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### The psychological underpinnings of diabetes-management for young people : an examination of relevant literature and lived experiences

Griffith, Llinos

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**The psychological underpinnings of diabetes-management for young people:  
An examination of relevant literature and lived experiences.**

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Bangor

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**Submitted in part fulfillment of the final degree award**

**Doctorate in Clinical Psychology**

**06/06/2014**

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## **Section 1**

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**The psychological underpinnings of diabetes-management for young people:  
An examination of relevant literature and lived experiences.**

**Thesis Abstract**

This thesis explores factors which may impact upon the diabetes-management and health-related outcomes of children and adolescents with diabetes.

A literature review examined the evidence regarding the association between parenting styles and the glycaemic control, adherence, quality of life and mental health of children and adolescents with diabetes. Overall, the evidence regarding parenting and glycaemic control and adherence was inconsistent. However, when parenting and outcome measures were completed by the same informant (either parent or child) parenting characterised by responsiveness, acceptance and involvement was associated with better quality of life and mental health, whilst parenting characterised by psychological control, demandingness and low warmth was associated with worse quality of life and mental health. It is important to highlight that when parenting and outcome measures were completed by different informants, no significant associations between parenting and quality of life or mental health was found. The review therefore indicated that parents and children may experience their relationship differently, and future studies need to explore the unique experiences of children and adolescents with diabetes.

A qualitative exploration of the lived experiences of adolescents with diabetes and poor glycaemic control is also presented. The findings indicate that participants grappled with intrapersonal and interpersonal conflicts as they struggled to accept and manage their diabetes. A cyclical pattern of glycaemic control was depicted as participants described feelings of guilt and shame when their poor glycaemic control and concealment of this was

exposed. However, subsequent improvements in their glycaemic control were short-lived as participants struggled with the burdensomeness of adhering to their regimes.

The final paper examines the contributions made to theory and clinical practice, whilst outlining areas requiring further research.

## **Section 2**

### **Literature Review**

# Journal of Clinical Psychology

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**The association between general parenting and the health-related outcomes of children  
and adolescents with diabetes: A literature review**

**Short Title:** General parenting and diabetes-outcomes

**Key words:** diabetes, parenting, child, adolescent, mental health,  
glycaemic control, adherence.

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## **Abstract**

### **Objective**

The aim of this literature review was to examine the evidence regarding the association between general parenting and the health-related outcomes of children and adolescents with diabetes.

### **Design**

An electronic literature search utilizing PsychInfo, Web of Science and an additional hand search identified 14 studies.

### **Results**

The evidence regarding the association between general parenting and glycaemic control and adherence was inconsistent. However, when the parenting and outcome measures were completed by the same informant (either parents or children), parental responsiveness and acceptance were significantly associated with better quality of life and mental health, whilst parental psychological control and low warmth were significantly associated with worse quality of life and mental health.

### **Conclusions**

The evidence base is still emerging but provides a basis from which parenting interventions aimed at improving the health-related outcomes of children and adolescents with diabetes can be developed. Recommendations for future research are also made.

### Introduction

Type 1 diabetes (DM1) is the most prevalent and severe metabolic illness affecting children and adolescents, with the peak age of onset being between the ages of 5 and 15 years (Hawa & Leslie, 2001). To reduce the likelihood of developing serious health complications associated with DM1 such as cardiovascular disease, retinopathy, and neuropathy, individuals need to maintain good levels of glycaemic control by adhering to a multi-faceted and demanding daily regime (Jubber, Rober, Poulsen & Mandleco, 2013). Unfortunately, approximately half of young people neglect their diabetes care resulting in poor glycaemic control, which raises both medical and psychological concerns (Kovacs, Goldston, Obrosky & Iyengar, 1992).

Considering the early onset of DM1, parents initially have an integral role in the management of their child's diabetes as they often assume responsibility for tasks such as injecting insulin, monitoring blood glucose levels and managing dietary intake. However, these responsibilities are transferred from parents to adolescents during adolescence (Sherifali, Ciliska & O'Mara, 2009) and parents are often faced with a difficult dilemma as they want to ensure that good glycaemic control is maintained whilst also trying to relinquish responsibility and support their child's autonomy (Mellin, Neumark-Sztainer, & Patterson, 2004). This can be a difficult balance, and whilst certain diabetes-specific parental behaviours such as increased monitoring have been positively associated with adherence and glycaemic control (Ellis et al., 2007), increased levels of parental distress and stress have been associated with increased child depression, lower quality of life and poor diabetes management (Whittemore, Jaser, Chao, Jang & Grey, 2012; Cousino & Hazen, 2013).

Whilst several studies have examined parental mental health and diabetes-specific parenting, far fewer studies have examined the association between *general* parenting

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

(encompassing parenting styles and dimensions which are not specifically associated with diabetes) and the health-related outcomes of children and adolescents with diabetes.

Parenting styles are considered to reflect the degree to which parents reflect the two global parenting domains of warmth/responsiveness and control/restrictiveness (Maccoby & Martin, 1983). Parents are thought to vary with regards to their warmth (characterized by parental support, sensitivity, nurture and care) and control (characterized by limit setting, monitoring and having appropriate expectations). Based on these parenting domains, Baumrind (1971; 1991) developed a parenting typology classifying parenting styles into four groups; authoritative parents who are warm and have firm control, authoritarian parents who have low warmth but firm control, permissive parents who are warm but have low control, and neglecting parents who have low warmth and low control.

There is a plethora of research indicating that regardless of gender or socioeconomic background, children whose parents have an authoritative parenting style characterised by being flexible, assertive and supportive have improved outcomes in areas such as school attainment, peer relationships, and have lower levels of depressive symptoms and behavioural problems (Lamborn, Mounts, Steinberg & Dornbusch, 1991; Steinberg, Lamborn, Darling, Mounts & Dornbusch, 1994; Liem, Cavell & Lustig, 2010). Conversely, studies indicate that children whose parents exhibit high levels of criticism and punishment consistent with an authoritarian parenting style have increased rates of depression and anxiety (Dumas, La Freniere & Serketich, 1995), whilst children whose parents exhibit low levels of monitoring consistent with a permissive parenting style have increased rates of early substance misuse and delinquency (Chilcoat & Anthony, 1996).

The parenting literature has also been extended by examination of specific parenting dimensions. For example, psychological control, characterised by over-intrusive attempts to



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regulate a child's thoughts, feelings or behaviours through criticism and guilt, has been associated with increased rates of depression (Barber & Harmon, 2002), whilst parental overprotection, characterised by overanxious parenting, is thought to discourage autonomy (Mullins et al., 2004).

There is increasing emphasis within the literature on the association between parenting and the health-related outcomes of children and adolescents. Studies have found that adolescents with authoritarian or disengaged parents have greater increases in Body Mass Index (BMI; Fuemmeler et al., 2012), whilst children and adolescents with authoritative parents are healthier, have lower BMIs and are more physically active (Sleddens, Gerards, Thijs, De Vries & Kremers, 2011). Similarly, maternal rejection have been associated with more severe illness status for children with asthma (Nagano et al., 2010), whilst higher levels of maternal acceptance and behavioural control has been associated with higher levels of adherence to treatments amongst children and adolescents with Spina Bifida (O'Hara & Holmbeck, 2013). Finally, for children and adolescents with Cerebral Palsy, a parenting style characterised by acceptance and autonomy-granting has been identified as the most important factor associated with better mental health and behavioural outcomes (Aran, Shalev, Biran & Gross-Tsur, 2007).

The evidence-base regarding general parenting and the health-related outcomes of children and adolescents with diabetes is increasing and is in need of synthesis. To the authors' knowledge, this is the first literature review examining the association between general parenting and the glycaemic control, adherence, mental health and quality of life of children and adolescents with diabetes. It is hoped that the findings will guide future research and the development of interventions to improve the health-related outcome of children and adolescents with diabetes.

## Method

### Search Strategy

A systematic search of two electronic databases (Psycinfo & Web of Science) was conducted in March 2014. The following search terms were used; “adolesc\*”, “child\*”, “young people”, “paediatric”, “pediatric”, “diabet\*”, “diabetes”, “parent\*” and “parenting style”. Additional hand-searches of relevant reference lists and citations identified further appropriate papers, which were screened for relevance.

### Eligibility Criteria

Studies were required to meet the following criteria:

1. Must be published in a peer-reviewed journal.
2. Participants comprised of children and adolescents with type 1 or type 2 diabetes under the age of 18 years.
3. A general measure of parenting style, parenting constructs or parenting behaviours completed by parents or children/adolescents must be included (measures of relationship quality, family constructs, or diabetes-specific parenting variables do not meet this criteria).
4. A measure of participants’ glycaemic control, self-care/adherence, quality of life, or mental health must be included.
5. Must be quantitative studies that clearly report how the outcome data relate to the parenting variables.

### Selection process

The study selection was undertaken in three stages (as outlined in Figure 1). Firstly, the 1712 papers identified from the electronic searches were screened according to their titles and abstracts. At this stage, 1675 papers were excluded for the following reasons; studies

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were duplicates, not published in a peer-reviewed journal, not about diabetes, included adult populations, or did not include relevant outcome data or appropriate parenting measures.

Secondly, the full texts of the remaining 37 papers were screened resulting in 24 papers being excluded for the following reasons; no relevant outcome data reported (n=4), only measures of parental mental health (n=1), parental use of language (n=1), diabetes specific parenting (n=8), relationship quality (n=2) or family constructs (n=8) included.

Finally, hand searches of the references and citations of the remaining 13 studies were undertaken, which identified a further six potentially relevant studies. Full text screening of these studies resulted in five studies being excluded for the following reasons; only measures of relationship quality (n=2), diabetes-specific parenting (n=2), or family constructs (n=1) were included. A total of 14 studies therefore met the inclusion criteria and were included in the review.

*[INSERT FIGURE 1]*

## **Results**

A narrative analysis of 14 studies which examined the association between general parenting and the health-related outcomes of children/adolescents with diabetes was undertaken. The findings are organised according to the following five categories; design and methods, sample characteristics, parenting measures, outcome measures, and findings per outcome variable. The final category is divided into four sub-categories; glycaemic control, adherence, quality of life and mental health. Extracted data is presented in chronological order in Table 1. A descriptive summary of the parenting and outcome measures are presented in Table 2 and Table 3 respectively.

### **Design and methods**

Twelve studies were cross-sectional, two of which included comparison groups. Graue, Wentzel-Larsen, Hanestad and Sovik (2005) included healthy controls and adolescents with physical disabilities, whilst Bourdeau, Mullins, Carpentier, Colletti and Christensen (2007) included adolescents with asthma and cystic fibrosis. Two studies were part of larger longitudinal treatment trials. Of these, one included assessments at baseline, 6-months and 12 months follow-up (Saletsky, Trief, Anderson, Rosenbaum, & Weinstock, 2014), whilst the other included assessment at baseline and 12 months follow-up (Botello-Harbaum, Nansel, Haynie, Iannotti, & Simons-Morton, 2008).

### **Sample characteristics**

Eleven studies were conducted in the USA, two in Norway and one in Canada. The sample size of the studies (including all children and/or caregivers who participated) ranged from 55 to 274. The age range of the children and adolescents who participated ranged from 4-18 years. Thirteen studies included participants diagnosed with type 1 diabetes (DM1), one study included a mixed sample of participants with DM1 and type 2 diabetes (DM2; Eckshtain, Ellis, Kolmodin, & Naar-King, 2010), and one study only included participants with DM2 (Saletsky et al., 2014). The illness duration of participants ranged from less than 1 year to 16 years.

Eleven studies reported the ethnicity of participants. Of these, all included white or Caucasian participants (10-99% of samples), eight included African American participants (2.3-87% of samples), five included Hispanic participants (2.3-26% of samples), two included Native American participants (5 and 12% of samples), one included Latino participants (5% of the sample) and one included Asian American participants (2% of sample). Of the remaining three studies, one described their sample as 'ethnically diverse' (Graue et al., 2005), one described the nationality of participants (82.9% Canadian; Sherifali

et al., 2009), and one did not describe the nationality or ethnicity of their participants (Shorer et al., 2011).

*[INSERT TABLE 1]*

### **Parenting measures**

As described in Table 2, 14 different instruments were used to measure parenting styles or dimensions. As four instruments were applied in more than one study, 18 parenting measures were completed in total. Whilst all studies included at least one parenting measure, two studies included two measures (Graue et al., 2005; Butler, Skinner, Gelfand, Berg & Wiebe, 2007) and one study included three measures (Weissberg-Benchell et al., 2009). Of the 14 studies, nine included measures completed by parents or caregivers, two included measures completed by children/adolescents (Graue et al., 2005; Botello-Harbaum et al., 2008) and three included measures completed by parents and children/adolescents (Butler et al., 2007; Weissberg-Benchell et al., 2009; Saletsky et al., 2014).

A range of different parenting styles and dimensions were measured. For example; five studies included measures examining one parenting dimension such as parental overprotection, psychological control or parental authority (Mullins et al., 2004; Graue et al., 2005; Bourdeau et al., 2007; Weissberg-Benchell et al., 2009; Jubber et al., 2013). Three studies included measures examining two parenting dimensions such as responsiveness and demandingness (Botello-Harbaum et al., 2008; Graue et al., 2005; Weissberg-Benchell et al., 2009). Four studies examined authoritarian, authoritative and permissive parenting styles (Greene et al., 2010; Shorer et al., 2011; Monaghan et al., 2012; Saletsky et al., 2014), whilst four studies examined multiple parenting dimensions such as warmth, restrictiveness, amount of control and physical punishment (Davis et al., 2001; Butler et al., 2007; Sherifali et al., 2009; Eckshtain et al., 2010).

The reliability of the parenting measures varied from acceptable to excellent, with the exception of the Parenting Dimensions Inventory (PDI; Power, 1993), as the internal consistency of its subtests ranged from poor to acceptable.

*[INSERT TABLE 2]*

### **Outcome measures**

As described in Table 3, many studies included numerous outcome measures. Overall, eight studies examined glycaemic control, seven studies examined adherence, four studies examined quality of life and four examined mental health. It is important to highlight that although good glycaemic control cannot be achieved without adhering to the diabetes regime (Rhee et al., 2005), adherence and glycaemic control are considered to be separate constructs. Indeed, even if a young person adheres to their diabetes regime, common illnesses such as influenza can still negatively impact on glycaemic control (Diabetes UK, 2010). Whereas glycaemic control may therefore provide an objective indication of a young person's adherence behaviours, adherence measures enable subjective appraisals of adherence behaviours to be examined.

Whereas glycaemic control was measured by blood tests measuring HbA1c values, and one study measured adherence through nurse reports (Saletsky et al., 2014), the remaining studies included measures completed by the child/adolescent or by parent-proxy reports. Of these, two studies included measures completed by parents (Davis et al., 2001; Monaghan et al., 2012), and five studies included measures completed by children/adolescents (Mullins et al., 2004; Graue et al., 2005; Butler et al., 2007; Botello-Harbaum et al., 2008; Greene et al., 2010;). Five studies included measures completed by parents and children/adolescents (Bourdeau et al., 2007; Sherifali et al., 2009; Weissberg-Benchell et al., 2009; Eckshtain et al., 2010; Shorer et al., 2011).

Five of the seven studies examining adherence reported the reliability of the measures used, which varied from acceptable to good ( $\alpha = .73-.80$ ). Four studies examined diabetes-related quality of life (DRQOL) and one study also examined general health-related quality of life (HRQOL). The reliability of these measures ranged from fair to excellent ( $\alpha = .63-.92$ ). Three of the four studies examining mental health included measures of depressive symptoms whilst one study included a measure of general mental health. Three studies reported the reliability of these measures which ranged from good to excellent ( $\alpha = 0.80-0.94$ ).

[INSERT TABLE 3]

### **Findings per outcome variable**

**Glycaemic control.** Eight studies examined the association between parenting and the glycaemic control of children and adolescents with diabetes.

*Comparison of maternal and paternal parenting.* Three studies explicitly compared the associations between glycaemic control and maternal and paternal parenting styles. Whilst both Greene et al. (2010) and Shorer et al. (2011) identified that maternal and paternal parenting had different associations with the glycaemic control of adolescents, some of the associations found were contradictory. For example, Greene et al. (2010) found that maternal but not paternal authoritative parenting was significantly associated with better glycaemic control, whilst Shorer et al. (2011) found that paternal but not maternal authoritative parenting was significantly associated with better glycaemic control. Furthermore, Greene et al. (2010) found that both maternal and paternal permissive parenting were significantly associated with poor glycaemic control, whilst Shorer et al. (2011) found no significant association between these variables. However, both Greene et al. (2010) and Shorer et al.

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(2011) consistently found no significant association between authoritarian parenting and glycaemic control.

Similar to Shorer et al. (2011), Jubber et al. (2013) found a significant association between paternal but not maternal parenting and glycaemic control. Specifically, paternal (but not maternal) use of psychological control was significantly associated with poor glycaemic control. Overall these findings may tentatively indicate that paternal rather than maternal use of psychological control is more closely associated with poor glycaemic control. However, this evidence-base is within its infancy and further research comparing the associations between maternal and paternal parenting and glycaemic control is required before any firm conclusions can be made.

*Comparison between age groups.* Few significant associations were found between general parenting and the glycaemic control of children and adolescents with diabetes. Indeed, studies including younger children (under 12 years old) such as Monaghan et al. (2012) found no significant differences between parents reporting high or low levels of authoritative parenting and glycaemic control. Similarly, Sherifali et al. (2009) found no significant association between parental support, control and structure and glycaemic control. Amongst this younger age group, the only significant association found was reported by Davis et al. (2001) who found that parental restrictiveness but not parental warmth was significantly associated with poor glycaemic control.

Similar to the insignificant associations found between parenting and glycaemic control amongst younger samples, Graue et al. (2005) found that although adolescents with DM1 described their parents as more controlling than adolescents with physical disabilities and healthy controls, no significant association between glycaemic control and parental care, control or bonding was found. Similarly, Eckstain et al. (2010) found no significant association between parental involvement and inconsistent discipline and the glycaemic



control of adolescents with either DM1 or DM2. However, a significant association was found between low levels of parental monitoring and poor glycaemic control. These findings may tentatively indicate that the association between parenting and glycaemic control may change with age, with high levels of restrictiveness being negatively associated with the glycaemic control of younger children and low levels of monitoring being negatively associated with the glycaemic control of adolescents. It is therefore important to consider that younger children are less likely to be responsible for their diabetes management, and parents may adjust their parenting styles as their child takes increasing responsibility during adolescence.

*Summary.* Overall the evidence indicating that general parenting is associated with the glycaemic control of children and adolescents is inconsistent. Indeed, the literature is limited by the fact that the majority of parents in studies such as Monaghan et al. (2012) and Greene et al. (2010) endorsed authoritative parenting styles thus limiting the ability of studies to meaningfully examine effects across different parenting styles. Further research including more heterogeneous samples is therefore required. Furthermore, considering the evidence indicating different associations between parenting and the glycaemic control of children and adolescents, longitudinal studies may be helpful in understanding whether associations change over time.

**Adherence.** Seven studies examined the association between general parenting and the adherence of children and adolescents to their diabetes regimes.

*Comparison of maternal and paternal parenting.* Two studies explicitly compared the associations between maternal and paternal parenting and the adherence of adolescents to their diabetes regimes. Greene et al. (2010) found that maternal but not paternal reports of authoritative parenting were significantly associated with child-reports of better adherence, whilst Shorer et al. (2011) found that paternal but not maternal authoritative reports of

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parenting was significantly associated with child-reports of better adherence. Furthermore, Greene et al. (2010) found no significant associations between parent reports of permissive parenting and adherence, whilst Shorer et al. (2011) found that maternal reports of permissive parenting were significantly associated with child-reports of poor adherence. No significant associations between authoritarian parenting and adherence were found by either study.

