1 diabetes.**

Type 1 diabetes is a chronic metabolic disorder, for which there is currently no cure. The incidence of Type 1 diabetes appears to be increasing, particularly amongst younger children (Bilous & Donnelly, 2010). In 2013-2014, approximately 2,400 children were newly diagnosed with Type 1 diabetes across England and Wales (Royal College of Paediatrics and Child Health, 2014). The peak age for diagnosis falls between 10 and 14 years (Department of Health, 2007).

Type 1 diabetes is the result of an autoimmune process which targets the pancreas and prevents insulin secretion through the destruction of insulin-producing islet cells (Drury & Gatling, 2005). Insulin allows glucose attached to the haemoglobin in the blood to enter into other cells in the body, to be used for energy. Without insulin, the glucose builds up in the blood in the body whilst the other cells in the body have to seek energy resources elsewhere i.e. from glycogen, protein and fat (Seiffge-Krenke, 2001). If insulin provision is not restored (through the delivery of external insulin) unwanted side effects occur, which can lead to significant short and long-term health difficulties (McCrimmon, Ryan, & Frier, 2012). These side effects include hyperglycaemia and ketoacidosis, which can eventually lead to fatal outcomes (Drury & Gatling, 2005).

### **1.3.2 Risks associated with poor diabetes management.**

There are a number of different side effects and health risks associated with poorly controlled Type 1 diabetes. Poor glycaemic control can lead to a variety of

short and long-term health conditions (McCrimmon et al., 2012) including, but by no means limited to, retinopathy, cardiovascular disease and renal disease. Longer-term complications are often initially identified during the period of adolescence (Dovey-Pearce & Christie, 2013).

It is important to consider the physiological aspects of diabetes and the potential physiological complications associated with its management, in order to grasp the demanding nature of the self-management regimens adolescents are required to undertake. Furthermore, an interaction between the biological, psychological and social aspects of diabetes has been noted, although is not yet thoroughly understood and is likely to be complex (Eilander et al., 2015). Successful management of Type 1 diabetes and achieving glycaemic control are vital for individuals with the condition to maintain their physical health, reduce health complications and achieve an optimal quality of life for the longest duration possible (Taddeo et al., 2008).

### ***1.3.2.1 Hyperglycaemia.***

The absence of insulin in the body, as is the case in Type 1 diabetes, results in hyperglycaemia (Bilous & Donnelly, 2010). Hyperglycaemia refers to elevated levels of glucose in the blood system. Without insulin, other body cells cannot access this glucose, which leads to a build up of glucose in the blood system. Prolonged periods of hyperglycaemia can lead to difficulties associated with eyesight, kidney function and atherosclerosis (The Diabetes Control and Complications Trial [DCCT] Research Group, 1993). Individuals with diabetes are 16 times more likely to undergo a lower limb amputation than individuals without diabetes; many of these amputations are a result of macrovascular complications that arise as a result of poor glycaemic control (Bilous & Donnelly, 2010). Short and long-term effects on the

central nervous system have also been identified as a result of prolonged hyperglycaemia (Rewers et al., 2009). Changes in the blood vessel network in the brain, as a result of on-going hyperglycaemia, can lead to atrophy and stroke which, in turn, can result in cognitive impairments (Wilson, 2012).

### ***1.3.2.2 Ketones and Diabetic Ketoacidosis (DKA).***

When the absence of insulin prevents the cells in the body from using glucose in the blood, the body has to use fat stores as a source of energy. As a result, acidic ketones are formed as a by-product of the breakdown of the fat in the body. These acidic ketones build up in the blood and consequently, the kidneys have to work harder to filter the high levels of glucose and ketones from the blood system. As a result, dehydration occurs and the body loses other essential salts, electrolytes and nutrients through more frequent urination (Seiffge-Krenke, 2001). Without insulin, these symptoms lead to Diabetic Ketoacidosis (DKA), which requires immediate treatment to prevent further severe physical health consequences such as respiratory difficulties, cerebral oedema and thromboembolism (Bilous & Donnelly, 2010).

The guidelines for diabetes care indicate that individuals with diabetes should check for ketones if they measure a blood glucose level of 15mmol/l or above (<https://www.diabetes.org.uk>). Updated NICE guidelines for the management of diabetes in children and young people (2015) now recommend that individuals should check for ketones if they measure a blood glucose level of 11mmol/l. The measures used in the current research were informed by earlier guidance and used the recommended value of 15mmol/l.

Adolescence has been noted as a peak period for recurrent episodes of DKA (Snoek & Skinner, 2006). Recurrent DKA has been associated with increased psychological difficulties amongst adolescents (Frank, 2005; Silverstein et al., 2005).

Social factors, including family conflict, parental involvement in diabetes care and family support have also been associated with recurrent episodes of DKA amongst adolescents (Snoek & Skinner, 2006). Thus, the overlap between biological, psychological and social aspects of diabetes and its management in adolescence is highlighted here.

### ***1.3.2.3 Hypoglycaemia.***

Hypoglycaemia occurs when the level of glucose in the blood falls below 4mmol/L (Wilson, 2012) and can occur due to the administration of too much insulin, exertion of more energy than can be provided by the food consumed or as a result of alcohol consumption (Gonder-Frederick, Nyer, Shepard, Vajda, & Clarke, 2011). Episodes of hypoglycaemia are common amongst individuals with Type 1 diabetes as a by-product of their attempt to achieve near-normoglycaemia in the management of the disease (DCCT, 1993; Hannonen, Tupola, Ahonen, & Riikonen, 2003). With recurring episodes of hypoglycaemia, an individual's threshold for hypoglycaemic symptoms and response to these alters, which can mean indicators of hypoglycaemic episodes are harder for the individual to detect and manage (Graveling et al., 2014). This is often referred to as *impaired hypoglycaemia awareness* (McCrimmon et al., 2012) and subsequently leads to more frequent episodes of hypoglycaemia.

Hypoglycaemia has been associated with both short and long-term effects on the central nervous system (Rewers et al., 2009). Brain function is dependent on glucose and therefore insulin is necessary in order for the brain to access the glucose from the blood. If the brain is without glucose for even a short period of time, cognitive impairments can occur and, if prolonged, it can result in the individual entering into a coma (Bilous & Donnelly, 2010).

Hypoglycaemic episodes can be categorised dependent on their severity: individuals can usually manage *mild* hypoglycaemia themselves, whereas *moderate* hypoglycaemia often requires the assistance of another individual (Hannonen et al., 2003). *Severe* hypoglycaemia occurs when the individual loses consciousness due to low blood glucose levels and may experience seizures or convulsions (Kodl & Seaquist, 2008). Hypoglycaemia is reported to be more common in young children, who are perhaps less familiar with the warning signs of hypoglycaemia or less able to communicate these to access the necessary support and interventions from their caregiver (Graveling, et al., 2014).

### **1.3.3 Cognitive aspects of Type 1 diabetes.**

In a meta-analysis reviewing cognitive performance studies of children with Type 1 diabetes compared with non-diabetic controls from 1985 to 2008, Gaudieri, Chen, Greer, and Holmes (2008) noted that children with Type 1 diabetes demonstrated poorer performance across most cognitive domains than the controls. These domains included overall intelligence, psychomotor activity, speed of information processing, attention and executive function, visual motor integration and academic achievement. However, effect sizes were small which indicates that the disparity of cognitive performance overall was not of clinical significance: children with Type 1 diabetes typically scored between one and three standard score points lower than their controls on cognitive measures. These score differences suggest that overall, children with Type 1 diabetes do not demonstrate developmentally different cognitive function compared to healthy peers. The subtle differences are unlikely to be detectable within a classroom or educational environment.



Research has indicated, however, that increased incidences of hypoglycaemia may be associated with poorer performance on cognitive tasks including processing speed, abstract reasoning, attention-based tasks and inhibition of behaviours (Kucera & Sullivan, 2011). There is conflicting evidence within the literature as to the presence and longevity of such an association (Gonder-Frederick et al., 2011). Some evidence exists to indicate associations between recurrent severe hypoglycaemic episodes and cognitive difficulties (Bade-White & Obrzut, 2009; Hannonen et al., 2003). Perantie et al. (2008) found that impairments in visual-spatial and delayed memory recall were related to recurrent episodes of hypoglycaemia in children and adolescents. Hannonen et al. (2003) found that children with a history of recurrent severe hypoglycaemia demonstrated poorer cognitive abilities in the domains of short-term memory and phonological processing than healthy controls. Conversely, other studies have not noted such associations (Musen et al., 2008). An 18-year follow up study by the DCCT Research Group (2007) did not identify any long-term effects of hypoglycaemia on cognitive function. Similarly, a meta-analysis conducted on research published between 1980 and 2004, exploring the effects of Type 1 diabetes on cognitive function in adults, concluded that there was no association between recurrent severe episodes of hypoglycaemia and cognitive difficulties (Brands, Biessels, de Haan, Kappelle, & Kessels, 2005).

In the meta-analysis by Gaudieri et al. (2008), children with early onset Type 1 diabetes (defined as before the age of 7 years) were found to demonstrate greater disruption in specific cognitive domains compared to children with later onset Type 1 diabetes. These cognitive domains included verbal and visual learning and memory and executive function. It was noted that although the effect sizes remained small, stronger effects were identified when comparing participants with early onset Type 1

diabetes to participants with late onset Type 1 diabetes, than when comparing the overall sample to non-diabetic controls. Furthermore, moderate effect sizes were detected for the observed lower cognitive performance by those with early onset than non-diabetic controls in the verbal and visual learning and memory, executive function and overall intelligence cognitive domains. The authors explained that these effect sizes equated to standard score differences of up to 6.5 or 7 points on the cognitive measures and noted such differences were likely to be detectable within a classroom or educational environment.

Researchers have explained the discrepancies in the results found within the literature by inconsistencies between participant ages at diagnosis of Type 1 diabetes and thus their ages when experiencing recurrent episodes of severe hypoglycaemia across research studies (Bade-White & Obrzut, 2009; Kodl & Seaquist, 2008). This proposed explanation is supported by the findings of the meta-analysis by Gaudieri et al. (2008) outlined above. Bilous and Donnelly (2010) noted that mild impairments in the areas of visuospatial and verbal functioning have been identified in children who have experienced repeated hypoglycaemic episodes and are more evident in children who were diagnosed with Type 1 diabetes before the age of five years.

Overall, the literature suggests that although children and adolescents with Type 1 diabetes do not differ from their non-diabetic peers in terms of cognitive functioning in general, there is some evidence indicating that children with diabetes are more vulnerable to developing neuropsychological difficulties (Bade-White & Obrzut, 2009), specifically in relation to episodes of hypoglycaemia (Griffin & Christie, 2012). Evidence suggests that it is children with *early onset* Type 1 diabetes that may be of greatest risk of cognitive impairments, potentially due to the impact of

hypoglycaemia on the developing brain (Bilous & Donnelly, 2010; Gonder-Frederick et al., 2011; Northam, Anderson, Werther, Warne, & Andrewes, 1999)

### **1.3.4 Psychological and social aspects of Type 1 diabetes**

It is generally accepted within the literature that better glycaemic control is associated with better psychological and emotional well-being (Frank, 2005).

Adjusting to diagnosis and living a life with Type 1 diabetes can evoke psychological and emotional responses (Bilous & Donnelly, 2010). As with all chronic illnesses, Type 1 diabetes impacts upon the whole family system and not just the individual with diabetes (Yeo & Sawyer, 2005). It is acknowledged that a diagnosis of Type 1 diabetes can result in an increase in stress associated with the change and adaptation that is often required within the family system (Court, Cameron, Berg-Kelly, & Swift, 2009).

Psychological aspects of Type 1 diabetes, such as depression and anxiety (Whittemore et al., 2010), self-esteem and coping skills have been associated with the self-management of diabetes (Delamater, Patino-Fernandez, Pulgaron, & Daigre, 2012; Jaser et al., 2012) and glycaemic control in adolescents (Bernstein, Stockwell, Gallagher, Rosenthal, & Soren, 2013). Similarly, social factors such as lifestyle, social support and social stressors impact on the individual's response to their diagnosis and subsequent self-management of Type 1 diabetes (Guo, Whittemore, & He, 2011; Wysocki & Greco, 2006). These include family conflict (Hilliard, Wu, Rausch, Dolan, & Hood, 2013), family and peer relationships, and social acceptance (Court et al., 2009).

The importance of psychosocial aspects of Type 1 diabetes has been highlighted, clinically and within research, particularly in relation to the self-management of the condition amongst adolescents (Delamater, 2009). An overview of these

psychological and social factors, pertinent to the developmental period of adolescence, is given in sections 1.4.3 and 1.4.4.

### **1.3.5 Treatment of Type 1 diabetes: Self-management and glycaemic control.**

The management of Type 1 diabetes places large behavioural demands upon individuals (Guo et al., 2011), which require sufficient cognitive abilities to plan, organise and initiate. The ultimate goal for individuals with Type 1 diabetes is to self-manage their disease (Silverstein et al., 2005). Diabetes *self-management* refers to the activities and behaviours performed to maintain glycaemic control. It encompasses the processes of collaboration between the individual, their family and healthcare services (Schilling, Grey, & Knafl, 2002). Self-management requires a multifaceted regimen including: exercise, a monitored diet, blood-glucose monitoring and insulin administration via injections or subcutaneous pump (McNally et al., 2010), with the aim of achieving near-normoglycaemia as safely as possible (Hannonen, et al., 2003). Improving glycaemic control as early on as possible from diagnosis has been demonstrated to reduce the occurrence of related health complications (Dovey-Pearce & Christie, 2013).

Glycated haemoglobin (HbA1c) provides an objective measure of an individual's glycaemic control. HbA1c has been identified as the best measure of glycaemic control and has demonstrated the most robust associations with health complications that arise from poorly controlled diabetes (Rewers et al., 2009). Achieving glycaemic control by reaching an identified target HbA1c level is the key goal of diabetes self-management (Hannonen, et al., 2003). It is recommended that young people should aim to achieve the lowest HbA1c value that is possible whilst avoiding episodes of hypoglycaemia, hyperglycaemia or DKA. Recent guidelines have indicated a HbA1c target level as  $< 48\text{mmol/mol}$ : a lower target level than

previously indicated at  $<58\text{mmol/mol}$  (NICE, 2015) for children and adolescents with Type 1 diabetes.

The DCCT Research Group (1993) identified that good glycaemic control is related to better health outcomes for individuals with diabetes and lower rates of diabetes-related health complications. Guo et al. (2011) demonstrated through their integrative review of the relevant literature from 1996 to 2010, that a positive relationship exists between diabetes self-management and glycaemic control in young people with Type 1 diabetes. Research has also identified that glycaemic control depends on treatment adherence (McNally et al., 2010).

Treatment programmes and management strategies have been improved and developed over time, to provide an effective treatment of the condition in a way that is manageable for the individual (Sherr, Cengiz, & Tamborlane, 2009). Intensive regimens involve the use of both short and long acting insulin, to enable a constant level of insulin which is topped up in accordance to meals – specifically carbohydrate consumption, and exercise. Such regimens have been developed with the aim to simulate the natural physiology and function of insulin that would be expected in a healthy individual without diabetes (Dovey-Pearce & Christie, 2013). The DCCT Research Group (1993) demonstrated, through a randomised control trial, that intensive treatment regimens were superior to conventional regimens (which comprise of one or two insulin injections per day) in improving glycaemic control, as measured by HbA1c, and reducing diabetes-related health complications. It has been noted, however, that intensive regimens do increase the likelihood of the individual experiencing more frequent episodes of hypoglycaemia (Hannonen et al., 2003), which adds to the complexity of achieving good self-management.

Different formats of insulin delivery exist amongst the various management strategies. These include basal-bolus injections or multiple daily injections, which involve administration of a combination of short and long-acting insulin throughout the day and night or insulin delivery via a subcutaneous pump (Bilous & Donnelly, 2010). Insulin pumps enable automatic infusion of insulin into the body, on top of which individuals can administer an insulin bolus in concordance with meal times. The rate of automatic infusion can be altered at any time, to match an individual's pattern of glycaemia (Phillip, Battelino, Rodriguez, Danne, & Kaufman, 2007).

Despite advances in the management strategies and tools available to individuals with diabetes, child and adolescent glycaemic control does not appear to be improving at the same rate (Dovey-Pearce & Christie, 2013). In 2013-2014 only 18.4% of children and young people in the UK reached the recommended glycaemic control target at that time of  $< 58\text{mmol/mol}$ . The national average HbA1c value for this population remains significantly elevated above the target value at  $71.6\text{mmol/mol}$  (Royal College of Paediatrics and Child Health, 2014). Considering the recent reduction in the recommended target HbA1c value to  $< 48\text{mmol/mol}$  (NICE, 2015) it is likely that these statistics are an underestimate of the levels of poor glycaemic control evident within the adolescent population with Type 1 diabetes today. Wood et al. (2013) noted similar trends in the United States of America: only 21% of adolescents with Type 1 diabetes, aged between 13 and 19 years achieved the targets for glycaemic control as recommended by the American Diabetes Association.

Considering the potential negative sequelae of poor diabetes management and glycaemic control and the threat these sequelae can pose to an individual's health and quality of life (Taddeo et al., 2008), it is important to address the observed

deterioration of diabetes self-management and glycaemic control identified amongst adolescents with Type 1 diabetes. Continuing to develop our understanding of Type 1 diabetes and factors affecting its management will not only help to improve the health and well-being of individuals with the condition, but it will provide further justification to the increase in cost associated with intensive regimens and may highlight ways to ensure the best outcomes are gained from the expenditure of our healthcare system. Furthermore, by improving our knowledge of factors affecting self-management and barriers experienced by adolescents trying to achieve this, we will be better set to prevent individuals experiencing longer-term health complications and reduce the burden on the healthcare system from the negative sequelae of poorly controlled diabetes (Bilous & Donnelly, 2010).

The following section addresses aspects of Type 1 diabetes and its management, specifically in relation to adolescence.

#### **1.4 Adolescence and Type 1 diabetes.**

Adolescence is a time of cognitive, biological and social change, when individuals attempt to forge their own identities and seek independence (Silverstein et al., 2005). Adolescents with Type 1 diabetes are expected to begin to self-manage their diabetes care, which not only involves mastering a set of diabetes-management skills but also the integration of these into their adolescent lives (Dovey-Pearce & Christie, 2013). As aforementioned, self-management has been shown to decline during adolescence (Drotar et al., 2013), at a time when individuals seek independence in all aspects of life (Nardi et al., 2008; Silverstein et al., 2005). As a result this has become a key point of interest within the diabetic research literature to attempt to understand this deterioration.

Biological, psychological and social factors have all been identified as potential contributors to the observed decline in diabetes self-management during adolescence (Luyckx, 2012). This section discusses key elements associated with adolescence that may contribute to the challenges of self-management during this developmental stage. The influence of physical and biological changes, the role of changing responsibility and the search for autonomy and psychological and cognitive factors are considered. Latterly, a theoretical framework is introduced as a potential means for conceptualising diabetes self-management amongst adolescents.

#### **1.4.1 Physical and biological development**

Puberty is a significant part of adolescence and marks the start of the physical and biological development from childhood to adulthood. Bodily changes during puberty, and the differing rates of pubertal development amongst peer groups can result in individual's developing low self-esteem (Christie & Viner, 2005).

Alterations in hormones during puberty lead to increased insulin resistance in the body (Frank, 2005). This in turn, increases the risk of hyperglycaemia in individuals who are in the pubertal stages of their lives (Dovey-Pearce & Christie, 2013). As aforementioned, hyperglycaemia may have repercussions on the cognitive functioning of individuals.

Childhood represents a crucial period for brain development (Biessels, Deary, & Ryan, 2008). Similarly, the period of adolescence is noted as an important time for the development of higher order cognitive functioning (Eilander et al., 2015) of which executive function is considered. Neural and cognitive changes associated with the developmental period of adolescence, which are of note in the case of this research, are detailed in sections 1.5.2 and 1.5.3.



### **1.4.2 Changes in autonomy and responsibility**

It is well recognised that from the start of adolescence individuals begin to develop their own autonomy across many domains of life. It is generally accepted that individuals start to adopt predominant responsibility for their self-care and illness treatment from the age of 12 years (La Greca, Follansbee, & Skyler, 1990). Adolescence represents the period of development in which an individual transits from a child requiring supervision and monitoring by an adult to an independent being who can be held responsible for his or her own behaviour (Dahl, 2004). This is no different within the diabetic population and as individuals progress through their adolescent years they begin to manage their diabetes more autonomously (Nardi et al., 2008).

It is well recognised within the literature and amongst healthcare professionals that managing diabetes can be challenging, particularly at life transition points. Healthcare guidance recommends practical transition plans to support individuals to progress from children and young people with diabetes to adults with diabetes, both in terms of their personal management and in the change of service provision for the different age groups (Chiang, Kirkman, Laffel & Peters, 2014; NICE, 2015). Interestingly, however, there is less specific guidance regarding the support of children through the transition to adolescence. Clinical support may not drastically change as adolescents often remain in the same diabetes service (only transitioning to adult services at 18 or 19 years), however, the individuals' management of the disease is likely to change as there is a gradual shift from parent-supervised diabetes care to self-management (Peters & Laffel, 2011). This raises the question as to whether enough supports are in place to assist adolescents in adopting more responsibility for their diabetes care. Similarly support may benefit family members,

to help them recognise the changing needs of their child during the transition to adolescence.

Within the diabetes literature, a shift of management responsibilities from parents to child has been identified (Ingerski, Anderson, Dolan, & Hood, 2010; Wiebe, et al., 2014). This transition of responsibility corresponds with a decline in self-management and glycaemic control.

It has been shown that responsibility for diabetes care is related to self-management (Helgeson, et al., 2008). However, a review of the literature has indicated that although there does appear to be a relationship between responsibility for diabetes care and self-management in adolescents with Type 1 diabetes, there is not, at present, a consensus as to nature of this relationship. The majority of evidence indicates that self-management and adherence to treatment regimens improves with greater levels of parental responsibility (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997; Anderson et al., 2002) and declines with increased levels of child or adolescent responsibility (Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010; Ingerski, et al., 2010). However, in contrast, other evidence has been presented which has identified a positive relationship between parent-adolescent shared responsibility and self-management (Helgeson et al., 2008; Ingerski et al., 2010; Vesco et al., 2010). Furthermore, Wiebe et al. (2014) suggested a more complicated relationship between responsibility for diabetes care and self-management through identifying adolescent self-efficacy as a potential mediator.

Further research is required to help to provide a greater understanding of the relationship between self-management and responsibility for diabetes care. In addition, if poorer self-management is associated with greater adolescent

responsibility, as the majority of the literature indicates, it is important that research starts to consider explanatory factors for this trend.

### **1.4.3 Psychological factors**

Adolescents have been identified as a population particularly vulnerable to psychological difficulties (Adal et al., 2015). Research indicates that Type 1 diabetes is a risk factor for the development of psychological difficulties, including depression, anxiety and eating disorders in young people (Whittemore, et al., 2010).

Evidence from research indicates the presence of psychological difficulties amongst adolescents with Type 1 diabetes (Dantzer, Swendsen, Maurice-Tison, & Salamon, 2003). Comorbidity has been noted between Type 1 diabetes and anxiety, depression and eating disorders (Balhara, 2011; Elber, Berlin, Grimaldi, & Bisserbe, 1997; McConnell, Harper, Campbell, & Nelson, 2001; Mommersteeg, Herr, Pouwer, Holt, & Loerbroks, 2013).

Depression has been identified as the most common psychological disorder amongst adolescents with Type 1 diabetes (Whittemore et al., 2010). Furthermore, Hassan, Loar, Anderson, and Heptulla (2006) noted that depression appeared to be more common amongst children and adolescents with poorly controlled diabetes than those with better glycaemic control.

Despite there being less extensive research regarding anxiety in adolescents with Type 1 diabetes, in comparison to depression, associations between anxiety and diabetes self-management have been identified (Herzer & Hood, 2010). Specific anxieties and phobias, including needle-phobias (Balhara, 2011) and fear of hypoglycaemia (Gonder-Frederick et al., 2011) have also been identified within this population. These psychological factors associated with Type 1 diabetes have the potential to inhibit successful diabetes self-management either directly or indirectly.

For example, needle phobia may directly impede the biological management of diabetes due to difficulties with injecting insulin regularly and depression may result in a loss of motivation or goal-directed behaviour, which may indirectly hinder self-management (Hood et al., 2014).

The necessity to include a focus on diet and body weight in diabetes management has been linked to the occurrence of eating disorders in the adolescent population with Type 1 diabetes (McConnell et al., 2001). The information provision around appropriate foods and diets and the focus on carbohydrate counting associated with diabetes management can lead to the individual developing difficulties associated with body image and eating disorders (Young et al., 2012). The occurrence of hyperglycaemia and the subsequent learning that this can lead to weight loss in Type 1 diabetes can lead to the misuse of insulin to control weight gain in individuals with Type 1 diabetes (Colton, Rodin, Bergenstal, & Parkin, 2009).

The NICE guidelines for children and young people with Type 1 diabetes (2015) acknowledge the incidence of associated mental health difficulties with this chronic condition and include recommendations for healthcare professionals to be aware and alert for indications of psychological difficulties and to offer psychological support when necessary. The Diabetes Best Practice Tariff (DBPT; Randell, 2012) also emphasises the importance of psychological aspects of Type 1 diabetes through its recommendation that each individual should have access to an assessment, annually, from clinical psychology.

#### **1.4.4 Social factors**

Adolescence is an important time for social development and the formation of self-identity (Court et al., 2009) and independence (Silverstein et al., 2005). Social

acceptance is of vital importance to adolescents. The very nature of having a chronic condition such as Type 1 diabetes immediately provides a difference between the adolescent and their peers. It is possible that adolescents with Type 1 diabetes will often dismiss their disease (and thus may not engage fully in self-management) in an attempt to minimise the differences between themselves and their peers (Dovey-Pearce & Christie, 2013) or as an expression of frustration of having to manage their condition (Yeo & Sawyer, 2005).

Furthermore, it is likely that diabetes management is not considered the priority for many adolescents who are simultaneously trying to manage the social and emotional challenges of this developmental and transitional stage (Court et al., 2009). The increased time spent with peers rather than family during adolescence increases the exposure of individuals to risk-taking opportunities and behaviours which can interfere with their health and thus diabetes management (Martinez-Aguayo et al., 2007). These social behavioural aspects of adolescence are discussed in section 1.4.5.

Characteristics of the family system and relationships within these, in addition to socio-economic status, have been identified as potential influential factors on the management of diabetes and glycaemic control (Silverstein et al., 2005). Children and adolescents with unmarried caregivers have been associated with poorer glycaemic control, than those with married caregivers (Hilliard et al., 2013). Low socioeconomic status has been associated with poor glycaemic control (Hassan et al., 2006). Parenting style has been associated with adolescent self-management of diabetes, where parental warmth, support and a structured environment are associated with better self-management in comparison to more critical parenting (Frank, 2005). Interventions targeting family conflict have demonstrated that

reducing conflict within the family system, improves diabetes management and glycaemic control amongst adolescents (Wysocki et al., 2007).

There is a large literature regarding the psychological and social aspects of Type 1 diabetes, particularly amongst adolescents and the influence of these on self-management and glycaemic control. Whilst it is important to acknowledge their existence here, a detailed review and critique of the research related to these factors is beyond the scale and scope of this thesis.

#### **1.4.5 Behavioural aspects of adolescence**

Adolescence is often referred to as a period of experimentation and this can translate into their approach to diabetes care (Dovey-Pearce & Christie, 2013). Alcohol consumption, smoking and drug taking can all lead to complications with diabetes management (Martinez-Aguayo et al., 2007). The exposure to alcohol, smoking and drugs during adolescence and the adolescents' greater propensity than young children or adults to engage with risk-taking behaviour (Frank, 2005; McConnell et al., 2001) further contribute to the declines observed in self-management and glycaemic control in adolescence.

Explanations of the heightened propensity of adolescents to engage in risk-taking behaviour identify that this is likely to be a result of interplay between psychosocial factors and the developing cognitive function of adolescents (Steinberg, 2007). The nature of adolescents' lifestyles and the increased time spent with peers during this period, increase the exposure of adolescents to risk-taking opportunities (Smith, Chein, & Steinberg, 2013). Similarly, the importance of social acceptance and peer influence during this developmental stage, results in a greater emotional importance being placed on how, as an individual, they respond to the risk-taking opportunity (Steinberg, 2007; Wysocki & Greco, 2006). Simultaneously, cognitive

abilities, specifically executive functioning skills, are still developing during the period of adolescence (Duke & Harris, 2014; see section 1.5.2). As a result, psychosocial factors appear to frequently undermine the self-regulatory executive processes involved in decision-making around risk-taking behaviour and render adolescents more likely to engage in such behaviours (Steinberg, 2007; Smith et al., 2013), which could contribute to deterioration in self-management.

In addition to risk-taking behaviours associated with adolescence (McConnell et al., 2001), the consolidation of health behaviours is also believed to occur during this developmental stage (Williams, Holmbeck, & Greenley, 2002). The risk of developing later-life diabetes-related health complications is reduced if glycaemic control is achieved during adolescence, irrespective of whether that good control is maintained in adulthood (Dovey-Pearce & Christie, 2013). This highlights the importance of the consolidation of positive health behaviours during this period of development. This emphasises the need to understand, thoroughly, the barriers to self-management relevant to this population and the need to consider how support systems and treatment packages can be improved to enable adolescents the best possible chance of successful self-management and achieving good glycaemic control. Adolescence may represent the most important and efficient age at which to intervene and improve self-management supports, when considering the potential magnitude of the effects on longer-term health benefits.

#### **1.4.6 A theoretical framework for understanding self-management in adolescence**

Poor self-management could be conceptualised as a reluctance or failure of an individual to engage with certain behaviours. As a result, the theoretical frameworks of the Behaviour Change Wheel (Michie, van Stralen, & West, 2011) and

specifically, the COM-B model, as a central component of this framework, may be of relevance in this research. The COM-B model (Michie et al., 2011) posits that the interaction between three components: Capability, Opportunity and Motivation (COM), causes Behaviour (B) and can be used to understand why individuals do and do not engage in certain behaviours (Jackson, Eliasson, Barber, & Weinman, 2014). This behavioural framework may be applicable to understanding the difficulties with self-management faced by adolescents with Type 1 diabetes and could provide a theoretical basis for developing targeted interventions to improve self-management.

Targeting interventions to improve diabetes self-management can be a complex process, particularly when all contributing factors to adhering to multifaceted treatment regimens are considered (Jones, Curley, Wildman, Morton, & Elphick, 2015). Furthermore, as outlined in this chapter, when addressing self-management in the adolescent population, biological, psychological and social developmental factors also need to be considered. In the UK, the Medical Research Council (MRC) emphasised that interventions targeting adherence should be underpinned by a clear theoretical framework to help to address the complexity of non-adherence behaviours (2000; Craig et al., 2008). In order for this guidance to be followed, in the case of adolescent Type 1 diabetes management, it is necessary that all biopsychosocial factors and cognitive aspects influencing self-management are understood, before accurate and theory-based interventions and support strategies can be developed and implemented. The COM-B model may provide an appropriate framework to incorporate these multiple factors in understanding adolescent diabetes self-management. Consideration as to how the COM-B model may apply, with reference to the results of this research study, is discussed in Chapter Four.



## 1.5 Executive Function

The execution of daily self-management regimens relies on a vast array of cognitive and behavioural skills and abilities (Duke & Harris, 2014). Diabetes treatment regimens are one of the most consistently demanding regimens for chronic illnesses (Viner, 2012). Self-management requires, amongst many others, planning, organisation, prioritisation, problem-solving and self-regulation skills; all of which fall into the category of *executive function* (Chung, Weyandt, & Swentosky, 2014). In order for successful self-management of Type 1 diabetes, executive functions appear to be key (Nylander et al., 2013).

The neural basis of executive functioning is complex. It is widely acknowledged that integral to executive function are the prefrontal cortices in the brain (Colver & Longwell, 2013). However, it has been demonstrated across research that executive function does not rely on these prefrontal cortices alone. Anterior and posterior brain areas have been implicated in the mediation of executive function processes and the inter-connectivity of the prefrontal cortices with almost all of the other areas of the brain appears to be vital for its functioning (Alvarez & Emory, 2006).

### 1.5.1 Defining executive function

There is inconsistency within the literature as to the definition of executive function (Livanis, Mertturk, Benvenuto, & Mulligan, 2014). Researchers agree, however, on the complexity and importance of executive function to adaptive behaviour (Jurado & Rosselli, 2007) and the range of skills the term encompasses. One of the most frequently adopted models of executive function within psychological research is that outlined by Gioia, Isquith, Guy, and Kenworthy (2000) which describes executive functions as cognitive abilities related to and involved in goal-directed or future-orientated behaviours. Executive function encompasses

multiple cognitive and metacognitive skills involved in self-monitoring and self-regulation (behaviourally and emotionally), the initiation of tasks, attention and cognitive flexibility, working memory processes, inhibition and organisation and planning (Goldstein, Naglieri, Princiotta, & Otero, 2014).

### **1.5.2 The development of executive function**

Executive function abilities develop over time, from childhood, through adolescence and into early adulthood (Duke & Harris, 2014). It is important to consider this developmental process when addressing the issue of executive function and its impact on other abilities in developing children and adolescents with diabetes within this research. Adolescence forms a critical period for neural development, particularly for the development of higher cognitive functions (Eilander et al., 2015).

The vital, albeit insufficient, role of the frontal lobes in executive functioning is important to consider here. Frontal regions of the brain develop from immaturity in early childhood throughout childhood and adolescence and this, alongside improved connectivity between neural regions and increases in the prefrontal regions of dopaminergic activity (Colver & Longwell, 2013) is understood to be related to the development of cognitive functioning and the adoption of more complex cognitive skills (Barnea-Goraly et al., 2005). Increased myelination, particularly in the frontal regions of the brain, occurs during the adolescent years (Blakemore & Choudhury, 2006). It is believed that this myelination supports the continued development and refinement of the range of executive functions that occurs during this same period.

Research indicates that although executive function skills emerge during infancy, they continue to develop throughout adolescence into adulthood (Otero & Barker, 2014). It is noted, however, that not all elements of executive function follow the same developmental trajectory (Anderson, 2002; Brocki, Fan, & Fossella, 2008)

and some executive functions may be better developed earlier on in development, such as processing speed and cognitive flexibility (Brocki & Bohlin, 2004) whilst others such as inhibitory control, working memory and decision making continue to be refined later into the adolescent years (Best & Miller, 2010; Luciana, Conklin, Hooper, & Yarger, 2005). Brocki and Bohlin (2004) identified that inhibitory control is fully developed between the ages of 10 and 12 years. Working memory, planning, task shifting and cognitive flexibility components of executive function have been shown to continue to develop and improve throughout childhood and adolescence and into adulthood (Brocki et al., 2008). Working memory abilities emerge early on in development; they continue to improve throughout adolescence, as individuals are exposed to more complex tasks, which increase the demands on the working memory abilities (Best & Miller, 2010). This on-going development of working memory skills is important to bear in mind when considering the complexity of diabetes self-management regimens for individuals with Type 1 diabetes and particularly, for the adolescent population. Adolescents are beginning to develop increased autonomy and responsibility for their diabetes care and thus there is likely to be an increased demand upon their working memory abilities when taking on more self-management tasks independently (Griffin, 2012). The largest gains in executive functioning are suggested to appear between 15 and 30 years of age (Wild & Musser, 2014).

In their 2014 position statement, the American Diabetes Association acknowledged the importance of age-appropriate care for individuals with Type 1 diabetes and emphasised the importance of considering the individual needs of different age groups (Chiang et al., 2014). Understanding the executive function skills of adolescents with Type 1 diabetes and if these are associated with their management of the disease, should enable health care guidance to be designed more

specifically to the needs and potential limitations of adolescents with Type 1 diabetes.

### **1.5.3 Executive function and Type 1 diabetes**

There is an emerging literature indicating that children with diabetes are vulnerable to developing neuropsychological difficulties (Bade-White & Obrzut, 2009) particularly in relation to episodes of hyper and hypoglycaemia (Griffin & Christie, 2012). Research has suggested a link between impairments in adolescents' executive functioning and reduced self-management and subsequent diabetes control (Miller et al., 2013).

Bagner, Williams, Geffken, Silverstein and Storch (2007) established that executive functioning level predicted treatment adherence, in their research involving children and adolescents aged 8-19 years. The results suggested that higher levels of functioning in the areas of problem solving, self-monitoring, and use of working memory were related to higher rates of adherence. They identified that both behavioural regulation and metacognitive aspects of executive function were positively associated with adherence to management regimens. McNally et al. (2010) indicated that executive functioning skills including planning, problem solving, organisation and working memory were related to treatment adherence, which was related to diabetes control. They identified that higher levels of executive functioning were related to better adherence, in their sample of children aged 9-11 years. If level of executive functioning is reduced, the individual's ability to self-manage is likely to be impaired due to their deficits in the skills required to effectively and efficiently plan, organise and problem-solve their daily lives in accordance with their treatment needs.

Graziano et al. (2011) continued this area of research and explored the relationship between executive function skills and adherence, and executive function skills and glycaemic control in adolescents aged 12-18 years, with Type 1 diabetes. The authors examined executive function skills including cognitive flexibility, attentional control and goal setting, and emotional regulation skills. The results indicated significant relationships between the executive functioning components and emotional regulation skills, and adherence to management regimens, and supported those of Bagner et al. (2007) and McNally et al. (2010). Graziano et al. (2011) identified that poorer levels of executive function and poorer emotional regulation skills were associated with poorer glycaemic control. However, these relationships were only identified amongst the male participants and not the female participants, thus suggesting the presence of gender differences in the relationship between executive function and adherence to diabetes management. Furthermore, additional analyses highlighted that emotional regulation skills were the key determinant of treatment adherence amongst the male participants, over and above their executive function skills, suggesting that an individual's propensity for emotional coping may have a greater impact on their treatment adherence than their cognitive abilities.

Miller et al. (2013) extended the work of McNally et al. (2010) in a longitudinal investigation into the relationship between changes in executive function and changes in diabetes self-management over a period of 2 years. Participants were aged 9-11 years upon entry into the study. Miller et al. (2013) identified improvements in only the behavioural regulation elements of executive function and not in the metacognition elements. The changes in behavioural regulation predicted improvements in overall diabetes self-management. These

results contrast with those of Bagner et al. (2007), who despite identifying a similar relationship between behavioural regulation executive functions and self-management, also identified a relationship between the metacognitive elements of executive function and self-management.