Considering that only two studies have examined the association between paternal and maternal parenting and adherence, and the inconsistent results found, further research is required before any conclusions can be made.

*Comparison of glycaemic control and adherence.* Despite the fact that adherence is considered to be an important prerequisite of good glycaemic control, both outcomes have been found to have different associations with parenting. For example, Greene et al. (2010) found a significant association between permissive parenting and poor glycaemic control but not adherence. Similarly, Shorer et al. (2011) found that maternal reports of permissive maternal parenting was significantly associated with poor adherence but not glycaemic control. This contrast has also been reflected in younger children as Monaghan et al. (2012) found that high levels of authoritative parenting were significantly associated with better adherence but not glycaemic control, and Davies (2001) found that parental warmth was significantly associated with better adherence but not glycaemic control.

Overall, the evidence regarding permissive parenting and adherence and glycaemic control is inconsistent. However, the studies indicate that for younger samples, authoritative parenting characterised by warmth is more closely associated with better adherence rather than glycaemic control. Further research exploring these associations may therefore be important in understanding the possibly distinct processes underlying adherence and glycaemic control.

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*Comparisons across informants.* Considering the significant discrepancies found between the views of children/adolescents with DM1 and their parents (Miller & Drotar, 2003), and recommendations outlining that parent proxy reports should be considered alongside the views of children and adolescents with DM1 (Sherifali & Pinelli, 2007), this may be an important limitation. This was addressed by the following studies which compared measures completed by children/adolescents and their parents.

Regardless of whether measures were completed by parents or children/adolescents, Bourdeau et al. (2007) found no significant associations between parental overprotection and adherence. Conversely, discrepancies were reported by Saletsky et al. (2014) as child-reports (but not parent-reports) of permissive parenting at baseline were a significant predictor of better adherence at 6 months follow-up. However, these results are constrained by methodological limitations as adherence was measured by nurses counting the number of pills remaining in blister packs rather than using validated measures.

Butler et al. (2007) also compared parenting measures completed by children/adolescents and their parents and found significant discrepancies. Indeed, whilst neither parent nor child reports of parental psychological control or firm control were significantly related to child-reports of adherence, parent-reports (but not child-reports) of parental acceptance were significantly associated with child-reports of adherence. Although these findings are consistent with previous findings indicating that authoritative parenting is associated with better adherence, it is important to consider whether a social desirability bias may have impacted upon parental self-reports of parenting thereby impacting upon the associations found.

**Quality of life.** Four studies examined the association between general parenting and the quality of life of children and adolescents with DM1.

*Different informants.* When different informants completed the parenting and quality of life measures, no associations were reported. For example, Sherifali et al. (2009) found that parent-reports of parental support, control and structure, were not significantly associated with child-reports of health-related quality of life (HRQOL). Similarly, Weissberg et al. (2009) found that child-reports of parental psychological control were not significantly associated with parent-proxy reports of HRQOL or diabetes-related quality of life (DRQOL).

*Consistent informants.* When the same informants (either parent or child) completed the parenting and quality of life measures, significant associations were reported. Sherifali et al. (2009) found that parent-reports of parental structure were significantly associated with parent-proxy reports of better HRQOL. Consistently, Botello-Harbaum et al. (2008) found that child-reports of parental responsiveness were significantly associated with child-reports of better DRQOL at baseline and 12-month follow-up. Significant results were also found by Graue et al. (2005) who found that child-reports of parental care and involvement (with exception of the 'worry' subscale) were significantly associated with child-reports of better DRQOL.

Parenting behaviours were also significantly associated with decreased quality of life. For example, Weissberg et al. (2009) found that child-reports of parental psychological control significantly predicted child-reports of lower HRQOL and diabetes-related quality of life (DRQOL). Similarly, Graue et al. (2005) found that child-reports of parental control were significantly associated with child-reports of lower DRQOL, whilst Botello-Harbaum et al. (2008) found that child-reports of parental demandingness were significantly associated with child-reports of lower DRQOL at baseline but not 12-month follow-up.

Overall, the results indicate that parenting characterised by responsiveness and care is associated with better DRQOL, whilst parenting characterised by psychological control and

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demandingness is associated with worse DRQOL. However, it is important to consider whether asking the same informants to complete both parenting and quality of life measures was more likely to produce significant associations between parenting styles and quality of life outcomes. Further research should therefore give close consideration to these methodological issues to clarify the findings. Furthermore, it is important to highlight that considering the findings by Botello-Harbaum et al. (2008) who found no significant associations between parenting and DRQOL at 12-months follow-up, further longitudinal studies are needed to examine whether associations change over time as this would inform any interventions developed to improve the quality of life of children and adolescents with diabetes.

**Mental health.** Four studies examined the association between general parenting and the mental health outcomes of children and adolescents with diabetes.

*Different informants.* Consistent with findings regarding quality of life, when different informants completed parenting and mental health measures, no associations were found between these constructs. Mullins et al. (2004) included the youngest sample of children with DM1 and found that parent-reports of parental overprotection were not significantly associated with child-reports of depressive symptoms. Butler et al. (2007) also found that parent-reports of parental psychological control, firm control and acceptance were not significantly associated with child-reports of depressive symptoms. Consistently, Eckshtain et al. (2010) included a mixed sample of participants with DM1 and DM2 and found no significant association between parent-reports of poor monitoring, involvement and inconsistent discipline, and child-reports of depressive symptoms.

*Consistent informants.* Significant associations were identified between parenting and the mental health of children and adolescents with diabetes when the parenting and mental health measure was completed by the same informants. Butler et al. (2007) found that child-

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reports of acceptance were significantly associated with lower child-reports of depressive symptoms. Similarly, Graue et al. (2005) found that child-reports of parental care and involvement were associated with child-reports of better mental health.

Negative parenting styles were also significantly associated with poor mental health outcomes. Butler et al. (2007) reported that child-reports of maternal psychological control were significantly associated with greater child-reports of depressive symptoms whilst maternal firm control was associated with increased depressive symptoms only for older adolescents. Similarly, Eckshtain et al. (2010) found that parent-reports of inconsistent discipline and low warmth were significantly associated with parent-proxy reports of increased depressive symptoms. Finally, Graue et al. (2005) found that child-reports of parental control were significantly associated with child-reports of poor mental health.

Overall the results indicate that when parenting and mental health measures were completed by the same informant, parenting characterised by acceptance, care and involvement was positively associated with mental health, whilst parenting characterised by low warmth, inconsistent discipline and parental control was negatively associated with mental health. However, the results should be interpreted with caution as this is based on a small number of studies and it is again important to consider methodological issues regarding whether consistent informants completed the measures. Furthermore, considering that only one study included participants under the age of 10 years, this highlights the dearth of literature currently examining the association between parenting and the mental health outcomes of younger children with diabetes.

### **Discussion**

The aim of this literature review was to examine the association between general parenting and the glycaemic control, adherence, mental health and quality of life of children

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and adolescents with diabetes. The majority of the fourteen studies examined children and adolescents with DM1 with only two studies including adolescents with DM2.

Overall, the evidence regarding the association between parenting and the health-related outcomes of children and adolescents with diabetes was mixed with evidence regarding glycaemic control and adherence being inconsistent. For example, evidence indicates that paternal (rather than maternal) use of psychological control is associated with poorer glycaemic control, whereas authoritative parenting characterised by warmth is associated with better adherence. Despite the largely insignificant associations found between general parenting and glycaemic control, differences across ages were found with high levels of restrictiveness being negatively associated with the glycaemic control of younger children and low levels of monitoring being negatively associated with the glycaemic control of adolescents. However, further research exploring these associations is necessary before any firm conclusions can be made.

The evidence regarding mental health and quality of life was more consistent. Although no significant associations were found between parenting and mental health outcomes when measures were completed by different informants, when measures were completed by the same informant, parenting characterised by responsiveness, acceptance and involvement was associated with better quality of life and mental health, whilst parenting characterised by psychological control, demandingness and low warmth was associated with worse quality of life and mental health. The findings therefore indicate that consistent with studies undertaken with healthy children and adolescents (Dumas, La Freniere & Serketich, 1995), the evidence indicates that parenting style is associated with the quality of life and mental health of children and adolescents with diabetes.

It is important to highlight that the literature is limited by the small sample sizes included in some studies and by the high rates of authoritative parenting styles reported, thus

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limiting the ability of studies to meaningfully examine effects across different parenting styles. Furthermore, methodological issues were raised as the majority of studies included parenting measures completed by parents, which may have been influenced by a social desirability bias. It is striking that no significant associations were found between parenting and quality of life and mental health outcomes when measures were completed by different informants which may indicate that parents and adolescents experience parenting in distinct ways (Butler et al., 2007). It is also important to highlight that the majority of studies were cross-sectional and therefore potentially reciprocal associations and bi-directional relationships between parents and children/adolescents could not be examined.

### **Theoretical and Clinical Implications**

Although causality could not be inferred from this review, the findings are consistent with the developmental literature indicating that authoritative parenting may have a protective role enabling children and adolescents to “cope with the stressors related to managing their disease” (Bottello-Harbaum et al., 2008, p678), whilst intrusive parenting may inhibit autonomy and negatively impact on emotional wellbeing.

In light of these findings, it may be useful to examine the effectiveness of parenting interventions in improving the quality of life and mental health of children and adolescents with diabetes. Although studies indicate that multi-component family-based interventions can reduce family conflict and improve the glycaemic control of children and adolescents with diabetes (McBroom & Enriques, 2009), these interventions are often costly and many paediatric services do not have adequate resources to support them (Wysocki et al., 2007).

Contrarily, parenting interventions are often delivered in group formats and are associated with lower costs. Indeed, despite the dearth of literature evaluating the effectiveness of parenting interventions, a randomized controlled trial is currently underway examining the effectiveness of an online intervention (which has an adolescent and parent



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component) in improving the mental health, quality of life and adherence of adolescents with DM1 (Hackworth et al., 2013). Specifically, the parenting intervention is focused on acceptance-based strategies aimed at strengthening parent-child relationships. Although this study is on-going, it highlights the increasing emphasis being placed on parenting and the health-related outcomes of children and adolescents with diabetes.

### **Limitations**

Although the aim of this literature review was to examine general parenting, perhaps examining diabetes-specific parenting would also have been beneficial to develop a more rounded understanding of the various parenting behaviours associated with the health-related outcomes of children and adolescents with diabetes. However, various studies have already demonstrated that diabetes-specific parenting behaviours such as monitoring are associated with improved outcomes (Ellis et al., 2007) and therefore the aim of this review was to examine general parenting. This review is also limited by the fact that a formal quality assessment tool was not used to evaluate studies and qualitative studies which may provide further insights into the association between parenting and diabetes were not included.

### **Research Implications**

Future research examining the association between parenting and the health-related outcomes of children and adolescents with diabetes need to address the numerous methodological limitations highlighted in this review. Firstly, the finding that no significant associations were found between parenting and quality of life and mental health when measures were completed by different informants indicates a disparity between the way children/adolescents and parents view or experience parenting. Although it has been argued that “it is the child’s experience of parenting that is most important to consider during adolescence” (Butler et al., 2007, p1234), nine of the fourteen studies included in this review only included parenting measures completed by parents. Studies therefore appear to neglect

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the experiences of adolescents with diabetes and future studies are likely to benefit from collating information from various sources such as children/adolescents, parents and observational measures to develop a more overarching understanding. Furthermore, considering the inconsistent evidence regarding parenting and glycaemic control and adherence, qualitative studies examining adolescents' experiences may provide new insights into factors which may positively or negatively impact upon adherence and glycaemic control.

The majority of studies included in this review adopted cross-sectional designs which could not capture potentially reciprocal associations between children/adolescents and their parents. Future studies may therefore benefit from adopting prospective longitudinal designs which could capture transactional associations. Furthermore, instead of assessing parenting at one time point thus indicating that parenting is a static concept, longitudinal designs could capture the dynamic nature of parenting and how this may change over time. It is also important to highlight that differences were identified between paternal and maternal parenting, with studies tentatively indicating that paternal rather than maternal parenting is more closely associated with glycaemic control. Indeed, the majority of parents included in the studies were mothers rather than fathers, which provides support for arguments that the role of fathers has not been adequately considered with regards to the adjustment of children and adolescents to chronic illnesses (Dashiff, Morrison, & Rowe, 2008).

Although the evidence regarding the association between general parenting and diabetes is still emerging, it provides a basis from which parenting interventions aimed at improving the health-related outcomes of children and adolescents with diabetes can be developed. However, future research needs to address the methodological limitations raised and therefore needs to ask adolescents about their views or experiences rather than relying on parental reports, before any firm recommendations can be made.

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**Table 1**

*Summary of studies examining the association between parenting variables and the health-related outcomes of children and adolescents with T1D and T2D.*

| References<br>Country                                | Sample characteristics                                                                                        |                           | Disease information                                                                      | Design          | Parenting measure | Health-related outcome measures           | Summary of results                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|---------------------------|------------------------------------------------------------------------------------------|-----------------|-------------------|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                      | Child                                                                                                         | Parent                    |                                                                                          |                 |                   |                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| 1.<br><b>Davis et al. (2001).</b><br><br><b>USA.</b> | n = 55<br>M = 24<br>F = 31<br><br>Aged 4-10 years.<br><br>58% White non-Hispanic<br>16% Black<br>26% Hispanic | n = 55<br>M = 9<br>F = 46 | DM1<br><br>27% of the sample diagnosed for less than 1 year.<br><br>Average HbA1C = 8.7% | Cross-sectional | PDI               | Mean HbA1C over 2 blood tests.<br><br>SCI | <p><u>Glycaemic control</u></p> <p>- Correlational</p> <p>Parent-reports of parental warmth was not significantly associated with glycaemic control. Parent-reports of parental restrictiveness was significantly associated with poorer glycaemic control (<math>p &lt; 0.05</math>).</p> <p><u>Adherence</u></p> <p>- Correlational</p> <p>Parent-reports of parental warmth was significantly associated with better parent-proxy adherence ratings (<math>p &lt; 0.001</math>). However, parent-reports of parental restrictiveness were not.</p> <p>- Regression analysis</p> <p>Controlling for demographic variables, warmth was the only significant predictor of adherence, explaining 27% of the variance (<math>p &lt; 0.001</math>).</p> |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                                                   |                                                                                   |                          |                                                                                                            |                                 |                                               |                                                                                    |                                                                                                                                                                        |
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| 2.<br><b>Mullins et al. (2004).</b>                               | n = 43<br>M = 15<br>F = 28                                                        | n= 43<br>M = 0<br>F = 43 | DM1<br><br>Duration range =<br>2 months - 8<br>years 6 months.<br>Average<br>HbA1C = 9.02%.                | Cross-<br>sectional             | PPS                                           | CDI                                                                                | <u>Depressive symptoms</u><br>- Correlational<br>Parent-reports of parental overprotection was not significantly associated with child-reports of depressive symptoms. |
| <b>USA.</b>                                                       | Aged 8-12<br>years<br>(mean age<br>= 10.1<br>years).                              |                          |                                                                                                            |                                 |                                               |                                                                                    |                                                                                                                                                                        |
|                                                                   | 93%<br>White<br>2.3%<br>African-<br>American<br>2.3%<br>Hispanic<br>2.3%<br>Other |                          |                                                                                                            |                                 |                                               |                                                                                    |                                                                                                                                                                        |
| 3.<br><b>Graue, Wentzel-Larsen, Hanestad, &amp; Sovik (2005).</b> | n = 115<br>M = 60<br>F = 55                                                       |                          | DM1<br><br>Duration range =<br>1-16 years<br>(mean duration =<br>6.99 years).<br><br>Mean HbA1c =<br>9.3%. | Control<br>study                | PBI                                           | HbA1C in<br>a recent<br>blood test.                                                | Participants with T1D reported higher levels of parental involvement and described their parents as more controlling than participants in the control groups.          |
| <b>Norway.</b>                                                    | Aged 11-<br>18 years<br>(mean age<br>= 14.5<br>years).                            |                          |                                                                                                            | Healthy<br>controls<br>(n=9345) | The<br>Parental<br>Involve-<br>ment<br>Scale. | Diabetes<br>Quality of<br>Life<br>Questionn-<br>aire<br>modified<br>for<br>Youths. | <u>Glycaemic control</u><br>No significant association between glycaemic control and child-reports of parental care, control or involvement was found.                 |

ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

Described as ethnically diverse.

CHQ-CF87

Diabetes-related quality of life (DRQOL)  
 - Partial Correlation coefficients adjusted for age and gender  
 Child-reports of parental care was positively and significantly associated with child-reports DRQOL (p<0.001). Child-reports of parental involvement (with exception of the 'worry' subscale) was also positively and significantly associated with child-reports of DRQOL (p<0.001). Child-reports of parental control was significantly and negatively associated with child-reports of DRQOL (p<0.001).