It is not possible to determine from the results of these limited studies alone, whether metacognitive elements of executive function are related to self-management. Miller et al. (2013) relied only on parent-report of executive function and noted themselves that this may not have provided a sensitive enough measure to detect the full extent of metacognitive behaviour in their child. Behavioural manifestations of metacognitive executive function may be more subtle and more difficult to detect than those drawing upon behavioural regulation components (Miller et al., 2013). The results of this study do, however, highlight the importance of determining which elements of executive functioning, if indeed any, are related to diabetes self-management or, in fact, to specific self-management behaviours.

Smith, Kugler, Lewin, Duke, & Storch (2014) investigated the relationship between executive function, adherence to self-management regimens and glycaemic control in 72 youths with Type 1 diabetes aged between eight and 18 years. They identified that executive function and adherence were moderately related, however no significant relationship was identified between executive function and glycaemic control. Further in-depth analysis revealed an interesting pattern of results. When dividing the children and adolescents into those with self-reported poor adherence and those with better adherence, associations between executive function and glycaemic control emerged. Adherence, as reported by the children and adolescents, was demonstrated to moderate the relationship between executive function and glycaemic control. In children and adolescents who reported better adherence, poorer

executive function was associated with poorer glycaemic control. In children and adolescents reporting poorer adherence, poorer executive functioning was related to better glycaemic control and better executive functioning was related to poor glycaemic control. The authors offered two potential explanations for these findings. Firstly, they questioned the reliability of self-reports of adherence from poorly adhering children. Secondly, they identified that the level of parental involvement in diabetes care amongst children and adolescents with varying executive function levels may have influenced adherence to treatment regimens. Smith et al. (2014) identified that there was greater disagreement between parents and children/adolescents regarding responsibility for diabetes care amongst children and adolescents with poor adherence, which may have resulted in neither parent nor child completing the management task, irrespective of the child's/adolescent's cognitive capacity to do so and thus may have contributed to the observed relationship between better executive function and poorer glycaemic control. Amongst participants with poor adherence, the authors found an association between lower levels of executive function and higher levels of perceived parent-criticism and nagging behaviour. Smith et al. (2014) posited that these critical behaviours from parents may support children and adolescents with poorer executive function to carry out their management tasks and achieve glycaemic control.

Duke, Raymond and Harris (2014) investigated the relationships between executive function, adherence and glycaemic control in a sample of adolescents aged 12-18 years. Setting this study apart from previous research was the use of a diabetes-specific measure of executive function: the Diabetes Related Executive Functioning Scale (DREFS). The DREFS is a 77-item measure, assessing the behavioural manifestations of executive functions, theoretically understood to be

involved in diabetes management. It contains eight domains consistent with those included in the Behavioural Rating Inventory of Executive Function measures (Gioia et al., 2000; Guy, Isquith, & Gioia, 2004) Planning, Organising Materials, Initiate Tasks, Monitoring, Shift, Emotional Regulation, Inhibit and Memory. The measure also includes three additional domains: Time Management, Distractibility and Sequential Task Completion. Higher scores on the DREFS equate to better executive function. The research revealed significant relationships between all study variables. A positive association between adherence and executive function was noted which means better adherence was associated with better executive function. A negative association between executive function and glycaemic control was identified, which means better executive function was associated with better glycaemic control, as measured by lower HbA1c values.

The results of this emerging literature indicate that a relationship does exist between executive function and diabetes self-management in children and adolescents. With the exception of the research of Smith et al. (2014), the general trend of results indicates that a relationship also exists between executive function and glycaemic control. The differences amongst results as to the details of the relationship between executive function and self-management and the unusual pattern of results regarding the association between executive function and glycaemic control highlighted by Smith et al. (2014), emphasises the need for further investigations into these relationships – their existence and nature.

Only six studies, as aforementioned, have directly investigated the relationship between executive functioning and Type 1 diabetes self-management and glycaemic control in young people. These studies are not without their limitations.



With the exception of Miller et al. (2013) all studies have been cross-sectional in design and therefore determining causality in the relationship identified between executive function and adherence to diabetes management is not possible. Furthermore, Bagner et al. (2007) excluded individuals using insulin pumps as a management method. This reduces the generalizability of their results to the wider adolescent diabetes population, especially in current practice, where pump therapy is frequently used amongst this age group (Johnson, Cooper, Jones, & Davis, 2013).

In the majority of those studies conducted, effect sizes have been small ( $d = 0.21$ ) such as in the work of Miller et al. (2013) and the strength of associations identified between variables have not been particularly strong, ranging from  $r = 0.27$ ,  $p < .001$  (McNally et al., 2010) to  $r = 0.38$ ,  $p < 0.01$  (Bagner et al., 2007). Graziano et al. (2011) did report stronger associations ( $r = 0.33$ ,  $p < .05$  to  $r = 0.58$ ,  $p < .001$ ), however, their findings were gender specific and relevant to specific constructs of executive function, rather than overall executive function composite scores. Duke et al. (2014) recently identified strong associations between self-management and diabetes-specific executive function skills ( $r = 0.59$ ,  $p < .01$  to  $r = 0.66$ ,  $p < .01$ ).

Glycaemic control was not measured in the research conducted by Bagner et al. (2007), so no objective measure of glycaemic control or self-management was included. McNally et al. (2010) identified a relationship between adherence and glycaemic control, but failed to identify a direct relationship between executive function and glycaemic control. Graziano et al. (2011) identified a relationship between specific constructs of executive function and glycaemic control, in boys only. Miller et al. (2013) found no predictive relationship between executive function and treatment adherence scores, and glycaemic control. Duke et al. (2014) did

identify a significant relationship between diabetes specific executive function skills and glycaemic control ( $r = -0.39, p < .01$  to  $r = -0.46, p < .01$ ).

The need for more robust data as to the presence and nature of the relationships between executive function, self-management and glycaemic control is highlighted upon review of the present literature and its inconsistencies.

The age ranges of participants recruited into the existing studies reviewed here highlight an area for improvement in study design in this area. Age ranges reported have either been rather broad for the investigation of relationships amongst adolescents, such as in the studies by Bagner et al. (2007) and Smith et al. (2014) who recruited youths aged between eight and 19 years, or too limited, such as in the work of McNally et al. (2010) and Miller et al. (2013) in which youths aged between nine and 11 years were recruited. Duke et al. (2014) and Graziano et al. (2011) have incorporated more appropriate age ranges within their recruitment (from 12 or 13 to 18 years) to reasonably explore executive function, self-management and glycaemic control in the adolescent population with Type 1 diabetes.

Bagner et al. (2007) did not identify age as a mediating factor of the relationship between executive function and adherence to diabetes treatment. The authors did suggest, however, that this might be a reflection of the possibility that responsibility for diabetes care, which changes with age, rather than age itself mediates this relationship. This study was designed to start to examine the possible relationship between responsibility for diabetes care and executive function.

With the exception of Duke et al. (2014), all aforementioned studies relied only on parent-report of the child's executive function, with no direct measure being retrieved from the young person themselves. This represents a further limitation of the existing literature, as parent-report may be vulnerable to response bias or perhaps

generalisation across responses on different elements of the measure (Graziano et al., 2011). In addition, when investigating the adolescent population, which as aforementioned is a time of developing autonomy, it is important to consider the perceptions of the young person themselves regarding their own ability. It is possible that the more responsibility for diabetes care held by the adolescent, the less accurate the parents responses on their diabetes-related behaviours will be (Bagner et al., 2007).

Furthermore, little consideration has been made to the amount of responsibility youths have for their diabetes care and what role this might play in self-management. As noted by McNally et al. (2010), the relationship between executive functioning ability and self-management may be stronger than has been identified in their research, or indeed, of greater importance in older adolescents who hold more responsibility for their diabetes care. Smith et al. (2014) suggest that youths with better executive functioning demonstrated poorer glycaemic control, because, in response to their executive functioning abilities, their parents may have withdrawn their support without ensuring the youth was taking the management tasks on themselves. This explanation further emphasises the need to establish the role responsibility for diabetes care may have on adolescent self-management.

## **1.6 Summary**

Executive function skills, as identified within this chapter, are important for carrying out diabetes self-management tasks. It is important to consider the abilities of adolescents in this cognitive domain in an attempt to better understand the barriers to successful diabetes self-management and diabetes control within this population. It is also necessary that we consider the potential extra importance of executive function skills during the transitional period of adolescence, as parents take a step

back and adolescents assume greater responsibility for their diabetes care and management activities (Nardi et al., 2008). In the independent management of diabetes, which is generally adopted during the period of adolescence, executive functions are likely to assume a role of even greater importance (Griffin, 2012). In light of this, it is not only necessary to continue research into the relationships between executive function and self-management and glycaemic control, and between responsibility for diabetes care and self-management and glycaemic control, but to consider if interrelations exist between executive function and responsibility for diabetes care.

Adolescence represents a time of development in numerous domains. With specific relevance to the diabetic population, it represents the period in which they are consolidating their learning of diabetes care knowledge and management strategies which they will carry with them throughout their lives (Williams et al., 2002). In light of this, adolescence represents an opportune time to enforce preventive strategies to reduce the chances of diabetes mismanagement and intervene with specifically tailored supports to enhance their learning and consolidate helpful and positive self-management behaviours and strategies.

### **1.7 Rationale for Current Study**

As there is currently no cure for Type 1 diabetes, it is important that we continue to understand the disease and the factors contributing to difficulties in its management, to ensure individuals are supported to achieve their optimal self-management and glycaemic control. There is an emerging literature indicating that children with diabetes are vulnerable to developing neuropsychological difficulties (Bade-White & Obrzut, 2009) and research has suggested an association between

impairments in adolescents' executive functioning and reduced self-management and subsequent diabetes control (Miller et al., 2013).

As discussed in section 1.5.3, only six studies, have directly investigated the relationship between executive functioning and Type 1 diabetes self-management in youths. There are inconsistencies in the results of these studies, specifically in terms of the nature of the relationship between executive functioning and self-management and executive function and glycaemic control. Furthermore, the research to date is limited by the variability in the age ranges of participants across the studies and an over-reliance on parent-report measures of adolescent executive function. Further research into this area is necessary to attempt to provide clarity as to the nature of the relationship between executive functioning and self-management and glycaemic control.

This chapter has outlined how responsibility for diabetes care has been shown to be associated with diabetes self-management amongst the adolescent Type 1 diabetes population (Helgeson et al., 2008). The evidence as to the nature of this relationship, however, remains inconsistent.

Little consideration has been given, in previous research, to potential contributing or mediating factors to the relationship between responsibility and diabetes self-management. If poorer self-management is associated with increased adolescent responsibility for diabetes care as suggested by Hsin et al. (2010) and Ingerski et al. (2010) it is important to explore why this might be. Griffin (2012) suggested that executive functions are likely to be of increased importance when adolescents take on greater independent responsibility for diabetes care. If increased adolescent responsibility is associated with poorer self-management, this association might indicate that adolescents do not have the necessary skills to carry out all self-

management tasks effectively, independently. The necessary skills may include cognitive abilities such as executive function skills, which have been identified as important for implementing self-management tasks (Nylander et al., 2013). Previous studies have suggested that responsibility for diabetes care may influence the potential relationship between executive function and diabetes self-management (McNally et al., 2010; Smith et al., 2014). Further research is required to develop our understanding of the role of responsibility on diabetes self-management and its possible association with potential factors affecting self-management such as executive function.

The current research aimed to identify if adolescent executive function and responsibility for diabetes care are associated with self-management and glycaemic control. The study also explored if executive function and responsibility for diabetes care are associated, to start to better understand the role of responsibility in adolescent self-management. The study was designed to address limitations of previous research (detailed in section 1.5.3) and summarised below.

Use of a direct adolescent measure of executive functioning addressed limitations of previous research, which have only relied on parent self-report measures. Parent report may be vulnerable to response bias or perhaps generalisation across responses on different elements of the measure. Inclusion of an adolescent-completed measure is important to enable an understanding of the perception of the individual with diabetes as to their own executive function abilities, particularly in the case of adolescents who are developing their autonomy. Bagner et al. (2007) suggested that increased adolescent responsibility for diabetes care may be associated with a less accurate parental report of their diabetes-related behaviours. Where possible, it would be beneficial to consider individual self-report alongside

parent-reports of executive function. Both adolescent-completed measures and parent-completed measures were included in this research study to address this.

This study aimed to improve upon the emerging literature in this area by ensuring the recruitment of a relevant participant sample to the study questions. The age ranges of participants recruited in previous research studies have been too broad (8-19 years) for the consideration of executive function and diabetes self-management during the period of adolescence (Bagner et al., 2007; Smith et al., 2014) or have provided too narrow an age range (9-11 years), at an earlier stage of development – that of pre-adolescence (McNally et al., 2010; Miller et al., 2013). This current study selected a participant age range of 11-18 years to enable a specific focus on the period of adolescence (World Health Organisation, 2014) and to fall in line with the age ranges supported by diabetes clinics before transition to adult services. In addition, the lower age limit coincides with the transition to high school for most children in the UK; a period in which responsibility levels for diabetes care start to change (Wiebe et al., 2014). Furthermore, this current research did not exclude adolescents using insulin pumps and included a measure of glycaemic control as an objective measure of self-management, to address limitations noted in the research by Bagner et al. (2007). The inclusion of individuals using insulin pumps in this current research, is particularly pertinent to current research and clinical practice as pump therapy is becoming more common amongst adolescents with Type 1 diabetes (Johnson et al., 2013). Provision of an objective measure of self-management through HbA1c values, alongside self-report measures of self-management helped to improve the robustness of results obtained in this study.

If we can establish whether there is a relationship between executive functioning and aspects of diabetes management, strategies and interventions can be

developed to support children and parents manage Type 1 diabetes more effectively as the child develops to adulthood. A greater understanding of responsibility for diabetes care and its association with executive function and self-management may also assist in providing patient-specific care to adolescents and their families at this transitional age.

### **1.8 Research Questions and Hypotheses**

The primary aim of the research was to establish if there was a relationship between adolescents' executive function - as measured by the parent-completed Behaviour Rating Inventory of Executive Function (BRIEF-Parent; Gioia et al., 2000) and the adolescent-completed Behaviour Rating Inventory of Executive Function – Self-Report Version (BRIEF-SR; Guy et al., 2004) and self-management of Type 1 diabetes, as measured by the Diabetes Self-Management Profile - Self-Report questionnaire (DSMP-SR; Wysocki, Buckloh, Antal, Lochrie, & Taylor, 2012) and glycaemic control, as measured by HbA1c values.

The research sought to establish if parent and adolescent reports of adolescent executive functioning and behaviour, amongst adolescents with Type 1 diabetes, were associated, as the majority of previous research has used only parent-report measures. In addition, it aimed to establish if responsibility, as measured by the Diabetes Family Responsibility Questionnaire (DFRQ; Anderson, Auslander, Jung, Miller, & Santiago, 1990), is related to diabetes self-management and glycaemic control and if a relationship exists between adolescent responsibility for diabetes care and executive functioning.

#### **1.8.1 Hypothesis 1**

Higher levels of adolescent executive functioning, as indicated by lower GEC scores on the adolescent and parent-completed BRIEF measures, will be



associated with better self-management of Type 1 diabetes, as indicated by higher total scores on the parent and adolescent-completed DSMP-SR.

### **1.8.2 Hypothesis 2**

Better adolescent self-management of Type 1 diabetes, as indicated by higher total scores on the parent and adolescent-completed DSMP-SR will be associated with better glycaemic control as indicated by lower HbA1c values.

### **1.8.3 Hypothesis 3**

Higher levels of adolescent executive functioning, as indicated by lower GEC scores on the adolescent and parent-completed BRIEF measures, will be associated with better glycaemic control as indicated by lower HbA1c values.

### **1.8.4 Primary research question 1**

Does adolescent executive function, as measured by the BRIEF measures and adolescent responsibility for diabetes care, as measured by DFRQ scores, predict adolescent self-management of Type 1 diabetes, as measured by DSMP-SR scores?

### **1.8.5 Primary research question 2**

Does adolescent executive function, as measured by the BRIEF measures and adolescent responsibility for diabetes care, as measured by DFRQ scores, predict adolescent glycaemic control, as measured by HbA1c values?

### **1.8.6 Secondary research question 1**

Is there a relationship between adolescent responsibility for diabetes care, as measured by DFRQ scores and adolescent executive function, as measured by the BRIEF measures?

**1.8.7 Secondary research question 2**

Are parent-completed and adolescent-completed measures of adolescent executive functioning, self-management and responsibility for diabetes care associated?

The measures used in this research will be described in greater detail in section 2.4 and the rationale for their selection will be provided.

## CHAPTER TWO

### 2. Methodology

#### 2.1 Chapter Overview

This chapter outlines the design of the research study, the participants recruited and the recruitment procedure. The measures selected for use in the study are then introduced and a rationale for their suitability for this research is given. Ethical considerations for the research study are outlined, followed by a detailed explanation of the study procedure. Finally, an overview of the planned analysis is provided.

#### 2.2 Design

This two-site study adopted a cross-sectional design to investigate if there is a relationship between executive function and self-management in adolescents with Type 1 Diabetes. The research also considered the role of responsibility for diabetes care in diabetes self-management. This study was designed to specifically identify and explore potential associations between adolescent executive function and adolescent responsibility for diabetes care and diabetes self-management and glycaemic control. Furthermore, it aimed to explore if adolescent executive function and responsibility for diabetes care were related.

A sample ( $n = 67$ ) of adolescents aged 11 to 18 years with a diagnosis of Type 1 diabetes completed a series of questionnaire measures assessing executive functioning, diabetes self-management and responsibility for diabetes care (detailed in section 2.4). The parents/caregivers of participating adolescents were also invited to take part and complete parent/caregiver versions of all the measures. Parent/caregiver participation was not compulsory and adolescents could still take part if their parent/caregiver did not wish to participate, provided the necessary

consent/assent were obtained. All measures were collected at a single time point. The data gathered were explored using correlational and multiple regression analyses.

## **2.3 Participants**

### **2.3.1 Sample size.**

Ninety participants were approached to take part in the study. Eight participants declined to take part, leaving a total sample of 82. Of these 82, 13 did not return their data sets and one participant returned the questionnaire measures before completing them. One participant disclosed upon return of the questionnaires that, at present, they were not requiring insulin to manage their diabetes. This data set was therefore removed from sample prior to analysis. The final sample consisted of data from 67 adolescents, both male and female, aged 11 to 18 years with Type 1 diabetes. Forty-one parents/caregivers also participated alongside their adolescent children.

An a priori power analysis was conducted using the heuristic,  $50 + 8(k)$ , where  $k$  is the number of predictor variables (Tabachnick & Fidell, 2007). This indicated a necessary sample size of 82 for multiple regression analyses to identify factors contributing to self-management or glycaemic control in Type 1 diabetes, based on the assumption that four predictor variables would be entered into the regression model. If only two predictor variables were included in the multiple regression analyses, based on the heuristic above, a sample size of 66 was required.

The power calculation indicated that a sample size of 82 was required in order to detect a medium-sized relationship, at the 0.05 level of significance, using multiple regression with four predictor variables or a sample size of 66 in order to detect a medium-sized relationship, at the 0.05 level of significance using multiple regression with two predictor variables. Due to challenges associated with

recruitment (discussed in section 4.7.2.1) only 67 adolescents and 41 parents/caregivers were recruited. Consequently, multiple regression analyses were conducted with only two predictor variables.

Power tables were referred to in order to estimate the necessary sample size for correlational analyses and paired t-tests, which were conducted to explore the research hypotheses and the secondary research questions. A sample size of between 20 and 25 participants was indicated for one-tailed Pearson correlation analyses, with 80% power to detect a moderate effect size ( $r = 0.50$ ) when exploring the research hypotheses (Clark-Carter, 2010, p 651). A sample size of between 25 and 30 participants was indicated for two-tailed Pearson correlation analyses, with 80% power to detect a moderate effect size ( $r = 0.50$ ) when exploring the secondary research questions (p 652). A necessary sample size of between 30 and 35 was indicated for a two-tailed paired t-test, with 80% power to detect a moderate effect size ( $d = 0.50$ ) when investigating secondary research question 1 (p 630).

### **2.3.2 Age range.**

Male and female adolescents aged 11 to 18 years were recruited for this research study. This age range was specified for adolescent recruitment, as it is relevant to both the clinical and social aspects of diabetes management. The World Health Organisation (2014) defines adolescence as the period between 10 and 19 years of age. In the United Kingdom, children transition to high school from age 11, which coincides with changes in responsibility levels for diabetes care amongst children and their parents (Wiebe et al., 2014; Ingerski et al., 2010). The DBPT (Randell, 2012) covers outpatient care of children up until their transfer to adult services at age 19. Due to many diabetes clinics supporting adolescents up to the age of 18 years, before their transition to adult services, this was chosen as the upper age

limit. Furthermore, the measures of executive function chosen for use in the research (see section 2.4) have been validated for the age range of the sample recruited.

### **2.3.3 Inclusion criteria.**

Recruitment for this study adhered to specific inclusion criteria, which are outlined below.

- The adolescent must have had their Type 1 diabetes diagnosis for at least one year.
- All participants were required to be able to understand written or spoken English to enable questionnaire completion.
- Any parents/caregivers who participated were required to cohabit predominantly (at least four out of seven days a week, on average) with the participating adolescent.

Participants must have had their diabetes diagnosis for at least one year in order to allow for sufficient time for individuals to become familiar with diabetes self-management and for appropriate use of the executive function measures. The measures of executive function required that respondents reported on the previous six months of behaviour, and it was necessary that the behaviours reported on were in the context of the adolescent having a diagnosis of Type 1 diabetes. Furthermore, this criterion prevented placing additional demands on the individual (and parent/caregiver) during the initial period of adjustment to a diabetes diagnosis.

The questionnaires investigated the adolescents' executive function, their diabetes self-management and their responsibility for diabetes care. It was necessary, therefore, that the participating parents/caregivers had knowledge of such behaviours. It was believed that in order for parents/caregivers to have sufficient knowledge of these behaviours it would require more frequent time to be spent

around the adolescent with Type 1 diabetes. Parents/caregivers were required to co-habit with the adolescent for, on average, at least four out of seven days per week. This helped to ensure they had sufficient knowledge of the adolescents' behaviours and functioning to complete the questionnaires.

Eligible adolescents were able to participate in the research study if their parent/caregiver did not also wish to take part in the study or if their parent/caregiver did not meet the eligibility criteria, provided that the necessary consent and assent was obtained.

#### **2.3.4 Exclusion criteria.**

Recruitment for this study also adhered to the following exclusion criteria.

- Individuals with a known diagnosed learning disability
- Individuals with a known severe psychiatric disorder
- Adolescents with a known co-morbid chronic condition such as renal disease or cystic fibrosis

Individuals with a diagnosed learning disability and those experiencing severe psychiatric distress were not eligible to participate, in order to prevent placing additional demands (such as questionnaire completion) upon such individuals and to prevent causing any additional distress associated with research participation. In addition, these criteria assisted in ensuring all individuals providing consent and assent for participation had capacity to do so.

Individuals with co-morbid chronic conditions such as renal disease or cystic fibrosis were not eligible for participation. All chronic conditions require management regimens including different components and place demands on individuals. This research was specifically interested in the management of diabetes and the relationship between this and executive function and adolescent

responsibility for diabetes care. Furthermore, cystic fibrosis-related diabetes is considered distinct from Type 1 diabetes, despite some overlapping aspects (Peckham & Morton, 2012) and inclusion of individuals with cystic-fibrosis-related diabetes would prevent the recruitment of a homogenous sample of adolescents specifically with Type 1 diabetes.

## **2.4 Measures**

This research study included four self-report questionnaire measures assessing participant demographic information, adolescent executive functioning, adolescent self-management of diabetes and responsibility for diabetes care as well as an objective measure of glycaemic control. These measures are described, in turn, below.

### **2.4.1 Demographic information sheet.**

Demographic questionnaires were designed for the purpose of this research study. The demographic questionnaires were administered in order to gather data on the cohort characteristics recruited for this research study. The demographic questionnaires also enabled collection of self-report information regarding the number of severe episodes of hypoglycaemia experienced by each participant. Previous research has suggested a relationship between severe hypoglycaemic episodes and cognitive function in individuals with Type 1 diabetes (see section 1.3.3) Information regarding episodes of hypoglycaemia was collected to enable the relationship between hypoglycaemic episodes and executive function to be explored (as a secondary analysis) if participants provided sufficient data.

Adolescents completed an adolescent version of a demographic questionnaire. Participating parents/caregivers were also asked to complete a parent/caregiver version of a demographic questionnaire. The parent/caregiver demographic



questionnaire included questionnaires regarding their own demographic information as well as questions related to the adolescent.

Copies of the demographic questionnaires can be found in Appendix A.

#### **2.4.2 Glycaemic control.**

Glycated haemoglobin (HbA1c) provides a measure of an individual's average blood-sugar levels over the previous 2-3 months. This is a standard recording taken at diabetes clinic appointments and is routinely collected for each attending patient. This recording was documented for each participant within the research study to provide a measure of his or her glycaemic control. Achieving glycaemic control by reaching an identified target HbA1c level, whilst avoiding severe episodes of hypoglycaemia (Rewers et al., 2009), is the key goal of diabetes self-management (Hannonen et al., 2003). Recent guidance for adolescents with Type 1 diabetes, identifies a target HbA1c value below 48mmol/mol (NICE, 2015).

Blood samples taken routinely in order to generate HbA1c recordings were analysed using a Tosoh G8 HPLC analyser or Siemens DCA analyser, depending on the recruitment site.

Participants were provided with a recording form to take into their clinic appointment to write down the HbA1c value. Clinic staff assisted in the completion of this form when necessary. A copy of this form can be found in Appendix B.

#### **2.4.3 Self-management of Type 1 diabetes.**

This research was interested in measuring adolescent self-management for diabetes, which refers to the activities/behaviours performed to maintain glycaemic control. It encompasses the processes of collaboration between the individual, their family and healthcare services (Schilling et al., 2002) and includes the following of

medical advice. As a result, a diabetes-specific measure of self-management behaviours was chosen for use in the research study.

The Diabetes Self-Management Profile – Self-Report questionnaire (DSMP-SR; Wysocki et al., 2012) was used as a measure of diabetes self-management. The necessary permissions from the first author of these measures were sought (Appendix C).

This measure was available for use in four different formats:

- i. DSMP-SR – Youth, Conventional
- ii. DSMP-SR – Youth, Flexible
- iii. DSMP-SR – Parent, Conventional
- iv. DSMP-SR – Parent, Flexible

Different formats of the DSMP-SR were used to enable both adolescents (youth versions) and parents/caregivers (parent version) to complete the measure. Different formats ensured that the measure was applicable to the type of diabetes management regime individuals were following, i.e. *Flexible* (insulin administration via subcutaneous pump or basal-bolus multiple daily injection regimen, and use of a carbohydrate counting dietary approach) or *Conventional* (fixed dose insulin regimens). Completion by both adolescents and parents/caregivers enabled the investigation of any association between adolescent and parent/caregiver perceptions of self-management behaviours.

The DSMP-SR is derived from the much longer, Diabetes Self-Management Profile (DSMP) structured interview (Harris et al., 2000). The DSMP-SR includes 24-items, which are categorised into five subscales relating to diabetes care: exercise, diet, hypoglycaemia, glucose testing and insulin. It was selected for use in this research, in part, as it does not simply measure an individual's adherence to given

medical advice or a treatment regimen and assesses performance of tasks specific to diabetes management, rather than general health behaviours or general management tasks of medical conditions. Diabetes management involves a number of specific and unique tasks such as carbohydrate counting and blood-glucose monitoring. Higher total scores indicated better adherence to self-management behaviours. A validation study of this measure (Wysocki et al., 2012) indicated that the measure demonstrates good internal consistency for both the youth and parent versions (Cronbach alpha = .82 and .80 respectively) and parent and youth scores on the DSMP-SR have been shown to be moderately associated ( $r = .60; p < .0001$ ), highlighting the relevance of the measure for this research study where both adolescent and parent/caregiver perceptions were sought. The measure was selected for use in this study as it was believed to provide a reliable measure of self-management behaviours. Youth and parent scores on the DSMP-SR have been shown to correlate significantly, at a moderate level, with HbA1c values ( $r = -.46; p < .0001$  and  $r = -.35; p < .0001$  respectively; Wysocki et al., 2012) indicating satisfactory concurrent validity. This correlation indicates that as DSMP-SR increase, demonstrating better self-management, HbA1c values decrease, indicating better glycaemic control. HbA1c values provide an objective measure of glycaemic control and thus, an objective indication as to how successful an individual's self-management is. The reliability and validity psychometric data for the DSMP-SR are similar to the data which are reported for the full DSMP interview (Lewin et al., 2010): child and parent scores on the DSMP have been shown to correlate significantly with HbA1c values ( $r = -.49; p < .001$  and  $r = -.43; p < .001$  respectively) and child and parent scores have been shown to be associated ( $r = .52; p < .001$ ).

The DSMP-SR is appropriate for use with youths from age 11 years and their parents/caregivers, the target participant sample for this research study. Completion time for this measure was between five and ten minutes, considerably less than the full DSMP (Harris et al., 2000), which takes between 20 and 30 minutes to complete. This reduced completion time was considered in the selection of a self-management measure, to help reduce participant burden in the research study. Parent and adolescent versions for conventional and flexible diabetes regimens were used as appropriate. All versions were equivalent in terms of scoring thus could be considered together for statistical analysis.

Copies of the DSMP-SR can be found in Appendix D.

#### **2.4.4 Responsibility for diabetes care**

The Diabetes Family Responsibility Questionnaire (DFRQ; Anderson et al., 1990) was used as a measure of responsibility for diabetes care in this research study.

The DFRQ is a 17-item questionnaire divided between three subscales of diabetes care responsibility: General Health Maintenance tasks, Regimen tasks, and Social Presentation of Diabetes. Higher scores indicate higher levels of adolescent responsibility for diabetes care. It was selected for use in this research study as it assesses the amount of responsibility taken by the adolescent for their diabetes care and was suitable for completion by both participating adolescents and parents/caregivers. The measure has demonstrated good internal consistency (Cronbach's  $\alpha = .85$ ; Anderson et al., 1990). Sand, Kleiberg and Forsander (2013) reported internal consistencies of Cronbach's  $\alpha = .87$  for both child and father-completed versions and Cronbach's  $\alpha = .90$  for mother-completed versions. For the current research study, items 3, 10 and 15 were amended from the original version (Anderson et al., 1990) to ensure applicability to adolescents using an insulin

pump, through the inclusion of the words “boluses” and “infusion set-ups” alongside the original words of “injections” and “injection sites”. These amendments were the same as those made by Vesco et al. (2010) in their research investigating responsibility sharing in adolescents with Type 1 diabetes. The measure demonstrated good internal consistency in their study for both adolescent and parent-completed versions (Cronbach’s alpha = .74 and .77, respectively). Research has identified moderate associations between adolescent and parent-completed versions of the DFRQ ( $r = .50, p < .0001$ ; Vesco et al., 2010). The DFRQ has been shown to demonstrate good concurrent validity. The concurrent validity of the DFRQ is indicated through research which has shown that adolescent responsibility for diabetes care, as measured by the DFRQ is strongly associated with adolescent age ( $r = .76, p < .000$ ; Sand et al., 2013). The DFRQ took the participating adolescents and parents/caregivers five minutes to complete.

Participating adolescents and parents/caregivers each were requested to complete all measures. Completion of the measures took between 30 and 45 minutes for each participant.

A copy of the DFRQ can be found in Appendix E.

#### **2.4.5 Executive function**

Two, related, measures of executive function were used in this research study:

- The Behaviour Rating Inventory of Executive Function – Self-Report (BRIEF-SR; Guy et al., 2004), which was completed by the participating adolescents.

- The Behaviour Rating Inventory of Executive Function – Parent (BRIEF-Parent; Gioia et al., 2000), which was completed by the participating parents/caregivers.

The two formats were included to enable a measure of the adolescents' executive function to be gathered from the adolescents themselves (BRIEF-SR) and from their parent/caregivers' perspective (BRIEF-Parent). Previous research has relied predominantly upon parent-completed measures of executive function, with the exception of Duke et al. (2014) who utilised a newly developed adolescent-completed measure of executive functioning – the DREFS, and included the BRIEF-SR in their pilot study. At the time of design, this current study was the first, to the researcher's knowledge, to include an adolescent-completed measure of executive functioning alongside a parent-completed measure. The use of an adolescent-completed measure of executive function hopes to extend the existing research to include adolescent perceptions of their executive function. Understanding the perception of the individual with diabetes as to their own executive function abilities is important, particularly in the case of adolescents who are developing their autonomy, in order to consider how this might relate to self-management.

The BRIEF measures are the most widely used measures of executive function and have been used across a wide variety of clinical populations (Roth, Isquith, & Gioia, 2014). The measures were selected for this research study as they provide ecologically valid assessments of executive function (Toplak, West, & Stanovich, 2013) and adopt a behavioural assessment approach (Roth et al., 2014). It has been demonstrated that although performance measures of executive function such as the Stroop Test (Jensen & Rohwer, 1966) or Tower Test (Strauss, Sherman & Spreen, 2006) provide a measure of the level of individual skills and processes

present within an individual, they are performed in highly standardised testing environments. This renders the results less applicable to the employment of executive function in everyday life for planning and implementing goal-directed behaviour, than ratings of executive function, such as the BRIEF measures (Toplak et al., 2013). Furthermore, it is acknowledged within the literature that performance based measures of executive function do not solely assess executive function as many of the tasks required by the assessments involve non-executive processes (Brocki & Bohlin, 2004). As a result, the BRIEF measures were used to ensure consistency across measures of executive function and to enable easier comparison with the emerging research in this area.

#### ***2.4.5.1 BRIEF-SR (Guy et al., 2004)***

The BRIEF-SR is an 80-item self-report questionnaire that assesses behavioural manifestations of executive functions. It is applicable for youths from age 11 and provides a rating of adolescents' own perceptions of their abilities and therefore was an appropriate measure to use for the purpose of this research. The measure allows for an overall executive function score - the *Global Executive Composite (GEC)* to be calculated. This composite score is comprised of two factors - the *Behavioural Regulation Index (BRI)* and the *Metacognition Index (MI)*. The BRI provides a measure of an individual's ability to control or regulate their behaviour and emotional responses. The MI provides an estimate of an individual's working memory ability and ability to initiate, plan, organise and complete tasks. Higher scores indicate more difficulty with executive function.

The two factors enabled for exploration of any trends in differences in ability between the two domains of executive function.

#### **2.4.5.2 BRIEF-Parent (Gioia et al., 2000)**

The BRIEF-Parent is an 86-item questionnaire that assesses the behavioural manifestations of executive function in youths aged 5 to 18 years, as rated by their parents. GEC, BRI and MI scores can be calculated. Higher scores suggest more difficulty with executive function.

Completion time for the BRIEF questionnaires was approximately 15 minutes.

The BRIEF-SR and BRIEF-Parent were selected for use in this research study as it has been shown that they provide reliable and valid measures of executive function. The BRIEF-SR demonstrates good internal consistency, ranging from moderate (Cronbach's alpha = .72) for fewer-item subscales to high (Cronbach's alpha = .96) for the full GEC (Guy et al., 2004). Similarly the BRIEF-Parent demonstrates high internal consistency, ranging from .80 to .97 for the full GEC (Gioia et al., 2000). The BRIEF-Parent has demonstrated good test-retest reliability over a period of two weeks for all subscales (range = .76-.85) and for the three index scores (GEC = .86, BRI = .84, MI = .88). The BRIEF-SR has demonstrated moderate to high test-retest reliability (range = .59-.85) over a period of 4.91 weeks for all subscales and good test-retest reliability for the three index scores (GEC = .89, BRI = .84, MI = .87).

Adolescent self-report ratings have been shown to be associated with parent ratings at a moderate level across the subscales (range = .36-.57) and for the three index scores (GEC = .56, BRI = .52, MI = .57; Guy et al., 2004). There is support within the literature for use of the BRIEF measures across a variety of different clinical settings and populations (Roth et al., 2014), including ADHD, epilepsy, schizophrenia and traumatic brain injury. Completion of the BRIEF measures by



both adolescents and parents/caregivers enabled associations between adolescent and parent/caregiver perceptions of adolescent executive functioning to be explored and to identify if, and how, these perceptions may differ.

The BRIEF measures are not available in the appendices as they are under copyright.

## **2.5 Management of Missing Data**

All questionnaire measures were scored according to the procedures outlined in the scoring manuals and instructions. Missing data on the BRIEF measures were managed by the procedure outlined in the respective manuals. Missing item responses on the BRIEF measures were assigned a value of one. None of the questionnaires obtained from the participant sample reached nor exceeded the maximum number of missing items recommended for reliable use of the measures (14 for the BRIEF-Parent and 16 for the BRIEF-SR). Missing data for the DSMP-SR measures were managed as per the instructions provided by the author. The maximum number of points for each missing item was subtracted from 86 (the maximum possible total score). The resultant score was then divided by 86, which produced a value between zero and one. The total score for the questionnaire being reviewed was then divided by this value to provide a total score adjusted for missing item responses. For the DFRQ, modal imputation was utilised for any missing item responses. Any questionnaire measures returned that had not been completed at all, were removed from the analysis. One DSMP-SR Parent questionnaire, one DFRQ-Parent questionnaire and three DFRQ-Youth questionnaires were returned without being completed at all and therefore were not included in the analyses.

## 2.6 Recruitment

Participants were recruited from two NHS diabetes clinics at two different hospital sites within the East Anglia region.

The researcher collated information packs and provided these to the lead Clinical Psychologist for each diabetes clinic team. Eligible adolescents were identified by the lead Clinical Psychologist, supported by members of the diabetes team and information packs were sent to these identified individuals. Information packs were addressed to the parents of adolescents aged between 11 and 15 years and to adolescents and parents for adolescents aged between 16 and 18 years. Information packs were also made available at the receptions of the diabetes clinics to enable access by individuals who met the inclusion criteria, who may have been missed during the initial identification process. This enabled individuals who had overlooked the information packs when sent through the post, or who never received the information pack, access to relevant study information. The Clinical Psychologist made the clinic staff aware of the eligibility criteria. The Clinical Psychologist at each site annotated the clinic lists to indicate which of the adolescents due to attend the clinic were eligible for participation.