Mental Health  
 - Partial Correlation coefficients adjusted for age and gender  
 Child-reports of parental care and involvement were positively and significantly associated with child-reports of mental health (p<0.001). Child-reports of parental control was significantly negatively associated with child-reports of mental health (p<0.001).

|                                                               |                            |                 |                                  |                 |       |     |                                                                                                                                                               |
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| <b>4. Butler, Skinner, Gelfand, Berg, &amp; Wiebe (2007).</b> | n = 78                     | n = 78          | DM1                              | Cross-sectional | CRPBI | SCI | <u>Adherence</u>                                                                                                                                              |
|                                                               | M = 41<br>F = 37           | M = 0<br>F = 78 | Duration of a minimum of 1 year. |                 | PRPBI | CDI | - Correlational<br>Child-reports of parental psychological control, firm control and acceptance were not significantly related to child-reports of adherence. |
|                                                               | Aged 11-17 years (mean age |                 |                                  |                 |       |     |                                                                                                                                                               |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                    |                                                       |                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
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| <p><b>USA.</b></p> | <p>= 14.21 years).<br/><br/>99% European-American</p> | <p>HbA1C values were only available for 53 children<br/><br/>Mean HbA1c = 8.66%.</p> | <p>Maternal-reports of parental psychological control and firm control were not significantly associated with child-reports of adherence. However, maternal-reports of parental acceptance was significantly associated with child-reports of better adherence (<math>p &lt; 0.05</math>).</p> <p><u>Depressive symptoms</u></p> <p>- Correlational<br/>Child-reports of parental psychological control was significantly associated with child-reports of greater depressive symptoms (<math>p &lt; 0.01</math>). Child-reports of parental firm control was not significantly associated with child-reports of greater depressive symptoms. Child-reports of parental acceptance was significantly associated with child-reports of lower depressive symptoms (<math>p &lt; 0.05</math>).<br/>Maternal-reports of parental psychological control, firm control and acceptance were not significantly associated with child-reports of depression.</p> <p>- Regression analysis<br/>Significant interactions were found as firm control was associated with higher depressive symptoms among older more than younger participants. Higher levels of acceptance was associated with lower depressive symptoms amongst girls but not boys.</p> |
|--------------------|-------------------------------------------------------|--------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                                                                          |                                                                                                                                                                                    |                                           |                                                                             |                                                                 |                                      |             |                                                                                                                                                                                                                                                                                         |
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| <p><b>5. Bourdeau, Mullins, Carpentier, Colletti, &amp; Christensen (2007). USA.</b></p> | <p>n = 124<br/>M = 92<br/>F = 108<br/>Aged 8-18 years (mean age 12.3 years).<br/>82% Caucasian<br/>7% African American<br/>5% Native American<br/>1.5% Hispanic<br/>4.5% Other</p> | <p>Mixed sample mothers &amp; fathers</p> | <p>DM1<br/>Mean duration of illness = 4.4 years.</p>                        | <p>Comparison groups Asthma (n=48), Cystic Fibrosis (n=28).</p> | <p>PPS</p>                           | <p>SCI</p>  | <p><u>Adherence</u><br/>- Regression analysis<br/>For the DM1 sample, after controlling for age and income, parent-reports of parental overprotection was not significantly associated with child-reports or parent-proxy reports of adherence.</p>                                     |
| <p><b>6. Botello-Harbaum, Nansel, Haynie, Iannotti, &amp; Simons-Morton (2008).</b></p>  | <p>n = 81<br/>M = 36<br/>F = 45<br/>Aged 11-16 years (mean age = 13.3 years).</p>                                                                                                  | <p>N/A</p>                                | <p>DM1<br/>Duration of a minimum of 1 year (mean duration = 7.7 years).</p> | <p>Baseline &amp; 12 month follow-up.<br/>Study was part</p>    | <p>Authoritative Parenting Index</p> | <p>DQOL</p> | <p><u>DRQOL</u><br/>- Correlational<br/>Child-reports of parent responsiveness was significantly associated with child-reports of DQOL at baseline and 12-month follow-up (p&lt;0.01).<br/>Child-reports of parent demandingness was significantly associated with child-reports of</p> |

ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                                   |                                                   |                              |                                         |                                            |                               |                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
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| <b>USA.</b>                                       | 85%<br>White<br>11%<br>Black<br>4%<br>Other       |                              |                                         | of a<br>larger<br>Interven-<br>tion trial. |                               |                                   | DQOL at baseline (p<0.01) but not 12-month follow-up.<br>- Regression analysis<br>At 12-month follow-up even after controlling for demographic and diabetes-specific variables, parent demandingness remained a significant predictor of HRQOL (p<0.00).                                                                                                                                                                                                                           |
| <b>7. Sherifali, Cliska, &amp; O'Mara (2009).</b> | n = 216<br>M = 108<br>F = 108<br>Aged 5-12 years. | n = 216<br>M = 39<br>F = 177 | DM1<br>Duration of a minimum of 1 year. | Cross-sectional                            | PDI                           | HbA1C during previous 3-4 months. | <u>Glycaemic control</u><br>- Correlational<br>Parent-reports of parental support, control and structure were not significantly associated with glycaemic control.                                                                                                                                                                                                                                                                                                                 |
| <b>Canada.</b>                                    | 82.9%<br>Canadian<br>17.1%<br>Other               |                              |                                         |                                            |                               | (PedsQL) 3.0 type 1 diabetes      | <u>Health-related Quality of Life (HRQOL)</u><br>- Correlational<br>No significant associations between parent-reports of parental support, control and structure, and child-reports of HRQOL were found.<br>No significant associations between parent-reports of parental support and control, and parent-proxy-reports of HRQOL were found.<br>A weak significant association between parent-reports of parental structure and parent-proxy reports of HRQOL was found (p<.01). |
| <b>8. Weissberg-Benchell et al. (2009).</b>       | n = 120<br>M = 60<br>F = 60                       | n = 120<br>M = 7<br>F = 110  | DM1                                     | Cross-sectional                            | Authoritative Parenting Index | (PedsQL) 3.0 type 1 diabetes      | <u>HRQOL</u><br>- Path models and multiple regression<br>After controlling for other parental behaviours and demographic variables, child-                                                                                                                                                                                                                                                                                                                                         |

ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                                                   |                                                                            |                                            |                                                                           |                             |                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                               |
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| <b>USA.</b>                                                       | Aged 9-14.5 years (mean age 12.1 years).                                   | Other relative s = 3                       | Duration of a minimum of 1 year (mean duration = 64.85 months).           | Psychological Control Scale | PedsQL, DM 3.0 type 1 diabetes.    | reports of high levels of parental psychological control significantly predicted lower levels of child-reported HRQOL (p<0.05). Child-reports of parental psychological control was not associated with parent-proxy reports of HRQOL.                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                               |
|                                                                   | 71.7% Caucasian<br>11.7% African American,<br>9.2% Hispanic.<br>7.4% Other |                                            | Mean HbA1c = 8.10%.                                                       | Parental Authority          |                                    | <p><u>DRQOL</u><br/>- <u>Path models and multiple regression</u><br/>After controlling for other parental behaviours and demographic variables child-reports of high levels of parental psychological control significantly predicted lower levels of child-reported DRQOL (p&lt;0.01). Child-reports of parental psychological control was not associated with parent-proxy reports of DRQOL.<br/>Child-reports of parental responsiveness, demandingness, authority and parent-reports of authority were not associated with child-reports or parent-proxy reports of HRQOL or DSQOL.</p> |                                                                                                                                                                               |
| <b>9. Greene, Mandleco, Roper, Marshall, &amp; Dyches (2010).</b> | n = 29<br>M = 14<br>F = 15<br><br>Aged 10-18 years (mean age               | n=29<br><br>Mixed sample mothers & fathers | DM1<br><br>Duration for a minimum of 2 years (mean duration = 6.23 years) | Cross-sectional             | 62-item Parenting Practices Report | Mean HbA1C over 4 blood tests<br><br>The Diabetes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Higher rates of maternal and paternal authoritative parenting style than authoritarian or permissive styles were reported.<br><br><u>Glycaemic control</u><br>- Correlational |



## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|             |                                     |                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
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| <b>USA.</b> | = 14<br>years).<br><br>90%<br>White | Mean HbA1C<br>over 4 blood tests<br>= 8.5% | <b>Self-Care<br/>Instrument</b> <p>Maternal reports of authoritative parenting was significantly associated with better glycaemic control (<math>p &lt; 0.05</math>). Maternal reports of permissive parenting was significantly associated with poor glycaemic control (<math>p &lt; 0.05</math>). Maternal reports of authoritarian parenting was not significantly associated with glycaemic control.</p> <p>Paternal reports of permissive parenting was significantly associated with poor glycaemic control (<math>p &lt; 0.05</math>). Paternal reports of authoritative and authoritarian parenting were not significantly associated with glycaemic control.</p> <p>- Regression analysis</p> <p>After controlling for demographic variables maternal authoritative parenting accounted for 25% of the variance in mean HbA1C values, was the strongest predictor of glycaemic control (<math>p &lt; 0.01</math>)</p> <p><u>Adherence</u></p> <p>- Correlational</p> <p>Maternal reports of authoritative parenting was significantly associated with better child-reports of adherence (<math>p &lt; 0.01</math>). Maternal reports of permissive and authoritarian parenting were not significantly associated with child-reports of adherence. Paternal reports of authoritative, permissive and authoritarian parenting were not</p> |
|-------------|-------------------------------------|--------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

significantly associated with a child-reports of adherence.

- Regression analysis

After controlling for demographic variables maternal authoritative parenting positively predicted child-reports of adherence and accounted for 36% of the variance ( $p < 0.001$ ).

|                                                                            |                                                                                                                                         |                                    |                                                                                                                                                 |                        |            |                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
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| <p><b>10. Eckshtain, Ellis, Kolmodin, &amp; Naar-King (2010). USA.</b></p> | <p>n = 61<br/>F = 62%<br/>M =<br/>Aged 10-17 years (mean age = 14.3 years).<br/>87% African-American<br/>10% Caucasian<br/>3% Other</p> | <p>n = 61<br/>M = 2<br/>F = 59</p> | <p>DM1 = 85<br/>DM2 = 15<br/>Duration of a minimum of 1 year (mean duration = 4.42 years).<br/>HbA1C of 8% or higher (mean HbA1C = 11.78%).</p> | <p>Cross-sectional</p> | <p>APQ</p> | <p>HbA1C in most recent blood test.<br/>CBCL<br/>YSR</p> | <p><u>Glycaemic control</u><br/>- Correlational<br/>Parent-proxy reports of low parental monitoring was significantly associated with poor glycaemic control (<math>p &lt; 0.01</math>). Parent-proxy reports of low involvement and inconsistent discipline were not significantly associated with glycaemic control.<br/><br/><u>Depressive symptoms</u><br/>- Correlational<br/>Parent-proxy reports of low involvement/warmth (<math>p &lt; 0.01</math>) and high levels of inconsistent discipline (<math>p &lt; 0.05</math>) were significantly associated with parent-reports of increased child depressive symptoms.<br/>Parent-proxy reports of low involvement/warmth, high levels of inconsistent discipline and low levels of parental monitoring were not significantly associated with child-reports of depression.</p> |
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## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

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| <p><b>11.</b><br/><b>Shorer,</b><br/><b>Btech,</b><br/><b>Schoenber</b><br/><b>g-Taz,</b><br/><b>Levavi-</b><br/><b>Lavi,</b><br/><b>Phillip, &amp;</b><br/><b>Meyerov-</b><br/><b>itch</b><br/><b>(2011).</b><br/><b>Israel.</b></p> | <p>n = 100<br/>M = 53<br/>F = 47<br/><br/>Aged 11-<br/>18 years<br/>(mean age<br/>= 14.37<br/>years).<br/><br/>Ethnicity<br/>not<br/>reported</p> | <p>n = 142<br/>M = 63<br/>F = 79</p> | <p>DM1<br/><br/>Duration for a<br/>minimum of 1<br/>year (mean<br/>duration = 4.92<br/>years)<br/><br/>Mean HbA1C =<br/>8%</p> | <p>Cross-<br/>sectional</p> | <p>Parental<br/>Authority<br/>Questio-<br/>nnaire</p> | <p>Mean<br/>HbA1C<br/>over 1<br/>year<br/>period.<br/><br/>Adherence<br/>to<br/>Diabetes<br/>Treatment<br/>Regimen<br/>Questio-<br/>naire.</p> | <p><u>Glycaemic control</u><br/>- Correlational<br/>Maternal reports of authoritative, permissive<br/>and authoritarian parenting were not<br/>significantly associated with glycaemic<br/>control.<br/>Paternal reports of authoritative parenting<br/>was significantly associated with better<br/>glycaemic control (p&lt;0.005). Paternal reports<br/>of permissive and authoritarian parenting<br/>were not significantly associated with<br/>glycaemic control.<br/><br/><u>Adherence</u><br/>- Correlational<br/>Maternal reports of permissive parenting was<br/>significantly associated with poorer<br/>adherence (p&lt;0.05). Maternal reports of<br/>authoritative and authoritarian parenting<br/>were not significantly associated with<br/>adherence.<br/>Paternal reports of authoritative parenting<br/>was significantly associated with better<br/>adherence (p&lt;0.05). Paternal reports of<br/>permissive and authoritarian parenting were<br/>not significantly associated with adherence.</p> |
| <p><b>12.</b><br/><b>Monaghan,</b><br/><b>Horn,</b><br/><b>Cogen, &amp;</b><br/><b>Streisand</b></p>                                                                                                                                  | <p>Aged 8-11<br/>years<br/>(mean age<br/>= 9.3<br/>years)</p>                                                                                     | <p>n = 95<br/>M = 7<br/>F = 87</p>   | <p>DM1<br/><br/>Duration for a<br/>minimum of 6<br/>months</p>                                                                 | <p>Cross-<br/>sectional</p> | <p>PSDQ</p>                                           | <p>Mean<br/>HbA1C<br/>over 3<br/>blood tests</p>                                                                                               | <p>97% of parents endorsed an authoritative<br/>parenting style and 3% endorsed a<br/>permissive parenting style.<br/>Authoritative scores were dichotomized to<br/>represent high and low scores.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

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| <b>(2012).<br/>USA.</b>                                                                               | 64%<br>Caucasian<br>21%<br>African<br>American<br>5%<br>Latino<br>10%<br>Other                                | Grand-<br>mother<br>= 1                                         | (mean duration =<br>3.42 years)<br><br>Mean HbA1C =<br>7.96           | SCI                 | <u>Glycaemic control</u><br>- Analyses of covariance<br>No significant differences were found between parents reporting higher levels of authoritative parenting behaviours and parents reporting lower levels of authoritative parenting behaviours with regards to glycaemic control.<br><br><u>Adherence</u><br>- Analyses of covariance<br>Parents reporting higher levels of authoritative parenting behaviours reported that their child engaged in more self-care behaviours than parents who reported less authoritative parenting behaviours (p<0.01). |                                                      |                                                                                                                                                                                                            |
| <b>13.<br/>Jubber,<br/>Roper,<br/>Yorgansen,<br/>Poulsen, &amp;<br/>Mandleco<br/>(2013).<br/>USA.</b> | n = 85<br>M = 36<br>F = 49<br><br>Aged 8-18<br>years<br>(mean age<br>=12.6<br>years).<br><br>96%<br>Caucasian | n = 85<br><br>Mixed<br>sample<br>of<br>mothers<br>&<br>fathers. | DM1<br><br>Mean duration =<br>4.69 years<br><br>Mean HbA1c =<br>7.94% | Cross-<br>sectional | 16-item<br>adaptation<br>of<br>Barber's<br>(1996)<br>psychologi<br>cal<br>control.                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Mean<br>HbA1C<br>over 4<br>recent<br>blood<br>tests. | <u>Glycaemic control</u><br>- Correlational<br>A significant association between poor glycaemic control and parent-reports of paternal (but not maternal) use of psychological control was found (p<0.01). |
| <b>14.</b>                                                                                            | n = 137<br>M = 46                                                                                             | n = 137                                                         | DM2                                                                   | Particip-<br>ants   | Modified<br>version of                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | Medicatio<br>n                                       | <u>Adherence</u>                                                                                                                                                                                           |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                                                      |                                                                                                                    |                                   |                               |                                                                             |                                |                                                                                          |                                                                                                                                                                                                                                                                |
|----------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|-----------------------------------|-------------------------------|-----------------------------------------------------------------------------|--------------------------------|------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Saletsky, Trief, Anderson, Rosenbaum, &amp; Weinstock (2014).</b> | F = 91<br>Aged 10-17 years (mean age = 14.5 years).                                                                | Mixed sample of mothers & fathers | Duration of less than 2 years | enrolled in the TODAY trial.<br><br>Baseline, 6 month & 12 month follow-up. | the Behavioural Autonomy Scale | adherence determined by nurses counting pills in blister packs over two 3-month periods. | - Multivariate analysis of covariance (ANCOVA).<br>Controlling for demographic variables and baseline levels of adherence, child-reports but not parent-proxy reports of permissive parenting was a significant predictor of medication adherence at 6 months. |
| <b>USA.</b>                                                          | 34%<br>Hispanic American<br>30%<br>African American<br>22%<br>White<br>12%<br>Native American<br>2% Asian American |                                   |                               |                                                                             |                                |                                                                                          |                                                                                                                                                                                                                                                                |

*Note.* M, Male; F, Female; T1D, Type 1 Diabetes; T2D, Type 2 Diabetes; HbA1C, glycated haemoglobin levels; SCI, Self-Care Inventory; PSDQ, Parenting Styles and Dimensions Questionnaire; PDI, The Parenting Dimensions Inventory; PedsQL 3.0 type 1 diabetes, The Pediatric Quality of Life; APQ, Alabama Parenting Questionnaire; CBCL, Child Behaviour Checklist; YSR, Youth Self-Report; PPS, Parent Protection Scale; CDI, The Children's Depression Inventory; CRPBI, Child-Report of Parent Behavior Inventory; PRPBI, Parent-Report of Parent Behavior Inventory; CDI, Children's Depression Inventory; PedsQL, Pediatric Quality of Life Generic Core 3.0 type 1 diabetes; PedsQL, DM, Pediatric Quality of Life Diabetes Module; DQOL, Diabetes Quality Of Life Scale; IFIRS, The Iowa Family Interaction Scales; PedsQL, Pediatric Quality of Life Inventory; PBI, Parental Bonding Instrument; DQOL-Y, Diabetes Quality of Life Questionnaire modified for Youths; CHQ-CF87, Child Health Questionnaire; TODAY, Adolescents and Youth trial.

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

**Table 2.***Summary of parenting measures.*

| Study                            | Parenting measure                                   | Constructs measured       | Internal consistency using Cronbach's alpha                         | Informant |        |           |       |
|----------------------------------|-----------------------------------------------------|---------------------------|---------------------------------------------------------------------|-----------|--------|-----------|-------|
|                                  |                                                     |                           |                                                                     | Mother    | Father | Caregiver | Child |
| <b>1. Davis et al. (2001).</b>   | The Parenting Dimensions Inventory (PDI).           | - Warmth                  | $\alpha = 0.85$                                                     | X         | X      |           |       |
|                                  |                                                     | - Restrictiveness         | $\alpha = 0.72$                                                     |           |        |           |       |
|                                  |                                                     | - Amount of control       | $\alpha = 0.61$                                                     |           |        |           |       |
|                                  |                                                     | - Physical punishment     | $\alpha = 0.85$                                                     |           |        |           |       |
| <b>2. Mullins et al. (2004).</b> | Parent Protection Scale (PPS).                      | - Parental Overprotection | $\alpha = 0.69$                                                     | X         |        |           |       |
| <b>3. Graue et al. (2005).</b>   | The Parental Bonding Instrument (PBI).              | - Control                 | $\alpha = 0.63$                                                     |           |        |           | X     |
|                                  |                                                     | - Care                    | $\alpha = 0.75$                                                     |           |        |           |       |
|                                  | The Parental Involvement Scale.                     | - Parental Involvement    | $\alpha = 0.88$                                                     |           |        |           | X     |
| <b>4. Butler et al. (2007).</b>  | Child-Report of Parent Behavior Inventory (CRPBI).  | - Psychological control   | $\alpha = 0.90$ (child version)<br>$\alpha = 0.90$ (parent version) |           |        |           | X     |
|                                  |                                                     | - Firm control            | $\alpha = 0.81$ (child version)<br>$\alpha = 0.81$ (parent version) |           |        |           |       |
|                                  | Parent-Report of Parent Behavior Inventory (PRPBI). | - Acceptance              | $\alpha = 0.93$ (child version)<br>$\alpha = 0.77$ (parent version) | X         |        |           |       |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                                |                                           |                                                                      |                                                                                                                                                                            |   |   |   |   |
|------------------------------------------------|-------------------------------------------|----------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|---|---|---|
| 5.<br><b>Bourdeau et al. (2007).</b>           | Parent Protection Scale (PPS).            | - Parental overprotection                                            | $\alpha = 0.61$                                                                                                                                                            | X | X |   |   |
| 6.<br><b>Botello-Harbaum et al. (2008).</b>    | Authoritative Parenting Index.            | - Responsiveness<br>- Demandingness                                  | $\alpha = 0.88$ (Baseline & 12 months)<br>$\alpha = 0.67$ (Baseline)<br>$\alpha = 0.66$ (12 months)                                                                        |   |   |   | X |
| 7.<br><b>Sherifali et al. (2009).</b>          | The Parenting Dimensions Inventory (PDI). | - Support<br>- Control<br>- Structure                                | (Overall internal consistency)<br>$\alpha = 0.56 - 0.79$                                                                                                                   | X | X |   |   |
| 8.<br><b>Weissberg-Benchell et al. (2009).</b> | Authoritative Parenting Index.            | - Responsiveness<br>- Demandingness                                  | $\alpha = 0.76$<br>$\alpha = 0.67$                                                                                                                                         |   |   |   | X |
|                                                | Psychological Control scale.              | - Psychological control                                              | $\alpha = 0.70$                                                                                                                                                            |   |   |   | X |
|                                                | Parental Authority.                       | - Parental Authority                                                 | $\alpha = 0.76$ (child version)<br>$\alpha = 0.84$ (parent version)                                                                                                        | X | X | X | X |
| 9.<br><b>Greene et al. (2010).</b>             | 62-item Parenting Practices Report.       | - Authoritative style<br>- Authoritarian style<br>- Permissive style | $\alpha = 0.91$ (mothers)<br>$\alpha = 0.88$ (fathers)<br>$\alpha = 0.87$ (mothers)<br>$\alpha = 0.86$ (fathers)<br>$\alpha = 0.75$ (mothers)<br>$\alpha = 0.75$ (fathers) | X | X |   |   |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                             |                                                        |                                                                      |                                                        |   |   |   |
|---------------------------------------------|--------------------------------------------------------|----------------------------------------------------------------------|--------------------------------------------------------|---|---|---|
| <b>10.<br/>Eckshtain et al.<br/>(2010).</b> | Alabama Parenting Questionnaire (APQ).                 | - Poor monitoring<br>- Involvement<br>- Inconsistent discipline      | $\alpha = 0.81$<br>$\alpha = 0.51$<br>$\alpha = 0.65$  | X | X |   |
| <b>11.<br/>Shorer et al.<br/>(2011).</b>    | Parental Authority Questionnaire.                      | - Authoritative style<br>- Authoritarian style<br>- Permissive style | Internal consistency not reported.                     | X | X |   |
| <b>12.<br/>Monaghan et al.<br/>(2012).</b>  | Parenting Styles and Dimensions Questionnaire. (PSDQ). | - Authoritative style<br>- Authoritarian style<br>- Permissive style | $\alpha = 0.84$<br>$\alpha = 0.70$<br>$\alpha = 0.74$  | X | X | X |
| <b>13.<br/>Jubber et al.<br/>(2013).</b>    | Psychological Control scale.                           | - Psychological control                                              | $\alpha = 0.78$ (mothers)<br>$\alpha = 0.81$ (fathers) | X | X |   |
| <b>14.<br/>Saletsky et al.<br/>(2014).</b>  | Behavioural Autonomy Scale                             | - Authoritative style<br>- Authoritarian style<br>- Permissive style | (Overall internal consistency)<br>$\alpha = 0.78$      | X | X | X |



## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

**Table 3.***Summary of outcome measures.*

| Study                           | Outcome measure                                             | Constructs measured | Internal consistency using Cronbach's alpha   | Informant |        |           |       |
|---------------------------------|-------------------------------------------------------------|---------------------|-----------------------------------------------|-----------|--------|-----------|-------|
|                                 |                                                             |                     |                                               | Mother    | Father | Caregiver | Child |
| 1.<br>Davis et al.<br>(2001).   | Mean HbA1C over 2 blood tests.                              | Glycaemic control   |                                               |           |        |           |       |
|                                 | Self-Care Instrument (SCI).                                 | Regimen Adherence   | $\alpha = 0.79$                               | X         | X      |           |       |
| 2.<br>Mullins et al.<br>(2004). | Children's Depression Inventory (CDI).                      | Depressive symptoms | $\alpha = 0.83$                               |           |        |           | X     |
| 3.<br>Graue et al.<br>(2005).   | HbA1C in recent blood test                                  | Glycaemic control   |                                               |           |        |           |       |
|                                 | Diabetes Quality of Life Questionnaire modified for Youths. | DRQOL               | Subscales range<br>$\alpha = 0.88-0.92$       |           |        |           | X     |
|                                 | Child Health Questionnaire (CHQ-CF87).                      | Mental Health       | Subscales ranged from<br>$\alpha = 0.80-0.94$ |           |        |           | X     |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

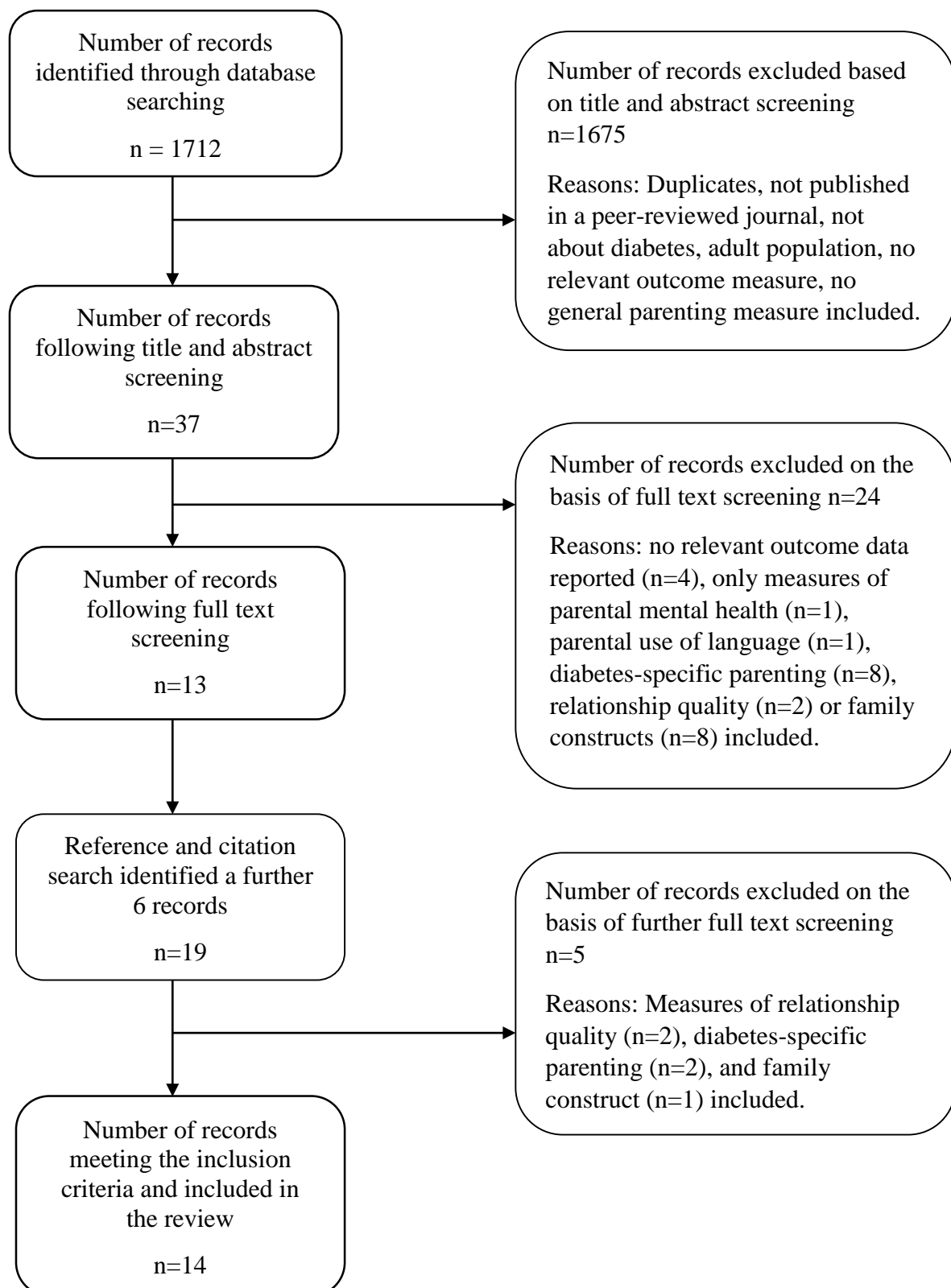
|                                             |                                                        |                     |                                                                             |   |   |   |
|---------------------------------------------|--------------------------------------------------------|---------------------|-----------------------------------------------------------------------------|---|---|---|
| <b>4. Butler et al. (2007).</b>             | Children's Depression Inventory (CDI).                 | Depressive symptoms | $\alpha = 0.90$                                                             |   |   | X |
|                                             | Self-Care Instrument (SCI).                            | Regimen Adherence   | $\alpha = 0.73$                                                             |   |   | X |
| <b>5. Bourdeau et al. (2007).</b>           | Self-Care Instrument (SCI).                            | Regimen Adherence   | $\alpha = 0.80$                                                             | X | X | X |
| <b>6. Botello-Harbaum et al. (2008).</b>    | Diabetes-related Quality of Life (DQOL).               | DRQOL               | $\alpha = 0.75$ (Baseline)<br>$\alpha = 0.81$ (12 months)                   |   |   | X |
| <b>7. Sherifali et al. (2009).</b>          | HbA1C during previous 3-4 months.                      | Glycaemic control   |                                                                             |   |   |   |
|                                             | Pediatric Quality of Life Diabetes Module (PedsQL, DM) | DRQOL               | $\alpha = 0.63-0.88$ (child report)<br>$\alpha = 0.68-0.89$ (parent-report) | X | X | X |
| <b>8. Weissberg-Benchell et al. (2009).</b> | Pediatric Quality of Life Generic Code (PedsQL).       | HRQOL               | $\alpha = 0.88$ (parent & child report)                                     | X | X | X |
|                                             | Pediatric Quality of Life                              | DRQOL               | $\alpha = 0.87$ (parent & child report)                                     | X | X | X |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

| Diabetes Module (PedsQL, DM).       |                                           |                      |                 |   |   |   |
|-------------------------------------|-------------------------------------------|----------------------|-----------------|---|---|---|
| <b>9. Greene et al. (2010).</b>     | Mean HbA1C over 4 blood tests.            | Glycaemic control    |                 |   |   |   |
|                                     | Self-Care Instrument (SCI).               | Regimen Adherence    | $\alpha = 0.79$ |   |   | X |
| <b>10. Eckshtain et al. (2010).</b> | HbA1C in most recent blood test.          | Glycaemic control    |                 |   |   |   |
|                                     | Child Behaviour Checklist (CBCL).         | Depressive symptoms. | Not reported.   | X | X |   |
|                                     | Youth Self Report (YSR).                  | Depressive symptoms  | Not reported.   |   |   | X |
| <b>11. Shorer et al. (2011).</b>    | Mean HbA1C over 1 year period.            | Glycaemic control    |                 |   |   |   |
|                                     | Diabetes Treatment Regimen Questionnaire. | Adherence            | Not reported.   | X | X | X |
| <b>12. Monaghan et al. (2012).</b>  | Mean HbA1C over 3 blood tests             | Glycaemic control    |                 |   |   |   |

## ASSOCIATION BETWEEN PARENTING AND HEALTH-RELATED OUTCOMES

|                                                        |                                                                                                         |                   |                         |   |   |   |
|--------------------------------------------------------|---------------------------------------------------------------------------------------------------------|-------------------|-------------------------|---|---|---|
|                                                        | Self-Care Instrument (SCI).                                                                             | Adherence         | $\alpha = 0.79$         | X | X | X |
| <b>13.</b><br><b>Jubber et al.</b><br><b>(2013).</b>   | Mean HbA1C over 4 recent blood tests.                                                                   | Glycaemic control |                         |   |   |   |
| <b>14.</b><br><b>Saletsky et al.</b><br><b>(2014).</b> | Medication adherence was determined by nurses counting pills in blister packs over two 3-month periods. | Adherence         | Could not be conducted. |   |   |   |



**Figure 1.** Study selection.

### **Section 3**

#### **Empirical paper**

# Journal of Clinical Psychology

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**Living in Conflict:**

**Adolescents' experiences of living with diabetes mellitus and poor glycaemic control**

**Short Title:** Experiences of poor glycaemic control

**Key words:** adolescent, experiences, diabetes, poor glycaemic control, qualitative

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## **Abstract**

### **Objectives**

The aim of the study was to explore adolescents' experiences of having diabetes mellitus (DM1) and poor glycaemic control.

### **Methods**

Six adolescents aged 12-17 years undertook individual semi-structured interviews.

Transcripts were analysed according to the principles of Interpretative Phenomenological Analysis (IPA).

### **Results**

Participants described numerous intrapersonal and interpersonal conflicts as they struggled to accept and manage their diabetes. Participants described feelings of guilt and shame when their poor glycaemic control was exposed in the diabetes clinic. However, improvements in their glycaemic control were always short-lived, with participants struggling to maintain a regime. A cyclical pattern of deteriorating and improving glycaemic control was therefore described.

### **Conclusions**

The impact of poor glycaemic control on the identities and relationships of these participants highlighted the need for further research. The clinical implications suggest the possible effectiveness of acceptance-based interventions and the potential benefits of developing training for healthcare professionals working with these adolescents.

## Introduction

Diabetes Mellitus (DM1) or Type I Diabetes is a chronic and life-threatening disease whereby the immune system destroys the cells which produce insulin. As insulin is a hormone which regulates the body's blood glucose levels, successfully managing DM1 requires individuals to manage their blood glucose levels by following a complex daily regime, which often involves coordinating insulin injections, monitoring blood glucose levels and managing diet and exercise levels (NICE guidelines, 2004).

The incidence of DM1 has increased five-fold over the past sixty years and has been described as a 'global epidemic' (Tuomilheto, 2013) with more than 24 per 100,000 children aged 14 years or younger in the UK receiving a diagnosis every year (International Diabetes Federation, 2011). To reduce the likelihood of children and adolescents developing serious health complications, the National Institute for Health and Clinical Excellence (NICE) recommend that glycated haemoglobin levels (HbA1C) of under 7.5% (58 mmol/mol) should be maintained (NICE Guidelines, 2004).

The life expectancy of individuals with DM1 is reduced on average by 23 years as having poor glycaemic control contributes to the development of serious health problems such as kidney disease, blindness, and cardiovascular disease (Department of Health, 2007). Furthermore, poor glycaemic control is associated with increased rates of depression, anxiety disorders and eating disorders (Hood et al., 2006; Anderson et al., 2002; Rodin et al., 2002). It is therefore recommended that adolescents with DM1 should have "timely and on-going access to mental health professionals" (NICE guidelines, 2004, p32) and that clinical psychologists should be an integrated part of diabetes care teams (Leichter, Dreelin & Moore, 2004).

Evidence suggests that adolescence is a crucial time for individuals with DM1 as they not only have to manage the physiological, psychological and social changes of adolescence, but they also take increasing responsibility from caregivers for adhering to their diabetes regimes. Evidence also suggests that adherence to diabetes regimes deteriorates during adolescence which negatively affects glycaemic control (Rausch et al., 2012). This deterioration has been associated with factors such as increased family conflict and stressful life events (Helgeson, Escobar, Siminerio & Becker, 2010).

Qualitative methodologies are increasingly being utilized to examine factors that may influence the management of diabetes among adolescents with DM1. A systematic review of this qualitative literature was undertaken by Spencer, Cooper and Milton (2010) which indicated that intrusive parental input and peer difficulties inhibited the development of successful diabetes management whilst increased parental support facilitated this process. However, limitations were identified as only six of the twenty studies reviewed explicitly stated an epistemological viewpoint and only three applied a theoretical framework. Furthermore, whereas eighteen studies were conducted in the USA, only one study was conducted in the UK (Waller, Eiser, Heller & Knowles, & Price, 2005) thus indicating that the experiences of adolescents in other countries remain largely unexplored.

It is also important to highlight that whilst three studies have specifically compared the experiences of adolescents with varying degrees of adherence to their diabetes regimes (Kyngas & Hentinen, 1995; Kyngas, Hentinen, & Barlow, 1998; Williams, 1999), only three studies have explicitly examined the experiences of adolescents with poor glycaemic control (defined as HbA1c  $\geq$ 8.0%; Carcone, Ellis, & Naar-King, 2012).

Leanord, Garwick and Adwan (2005) interviewed adolescents aged 14-16 years regarding the role of their parents in their diabetes management. Content analysis revealed

that adolescents considered their parents' involvement to be annoying, which resulted in increased conflicts. A second study recorded the sessions of a coping skills group attended by adolescents aged 13-17 years and conducted a content analysis. The main findings indicated that adolescents wanted "individualised and non-judgemental care from parents and health care professionals" (Davidson, Penney, Muller, & Grey, 2004, p72). Finally Schur, Gamsu and Barley (1999) examined the experiences of adolescents and young adults (aged 16-22 years) of living and coping with DM1. Using Interpretative Phenomenological Analysis (IPA; Smith, 1996) it was identified that participants felt different from their peers and feared that diabetes would overwhelm them. Despite this, none of these studies explicitly asked participants about having poor glycaemic control and how this may have affected their lives.

The aim of the present study was therefore to examine the experiences of adolescents aged 12-17 years of having DM1 and poor glycaemic control. The study also aimed to examine whether having poor glycaemic control affected adolescents' sense of self and relationships with others. To the authors' knowledge, this is the first study to address this research objective, and therefore a qualitative methodology was chosen.

## **Method**

### **Participants**

Participants were six adolescents recruited from a hospital-based paediatric service between July 2013 and January 2014. All participants met the following inclusion criteria.

1. Aged 12-17 years.
2. Adolescents with a diagnosis of DM1 for a minimum of 1 year.



3. Adolescents identified as having poor glycaemic control. This was defined as having average glycated haemoglobin levels (HbA1c) of  $\geq 8.0\%$  (expressed in the UK as 64 mmol/mol) over their two most recent blood tests at the time of recruitment. This measurement gives an average of a person's glycated haemoglobin levels over a period of approximately three months.

As a fairly homogeneous sample is sought when conducting IPA (Smith, Flower, & Larkin, 2009), the exclusion criteria included adolescents with learning disabilities. Adolescents with 'insulin pumps' to administer medications were also excluded as their diabetes management and routines are different to those who inject insulin. Table 1 details participants' demographic data.

*[INSERT TABLE 1]*

## **Procedure**

Ethical approval was granted by Bangor University School of Psychology Ethics Committee (see Appendix 5A). NHS research approval and Research and Development approval was also granted by the relevant organisation (see Appendix 5A).

Clinicians working in a hospital-based paediatric service, were provided with a 'Participant Recruitment Information Sheet' (see Appendix 5B), outlining the study rationale and inclusion criteria. Clinicians were asked to give eligible adolescents and their guardian an information pack (see Appendix 5B) containing a 'Participant Information Sheet', a 'Parent/guardian information sheet' and an 'Opt-In form'. Adolescents and their guardian were asked to complete the opt-in form, if they wanted the primary researcher to contact them via telephone to answer questions and possibly arrange an interview.

On receipt of the Opt-in form, telephone contact was made by the primary researcher and interviews arranged. Prior to the interviews, written consent was provided by all participants on a 'Participant Consent Form' (see Appendix 5B) and written assent was provided by guardians on a 'Parent/guardian Assent Form' (see Appendix 5B).

### **Semi-Structured Interviews**

Individual semi-structured interviews were conducted by the primary researcher (L.G.). The interviews were audio-recorded, transcribed and analysed consecutively. As recommended by Smith and Osbourne (2008) the interviews were guided by an interview schedule (see Appendix 5B) developed with the research team. The interview schedule focused on participants' experiences of managing their diabetes, and whether their poor glycaemic control affected their sense of self and relationships with others.

All participants received a £5 gift voucher as a thank you for participating. Three participants chose to be interviewed in the hospital and three chose to be interviewed at home. Three participants chose to conduct the interview in English and three participants chose to conduct the interview in Welsh. The translation of the Welsh transcripts into English was undertaken by the primary researcher, which further enabled the researcher to become immersed in the data. Review articles examining translation issues in qualitative research have identified that researchers who complete the translation of transcripts themselves are provided with "significant opportunities for close attention to cross cultural meanings and interpretations and potentially brings the researcher up close to the problems of meaning equivalence within the research process" (Temple & Young, 2004, p168.). The lack of "one to one relationship between language and meaning" (Temple & Young, 2004, p168.) was therefore openly acknowledged and the researcher endeavoured to translate the transcripts to accurately reflect the meanings and interpretations made by participants.

### **Study design**

Interpretative Phenomenological Analysis (IPA) was chosen as the most appropriate qualitative methodology as it views individuals as experts of their own experience and allows in-depth examination of how people make sense of their personal worlds (Smith, Flowers & Larkin, 2009).

It is important to note that IPA is concerned with phenomenology, and therefore with personal or subjective accounts of events rather than pursuing objective truths (Smith & Osborn, 2008). Furthermore, as hermeneutics, the theory of interpretation, is an important theoretical underpinning of IPA, the dynamic nature of research is openly recognised. Within IPA, the researcher is engaged in a 'double hermeneutic' as "participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2008, p53).