A poster outlining the research was displayed in each of the diabetes clinics (Appendix F). This was used to help increase awareness of the research study amongst attendees at the clinics. It also provided an additional opportunity to raise awareness of the research amongst individuals who may have been missed during the initial identification process.

Information packs included age-appropriate participant information sheets (Appendix G), the eligibility criteria, the requirements of participants, contact details for the researcher, a letter signed by the Clinical Psychologist and Medical

Consultant for each diabetes service and a consent to contact form. The letter notified potential participants that the researcher was going to be present in diabetes clinics. The information packs also indicated that participants, following their participation, could be entered into a prize draw to win one of five £10 Amazon vouchers.

Eligible adolescents and parents/caregivers completed and returned their consent to contact form (that they received with their information pack) to hospital staff if they were happy for the researcher to approach them when they attended hospital for their clinic appointment. All individuals who attended the clinic were prompted by a member of hospital staff, upon arrival, that the researcher was present and were reminded to hand in their completed consent to contact form if they wished to do so. Blank consent to contact forms were made available at clinic receptions for individuals to complete if they had failed to bring theirs with them. If individuals had not received an information pack, a member of the diabetes clinic team referred to the annotated clinic list to establish if that individual had been identified as eligible for participation. If they had, they were offered an information pack and asked to complete a consent to contact form, if they wished to do so.

Consent to contact was obtained from all parents of participating adolescents aged between 11 and 15 years and from adolescents aged between 16 and 18 years. Adolescents aged between 11 and 15 years were asked to provide assent to be contacted by the researcher. Participating parents/caregivers also provided consent to be contacted. The researcher attended the diabetes clinics and approached these eligible participants in order to gain informed consent/assent.

The participant information sheets were provided for review during the consent/assent process. All potential participants were asked to confirm their age, and duration of Type 1 diabetes diagnosis when providing informed consent/assent.

After informed consent/assent was obtained, each participant was assigned a Personal Identification Code (PIC) to enable the location of data if participants wished to withdraw at a later stage (up until the point at which data had been entered onto the computer system for analysis). Participants were instructed to use their PIC to label their questionnaire measures, rather than their names or other personally identifiable information.

## **2.7 Ethical Considerations**

The proposed research was granted ethical approval via proportionate review from the NHS Ethics Committee (see Appendix H for letter of approval). NHS Research Governance Approval was sought for each recruitment site (see Appendix H for letters of approval). The British Psychological Society guidelines for Ethics and Conduct (2009) and the Code for Human Research Ethics (2014) were adhered to throughout the development and conduction of the research study, with particular consideration made to the guidance for research with children.

### **2.7.1 Consent.**

Information sheets were included in the information packs and provided to each potential participant approximately 14 days before their clinic appointment to enable sufficient time for familiarisation of the research, prior to gaining informed consent. These information sheets outlined the purpose of the research and the requirements of participants. The information sheets explicitly explained that participation in the research study was voluntary and that any decision to partake or refuse participation would not affect their diabetes care.

First, consent and assent to contact was obtained from all participants and, where necessary, their parents as outlined in section 2.6. The researcher attended the

diabetes clinics and approached these individuals to discuss the research and to obtain informed consent to participate.

Informed consent was obtained from all parents of adolescents aged 11 to 15 years and from adolescents aged 16 to 18 years prior to participation. Adolescents aged 11 to 15 years provided informed assent. Informed consent from parents/caregivers regarding their own participation was also obtained. All consent/assent forms were completed in the presence of the researcher to allow for discussion of the research.

Copies of the consent to contact, consent and assent forms are included in Appendix I.

### **2.7.2 Confidentiality.**

Each participant was assigned a Personal Identification Code (PIC) to enable the location of data if participants wished to withdraw. Participants were able to withdraw up until the point at which data had been entered onto the computer system for analysis. The PIC consisted of the first two letters of the participant's clinic's site name, the first two letters of their parent/carer's name and two numbers indicating the day they were born. This method enabled participants to recreate their PIC if they could not remember it.

Participants completed a form including their name, date of birth and PIC (Appendix J). This information was entered into a computer database. It was stored on a separate database to the questionnaire data. The paper PIC forms were then destroyed. This enabled participants to be followed-up by the clinical team if their outcome scores for the executive function measures, once standardised, were equal to or above 65 (see section 2.7.7 for more detailed information regarding this). The separate database was stored on an encrypted data stick. All other

forms/questionnaires, with the exception of consent/assent forms, were only labelled with the participants' PIC.

If participants wished to be entered into the prize draw, they provided their email address to the researcher. Email addresses were stored on a separate database on an encrypted data stick to ensure that they could not be traced back to the participants. Following the completion of the prize draw and after the winners had been notified, the database of email addresses was destroyed.

All data were stored according to the Data Protection Act (1998) and were not shared with any external agencies. The data were locked in an archive room at the University of East Anglia following the completion of the research and will now remain there for 10 years.

These confidentiality and data storage procedures were outlined to all participants on the participant information sheets.

### **2.7.3 Right to withdraw.**

All participants were informed, prior to participation and upon providing informed consent that they retained the right to withdraw from the research, up until the data had been entered for analysis, without identifying a reason.

No participants formally opted to withdraw from the research study, however 13 participants did not return their questionnaire measures and one participant returned questionnaire measures but had not completed them.

### **2.7.4 Coercion.**

The researcher was not involved in the identification of potential participants. A member of the diabetes team at each site contacted the potential participants in the first instance through the posting of information packs. All participants provided consent to be contacted by the researcher to discuss participation. The research was

discussed before informed consent/assent was obtained and opportunities were provided for participants to ask any questions they may have had about the research or their involvement.

#### **2.7.5 Debrief.**

A debrief information sheet was provided to all participants following the return of their questionnaires. This included contact details for the researcher and websites for participants to access other relevant support if they wished to. The debrief information sheet also explained to participants that a summary of the research findings would be available from the diabetes clinic once the research had been completed.

A copy of the debrief information sheet can be found in Appendix K.

#### **2.7.6 Distress.**

The inclusion and exclusion criteria were designed to minimise the possibility of participants experiencing distress. Adolescents were required to have had their diagnosis for at least one year in order to participate in the research, to prevent placing additional demands on the individual (and parent/caregiver) during the period of adjustment to a diabetes diagnosis. It is noted that psychological difficulties, emotional distress and challenges with coping can arise following diagnosis of diabetes amongst children and adolescents and are associated with a period of adjustment, but that these often subside after a period of six months (Bilous & Donnelly, 2010). The research did not involve harmful or unpleasant procedures. Points of support were included on the debrief information sheet to prepare for the unlikely event that a participant became distressed whilst completing the questionnaires. No participants became visibly distressed during their completion of

the questionnaires nor did they voice any concerns when returning the questionnaires to the researcher and during the debrief process.

### **2.7.7 Protocol if questionnaire scores suggested difficulties of clinical significance.**

Although none of the questionnaires used in the research study were diagnostic tools, scores on the BRIEF measures can provide some indication of potential difficulties in executive function if they exceed a certain level. If a participant's score on either one of the three indexes on the parent or adolescent-completed BRIEF measures, once standardised, was equal to or above 65, the diabetes clinic team for that participant was informed. Such scores may have been indicative of that individual experiencing difficulties in areas of executive function that are of clinical significance and therefore, the adolescent may have benefitted from additional follow-up contact and support.

When such cases arose, the researcher obtained the necessary identifying information from the PIC database and wrote a summary of the results. This report was provided to the Clinical Psychologist of the relevant diabetes team for review. The Clinical Psychologist then offered a follow-up contact with the participant and/or their parent/caregiver.

Twelve participants' scores exceeded the cut off of 65 and required follow-up contact from the Clinical Psychologist.

A template of this summary report can be found in Appendix L.

## **2.8 Procedure**

Once all consent and assent procedures had been conducted (as outlined in sections 2.6 and 2.7.1) participants were supported to create their PIC (see section 2.7.2) and then proceeded to questionnaire completion. The questionnaires were



completed whilst adolescents attended the hospital for their diabetes clinic appointment. Some participants began questionnaire completion during their attendance at the hospital for their diabetes clinic appointment and then completed them at home before returning them through the post. All participating adolescents were provided with an HbA1c recording form to take into their clinic appointment to be completed.

For those participants who opted to finish the questionnaires at home before returning them through the post, all consent/assent forms, PIC forms and the HbA1c record form were all completed whilst at the clinic.

Upon completion and return of the questionnaires to the researcher, a debrief information sheet was provided to each participant. At this point, participants were provided with the opportunity to enter into the prize draw and completed a prize draw entry form if they wished (Appendix M).

## **2.9 Planned Analysis**

This section outlines the planned analysis based on the research questions and hypotheses, which were formulated during the development of the research study. Any deviations from this plan, based on the data gathered from the conduction of the study, are outlined in Chapter 3.

The statistical software package, IBM SPSS version 22, was chosen to explore the data and conduct all statistical analyses. It was planned that the data set would be screened for errors in the data entry and for any missing data. Normality curves and Kolmogorov-Smirnov tests would then be used to assess the distribution of the variables. Where necessary, transformations were to be applied to those variables that differed, significantly, from a normal distribution. In order to ensure

that inter-correlated data were within an acceptable range for the purpose of the research, collinearity checks were also planned.

Descriptive statistics for the participant sample and the outcome measure variables were planned to be identified.

Multiple regression analyses were planned to establish relationships between predictor variables and the outcome variables of self-management and glycaemic control. Correlational analyses and independent samples t-tests were planned to establish the relationships between parent-completed and adolescent-completed measures.

## CHAPTER THREE

### 3. Results

#### 3.1 Chapter Overview

This chapter contains the results of the key analyses in relation to the study hypotheses and research questions. First, participant characteristics and demographic information are presented for the total sample. Relevant descriptive statistics are reported and any deviations from normality are acknowledged and statistical responses to this are identified. Each research question and research hypothesis is then addressed in turn: the relevant analyses are described and the results reported.

All data were entered and analysed using IBM SPSS statistical software package, version 22.

#### 3.2 Participant Sample

Recruitment for this research study took place from September 3<sup>rd</sup> 2015 to December 17<sup>th</sup> 2015. Ninety participants were approached to take part in the study. Eight participants declined to take part, leaving a total sample of 82. Of these 82, 13 did not return the questionnaires and one participant returned the questionnaire measures uncompleted. One participant disclosed upon return of the questionnaires that, at present, they were not requiring insulin to manage their diabetes. This data set was therefore removed from the analysis. Sixty-seven data sets were scored and analysed. Any missing data were managed as outlined in the methodology (see section 2.5). One DSMP-SR Parent questionnaire, one DFRQ-Parent questionnaire and three DFRQ-Youth questionnaires were returned without being completed at all and therefore were not included in the analyses.

Not all participants took part in the research with an accompanying parent or caregiver. Forty one (61.2%) of the sample provided parent-completed and

adolescent-completed measures, with a further 26 (38.8%) providing only adolescent-completed measures.

There were 41 sets of parent-completed measures, compared to 67 sets of adolescent data and therefore, after a priori power analyses, regression analyses carried out with the data (detailed later in the chapter) were only conducted using adolescent data and not parent data. As aforementioned, three DFRQ-Youth questionnaires were returned without being completed at all and were removed from the analyses. This resulted in two out of the three regression analyses being conducted with 64 full sets of adolescent data, rather than 66, which was indicated by the a priori power analyses for a powered analysis.

Sixty-six participants were identified as following a flexible diabetes management regimen (insulin pump or basal bolus injections with carbohydrate counting) and one participant reported following a conventional regimen that did not require carbohydrate counting or insulin corrective factors.

Table 1 reports the number of male and female participants and the type of diabetes regimen followed for the whole sample and divided into those with a participating parent/caregiver and those without.

Table 1

*Gender and Regimen Type for Participants With and Without a Participating Parent/Caregiver*

		With	Without	Total Sample
Gender	Male	15	19	34
	Female	26	7	33
Regimen Type	Flexible	40	26	66
	Conventional	1	0	1

There was one more male participant than there were female participants within the sample. A greater number of female participants (26) took part with an accompanying parent/caregiver than without (7), whereas more male participants took part without an accompanying parent/caregiver (19) than with an accompanying parent/caregiver (15). More females (26) took part with an accompanying parent/caregiver than males (15).

Demographic information for the whole participant sample is reported in Table 2.

Table 2

*Demographic Information for the Whole Sample of Participants*

	Mean ( <i>SD</i> )	Range	
		Minimum	Maximum
Adolescent Age	15.04 (2.07)	11.08	18.50
Adolescent Age at Diagnosis of Type 1 Diabetes	7.48 (3.88)	1.00	15.00
Duration of Type 1 Diabetes	7.22 (4.03)	1.00	17.00

The adolescent sample for this research study had a mean age of 15.04 years, a mean age of diagnosis of Type 1 diabetes of 7.48 years and a mean duration of Type 1 diabetes of 7.22 years. The sample included adolescents spanning the range of the inclusion criteria for age, from 11.08 years to 18.50 years.

Demographic information for the participants with a participating parent/caregiver and those without a participating parent/caregiver is presented in Table 3.

Table 3

*Demographic Information for Participants With and Without a Participating Parent/Caregiver*

	With			Without		
	Mean ( <i>SD</i> )	Range		Mean ( <i>SD</i> )	Range	
		Minimum	Maximum		Minimum	Maximum
Adolescent Age	14.42 (1.93)	11.08	17.92	16.03 (1.93)	12.50	18.50
Adolescent Age at Diagnosis of Type 1 Diabetes	6.62 (3.53)	1.00	14.00	9.02 (3.93)	1.00	15.00
Duration of Type 1 Diabetes	7.54 (4.15)	1.00	17.00	6.72 (3.86)	1.00	15.00

Adolescents who took part with a participating parent/caregiver were younger in age ( $M = 14.42$ ) than those who took part without a participating parent/caregiver ( $M = 16.03$ ). Adolescents who took part with a participating parent/caregiver were, on average, younger at age of diagnosis ( $M = 6.62$ ) and had a longer duration of Type 1 diabetes ( $M = 7.54$ ) than those who took part without a participating parent/caregiver who were older at age of diagnosis ( $M = 9.02$ ) and had a shorter duration of Type 1 Diabetes ( $M = 6.72$ ).

Demographic information, executive functioning scores and HbA1c values for those individuals reporting previous episodes of severe hypoglycaemia are

presented in Table 4. A standardised score of 65 or above on any one of the BRIEF measures, on any one of the three indexes (GEC, BRI, MI) was used as an indicator of potential difficulties of clinical significance within those executive function domains (Gioia et al., 2000; Guy et al., 2004).

Table 4

*Demographic Information, Executive Function Scores and HbA1c Values for Adolescents Who Reported Previous Episodes of Severe Hypoglycaemia*

Gender	Age at diagnosis	Episodes of severe hypoglycaemia	Executive Function						HbA1c
			BRIEF-SR			BRIEF-Parent			
			GEC	BRI	MI	GEC	BRI	MI	
M	5	1 to 2	41	40	43	-	-	-	56
F	14	1 to 2	<b>80</b>	<b>73</b>	<b>81</b>	64	58	<b>67</b>	53
F	8	1 to 2	53	54	52	48	52	45	59
F	2	1 to 2	49	49	50	54	46	58	64
M	1	3 to 5	<b>67</b>	<b>68</b>	64	-	-	-	76
F	1	1 to 2	49	47	50	47	47	48	57
F	3	1 to 2	62	54	<b>67</b>	49	45	51	71
F	6	1 to 2	35	35	37	38	40	37	65

*Note: Scores in bold typeface exceed the cut off of 65 on the respective BRIEF index*



Six of the eight adolescents who reported having experienced one or more episode of severe hypoglycaemia were female. All HbA1c values recorded for the eight adolescents who reported one or more previous episodes of severe hypoglycaemia were above the recommended target value of 48mmol/mol (NICE, 2015). One adolescent reported experiencing more than two episodes of severe hypoglycaemia. This individual was male, had the highest HbA1c value (76mmol/mol) out of the eight adolescents who reported previous episodes of severe hypoglycaemia and exceeded the cut off of 65 on two indexes of the BRIEF-SR. A total of three adolescents, who reported previous episodes of severe hypoglycaemia, exceeded the cut off of 65 on at least one index of one of the BRIEF measures.

### **3.3 Exploration of Data**

The demographic and outcome measure data were explored for normality and assumption violations for subsequent parametric testing. Exploration of the HbA1c data revealed that the distribution was significantly non-normal,  $D(67) = .11, p = .03$ . Three significant outliers were identified (see Figure 1). These outliers were confirmed as accurate data points and despite their extreme value were not considered to be invalid. For the purpose of the subsequent analyses, these three data points were transformed. The data points were placed in order of increasing value and altered to the highest “normal” HbA1c value in the data set plus one, plus two or plus three (respective to their order of value). As a result, the distribution of the HbA1c data did not differ significantly from the normal distribution,  $D(67) = .09, p = .20$ .

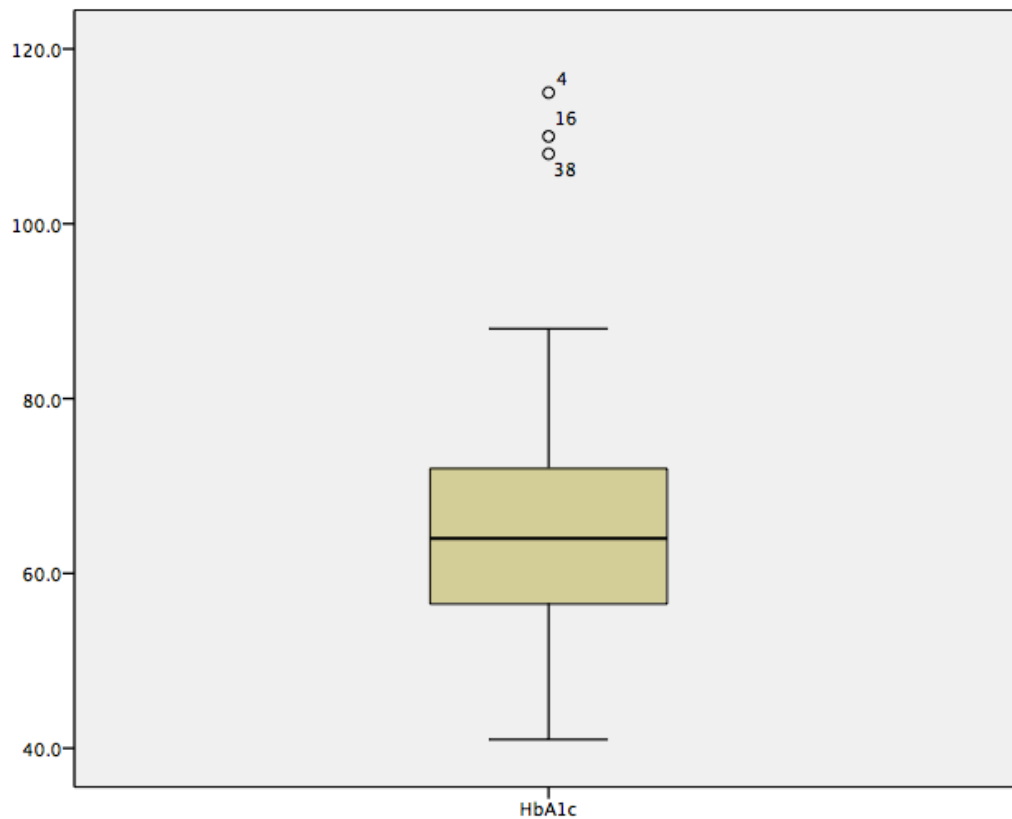


Figure 1. Outliers within the sample distribution of the HbA1c values, before transformation

The distribution of data for the Duration of Type 1 Diabetes within the whole sample was also identified as significantly non-normal,  $D(67) = .12, p = .02$ . However, as these data were to be used to identify if adolescents with a participating parent differed from those without a participating parent on this demographic variable, it was the distribution of this data within each group that was of importance. This data for adolescents without a participating parent/caregiver did not significantly differ from the normal distribution,  $D(26) = .12, p = .20$ . For adolescents with a participating parent/caregiver the Kolmogorov-Smirnov test just reached significance for the Duration of Type 1 Diabetes data,  $D(41) = .14, p = .05$ . Levene's test for homogeneity of variance between the two groups, however, did not reach significance for this data,  $F = .17, p = .68$ . For the purpose of subsequent

comparative analysis the Duration of Type 1 Diabetes data for each group (with and without a participating parent/caregiver) was treated as meeting the necessary assumptions for parametric testing (independent t-tests).

Descriptive statistics for the outcome measures are presented in Table 5 and Table 6.

Table 5

*Descriptive Statistics for Outcome Measures from the Whole Sample*

	n	Mean (SD)	Range	
			Minimum	Maximum
BRIEF-SR GEC	67	48.15 (10.95)	32.00	80.00
BRIEF-Parent GEC	41	52.51 (9.40)	38.00	78.00
DSMP-SR Youth	67	57.66 (9.27)	35.00	79.00
DSMP-SR Parent	40	57.80 (10.30)	27.00	74.00
DFRQ Youth	64	37.88 (5.82)	21.00	50.00
DFRQ Parent	40	33.80 (5.10)	26.00	46.00
HbA1c <sup>a</sup>	67	65.05 (11.71)	41.00	91.00

<sup>a</sup>HbA1c values were measured in mmol/mol

The mean scores on the GEC index for both the BRIEF-SR ( $M = 48.15$ ) and BRIEF-Parent ( $M = 52.51$ ) in the sample were below the cut off of 65. The mean adolescent-completed BRIEF-SR GEC scores were lower (indicating better executive function) than those reported from the parent/caregiver-completed BRIEF-Parent. The mean HbA1c value ( $M = 65.05$ ) for the adolescent sample was above the recommended target for adolescents with Type 1 diabetes of 48mmol/mol (NICE, 2015). Scores from the adolescent-completed DFRQ Youth were higher, indicating greater adolescent responsibility for diabetes care ( $M = 37.88$ ) than the parent/caregiver-completed DFRQ Parent ( $M = 33.80$ ).

Table 6

*Descriptive Statistics for the BRIEF-SR Measure for the Whole Adolescent Sample, Including Overall and Index Scores*

	n	Mean (SD)	Range	
			Minimum	Maximum
BRIEF-SR GEC	67	48.15 (10.95)	32.00	80.00
BRIEF-SR BRI	67	47.27 (10.43)	32.00	89.00
BRIEF-SR MI	67	49.08 (11.56)	31.00	81.00

The mean scores on all three indexes of the BRIEF-SR: the GEC ( $M = 48.15$ ), BRI ( $M = 47.27$ ) and MI ( $M = 49.08$ ) in the sample were below the cut off of 65. Review of the maximum scores from the calculated range for each of the index

scores (reported in Table 6) indicates however, that the sample did include participants with scores, which exceeded 65 on the BRIEF indexes.

Exploration of the sample data showed that 12 out of 67 participants scored above 65 on at least one index on one of the BRIEF measures. This suggests, that 17.91% of the participant sample had difficulties with areas of executive function, which may be of clinical significance, as measured by the BRIEF questionnaires. Table 7 displays the scores on each index of the BRIEF measures for those individuals who exceeded 65 on at least one of the indexes on either the BRIEF-SR or the BRIEF-Parent.

Table 7

*Demographic Information and Executive Function Scores for Individuals Exceeding 65 on One or More Index of the BRIEF Measures Within the Sample*

Gender	Age	Age at diagnosis	Executive Function					
			BRIEF-SR			BRIEF-Parent		
			GEC	BRI	MI	GEC	BRI	MI
M	18.25	13	<b>66</b>	61	<b>68</b>	-	-	-
M	17.42	10	59	46	<b>68</b>	59	47	63
M	16.67	6	61	50	<b>68</b>	-	-	-
F	15.00	14	<b>80</b>	<b>73</b>	<b>81</b>	64	58	<b>67</b>
M	13.83	1	<b>67</b>	<b>68</b>	64	-	-	-
F	13.00	3	62	54	<b>67</b>	49	45	51
M	16.50	0	55	43	63	<b>68</b>	55	<b>71</b>
F	11.92	10	<b>66</b>	52	<b>76</b>	63	63	62
F	13.92	8	44	42	46	<b>67</b>	<b>72</b>	62
M	15.58	4	63	63	61	<b>70</b>	61	<b>72</b>
F	12.75	2	64	55	<b>69</b>	<b>78</b>	<b>68</b>	<b>81</b>
F	14.00	11	<b>77</b>	<b>89</b>	63	58	<b>67</b>	52

*Note: Scores in bold typeface exceed the cut off of 65 on the respective BRIEF index*

Scores for nine of the 12 participants exceeded the cut off score of 65 on the GEC. Scores for nine of the 12 participants exceeded the cut off score of 65 on the MI. In contrast, scores for only five participants exceeded the cut off score of 65 on the BRI. One participant exceeded the cut off score of 65 on all three indexes of the BRIEF-SR and similarly, one participant exceeded the cut off score of 65 on all three indexes of the BRIEF-Parent. Both of these participants were female.

Children and adolescents are given an HbA1c target level of  $< 48\text{mmol/mol}$  (NICE, 2015). Exploration of the data from this sample showed that only three participants achieved this target with 64 participants reporting an HbA1c value above  $48\text{mmol/mol}$ . This suggests that overall the participant sample did not demonstrate good glycaemic control. In light of the fact that the HbA1c target value was only recently reduced in 2015, it is important to note that 24 of the 67 participants (35.8%) achieved the previous target value of  $58\text{mmol/mol}$  or below. This may suggest that glycaemic control within this participant sample could be slightly better than the initial figure (three participants), achieving the present target suggests, and could be indicative of an adjustment phase of children and adolescents working towards the new recommended target. Even taking this recent change in target values into consideration, however, the majority (64.2%) of the participant sample failed to reach an HbA1c value in line with either the previous or present targets.

Further analyses were planned to explore the associations between parent-completed and adolescent-completed measures. It was necessary therefore, to establish if there were any significant differences between the adolescents with a participating parent and those without, in terms of demographic information and outcome measure data, in order to accurately inform interpretation of the results.

Descriptive statistics were therefore generated for adolescents with and without a participating parent/caregiver. These are displayed in Table 8.

Table 8

*Descriptive Statistics for Adolescents With and Without a Participating Parent/Caregiver on the Study Measures*

	With		Without	
	n	Mean (SD)	n	Mean (SD)
BRIEF-SR GEC	41	47.66 (11.84)	26	48.92 (9.57)
BRIEF-SR BRI	41	46.49 (11.16)	26	48.50 (9.25)
BRIEF-SR MI	41	48.85 (12.75)	26	49.42 (9.61)
DSMP-SR Youth	41	57.76 (10.12)	26	57.50 (7.93)
DFRQ Youth	39	36.59 (4.59)	25	39.88 (6.99)
HbA1c	41	65.59 (10.91)	26	64.20 (13.06)

*Note.* *n* refers to the number of completed measures within the sample

Independent t-tests were conducted in order to establish if there were significant differences between demographic and outcome data for the adolescents with and without a participating parent/caregiver, using the data in Tables 3 and 8. The Bonferroni-Holm correction (1979) for multiple comparisons was used in order to control the family-wise error rate. (See Table N1 for a full overview of the t-test results).



The results showed that adolescents with a participating parent/caregiver were significantly younger ( $M = 14.42$ ,  $SD = 1.93$ ) than adolescents without a participating parent/caregiver ( $M = 16.04$ ,  $SD = 1.93$ ),  $t(65) = 3.35$ ,  $p = .001$ . The two groups of adolescents did not significantly differ on any other variable or outcome measure.

### 3.4 Main Statistical Analyses

#### 3.4.1 Research hypotheses.

*3.4.1.1 Hypothesis 1: Higher levels of adolescent executive functioning, as indicated by lower GEC scores on the adolescent and parent-completed BRIEF measures, will be associated with better self-management of Type 1 diabetes, as indicated by higher total scores on the parent and adolescent-completed DSMP-SR.*

Pearson correlations indicated that BRIEF-SR GEC scores and DSMP-SR Youth scores were negatively correlated,  $r(67) = -.42$ ,  $p < .001$ . This negative correlation means that as BRIEF-SR GEC scores decrease, indicating better executive functioning, DSMP-SR scores increase, indicating better diabetes self-management. This relationship is presented graphically in Figure 2. Similarly, BRIEF-Parent GEC scores were also negatively correlated with DSMP-SR Parent scores,  $r(40) = -.46$ ,  $p = .003$ . This negative correlation means that as BRIEF-Parent GEC scores decrease, indicating better executive functioning, DSMP-SR Parent scores increase, indicating better diabetes self-management. This relationship is presented graphically in Figure 3.

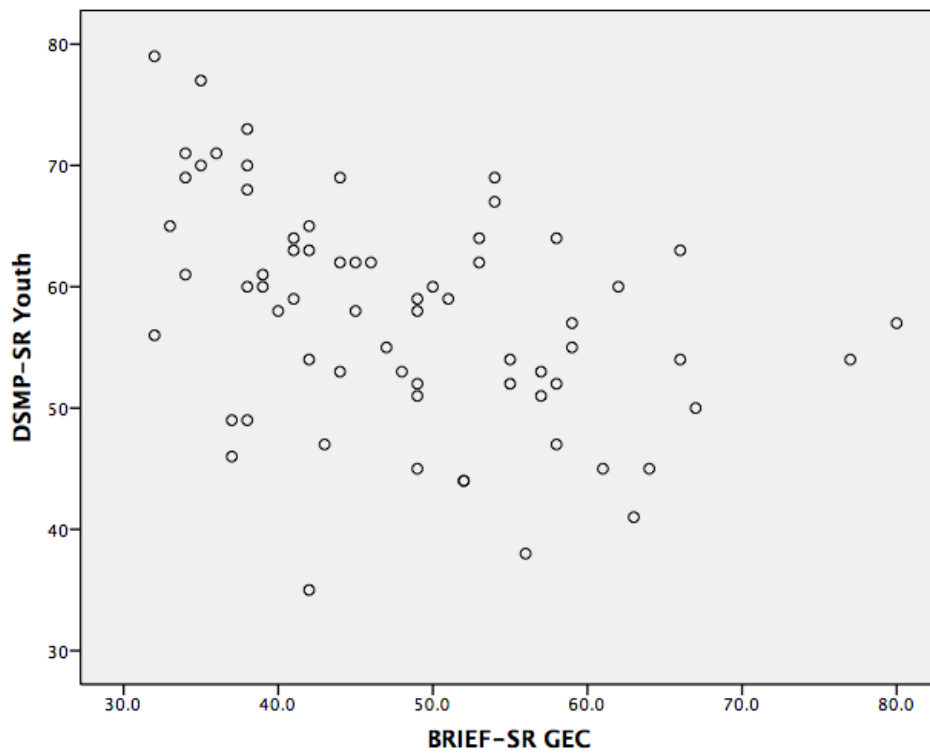


Figure 2. Negative correlation between BRIEF-SR GEC scores and DSMP-SR Youth scores

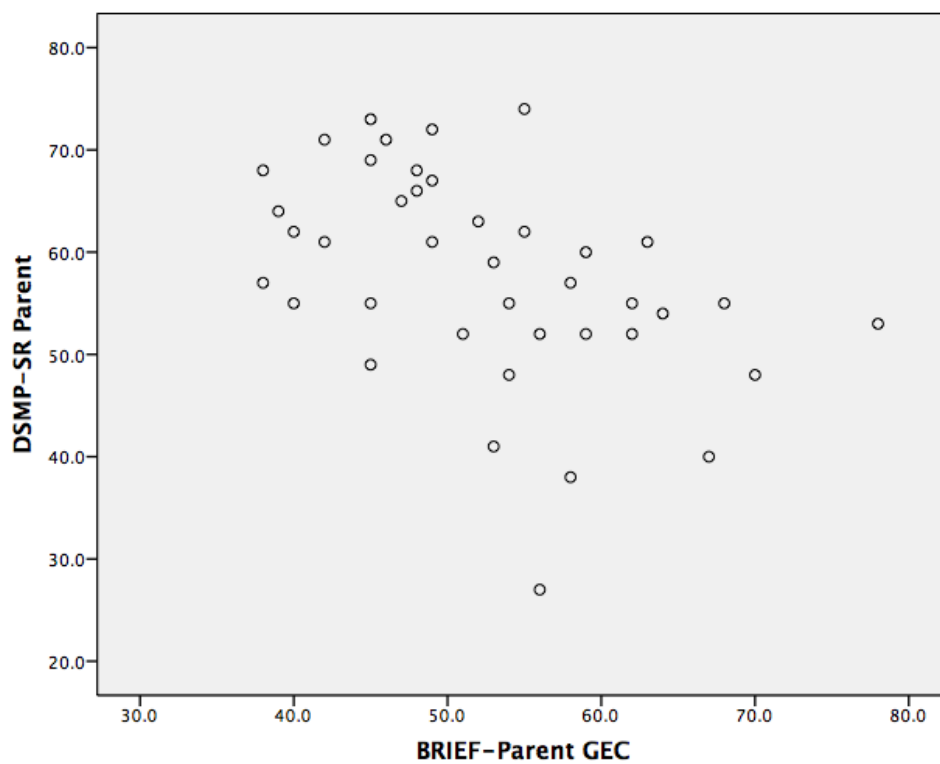


Figure 3. Negative correlation between BRIEF-Parent GEC scores and DSMP-SR Parent scores

The results of this analysis support the hypothesis that better adolescent executive functioning, as indicated by lower BRIEF GEC scores is associated with better self-management of Type 1 diabetes, as indicated by higher total scores on the DSMP-SR with both adolescent and parent-completed measures.

***3.4.1.2 Hypothesis 2: Better adolescent self-management of Type 1 diabetes, as indicated by higher total scores on the parent and adolescent-completed DSMP-SR will be associated with better glycaemic control as indicated by lower HbA1c values.***

Pearson correlations indicated that DSMP-SR Youth scores and HbA1c values were negatively correlated,  $r(67) = -.26, p = .03$ . This negative correlation means that as DSMP-SR Youth scores increase, indicating better diabetes self-management, HbA1c values decrease, indicating better glycaemic control. This relationship is presented graphically in Figure 4. Similarly, DSMP-SR Parent scores were also negatively correlated with HbA1c values,  $r(40) = -.45, p = .003$ . This negative correlation means that as DSMP-SR Parent scores increase, indicating better diabetes self-management, HbA1c values decrease, indicating better glycaemic control. This relationship is presented graphically in Figure 5.

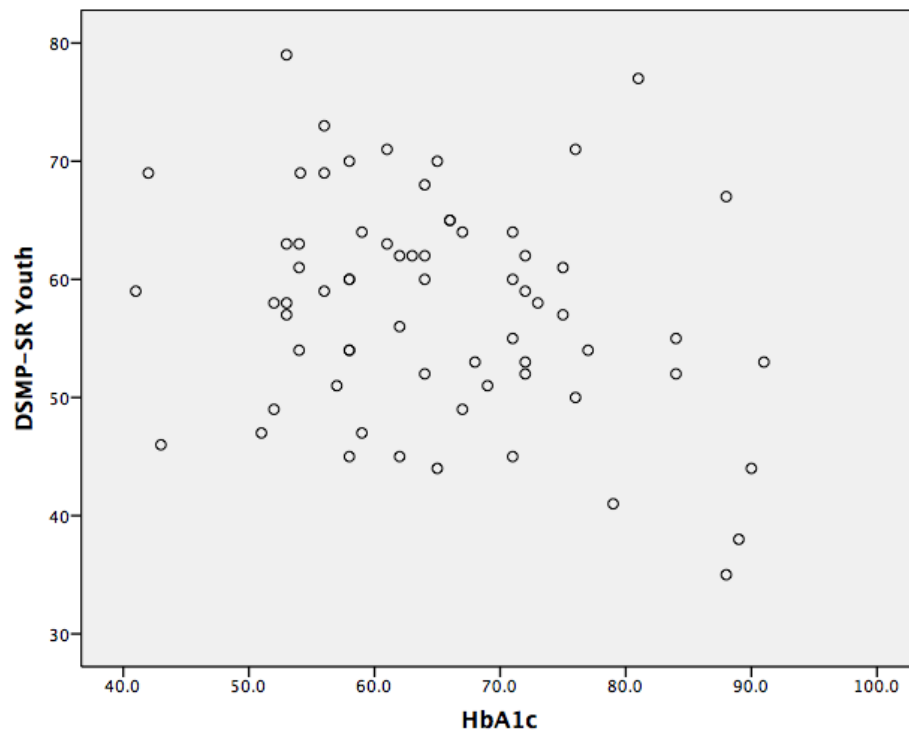


Figure 4. Negative correlation between DSMP-SR Youth scores and HbA1c values

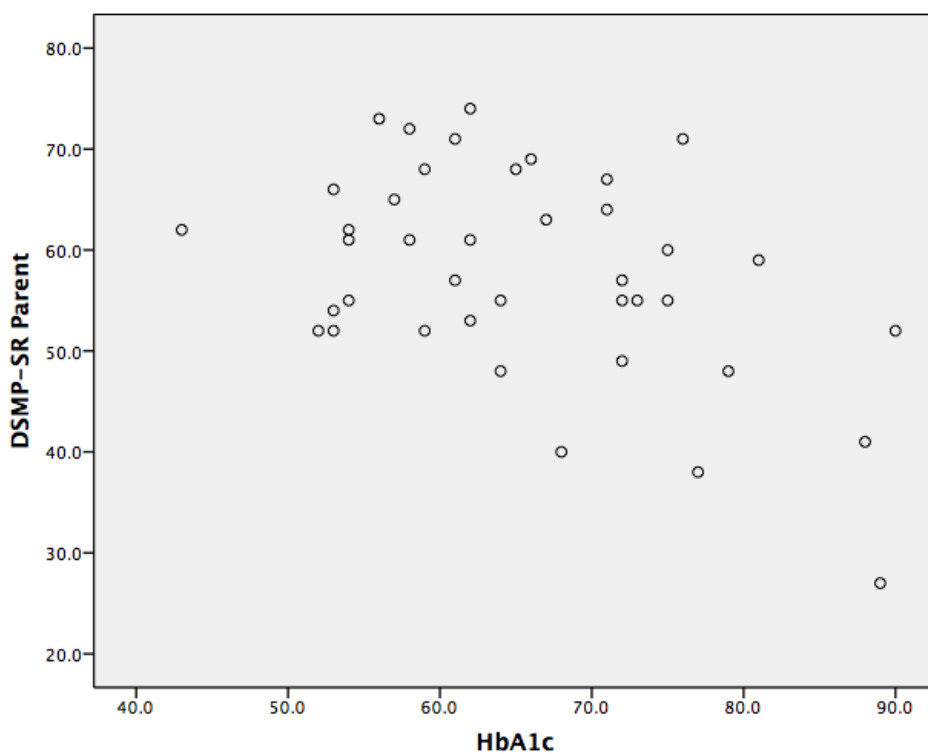


Figure 5. Negative correlation between DSMP-SR Parent scores and HbA1c values

The results of this analysis support the hypothesis that better adolescent self-management of Type 1 diabetes, as indicated by higher DSMP-SR scores are

associated with better glycaemic control, as indicated by lower HbA1c values, with both adolescent and parent-completed measures.

**3.4.1.3 Hypothesis 3: Higher levels of adolescent executive functioning, as indicated by lower GEC scores on the adolescent and parent-completed BRIEF measures, will be associated with better glycaemic control as indicated by lower HbA1c values.**

Pearson correlational analyses indicated that there was no significant relationship between BRIEF-SR GEC scores and HbA1c values,  $r(67) = .22, p = .08$ . A scatterplot demonstrating this relationship is presented in Figure 6. Furthermore, no significant linear relationship was identified between BRIEF-Parent GEC scores and HbA1c values,  $r(41) = .09, p = .56$ , as can be seen in Figure 7.

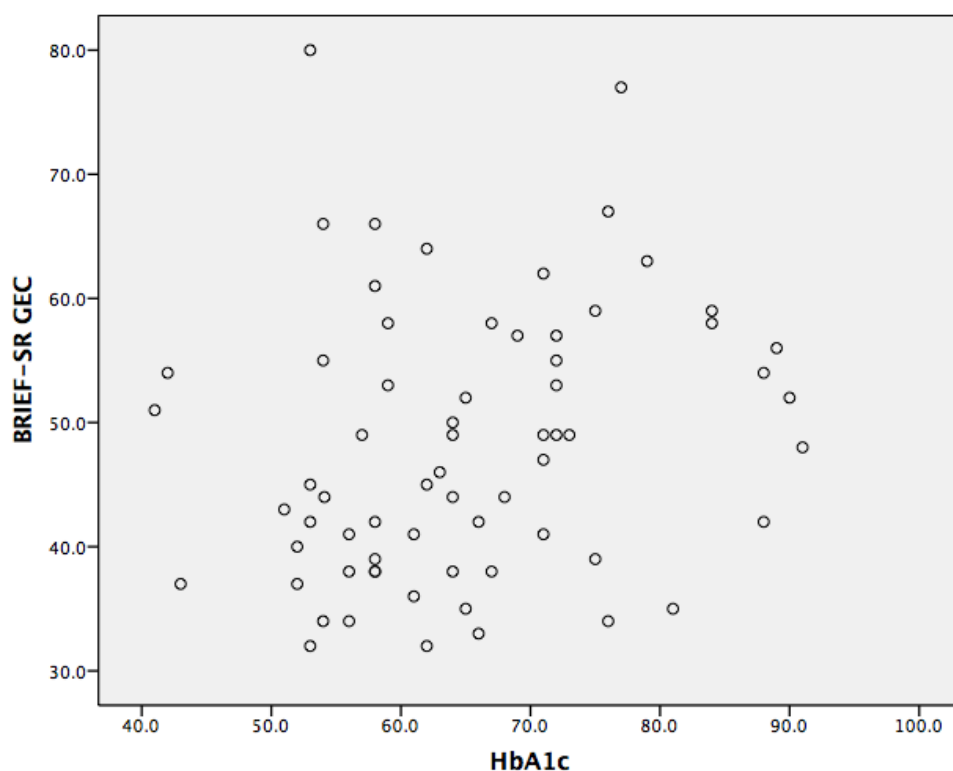


Figure 6. Non-significant correlation between BRIEF-SR GEC scores and HbA1c values

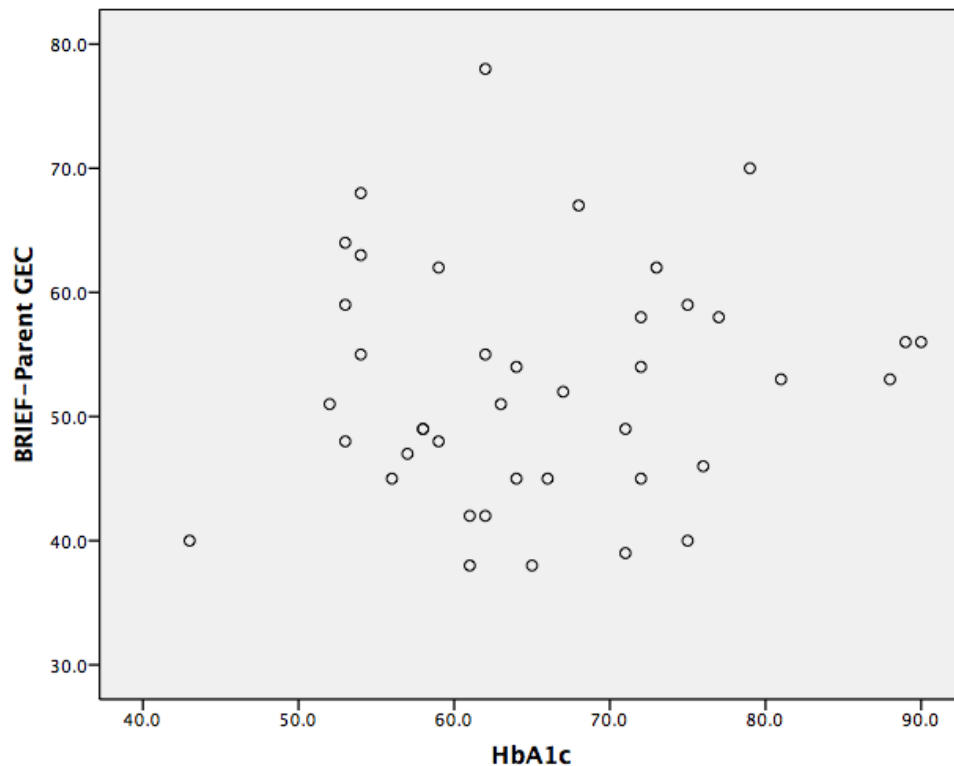


Figure 7. Non-significant correlation between BRIEF-Parent GEC scores and HbA1c values

The results of this analysis do not support the hypothesis that higher levels of adolescent executive functioning, as indicated by lower BRIEF-SR GEC scores were associated with better glycaemic control as indicated by lower HbA1c values.

### 3.4.2 Primary research questions.

**3.4.2.1 Primary research question 1: Does adolescent executive function, as measured by the BRIEF measures and adolescent responsibility for diabetes care, as measured by DFRQ scores, predict adolescent self-management of Type 1 diabetes, as measured by DSMP-SR scores?**

A multiple regression analysis was conducted in order to address this research question. Because of the size of the data set and after a priori power analyses, this regression analysis was conducted using only the adolescent data. Regression analyses were not conducted on the 41 sets of parent data.

The multiple regression analysis was conducted with BREIF-SR GEC scores and DFRQ Youth scores as predictor variables and DSMP-SR Youth scores as the outcome variable. The data were examined for violations of assumptions.

The data met the necessary assumptions for multiple regression analyses (see Appendix O for details and relevant test statistics).

The predictor variables BRIEF-SR GEC and DFRQ Youth were entered into the regression model using simultaneous entry. The results revealed that BRIEF-SR GEC scores and DFRQ Youth scores explain a significant amount of the variance in DSMP-SR Youth scores,  $F(2, 61) = 6.98, p = .002$ . The results of this multiple regression analysis are displayed in Table 9.

Table 9

*Results of the Multiple Regression Analysis Predicting DSMP-SR Youth Scores from BRIEF-SR GEC and DFRQ Youth Scores*

	<i>B</i>	<i>SE B</i>	$\beta$
Constant	71.84	9.06	
BRIEF-SR GEC	-0.35	0.10	-.42*
DFRQ Youth	0.08	0.18	.05

*Note.*  $R^2 = .19, R^2_{\text{Adjusted}} = .16. * p = .001.$

The results of this multiple regression analysis indicate that DFRQ Youth scores did not significantly predict DSMP-SR Youth scores, however, BRIEF-SR GEC scores significantly predicted 19% of the variance in DSMP-SR Youth scores.

The difference between the value of  $R^2$  (.19) and the value of  $R^2_{\text{Adjusted}}$  (.16) is .03.

This reduction means that this multiple regression model would account for 3% less variance in DSMP-SR Youth scores if it were derived from a population rather than a sample. This suggests reasonable generalizability of the regression model, as the model would still account for 16% of variance in DSMP-SR Youth scores when derived from a population.

As BRIEF-SR GEC scores were identified as a significant predictor of DSMP-SR Youth scores in the above model, an additional multiple regression analysis was conducted to investigate if different aspects of executive function (as measured by the BRIEF measures) accounted for different amounts of variance in DSMP-SR Youth scores. A multiple regression analysis was conducted with BRIEF-SR BRI scores (a measure of an individual's ability to control or regulate their behaviour and emotional responses) and BRIEF-SR MI scores (an estimate of an individual's ability to initiate, plan, organise and complete tasks) as predictor variables and DSMP-SR Youth scores as the outcome variable. The data were examined for violations of assumptions.

The data met the necessary assumptions for multiple regression analyses (see Appendix P for details and relevant test statistics).

The predictor variables BRIEF-SR BRI and BRIEF-SR MI were entered into the regression model using simultaneous entry. The results revealed that BRIEF-SR BRI scores and BRIEF-SR MI scores explain a significant amount of the variance in DSMP-SR Youth scores,  $F(2, 64) = 9.95, p < .001$ . The results of this multiple regression analysis are displayed in Table 10.



Table 10

*Results of the Multiple Regression Analysis Predicting DSMP-SR Youth Scores from BRIEF-SR BRI and BRIEF-SR MI Scores*

	<i>B</i>	<i>SE B</i>	<i>β</i>
Constant	74.64	4.96	
BRIEF-SR BRI	-0.11	0.13	.12
BRIEF-SR MI	-0.45	0.12	-.56*

*Note.*  $R^2 = .24$ ,  $R^2_{\text{Adjusted}} = .21$ . \*  $p < .001$ .

The results of this multiple regression analysis indicate that BRIEF-SR BRI scores did not significantly predict DSMP-SR Youth scores, however, BRIEF-SR MI scores significantly predicted 24% of the variance in DSMP-SR Youth scores. The difference between the value of  $R^2$  (.24) and the value of  $R^2_{\text{Adjusted}}$  (.21) is .03. This reduction means that this multiple regression model would account for 3% less variance in DSMP-SR Youth scores if it were derived from a population rather than a sample. This suggests reasonable generalizability of the regression model, as the model would still account for 21% of variance in DSMP-SR Youth scores when derived from a population.

***3.4.2.2 Primary research question 2: Does adolescent executive function, as measured by the BRIEF measures and adolescent responsibility for diabetes care, as measured by DFRQ scores, predict adolescent glycaemic control, as measured by HbA1c values?***

A multiple regression analysis was conducted in order to address this research question. Because of the size of the data set and after a priori power analyses, this regression analysis was conducted using only the adolescent data. Regression analyses were not conducted on the 41 sets of parent data.

The multiple regression analysis was conducted with BREIF-SR GEC scores and DFRQ Youth scores as predictor variables and HbA1c values as the outcome variable. The data were examined for violations of assumptions.

The data met the necessary assumptions for multiple regression analyses (see Appendix Q for details and relevant test statistics).

The predictor variables; BREIF-SR GEC and DFRQ Youth were entered into the regression model using simultaneous entry. The results revealed that BRIEF-SR GEC scores and DFRQ Youth scores did not explain a significant amount of the variance in HbA1c values,  $F(2, 61) = 1.09, p = .341$ . The results of this multiple regression analysis are displayed in Table 11.

Table 11

*Results of the Multiple Regression Analysis Predicting HbA1c Values from BRIEF-SR GEC and DFRQ Youth Scores*

	<i>B</i>	<i>SE B</i>	$\beta$
Constant	49.79	12.33	
BRIEF-SR GEC	0.19	0.13	.18
DFRQ Youth	0.15	0.25	.08

*Note.*  $R^2 = .04$ ,  $R^2_{\text{Adjusted}} = .003$ .

The results of this multiple regression analysis indicate that neither DFRQ Youth scores nor BRIEF-SR GEC scores significantly predicted HbA1c values. The  $R^2$  value (.04) shows that the model accounts for only 4% variance in HbA1c values. The difference between the value of  $R^2$  (.04) and the value of  $R^2_{\text{Adjusted}}$  (.003) is 0.037. This reduction means that this multiple regression model would account for 3.7% less variance in HbA1c scores if it were derived from a population rather than a sample. This means the model would only account for 0.3% of variance in HbA1c values when derived from a population, which suggests poor generalizability of the model.

### **3.4.3 Secondary research questions.**

#### ***3.4.3.1 Secondary research question 1: Is there a relationship between adolescent responsibility for diabetes care, as measured by DFRQ scores and adolescent executive function, as measured by the BRIEF measures?***

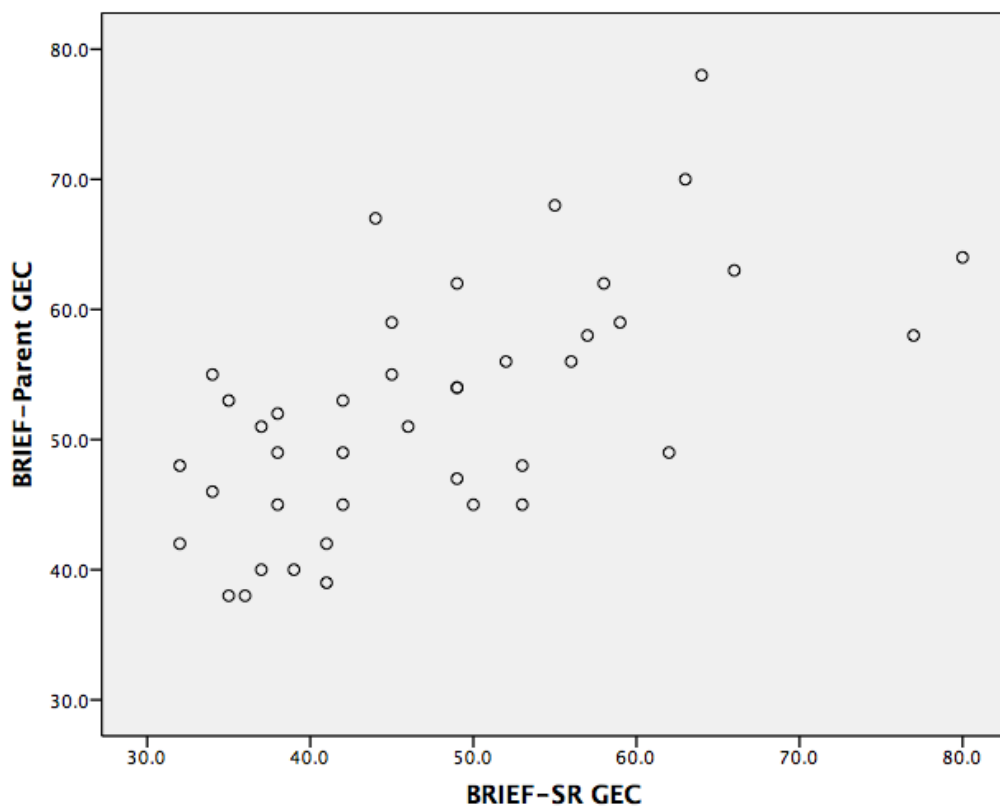
Pearson correlational analyses were conducted to establish if there was a relationship between DFRQ Youth scores and BRIEF-SR GEC scores and a relationship between DFRQ Parent and BRIEF-Parent GEC scores.

There was no significant relationship between the DFRQ Youth scores and BRIEF-SR GEC scores,  $r(64) = -.17, p = .18$ . There was no significant relationship between the DFRQ Parent scores and BRIEF-Parent GEC scores,  $r(40) = -.25, p = .12$ . These results indicated that adolescent responsibility for diabetes care and adolescent executive function were not associated within the research sample.

#### ***3.4.3.2 Secondary research question 2: Are parent-completed and adolescent-completed measures of adolescent functioning and behaviour associated?***

Pearson correlational analyses and paired t-tests were performed to examine the relationship between BRIEF-SR GEC and BRIEF-Parent GEC scores, DSMP Youth and DSMP Parent scores and DFRQ Youth and DFRQ Parent scores.

BRIEF-SR GEC scores and BRIEF-Parent GEC scores were positively correlated,  $r(41) = .63$ ,  $p < .001$  (Figure 8). This positive correlation means that as BRIEF-SR GEC scores increased, indicating poorer adolescent executive function, BRIEF-Parent GEC scores increased, also indicating poorer adolescent executive function.



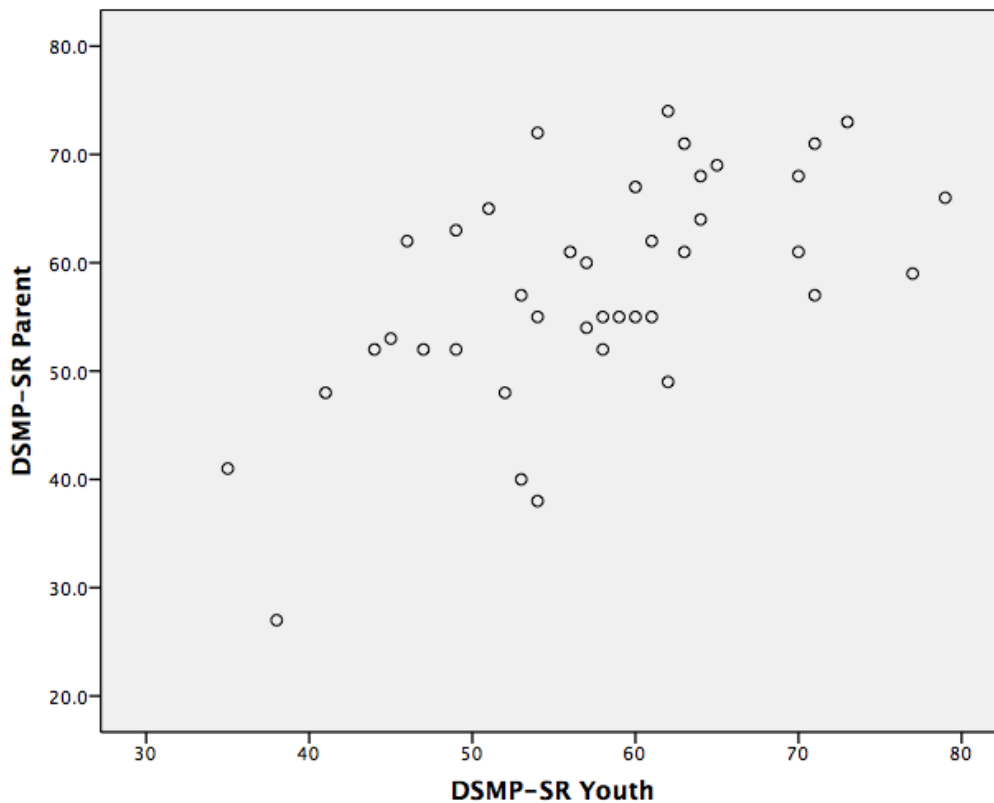
*Figure 8.* Positive correlation between BRIEF-SR GEC scores and BRIEF-Parent GEC scores

The scatterplot depicts the moderate positive linear relationship ( $r = .63$ ) identified between BRIEF-SR GEC and BRIEF-Parent GEC scores within the participant sample.

A paired t-test indicated that BRIEF-SR GEC scores were significantly lower ( $M = 47.66$ ,  $SD = 11.84$ ) than BRIEF-Parent GEC scores ( $M = 52.51$ ,  $SD = 9.40$ ),  $t(40) = -3.32$ ,  $p = .002$ . Lower BRIEF GEC scores indicate better executive function.

DSMP-SR Youth scores and DSMP-SR Parent scores were positively correlated,  $r(40) = .61$ ,  $p < .001$  (Figure 9). This positive correlation means that as

DSMP-SR Youth scores increased, indicating better diabetes self-management, DSMP-SR Parent scores increased, also indicating better diabetes self-management.



*Figure 9.* Positive relationship between DSMP-SR Youth scores and DSMP-SR Parent scores

The scatterplot depicts the moderate positive linear relationship ( $r = .61$ ) identified between DSMP-SR Youth and DSMP-SR Parent scores within the participant sample.

A paired t-test indicated that there was no significant difference between adolescent-reported ( $M = 57.65$ ,  $SD = 10.23$ ) and parent-reported scores ( $M = 57.80$ ,  $SD = 10.30$ ) on this measure,  $t(39) = -.11$ ,  $p = .92$ .

DFRQ Youth scores and DFRQ Parent scores were positively correlated,  $r(38) = .57, p < .001$  (Figure 10). This positive correlation means that as DFRQ Youth scores increased, indicating greater levels of adolescent responsibility for diabetes care, DFRQ Parent scores increased, also indicating greater levels of adolescent responsibility for diabetes care.

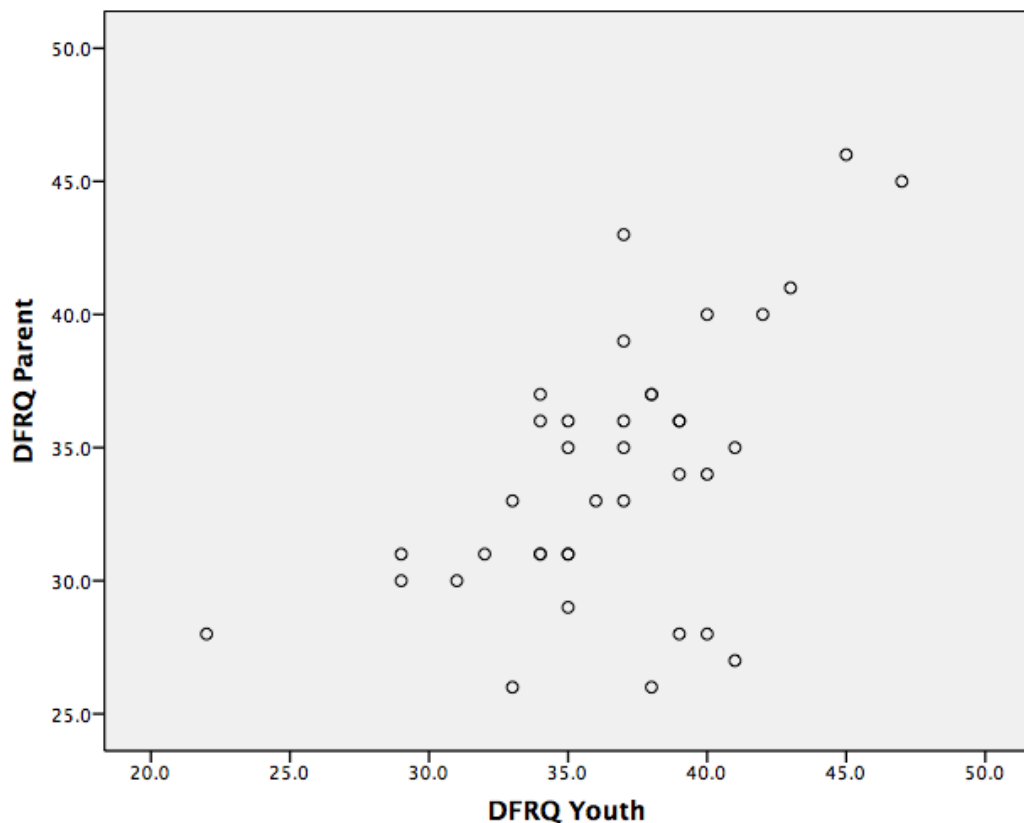


Figure 10. Positive correlation between DFRQ Youth and DFRQ Parent scores

The scatterplot depicts the moderate positive linear relationship ( $r = .57$ ) identified between DFRQ Youth and DFRQ Parent scores within the participant sample.

A paired t-test indicated that DFRQ Youth scores ( $M = 36.58, SD = 4.65$ ) were significantly higher than DFRQ Parent scores ( $M = 34.08, SD = 5.04$ ),  $t(37) =$

3.40,  $p = .002$ . Higher scores on the DFRQ indicate a greater level of adolescent responsibility for diabetes care.

### **3.5 Summary of Results**

In summary, the results of correlational analyses supported Hypothesis 1 and Hypothesis 2. Correlational analyses indicated that better adolescent executive functioning was associated with better self-management of Type 1 diabetes and that better self-management of Type 1 diabetes was associated with better glycaemic control. These associations were found with both adolescent-completed and parent-completed measures of executive function and diabetes self-management.

Hypothesis 3, however, was not supported by the correlational analyses as no significant relationship was identified between adolescent executive functioning and glycaemic control (as measured by HbA1c values). The research study addressed four research questions, for which evidence amongst previous research is limited. Multiple regression analyses indicated that adolescent executive function was a significant predictor of diabetes self-management, but not of glycaemic control.

More specifically, the results suggested that it was the Metacognitive Index of the BRIEF-SR which was the strongest predictor of self-management within this sample. Adolescent responsibility for diabetes care was not found to be a significant predictor of diabetes self-management or glycaemic control (as measured by HbA1c).

Furthermore, no significant association was found between adolescent responsibility for diabetes care and adolescent executive function. The results showed that adolescent-completed measures and parent-completed measures of adolescent executive functioning, diabetes self-management and responsibility for diabetes care were positively associated within the adolescent Type 1 diabetes investigated here. Adolescents tended to report better executive function performance than their



parents/caregivers and reported elevated levels of responsibility for diabetes care than noted by their parents/caregivers. In contrast, no significant difference was identified between adolescent and parent reports of diabetes self-management behaviours. Due to differences noted between the ages of adolescents who participated with a parent/caregiver and those who participated on their own, the generalizability of the results examining the associations and differences between adolescent and parent-completed measures is limited.

## CHAPTER FOUR

### 4. Discussion

#### 4.1 Chapter Overview

The key aim of this research was to investigate factors that may be associated with diabetes self-management and glycaemic control amongst adolescents with Type 1 diabetes and to contribute to the knowledge base in this area. Similarly, it sought to achieve a better understanding of the deterioration in self-management and glycaemic control, which has been observed within the adolescent population with Type 1 diabetes (Johnson et al., 1992; Rausch et al., 2012; Taddeo et al., 2008).

This study was designed to explore if adolescent executive function and responsibility for diabetes care are associated with self-management and glycaemic control. The study also explored if executive function and responsibility for diabetes care are associated, to start to better understand the role of responsibility in adolescent self-management.

Six studies have previously investigated if there is a relationship between executive function and diabetes self-management and glycaemic control in children and adolescents (Bagner, et al., 2007; Duke et al., 2014; Graziano et al., 2011; McNally et al., 2010; Miller et al., 2013; Smith et al., 2014). The general trend of the findings indicates that a relationship does exist between executive function and self-management of diabetes in adolescents, whereby higher levels of executive function are associated with better diabetes management. With the exception of the research of Smith et al. (2014), the general trend of results indicates that a relationship also exists between executive function and glycaemic control.

As discussed in section 1.5.3, the emerging literature notes some inconsistencies as to the nature of the association between executive function and

self-management, and these are summarised again here. Graziano et al., (2011) only identified a relationship between executive function and self-management amongst male participants, and not females. These gender effects were not highlighted amongst the other research studies discussed. Miller et al. (2013) only identified an association between the behavioural regulation aspects of executive function and diabetes management and not the metacognitive aspects of executive function, or in fact, executive function overall. Similarly, although overall the literature to date indicates that executive function and glycaemic control are associated (poorer executive function is associated with poorer glycaemic control), findings are not consistent. Graziano et al. (2011) only identified such a relationship amongst male participants and Smith et al. (2014) only identified such an association amongst children and adolescents who reported better adherence to management regimens.

The methodological limitations associated with these studies (discussed previously in section 1.5.3) and the variability in the details of the relationships between executive function and self-management, and executive function and glycaemic control, suggested the need for further investigations into the nature of this relationship.

The use of adolescent-completed measures of executive functioning and self-management behaviour, the inclusion of a measure of responsibility of diabetes care and the exploration of this variable in relation to adolescents' self-management and executive function ensured the novelty of this investigation.

This chapter first reviews the outcomes of the research study. Each hypothesis and research question is addressed in turn. The results from the relevant statistical analyses are discussed with consideration to previous research findings. Theoretical and clinical implications for the research findings are identified and

suggestions are made for future areas of research. A methodological critique is then provided, acknowledging both the strengths and limitations of this research study.

Finally, a conclusion of the research findings is given.

## **4.2 Evaluation of Findings in Relation to Each Hypothesis**

**4.2.1 Hypothesis 1: Higher levels of adolescent executive functioning, as indicated by lower GEC scores on the adolescent and parent-completed BRIEF measures, will be associated with better self-management of Type 1 diabetes, as indicated by higher total scores on the parent and adolescent-completed DSMP-SR.**

The results showed that adolescent executive functioning, as indicated by the BRIEF measures, was significantly negatively associated with adolescent self-management of Type 1 diabetes, as indicated by the DSMP-SR, for both adolescent self-report and parent-report measures. This suggests that adolescents with better executive functioning, indicated by lower BRIEF GEC scores, demonstrate better self-management of Type 1 diabetes, indicated by higher DSMP-SR scores. These results support Hypothesis 1.

This result is consistent with overall findings from previous research, using self and informant-reports of executive function, which indicate that better executive function is associated with better diabetes self-management (Bagner et al., 2007; McNally et al., 2010; Miller et al., 2013; Smith et al., 2014). Duke et al. (2014) found the same relationship between executive functioning and diabetes self-management in their research study, but only when using a new, diabetes-specific, measure of executive functioning; the DREFS. Associations between BRIEF measures and diabetes self-management did not reach significance in their research study. Graziano et al. (2011) also identified this pattern of association between

executive functioning and treatment adherence, but only with males and did not identify the same significant association within females. Due to the smaller sample size, gender differences were not examined in this research study.

Previous research in this area has relied predominantly upon parent-completed measures of executive function, with the exception of Duke et al. (2014). Duke et al. (2014) utilised both caregiver-completed and adolescent-completed versions of the BRIEF and a newly developed adolescent-completed measure of executive functioning – the DREFS in their pilot study.

The consistency of the results from this current study with those within the previous literature enables the conclusion that higher levels of executive functioning are associated with better self-management amongst adolescents with Type 1 diabetes. Due to the cross-sectional design of this research it is not possible to determine causality within this relationship. Based on clinical and theoretical knowledge, however, it is reasonable to hypothesise that executive function skills are required for the effective enactment of diabetes self-management tasks and this may explain the observed association. For example, planning and organisational skills and task switching may be necessary for individuals to effectively navigate the multifaceted management regimens, working memory is involved in carbohydrate counting, and prioritisation and problem-solving skills may be required to enable an individual to respond to symptoms of hypoglycaemia or prepare for situations involving increased physical exercise (Nylander et al., 2013). It is likely that the better the executive function skills required to carry out such tasks are, the better and more efficiently the management tasks will be executed.

**4.2.2 Hypothesis 2: Better adolescent self-management of Type 1 diabetes, as indicated by higher total scores on the parent and adolescent-completed DSMP-SR will be associated with better glycaemic control as indicated by lower HbA1c values.**

The results showed that better adolescent self-management of Type 1 diabetes, as indicated by higher DSMP-SR scores, was associated with better glycaemic control, as indicated by lower HbA1c values, with both adolescent and parent-completed measures, supporting Hypothesis 2. Accordingly, adolescents with reported better self-management of Type 1 diabetes did in fact appear to objectively achieve better glycaemic control, as indicated by lower HbA1c values. This is consistent with the findings in the literature that self-management is strongly associated with better glycaemic control in adolescents, including those of Graziano et al. (2011), Guo et al. (2011), McNally et al. (2010) and Smith et al. (2014).

The main aim of self-management is to achieve good glycaemic control, which for adolescents is considered as achieving an HbA1c value below 48mmol/mol as safely as possible (NICE, 2015). Self-management tasks are designed with this goal in mind (Hannonen et al., 2003; Schilling et al., 2002; Silverstein et al., 2005) and therefore, it is reasonable to deduce that better enactment of self-management tasks, such as blood glucose monitoring, carbohydrate counting and insulin administration (McNally et al., 2010), results in better glycaemic control.

**4.2.3 Hypothesis 3: Higher levels of adolescent executive functioning, as indicated by lower GEC scores on the adolescent and parent-completed BRIEF measures, will be associated with better glycaemic control as indicated by lower HbA1c values.**

There was no significant relationship identified between adolescent executive functioning and HbA1c values, neither with adolescent-completed measures nor parent-completed measures. Hypothesis three, therefore, is not supported by this study.

This finding is consistent with the findings of Bagner et al. (2007) and Smith et al. (2014) in which no relationship was identified between executive function and glycaemic control in children aged 8-19 years and 8-18 years, respectively.

This finding is in contrast to some previous research results, which have identified an association between executive function and glycaemic control, as measured by HbA1c (albeit with some inconsistencies). Graziano et al. (2011) found that executive functioning was significantly associated with HbA1c values in adolescents aged 12-18 years, whereby poorer executive function was associated with higher HbA1c values indicating poorer glycaemic control. This association was only identified with data from the male participants and not the female participants. Graziano et al. (2011) identified significant differences between the executive function of males and females in their sample, with males demonstrating poorer abilities. Gender differences were not examined in this current study and therefore it is not possible to establish if gender differences in terms of executive function and its relationship to glycaemic control were present in this sample.

Graziano et al. (2011) explored specific areas of executive function in their research including attentional control, goal setting, emotion regulation, and cognitive

flexibility. Despite using the BRIEF measures of executive function (Gioia et al., 2000), Graziano et al. (2011) did not use the standardised indexes (i.e. GEC, BRI, MI). The authors used two of the standardised subscales and also created two distinct measures of *attentional control* and *goal setting* through the standardisation (using z-scores) and combination of the inhibit and shift subscales, and the plan/organise and monitor subscales, respectively. As a result of this, it is not possible to directly compare the executive function abilities of adolescents in the study sample of Graziano et al. (2011) and the executive function abilities of the sample in the current research study. It is possible that differences in overall executive function performances may have contributed to the differences in detection of an association between executive function and glycaemic control.

Duke et al. (2014) did identify a significant association between adolescent executive functioning and HbA1c values in a sample of 12-18 year olds, but only when using the DREFS as a measure of executive functioning. When using the BRIEF measures, Duke et al. (2014) did not identify an association between executive functioning and glycaemic control, as measured by HbA1c values, which is consistent with the findings of the current study. The DREFS is a new measure and the pilot study by Duke et al. (2014) represents its first use in research. As a result, the DREFS does not possess a large evidence base. Its validity and reliability for assessing behavioural manifestations of executive functions is not, therefore, comparable to that of the BRIEF measures, for which there is a large evidence base. In addition, there are a number of methodological and statistical limitations associated with the pilot study, which suggests that the results should be interpreted with caution. These include a limited sample size and the absence of corrective



procedures to control for multiple comparisons when conducting correlational analyses.

Interpretation of the absence of a direct association between executive function and glycaemic control in the current study, which is in contrast to previous research, suggests that there may be additional factors that could explain the relationship.

In summary, Hypothesis 1 and Hypothesis 2 were supported by this research study, but Hypothesis 3 was unsupported. The results of this research study showed that there was a significant relationship between executive functioning and diabetes self-management. Higher levels of executive functioning were associated with better diabetes self-management and lower levels of executive functioning were associated with poorer self-management. The results also demonstrated that better diabetes self-management was significantly associated with better glycaemic control, as measured by lower HbA1c values. There was no direct significant relationship between executive function and HbA1c values identified. Subsequent regression analyses provided further information regarding the relationship between these variables and are discussed later in this chapter (see section 4.3).

The findings of this research study, in relation to these hypotheses, contribute to the emerging literature in this area.

### **4.3 Evaluation of Findings in Relation to Each Research Question**

**4.3.1 Primary research question 1: Does adolescent executive function, as measured by the BRIEF measures and adolescent responsibility for diabetes care, as measured by DFRQ scores, predict adolescent self-management of Type 1 diabetes, as measured by DSMP-SR scores?**

The results of the multiple regression analysis revealed that adolescent executive function, as measured by the BRIEF-SR is a significant predictor of adolescent self-management as measured by the DSMP-SR Youth. Responsibility for diabetes care, as measured by the DFRQ, was not identified as a significant predictor of adolescent self-management as measured by the DSMP-SR Youth. The results also suggest that this model is relatively well generalizable to a population model, losing only 3% of its predictive power and still predicting 16% of the variance in self-management scores.

The presence of this relationship indicates that executive function skills, including the ability to plan and organise may predict the success of self-management. It suggests that in order to improve self-management in adolescents with Type 1 diabetes, the individual's executive function should be considered and supports should be put in place to optimise executive functioning abilities. Such supports could include skills-based workshops focussing on diabetes-related management tasks utilising executive function skills, including problem solving and decision-making, carbohydrate counting practice and sessions focussing on strategies to support organisation and planning. In addition, individualising management plans to acknowledge each adolescent's strengths and weaknesses in executive functioning may prove beneficial in improving diabetes self-management. As discussed in section 4.2.1, this finding is in line with relevant theory and knowledge. Diabetes self-management requires executive function skills, such as planning and organisational skills, working memory and problem-solving abilities (Nylander et al., 2013) in order to carry out the multitude of tasks involved (McNally et al., 2010). The better developed these executive function skills are, the more accurately and efficiently tasks, which require their use, can be carried out (Duke & Harris, 2014;

Jurado & Rosselli, 2007). It makes theoretical sense, therefore, that higher levels of executive function predicts better self-management of diabetes. The observed deterioration of diabetes self-management amongst adolescents (Drotar et al., 2013) may be present as many executive function skills, required for the complex self-management tasks, are still developing (Eilander et al., 2015; Wild & Musser, 2014) and may not be appropriately developed for the independent enactment of some or all of the self-management tasks (Griffin, 2012).

The results of this multiple regression analysis are consistent with the findings of Smith et al. (2014) who found that parent-reports of adolescent executive function significantly predicted treatment adherence behaviours, as reported by the child. Smith et al. (2014) used the DSMP structured interview to measure adherence to diabetes management. The current study extends this research by replicating the finding with adolescent reports of their executive functioning and utilising a more time-efficient measure of diabetes self-management.