Another important facet of IPA is idiography, as detailed analysis of the phenomenology of a fairly homogenous group of people is undertaken (Smith, Flowers & Larkin, 2009). Although generalizations are thus made cautiously, IPA has particular relevance to health psychology, as there is a growing recognition of the constructed nature of illness (Brocki & Wearden, 2005).

### **Data Analysis**

The transcription, translation and analysis of the interviews were undertaken consecutively. The interviews were therefore read and re-read several times enabling the researcher to become immersed in the data. As recommended by Smith, Flower and Larkin (2009), line-by-line analysis of the interviews was undertaken making descriptive, linguistic and conceptual comments, which enabled more abstract concepts to be identified. These concepts were then continuously compared to develop emergent themes. Through a

subsequent process of abstraction, where areas of commonality and divergence both within and between transcripts were examined, super-ordinate themes were developed.

The quality and validity of the data analysis was guided by the frameworks outlined by Yardley (2008) and Elliot et al. (1999). The researcher's subjective recollections and perspectives were noted following each interview and efforts were made to bracket these to reduce subjectivity and allow the researcher to focus on the original data. Initial transcripts were also analysed simultaneously by another member of the research team (R.R.) who also examined the researcher's initial comments and themes to check their validity in relation to the transcripts (see Appendix 5C for a section of an annotated transcript).

## **Results**

Four super-ordinate themes emerged from the analysis; 'impact on self', 'the social self', 'the self and relationships' and 'the cyclical nature of glycaemic control', which are summarized in Table 2. Pseudonyms have been used to denote the quotations.

*[INSERT TABLE 2]*

### **Theme 1: Impact on self**

Many participants described experiencing a fragmentation of their sense of self as a result of having diabetes. This may be particularly salient during adolescence as this is a period when the sense of self is being developed (Blasi & Milton, 1991). Participants described struggling to establish a firm sense of self as they oscillated between rejecting their diabetes and subsequently having poor glycaemic control, to then wanting to adhere to their regimes and having improved glycaemic control. This is illustrated in a passage from Chloe who described that the intensity of this internal struggle resulted in a splitting of the self.

*“Sometimes it seems like there’s two different people... like I’m angry at myself and then I’m angry at this... other per, other Chloe who’s got diabetes... and... it’s like it’s weird... cos I don’t want it I split like myself in two... and like sometimes... we both merge together and that’s when my diabetes is really, really good” Chloe*

In this extract Chloe described how having diabetes at times, felt like it divided her into two different people. She described how the opposing selves merged, when her glycaemic control was ‘good’, indicating that having poor glycaemic control may be pivotal when she feels split in two. In the following extract Chloe appeared confused as she described trying to preserve an identity, which was not dominated by her diabetes.

*“It’s like the defining factor of me... and I just don’t, I want it to be the opposite way around, I want me to be the defining factor of me rather than the... diabetes” Chloe*

This is similar to the following passage from Shaun, who rejected that diabetes was part of his identity and referred to it as something separate from himself. However, Shaun also acknowledges that he becomes more irritable when he has high blood glucose levels, which ‘turns’ him into a person who others dislike.

*“Diabetes is nothing on my personality or whatever I am... Unless I am unless, unless I am a bit high... and which I turn into a... person you can’t stand” Shaun*

Many participants appeared to wrestle with the fact that having poor glycaemic control negatively impacted on their mood and behaviour, as highlighted in the following passage from Lucy.

*“I get angry when I’m high... And... pretty dopey when I’m low... Just like I get confused” Lucy*

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In fact, all participants described how difficult it was to oscillate between having high and low blood glucose levels with many appearing to struggle to make sense of their identities and sense of selves when embroiled in these opposing states. This is highlighted in the following quote from Chloe, who describes that the anger she directs towards her diabetes becomes directed towards herself.

*“Like I become more angry at, like at the other side of me... but then... it's the same person, like when I'm angry at the diabetes I'm angry at me...umm... and it's confusing” Chloe*

In addition to anger, four participants described struggling with feelings of guilt and shame, which resulted in them feeling angry and scolding themselves when their health deteriorated and their poor glycaemic control was exposed to healthcare professionals or parents.

*“You feel bad about yourself cos you really want to try your best with it but like... sometimes it's like stuff it doesn't matter but then thinking about it properly you have to control it right or you'll get ill” Lucy*

*“I get angry with myself again then cos... I know I need to do better sometimes like now I get I'm high a lot” Sarah*

Building on the feelings of guilt and shame, three participants went on to make more global negative evaluations about themselves, describing themselves as 'pathetic', 'horrible' and 'childish'. It is therefore important to consider the detrimental effect these negative beliefs could have on the developing self-esteem and forming identities of these adolescents as they transition into adulthood.

*“I'm not strong enough and stuff to like battle myself like... So it makes me feel like I'm a weak person... because I've been ill and I can't make myself better” Amy*

*“I feel umm disappointed in myself... like I’m a like not a poor excuse of a person, but just a weak person... like the motivation to be healthy should be enough for someone to just do their injections every single day... and look after themselves... it’s like I’m, it’s stupid, I feel stupid in myself” Chloe*

It is also important to note that whilst participants described feeling extremely negative about themselves, this was juxtaposed with four participants imagining having a more positive self-concept if their glycaemic control were to improve. This highlighted the importance placed by participants on their glycaemic control and the effect this had on their sense of self and self-worth as well as a direct impact on their mood.

*“I’m sure I’d feel better as a... person or how I am like with my moods and stuff”*

*Sarah*

## **Theme 2: The social self**

The difficult feelings described by participants regarding their sense of self was particularly acute in the context of their social worlds. A struggle was described between feeling ‘different’ yet wanting to be ‘normal’ with their peers. This struggle is captured in the following extracts with Lucy listing how diabetes made her feel different. Furthermore, both male and female participants described how diabetes affected their appearance.

*“I’ve got a lot of bruises... on my arms and legs... the fact that I have to do it, the fact I have to... carry a bag, the fact that I can’t eat whatever I want like everyone else... or I can’t go drinking or go to a party or something... generally everything about it” Lucy*

*“Just the... look of the whole thing like marks on my tummy, marks on my legs and that, and I felt like... not a normal 14 year old girl” Amy*

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Two participants described that having diabetes and not being 'normal' was 'embarrassing' and a reason for them not to follow their diabetes regime.

*"With the pressure of school and everything I just like give up, wanted to be like everyone else like didn't want to do injections, didn't want to check my blood so I just left it and didn't do it but I told everyone that I was doing it... So I was like faking everything" Amy*

Two participants spoke of how diabetes had stolen their ability to have a 'normal' adolescence and that by rejecting their regimes they attempted to reclaim their 'normality'. Furthermore, five participants emphasised the importance of their peer relationships with Lucy describing worrying more about not being able to socialize with friends than dying as a result of her poor glycaemic control.

*"I was actually scared that I was going to die... but the thing is I panic more about not being able to do things everyone else can do... with my friends and that" Lucy*

Similarly, in the following extract Sarah describes being more concerned with the wishes of her peer group rather than her deteriorating glycaemic control. Indeed, due to her diabetes Sarah was allowed to have one friend accompany her to have 'early lunch' in school. However, despite knowing that her blood sugar levels were too low and feeling as though she may develop hypoglycaemia, she would often wait for her friends to decide who would accompany her rather than eating immediately.

*"It takes at least 5 minutes for them to decide even though they know that I'm hypo... so I start feeling worse... I start to panic and I start to cry" Sarah*

A fear of being perceived negatively by her peers resulted in Sarah neglecting her own needs. Several participants described being concerned with what other people thought of



them and compared themselves unfavourably with others. Three participants spoke of having a negative sense of self at a wider societal level.

*“Cos well I’m a hindrance to the NHS... I’m a waste of tax... payers money” Shaun*

*“Like I’ve been like a horrible person, and like I feel sick with myself like how can you be making yourself ill... when there’s so many people out there who are really, really ill, like people with terminal cancer or like people in Africa who have no food and water... but I’ve got the opportunity to... make myself better... and to be healthy... and like they don’t have no chance at all but I do” Chloe*

### **Theme 3: The self and relationships**

All participants described how having poor glycaemic control negatively impacted on their relationships with parents or healthcare professionals. Indeed, all participants described having conflicts with their mothers, who encouraged them to improve their glycaemic control. For example, in the extract below Ben describes arguing with his mother about his blood sugar readings.

*“Basically she says my numbers which I don’t agree with and she goes I don’t even know why I bother helping you [laugh] ... Cos I always say no to everything... she says” Ben*

Whilst many adolescents described not wanting help or input from family members, they also recognised that they found the help useful. This highlighted that these participants were very much in transition between childhood and adulthood as they grappled between wanting to elicit care from parents, enjoying being ‘looked after’ and also wanting to be independent.

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*"I don't like that they're constantly on me like do this do that but also I need them there to check" Amy*

In response to their parents' questions and to avoid getting into trouble two participants described frequently lying to their parents about their adherence behaviours including their diet, insulin injections and blood glucose testing.

*"Mum was like, or she'd ask when I get home, 'have you done the injection?' 'Yes'... it's just easy to say it" Amy*

*"I lie... but I think that's the worst thing you can do 'cos you just get into lies... like one big lie and you can't get out of it... So it sort of becomes a habit that I lie every time my blood isn't right" Lucy*

Participants described that lying to their parents resulted in both inter-personal and intra-personal conflicts as they argued with their parents alongside feeling extremely guilty as they believed their parents no longer trusted them. It is therefore important to consider not only the effect these behaviours had on their relationships but also on the way the participants viewed themselves and their roles within relationships.

*"I remember going to bed at night and... I couldn't sleep and I'd lie there for ages and think about everything I'd done and that I'd lied and just feel really bad about yourself and everything you've done" Lucy*

*"I felt awful because I was... like really upset and that because I felt like I had betrayed them kind of thing... Because with me doing everything wrong and that... because they trusted me to... do it myself" Amy*

Participants described times when they were overwhelmed by feelings of guilt and shame about how their lies and poor glycaemic control effected family members.

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Furthermore, participants recognised that it was the consistency with which they told small lies that corroded their relationships in the longer term.

*"I say sorry so often to them and like they don't think I mean it" Sarah*

Similar to the feelings of guilt evoked when participants concealed the truth from their parents, many described intense feelings of shame when attending the diabetes clinic as the 'truth' about their lack of adherence behaviours was revealed. Whilst some participants considered health professionals to be helpful, many described being criticised by them as 'too much'. Furthermore, three participants believed that health professionals were angry with them, but were disingenuous in trying to conceal their true feelings and 'act ok about it'.

*"It was just like how they spoke to me... they were like dismissive and... they'd always see like the negative... side of things rather than the what I'm doing... good"*

*Chloe*

*"They don't give me a row but you feel the way they speak to you, you can just tell that they... want to go nuts with you type of thing" Lucy*

It is important to consider whether these evaluations were accurate or whether the participants were projecting their negative evaluations of themselves onto professionals. In the following quotes Shaun and Chloe emphasise that as it was the professionals 'job' to care for them, thus indicating that professionals' did not understand the burdensomeness of diabetes as they were not diabetic themselves; evoking a sense of isolation and difference.

*"It's her job... That's generally how I feel towards her" Shaun*

*"Doctors who haven't got it, it's like... they come into clinic and they think I'll tell you this and you're not doing well, you're not injecting... and they can just walk out of clinic and they're like... they're fine... it's like their job" Chloe*

Shaun's lack of identification with professionals led him to ignore the guidance and advice provided.

*"I just sort of sit there and listen, that's my bit... and then I leave... and I don't do anything that she says" Shaun*

In addition to describing difficult relationships with healthcare professionals, many participants described attending clinic as a 'nerve wrecking' experience, because they knew their blood glucose levels would be shared with their parents. As illustrated in the following extracts, three adolescents described experiencing high levels of anxiety prior to attending clinic.

*"It's just like this horrible like sick feeling you get before clinic... and then it feels like... I'm going to let them down, like I don't want to let them down" Chloe*

*"I know that I've been doing my bad habits and it's going to show in clinic like and they'd know the truth and stuff about things... and I just hate saying it" Amy*

These participants described being 'exposed' in the diabetes clinic, indicating that attending was often a shaming experience, resulting in them feeling guilty and bad about themselves. Furthermore, in the following extract Lucy describes that the guilt evoked in clinic was not limited to herself as her mother also felt blamed, which in turn appeared to perpetuate Lucy's sense of guilt.

*"I don't like to go there because... the truth comes out there all of it... If I've lied or something or if the blood's high it makes mum feel rubbish cos she feels to blame"*

*Lucy*

#### **Theme 4: The cyclical nature of glycaemic control**

The final theme represents the constantly changing and cyclical nature of the

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thoughts, feelings, behaviours and glycaemic control of participants. All participants demonstrated knowledge of DM1 and the associated health complications, and initially described being motivated to adhere to their regimes. Furthermore, they described worrying about their futures and the complications associated with poor glycaemic control.

*“Mum warns me a lot cos with my feet and my eyes and that cos there’s damage or something to my eye already... and just with like... my organs and that... If I don’t look after myself it will affect them too” Lucy*

However, although very knowledgeable of the risks involved with non-adherence, participants described that in reality they only managed to adhere to their regimes for short periods of time, before slipping back into poor glycaemic control.

*“I’ll start doing it for like two days and I’ll lose motivation and then about a week later I’ll check again and do it again for like two days” Sarah*

The inability of participants to adhere to their regimes in the long-term appeared to be perpetuated by oscillating between feeling distressed by their poor glycaemic control and then feeling ambivalent about adhering to the regime and ‘giving up’. Perhaps reflecting their developmental stage, five adolescents portrayed a sense of indestructability, rebellion and ambivalence regarding risks, which in turn enabled them to stop adhering to their regimes.

*“I don’t really care what the consequences are at the moment” Shaun*

*“I feel that because I’m diabetic... and I’m not supposed to eat loads of sugar and that, I do eat lots of sugar... Because I know I’m not supposed to, so I do” Amy*

Furthermore, their ambivalence appeared to be reinforced by hidden hopes that a diabetes cure would be found. Three participants fantasised that their diabetes was not real or permanent, which negatively impacted on their adherence behaviours.

*“There’s a part of me like that... that wants to believe that... there will be a cure , it will just magically stop or like it’s not really diabetes, it’s just something... in my pancreas... that’s stopping the insulin... and they just haven’t found it yet... I think that’s a reason for me not wanting to inject... and test because... always think what’s the point putting myself through this... if I don’t have it” Chloe*

*“Well I don’t know how long it will take them or if they are going to find a cure for it... I’d like them to find it before I sort of grow up” Lucy*

Ambivalence regarding the need for adherence resulted in non-adherence in the short-term. However, non-adherence was not sustainable in the long-term due to deteriorating glycaemic control and the resurfacing of associated feelings of guilt, thus resulting in a cyclical pattern of deteriorating and improving glycaemic control. Perhaps being ambivalent initially served as a buffer which protected participants from their self-critical thoughts. It is also important to consider whether the ambivalence served as a façade enabling participants to hide their difficult feelings from others. Unfortunately, regardless of the function of this ambivalence, it seems that it ultimately deepened the participants’ intra-personal struggles with guilt and shame. Indeed, this indicates that if adolescents were better able to accept their diabetes, their glycaemic control and psychological wellbeing could improve. The oscillating model of glycaemic control captured in this theme is represented diagrammatically in Figure 1.

## **Discussion**

This study aimed to explore adolescents’ experience of living with DM1 and poor glycaemic control. The four superordinate themes indicated that participants struggled to develop a cohesive identity as they attempted to reject their diabetes and associated feelings

of difference and burdensomeness. Participants not only compared themselves unfavourably with others but described overwhelming feelings of guilt and shame when their poor glycaemic control and lies were exposed to parents and health professionals in the diabetes clinic. This led to a cycle of oscillating glycaemic control as the feelings of guilt caused participants to scold themselves and improve their glycaemic control in the short term. However, adhering to the regime quickly became burdensome and participants grew ambivalent, thus resulting in deteriorating glycaemic control.

### **Comparisons With Published Literature**

Some of the themes identified are consistent with existing literature. For example, studies have identified that adolescents with DM1 struggle with feeling different from peers (Herrman, 2006), having conflicts with parents (Weinger, O'Donnell, & Ritholz, 2001) and having difficult relationships with healthcare professionals (Kyngas, Hentinen, & Barlow, 1998). Adolescents with poor glycaemic control have also described grappling with dilemmas such as whether to tell the truth about their glycaemic control (Davidson, Penney, Muller & Grey, 2004), whilst adolescents with poor adherence to diabetes regimes have described growing accustomed to lying (Kyngas & Hentinen, 1995).

The findings of the current study also expand this literature as the intense feelings of guilt and shame described by adolescents with regards to lying to parents was not previously described. Indeed, although Kyngas and Barlow (1995) identified that feelings of guilt contributed to the development of depressive symptoms for adolescents with DM1, the enduring negative evaluations made regarding the self and the cyclical nature of glycaemic control has not been previously reported.

Attempting to reject diabetes and the associated regime appeared to be an important factor impeding the ability of participants to adhere to their regimes and develop a positive

and coherent sense of self. Conversely, high levels of acceptance have been associated with reduced anxiety, depression and “better emotional, social and physical functioning” (Casier et al., 2013, p1338) for adolescents with various chronic illnesses such as cystic fibrosis (Casier et al., 2011), asthma (Kinter, 2007) and sickle cell disease (Masuda, Cohen, Wicksel, Kemani, & Johnson, 2011). Higher levels of acceptance have also been associated with improved wellbeing (Casier et al., 2013), adherence and adjustment (Graue et al., 2004) for adolescents with DM1.

Further support for the role of acceptance can be found within the qualitative literature as adolescents with DM1, who did not specifically have poor glycaemic control have acknowledged that acceptance of DM1 develops over time (Burke & Dowling, 2007). However, participants in the present study did not describe a linear trajectory of adjustment but rather a continuous struggle, as they oscillated between rejecting their diabetes and having poor glycaemic control to then trying to accept it and having improved glycaemic control. The experiences of participants may therefore be better understood within The Shifting Perspectives model (Paterson, 2001) which stipulates that living with a chronic illness “is an ongoing, continually shifting process in which people experience a complex dialectic between themselves and their ‘world’” (Paterson, 2001, p23). This model therefore advances traditional stage models of adjustment by acknowledging that social and personal contexts influence the shifting perspectives of individuals with chronic illnesses. Indeed, the cyclical model of glycaemic control presented also advances upon current theories by capturing the oscillating nature of glycaemic control for adolescents and the shifting feelings associated with this process.



### **Clinical Implications**

It is important to note that although participants demonstrated good knowledge of DM1 and associated health complications, they continued to struggle with adherence and hence poor glycaemic control. The findings therefore indicate that poor glycaemic control did not arise from a lack of knowledge, but rather from oscillating feelings towards and acceptance of their diabetes. This is consistent with evidence indicating that educational interventions have only yielded low to medium effect sizes with regards to improving the glycaemic control of adolescents with DM1 (Hampson et al., 2001). The importance of acceptance may also provide insight into why only weak evidence supports the effectiveness of psychological interventions such as cognitive-behavioural therapy (CBT), as their focus is on controlling thoughts or eliminating distress rather than encouraging individuals to notice that they are engaged in a futile battle with their experience (Winkley, 2006), and enabling them to move towards acceptance of their diabetes and what this entails.

Over recent years, an emerging evidence base has emphasised the value of applying acceptance-based interventions, such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999). Gregg, Callaghan, Hayes and Glenn-Lawson (2007) conducted a randomized-controlled trial, where adults with type 2 diabetes were assigned to a one day workshop consisting of education alone or a combination of education and ACT. At 3 months follow up, no significant differences were found for individuals in the education intervention. However, at 3 months follow-up the glycaemic control of individuals in the combination workshop significantly improved.