Previous research has indicated an association between responsibility for diabetes care and self-management, although the nature of this relationship is still unclear within the literature. The results of Anderson et al. (1997) and Anderson et al. (2002) suggested that lower levels of child or adolescent responsibility for diabetes care and higher levels of parental involvement in diabetes care were associated with better treatment adherence and more frequent engagement in diabetes care activities. Similar results were found by Hsin et al. (2010) in a sample of Hispanic youths. Furthermore, Helgeson et al. (2008) and Ingerski et al. (2010) found that increased adolescent responsibility for diabetes care was associated with less frequent blood-glucose monitoring. However, Vesco et al. (2010) only identified such a pattern of association for direct diabetes management tasks and not indirect

tasks and Wu, Hilliard, Rausch, Dolan, and Hood (2013) only found this pattern of association when using parent-reports of responsibility and not when using adolescent-reports. Wiebe et al. (2014) found that parental responsibility was positively associated with adherence to diabetes treatment regimens but only when mediated by adolescent reported self-efficacy. Conversely, Anderson et al. (1990) found that when examining adolescent-completed measures, increased adolescent-perceived responsibility for diabetes care was associated with better adolescent-perceived diabetes self-management; this relationship was not replicated with parent-completed measures.

An additional finding of the studies by Helgeson et al. (2008), Ingerski et al. (2010) and Vesco et al. (2010) was that in families where adolescents and caregivers shared the responsibility for diabetes care this was associated with good self-care behaviour (Helgeson et al., 2008) and higher Blood Glucose Monitoring (BGM) frequency (Ingerski et al., 2010; Vesco et al., 2010). The rate of shared responsibility for diabetes care between adolescents and parents/caregivers was not examined in this study.

Since the development of the DFRQ (Anderson et al., 1990) researchers have employed different scoring techniques. Anderson et al. (1990) originally used the measure to calculate the level of disagreement between parents and children/adolescents as to who took responsibility for diabetes care tasks. Care task items upon which neither child/adolescent nor parent adopted responsibility for were marked as “No One Takes Responsibility” and were attributed one point. This scoring system meant that higher scores indicated higher incidences of neither parent nor child/adolescent adopting responsibility for diabetes care tasks. More recently, scoring techniques have included continuous scoring (Holmes et al., 2006), where

higher scores indicate higher levels of responsibility, scoring through the recording of frequency of different response options (i.e. child/adolescent responsibility, parent responsibility, shared responsibility or no-one takes responsibility; Hsin et al., 2010) and finally through the calculation of a percentage representing the proportion of items upon which child/adolescents and parents report shared responsibility (Helgeson et al., 2008).

The different scoring methods may contribute to the varied results within the literature. In this current research study, a continuous scoring system was adopted in order to measure the amount of responsibility adopted by the adolescent, as was adopted by Holmes et al. (2006). The level of shared responsibility or disagreement regarding responsibility taking was not established. It may be that the division of responsibility/sharing of responsibility or the disagreement regarding who adopts responsibility is more important to consider than the level of adolescent responsibility on its own when exploring factors associated with diabetes self-management. This may explain why no association was identified in the current research study between responsibility for diabetes care and diabetes self-management.

Due to the number of parent/caregiver participants in the current research study ( $n = 41$ ), parent-completed measures of adolescent responsibility for diabetes care and executive function were not included in the regression analysis and it is therefore not possible to generalise this finding to parent perceptions. That is, it is not possible to say that parent ratings of adolescents' executive function significantly predict self-management of diabetes as measured by the DSMP-SR measures. Similarly, it is not possible to say that parent ratings of responsibility for diabetes care do not significantly predict self-management of diabetes as measured by the

DSMP-SR measures. This may be particularly pertinent to the possible association between responsibility for diabetes care and diabetes self-management. Previous research has obtained different results from parent-completed measures compared to adolescent-completed measures, as to the existence and nature of the relationship between responsibility for diabetes care and diabetes self-management (Anderson et al., 1990; Wu et al., 2013).

A second multiple regression analysis was conducted to explore if different aspects of executive function were differentially associated with diabetes self-management. The results of a second multiple regression analysis indicated that it was the Metacognitive Index (MI) scores from the BRIEF-SR which significantly predicted the DSMP-SR Youth scores, and not the Behavioural Regulation Index (BRI). The results also suggest that this model is relatively well generalizable to a population model, losing only 3% of its predictive power and still predicting 21% of the variance in self-management scores.

The presence of this relationship indicates that metacognitive aspects of executive function, including working memory skills and planning and organisation and not behavioural regulation aspects of executive function, including inhibition and emotional regulation, may predict the success of self-management. This is in line with theoretical knowledge and understanding regarding the cognitive functions presumed to be involved in carrying out the tasks of diabetes self-management (Nylander et al., 2013). Self-management of diabetes requires a multifaceted treatment regimen, co-ordinating a number of different tasks in the context of a busy adolescent lifestyle (McNally et al., 2010). In order to accomplish successful self-management, based upon theoretical knowledge, it is logical to expect that an individual must utilise their planning and organisational abilities as well as working

memory and problem solving skills (Duke & Harris, 2014; Jurado & Rosselli, 2007; Nylander et al., 2013).

The result of this analysis is contradictory to the finding of Miller et al. (2013) who identified BRIEF-BRI scores as a significant predictor of diabetes self-management, but not BRIEF-MI. Similarly, Graziano et al. (2011) found that it was the specific component of executive function; emotion regulation skills (*Emotional Control* forms part of the BRIEF-BRI) which accounted for the variance predicted in diabetes treatment adherence amongst the male participants in their study.

Different components of executive function develop at different rates and follow different developmental trajectories (Anderson, 2002; Brocki et al., 2008). The BRIEF-BRI (Guy et al., 2004) encompasses executive function skills such as impulse control, cognitive flexibility, emotional control and regulation of behaviours (including consideration of the impact of behaviours upon others). In contrast, the BRIEF-MI, includes working memory skills and, planning and organisational processes. Research suggests that working memory, planning, and decision-making abilities continue to develop and be refined throughout adolescence, approaching early adulthood (Best & Miller, 2010; Brocki et al., 2008; Luciana et al., 2005), whereas, inhibition skills fully mature between the ages of 10 and 12 years (Brocki & Bohlin, 2004). Similarly, self-monitoring skills, which enable an individual to keep track of their behaviour and task errors, and identify the impact of their behavioural responses, continues to develop until mid-adolescence (Best & Miller, 2010).

The discrepancy between the results of the current study and those of Miller et al. (2013) could be explained, therefore, by possible differences in participants' executive function development between the study samples. The study of Miller et

al. (2013) was based upon a participant sample aged between 9 and 11 years ( $M = 10.54$ ). It is possible, therefore, that for these individuals their inhibitory and self-regulatory skills were still developing and may have been at a lower ability level than the participant sample recruited in the current study. The current study included an older age range, between 11 and 18 years ( $M = 15.04$ ) and thus was likely to have included more participants with matured inhibitory and self-regulatory skills (Brocki & Bohlin, 2004).

Review of the current study findings alongside previous literature, suggests that earlier on in childhood and early adolescence, behavioural regulation aspects of executive function may be more influential to an individual's behaviour and activity performance than later in adolescence. This could account for the differences in research findings between the current study and that of Miller et al. (2013).

Due to the older age of participants in this current study, in comparison to those within the research of Miller et al. (2013), it is possible that levels of adolescent responsibility for diabetes care were higher in this current study sample. As aforementioned, working memory skills continue to improve as they are exposed to more challenging and complex tasks (Best & Miller, 2010). Demand upon executive function skills, such as working memory, is likely to increase as adolescent responsibility for diabetes care increases and they take on more self-management tasks independently (Griffin, 2012). Therefore, the requirements of different aspects of executive functions may be different for different self-management tasks for which adolescents are more or less independently responsible for depending on their age and/or developmental stage. This could also contribute to the observed differences between study results.



Further research into the relationships between specific elements of executive function and diabetes self-management will help to clarify the discrepancies within the current literature. Furthermore, such research may help to highlight more precisely which constructs of executive function impact most significantly on self-management.

**4.3.2 Primary research question 2: Does adolescent executive function, as measured by the BRIEF measures and adolescent responsibility for diabetes care, as measured by DFRQ scores, predict adolescent glycaemic control, as measured by HbA1c values?**

The results showed that executive function, as measured by the BRIEF-SR and adolescent responsibility for diabetes care, as measured by the DFRQ did not significantly predict glycaemic control. There is little previous research, examining the predictive relationship between the above variables and glycaemic control. Graziano et al. (2011) found that executive functioning measures predicted a significant amount of variance in HbA1c values, but only with data from male participants and not with females. Furthermore, the executive functioning abilities noted amongst the study sample from Graziano et al. (2011) were not easily comparable to those measured for the participants in this current study as previously explained in section 4.2.3.

The finding from this current research suggests that other factors may be involved in predicting HbA1c. Earlier analyses found a significant relationship between self-management and HbA1c and showed that executive function significantly predicted diabetes self-management. No direct relationship between executive function and HbA1c was found and executive function and responsibility for diabetes care have not been found to be significant predictors of HbA1c levels.

Taken together, these results suggest other factors are likely to be involved in the prediction of glycaemic control. Smith et al. (2014) suggested that diabetes self-management mediates a relationship between executive function and glycaemic control. They did not identify a direct relationship between executive function and glycaemic control for their overall study sample. However, amongst children and adolescents who reported better adherence, lower levels of executive function were associated with poorer glycaemic control. Amongst children and adolescents who reported poorer adherence, lower levels of executive function were associated with better glycaemic control and higher levels of executive function were associated with poorer glycaemic control (see section 1.5.3 for a review of the proposed explanations of Smith et al. (2014) for these results).

Due to the sample size in the current study it was not possible to conduct mediation analyses and highlights an area for future research with a sufficiently powered study.

#### **4.3.3 Secondary research question 1: Is there a relationship between adolescent responsibility for diabetes care, as measured by DFRQ scores and adolescent executive function, as measured by the BRIEF measures?**

The results showed no significant relationship between adolescent responsibility for diabetes care, as measured by the DFRQ and adolescent executive function, as measured by the BRIEF measures for either the adolescent-completed measures or the parent-completed measures.

This result may be a true reflection of the absence of an association between adolescent responsibility for diabetes care and level of executive functioning.

Alternatively, as discussed in section 4.3.1, the method of scoring adopted for the DFRQ (Anderson et al., 1990) as used by Holmes et al. (2006), may not have been

sensitive to the elements of responsibility for diabetes care which are of importance and thus might be associated with executive function. It may be that the level of shared responsibility or disagreement regarding responsibility taking is important when considering an association between responsibility for diabetes care and executive function. If parents/caregivers are aware of their child having lower levels of executive function they may continue to provide greater levels of support in the management of their diabetes, as they may perceive their adolescents as less capable to manage the multifaceted self-management regimens themselves. Simultaneously, however, the adolescent themselves may not be aware of this continued involvement (either through a lack of insight or through implicit support from parents). The exploration of such a hypothesis and exploration of responsibility using different scoring methods, may be supported by the fact that adolescents can often endorse higher levels of responsibility for tasks than is evident in reality (Geffken et al., 2008). It would be interesting to establish if over-endorsement or parent-adolescent disagreement regarding task responsibility is associated with executive function.

Furthermore, it is possible that additional factors may account for the relationship between adolescent responsibility for diabetes care and adolescent executive functioning. Future research should consider investigating the relationship between these two variables further.

#### **4.3.4 Secondary research question 2: Are parent-completed and adolescent-completed measures of adolescent executive functioning, self-management and responsibility for diabetes care associated?**

The results of this research showed that parent-completed and adolescent-completed measures of executive functioning, diabetes self-management and responsibility for diabetes care were associated.

#### *4.3.4.1 Executive functioning.*

Adolescent-completed and parent-completed BRIEF measures were positively associated which means that both adolescents and parents rate adolescents' executive function in the same direction; as one recognised better or worse executive function this was similarly reflected in the others' scores. This finding is consistent with those reported by Duke et al., (2014) who also found that adolescent and parent-completed measures of executive function were positively associated both when examining the DREFS and the BRIEF measures. T-tests conducted in this current study, concluded that scores from parent-completed measures were significantly higher than those from adolescent-completed measures. This suggests that parents rated their children as having a poorer level of executive function than the adolescents reported themselves. Duke et al. (2014) did not examine if there were significant differences between the parent and adolescent-completed executive function measures. This positive association between scores from parent-completed measures and adolescent-completed measures and the tendency for adolescents to report better executive function was noted during the examination of normative data during the standardisation and validation process of the BRIEF measures (Guy et al., 2004).

There are a number of factors that could have contributed to the pattern of results observed in this research.

It is possible that adolescents with poorer or less developed executive function performance have poorer insight into their difficulties, resulting in lower scores on the self-report BRIEF measure (lower scores indicate better executive function). Executive function encompasses the very cognitive skills required to regulate, reflect upon and evaluate higher order cognitive skills, emotional responses

and behaviours (Roth et al., 2014). The self-report BRIEF measures require individuals to rate their perception of how they manage with certain behaviours and everyday tasks, which require the use of executive functioning skills (Guy et al., 2004). It is possible that the adolescents' ability to self-monitor in the real-life moment may have been reduced, due to poorer or less developed executive function skills. This may have meant that the adolescents' ability to identify that they may have struggled with the task at hand was reduced. If this was the case, it is unlikely that they would have been able to accurately reflect on this at a later stage (when completing the questionnaires). This could have resulted in the adolescents rating themselves as having better executive functioning skills than they have in reality. Similarly, the fact that parents have fully developed executive function may account for their tendency to rate their child as having poorer executive function, due to greater insight into their child's behaviour.

Adolescence is a period when self-esteem and self-image becomes important as individuals attempt to forge their own independent identities (Silverstein et al., 2005). Social acceptance and social recognition are important aspects of adolescent life (Court et al., 2009; Delamater, 2009). As a result, adolescents may underreport difficulties associated with their executive function in an attempt to protect an image they or others hold of them, to promote their independence or to suggest to themselves or others that their diabetes does not impact on their life. It is possible that this social desirability bias was evident within this research and could contribute to the observed pattern of results.

When interpreting these results, the role of responsibility for diabetes care was considered. The idea that parents who assume greater responsibility for their child's diabetes care may rate their child as having poorer executive function skills,

was considered. However, subsequent analyses indicated that levels of responsibility for diabetes care (DFRQ scores) and executive functioning (BRIEF measures) were unrelated (see section 4.3.3).

It is important to note that 41 of the adolescent participants took part with an accompanying parent/caregiver, and solely these data were used in the comparative analyses. Earlier analyses demonstrated that adolescents with a participating caregiver were younger in age than those without a participating caregiver. It is not possible therefore, to generalise the finding that parents tend to rate their child's executive functioning as poorer than their child self-reports, to older adolescents.

These findings suggest that adolescent-completed measures of executive function within the Type 1 diabetes population are a useful indication of the adolescents' perception of their functioning, but should not be used in isolation due to the possibility that adolescents might underestimate their difficulties (Guy et al., 2004). Adolescent-completed measures should be used in conjunction with parent and/or teacher-completed measures and the use of additional performance-based, objective measures of executive function should also be considered. Obtaining adolescent perceptions of their executive function in this population may provide information regarding their approach to diabetes management tasks, their beliefs regarding their self-efficacy and may impact on their self-confidence. Future research should examine these aspects.

#### ***4.3.4.2 Diabetes self-management.***

Adolescent-completed and parent-completed DSMP-SR measures were positively associated, which means that both adolescents and parents rated adolescents' self-management of Type 1 diabetes in the same direction – as one recognised better or worse self-management this was similarly reflected in the

others' scores. T-tests showed that scores from parent-completed measures did not differ significantly from adolescent-completed measures. This suggests that parents and adolescents held similar views on how well an adolescent is managing their diabetes.

It is important to acknowledge here, that not all adolescent participants in this research took part with an accompanying parent/caregiver. As noted earlier, comparative analyses between adolescent-completed and parent-completed measures were only conducted with adolescent data from those with a participating parent/caregiver. Earlier analyses demonstrated that adolescents with a participating caregiver were younger in age than those without a participating caregiver. It is not possible, therefore, to say that this finding would be apparent with older adolescents.

In light of the above, it is suggested that a key determinant of this finding is the involvement of the parent/caregiver in their adolescents' day-to-day life, whether that be observation of their behaviour and abilities or involvement in their diabetes care. It could be hypothesised that parents who took part with their child may have had a good understanding of their child's diabetes management, not least because they were attending their diabetes clinic appointment with them at the time of recruitment. This means it was likely that they had some level of awareness of their child's regular blood-glucose levels and awareness of their diabetes clinic appointments. In addition, in most cases, parents or caregivers are likely to be the main source of support if there are any complications, such as hypoglycaemic episodes, which would enable them to make a relatively accurate interpretation of overall self-management. It would be interesting, in future research, to establish if parent and adolescent perceptions of adolescent self-management are different

amongst older adolescents, when parents/caregivers are likely to be less involved in their diabetes care (Dahl, 2004; La Greca, 1990; Nardi et al., 2008).

#### ***4.3.4.3 Responsibility for diabetes care.***

Adolescent-completed and parent-completed DFRQ measures were positively associated which means that both adolescents and parents rated adolescents' responsibility for diabetes care in the same direction; as one recognised more adolescent responsibility for diabetes care, this was similarly reflected in the others' scores. T-tests concluded, that scores from adolescent-completed measures were significantly higher than scores from parent-completed measures. This indicated that adolescents perceived themselves as adopting greater levels of responsibility for their diabetes care than their parents, who perceived the adolescent as taking less responsibility for their diabetes care. Geffken et al. (2008) noted a similar tendency of adolescents to over-endorse their level of responsibility for tasks. Furthermore, the results of the current research study are in line with the trend of results found in a small-scale research study conducted by Dashiff (2003) in which it was noted that adolescents reported significantly higher levels of adolescent responsibility for diabetes care than their fathers' reported. However, this significant difference in perception of responsibility was only present when comparing father and adolescent perceptions and not when comparing mother and adolescent perceptions. In the sample of the current study parental perceptions were not analysed separately (i.e. mother, father or caregiver) rather, simply grouped into parental perceptions.

Higher perceived levels of adolescent responsibility for diabetes care amongst adolescents in comparison to their parent/caregiver may be a reflection of their striving to be autonomous; a key part of adolescence (Dahl, 2004; Nardi et al., 2008) or possibly a lack of realisation of the role their parent/caregiver is still taking



in their care behaviours. The latter may be important to consider, especially if the parent/caregiver is preparing for the transition of diabetes care responsibility to the adolescent and therefore is supporting the adolescent more implicitly.

#### ***4.3.4.4 Summary***

In summary, adolescent-completed measures and parent-completed measures of adolescent executive functioning, diabetes self-management and responsibility for diabetes care are positively associated within the adolescent Type 1 diabetes sample investigated here. Adolescents tended to report better executive function performance than their parents/caregivers and reported elevated levels of responsibility for diabetes care than noted by their parents/caregivers. In contrast, no significant difference was identified between adolescent and parent reports of diabetes self-management behaviours. Generalizability of these results is limited due to the differences noted between the ages of adolescents who participated with a parent/caregiver and those who participated on their own.

#### **4.4 Theoretical Implications of Findings**

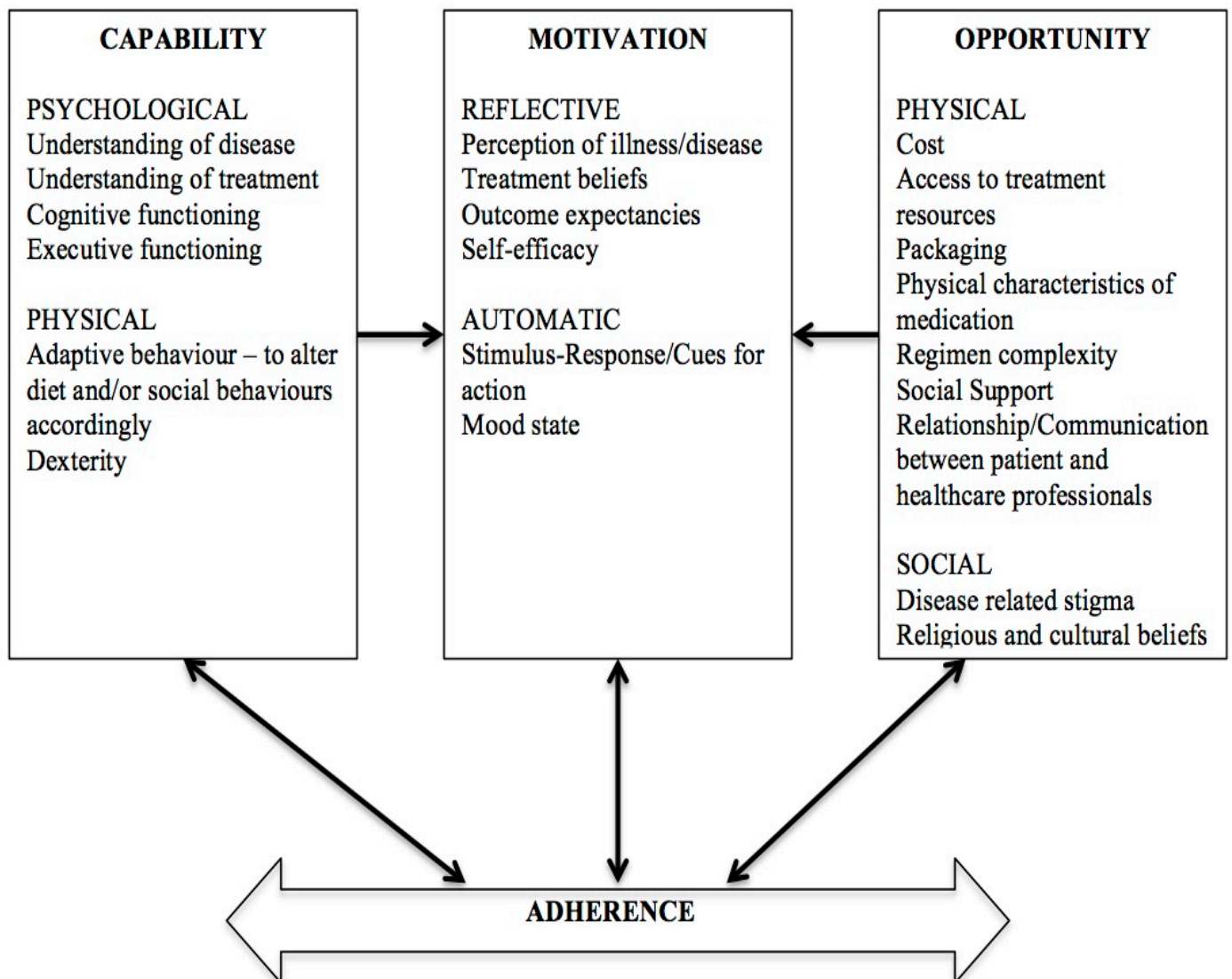
Executive functioning is a complex construct, encompassing a number of different metacognitive and regulatory skills and processes (Goldstein et al., 2014; Jurado & Rosselli, 2007). This research indicates that executive function does play a significant role in the self-management of Type 1 diabetes amongst the adolescent population. The fact that the Metacognitive Index of the BRIEF-SR was identified as a significant predictor of self-management and the Behavioural Regulation Index of the BRIEF-SR was not, suggests that different executive functions may have different levels of impact upon self-management. Future research should focus on the individual aspects of executive function to establish their differing levels of influence on diabetes self-management, which will help to clarify the findings of previous

research. Furthermore, the potential role of different executive functions in diabetes self-management should be considered throughout different stages of development. As different aspects of executive function develop at different rates and follow different developmental trajectories (Best & Miller, 2010; Brocki & Bohlin, 2004; Luciana et al., 2005), it is possible that different components of executive function will be of importance to different individuals and their self-management, depending on their developmental stage and independence in diabetes care.

The absence of a relationship between responsibility for diabetes care and executive function and diabetes self-management might be an indication that another variable mediates these relationships. For example, Wiebe et al. (2014) found that parental responsibility was positively associated with adherence to diabetes treatment regimens but only when mediated by adolescent reported self-efficacy. Future research should continue to investigate to what extent responsibility is related to executive function and diabetes self-management.

It is important to consider the findings of this research in the context of the COM-B model (Michie et al., 2011) introduced earlier (section 1.4.5). Michie et al. (2011) defined the model components as follows: *Capability* refers to the “psychological and physical capacity to engage” in the behaviour and encompasses executive functioning skills, *Motivation* refers to the automatic and reflective “brain processes that energise and direct behaviour” and *Opportunity* refers to factors external to the individual “which make the behaviour possible or prompt it” – these include both physical environmental factors and social influences (p. 4). The model is dynamic and allows for interaction between these different components. Jackson et al. (2014) adapted the COM-B model to apply specifically to medication adherence and to encompass the noted factors associated with adherence. Figure 11 outlines the

use of the COM-B model for understanding medication adherence, as proposed by Jackson et al. (2014), with the inclusion of their identified contributing factors to medication adherence.



*Figure 11.* Application of the COM-B model to medication adherence as proposed by Jackson et al. (2014) with the inclusion of their identified contributing factors to medication adherence.

Review of this model applied to medication adherence highlights its likely applicability to diabetes self-management and therefore its relevance to this current research. The COM-B model provides a framework, which incorporates biopsychosocial factors, which as discussed in Chapter One, are vital to the understanding and exploration of Type 1 diabetes and its management amongst adolescents (Adal et al., 2015; Eilander et al., 2015; Luyckx, 2012).

The COM-B model would be a useful tool to understanding diabetes self-management and difficulties associated with this (i.e. why individuals may not fully engage in self-management behaviours) and for informing interventions to address difficulties with self-management. This research demonstrated that executive function is a significant predictor of diabetes self-management in adolescents. Executive function falls under the *Capability* component. The previously identified influences of demographic factors (Hassan et al., 2006; Hilliard et al., 2013), social supports and conflicts (Anderson et al., 2002; Guo et al., 2011; Wysocki & Greco, 2006) and communication between the adolescent and diabetes healthcare professionals (Christie & Viner, 2005), upon diabetes self-management can be categorised under the *Opportunity* component. The *Social* division of the *Opportunity* component also provides the ability to acknowledge the specific social aspects associated with Type 1 diabetes in adolescence, such as the importance of social acceptance (Delamater, 2009) within the model. The *Motivation* component could encompass the identified relationships between emotional distress and psychological difficulties such as anxiety and depression upon self-management (Bernstein et al., 2013).

The COM-B model allows for the integration of the biopsychosocial understanding of Type 1 diabetes and could provide a clear framework to

understanding this behaviour and difficulties identified with this within the adolescent population. Future research should continue to develop the application of this model to diabetes self-management. Developing a sound theoretical underpinning to approaches to self-management in adolescence and to developing interventions to target and improve self-management in this population is key to efficient and effective outcomes. Furthermore, it is a recommended requirement from the Medical Research Council (2000).

#### **4.5 Clinical Implications of Findings**

In order to address difficulties with self-management it is necessary to understand the nature of such difficulties (Delamater et al., 2012). The better this is understood by researchers and healthcare professionals, the better informed clinical practice and more targeted the supports and guidance offered to individuals, in this case specifically adolescents with Type 1 diabetes, can be. This research adds to an emerging literature and thus, as the literature base is only in its infancy, further research is required before robust recommendations for or changes to clinical practice should be made. However, it remains important to consider the results of this research to establish if they can begin to inform clinical practice to support adolescents to better manage their diabetes and achieve better glycaemic control.

##### **4.5.1 Assessment and identification.**

As a significant relationship between executive function and self-management has been identified here, and supported by previous research, the executive functioning of adolescents with Type 1 diabetes should be considered in their care and diabetes management regimens. If individuals' executive functioning capacity can be assessed by the diabetes clinic teams, then self-management

regimens could be tailored towards the strengths and weaknesses of the individuals' executive functioning profiles.

Overall, the sample investigated in this research did not exhibit executive function difficulties which would be considered of clinical significance (BRIEF-SR GEC;  $M = 48.15$ , BRIEF-SR BRI;  $M = 47.27$ , BRIEF-SR MI;  $M = 49.08$ ). Twelve out of the 67 adolescents did exhibit executive function scores above the cut off of 65, indicating potential difficulties of clinical significance (see Table 7, section 3.3). This suggests that there may be a subset of adolescents with Type 1 diabetes who may exhibit difficulties with executive function. If such individuals could be identified early on in their diagnosis, supports could be put in place from an early stage to support them to achieve their optimal self-management. In addition, this may help to harness self-confidence in the individual in self-management by setting the individuals tasks and goals in line with their abilities.

At present, the transfer of diabetes care responsibility between parent and child is largely dependent on age and can be influenced by the service context of paediatric and adult services (Dovey-Pearce & Christie, 2013). The results of this research suggest that a more developmental approach should be adopted, including consideration of the child's executive function when planning for this transition. If individuals with poor executive function are identified prior to the point of transition of responsibility for diabetes care it may help to prevent the premature transfer of responsibility, which may contribute to poor self-management.

#### **4.5.2 Management and intervention.**

Improving self-management of Type 1 diabetes in adolescents could help to improve the use of clinic resources and reduce the financial impact on the NHS and society as a whole, to which poor management of diabetes and the subsequent

complications contribute (Holloway & van Dijk, 2011). It is important for individual practitioners and services to continue developing service provision to ensure a specific and supportive service for adolescents with Type 1 diabetes, addressing the factors identified as impacting on self-management and glycaemic control, not only for the benefit of the patient and their families, but for the NHS.

As mentioned previously, only 12 adolescents within the sample scored above the clinical cut off on any one of the indexes on the BRIEF measures and therefore it cannot be concluded that individuals with Type 1 diabetes overall, present with impairments in executive function (see Table 7, section 3.3). The results of the research do indicate, however, that executive function skills contribute to the self-management of Type 1 diabetes. It could be argued, therefore, that it would be beneficial to support all individuals to improve or maximise their potential in terms of executive function skills in order to enhance their self-management. Or, perhaps more feasibly, Type 1 diabetes management instructions, procedures and supports should be reviewed and re-designed to reduce the cognitive load on executive functions. This would be beneficial for all individuals, not just those with poor executive function (although they may benefit more) and perhaps make better self-management more achievable and sustainable for adolescents with this chronic disease.

Cook, Herold, Edidin, and Briars (2002) found that adolescents with Type 1 diabetes appeared to benefit from a short-term problem-solving intervention, which resulted in improved problem-solving scores and glycaemic control after completion. In their study, participants were assigned to a six-week, psycho-education programme in which they attended a two hour session focussing on learning cognitive and behavioural skills associated with diabetes management, or were

assigned to treatment as usual. The psycho-education programme included sessions focussing on learning and developing cognitive and behavioural skills relevant to diabetes management (including problem-solving, decision making and planning), improving motivation to engage with self-management and supporting the integration of good self-management into the adolescents' daily lives. The results suggested that, brief, short-term skills-based sessions focussing on specific aspects of executive functioning may be an effective method for improving adolescents' executive functioning and thus, contributing to better diabetes self-management and as a result, improving glycaemic control. In order to ensure the most efficient use of resources, it would be beneficial if future research could explore in more depth which aspects of executive function may have the greatest influence over self-management.

Establishing which aspects of executive function are applicable to diabetes self-management would help to better inform clinical practice. An assessment process could be introduced, perhaps in line with the annual clinical psychology reviews as indicated in the DBPT (Randell, 2012), to examine the executive function profiles of adolescents with Type 1 diabetes. This would enable those with impaired executive function to be identified early on. Furthermore, such an assessment process would enable the profiles of executive function to be identified for those with no overall deficits in executive function (as determined by index scores) and their strengths and weaknesses highlighted. The identification of individual strengths and weakness will help to inform individualised care plans and the development of specific supports to adolescents which draw upon their strengths and address areas of difficulty.



## 4.6 Methodological Critique

### 4.6.1 Strengths.

The current research study included both parent and adolescent-completed measures of executive function, self-management and responsibility for diabetes care. This advances previous research by providing an indication of adolescents' perceptions of their abilities and how these relate to the perceptions of their parents/caregivers. The perceptions of adolescents regarding their own abilities become increasingly important to consider, as they begin to take on more independent responsibility for their care (Bagner et al., 2007).

The measures chosen for use in this research study demonstrated good reliability and validity and had been used within other research within this area. In addition, they enabled collection of a large amount of data regarding multiple factors (i.e. executive function, self-management, responsibility for diabetes care and demographic information) whilst keeping participant burden to a minimum.

HbA1c values were collected for the research sample. HbA1c values are the most widely used indicator of glycaemic control (Rewers et al., 2009). This provided an objective measure of diabetes management alongside the adolescent and parent-completed reports of self-management behaviour and also enabled associations between study variables and glycaemic control to be explored.

A strength of this study, paramount to the literature regarding diabetes self-management in adolescence is the age-range of adolescents recruited. This study recruited an age range specific to the period of adolescence (11-18 years) and one which is concordant with the beginning of major transitions for adolescents in the UK: transitioning to high school and adopting greater independent responsibility for their diabetes care (Ingerski et al., 2010; Wiebe, et al., 2014). This improves upon

previous studies in this area, which recruited participants within the pre-adolescence stage (9-11 years; McNally et al., 2010; Miller et al., 2013) or spanning the pre-adolescent and adolescent stages (8-18/19; Bagner et al., 2007; Smith et al., 2014).

In addition, despite not meeting the target sample size this study was able to recruit a substantial sample of adolescents ( $n = 67$ ) and their parents/caregivers ( $n = 41$ ), particularly when considering the scale and scope of this thesis research.

#### **4.6.2 Limitations.**

##### ***4.6.2.1 Design***

The target sample size of 82 was not reached for this research project. Difficulties associated with adolescents not attending diabetes clinics for their scheduled appointments contributed to under recruitment. Due to time and practical constraints associated with this research being conducted as part of doctoral training it was not possible to extend the recruitment period prior to thesis submission. Non-attendance at hospital appointments could reflect difficulties associated with planning and organisation skills amongst adolescents with Type 1 diabetes preventing them from attending clinic. Alternatively, it may reflect that, for those not attending their clinic appointments, diabetes care is not considered a priority within the context of other social demands (Court et al., 2009). Upon reflection, the study design would have benefitted from having additional support for recruitment, aside from the researcher.

This study did not collect data on comorbid mental health and developmental conditions. The study did not include measures of factors affecting mental health and wellbeing such as anxiety, depression, self-efficacy or eating disorders. This was to minimise participant burden during questionnaire completion and to ensure that the study remained focussed on investigating executive function and its relationship to

self-management. This was identified as particularly important, considering that this area is in its infancy within research and this study aimed to contribute to an emerging area of literature. Furthermore, the inclusion of additional variables in the investigation would have required a much larger sample size in order to reach adequate power for statistical analysis and was beyond the scale and scope of this thesis. The decision not to collect data regarding comorbid mental health and developmental conditions helped to improve the generalizability of the study, but has limited the extent to which the details of the relationships between study variables can be understood. Previous research has identified a high prevalence of mental health difficulties within the adolescent Type 1 diabetes population, including anxiety, depression and eating disorders (Bernstein et al., 2013). Such mental health difficulties have been associated with diabetes management (Whittemore et al., 2010) and glycaemic control (Bernstein et al., 2013). Similarly, behavioural and developmental disorders have also been associated with difficulties with executive function such as Attention Deficit Hyperactivity Disorder (Brown, 2013) and autism (Kenworthy, Black, Harrison, della Rosa, & Wallace, 2009). It is not possible to deduce if the relationship identified between executive function and self-management in this sample is independent of such psychological difficulties. This may be particularly important in the case of the adolescent eating disorder population, due to the potential association between recurrent hypoglycaemia and cognitive function, formerly discussed in this thesis. Hypoglycaemia can occur as a result of an individual exerting too much energy than can be provided by the food they have consumed (Gonder-Frederick et al., 2011) – a behaviour associated with eating disorders (Colton et al., 2009). Similarly, as aforementioned, self-induced hyperglycaemia through insulin manipulation can occur amongst diabetic individuals

with a comorbid eating disorder (Colton et al., 2009) and can impact upon the central nervous system and thus cognitive function (Rewers et al., 2009). As this study did not control for eating disorders, it is not possible to deduce if hyperglycaemia or hypoglycaemia associated with an eating disorder impacted upon the observed relationships in this study.

Previous research has identified that these psychological difficulties can impact on diabetes self-management and diabetes control. As such, it would be important to consider the impact of these difficulties on the relationships explored in this research in future studies. The current research explored associations and as such, causal inferences cannot be drawn. In addition, it set out to establish if executive function impacts on self-management and glycaemic control. Comorbid conditions were not investigated and it would be useful, in future research, to assess whether the observed relationships in studies such as this one could be accounted for by potentially transient conditions such as anxiety or depression. Ultimately, however, irrespective of the stability of executive functioning difficulties, this research indicates that executive function does significantly predict diabetes self-management and suggests it should be assessed and addressed to help aid management.

Parent/caregiver participation in the research was optional. This resulted in a smaller number of parent-completed data than adolescent data being collected. Consequently, regression analyses could only be conducted using the adolescent-completed data and not the parent-completed data. In addition, due to the smaller number of parent-completed measures, adolescent-parent/caregiver dyad responses could not be investigated on the DFRQ questionnaire (Anderson et al., 1990) and the level of shared responsibility or disagreement regarding responsibility taking

between adolescent and parent/caregiver was not established. This may have contributed to the lack of identified relationship between responsibility for diabetes care and diabetes self-management in this study. It is possible that if the study design identified parent/caregiver participation as compulsory rather than optional, a greater number of parents/caregivers may have been recruited. This could have enabled parent/caregiver data to be included in the regression analyses and for the responsibility data to be explored in terms of the dyadic responses. Please refer to section 4.3.1 for a full exploration of this limitation.

#### ***4.6.2.2 Sample.***

Only 12 participants scored above the clinical cut off of 65 on one or more of the indexes of the BRIEF measures. It could therefore be argued that the sample recruited for this study were particularly well-functioning and may not be reflective of the adolescent diabetic population as a whole, as the majority (82.09%) did not demonstrate impairments in executive function which would be considered of clinical significance. It is not possible, therefore, to generalise the findings regarding the relationship between executive function and self-management, as they may not be applicable to those individuals with a significantly poorer executive function. However, even if this research sample was considered to be generally well-functioning, the relationships identified still suggest that better executive function is related to better self-management and therefore should be optimised in all individuals with Type 1 diabetes to maximise their self-management success.

This study examined the relationships of these variables to HbA1c values as a measure of glycaemic control. It is important to note, that it is possible that an adolescent may achieve an HbA1c value at a low level that could be considered unsafe. This would occur after a frequent number of hypoglycaemic episodes over

the preceding two to three months and would indicate poor glycaemic control. However, in this sample the lowest HbA1c value recorded was 41mmol/mol (see Table 5 section 3.3), which is only one point below the recommended target for individuals without diabetes ([www.diabetes.co.uk](http://www.diabetes.co.uk)) and therefore is unlikely to be considered unsafe. This should be considered when interpreting these findings, as they may not apply to individuals who may demonstrate poor glycaemic control by achieving too low an HbA1c value.

The study was initially designed to enable exploration into the effect of prior hypoglycaemic episodes on executive function. Previous research into this area has been mixed, with some suggesting a long-term impact of hypoglycaemia on executive function (Bade-White & Obrzut, 2009; Hannonen et al., 2003) and others suggesting no difference amongst individuals with a history of hypoglycaemia and those without (Musen et al., 2008). Unfortunately, the study sample did not provide enough data on this measure to allow for statistical investigations to be conducted – only eight (11.94%) participants reported having had a severe hypoglycaemic episode. Seven reported having 1-2 in their lifetime and one participant reported having had 3-5 episodes.

#### ***4.6.2.3 Measures.***

This research utilised predominantly self and informant-report measures and therefore there is a potential for generalizability and desirability biases to affect the questionnaire results. However, the measures selected for use had demonstrated good validity and reliability and had been used in other research studies within this domain.

This research study utilised a self-report measure of executive function rather than a performance-based measure. The BRIEF measures (Gioia et al., 2000; Guy et

al., 2004) do not account for differences in individuals' social contexts, which may impact on their ability to use and demonstrate their executive functioning abilities. The BRIEF measures ask respondents to base their answers upon the adolescents' behaviour over the previous six months. It is possible that children who spend a large proportion of their time in busy, disorganised and/or chaotic environments report poorer function, because they believe their behaviours have not been successful in their environment, than those who spend a large proportion of their time in calmer, better-organised and less demanding environments. It is therefore possible that the level of executive function measured by the BRIEF measures is context-specific and not generalizable to an individual's function in different environmental contexts (e.g. school vs. home). The inclusion of an additional experimental condition in which the individual completed a performance-based measure of executive function and/or teacher-completed measures of executive function could potentially help to address this.

The current research would have benefitted from the additional inclusion of a performance-based measure of executive function in conjunction with the self and parent/caregiver reports. This would have provided an objective measure of executive function ability, which could have contributed to the overall interpretation of an adolescent's executive function. Objective measures, however, have their limitations and are less ecologically valid than reports based on the individual's actual behaviour in real-life settings and therefore used alone are poorly generalizable (Toplak et al., 2013).

The BRIEF measures offer a global and general view of executive function and are not specific to diabetes management. Duke et al. (2014) developed and piloted a new measure of executive function, specific to diabetes management: the

DREFS. It would be beneficial to continue research into the reliability and validity of this new measure as it could prove a useful disease-specific tool in the investigation of the role of executive function in self-management and glycaemic control in adolescents with Type 1 diabetes.

#### ***4.6.2.4 Statistical analysis.***

Due to the difficulties with under recruitment resulting in a smaller sample size and the return of uncompleted questionnaire measures, two of the regression analyses could only be conducted on 64 full sets of adolescent data. The recommended sample size based on a priori power analyses was 66 (Tabachnick & Fidell, 2007) for a multiple regression analysis including two predictor variables. Post hoc power analyses were conducted to establish the estimated statistical power of the multiple regression analyses conducted with only 64 sets of the data (Clark-Carter, 2010, p.657). In order to investigate whether executive function and responsibility for diabetes care predicted diabetes self-management (Primary Research Question 1), a multiple regression analysis was conducted with two predictor variables, using 64 data sets and reported an effect size,  $R^2 = .19$ . The post hoc power analysis estimated the statistical power of this regression as .92. This multiple regression, therefore, had good statistical power, despite having a smaller sample size than was estimated as necessary prospectively. In contrast, a multiple regression analysis was conducted to establish if executive function and responsibility for diabetes care predicted glycaemic control, as measured by HbA1c values (Primary Research Question 2). This multiple regression analysis was conducted with two predictor variables, using 64 sets of data and reported an effect size,  $R^2 = .04$ . The post hoc power analysis estimated the statistical power of this regression as .28. This multiple regression, therefore, had weak statistical power and



the probability of having made a Type II error was high,  $\beta = .72$ , i.e. the probability that the analysis failed to detect an existing relationship between executive function and responsibility for diabetes care and glycaemic control, as measured by HbA1c.

Due to the small sample size, parent-completed measures of executive function, diabetes self-management and responsibility for diabetes care could not be included in the regression analyses.

#### **4.7 Future Research**

Smith et al. (2014) noted that executive function was likely to be particularly important for individuals using intensive regimens to manage their diabetes. This research study supports this suggestion, indicating a specific predictive relationship between executive function and self-management amongst the study sample (as only one participant was following a conventional management regimen). There are of course, different forms of intensive insulin regimens: insulin delivery via multiple daily injections or insulin infusion via subcutaneous pump, with carbohydrate counting. Insulin pump therapy is becoming more and more popular, particularly amongst youth with Type 1 diabetes (Johnson et al., 2013) and pump therapy has been associated with better glycaemic control in comparison to multiple daily injections (Smith et al., 2014). Future research could investigate if there are differences in the relationships between the study variables explored here, amongst adolescents using a pump compared to those using multiple daily injections for insulin delivery.

Future research may also seek to explore executive function and its relationship to diabetes self-management, in greater depth, to establish if there are specific aspects of executive function that are related to self-management more so than others. The data from this study suggests that aspects of executive function that

fall under the metacognitive domain may have a greater influence on self-management than those considered behavioural regulation skills. However, Miller et al. (2013) has reported the opposite finding. As noted earlier, Graziano et al. (2011) found that emotion regulation was significantly associated with treatment adherence in boys with Type 1 diabetes and that this formed the primary self-regulation measure associated with adherence, over and above the other aspects of executive function investigated. Emotion regulation is considered to fall under the subscale of Emotional Control within the BRIEF measures of executive function. These results appear to be more in line with the findings of Miller et al. (2013) than with the results of the current research. Future research may help to clarify the specific nature of the relationship between executive function and self-management in adolescents with Type 1 diabetes.

This research has started to explore the role of responsibility on self-management of diabetes and investigate if responsibility is related to executive function. It did not, however, consider the effect of parent-adolescent disagreement regarding who holds responsibility for different management tasks. Anderson et al. (1990) designed a scoring structure for the DFRQ, which enabled identification of different response patterns when analysing parent-adolescent dyads (see section 4.3.1). It is possible that disagreement between parent and adolescents as to who holds responsibility for diabetes care tasks will have a greater impact for children and adolescents with poorer executive functioning. Parental involvement in diabetes care may be of greater importance for those children and adolescents with poorer executive function, as they may be less capable of carrying out the necessary tasks accurately and efficiently. Although the current research did not identify a relationship between adolescent responsibility and executive function, it only

examined overall level of perceived responsibility and did not examine level of disagreement of responsibility or sharing of responsibility.

Due to the small sample size, gender differences were not examined in this study. Recent studies have suggested that gender differences do exist within the Type 1 diabetes population, in terms of executive functioning, self-management and diabetes control. The findings of Graziano et al. (2011), in particular, indicate that the contributing factors to self-management and glycaemic control in Type 1 diabetes may be different for girls than they are for boys. Additional future research would help to inform these findings.

#### **4.8 Conclusion**

The key aim of this research study was to explore the potential relationship between executive function and self-management in adolescents with Type 1 diabetes. This chapter has considered the study findings in relation to the hypotheses, research questions and relevant literature. The results offer further support for the existence of an association between executive function and self-management amongst an adolescent population, for which successful management and achieving glycaemic control appears to be challenging. The results indicated that higher levels of executive function were associated with better self-management.

Furthermore, the study results suggest the potential importance of metacognitive aspects (including working memory, planning and organisational skills), over and above behavioural regulation aspects (including inhibition and impulse control) of executive function in adolescent Type 1 diabetes self-management. This finding highlights the need for research to continue to explore specific aspects of executive function and to establish if there are differences as to how they are associated with diabetes self-management. The different developmental

trajectories of different components of executive function should be considered when exploring such associations, specifically in relation to children and adolescents at different stages of development.

The absence of a relationship between executive functioning, responsibility for diabetes care and glycaemic control suggests that other factors may be involved in predicting this outcome and warrants further research. This research study was the first (to the author's knowledge) to consider if a relationship exists between adolescent responsibility for diabetes care and executive function. Despite no association being identified in this study, the potential importance of exploring adolescent responsibility during this developmental period, and its potential impact upon diabetes self-management, has been identified.

Implications for clinical practice, based on the study outcomes have been discussed. Given the fact that this area of research is still in its infancy and that this current study was exploratory in its design and not without its limitations, the clinical implications of the results have been reported tentatively and should be interpreted with caution. The findings support the notion that it may be important for healthcare professionals and parents to be aware of the development of executive function amongst adolescents. It is suggested that they should consider the abilities of individuals when supporting their self-management, specifically with regards to the transfer of responsibility for diabetes management tasks to ensure this happens at a time and at a rate appropriate for the individuals' capabilities.

The main limitations of the study have been discussed and include the cross-sectional nature of the research preventing causal inferences from being established, the limited sample size (particularly in terms of the parent participation) and the scoring pattern used for the measure of responsibility for diabetes care. Despite these

limitations, this research has contributed to the emerging literature base in the area of executive function and self-management in Type 1 diabetes and extends the findings of the existing studies through the provision of measures of adolescents' own perceptions of their executive function and self-management abilities. It is important to start to consider these within this population as they begin to develop their autonomy and independence in diabetes care. The results have highlighted areas for future research, namely the need to explore specific aspects of executive function and their association with self-management and possible considerations for clinical practice.

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*Appendix A*

Demographic Questionnaires

- A1 Demographic questionnaire – Adolescents 11-18 years
- A2 Demographic questionnaire - Parents/caregivers

*Appendix A1*

Demographic Questionnaire - Adolescent 11-18 Years



Doctorate of Clinical Psychology Course  
Department of Psychological Sciences  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich  
NR4 7TJ

**Participant Identification Code (PIC):**

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

---

**DEMOGRAPHIC QUESTIONNAIRE**

**Your parent/caregiver may be able to help you to answer some of these questions. If you are unsure do not worry – a member of your diabetes team might be able to help you.**

---

**Are you male or female?**    MALE    FEMALE

**How old are you?** (Years and Months)

**Are you still attending school/college?**    YES    NO

**What is your nationality?**

**How old were you when you received your diagnosis of Type 1 Diabetes?**

**When did you receive your diagnosis of Type 1 Diabetes?**

**How long have you known that you have had Type 1 Diabetes?**

**Have you ever had an episode of severe hypoglycaemia (resulting in a loss of consciousness or coma)?**

**If yes, approximately how many episodes have you had?**

- |     |             |
|-----|-------------|
| 1-2 | 6-8         |
| 3-5 | More than 9 |

*Appendix A2*

Demographic Questionnaire – Parent/Caregiver



Doctorate of Clinical Psychology Course  
Department of Psychological Sciences  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich  
NR4 7TJ

**Participant Identification Code (PIC):**

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

---

**DEMOGRAPHIC QUESTIONNAIRE**

**If you are unsure do not worry – a member of the diabetes team might be able to help you.**

---

**Are you male or female?**    MALE    FEMALE

**Relationship to adolescent:** \_\_\_\_\_

**How old are you?**

**What is your marital status?**

Single, never married            Married            Widowed  
Co-habiting                        Divorced            Rather not say

**What is your occupation?**

**What is your nationality?**

**Is your child currently in full-time education?**

**What national curriculum level are they currently studying?**

Key Stage 2    Key Stage 3    Key Stage 4

**Is your child currently working towards exams? If so what are they (E.g. SATS, GCSE's, AS-levels, A-levels)?**

**How old was your child when they received their diagnosis of Type 1 Diabetes?**

**When did they receive their diagnosis of Type 1 Diabetes?**

**How long have you and your child known that your child has Type 1 Diabetes?**

**Has your child ever had an episode of severe hypoglycaemia (resulting in a loss of consciousness or coma)?**

**If yes, approximately how many episodes have they had?**

1-2      6-8

3-5      More than 9

*Appendix B*

HbA1c Recording Form



Doctorate of Clinical Psychology Course  
Department of Psychological Sciences  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich  
NR4 7TJ

**Participant Identification Code (PIC):**

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

---

**PLEASE TAKE THIS FORM INTO YOUR CLINIC APPOINTMENT AND ASK THE NURSE/DOCTOR TO ASSIST YOU TO COMPLETE IT**

---

HbA1c value: \_\_\_\_\_

Date of clinic appointment: \_\_\_\_\_

Please return this form to the researcher. Thank you.

\_\_\_\_\_  
Job title of person  
providing the HbA1c value

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*Appendix C*

## Permissions from First Author for use of DSMP-SR in the Research Study

**From:** Eleanor Wells (MED) [<mailto:Eleanor.Wells@uea.ac.uk>]  
**Sent:** Friday, August 22, 2014 7:03 AM  
**To:** Wysocki, Tim  
**Subject:** Request for consideration of DSMP-SR for use in thesis research

Dear Dr Wysocki,

I am a Clinical Psychology Doctorate Trainee at the University of East Anglia in the UK. I am currently developing my research thesis project to investigate the relationship between executive functioning and self-management of Type 1 diabetes in children/adolescents.

I would like to consider the use of the Diabetes Self-Management Profile - Self-Report measure in my research. I wondered if you would be able to send me a copy of the measure so I can consider its use in greater detail?

If the measure proves to be suitable for my research, would you offer your permission for its use (provided this was clearly acknowledged within the research of course)?

I appreciate your time in considering this request. I look forward to hearing from you.

Yours Sincerely,

Eleanor Wells

**From:** Wysocki, Tim<[Tim.Wysocki@nemours.org](mailto:Tim.Wysocki@nemours.org)>  
**Sent:** 22 August 2014 16:10  
**To:** Eleanor Wells (MED)  
**Subject:** RE: Request for consideration of DSMP-SR for use in thesis research

I have attached the four versions of the DSMP-SR (Parent and adolescent versions for either conventional or flexible regimens). Flexible means 1) Use of an insulin pump or basal-bolus multiple daily injection regimen and 2) Use of a carbohydrate counting dietary approach. Every other regimen should be considered Conventional. I also attached a scoring guide for the Flexible Regimen version. I couldn't find the corresponding conventional scoring guide, but I think you can figure it out, because the two versions are parallel except for some slight differences. Also, here is an excerpt from a recent study procedure manual in which this measure was used. You are welcome to use this measure if it meets your needs. I would simply ask that you administer and score it exactly as described here and that you send me a copy of any publications, abstracts or presentations in which you report results from using it.

***Diabetes Self Management Profile – Self Report form (DSMP-SR)*** This 24-item self-report questionnaire was derived from a previously validated structured

interview. It yields subscale scores for five domains of diabetes adherence (Exercise, Diet, Hypoglycemia, Glucose Testing and Insulin) and a total adherence score. Items are rated on Likert response scales, with higher scores indicating better diabetes-related adherence. Cronbach's alpha coefficient was .76 for the total score and inter-rater agreement was .94. The correlation between total scores of parents and adolescents was .72. Correlations with HbA<sub>1C</sub> reported by several research groups were consistently significant (range -.25 to -.60). Based on administration of the self-report version to 36 parents and youths in another ongoing study, internal consistency was .83 for parents and .71 for youths. Parent-youth scores correlated 0.59.

*Administration:* Administer the parent form to parents and the youth form to youth 11 years old and up.

*Scoring:* Each response option yields a specified numerical score per the DSMP Scoring Sheet. Enter the score for each item, total the individual item scores. Possible range is 0 to 86. Higher total scores indicate better overall treatment adherence and more meticulous diabetes management.

*Data Entry:* Enter the numerical score for each item of the scale and the total score separately for parents and adolescents. If one or more item scores is missing, subtract the maximum number of points for each missing item from 86. Then divide that quantity by 86, yielding a value between 0 and 1. Divide the total score for that participant by this value, which will provide a total score adjusted for any missing items.

*Appendix D*

Diabetes Self-Management Profile-Self-Report (DSMP-SR)

- D1 DSMP-SR - Youth Flexible
- D2 DSMP-SR - Parent Flexible
- D3 DSMP-SR - Youth Conventional
- D4 DSMP-SR - Parent Conventional



*Appendix D1*

## Diabetes Self Management Profile-SR (Youth Version, Flexible Regimens)

**DSMP-SR Youth Version**

(For Patients on **Flexible Regimens** such as insulin pumps or basal-bolus injections using carbohydrate counting)

It's hard for most people with diabetes to do everything that their doctors and nurses want them to do all of the time. These are questions about how you have usually taken care of your diabetes during the past 3 months. Please answer each question as truthfully as you can. Remember, your answers will not be shared with any members of your medical team.

**1. In the past 3 months, how often have you done exercise such as running, bike riding, swimming, skating, or playing team sports for at least 20 minutes?**

- More than three times per week
- 2 – 3 times per week
- Once a month
- Less than once per month

**2. In the past 3 months, if you did more exercise than usual, or planned to do more exercise than usual, what did you usually do about the meal plan or insulin?**

- I exercise so consistently that adjustments are unnecessary
- I always eat more or give less insulin
- I frequently eat more or give less insulin (2-3 times per week)
- Sometimes I eat more or give less insulin (once a week)
- Occasionally I eat more or give less insulin (few times a month)
- I eat less than usual or give more insulin
- I never adjust my eating or insulin

**3. In the past 3 months, if you did less exercise than usual, or if you planned to do less exercise, what did you usually do about the meal plan or insulin?**

- I exercise so consistently that adjustments are unnecessary
- I always eat less or give more insulin
- I frequently eat less or give more insulin (2-3 times per week)
- Sometimes I eat less or give more insulin (once a week)
- Occasionally I eat less or give more insulin (few times a month)
- I eat more than usual or give less insulin
- I never adjust my eating or insulin

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- 4. Do you keep something handy in case your sugar gets too low? For example, when you are at school or an outing away from home, or in the car and your sugar gets too low, do you have something handy to eat?**
- Yes
  - No
- 5. If you think you are having a low blood sugar, how often do you check your blood sugar before treating?**
- I have not had a low blood sugar in past 3 months
  - I always check before treating a low blood sugar
  - I usually check before treating a low blood sugar  
(more than half the time)
  - Sometimes I check before treating a low blood sugar  
(about half the time)
  - I check infrequently before treating a low blood sugar  
(less than half the time)
  - I never check before treating a low blood sugar
- 6. People take care of low blood sugars in many different ways. What did you usually do to treat your low blood sugars in the past 3 months?**
- I have not had a low blood sugar in the past 3 months
  - I am careful to quickly take the right amount of carbohydrates and check my blood sugar after 10 minutes
  - I take the right amount of carbohydrates but I do not check blood my sugar afterwards
  - I take some carbohydrates without thinking about how much I need
  - I keep taking carbohydrates until I feel better
  
  - I ignore symptoms until there's a better time to treat my low blood sugar
- 7. Do you wear or carry any kind of diabetic identification, like a card or bracelet?**
- I wear a necklace, bracelet or charm
  - I carry an ID card in my wallet or purse
  - I don't wear or carry diabetic ID
- 8. In the past 3 months, did you usually count carbs, measure or weigh food, or use exchanges to figure out how much to eat?**
- I use carbohydrate counting (or exchange list) as a guide and either measure food or read labels
  - I use carbohydrate counting (or exchange list) as a guide, but I know my meal plan well enough so that I can eat the right amounts without measuring or reading labels

- I eat about the same amounts of food each meal, but I don't use carbohydrate counting, measuring or an exchange list
- I eat the amount I am hungry for and I don't follow any set patterns of types or amounts of foods

**9. In the past 3 months, how often have you eaten "fast foods" or "junk foods" such as sweets, biscuits, cakes, ice-cream, crisps, pizza, chips, hot dogs, or others?**

- Occasionally (few times a month or less)
- Sometimes (once a week)
- Frequently (2-3 times per week)
- Almost always (4 or more times per week)
- Every day

**10. In the past 3 months, how often have you eaten more than what was on your meal plan?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

**11. In the past 3 months, before you ate more than usual, did you make any insulin changes?**

- I give MORE insulin when I eat more
- I give LESS insulin when I eat more
- I do not change my insulin

**12. In the past 3 months, how often have you eaten less than what was planned?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

**13. Before you eat less than usual, do you make any insulin changes? What do you do?**

- I give LESS insulin when I eat less
  - I give MORE insulin when I eat less
- I do not adjust my insulin

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**14. In the past 3 months, how often have you checked your blood sugar?**

- 6 or more times daily
- 4 or 5 times daily
- 2 or 3 times daily
- At least once daily
- Less than once daily
- I do not check my blood sugar

**15. In the past 3 months, how often did you do a blood sugar check within 30 minutes before a meal?**

- I always check my blood sugar within 30 minutes before every meal
- I usually check within 30 minutes before meals (more than half the time)
- Sometimes I check within 30 minutes before meals (about half the time)
- I check within 30 minutes before meals less than half the time
- I never check within 30 minutes before meals

**16. In the past 3 months, how often did you do a blood sugar check within 2-3 hours after a meal?**

- I check my blood sugar within 2-3 hours after a meal 4 or more times per week
- I check within 2-3 hours after a meal 3 times per week
- I check within 2-3 hours after a meal 2 times per week
- I check within 2-3 hours after a meal once a week
- I never check within 2-3 hours after meals

**17. In the past 3 months, how often did you do a blood sugar check within 2-3 hours after heavy exercise?**

- I always check my blood sugar within 2-3 hours after exercise
- I check 2-3 hours after exercise more than half the time
- I check 2-3 hours after exercise about half the time
- I check 2-3 hours after exercise less than half the time
- I never check 2-3 hours after exercise

**18. In the past three months, how often have you changed either the insulin dose, diet or exercise when the blood sugars were running high?**

- I made a change every time it was needed
- I made a change when needed more than half the time
- I made a change when needed about half the time
- I made a change when needed less than half the time
- I never made a change when needed

**19. In the past 3 months, if you had two blood sugar results above 15mmol/mol in a row, how often did you do a ketone test?**

- I did not have two blood sugars in a row above 15mmol/mol
- I always checked for ketones after 2 blood sugars in a row above 15mmol/mol
- I usually checked for ketones after 2 blood sugars in a row above 15mmol/mol

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- I occasionally checked for ketones after 2 blood sugars in a row above 15mmol/mol
- I never checked for ketones after 2 blood sugars in a row above 15mmol/mol

**20. When you've been sick, how often did you do a ketone test?**

- I always check for ketones several times a day when I am sick
- I always check for ketones once a day when I am sick
- I usually check for ketones once a day when I am sick
- Occasionally tests ketones when I am sick
- Never tests for ketones when I am sick

**16. In the last three months, how often have you bolused or taken an insulin shot more than 30 minutes late?**

- Never, I always take insulin on time
- I have been late once a month or less
- I have been late once a week or less
- I have been late more than once a week

**17. In the past 3 months, how often have you bolused or taken MORE insulin than you should have?**

- I always took the prescribed amount
- I took more than prescribed amount 1 -3 times
- I took more than prescribed amount 4 - 6 times
- I took more than prescribed amount 7 - 10 times
- I took more than prescribed amount more than 10 times

**18. In the past 3 months, how often have you bolused or taken LESS insulin than you should have?**

- I always took the prescribed amount
- I took less than prescribed amount 1 - 3 times
- I took less than prescribed amount 4 - 6 times
- I took less than prescribed amount 7 - 10 times
- I took less than prescribed amount more than 10 times

**19. In the last three months, how often have you missed a bolus or injection because you forgot or were too busy, or failed to give your basal insulin because your pump was not working or inserted?**

- I never forgot, I always take insulin
- I forgot once a month or less (1 - 3 times in the last 3 months)
- I forgot once a week or less
- I forgot more than once a week

**Thank you.**

PIC:\_\_\_\_\_

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*Appendix D2*

## Diabetes Self Management Profile-SR (Parent Version, Flexible Regimens)

**DSMP-SR Parent Version**

(For Patients on **Flexible Regimens** such as insulin pumps or basal-bolus injections using carbohydrate counting)

It's hard for most families of children with diabetes to do everything that their doctors and nurses want them to do all of the time. These are questions about how you and your child have usually taken care of your child's diabetes during the past 3 months. Please answer each question as truthfully as you can. Remember, your answers will not be shared with any members of your child's medical team.

1. **In the past 3 months, how often has your child done exercise such as running, bike riding, swimming, skating, or playing team sports for at least 20 minutes?**
  - More than three times per week
  - 2 – 3 times per week
  - Once a month
  - Less than once per month
  
2. **In the past 3 months, if your child got more exercise than usual, or planned to get more exercise than usual, what did you or your child usually do about the meal plan or insulin?**
  - Exercises so consistently that adjustments are unnecessary
  - Always eats more or gives less insulin
  - Frequently eats more or gives less insulin (2-3 times per week)
  - Sometimes eats more or gives less insulin (once a week)
  - Occasionally eats more or gives less insulin (few times a month)
  - Eats less than usual or gives more insulin
  - Never adjusts eating or insulin
  
3. **In the past 3 months, if your child got less exercise than usual, or if your child planned to get less exercise, what did you or your child usually do about the meal plan or insulin?**
  - Exercises so consistently that adjustments are unnecessary
  - Always eats less or gives more insulin
  - Frequently eats less or gives more insulin (2-3 times per week)
  - Sometimes eats less or gives more insulin (once a week)
  - Occasionally eats less or gives more insulin (few times a month)
  - Eats more than usual or gives less insulin
  - Never adjusts eating or insulin

- 4. Does your child keep something handy in case of an insulin reaction or low blood sugar low? For example, when your child is at school or on an outing away from home, or in the car and your child's sugar gets too low, does your child have something handy to eat?**
- Yes
  - No
- 5. If your child thinks a low blood sugar is happening, how often does your child do a blood sugar check before treating?**
- Always checks before treating a low blood sugar
  - Child has not had a low blood sugar in past 3 months
  - Usually checks before treating a low blood sugar (75% of the time) or (more than half the time)
  - Sometimes checks before treating a low blood sugar (50% of the time) or (half the time)
  - Infrequently checks before treating a low blood sugar (25% of the time) or (less than half the time)
  - Never checks before treating a low blood sugar
- 6. People take care of low blood sugars in many different ways. What did you or your child usually do to treat your child's low blood sugars in the past 3 months?**
- Child has not had a low blood sugar in the past 3 months
  - Careful to quickly take the prescribed amount of carbohydrates and check the blood sugar after 10 minutes
  - Take prescribed amount of carbohydrates but does not check blood sugar afterwards
  - Take carbohydrates (not the prescribed amount) without considering how much
  - Continue taking carbohydrates until symptoms go away
  - Ignore symptoms until it's more convenient to treat the low blood sugar
- 7. Does your child wear or carry any kind of diabetic identification, like a card or bracelet?**
- Wears necklace, bracelet or charm
  - Carries ID card in wallet or purse
  - Does not wear or carry diabetic ID
- 8. In the past 3 months, did your child usually count carbs, measure or weigh food, or use exchanges to figure out how much to eat?**
- Uses carbohydrate counting (or exchange list) as a guide and either measures food or reads labels



- Uses carbohydrate counting (or exchange list) as a guide, but knows meal plan well enough so that he/she can eat the right amounts without measuring or reading labels
- Eats about the same amounts of food each meal, but doesn't use carbohydrate counting, measuring or exchange list
- Eats the amount he/she is hungry for and doesn't follow any set patterns of types or amounts of foods

**9. In the past 3 months, how often has your child eaten "fast foods" or "junk foods" such as sweets, biscuits, cakes, ice cream, crisps, pizza, chips, hot dogs, or others?**

- Occasionally (few times a month or less)
- Sometimes (once a week)
- Frequently (2-3 times per week)
- Almost always (4 or more times per week)
- Everyday

**10. In the past 3 months, how often has your child eaten more than what was on the meal plan?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

**11. In the past 3 months, before your child ate more than usual, did your child make any insulin changes?**

- Gives MORE insulin when eats more
- Gives LESS insulin when eats more
- Does not change insulin

**12. In the past 3 months, how often has your child eaten less than what was planned?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

**13. Before your child eats less than usual, does your child make any insulin changes? What does [he/she] do?**

- Gives LESS insulin when eats less
- Gives MORE insulin when eats less
- Does not adjust insulin

**14. In the past 3 months, how often has your child checked his/her blood sugar?**

- Checks blood sugar 6 or more times daily
- Checks blood sugar 4 or 5 times daily
- Checks blood sugar 2 or 3 times daily
- Checks blood sugar at least once daily
- Checks blood sugar less than once daily
- Does not check blood sugar

**15. In the past 3 months, how often did your child do a blood sugar check within 30 minutes before a meal?**

- Always checks within 30 minutes before every meal
- Usually checks within 30 minutes before meals (75% of the time) or (more than half the time)
- Sometimes checks within 30 minutes before meals (50% of the time) or (half the time)
- Infrequently checks within 30 minutes before meals (25% of the time) or (less than half the time)
- Never checks within 30 minutes before meals

**16. In the past 3 months, how often did your child do a blood sugar check within 2-3 hours after a meal?**

- Checks within 2-3 hours after a meal 4 or more times per week
- Checks within 2-3 hours after a meal 3 times per week
- Checks within 2-3 hours after a meal 2 times per week
- Checks within 2-3 hours after a meal once a week
- Never checks within 2-3 hours after meals

**17. In the past 3 months, how often did your child do a blood sugar check within 2-3 hours after heavy exercise?**

- Always tests within 2-3 hours after exercise
- Usually tests within 2-3 hours after exercise (75% of the time) or (more than half the time)
- Sometimes tests within 2-3 hours after exercise (50% of the time) or (half the time)
- Infrequently tests within 2-3 hours after exercise (25% of the time) or (less than half the time)
- Never tests within 2-3 hours after exercise

PIC: \_\_\_\_\_

**18. In the past three months, how often has your child changed either the insulin dose, diet or exercise when the blood sugars were running high?**

- Made a change every time it was needed

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- Usually made a change when needed (> 75%) or (more than half the time)
- Sometimes made a change when needed (>50%) or (half the time)
- Infrequently made a change when needed (<50%) or (less than half the time)
- Never made a change when needed

**19. In the past 3 months, if your child had two blood sugar results above 15mmol/mol in a row, how often did your child do a ketone test?**

- Child did not have two blood sugars in a row above 15mmol/mol
- Always tested for ketones after 2 blood sugars in a row above 15mmol/mol
- Usually tested for ketones after 2 blood sugars in a row above 15mmol/mol
- Occasionally tested for ketones after 2 blood sugars in a row above 15mmol/mol
- Never tested for ketones after 2 blood sugars in a row above 15mmol/mol

**20. When your child is sick, how often does your child do a ketone test?**

- Always tests for ketones several times a day when sick
- Always tests for ketones once a day when sick
- Usually tests for ketones once a day when sick
- Occasionally tests ketones when sick
- Never tests for ketones when sick

**21. In the last three months, how often has your child bolused or taken an insulin shot more than 30 minutes late?**

- Never, always take insulin on time
- Late once a month or less (1 - 3 times in the last 3 months)
- Late once a week or less
- Late more than once a week

**22. In the past 3 months, how often has your child bolused or taken MORE insulin than needed?**

- Always took prescribed amount
- Took more than prescribed amount 1 - 3 times
- Took more than prescribed amount 4 - 6 times
- Took more than prescribed amount 7 - 10 times
- Took more than prescribed amount more than 10 times

**23. In the past 3 months, how often has your child bolused or taken LESS insulin than needed?**

- Always took the prescribed amount
- Took less than prescribed amount 1 - 3 times
- Took less than prescribed amount 4 - 6 times

PIC: \_\_\_\_\_

- Took less than prescribed amount 7 - 10 times
- Took less than prescribed amount more than 10 times

**24. In the last three months, how often has your child missed a bolus or shot because of forgetting or being too busy, or didn't give basal insulin because the insulin pump was not working or inserted?**

- Never forgot, always take insulin
- Forgot once a month or less (1 - 3 times in the last 3 months)
- Forgot once a week or less
- Forgot more than once a week

**Thank you.**

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*Appendix D3*

## Diabetes Self Management Profile-SR (Youth Version, Conventional Regimens)

**DSMP-SR Youth Version**

(For Patients on **Conventional Regimens** who are not using carb counting or insulin correction factors)

It's hard for most people with diabetes to do everything their doctors and nurses want them to do all of the time. These are questions about how you have usually taken care of your diabetes during the past 3 months. Please answer each question as truthfully as you can. Remember, your answers will not be shared with any members of your child's medical team.

**1. In the past 3 months, how often have you done exercise such as running, bike riding, swimming, skating, or playing team sports for at least 20 minutes?**

- More than three times per week
- 2 – 3 times per week
- Once a month
- Less than once per month

**2. In the past 3 months, if you got more exercise than usual, or planned to get more exercise than usual, what did you usually do about the meal plan or insulin?**

- Exercises so consistently that adjustments are unnecessary
- I always eat more or give less insulin
- Frequently I eat more or give less insulin (2-3 times per week)
- Sometimes I eat more or give less insulin (once a week)
- Occasionally I eat more or give less insulin (few times a month)
- I eat less than usual or give more insulin
- I never adjust my eating or insulin

**3. In the past 3 months, if you got less exercise than usual, or if you planned to get less exercise, what did you child usually do about your meal plan or insulin?**

- I exercise so consistently that adjustments are unnecessary
- I always eat less or give more insulin
- Frequently I eat less or give more insulin (2-3 times per week)
- Sometimes I eat less or give more insulin (once a week)
- Occasionally I eat less or give more insulin (few times a month)
- I eat more than usual or give less insulin
- I never adjust my eating or insulin

**4. Do you keep something handy in case you have an insulin reaction or your sugar gets too low? For example, when you are at school or on an outing away from**

PIC: \_\_\_\_\_

**home, or in the car and your sugar gets too low, do you have something handy to eat?**

- Yes
- No

**5. If you think you have a low blood sugar, how often do you check the blood sugar before treating?**

- I always check before treating a low blood sugar
- I have not had a low blood sugar in the past 3 months
- Usually I check before treating a low blood sugar (75% of the time) or (more than half the time)
- Sometimes I check before treating a low blood sugar (50% of the time) or (half the time)
- I infrequently check before treating a low blood sugar (25% of the time) or (less than half the time)
- I never check before treating a low blood sugar

**6. People take care of low blood sugars in many different ways. What did you usually do to treat your low blood sugars in the past 3 months?**

- I have not had a low blood sugar in the past 3 months
- I am careful to quickly take the prescribed amount of carbs (15 grams if applicable) and check the blood sugar after 10 minutes
- I take prescribed amount of carbs but I don't check my blood sugar afterwards
- I take carbs (not the prescribed amount) without considering how much
- I keep taking carbs until I feel OK
- I ignore my symptoms until it's a better time to treat the low blood sugar

**7. Do you carry any kind of diabetic identification, like a card or bracelet?**

- I wear a necklace, bracelet or charm
- I carry an ID card in my wallet or purse
- I don't wear or carry diabetic identification

**8. In the past 3 months, did you usually count carbohydrates, measure or weigh food, or use exchanges to figure out how much to eat?**

- I use carbohydrate counting (or exchange list) as a guide and I either measure my food or read labels
- I use carbohydrate counting (or exchange list) as a guide, but I know my meal plan well enough so that I can eat the right amounts without measuring or reading labels
- I eat about the same amounts of food each meal, but I don't use carb counting, measuring or an exchange list
- I eat the amount I am hungry for and I don't follow any set patterns of types or amounts of foods

**9. In the past 3 months, how often have you eaten "fast foods" or "junk foods" such as sweets, biscuits, cakes, ice-cream, crisps, pizza, chips, hot dogs, or others?**

- Occasionally (few times a month or less)
- Sometimes (once a week)
- Frequently (2-3 times per week)
- Almost always (4 or more times per week)
- Every day

**10. In the past 3 months, how often have you child eaten more than what was on your meal plan?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

**11. In the past 3 months, before you ate more than usual, did you make any insulin changes?**

- I gave MORE insulin when I ate more
- I gave LESS insulin when I ate more
- I don't change how much insulin I take

**12. In the past 3 months, how often have you eaten less than what was planned?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

**13. Before you eat less than usual, do you make any insulin changes? What do you do?**

- I gave LESS insulin when I ate less
- I gave MORE insulin when I ate less
- I don't change how much insulin I take

**14. In the past 3 months, how often have you checked your blood sugar?**

- 6 or more times daily
- 4 or 5 times daily

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- 2 or 3 times daily
- At least once daily
- Less than once daily
- I don't check my blood sugar

**15. In the past 3 months, how often did you do a blood sugar check within 30 minutes before a meal?**

- I always check within 30 minutes before every meal
- I usually check within 30 minutes before meals (75% of the time) or (more than half the time)
- Sometimes I check within 30 minutes before meals (50% of the time) or (half the time)
- I infrequently check within 30 minutes before meals (25% of the time) or (less than half the time)
- I never check within 30 minutes before meals

**16. In the past 3 months, how often did you do a blood sugar check within 2-3 hours after a meal?**

- I check within 2-3 hours after a meal 4 or more times per week
- I check within 2-3 hours after a meal 3 times per week
- I check within 2-3 hours after a meal 2 times per week
- I check within 2-3 hours after a meal once a week
- I never check within 2-3 hours after meals

**17. In the past 3 months, how often did you do a blood sugar check within 2-3 hours after heavy exercise?**

- I always test within 2-3 hours after exercise
- I usually test within 2-3 hours after exercise (75% of the time) or (more than half the time)
- Sometimes I test within 2-3 hours after exercise (50% of the time) or (half the time)
- I infrequently test within 2-3 hours after exercise (25% of the time) or (less than half the time)
- I never test within 2-3 hours after exercise

**18. In the past three months, how often has your child changed either the insulin dose, diet or exercise when the blood sugars were running high?**

- I made a change every time it was needed
- I usually made a change when needed (> 75%) or (more than half the time)
- Sometimes I made a change when needed (>50%) or (half the time)
- I infrequently made a change when needed (<50%) or (less than half the time)
- I never made a change when needed

**19. In the past 3 months, if you had two blood sugar results above 15mmol/mol in a row, how often did you do a ketone test?**

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- I did not have two blood sugars in a row above 15mmol/mol
- I always tested for ketones after 2 blood sugars in a row above 15mmol/mol
- I usually tested for ketones after 2 blood sugars in a row above 15mmol/mol
- I occasionally tested for ketones after 2 blood sugars in a row above 15mmol/mol
- I never tested for ketones after 2 blood sugars in a row above 15mmol/mol

**20. When you are sick, how often do you do a ketone test?**

- I always test for ketones several times a day when I'm sick
- I always test for ketones once a day when I'm sick
- Usually I test for ketones once a day when I'm sick
- Occasionally I test for ketones when I'm sick
- I never test for ketones when I'm sick

**21. In the last three months, how often have you an insulin shot more than 30 minutes late?**

- Never, I always take insulin on time
- Late once a month or less (1 - 3 times in the last 3 months)
- Late once a week or less
- Late more than once a week

**22. In the past 3 months, how often have you taken MORE than the prescribed amount of insulin, even more than your sliding scale allows for?**

- I always took the prescribed amount
- I took more than the prescribed amount 1 -3 times
- I took more than the prescribed amount 4 - 6 times
- I took more than the prescribed amount 7 - 10 times
- I took more than the prescribed amount more than 10 times

**23. In the past 3 months, how often have you taken LESS than the prescribed amount of insulin, even less than your sliding scale allows for?**

- I always took the prescribed amount
- I took less than prescribed amount 1 - 3 times
- I took less than prescribed amount 4 - 6 times
- I took less than prescribed amount 7 - 10 times
- I took less than prescribed amount more than 10 times

PIC: \_\_\_\_\_

Page 5 of 6

**24. In the last three months, how often have you missed giving an insulin shot because you forgot or were too busy?**

- I never forgot, I always take insulin
- I forgot once a month or less (1 - 3 times in the last 3 months)
- I forgot once a week or less
- I forgot more than once a week

**Thank you**

PIC: \_\_\_\_\_

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*Appendix D4*

## Diabetes Self Management Profile-SR (Parent Version, Conventional Regimens)

**DSMP-SR Parent Version**

(For Patients on **Conventional Regimens** who are not using carb counting or insulin correction factors)

It's hard for most families of children with diabetes to do everything their doctors and nurses want them to do all of the time. These are questions about how you and your child have usually taken care of your child's diabetes during the past 3 months. Please answer each question as truthfully as you can. Remember, your answers will not be shared with any members of your child's medical team.