ACT interventions have also provided positive results for adolescents with chronic pain (Wicksell et al., 2007) and sickle cell disease (Masuda et al., 2010), whilst Hadlandsmayth, White, Nesin and Greco (2013) have proposed an ACT intervention for

adolescents with DM1. Although this evidence-base is in its infancy, clinicians should be aware of the growing emphasis placed on acceptance-based interventions, which may in the future enable adolescents to disrupt the cyclical nature of glycaemic control described by participants in this study.

Another important finding is that participants described difficult relationships with healthcare professionals and described that attending the diabetes clinic evoked feelings of anxiety and shame. It is important to consider whether healthcare professionals are aware of the intrapersonal and interpersonal conflicts described by participants. Indeed, perhaps the sense of ambivalence described by participants is more apparent to professionals, which in turn may evoke more negative responses from them. Developing training for clinicians to increase their awareness of the difficulties faced by adolescents, may therefore be helpful in reducing these negative experiences and helping them develop a shared understanding of their patient's difficulties.

Although the mental health of participants in this study was not assessed, participants made global negative self-evaluations as they struggled to develop a coherent identity that incorporated their diabetes. Indeed, evidence suggests that individuals with DM1 who fail to develop a strong identity, have higher levels of depression and diabetes complications during early adulthood (Luyckx et al., 2008). The findings therefore indicate that multi-disciplinary assessments which include screening for mental health problems, may be beneficial for adolescents with DM1 and poor glycaemic control (Delamater, 2009). Within the UK, only about 10% of diabetes care teams regularly screen for psychological problems, whilst only 31.5% of individuals with DM1 have access to specialist psychological provision (Diabetes UK, 2008). This lack of equity across the UK therefore needs to be addressed at a national level to ensure that the psychological wellbeing of adolescents with DM1 is not being overlooked.

### **Limitations**

Due to the qualitative methodology, a small sample size was selected, which limits the generalizability of the findings. However, key themes were described by several participants thus indicating that the findings may have wider applicability. A key assumption within IPA is that participants are able to clearly articulate their thoughts regarding a key phenomenon (Smith & Osborn, 2008). However, it is acknowledged that due to the developmental age of participants and emotive topics discussed, participants may have chosen not to disclose certain experiences or may have struggled to express themselves. Social desirability bias and contextual cues may have also resulted in participants withholding difficult beliefs, especially for those who conducted the interviews in a hospital setting. These factors were addressed by the researcher adopting an open, non-judgemental approach, and the richness of the data suggests that participants were able to meaningfully articulate difficult thoughts and feelings.

### **Future Research**

The experiences of adolescents with DM1 who have poor glycaemic control remains an under-researched phenomenon. Further research is therefore required to determine whether the findings have wider applicability. As adolescents with DM1 and poor glycaemic control have an increased likelihood of developing physiological and psychological difficulties (Delamater, 2009), longitudinal studies examining these factors as individuals' progress through adult services are needed.

Considering the findings indicating that acceptance may be a key factor influencing adolescents' adjustment and adherence to DM1 management, further research is required to examine the effectiveness of acceptance-based interventions such as ACT (Hayes, Strosahl, & Wilson, 1999) in improving the glycaemic control and psychological wellbeing of

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adolescents with DM1. Qualitative studies examining adolescents' experiences of undertaking these interventions would provide insight into how adolescents respond to and evaluate their effectiveness.

Finally, in light of the difficult experiences described by participants with regards to attending the diabetes clinic, establishing the level of psychological provision or training available to diabetes care teams may be useful to establish any gaps in service provision. Undertaking qualitative research with healthcare professionals could also provide insight into how professionals view adolescents with DM1 who have poor glycaemic control, which in turn could inform any training developed for care teams.

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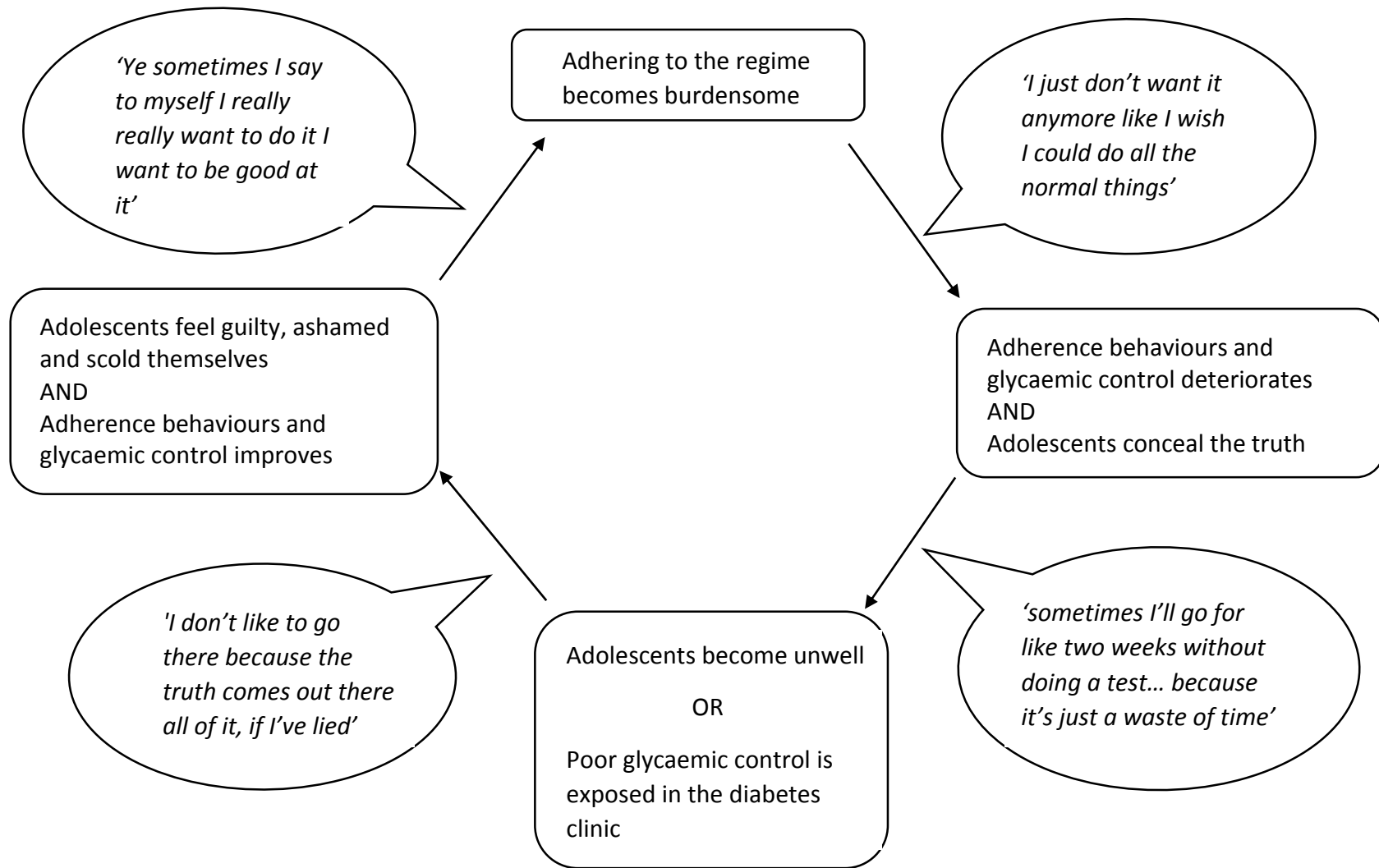
**Table 1.***Demographic profile of interviewed participants.*

| <b>Participant Number</b> | <b>Pseudonym</b> | <b>Gender</b> | <b>Age</b> | <b>Age diagnosed with DM1</b> | <b>Ethnicity</b> | <b>Language completed interview</b> |
|---------------------------|------------------|---------------|------------|-------------------------------|------------------|-------------------------------------|
| <b>P1</b>                 | Shaun            | Male          | 16         | 14                            | White<br>British | English                             |
| <b>P2</b>                 | Ben              | Male          | 13         | 8                             | White<br>British | English                             |
| <b>P3</b>                 | Chloe            | Female        | 17         | 7                             | White<br>British | English                             |
| <b>P4</b>                 | Amy              | Female        | 16         | 10                            | White<br>Welsh   | Welsh                               |
| <b>P5</b>                 | Sarah            | Female        | 14         | 8                             | White<br>Welsh   | Welsh                               |
| <b>P6</b>                 | Lucy             | Female        | 12         | 6                             | White<br>Welsh   | Welsh                               |

**Table 2.***Super-ordinate Themes Following Analysis*

| <b>Super-ordinate theme</b>                        |                                                                           |
|----------------------------------------------------|---------------------------------------------------------------------------|
| <b>1. Impact on self</b>                           | Fragmentation of self                                                     |
|                                                    | Rejecting diabetes                                                        |
|                                                    | Guilt and shame regarding glycaemic control                               |
|                                                    | Impact on self-concept                                                    |
| <b>2. The social self</b>                          | Feeling 'different' yet wanting to be 'normal'                            |
|                                                    | Prioritizing peer group                                                   |
|                                                    | Downward comparisons with others                                          |
| <b>3. The self and relationships</b>               | Conflicts with mothers                                                    |
|                                                    | Lying about glycaemic control and subsequent guilt                        |
|                                                    | Difficult relationship with healthcare professionals and attending clinic |
|                                                    |                                                                           |
| <b>4. The cyclical nature of glycaemic control</b> | Knowledge of DM1                                                          |
|                                                    | Burdensomeness and ambivalence                                            |
|                                                    | Hopes of a cure                                                           |
|                                                    | Guilt and improving glycaemic control                                     |

ADOLESCENTS' EXPERIENCE OF DM1 AND POOR GLYCAEMIC CONTROL



**Figure 1.**

*A conceptual diagram depicting the oscillating nature of glycaemic control.*

## **Section 4**

### **Contributions to Theory and Clinical Practice**

**Contributions to Theory and Clinical Practice**

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## **Introduction**

The aim of this thesis was two-fold: the literature review examined whether general parenting is associated with the health-related outcomes of children and adolescents with diabetes, whilst the empirical paper enabled an in-depth exploration of the lived experiences of adolescents struggling with one of these health-related outcomes (poor glycaemic control). Whereas the evidence regarding general parenting and glycaemic control and adherence was inconsistent, parenting characterised by responsiveness, acceptance and involvement was associated with better quality of life and mental health, whilst parenting characterised by psychological control, demandingness and low warmth was associated with worse quality of life and mental health. Although these findings provide valuable insights, methodological limitations were also raised as the majority of studies neglected the views of adolescents and only included parenting measures completed by parents. This appeared to be a poignant limitation considering that no significant associations between parenting and quality of life or mental health were found when the parenting and outcome measures were completed by different informants.

Through qualitative exploration, the empirical paper explored the lived experiences of adolescents with poor glycaemic control. The findings indicated that participants struggled to develop a cohesive identity and experienced intense feelings of guilt and shame when their poor glycaemic control and subsequent lies about their adherence behaviours were exposed to parents. An oscillating cycle of glycaemic control was described as participants scolded themselves and improved their glycaemic control in the short-term, but quickly found that their regimes became burdensome, which gradually slid into ambivalence and deteriorating glycaemic control. Similar to the inconsistent findings identified by the literature review regarding parenting and glycaemic control, a clear association between parenting and

glycaemic control was not described by participants. In fact, a complex picture was presented as glycaemic control appeared to be affected by an on-going interplay between intrapersonal and interpersonal conflicts.

### **Implications for future research and theory development**

#### **Addressing methodological limitations**

A clear implication for future research is the need to address the methodological limitations in the diabetes literature as highlighted by the literature review. The majority of studies included parenting measures completed by parents and insignificant associations between parenting and mental health and quality of life were found when parenting and outcome measures were completed by different informants. These findings are consistent with the developmental literature indicating that significant discrepancies are consistently found between parent and child reports of various outcomes such as child emotional and behavioural problems and family functioning (Achenbach, McConaughy, & Howell, 1987; Feinberg et al., 2000). Such discrepancies have been described as a methodological nuisance (Reidler & Swenson, 2012), which “hinder the interpretation of research findings as well as diagnostic and treatment decisions in clinical practice” (Guion, Mrug, & Windle, 2009, p17).

Historically, parents have been considered to be more accurate informants than children, which is highlighted by the fact that only 9% of studies examining quality of life have included self-report measures completed by children (Ravens-Sieberer & Bullinger, 1998). However, recent studies have argued that discrepancies between parent and child reports should not only lead “to consideration of which informant is most objective or valid, but also to questions about what meaning these differences have” (VanRoy, Groholt, Heyerdahl, & Clench-Aas, 2010, p11). Studies have therefore theorized that discrepancies between parent and child reports may reflect poor family communication (Guion, Mrug, &

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Windle, 2009). Furthermore, studies have found that larger discrepancies between parent and child reports are significant predictors of poor child adjustment and increased internalising problems (Reidler & Swenson, 2012). It is therefore important to recognise that albeit having different views regarding parenting, the perspectives of parents and adolescents may be equally valid thus highlighting the need to understand the complexity of these relationships.

Future studies may benefit from incorporating the views of various informants (including child and parent reports) as discrepancies between them may provide clinically meaningful information regarding the outcomes of children and adolescents with diabetes. For example, it may be useful for future studies to examine whether larger discrepancies between the views of children and parents are in and of themselves predictors of worse health-related outcomes for children and adolescents with diabetes. Furthermore, it may be useful for future studies to adopt longitudinal rather than cross-sectional designs to not only examine reciprocal associations between parenting and child outcomes but to also examine whether discrepancies change over time (Guion, Mrug & Windle, 2009).

### **Discrepancies between maternal and paternal parenting**

The literature review also identified discrepancies between maternal and paternal parenting and their association with glycaemic control and adherence. This may indicate that mothers' and fathers' have different parenting styles, which is consistent with the findings of a meta-analysis, which identified that fathers generally interact and communicate with their children in distinct and different ways to mothers (Russell & Saebel, 1997). Indeed, fathers have not only been found to dedicate more time to leisure activities with their children, but to also encourage more independence than mothers (Hauser et al., 1986).

Unfortunately, despite the evidence indicating that fathers' have distinct parenting styles, the majority of parents included in the reviewed studies were mothers, thus reflecting

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the fact that “in studies of paediatric patients, little attention has been devoted to fathers” (Seiffge-Krenke, 2002, p441). Future studies may therefore benefit from examining the distinct role of paternal parenting and the health-related outcomes of children and adolescents with diabetes. This may be especially important considering that the literature review found more evidence indicating that paternal rather than maternal use of psychological control was associated with worse adherence. Furthermore, Seiffge-Krenke (2002) found that fathers of diabetic adolescents encouraged independence less than fathers of healthy adolescents, which highlights the need to further examine and clarify the roles of fathers with regards to parenting children and adolescents with diabetes. The findings of such studies could inform future interventions for the parents or families of children with diabetes, thus highlighting that mothers and fathers may require different support or input.

**Examining adolescents’ mental health and oscillating glycaemic control**

Another implication for future research is the need to further examine the feelings of guilt and shame described by adolescents in the empirical paper. Although the empirical paper did not examine mental health, longitudinal quantitative studies may be invaluable in identifying whether adolescents’ feelings of guilt and shame are associated with negative mental health and quality of life outcomes. Considering the negative evaluations made regarding the self, with participants describing themselves as ‘stupid’ and ‘weak’, future studies may also benefit from examining the self-concept and self-esteem of adolescents with poor glycaemic control as they transition from adolescence into adulthood.

The oscillating model of glycaemic control proposed stipulates that when adolescents’ poor glycaemic control is exposed to parents and health professionals, they scold themselves and improve their glycaemic control in the short-term. However, adolescents quickly find that their regimes became burdensome and they attempt to reject their diabetes as they gradually

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grow increasingly ambivalent and their glycaemic control deteriorates. This model is the first to describe the process of poor glycaemic control during adolescence and therefore it needs to be further examined and developed to identify whether it captures the experiences of other adolescents who have poor glycaemic control. Asking adolescents whether they feel the model accurately reflects their experiences of poor glycaemic control may be an important part of this process in order to develop a model which is closely related to their lived experiences. Indeed, the current model highlights that adolescents' attempts to reject their diabetes is a key factor which appears to contribute to deteriorating glycaemic control. It may therefore be invaluable to explore whether acceptance-based interventions such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999) can help adolescents to accept their diabetes thus disrupting this cycle, enabling them to develop better glycaemic control.

**Exploring the awareness of parents and professionals**

Perhaps bridging the findings of the literature review and empirical paper, future qualitative studies with both parents and adolescents may benefit from examining whether parents are aware of the difficult feelings and conflicts experienced by adolescents with poor glycaemic control and whether adolescents want their parents to be aware of this. Although previous qualitative studies have identified that parents of children with diabetes want to protect their children from health complications and the stigma associated with having diabetes (Nurmi & Stiber-Roger, 2012), parents' understanding of their children's thoughts or experiences have not been examined. Considering that the literature review identified that parenting characterized by responsiveness, acceptance and involvement is significantly associated with better quality of life and mental health outcomes for children and adolescents

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with diabetes, it may be useful to examine whether children of parents with increased understanding of their psychological difficulties also have better outcomes.

There is a dearth of literature examining professionals' understanding of the experiences of adolescents who have poor glycaemic control. Furthermore, there is also a lack of research examining the experiences of professionals who are working with these adolescents and the possible stressors and challenges they face. Exploring these issues may provide valuable insights into professionals' understanding of the psychological processes underlying poor glycaemic control, the feelings this may evoke for professionals and how this may influence the decisions they make. The results of such studies may therefore help to identify any additional training needs or support required by professionals working with children and adolescents with diabetes.

### **Implications for theory development**

With regards to theory development, the proposed model of oscillating glycaemic control needs to be empirically tested to quantify the findings and possibly develop a theory of poor glycaemic control during adolescence. Quantitative studies could therefore examine whether adolescents' attempts to reject their diabetes regimes negatively impacts on their glycaemic control. Indeed, although there are several theories examining child and adolescent adherence to chronic illness treatments, many do not apply directly to the findings of the empirical paper or literature review, thus highlighting the importance of testing the proposed model of poor glycaemic control.

The Children's Health Belief Model (Bush & Iannotti, 1990) examines adherence to treatment and emphasises both child and parent factors, whilst also highlighting the role of the young person's cognitions, emotions, environment and motivation. However, this model does not capture the conflicts described by adolescents in the empirical study and emphasis is

placed on illness-specific parental attitudes and beliefs rather than the role of parenting styles. Similarly, the adapted version of The Childhood's Adaptation Model to Chronic Illness: Diabetes Mellitus (Whittemore, Jaser, Guo & Grey, 2010), considers both child and parent factors, whilst also examining psychological responses such as self-efficacy and depression. However, the oscillating nature of glycaemic control and subsequent feelings of guilt and shame described by adolescents in the empirical study is not captured within this model.

Considering current models of adherence and adjustment to chronic illness, perhaps a more integrated and dynamic model is required to capture the complexity of the experiences of adolescents with diabetes. In light of the findings of the literature review and empirical paper, such a model would need to consider how child, parental and professional factors interact to influence not only glycaemic control, but also adherence, quality of life and mental health. However, to develop such a model, further research is required examining these constructs and the reciprocal relationships between them. The proposed model of glycaemic control provides a good basis as it captures dynamic interpersonal and intrapersonal processes; highlighting how glycaemic control changes over time.