- 1. In the past 3 months, how often has your child done exercise such as running, bike riding, swimming, skating, or playing team sports for at least 20 minutes?**
  - More than three times per week
  - 2 – 3 times per week
  - Once a month
  - Less than once per month
  
- 2. In the past 3 months, if your child did more exercise than usual, or planned to get more exercise than usual, what did you or your child usually do about the meal plan or insulin?**
  - Exercises so consistently that adjustments are unnecessary
  - Always eats more or gives less insulin
  - Frequently eats more or gives less insulin (2-3 times per week)
  - Sometimes eats more or gives less insulin (once a week)
  - Occasionally eats more or gives less insulin (few times a month)
  - Eats less than usual or gives more insulin
  - Never adjusts eating or insulin
  
- 3. In the past 3 months, if your child did less exercise than usual, or if your child planned to get less exercise, what did you or your child usually do about the meal plan or insulin?**
  - Exercises so consistently that adjustments are unnecessary
  - Always eats less or gives more insulin
  - Frequently eats less or gives more insulin (2-3 times per week)
  - Sometimes eats less or gives more insulin (once a week)
  - Occasionally eats less or gives more insulin (few times a month)
  - Eats more than usual or gives less insulin
  - Never adjusts eating or insulin

PIC: \_\_\_\_\_

- 4. Does your child keep something handy in case [he/she] has an insulin reaction or [his/her] sugar gets too low? For example, when [he/she] is at school or on an outing away from home, or in the car and [his/her] sugar gets too low, does [he/she] have something handy to eat?**
- Yes
  - No
- 5. If your child thinks [he/she] has a low blood sugar, how often does [he/she] check the blood sugar before treating?**
- Always checks before treating a low blood sugar
  - Child has not had a low blood sugar in past 3 months
  - Usually checks before treating a low blood sugar (75% of the time) or (more than half the time)
  - Sometimes checks before treating a low blood sugar (50% of the time) or (half the time)
  - Infrequently checks before treating a low blood sugar (25% of the time) or (less than half the time)
  - Never checks before treating a low blood sugar
- 6. People take care of low blood sugars in many different ways. What did you or your child usually do to treat your child's low blood sugars in the past 3 months?**
- Child has not had a low blood sugar in the past 3 months
  - Careful to quickly take the prescribed amount of carbohydrates (15 grams if applicable) and check the blood sugar after 10 minutes
  - Take prescribed amount of carbohydrates but does not check blood sugar afterwards
  - Take carbohydrates (not the prescribed amount) without considering how much
  - Continue taking carbohydrates until symptoms go away
  - Ignore symptoms until it's more convenient to treat the low blood sugar
- 7. Does your child wear or carry any kind of diabetic identification, like a card or bracelet?**
- Wears necklace, bracelet or charm
  - Carries billfold identification card in wallet or purse
  - Does not wear or carry diabetic identification
- 8. In the past 3 months, did your child usually count carbs, measure or weigh food, or use exchanges to figure out how much to eat?**
- Uses carbohydrate counting (or exchange list) as a guide and either measures food or reads labels
  - Uses carbohydrate counting (or exchange list) as a guide, but knows meal plan

PIC: \_\_\_\_\_

well enough so that he/she can eat the right amounts without measuring or reading labels

- Eats about the same amounts of food each meal, but doesn't use carbohydrate counting, measuring or exchange list
- Eats the amount he/she is hungry for and doesn't follow any set patterns of types or amounts of foods

**9. In the past 3 months, how often has your child eaten "fast foods" or "junk foods" such as sweets, biscuits, cakes, ice cream, crisps, pizza, chips, hot dogs, or others?**

- Occasionally (few times a month or less)
- Sometimes (once a week)
- Frequently (2-3 times per week)
- Almost always (4 or more times per week)
- Every day

**10. In the past 3 months, how often has your child eaten more than what was on your child's meal plan?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

**11. In the past 3 months, before your child ate more than usual, did your child make any insulin changes?**

- Gives MORE insulin when eats more
- Gives LESS insulin when eats more
- Does not change insulin

**12. In the past 3 months, how often has your child eaten less than what was planned?**

- Never or hardly ever (1-2 times in the last 3 months)
- Seldom (once a month)
- Occasionally (few times each month)
- Frequently (2-3 times per week)
- Almost daily (4 or more times per week)

PIC: \_\_\_\_\_

**13. Before your child eats less than usual, does your child make any insulin changes? What does [he/she] do?**

- Gives LESS insulin when eats less
- Gives MORE insulin when eats less
- Does not adjust insulin

**14. In the past 3 months, how often has your child checked his/her blood sugar?**

- Checks blood sugar 6 or more times daily
- Checks blood sugar 4 or 5 times daily
- Checks blood sugar 2 or 3 times daily
- Checks blood sugar at least once daily
- Checks blood sugar less than once daily
- Does not check blood sugar

**15. In the past 3 months, how often did your child do a blood sugar check within 30 minutes before a meal?**

- Always checks within 30 minutes before every meal
- Usually checks within 30 minutes before meals (75% of the time) or (more than half the time)
- Sometimes checks within 30 minutes before meals (50% of the time) or (half the time)
- Infrequently checks within 30 minutes before meals (25% of the time) or (less than half the time)
- Never checks within 30 minutes before meals

**16. In the past 3 months, how often did your child do a blood sugar check within 2-3 hours after a meal?**

- Checks within 2-3 hours after a meal 4 or more times per week
- Checks within 2-3 hours after a meal 3 times per week
- Checks within 2-3 hours after a meal 2 times per week
- Checks within 2-3 hours after a meal once a week
- Never checks within 2-3 hours after meals

**17. In the past 3 months, how often did your child do a blood sugar check within 2-3 hours after heavy exercise?**

- Always tests within 2-3 hours after exercise
- Usually tests within 2-3 hours after exercise (75% of the time) or (more than half the time)
- Sometimes tests within 2-3 hours after exercise (50% of the time) or (half the time)
- Infrequently tests within 2-3 hours after exercise (25% of the time) or (less than half the time)
- Never tests within 2-3 hours after exercise

PIC: \_\_\_\_\_

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**18. In the past three months, how often has your child changed either the insulin dose, diet or exercise when the blood sugars were running high?**

- Made a change every time it was needed
- Usually made a change when needed (> 75%) or (more than half the time)
- Sometimes made a change when needed (>50%) or (half the time)
- Infrequently made a change when needed (<50%) or (less than half the time)
- Never made a change when needed

**19. In the past 3 months, if your child had two blood sugar results above 15mmol/mol in a row, how often did your child do a ketone test?**

- Child did not have two blood sugars in a row above 15mmol/mol
- Always tested for ketones after 2 blood sugars in a row above 15mmol/mol
- Usually tested for ketones after 2 blood sugars in a row above 15mmol/mol
- Occasionally tested for ketones after 2 blood sugars in a row above 15mmol/mol
- Never tested for ketones after 2 blood sugars in a row above 15mmol/mol

**20. When your child is sick, how often does your child do a ketone test?**

- Always tests for ketones several times a day when sick
- Always tests for ketones once a day when sick
- Usually tests for ketones once a day when sick
- Occasionally tests ketones when sick
- Never tests for ketones when sick

**21. In the last three months, how often has your child taken an insulin shot more than 30 minutes late?**

- Never, always take insulin on time
- Late once a month or less (1 - 3 times in the last 3 months)
- Late once a week or less
- Late more than once a week

**22. In the past 3 months, how often has your child taken MORE than the prescribed amount of insulin, even more than [his/her] sliding scale allows for?**

- Always took prescribed amount
- Took more than prescribed amount 1 -3 times
- Took more than prescribed amount 4 - 6 times
- Took more than prescribed amount 7 - 10 times
- Took more than prescribed amount more than 10 times

PIC: \_\_\_\_\_

Page 5 of 6

**23. In the past 3 months, how often has your child taken LESS than the prescribed amount of insulin, even less than [his/her] sliding scale allows for?**

- Always took the prescribed amount
- Took less than prescribed amount 1 - 3 times
- Took less than prescribed amount 4 - 6 times
- Took less than prescribed amount 7 - 10 times
- Took less than prescribed amount more than 10 times

**24. In the last three months, how often has your child missed giving an insulin shot because [he/she] forgot or was too busy?**

- Never forgot, always take insulin
- Forgot once a month or less (1 - 3 times in the last 3 months)
- Forgot once a week or less
- Forgot more than once a week

**Thank you.**

PIC: \_\_\_\_\_

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*Appendix E*

## Diabetes Family Responsibility Questionnaire

Below are different tasks or situations that relate to diabetes management in your family. Choose one number from the three statements that best describes the way each task or situation is handled in your family.

1 = Parent(s) take or initiate responsibility for this almost all of the time.

2 = Parent(s) and child share responsibility for this about equally.

3 = Child takes or initiates responsibility for this almost all of the time.

Situations or tasks:

- \_\_\_ 1. Remembering day of clinic appointment. (GH)\*
- \_\_\_ 2. Telling teachers about diabetes. (S)
- \_\_\_ 3. Remembering to take morning or evening injection or boluses (pump). (R)
- \_\_\_ 4. Making appointments with dentists and other doctors. (GH)
- \_\_\_ 5. Telling relatives about diabetes. (S)
- \_\_\_ 6. Taking more or less insulin according to results of blood sugar or urine tests. (GH)
- \_\_\_ 7. Noticing differences in health, such as weight changes or signs of an infection. (GH)
- \_\_\_ 8. Telling friends about diabetes. (S)
- \_\_\_ 9. Noticing the early signs of an insulin reaction. (R)
- \_\_\_ 10. Giving insulin injections or boluses (pump). (R)
- \_\_\_ 11. Deciding what should be eaten when family has meals out (restaurants, friend's home). (GH)
- \_\_\_ 12. Examining feet and making sure shoes fit properly. (GH)
- \_\_\_ 13. Carrying some form of sugar in case of an insulin reaction. (R)
- \_\_\_ 14. Explaining absences from school to teachers or other school personnel. (S)
- \_\_\_ 15. Rotating injection sites or infusion set-ups (pump). (R)
- \_\_\_ 16. Checking expiration dates on medical supplies. (GH)
- \_\_\_ 17. Remembering times when blood sugar or urine should be tested. (R)

PIC: \_\_\_\_\_

*Appendix F*

## Research Poster



Recruitment site logo

**RESEARCH STUDY**

**Is There a Relationship Between Executive Function and Self-Management in Adolescents with Type 1 Diabetes?**

Eleanor Wells, Trainee Clinical Psychologist

**★ What is the study about?**

Type 1 Diabetes can be difficult to manage. This study wants to find out if the ability to plan, organise and use working memory affects how well adolescents can self-manage Type 1 Diabetes.

This is so we can find better ways to help adolescents self-manage their diabetes better and more easily.

**★ WIN £10 Amazon Voucher ★**

All participants can enter a prize draw to win one of the vouchers up for grabs.

**★ Who can take part?**

You can take part if you:

- Are between **11 and 18 years old**
- Have had a diagnosis of **Type 1 diabetes** for at least **1 year**
- Can understand written or spoken English

And do NOT have:

- A diagnosed learning disability
- A severe psychiatric disorder
- Another chronic condition like renal disease or cystic fibrosis

Your parent/caregiver can also take part as long as you live with them most of the time.

If you are unsure if you are eligible to take part you can speak to the researcher.

**★ What do I have to do?**

You have probably already received an information pack from your diabetes team through the post. If you haven't, ask at reception for one.

If you would like to take part you will have to sign a form to say that it is ok for the researcher to come and talk to you about the study.

The researcher will be attending the diabetes clinic at this hospital and will talk through the study with you.

If you agree to take part you will then fill in some questionnaires. This will take about 30 minutes. You can decide if you would like to fill the questionnaires in whilst you are at the hospital, over the telephone or arrange for the researcher to visit you at home.

Your parent/caregiver can also take part.

**★ Contact**

Chief Investigator: Eleanor Wells

Tel: 0XXXXXXXXXXXX

Email: XXXXX@XXXXXX

Department of Psychological Sciences  
School of Medicine  
University of East Anglia  
Norwich  
NR4 7TJ

*Appendix G*

Participant Information Sheets

- G1 Participant Information Sheet (11-15 years)
- G2 Participant Information Sheet (16-18 years)
- G3 Participant Information Sheet (Parent/Caregiver)

*Appendix G1*

## Participant Information Sheet (11-15 years)



Doctorate of Clinical Psychology Course  
Department of Psychological Sciences  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich  
NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

---

**INFORMATION ABOUT THE RESEARCH**

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We would like to invite you and your parent/caregiver to take part in our research study. Before you decide we would like to tell you why we are doing the research and what you will have to do to take part. If you have any questions, please contact the researcher using the details below or at the address above. Please talk to your friends, family, doctor or nurse before you make a decision.

**What is the purpose of the study?**

This research study hopes to find out how different things affect how well young people manage their Type 1 diabetes. This study is interested in finding out if the way that individuals plan, organise, problem-solve and use their memory affects how well they can self-manage their diabetes.

**Why have I been asked to take part in this research?**

You have been chosen to take part in this research as you have a diagnosis of Type 1 Diabetes and are between 11 and 18 years old. The diabetes team helped identify you as being in the right age range for the research.

**What will happen to me if I take part?**

You will be asked to complete some questionnaires. These will take about 30 minutes to complete. If your parent/caregiver is taking part they will also be asked to complete a set of questionnaires. You will meet with the researcher first to talk about the research and to make sure you are happy to take part. You will be able to ask the researcher any questions you have about taking part.

Please complete your questionnaires on your own. If you are finding it difficult to read the questionnaires or understand the questions then please ask the researcher for help. It is important that your parent/caregiver does not help you answer the questions. If your parent/caregiver is also taking part please do not help them with their answers.

**Do I have to take part?**

It is up to you if you would like to take part in this research. If you want to take part, we will ask you to show that you are happy to by signing a form. You can stop taking part at any time, up until the point the questionnaires have been put into the computer system. You do not have to give a reason why you want to stop taking part. Not taking part or stopping taking part during the research will not affect the care you receive at the clinic.

**Does my parent/caregiver have to take part?**

Page 1 of 3

No. You can still take part in the research even if your parent/caregiver does not want to. Your parent/caregiver will be given his/her own information sheet to read about the research study.

**What if I am unable to take part today?**

If you would like to take part in this research but you are unable to complete the questionnaires today please contact the researcher. The researcher will arrange with your parent/caregiver an appropriate time for her to telephone you or visit you at home in order to complete the questionnaires.

**Is there a reward for taking part?**

To thank you for your time completing this research, you can choose to enter into a prize draw to win one of five £10 Amazon vouchers. To enter the draw you will need to give your email address to the researcher so that you and your parent/caregiver can be contacted if you win. The draw will take place after all of the questionnaires needed for the study have been collected. The winners will be told as soon as the draw has taken place. You do not have to enter this prize draw. Your email address will not be linked to your answers given in the questionnaires.

**Will our answers be anonymous?**

Your answers will only be identifiable by a special code that you will create. If your parent/caregiver is taking part they will share this code with you. All information will remain anonymous and confidential which means we will not be able to tell which questionnaires belong to you. We will not tell anyone about any of the answers you give. The only time we might not follow these rules is if we need to discuss your answers with the diabetes team (see below). If you and your parent/caregiver wish to enter the prize draw, your email address will be kept confidentially and stored in line with the Data Protection Act (1998) and will not be linked to your answers. We will not keep your email address after we have completed the prize draw and the winners have been told.

**Who will you tell about me taking part?**

As this research is taking place at your diabetes clinic, if you agree to take part in the research we will let your diabetes team know. We will not tell the diabetes team about the answers you give to the questionnaires, unless your answers or your parents answers on one of the questionnaires (BRIEF) suggest that it might be helpful for you to have some extra support from the team (please see below).

**Why might you need to discuss our responses with the team?**

Sometimes, answers to one of the questionnaires can let us know that it might be helpful for you if you received some extra support from the diabetes team. One of the questionnaires (BRIEF) measures how well you can plan, organise, problem-solve and use working memory in everyday life. If the total score on this measure, either completed by you or your parent/caregiver, equals 65 or more once the researcher has scored it up, it might tell us that you have some difficulties in these areas. It is important to not be worried about this as the measure does not tell us that there is something wrong. It can simply tell us if you might benefit from some support to help you with the tasks you might find more difficult. In these cases the researcher will discuss the results with the diabetes team who will make follow up contact with your parent/caregiver and yourself.

**What are the possible benefits of me taking part?**

We cannot promise that the research will help you directly, but by taking part you will be helping us to understand the things that affect self-management of Type 1 diabetes in adolescents better. This will help us to improve the supports available for young people with Type 1 diabetes and help them to self-manage their diabetes more successfully. Taking part also means that we can measure your planning, organisational, problem solving and working memory skills. You might be able to get some extra support with things you find a bit more difficult, if the diabetes team think that this might be helpful.

**What are the possible disadvantages of me taking part?**

The potential disadvantages are that it takes approximately 30 minutes to complete the questionnaires.

**What if there is a problem?**

If you are worried about any part of the study, you should ask to speak to the researcher (contact details below) who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Ken Laidlaw at the University of East Anglia at the address on the first page or via email on [k.laidlaw@uea.ac.uk](mailto:k.laidlaw@uea.ac.uk).

**How do I withdraw?**

You can stop taking part in the study at any point up. You can do this by giving the questionnaires to the researcher to be destroyed and telling her that you do not wish to carry on. If you decide to withdraw after returning the questionnaires you may contact the researcher using the details below, provide your PIC and state that you wish to stop taking part. You may stop taking part without giving a reason and this will not affect the care you receive from the diabetes team. Once your answers from the questionnaires have been put into the computer system you will no longer be able to withdraw from the research. At this point, we cannot tell which results belong to you and so we cannot remove them from the computer system.

**What will happen to the results of the research?**

The results of the research will contribute to a Doctoral Thesis in Clinical Psychology at the University of East Anglia. The results may also be included in an article and published in a professional journal. No identifiable information of the people taking part will be written in the articles and no individual results will be reported.

**Who is organising and funding the research?**

The ~~research is funded by the University of East Anglia.~~

**Who has reviewed the study?**

This research has been reviewed by staff at the University of East Anglia and has been granted ethics by the University and NHS Ethics boards.

**Contact details**

If you have any questions, queries or problems, please contact me on:

**Name of Researcher:** Eleanor Wells

**Email address:** [xxxxxxxxx@Xxxx](mailto:xxxxxxxxx@Xxxx)

**Telephone number:** 0XXXX XXXXXX



*Appendix G2*

## Participant Information Sheet (16-18 years)



Doctorate of Clinical Psychology Course  
 Department of Psychological Sciences  
 Faculty of Medicine and Health Sciences  
 University of East Anglia  
 Norwich Research Park  
 Norwich  
 NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

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**INFORMATION ABOUT THE RESEARCH**


---

We would like to invite you and your parent/caregiver to take part in our research study. Before you decide we would like you to understand why the research is being done and what you will have to do to take part. If you have any questions, please contact the researcher using the details below or at the address above. Please talk to your friends, family, doctor or nurse before you make a decision.

**What is the purpose of the study?**

This research study hopes to find out how different things affect how well individuals manage their Type 1 diabetes. This study is interested in finding out if the way that individuals plan, organise, problem-solve and use their memory affects how well they can self-manage their diabetes.

**Why have I been asked to take part in this research?**

You have been chosen to take part in this research as you have a diagnosis of Type 1 Diabetes and are between 11 and 18 years old. The diabetes team helped identify you as being in the right age range for the research.

**What will happen to me if I take part?**

You will be asked to complete some questionnaires. These will take about 30 minutes to complete. If your parent/caregiver is taking part they will also be asked to complete a set of questionnaires. You will meet with the researcher first to talk about the research and to make sure you are happy to take part. You will be able to ask the researcher any questions you have about taking part.

Please complete your questionnaires on your own. If you are finding it difficult to read the questionnaires or understand the questions then please ask the researcher for help. It is important that your parent/caregiver does not help you answer the questions. If your parent/caregiver is also taking part please do not help them with their answers.

**Do I have to take part?**

It is up to you if you would like to take part in this research. This information sheet tells you about the study and you can ask the researcher any questions. If you want to take part, we will ask you to show that you are happy to by signing a form. You can stop taking part at any time, up until the point the questionnaires have been put into the computer system. You do not have to give a reason why you want to stop taking part. Not taking part or stopping taking part during the research will not affect the care you receive at the clinic.

**Does my parent/caregiver have to take part?**

No. You can still take part in the research even if your parent/caregiver does not want to. Your parent/caregiver will be given his/her own information sheet to read about the research study.

Page 1 of 3

**What if I am unable to take part today?**

If you would like to take part in this research but you are unable to complete the questionnaires today please contact the researcher. The researcher will arrange with your parent/caregiver an appropriate time for her to telephone you or visit you at home in order to complete the questionnaires.

**Is there a reward for taking part?**

To thank you for your time completing this research, you can choose to enter into a prize draw to win one of five £10 Amazon vouchers. To enter the draw you will need to give your email address to the researcher so that you and your parent/caregiver can be contacted if you win. The draw will take place after all of the questionnaires needed for the study have been collected. The winners will be told as soon as the draw has taken place. You do not have to enter this prize draw. Your email address will not be linked to your answers given in the questionnaires.

**Will our answers be anonymous?**

Your answers will only be identifiable by a unique personal identification code (PIC) that you will create. If your parent/caregiver is taking part they will share this PIC with you. All information will remain anonymous and confidential which means we will not be able to tell which questionnaires belong to you. We will not tell anyone about any of the answers you give. The only time we might not follow these rules is if we need to discuss your responses with the diabetes team (see below). If you and your parent/caregiver wish to enter the prize draw, your email address will be kept confidentially and stored in line with the Data Protection Act (1998) and will not be linked to your answers. We will not keep your email address after we have completed the prize draw and the winners have been notified.

**Who will you tell about me taking part?**

As this research is taking place at your diabetes clinic, if you agree to take part in the research we will let your diabetes team know. We will not tell the diabetes team about the answers you give to the questionnaires, unless your answers or your parents answers on one of the questionnaires (BRIEF) suggest that it might be helpful for you to have some extra support from the team (please see below).

**Why might you need to discuss our responses with the team?**

Sometimes, answers to one of the questionnaires can let us know that it might be helpful for you if you received some extra support from the diabetes team. One of the questionnaires (BRIEF) measures your executive functioning. It measures how well you can plan, organise, problem-solve and use working memory in everyday life. If the total score on this measure, either completed by you or your parent/caregiver, equals 65 or more once the researcher has scored it up, it might indicate that you have some difficulties in these areas. It is important to not be worried about this as the measure does not tell us that there is something wrong. It can simply tell us if you might benefit from some support to help you with the tasks you might find more difficult. In these cases the researcher will discuss the results with the diabetes team who will make follow up contact with your parent/caregiver and yourself.

**What are the possible benefits of me taking part?**

We cannot promise that the research will help you directly, but by taking part you will be helping us to better understand the things that affect self-management of Type 1 diabetes in adolescents. This will help improve the supports available to help adolescents self-manage their diabetes more successfully and independently in the future. Taking part also means that we can measure your executive functioning and you might be able to get some extra support with things you find a bit more difficult, if the clinical team think that this might be helpful.

**What are the possible disadvantages of me taking part?**

The potential disadvantages are that it takes approximately 30 minutes to complete.

**What if there is a problem?**



If you are worried about any part of the study, you should ask to speak to the researcher (contact details below) who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Ken Laidlaw at the University of East Anglia at the address on the first page or via email on [k.laidlaw@uea.ac.uk](mailto:k.laidlaw@uea.ac.uk).

**How do I withdraw?**

You can stop taking part in the study at any point up to the submission of your questionnaires, by returning the questionnaires to the researcher to be destroyed and telling her that you do not wish to carry on. If you decide to withdraw after returning the questionnaires you may contact the researcher using the details below, provide your PIC and state that you wish to stop taking part. You may stop taking part without giving a reason and this will not affect the care you receive from the diabetes team. Once your answers from the questionnaires have been put into the computer system you will no longer be able to withdraw from the research. At this point, we cannot tell which results belong to you and so we cannot remove them from the computer system.

**What will happen to the results of the research?**

The results of the research will contribute to a Doctoral Thesis in Clinical Psychology at the University of East Anglia. The results may also be included in an article and published in a professional journal. No identifiable information of the people taking part will be written in the articles and no individual results will be reported.

**Who is organising and funding the research?**

The research is funded by the University of East Anglia.

**Who has reviewed the study?**

This research has been reviewed by staff at the University of East Anglia and has been granted ethics by the University and NHS Ethics boards.

**Contact details**

If you have any questions, queries or problems, please contact me on:

**Name of Researcher:** Eleanor Wells

**Email address:** [xxxxxxxx@Xxxx](mailto:xxxxxxxx@Xxxx)

**Telephone number:** 0XXXX XXXXX

*Appendix G3*

## Participant Information Sheet (Parent/Caregivers)



Doctorate of Clinical Psychology Course  
 Department of Psychological Sciences  
 Faculty of Medicine and Health Sciences  
 University of East Anglia  
 Norwich Research Park  
 Norwich  
 NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

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**INFORMATION ABOUT THE RESEARCH**


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We would like to invite you and your child to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you and your child. If you have any questions, please contact the researcher using the details below or at the address above.

**What is the purpose of the study?**

The purpose of this research is to investigate how different things affect the way Type 1 diabetes is managed. This study is specifically interested in whether abilities to plan, organise and problem-solve affect self-management of diabetes and the ability to achieve glycaemic control.

**What will happen to my child if he/she takes part?**

This research involves your child completing a series of questionnaires. It would take up to 30 minutes for your child to complete the questionnaires. You and your child will meet with the researcher initially to talk through the research. You and your child will be asked to sign a form to indicate you are both happy for your child to take part. Your child will then be given the questionnaires to complete independently. Please do not help your child complete the questionnaires. If your child needs some support to read or complete the questionnaires, please ask the researcher for assistance.

**What will happen to me if I take part?**

You will be asked to complete a series of questionnaires, which will take up to 30 minutes to complete. You will meet with the researcher initially to talk through the research and you will be asked to sign a form to indicate that you are happy to take part. Please complete your questionnaires independently. Of course, you may sit with your child but please do not discuss answers with her/him. If you need any support in completing the questionnaires, please ask the researcher for assistance.

**Does my child have to take part?**

It is up to you to decide whether you would like your child to take part in this research. This information sheet will give details of the study and you can contact the researcher with any questions. If you agree for your child to take part, we will then ask you to indicate your consent. You are free to withdraw your child at any time up until the point the questionnaires have been put into the computer system for analysis, without giving a reason. This would not affect the standard of care your child receives.

We will also ask your child to read their own information sheet for the research and they will be encouraged to ask any questions they may have about their participation. Your child will be asked to give their agreement to take part in the study.

Page 1 of 3

**Do I have to take part?**

It is up to you to decide whether you would like to take part in this research. Your child will still be able to take part in the research even if you do not want to take part yourself. Unfortunately, you cannot take part if your child is not eligible to take part or if you do not consent for them to participate.

**Is my child eligible to take part?**

In order to take part in this research, your child must be between 11 and 18 years old. They must have had their diagnosis of Type 1 diabetes for at least one year. Your child must be able to understand written or spoken English.

If your child has a diagnosed learning disability or a severe psychiatric disorder, unfortunately they will not be able to take part. If your child has an additional chronic condition apart from their diabetes, such as renal disease or cystic fibrosis they will be unable to take part. If your child has an additional chronic health condition and you are unsure if they are eligible to take part please seek advice from the researcher.

**Am I eligible to take part?**

To be able to take part in this research you must live with your child for most of the time (so that you know how they behave most often) and you must be able to understand written or spoken English.

**What if I am unable to take part today?**

If you or your child would like to take part in this research but are unable to complete the questionnaires today please contact the researcher. The researcher will offer an appropriate time for either a telephone appointment or a time for her to visit you at home in order to complete the questionnaires.

**Is there a reward for taking part?**

To thank you and your child for your time completing this research, you and your child can choose to enter into a prize draw to win one of five £10 Amazon vouchers. To enter the draw you will need to give your email address to the researcher so that you and your child can be contacted if you win. The draw will be conducted at the end of the data collection period and the winners notified. You do not have to enter this prize draw. Your email address will not be linked to your answers given in the questionnaires.

**Will our answers be anonymous?**

Your child's and your answers will be identifiable only by a unique personal identification code (PIC) that you and your child will create. You and your child will share the same PIC (if you take part). All information will remain anonymous and confidential, unless we identify a need to discuss your or your child's responses further (please see below). If you and your child wish to enter the prize draw, your email address will be kept confidentially and stored in line with the Data Protection Act (1998) and will not be linked to your answers.

**Who will you tell about my child and I taking part?**

As this research is taking place at your child's diabetes clinic, if you agree for your child to take part in the research we will let their diabetes team know. If you decide to take part we will let the diabetes team know this. We will not tell the diabetes team about the answers you or your child give to the questionnaires, unless your answers or your child's answers on one of the questionnaires (BRIEF) suggest that it might be helpful for your child to have some extra support from the team (please see below).

**Why might you need to discuss our responses with the team?**

This includes circumstances when responses on one of the questionnaires might indicate that your child would benefit from some additional support from a member of the diabetes team. One of the questionnaires (BRIEF) measures your child's level of executive functioning, which is a measure of his/her abilities to plan, organise, problem-solve and use working memory. If the total score on this measure, either completed by you or your child, once standardised, is at or above 65 it may indicate that your child has some difficulties in these areas. It is



**important to note that the questionnaire is not a diagnostic tool but might highlight areas where your child would benefit from some additional support.** In these cases the researcher will inform the diabetes team of the results who will make follow up contact with you, if appropriate.

**What are the possible benefits of me taking part?**

We cannot promise that the research will help you or your child directly but by taking part you will be contributing to research looking to better understand the factors affecting self-management of Type 1 diabetes in adolescents. This will aim to help improve the resources and supports available to help adolescents self-manage their diabetes more successfully and independently in the future. Taking part also provides an opportunity for your child's executive functioning to be assessed and may lead to them accessing additional support, if the clinical team think that this might be helpful.

**What are the possible disadvantages of me taking part?**

The potential disadvantages are that it takes approximately 30 minutes to complete.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher (contact details below) who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Ken Laidlaw at the University of East Anglia at the address on the first page or via email on [k.laidlaw@uea.ac.uk](mailto:k.laidlaw@uea.ac.uk).

**How do I withdraw?**

You and your child can withdraw at any point, up to the submission of your questionnaires, by returning the questionnaires to the researcher to be destroyed and reporting that you wish to withdraw. If you or your child decides to withdraw after returning the questionnaires you may contact the researcher using the details below, provide your PIC and state that you wish to withdraw. You may withdraw without providing a reason and this will not affect the care your child is receiving. Once you and your child's answers from the questionnaires have been put into the computer system for analysis you will no longer be able to withdraw from the research as each result will be anonymous and no longer identifiable as belonging to specific individuals at this stage and therefore cannot be identified for removal.

**What will happen to the results of the research?**

The results of the research will contribute to a Doctoral Thesis in Clinical Psychology at the University of East Anglia. The results may also be published in a professional journal. No identifiable information will be published. Data will be analysed as a whole group and so no individual's responses will be reported.

**Who is organising and funding the research?**

The research is funded by the University of East Anglia.

**Who has reviewed the study?**

This research has been reviewed by staff at the University of East Anglia and has been granted ethics by the University and NHS Ethics boards.

**Contact details**

If you have any questions, queries or problems, please contact me on:

**Name of Researcher:** Eleanor Wells

**Email address:** [xxxxxxxx@Xxxx](mailto:xxxxxxxx@Xxxx)

**Telephone number:** 0XXXX XXXXX

*Appendix H*

Ethical Approval Documents

H1 NHS Ethics Committee Approval Letter

H2 Research Governance Approval Letters for Recruitment Sites

*Appendix H1*

## NHS Ethics Committee Approval Letter

**Health Research Authority**  
**NRES Committee South Central - Hampshire A**Level 3, Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NTTelephone: 0117 342 1381  
Fax: 0117 342 0445

25 June 2015

Miss Eleanor Wells  
PGR Office  
2.30 Elizabeth Fry Building  
University of East Anglia  
NR4 7TJ

Dear Miss Wells

<b>Study title:</b>	<b>Is There a Relationship Between Executive Function and Self-Management in Adolescents with Type 1 Diabetes?</b>
<b>REC reference:</b>	<b>15/SC/0389</b>
<b>IRAS project ID:</b>	<b>172397</b>

The Proportionate Review Sub-committee of the NRES Committee South Central - Hampshire A reviewed the above application on 18 June 2015.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Maxine Knight, nrescommittee.southcentral-hampshirea@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

**Ethical opinion**

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

#### **Approved documents**

The documents reviewed and approved were:

Document	Version	Date
Copies of advertisement materials for research participants [Research Poster]	1	27 April 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance certificate]		08 June 2015
GP/consultant information sheets or letters [Template for letter of notification to diabetes teams of an individual's participation in the research study]	1	26 May 2015
IRAS Checklist XML [Checklist_12062015]		12 June 2015
Non-validated questionnaire [Adolescent Demographic Questionnaire]	1	27 April 2015
Non-validated questionnaire [Parent/Caregiver Demographic Questionnaire]	1	27 April 2015
Participant consent form [Consent to Contact Form]	1	27 April 2015
Participant consent form [Consent Form Parent]	1	26 May 2015
Participant consent form [Consent Form Adolescent 16-18 years]	1	26 May 2015
Participant consent form [Adolescent Assent Form]	1	26 May 2015
Participant information sheet (PIS) [Participant Information Sheet Parent/Caregiver]	1	26 May 2015
Participant information sheet (PIS) [Participant Information Sheet Adolescent 11-15]	1	26 May 2015
Participant information sheet (PIS) [Participant Information Sheet Adolescent 16]	1	26 May 2015
REC Application Form [REC_Form_12062015]		12 June 2015
Referee's report or other scientific critique report [Thesis Proposal Feedback from Internal Review Process]	1	27 April 2015
Research protocol or project proposal [Thesis Proposal]	1	26 May 2015
Summary CV for Chief Investigator (CI) [Research CV for Chief Investigator]	1	27 April 2015
Summary CV for supervisor (student research) [Supervisor Research CV]	1	27 April 2015
Validated questionnaire [DSMP Youth, Flexible Regimen]	1	27 April 2015
Validated questionnaire [DSMP Youth, Conventional Regimen]	1	27 April 2015
Validated questionnaire [DSMP Parent, Conventional Regimen]	1	27 April 2015
Validated questionnaire [DSMP Parent, Flexible Regimen]	1	27 April 2015
Validated questionnaire [DFRQ]	1	27 April 2015

#### Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review



#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

15/SC/0389

Please quote this number on all correspondence

Yours sincerely



pp

**Dr Simon Kolstoe**  
**Vice Chair**

Email: [nrescommittee.southcentral-hampshirea@nhs.net](mailto:nrescommittee.southcentral-hampshirea@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*  
*"After ethical review – guidance for researchers"*

**NRES Committee South Central - Hampshire A****Attendance at PRS Sub-Committee of the REC meeting on 18 June 2015****Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Clifford Allen	Corporate Development and Learning	Yes	
Mr Richard Andoh	Pharmacist	Yes	
Dr Simon Kolstoe	Senior Fellow, Structural Immunology	Yes	

*Appendix H2*

Research Governance Approval Letters for Recruitment Sites



**Research and Development Department**

R&D ref: A093737

17<sup>th</sup> July 2015

Ms. Eleanor Wells

Box 277  
Addenbrooke's Hospital  
Hills Road  
Cambridge  
CB2 0QQ

Direct Dial: 01223 256407  
Switchboard: 01223 245151

Dear Ms. Wells

E-mail: [sonakshi.kadyan@addenbrookes.nhs.uk](mailto:sonakshi.kadyan@addenbrookes.nhs.uk)  
[r&denquiries@addenbrookes.nhs.uk](mailto:r&denquiries@addenbrookes.nhs.uk)  
[www.addenbrookes.org.uk](http://www.addenbrookes.org.uk)

**Re: 15/SC/0389 "Executive Functioning and Self-Management in Adolescents with T1D (1)"**

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

R&D have reviewed the documentation submitted for this project, and has undertaken a **site specific assessment** based on the information provided in the SSI form, and I am pleased to inform you that we have no objection to the research proceeding within Cambridge University Hospitals NHS Foundation Trust.