### **Implications for clinical practice**

#### **Parenting and health-related outcomes**

A clear implication for clinical practice arising from the literature review is the need to further consider the role of parenting in adolescents' management of their diabetes and mental health. It is well established that adolescence is a difficult period of transition where individuals often strive for independence, yet continue to rely on the support of their parents. Indeed, the role of parenting cannot be overlooked as the findings of the literature review

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highlight that adolescents with diabetes whose parents are responsive and accepting have better quality of life and mental health outcomes. Considering this, it may be important for services to consider what support is available for parents with regards to parenting children and adolescents with diabetes, and how positive parenting behaviours can be promoted.

NICE guidelines (2004) recommend that the families of children and adolescents with diabetes should have ongoing access to psychosocial support and be offered family interventions to reduce family conflict. However, no recommendations are made with regards to how caregivers should be supported in parenting children and adolescents with diabetes. Furthermore, although the Welsh Assembly Government (2007), acknowledges that parents of children with diabetes may experience grief, depression and frustration, and therefore require access to psychosocial support, no specific recommendations are made with regards to the type of parental support required. Based on the findings of this thesis, parents may benefit from interventions aimed at developing positive parenting styles. Providing parents with psycho-education regarding the intrapersonal and interpersonal difficulties experienced by adolescents with diabetes may also encourage parents to discuss difficult topics such as poor glycaemic control with their children in an open and supportive way.

A mapping exercise may therefore be useful to determine what support is being offered to parents of children and adolescents with diabetes, which may then contribute to the development of standards and equity across services. Involving parents in this process may be helpful to determine whether in fact parents want additional support and if they do, what format they would like this to take. Holtslander, Kornder, Letourneau, Turner and Paterson (2012) asked parents of children with diabetes what they would like from an online support intervention. Four main themes were identified which were: wanting straight answers to



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medical questions, help with parenting, help with transitioning the responsibility for diabetes management to their child and help connecting with other parents of children with diabetes.

### **Parenting interventions**

The evidence regarding the effectiveness of parenting interventions for parents of children with diabetes is in its infancy. Grey, Jaser, Whittemore, Jeon and Lindemann (2011) randomly assigned parents of children with diabetes to a group-based educational intervention or a coping-skills training intervention. Although no improvements in the glycaemic control of their children was found, parents in both groups reported improved parental coping and quality of life at 12 months follow-up. The findings therefore indicate that regardless of the content of the intervention, group-based parenting interventions resulted in improved outcomes for parents of children with diabetes.

In light of these findings, it may be useful for services to examine whether group-based interventions which are associated with low financial costs, may be a way of improving the wellbeing of parents and perhaps promoting more positive parenting behaviours. This could enable future studies to examine whether improvements in parental quality of life are associated with improved parenting behaviours and whether this in turn is associated with improved health-related outcomes for children and adolescents with diabetes.

### **Interactions with healthcare professionals**

It is important to highlight that many participants described having difficult interactions with healthcare professionals, who were sometimes perceived as being angry or dismissive of them. This is consistent with the literature indicating that children and adolescents with chronic illnesses struggle to talk openly with healthcare professionals (Beresford & Sloper, 2003). This is an emerging evidence-base as research has traditionally

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focused on interactions between professionals and parents, which again indicates that the views of children and adolescents with chronic illnesses have largely been neglected (Tates & Meeuwesen, 2001).

In a qualitative study examining the experiences of adolescents with a variety of chronic illnesses, Beresford and Sloper (2003) found that adolescents described several barriers to interacting with doctors. For example, they described that the presence of a parent could both inhibit and support interactions, whilst doctors who directed information towards parents inhibited communication. Furthermore, some adolescents described that doctors mainly asked questions about their medical condition, rather than encouraging them to ask questions. Interestingly, it was also found that adolescents were less likely to ask questions if they anticipated a negative response and therefore were less likely to disclose 'risky' or poor adherence behaviours. Woodgate (1998) similarly examined the experiences of adolescents with chronic illnesses and found that adolescents wanted clinicians to treat them as a person, try to understand their difficulties and give them encouragement.

Considering the consistencies between the findings of these studies and the difficulties described by participants in the empirical paper, this indicates that perhaps further exploration of interactions between adolescents with diabetes and clinicians is required. Qualitative methodologies such as discourse analysis would enable these interactions and the language used to be directly analysed, therefore potentially providing invaluable insights into how the roles of clinicians and adolescents are shaped within consultations (Starks & Trinidad, 2007). Furthermore, qualitative studies exploring clinicians' views of such interactions may be useful to identify any difficulties or training needs.

Channon, Hambly, Robling, Bennert and Gregory (2010) completed a survey with doctors and specialist diabetes nurses and identified that they found engaging families to be a

significant challenge. In addition, despite many clinicians reporting that they tried to encourage behaviour change, some struggled to quantify how they did this. In light of such findings, Robling et al. (2012) conducted a cluster randomised-controlled trial of the 'Talking Diabetes' programme which provided training to diabetes clinicians about how to guide communication, set shared agendas and have more constructive consultations. However, the intervention had no impact on glycaemic control and despite having a positive short-term impact on the self-reported coping skills of adolescents with diabetes, a negative longer-term impact on elements of adolescents' self-reported quality of life was found. Considering this, it was advised that the programme not be disseminated within the NHS and that perhaps modifying the training by adding an active listening component may be helpful. It therefore appears that further exploration of the communication between clinicians and adolescents with diabetes is required before any firm recommendations can be made with regards to how this can be improved.

### **Screening for psychosocial difficulties**

Although the mental health of participants in the empirical study was not examined, several participants described struggling with intense feelings of guilt and shame which negatively impacted upon their sense of self. Such findings are consistent with the literature indicating that adolescents with diabetes and poor glycaemic control are at increased risk of developing mental health difficulties such as anxiety, depression and eating disorders (Hood et al., 2006; Anderson et al., 2002; Rodin et al., 2002). Furthermore, evidence suggests that psychosocial difficulties or a lack of psychosocial support are the most important factors affecting diabetes management (Hanas, Donaghue, Klingensmith & Swift, 2009).

Considering such findings, NICE guidelines recommend that adolescents with diabetes should not only have timely access to mental health professionals but that

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adolescents with “consistently poor glycaemic control should be offered screening for anxiety and depression” (NICE guidelines, 2004, p30). Furthermore, Welsh Assembly Government guidelines outline that psychological and social difficulties are commonly associated with poor glycaemic control and that “timely intervention may be the most effective way to improve control” (Welsh Assembly Government, 2007, p.8). The importance of mental health screening for adolescents with diabetes has been consistently reported within national and international guidelines as screening could enable psychological provision to be allocated to those at increased risk therefore preventing future complications.

In light of such recommendations, Schwartz, Axelrad, Cline and Anderson (2011) developed a 30-minute psychosocial screening method, including a variety of psychosocial measures, which can be adopted by clinical psychologists in paediatric settings. Although the screening method was only piloted, it was effective in identifying adolescents who were at increased risk of developing difficulties with their diabetes management and it provided a basis for the development of treatment goals. Furthermore, Perfect et al. (2011) examined the acceptability of a mental health screen for adolescents with diabetes and their parents and found that although adolescents were not embarrassed or distressed by the process, some concerns were raised with regards to confidentiality and the potential outcomes of the screening. These issues would therefore need to be carefully considered by services developing screening programs.

It is important to highlight that despite the emphasis placed on mental health screening and the integration of psychological provision within diabetes care-teams, the provision of these services is inconsistent across the UK (Department of Health, 2007). Despite evidence indicating that psychological input can improve glycaemic control (Gelfand et al., 2004), 87% of children and adolescents with diabetes never see a psychologist

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(Diabetes UK, 2010) and only 10% of diabetes care teams regularly screen for psychological problems (Diabetes UK, 2008). Services may therefore benefit from undertaking a mapping exercise to establish what psychological provision is available within diabetes care-teams to develop equity across services. Furthermore, services may benefit from adopting psychosocial screening methods to identify adolescents who are at increased risk of experiencing difficulties and are likely to benefit from psychological provision. Adopting a screening method could potentially enable all children and adolescents with diabetes to be screened for psychosocial difficulties, thus providing a baseline measurement which could be repeated and reviewed at later time-points if necessary. Crucially, a screening method may also enable psychological provision to be targeted towards individuals who are identified as being at increased risk of developing difficulties, thus ensuring that NHS resources are targeted towards individuals with the greatest needs.

### **Service-user involvement**

Many issues raised by both the literature review and the empirical paper highlight that the views of adolescents with diabetes have largely been overlooked. Not only were the majority of parenting measures included in the literature review completed by parents but the empirical paper indicates that adolescents feel unable to discuss difficult topics with healthcare professionals and parents. Considering this, involving adolescents in the planning, delivery and evaluation of diabetes services may be an effective way of ensuring that their views are considered. Indeed, it is important to highlight that the National Health Service Act (2006) places a legal duty on NHS trusts to involve service-users in service development and delivery. Furthermore, the Children's Act (2004) outlines that services should work collaboratively with young people in the development of services.

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Multiple potential benefits exist for involving adolescents in the planning of services such as developing services which are more responsive and accountable (YoungMinds, 2005). Furthermore, it has been highlighted that involving children and adolescents in diabetes services could empower young people, and foster respect and stronger relationships between them and healthcare teams (Diabetes UK, 2007). There are several ways of facilitating the involvement of adolescents in diabetes services such as developing consultation or focus groups. Staff facilitating such groups would need to be adequately trained to ensure that adolescents feel able and confident expressing their views and therefore any cultural or language needs would need to be carefully considered. In addition, it would be crucial that the contribution of adolescents be used in a non-tokenistic and meaningful way to guide service delivery.

### **Reflective commentary**

Actively reflecting on the experience of conducting the research was an important part of the process of collecting and analysing the data. Keeping reflective notes throughout the data collection and analysis enabled me to become aware of my own preconceptions and attempt to bracket them to focus on the lived experiences of participants.

### **Conducting the interviews**

As a researcher who had not previously undertaken qualitative interviews, the experience was both a challenge and a privilege. During the interviews, I became aware of the influence of my own training within clinical psychology and my experience of working within a paediatric setting. Although this training may have helped me to establish and develop rapport with participants, I became aware of my desire to sometimes challenge

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difficult beliefs or provide alternative interpretations as would be the case within a clinical session. Throughout the process I therefore re-directed myself to the principles of Interpretative Phenomenological Analysis (IPA; Smith, Flower & Larkin, 2009) to ensure that the interviews were conducted in a way that enabled participants' lived experiences to be at the fore, whilst attempting to bracket my own views.

During the interviews participants described their experiences of concealing the truth and struggling to discuss their poor adherence behaviours with adults, including their parents and healthcare professionals. I therefore became acutely aware of the power-dynamics that could unfold during the interview and I tried to encourage participants to share their experiences without feeling inhibited. Although participants were given a choice of whether to conduct the interviews at the hospital or at home, upon reflection I think that conducting three interviews in the hospital setting may have prompted social desirability cues, which may have been an additional barrier to them openly describing their experiences. Despite this, I admired the ability of participants to openly describe complex and emotive topics and I believe that giving participants the choice of conducting interviews through the medium of Welsh or English facilitated this process.

Three participants chose to conduct their interviews in Welsh and whilst doing so flexibly alternated from using Welsh and English phrases in what appeared to be a very conversational and natural way. I personally believe this enabled participants to be 'free' in their reflections without worrying about finding the correct words in one particular language. As some participants appeared relieved that they could conduct the interview in Welsh, I recognised that as an adolescent, I may also have felt similarly, and upon reflection I was quite proud that I was able to facilitate this. Although transcribing the Welsh transcripts into

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English was a time-consuming process, I am pleased that I undertook this task as it ensured that I became immersed in the data in a very detailed way.

It was interesting to reflect that for some participants, their conflicted feelings and the oscillating nature of their glycaemic control appeared to be replicated within the interview. For example, some participants described difficult feelings associated with poor glycaemic control, such as guilt and shame, and then immediately appeared to shift to a stance of ambivalence or indifference. At times, I found this to be quite striking as participants appeared to be actively grappling with their conflicted feelings during the interview, thus indicating that this is an ongoing and ever-present struggle for them. Perhaps unsurprisingly, following the interviews I found myself empathizing with the participants and upon reflection, feeling quite guilty for not appreciating the extent of their difficulties prior to undertaking the interviews. As the interviews progressed, my appreciation or understanding of the complexity of their lives intensified and I felt a responsibility to capture their lived experiences within the analysis.

### **Data analysis**

Despite initially feeling overwhelmed by the task of analysing the data, in accordance with the principles of IPA, I was committed to being actively engaged in a 'double hermeneutic' as I tried to make sense of participants' making sense of their experiences. By immersing myself in the data, I found myself becoming increasingly aligned with the theoretical underpinnings of IPA, as I realised there is no 'objective truth' regarding the experiences of adolescents with glycaemic control, as it is often contradictory and complex. Throughout the process of analysing the data I regularly met with members of the research team and endeavoured to ensure that the emergent themes were grounded in the experiences of participants without over-interpreting the findings based on my own preconceptions or



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biases. Equally, I did not want the interpretations to be too shallow as I felt that capturing the complexity of participants' lives was central to their experiences. During the analysis, I tried to represent every participant but concede that given the richness of some interviews, some participants were represented more than others. However, I do not believe that this is a weakness, but rather a reflection of the interviews themselves.

Finally, it is important to highlight that at several points during the analysis, I felt confused by the often contradictory statements made by participants before realising that an oscillating process of glycaemic control was being described. Indeed, my confusion appeared to echo theirs and I realised that glycaemic control is a fluid construct that changes over time depending on the intrapersonal and interpersonal conflicts experienced by these adolescents. Personally, I believe that a strength of this study is that participants described grappling with feelings of both shame and ambivalence, therefore challenging over-simplified accounts of their experiences or poor-glycaemic control. In light of such findings, I found myself wanting to give voice and advocate for them.

### **Conclusion**

Both the literature review and empirical paper highlight areas requiring further exploration and I believe the findings provide new and valuable insights into the complex lives of adolescents with diabetes. Furthermore, given the evidence indicating that the views of children and adolescents have been previously under-represented within the literature, I hope that future studies appreciate that only by putting the experiences of these adolescents in the foreground can we begin to understand and effectively address the difficulties they face.

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## **Section 5**

### **Appendices**

**Appendix 5A.**  
**Approvals and permissions**



**Date:** Fri, 19 Apr 2013 12:53:27 -0000 [19/04/13 01:53PM BST]  
**From:** Bangor Research Applications <psse09@bangor.ac.uk>   
**To:** pspefb@bangor.ac.uk  
**Subject:** Ethics Application Approved

Dear Llinos,

2013-9445 How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?

Your research proposal number 2013-9445 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

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Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)  
Adolescents experience of Diabetes Mellitus and poor glycaemic control

1. Is your project research?

Yes  No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation?  Yes  No
- b) Will you be taking new human tissue samples (or other human biological samples)?  Yes  No
- c) Will you be using existing human tissue samples (or other human biological samples)?  Yes  No

3. In which countries of the UK will the research sites be located? (Tick all that apply)

- England
- Scotland
- Wales
- Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

NHS REC Form

Reference:  
13/WA/0155

IRAS Version 3.5

- England  
 Scotland  
 Wales  
 Northern Ireland  
 This study does not involve the NHS

4. Which review bodies are you applying to?

- NHS/HSC Research and Development offices  
 Social Care Research Ethics Committee  
 Research Ethics Committee  
 National Information Governance Board for Health and Social Care (NIGB)  
 National Offender Management Service (NOMS) (Prisons & Probation)

*For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PTs or local collaborators.*

5. Will any research sites in this study be NHS organisations?

- Yes    No

6. Do you plan to include any participants who are children?

- Yes    No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes    No

*Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.*

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- Yes    No

9. Is the study or any part of it being undertaken as an educational project?

- Yes    No

Please describe briefly the involvement of the student(s):

This study is being completed as part of the Doctorate of Clinical Psychology qualification. The Principal researcher is a trainee on this doctorate program and will undertake the research under the supervision of Dr Liz Whitehead and Dr Renee Rickard.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- Yes    No

NHS REC Form

Reference:  
13/WA/0155

IRAS Version 3.5

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes  No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes  No

Integrated Research Application System  
Application Form for Research involving qualitative methods only



Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)  
Adolescents experience of Diabetes Mellitus and poor glycaemic control

Please complete these details after you have booked the REC application for review.

REC Name:  
North Wales REC/West

REC Reference Number:  
13/WA/0155

Submission date:  
06/05/2013

## PART A: Core study information

### 1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?

A2-1. Educational projects

Name and contact details of student(s):

Student 1

|           | Title                                | Forename/Initials | Surname  |
|-----------|--------------------------------------|-------------------|----------|
|           | Miss                                 | Linos             | Griffith |
| Address   | 42 Penrhos Road<br>Bangor<br>Gwynedd |                   |          |
| Post Code | LL57 2AX                             |                   |          |
| Email     | pspefb@bangor.ac.uk                  |                   |          |
| Telephone | 07717805611                          |                   |          |
| Fax       |                                      |                   |          |

Give details of the educational course or degree for which this research is being undertaken:

NHS REC Form

Reference:  
13/WA/0155

IRAS Version 3.5

Name and level of course/degree:  
North Wales Clinical Psychology ProgrammeName of educational establishment:  
Bangor University

## Name and contact details of academic supervisor(s):

## Academic supervisor 1

|           |                                                                                        |                   |         |
|-----------|----------------------------------------------------------------------------------------|-------------------|---------|
|           | Title                                                                                  | Forename/Initials | Surname |
|           | Dr                                                                                     | Renee             | Rickard |
| Address   | North Wales Clinical Psychology Programme<br>School of Psychology<br>Bangor University |                   |         |
| Post Code | LL57 2DG                                                                               |                   |         |
| E-mail    | r.rickard@bangor.ac.uk                                                                 |                   |         |
| Telephone | 01248 383778                                                                           |                   |         |
| Fax       |                                                                                        |                   |         |

## Academic supervisor 2

|           |                                                                             |                   |           |
|-----------|-----------------------------------------------------------------------------|-------------------|-----------|
|           | Title                                                                       | Forename/Initials | Surname   |
|           | Dr                                                                          | Liz               | Whitehead |
| Address   | Paediatric Clinical Psychology, Minffordd Ward,<br>Ysbyty Gwynedd<br>Bangor |                   |           |
| Post Code | LL57 2PW                                                                    |                   |           |
| E-mail    | liz.whitehead@wales.nhs.uk                                                  |                   |           |
| Telephone | 01248 385488                                                                |                   |           |
| Fax       |                                                                             |                   |           |

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

| Student(s)                      | Academic supervisor(s)                                                                                       |
|---------------------------------|--------------------------------------------------------------------------------------------------------------|
| Student 1 Miss Llino's Griffith | <input checked="" type="checkbox"/> Dr Renee Rickard<br><input checked="" type="checkbox"/> Dr Liz Whitehead |

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

## A2-2. Who will act as Chief Investigator for this study?

- Student  
 Academic supervisor  
 Other

## A3-1. Chief Investigator:

NHS REC Form

Reference:  
13/MA/0155

IRAS Version 3.5

|                             |                                         |
|-----------------------------|-----------------------------------------|
|                             | Title Forename/Initials Surname         |
|                             | Miss Llinos Griffith                    |
| Post                        | Trainee Clinical Psychologist           |
| Qualifications              | BSc Psychology (Hons)                   |
| Employer                    | Betsi Cadwaladr University Health Board |
| Work Address                | NWCPP<br>School of Psychology           |
| Post Code                   | LL57 2AS                                |
| Work E-mail                 | pspefb@bangor.ac.uk                     |
| * Personal E-mail           | llinos.g@live.co.uk                     |
| Work Telephone              | 07717805611                             |
| * Personal Telephone/Mobile |                                         |
| Fax                         |                                         |

*\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.  
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?  
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

|           |                                                                 |
|-----------|-----------------------------------------------------------------|
|           | Title Forename/Initials Surname                                 |
|           | Mr H.F Francis                                                  |
| Address   | School of Psychology<br>Bangor University<br>Brigantia Building |
| Post Code | LL57 2AS                                                        |
| E-mail    | h.francis@bangor.ac.uk                                          |
| Telephone | 01248 388339                                                    |
| Fax       | 01248382599                                                     |

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project website:

Additional reference number(s):

| Ref.Number | Description | Reference Number |
|------------|-------------|------------------|
|------------|-------------|------------------|

*Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.*

A5-2. Is this application linked to a previous study or another current application?