Sponsor: The University of East Anglia

Funder: N/A

End date: 30/09/2016

Protocol: version 01 dated 26/05/2015

**Conditions of Trust Approval:**

- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management. Any mobile devices used must also comply with Trust policies and procedures for encryption to AES 256.
- You and your research team must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998 and are aware of your responsibilities in relation to the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.
- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.
- You and your research team must provide to R&D, as soon as available, the date of first patient first visit.

**If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:**

- the EU Directive on Clinical Trials (Directive 2001/20/EC) and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials ) Regulations 2004;
- the EU Directive on Principles and Guidelines for Good Clinical Practice (EU Commission Directive 2005/28/EC); and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Amendment Regulations 2006;

**Amendments**

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

**Annual Report**

It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Please refer to our website [www.cuh.org.uk/research](http://www.cuh.org.uk/research) for all information relating to R&D including honorary contract forms, policies and procedures and data protection.

Should you require any further information please do not hesitate to contact us.

Yours sincerely



Louise Stockley  
Research Governance Manager

*Appendix I*

Consent Forms

- I1 Consent to Contact Form
- I2 Participant Assent Form
- I3 Adolescent Consent Form
- I4 Parent/Caregiver Consent Form

*Appendix II*

Consent to Contact Form



Doctorate of Clinical Psychology Course  
Department of Psychological Sciences  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich  
NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

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**CONSENT TO CONTACT FORM**

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**Completion of this form indicates that you are happy for the researcher for this study, Eleanor Wells, to contact you to discuss your possible participation.**

Name of Adolescent: \_\_\_\_\_

Age of Adolescent: \_\_\_\_\_

I agree that the researcher for this study, Eleanor Wells, can contact me to discuss my possible participation in the research.

Signature of Adolescent: \_\_\_\_\_

Date: \_\_\_\_\_

**If you are under 16 years of age, your parent/caregiver must also sign below** to show that they are happy for you to be contacted by the researcher to discuss your possible participation.

Signature of Parent/Caregiver: \_\_\_\_\_

Relationship to Adolescent: \_\_\_\_\_

Date: \_\_\_\_\_

I agree, as the parent/caregiver for the above named adolescent, for the researcher to contact me to discuss my possible participation in the study.

Signature of Parent/Caregiver: \_\_\_\_\_

Date: \_\_\_\_\_

*Appendix I2*

## Participant Assent Form



Doctorate of Clinical Psychology Course  
 Department of Psychological Sciences  
 Faculty of Medicine and Health Sciences  
 University of East Anglia  
 Norwich Research Park  
 Norwich  
 NR4 7TJ

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**ASSENT FORM**


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**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

**Name of Researcher:** Eleanor Wells

Please answer 'Yes' or 'No' to the following statements and write your initials in the boxes provided:

	Yes	No	Initials
1. Do you understand what this research study is about?	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 40px; height: 20px;" type="text"/>
2. Do you understand that you do not have to take part?	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 40px; height: 20px;" type="text"/>
3. Have you asked all the questions you wanted to about the research?	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 40px; height: 20px;" type="text"/>
4. Have all of your questions been answered in a way that you understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 40px; height: 20px;" type="text"/>
5. Do you understand that you can change your mind at any point during the study and stop taking part, up until the questionnaires are input to the computer for analysis, without giving any reason?	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 40px; height: 20px;" type="text"/>

Consent form date of issue:

Page 1 of 2

Consent form version number:



6. Do you understand that if you do not wish to take part or stop taking part later on this will not affect the care you receive from the diabetes clinic?
7. Do you understand that all of your answers are confidential which means the researchers will not tell anyone about your answers, unless it might be helpful for you if we tell the diabetes team about some of your scores?
8. Do you understand that if you decide to take part, we will let your diabetes clinical team know that you are participating in the research?
9. Are you happy to take part?

If you answered 'No' to any of the questions above or you do not want to take part do not write your name below.

If you do want to take part, please write your name below.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person                      Date                      Signature

~~giving~~ assent.

Assent form date of issue:

Assent form version number:

*Appendix I3*

## Adolescent Consent Form



Doctorate of Clinical Psychology Course  
 Department of Psychological Sciences  
 Faculty of Medicine and Health Sciences  
 University of East Anglia  
 Norwich Research Park  
 Norwich  
 NR4 7TJ

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**CONSENT FORM**


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**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

**Name of Researcher:** Eleanor Wells

Please indicate 'Yes' or 'No' to the following statements and write your initials in the boxes provided:

- |  | Yes                      | No                       | Initials             |
|--|--------------------------|--------------------------|----------------------|
| 1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| 2. I understand that I do not have to participate and that I am free to withdraw from the study at any time, up until the questionnaires are input to the computer for analysis, without giving any reason, <del>without</del> my medical care or legal rights being affected. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| 3. I understand that my answers are confidential and that the researcher will be unable to follow up on anything I have written unless it is identified that I may benefit from further input from the diabetes team.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |

Consent form date of issue:

Page 1 of 2

Consent form version number:

4. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is applicable to my participation in the research. I give permission for these individuals to have access to my records.
5. If I consent to take part in this research study, I understand that my diabetes clinical team will be informed of my participation.
6. In the event that the scores on the BRIEF-Parent and/or BRIEF-SR questionnaire, once standardised, are equal to or above 65, I agree to my diabetes team being sent a summary report of these results.
7. I consent to participating in this research study

\_\_\_\_\_  
 Name of Participant                      Date                      Signature

\_\_\_\_\_  
 Name of Person                      Date                      Signature

~~to~~ giving consent.

Consent form date of issue:

Consent form version number:

*Appendix I4*

## Parent/Caregiver Consent Form



Doctorate of Clinical Psychology Course  
 Department of Psychological Sciences  
 Faculty of Medicine and Health Sciences  
 University of East Anglia  
 Norwich Research Park  
 Norwich  
 NR4 7TJ

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**CONSENT FORM**


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**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

**Name of Researcher:** Eleanor Wells

Please indicate 'Yes' or 'No' to the following statements and write your initials in the boxes provided:

- |   | Yes                      | No                       | Initials             |
|---|--------------------------|--------------------------|----------------------|
| 1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| 2. I understand that my child does not have to participate and that I am free to withdraw my child from the study at any time, up until the questionnaires are input to the computer for analysis, without giving any reason, without my medical care or legal rights being affected. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time, up until the time the questionnaires are input to the computer for analysis, without giving any reason, without my medical care or legal rights being affected.                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |

Consent form date of issue:

Page 1 of 2

Consent form version number:

4. I confirm that my child is between 11 and 18 years of age and meets the eligibility criteria outlined on the information sheet.
5. I understand that my own and my child's answers are confidential and that the researcher will be unable to follow up on anything I or my child has written unless it is identified that my child may benefit from further input from the diabetes team.
6. I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is applicable to his/her participation in the research. I give permission for these individuals to have access to their records.
7. If I consent for my child to take part in the research study, I understand that my child's diabetes clinical team will be informed of their participation.
8. If I consent to take part in the research study, I understand that my child's diabetes clinical team will be informed of my participation.
9. In the event that the scores on the BRIEF-Parent and/or BRIEF-SR questionnaire, once standardised, are equal to or above 65, I agree to my child's diabetes team being sent a summary report of these results.
10. I consent to my child participating in this research study
11. I consent to participating in this research study

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

*Appendix J*

## Participant Identification Code (PIC) Form



Doctorate of Clinical Psychology Course  
 Department of Psychological Sciences  
 Faculty of Medicine and Health Sciences  
 University of East Anglia  
 Norwich Research Park  
 Norwich  
 NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

---

**PARTICIPANT IDENTIFICATION CODE**

---

Participant (Adolescent) Name \_\_\_\_\_

Participant (Adolescent) Date of Birth \_\_\_\_\_

**Please follow these instructions carefully:**

Take the first two letters of your clinic location (Addenbrookes=AD, West Suffolk=WS)  
 \_\_\_\_\_

Take the first 2 letters of your participating parent's/carer's first name. If he/she is not participating, take the first two letters of the person attending your clinic appointment with you today.  
 \_\_\_\_\_

Take the two numbers of the date on which you were born  
 \_\_\_\_\_

Combine these four letters and two numbers to create a six digit code  
 \_\_\_\_\_

This is your unique Participant Identification Code (PIC). Please try your best to remember this.

Please write this code on every questionnaire measure that you complete. You will need this code if you wish to withdraw from the research study. If your parent/caregiver is also participating in the research study they will also use this PIC for the completion of questionnaires.

The information on this form will be input to a computer database, which will only be accessed if it is identified from your questionnaire responses that you might benefit from further support from the diabetes team. The database will be stored on an encrypted data stick. Once the information has been input, this paper copy will be destroyed.

*Appendix K*

## Debrief Information Sheet



Doctorate of Clinical Psychology Course  
Department of Psychological Sciences  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich  
NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

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**RESEARCH DEBRIEF**

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**Thank you for taking part in this study!**

This research looked at how planning, organisation and problem solving skills might be related to how individuals manage their diabetes and how well they can achieve glycaemic control. It also looked at how differences in these skill might determine the amount of responsibility adolescents have over their diabetes care.

We expect that adolescents who find planning, organisation and problem-solving more difficult will not manage their diabetes as well as adolescents who have better planning, organisation and problem-solving skills. We also expect that adolescents who find these skills more difficult will also find it more difficult to maintain glycaemic control.

We expect that adolescents who are not as good at planning, organising and problem-solving will not take as much responsibility for their diabetes care as adolescents who find these skills easier to perform.

If you are interested in finding out the results of the research, these will be made available at your diabetes clinic at a later date. It is estimated the results of this research will be available around Autumn 2016.

We don't anticipate that this research will have caused you any distress, but if it has please contact your GP or a member of the diabetes team. The following websites may also be helpful:

[www.NHS.uk](http://www.NHS.uk)

[www.diabetes.org.uk](http://www.diabetes.org.uk)

If you would like to enter the ballot for a chance to win one of five £10 Amazon vouchers then please provide the researcher with your email address.

If you would like further information about the research, please contact me using the details below.

Thank you again for your help.

Eleanor Wells

**Name of Researcher:** Eleanor Wells

**Email address:** [xxxxxxxxxx@Xxxx](mailto:xxxxxxxxxx@Xxxx)

Telephone number: 0XXXX XXXXXX

*Appendix L*

## Summary Report Form



Doctorate of Clinical Psychology Course  
 Department of Psychological Sciences  
 Faculty of Medicine and Health Sciences  
 University of East Anglia  
 Norwich Research Park  
 Norwich  
 NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

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**SUMMARY OF BRIEF QUESTIONNAIRE RESULTS**

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**FOR THE ATTENTION OF:** \_\_\_\_\_

**DATE REPORT WRITTEN:** | \_\_\_\_\_

**DATE REPORT SUBMITTED:** \_\_\_\_\_

This report has been submitted as an individual's scores on one or both of the parent or adolescent completed BRIEF measures, completed as part of the above research project, has been calculated as scoring above the cut-off (65). This suggests that the score may indicate that the individual experiences difficulties in areas of executive functioning which are of clinical significance and the individual may benefit from additional support from the diabetes clinical team. The BRIEF measure is NOT A DIAGNOSTIC TOOL.

Please read the results below, discuss with the clinical team and arrange follow up contact with the individual and/or their parents as appropriate.

**Participant Personal Identification Code:** \_\_\_\_\_

**Participant Name:** \_\_\_\_\_

**Participant Date of Birth:** \_\_\_\_\_

**Which BRIEF measure indicated a score above the cut off for this individual? (Circle as appropriate)**

BRIEF-SR	BRIEF-parent	Both
BRIEF-SR GEC score: _____		BRIEF-Parent GEC score: _____
BRIEF-SR BRI score: _____		BRIEF-Parent BRI score: _____
BRIEF-SR MI score: _____		BRIEF-Parent MI score: _____

The **Global Executive Composite (GEC)** provides an overall score of executive functioning ability.

Page 1 of 2

The **Behaviour Regulation Index (BRI)** encompasses the *Inhibit, Shift* and *Emotional Control* scales for the BRIEF-parent and, additionally, the *Monitor* scale on the



BRIEF-SR. The BRI is interpreted as "reflecting an individual's general ability to regulate or control his or her behaviour and emotional responses, including appropriate inhibition of thoughts and actions, flexibility in shifting problem-solving set and adjusting to change, regulation of emotional responses, and, for adults and adolescents, monitoring of their own behavioural output" (Roth, Isquith, & Gioia, 2014, p304).

**The Metacognition Index (MI)** encompasses the Initiate (or Task Completion for the BRIEF-SR), Working Memory, Plan/Organise, Organisation of Materials and Monitor (BRIEF-parent) scales for the BRIEF measures. The MI can be interpreted as "reflecting one's ability to get started on an activity, to hold information in working memory, to plan and organise problem-solving approaches, to complete tasks (BRIEF-SR only), and to maintain organisation in the environment" (Roth et al, 2014, p304).

**Additional Information:**

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**Signed:**

Eleanor Wells  
 Trainee Clinical Psychologist  
 Chief Investigator for the research project

**Contact details**

If you have any questions, queries or problems, please contact me on:

**Name of Researcher:** Eleanor Wells

**Email address:** [xxxxxxxx@Xxxx](mailto:xxxxxxxx@Xxxx)

**Telephone number:** 0XXXX XXXXXX

*Appendix M*

Prize Draw Entry Form



Doctorate of Clinical Psychology Course  
Department of Psychological Sciences  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich  
NR4 7TJ

**Title of Project:** Is executive functioning related to self-management of Type 1 diabetes?

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**PRIZE DRAW ENTRY FORM**

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**Thank you for taking part in this study!**

As a thank you for taking part in this research study you are eligible to enter a prize draw to win one of five £10 Amazon vouchers.

If you would like to be entered into this prize draw all you need to do is write your email address below and return this form to the Researcher.

Five email addresses will be selected, at random, for the prize draw. Each entry selected will receive one £10 Amazon voucher.

Winners will be notified via email.

Email address: \_\_\_\_\_

Thank you again for your help.

Eleanor Wells

**Name of Researcher:** Eleanor Wells

**Email address:** [xxxxxxxx@Xxxx](mailto:xxxxxxxx@Xxxx)

**Telephone number:** 0XXXX XXXXXX

*Appendix N*Independent T-Tests Comparing Demographic And Outcome Measure Data Between  
Adolescents With And Without A Participating Parent

	Mean ( <i>SD</i> )		<i>t</i>	df
	With	Without		
Adolescent age	14.42 (1.93)	16.04 (1.93)	<b>3.35*</b>	65
Duration of Type 1 Diabetes	7.54 (4.15)	6.72 (3.86)	-0.81	65
Age when diagnosed with Type 1 Diabetes	6.51 (3.56)	9.02 (3.93)	2.7**	65
BRIEF-SR GEC	47.66 (11.84)	48.92 (9.57)	0.46	65
BRIEF-SR BRI	46.49 (11.16)	48.500 (9.25)	0.77	65
BRIEF-SR MI	48.85 (12.75)	49.42 (9.61)	0.20	65
DSMP-SR Youth	57.76 (10.12)	57.50 (7.93)	-0.11	65
DFRQ Youth	36.59 (4.59)	39.88 (6.99)	2.08 <sup>a***</sup>	37.28
HbA1c	65.59 (10.91)	64.20 (13.06)	-0.47	65

*Note.* Ages and durations are given in years. Statistics in bold typeface remained significant following Bonferroni-Holm correction for multiple comparisons

\*  $p = .001$

\*\*  $p = .009$

\*\*\*  $p = .04$

<sup>a</sup>Equal variances not assumed,  $F = 4.47$ ,  $p = .04$ .

*Appendix O*

Results Of The Examination Of The Data For Violations Of Assumptions For  
Multiple Regression Analysis With BRIEF-SR GEC And DFRQ Youth As Predictor  
Variables And DSMP-SR Youth As The Outcome Variable

Analysis of the standardised residuals showed that only two values exceeded the expected limits of  $\pm 2$  (-2.91 and -2.06). The usual expectation is for 95% of cases within a sample to have standardised residuals falling within these limits. This data meets this assumption with 97.01% of cases having standardised residuals falling within these limits.

The data met the assumption of multicollinearity: VIF = 1.03 and tolerance = .97 for both BRIEF-SR GEC and DFRQ Youth. The assumption of independent errors was also met Durbin-Watson = 1.83.

Examination of a histogram (Figure O1), a normal P-P plot (Figure O2) and a scatterplot of the standardised residuals (Figure O3) indicated that the data met the assumptions of normally distributed errors, homoscedasticity and linearity. The data also met the assumption of non-zero variance, this information is presented in Table O1.

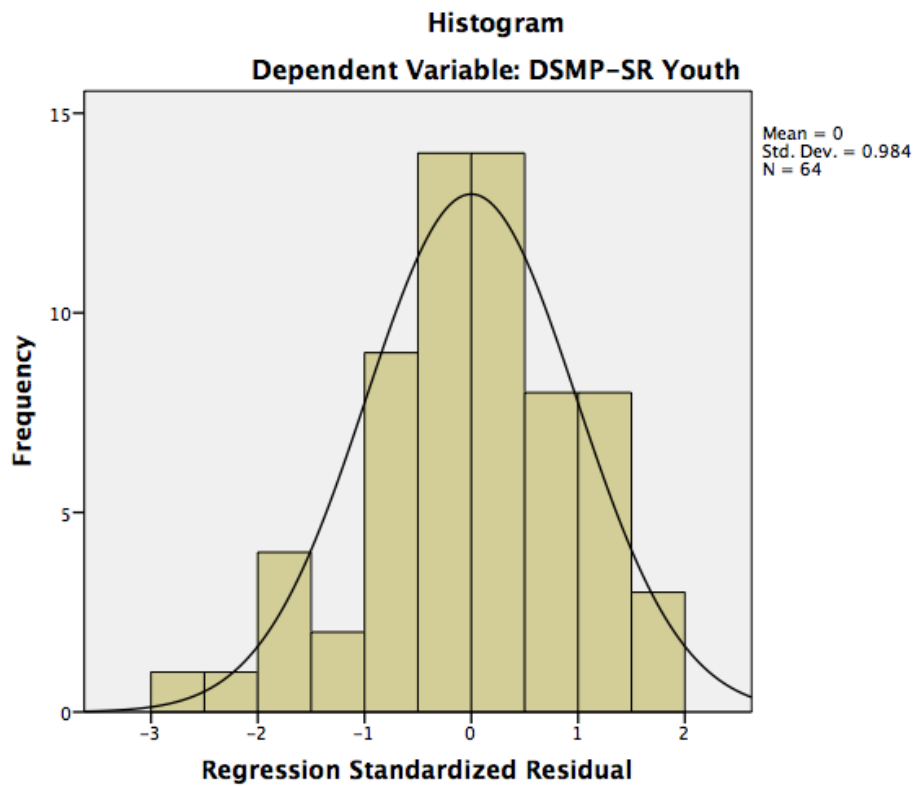


Figure 01. Distribution of standardized residuals for the regression model

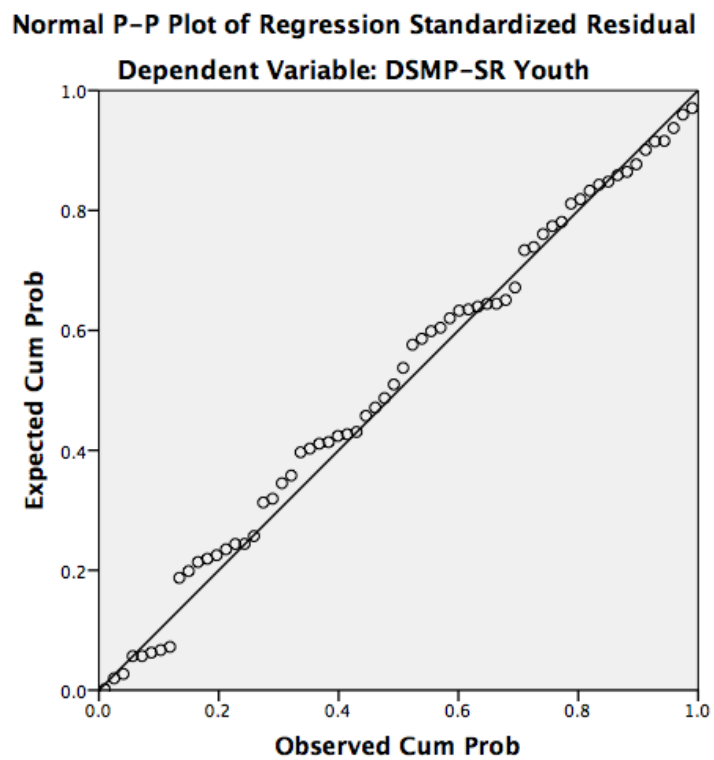
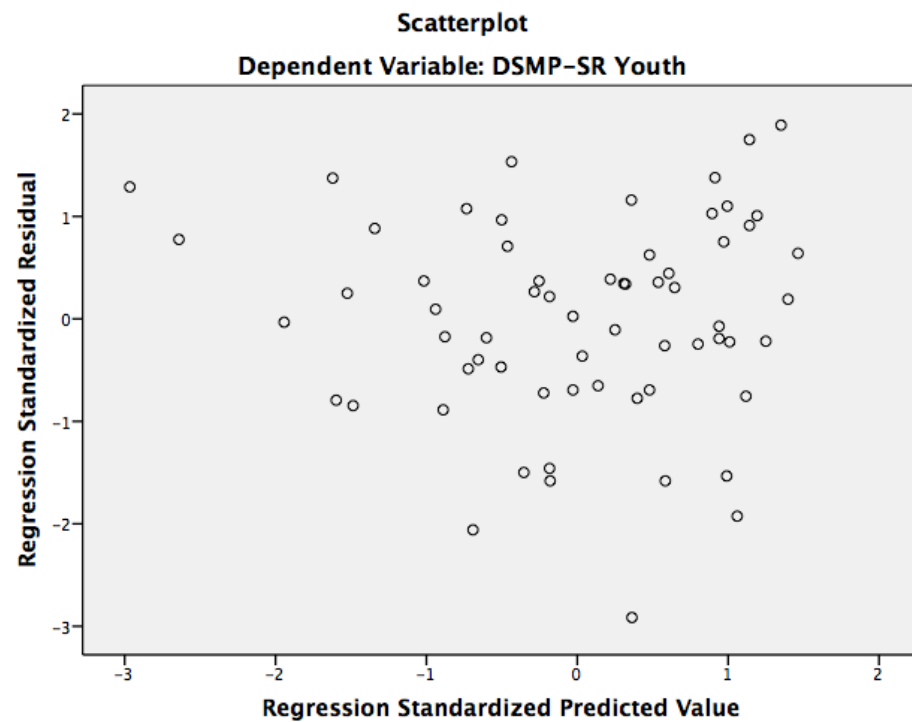


Figure 02. Standardised residuals for the regression model



*Figure O3.* No clear relationship between standardised residuals and predicted values for the regression model

Table O1

*Variance Statistics for the Variables Input to the Multiple Regression Model*

	Variance
BRIEF-SR GEC	119.98
DFRQ Youth	33.92
DSMP-SR Youth	85.90

*Appendix P*

Results Of The Examination Of The Data For Violations Of Assumptions For Multiple Regression Analysis With BRIEF-SR BRI And BRIEF-SR MI As Predictor Variables And DSMP-SR Youth Scores As The Outcome Variable

Analysis of the standardised residuals showed that only two values exceeded the expected limits of  $\pm 2$  (-2.48 and 2.06). The usual expectation is for 95% of cases within a sample to have standardised residuals falling within these limits. This data meets this assumption with 97.01% of cases having standardised residuals falling within these limits.

The data met the assumption of multicollinearity: VIF = 1.87 and tolerance = .54 for both BRIEF-SR BRI and BRIEF-SR MI. The assumption of independent errors was also met, Durbin-Watson = 2.10.

Examination of a histogram (Figure P1), a normal P-P plot (Figure P2) and a scatterplot of the standardised residuals (Figure P3) indicated that the data met the assumptions of normally distributed errors, homoscedasticity and linearity. The data also met the assumption of non-zero variance, this information is presented in Table P1.

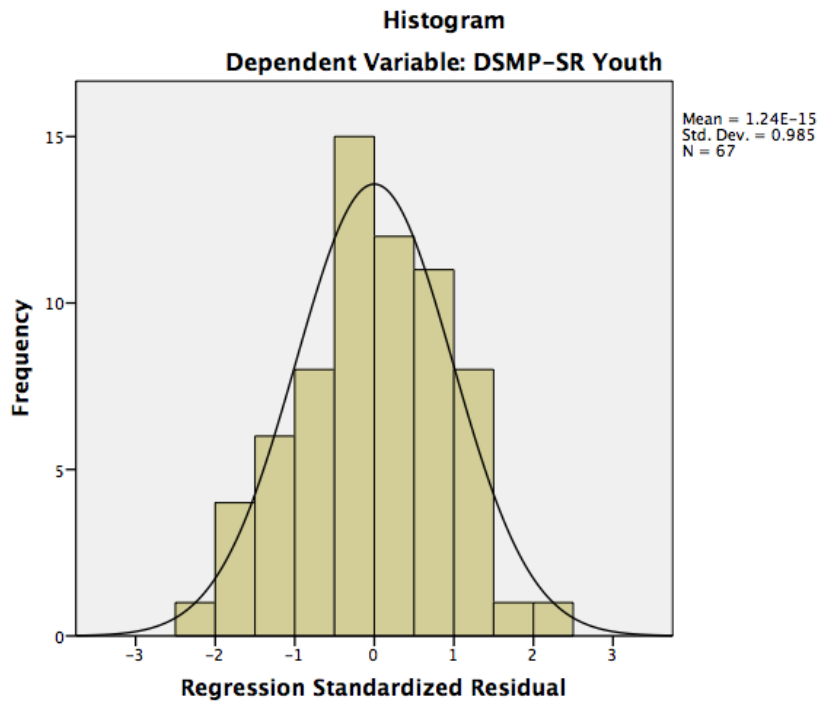


Figure P1. Distribution of standardized residuals for the regression model

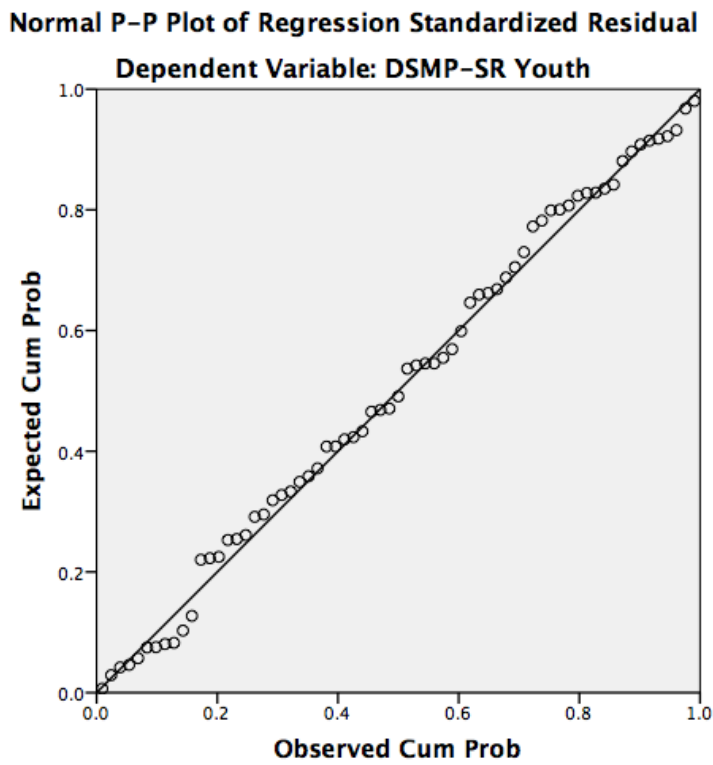
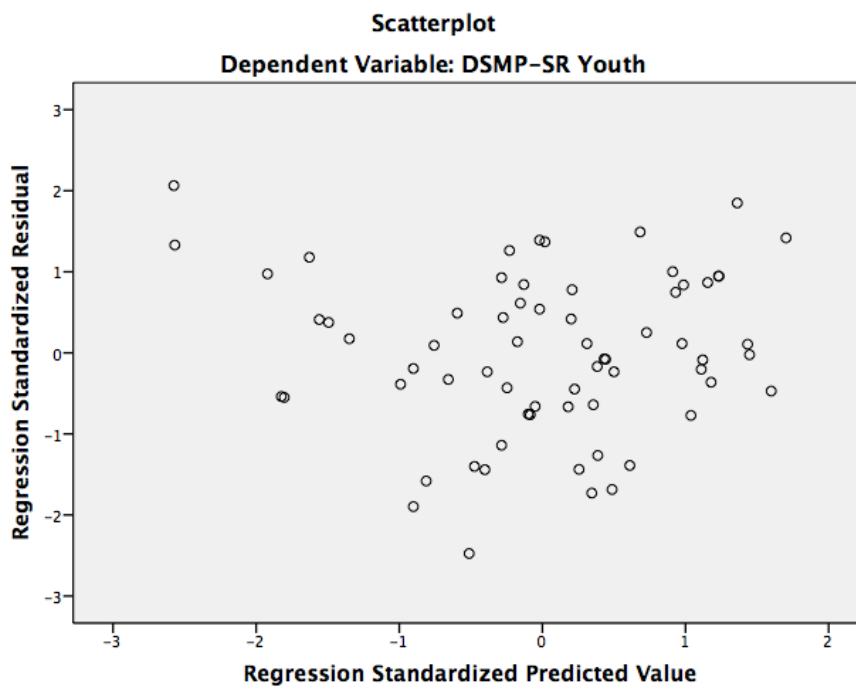


Figure P2. Standardised residuals for the regression model





*Figure P3.* No clear relationship between standardised residuals and predicted values for the regression model

Table P1

*Variance Statistics for the Variables Input to the Multiple Regression Model*

	Variance
BRIEF-SR BRI	108.81
BRIEF-SR MI	133.59
DSMP-SR Youth	85.90

*Appendix Q*

Results Of The Examination Of The Data For Violations Of Assumptions For Multiple Regression Analysis With BRIEF-SR GEC And DFRQ Youth As Predictor Variables And Hba1c Values As The Outcome Variable

Analysis of the standardised residuals within the data set identified that five values exceeded the expected limits of  $\pm 2$ , but none exceeded  $\pm 2.5$ . The usual expectation is for 95% of cases within a sample to have standardised residuals falling within the limit of  $\pm 2$  and 99% of cases within a sample to have standardised residuals falling within the limit of  $\pm 2.5$ . This data is within 3% of what we would expect with 92.2% of cases falling within the limit of  $\pm 2$ , and all cases falling within the limit of  $\pm 2.5$ .

The data met the assumption of multicollinearity: VIF = 1.03 and tolerance = .97 for both the BRIEF-SR GEC and DFRQ Youth. The assumption of independent errors was also met Durbin-Watson = 1.98.

Examination of a histogram (Figure Q1), a normal P-P plot (Figure Q2) and a scatterplot of the standardised residuals (Figure Q3) indicated that the data met the assumptions of normally distributed errors, homoscedasticity and linearity. The data also met the assumption of non-zero variance, this information is presented in Table Q1.

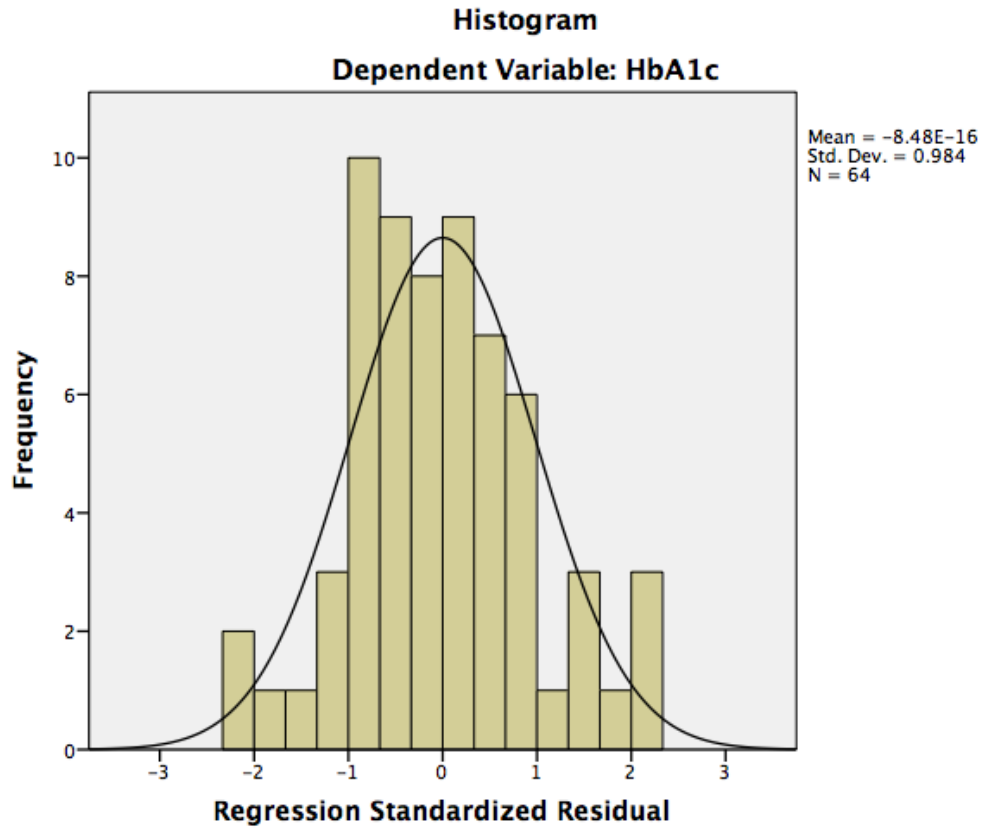


Figure Q1. Distribution of standardised residuals for the regression model

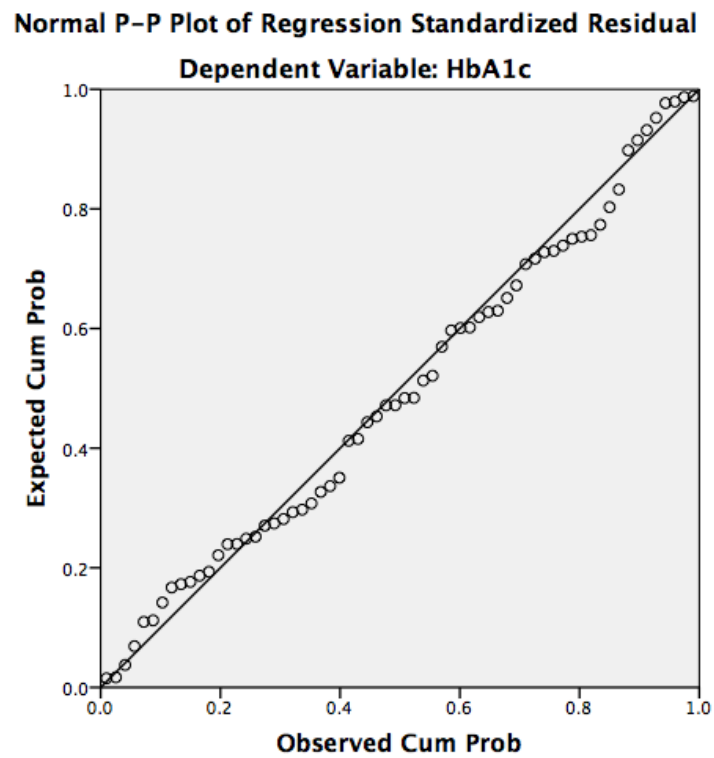
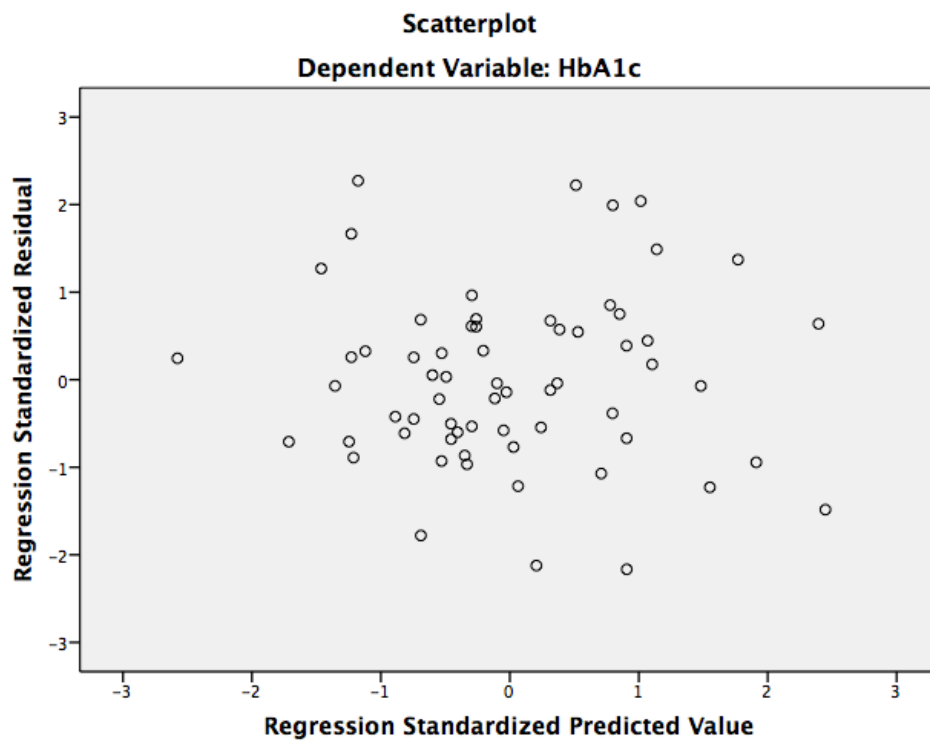


Figure Q2. Standardised residuals for the regression model



*Figure Q3.* No clear relationship between the standardised residuals and predicted values for the regression model

Table Q1

*Variance Statistics for the Variables Input to the Multiple Regression Model*

	Variance
BRIEF-SR GEC	119.98
DFRQ Youth	33.92
HbA1c	137.19