Yes  No

Please give brief details and reference numbers.

## 2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?

This study aims to interview between 8-10 adolescents between the ages of 12 and 17 who have type 1 Diabetes Mellitus and poor glycaemic control. The interview therefore aims to collect detailed information about the adolescent's experience of having poorly controlled Diabetes Mellitus. Questions will also focus on how their difficulties effect their identity and relationships with others. It is hoped the findings will inform clinical therapies with this client group.

Participants will be recruited from the paediatrics department in Ysbyty Gwynedd. If I am unable to recruit at least 8 participants from Ysbyty Gwynedd, it is planned to recruit from the paediatrics department in Ysbyty Glan Clwyd.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Assent: Information sheets for parents/guardians of potential participants have been developed. In addition, assent forms have been developed for parents/guardians to read and sign if the adolescent is under the age of 16 years.

Consent: Information sheets have been developed and will be given to all potential participants. These forms invite the adolescent to ask any additional questions they may have. If the adolescent wishes to participate after reading the information sheet, they will be asked to read and sign a consent form.

Incentives: Ethical considerations regarding the use of incentives have been carefully considered. A detailed examination of the ethical implications that must be considered when using incentives in research was completed by Grant and Sugarman (2004). The authors indicate that incentives only become ethically inappropriate in the following circumstances 1) the incentive constitutes as an undue influence or acts as a coercive inducement to participate and 2) the use of incentive compromises the dignity of the subject. Considering this, the use of incentives in this research project is considered to be ethically appropriate. Indeed, the incentive of a £5 gift voucher is relatively small and is not thought to cause undue influence or act as a coercive inducement. In addition, within the participant information sheet and the parent/guardian information sheet, the incentive will be described as a thank you for the participant's time and for sharing their experiences. The adolescent's dignity will therefore not be compromised.

Confidentiality: Information obtained during interviews will not be shared with clinicians working with the participant or their parents/guardians. The only exception to this would be if a risk issue was disclosed. All participants will be informed that their details will be anonymised and all identifiers will be removed before it is shared with the research team.

Risk: Adolescents will be well known to the Paediatrics department in Ysbyty Gwynedd or the Paediatrics department in Ysbyty Glan Clwyd. If any risk issues have been identified, these individuals will be excluded from the study. It is hoped that all interviews will be conducted in consulting rooms within departments rather than home visits to minimize risk. If the researcher undertakes home-visits, the Bangor University Lone worker Policy will be adhered to.



De-briefing: As participants will be discussing their experiences of having Diabetes Mellitus and having poor glycaemic control, it is possible that individuals may become distressed. A comprehensive debriefing at the end of the interview will be conducted regardless of whether the participant is visibly distressed to ensure that the participant leaves the interview in a satisfactory state of well-being.

A6-3. Proportionate review of REC application: *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

Yes - proportionate review  No - review by full REC meeting

*Further comments (optional):*

*Note: This question only applies to the REC application.*

### 3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply.*

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

The aim of this research project is to increase the psychological understanding of the experience of having Diabetes Mellitus and poor glycaemic control within an adolescent population. Therefore, the study will qualitatively assess how adolescents experience having type 1 Diabetes Mellitus and poor glycaemic control.

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

The secondary aims of this project are:

- to assess whether having Diabetes Mellitus and poor glycaemic control affects how adolescents view themselves and their identity.
- to assess whether having Diabetes Mellitus and poor glycaemic control affects adolescents relationships with others.

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Adolescents with Diabetes Mellitus not only have an increased risk of developing health complications but they are also at increased risk of developing emotional and behavioural problems (NICE guidelines, 2004). Specifically,

adolescents with Diabetes Mellitus may develop anxiety and/or depression, particularly if they are experiencing difficulties with managing their diabetes. Indeed, it is recommended that adolescents with Diabetes Mellitus should have "timely and on-going access to mental health professionals" (NICE guidelines, 2004).

A review by Spencer, Cooper and Milton (2010) examining metabolic control in adolescents with Diabetes Mellitus, recommended that future research should examine the lived experiences of adolescents with Diabetes Mellitus in countries other than the USA.

Considering the detrimental effect that poor glycaemic control may have on the health and well-being of adolescents with Diabetes Mellitus, it is hoped that the findings of this research project will inform clinical interventions and therapeutic relationships with this client group.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

To enable the lived experiences of adolescents who have type 1 Diabetes Mellitus and poor glycaemic control to be examined in detail, a qualitative approach has been selected. Qualitative methods are particularly recommended in areas where there is little existing research (Elliot et al., 1999). A qualitative research design allows a flexible and open approach which will enable participants to describe their experiences in their own words.

Adolescents participating in the study will be well known to clinicians in the Paediatrics department in Ysbyty Gwynedd or the Paediatrics Department in Ysbyty Glan Clwyd. The principal investigator will visit the sites to inform clinicians of the research and ask clinicians to ascertain whether any of the adolescents on their case-load fulfil the inclusion criteria. Clinicians will be given a recruitment information sheet outlining the purpose of the study and the inclusion/exclusion criteria.

The option of taking part in the research will first be raised with the adolescent by a clinician known to them, who is a member of their healthcare team. If the adolescent is interested in taking part in the research, the clinician will give the adolescent a participant information sheet. The parent/guardian of the adolescent will also be given a parent/guardian information sheet.

If the adolescent wants to take part in the study and would like to talk to Llinos Griffith to discuss this and arrange an interview date and time, they will be given an opt-in form to complete. This form will ask for a telephone number for Llinos Griffith to contact them. The adolescent and their parent/guardian will be required to sign this opt-in form before any telephone contact is made.

Upon receipt of the opt-in form, Llinos Griffith will contact the adolescent via telephone and will speak with both the adolescent and their parent/guardian to discuss the study and answer any questions. If the adolescent and their parent/guardian are happy for the adolescent to take part, Llinos Griffith will arrange an interview date and time.

Prior to commencing the interview, the adolescent and the parent/guardian will be given the information sheets to read again. If the adolescent wants to take part, they will be required to complete and sign a consent form. The parent/guardian will also be required to complete and sign a parent/guardian assent form. Interviews will only be conducted if both the consent form and the assent form are completed and signed.

It is hoped that the interviews will be conducted in the paediatrics department in Ysbyty Gwynedd or Ysbyty Glan Clwyd. If this is not convenient, home-visits will be arranged and Llinos Griffith will adhere to the Bangor University lone-worker policy.

Participants will be informed that they will not receive individual feedback from the interviewer. However, a brief and general review of the topics raised in the research will be provided should participants request it. Each participant will be offered a small incentive of a £5 voucher of his or her choice, to take part.

It is not expected that individuals will find the interview distressing. However, as a safeguard, prior to commencing the interview participants will be asked to identify a supportive individual they can access should they be distressed after the interview. The interview will not be conducted if the adolescent is unable to identify a supportive individual.

The interview will consist of 2 parts. Firstly, the adolescent will be asked demographic questions. Following this, a semi-structured interview will be conducted. The interview will be guided by an interview schedule which has been developed with Dr Renee Rickard and Dr Liz Whitehead. The main themes covered in the interview will explore the adolescent's experience of living with Diabetes Mellitus and poor glycaemic control. Themes surrounding how this may have affected their identity and relationships with others will also be explored.

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All interviews will be audio-recorded.

At the end of each interview, participants will have the opportunity to discuss their feelings about the interview. Should the participants require further support following the interview, they will be recommended to speak with their supportive individual.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

In order to develop the interview schedule, the interview will be administered to a member of the public who has Diabetes Mellitus and an adolescent. Their feedback on the questions and the structure will inform the interview schedule.

#### 4. RISKS AND ETHICAL ISSUES

##### RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

1. Adolescents between the ages of 12 to 17 years.
2. Adolescents with a diagnosis of Type 1 Diabetes Mellitus for a minimum of 1 year.
3. Adolescents identified as having poor glycaemic control defined as HbA1c levels of greater than or equal to 9% in their 2 most recent blood tests at the time of recruitment.

HbA1c stands for glycated haemoglobin A1c. This measurement gives an average of a person's blood glucose level over a period of time (approximately 6-8 weeks). For adolescents, NICE guidelines recommend that HbA1c levels of less than 7.5% is the long-term target for glycaemic control (NICE, 2004).

By setting the HbA1c levels of greater than or equal to 9% over their two most recent blood tests as an inclusion criteria, this will ensure that participants have consistently had poor glycaemic control. Previous studies examining poor glycaemic control have also used HbA1c levels of 9% as a cut-off score indicating poor glycaemic control (Iqbal, Morgan, Maksoud and Idris, 2008; Juarez et al., 2012).

NICE guidelines (2004) outline that young people with HbA1c levels consistently above 9.5% should be offered additional support by their diabetes care teams because they are at increased risk of developing long-term complications.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

1. Adolescents with Type 2 Diabetes Mellitus.
1. Adolescents who have 'insulin pumps' to administer medications.
2. Adolescents with learning disabilities.

These groups will not be included as the researcher believes that these are distinct groups that should be investigated independently.

##### RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

| Intervention or procedure                                                                                                            | 1 | 2  | 3              | 4                                                                                                                                             |
|--------------------------------------------------------------------------------------------------------------------------------------|---|----|----------------|-----------------------------------------------------------------------------------------------------------------------------------------------|
| Discussing the research and asking potential participants to opt-in to the study.                                                    | 1 | NA | 20 mins        | A clinician working in the Paediatrics department in Ysbyty Gwynedd or Ysbyty Glan Clwyd.                                                     |
| Discussing the research. Organizing an interview date and time.                                                                      | 1 | NA | 20 mins        | Linos Griffith, Trainee Clinical Psychologist, will telephone the adolescent and their parent/guardian to arrange an interview time and date. |
| Seeking consent. Asking participants to complete the consent forms. A Parent/guardian will also be asked to complete an assent form. | 1 | NA | 20 mins        | Linos Griffith, Trainee Clinical Psychologist, at the Paediatrics outpatient department in Ysbyty Gwynedd or Ysbyty Glan Clwyd.               |
| Audio-recorded interview                                                                                                             | 1 | NA | 90 mins approx | Linos Griffith, Trainee Clinical Psychologist, at the Paediatrics outpatient department in Ysbyty Gwynedd or Ysbyty Glan Clwyd.               |

A21. How long do you expect each participant to be in the study in total?

It is envisaged that the time span from gaining informed consent and completing the interview will be no more than 3 weeks. The interviews themselves should not take longer than 90 minutes.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

**Distress:** The interview will focus upon the experience of having Diabetes Mellitus and poor glycaemic control, which may be distressing for some participants. The interviewer will therefore emphasize that participants can withdraw at anytime and can choose not to answer questions. At the end of the interview, all participants will be given the opportunity to discuss their experience of the interview and any distress they may have arisen. In addition, all participants will be asked to identify a supporting individual prior to the interview to ensure that they have support if they require it.

**Inconvenience:** Interviews will be arranged at a date and time which is convenient for participants. The interview times will also be sensitive to times of the year where participants may be sitting school examinations.

A23. Will interviews/questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes  No

*If Yes, please give details of procedures in place to deal with these issues:*

**Sensitive, embarrassing and upsetting issues:** It will be emphasized that participants can withdraw at anytime during the interview and can choose not to answer questions if they will be unduly upset or embarrassed by it.

**Criminal disclosures:** The consent form will inform participants that confidentiality will only be broken if either the participant or someone else is at risk of harm or if the participant discloses they have committed a serious crime.

A24. What is the potential for benefit to research participants?

It is not a research aim that adolescents will benefit from participating. However, adolescents may find the interviews to be enjoyable as their views and experiences will be listened to in an open manner. Participants may also like contributing to research which may inform ways of working with adolescents who have diabetes and poor glycaemic control in the future.

A26. What are the potential risks for the researchers themselves? (if any)

The risk to the principal investigator who will be conducting the interviews is small and would not exceed risk in typical clinical practice. All participants will be well known to the Paediatrics department in Ysbyty Gwynedd or Ysbyty Glan Clwyd. For adolescents where risk has been identified, they will be excluded from the study. It is hoped that all interviews will be conducted in consulting rooms within departments in Ysbyty Gwynedd or Ysbyty Glan Clwyd rather than home visits to minimize risks. However, if home visits are undertaken, the Bangor University and BCUHB Lone worker Policy will be adhered to.

#### RECRUITMENT AND INFORMED CONSENT

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

In the first instance, potential applicants will be recruited from the Paediatrics department, Ysbyty Gwynedd. Should it be necessary, participants will be recruited from the Paediatrics department in Ysbyty Glan Clwyd.

Adolescents participating in the study will be well known to clinicians in the Paediatrics department in Ysbyty Gwynedd or the Paediatrics Department in Ysbyty Glan Clwyd. Llinos Griffith will visit the sites to inform clinicians of the research and ask clinicians to ascertain whether any of the adolescents on their case-load fulfil the inclusion criteria. Clinicians will be given a recruitment information sheet outlining the purpose of the study and the inclusion/exclusion criteria. The clinician who will be a member of the adolescent's healthcare team will review their medical records to ascertain whether they meet the inclusion criteria.

The option of taking part in the research will first be raised with the adolescent by a clinician known to them, who is a member of their healthcare team. If the adolescent is interested in taking part, the clinician will give the adolescent a participant information sheet. The parent/guardian of the adolescent will also be given a parental/guardian information sheet.

If the adolescent wants to take part in the study and would like to talk to Llinos Griffith to discuss this and arrange an interview date and time, they will be given an opt-in form to complete. This form will ask for a telephone number for Llinos Griffith to contact them. The adolescent and their parent/guardian will be required to sign this opt-in form before any telephone contact is made.

Upon receipt of the opt-in form, Llinos Griffith will contact the adolescent via telephone and will speak with both the adolescent and their parent/guardian to discuss the study and answer any questions. If the adolescent and their parent/guardian are happy for the adolescent to take part, Llinos Griffith will arrange an interview date and time.

Prior to commencing the interview, the adolescent and the parent/guardian will be given the information sheets to read again. If the adolescent wants to take part, they will be required to complete and sign a consent form. The parent/guardian will also be required to complete and sign a parent/guardian assent form. Interviews will only be conducted if both the consent form and the assent form are completed and signed.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes  No

Please give details below:



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Potential participants will be identified by clinicians who are members of their healthcare team. Llinos Griffith will inform clinicians of the research and ask them to ascertain whether any of the adolescents on their case-load fulfil the inclusion criteria. Clinicians will be given a recruitment information sheet outlining the purpose of the study and the inclusion/exclusion criteria.

It will not be necessary for the principal investigator to review any identifiable personal information at the recruitment stage.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

Yes  No

A27-5. Has prior consent been obtained or will it be obtained for access to identifiable personal information?

Yes  No

*If Yes, please give details below.*

The principal investigator, Llinos Griffith, will not have access to identifiable personal information at the recruitment stage.

Consent will be explicitly obtained on the participant consent form and the parent/guardian assent form for Llinos Griffith to access the adolescent's medical records to extract information regarding their diabetes and glycaemic control. Llinos Griffith will not have access to any identifiable personal information until participant consent and parent/guardian assent has been provided.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes  No

A29. How and by whom will potential participants first be approached?

Potential participants will first be approached by a clinician known to them who is a member of their healthcare team. If the adolescent is interested in taking part, the clinician will give the adolescent a participant information sheet. The parent/guardian of the adolescent will also be given a parent/guardian information sheet.

If the adolescent wants to take part in the study and would like to talk to Llinos Griffith to discuss this and arrange an interview date and time, they will be given an opt-in form to complete. This form will ask for a telephone number for Llinos Griffith to contact them. The adolescent and their parent/guardian will be required to sign this opt-in form before any contact is made by Llinos Griffith.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes  No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, video, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

Adolescents will be provided with a detailed participant information sheet. They will also be given the opportunity to ask any questions and discuss the research with the principal investigator, Llinos Griffith. Written consent will be obtained.

For adolescents under the age of 16, their parent/guardian will be provided with a detailed parent/guardian information sheet. Their parent/guardian will also be given the opportunity to ask any questions and discuss the research with the principal investigator. Written parent/guardian consent will be obtained on a parent/guardian assent form.

All adolescents taking part in the study will be well known to clinicians within the paediatrics department in Ysbyty Gwynedd or the paediatrics Department in Ysbyty Glan Clwyd. Only adolescents who are considered to have capacity will be approached to take part by a member of their care-team.

*If you are not obtaining consent, please explain why not.*

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes  No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be given 4 weeks after the initial contact to express an interest in participating in the research.

If a potential participant declines to take part in the research, no further contact will be made.

If the potential applicant and their parent/guardian complete the opt-in form, Llinos Griffith will make telephone contact within a week of receiving the opt-in form.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

Individuals will have the option of completing the interview through the medium of Welsh or English. Participants will therefore need to display adequate receptive and expressive language skills in Welsh or English to participate in the study.

Adolescents with a Learning Disability are excluded from the study as it is believed that their experiences of managing Diabetes Mellitus would be different to adolescents who do not have a learning disability.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

Llinos Griffith, the chief investigator, is fluent in both Welsh and English. All participants will therefore be given the opportunity of participating through the medium of Welsh or English.

All written information provided to clinicians and potential participants will be provided in Welsh and English. The recruitment information sheet, participant information sheet, parent/guardian information sheet, opt-in form, consent form and assent form will be translated into Welsh after ethical approval has been granted.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

*If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.*

#### CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

#### Storage and use of personal data during the study:

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
  - Manual files including X-rays
  - NHS computers
  - Home or other personal computers
  - University computers
  - Private company computers
  - Laptop computers

#### Further details:

Completed opt-in slips, consent forms and assent forms will have the participant's name and a unique research number. The research number will be used to link this information to their transcript.

Interviews will be recorded on a voice recorder. Interviews will be transferred onto an encrypted memory stick device immediately upon completion of the interview and deleted from the voice recorder.

Direct quotes from interviews may be used in the write up of the research. No quote which contains information that may identify participants will be used. If a participant chooses to participate in Welsh, the quote will be translated into English to minimize the chance of the participant being identified.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

In order to ensure the confidentiality of personal data, no identifiers will be present in the data collected or in the writeup of findings. Participants will be assigned a pseudonym in order to preserve their anonymity.

Contact details will only be required to arrange interviews and communicate the findings of the study. This information will be stored separately from investigation data to preserve anonymity.

BCUHB and Bangor University policies on data protection and confidentiality will be followed.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.



The Chief investigator (Linos Griffith, Trainee Clinical Psychologist) and the research supervisors (Dr Liz Whitehead and Dr Renee Rickard) will have access to personal data during the study.

Only the chief investigator will have access to identifying information and will assign a pseudonym to each participant before supervisors have access to the information.

#### Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- Over 3 years

#### INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes  No

*If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined. Ethical considerations regarding the use of incentives have been carefully considered. A relatively small value incentive of a £5 voucher will be used in this research project.*

A detailed examination of the ethical implications that must be considered when using incentives in research was completed by Grant and Sugarman (2004). The authors indicate that incentives only become ethically inappropriate in the following circumstances 1) the incentive constitutes as an undue influence or acts as a coercive inducement to participate and 2) the use of incentive compromises the dignity of the subject. Considering this, the use of incentives in this research project is considered to be ethically appropriate. Indeed, the incentive of a £5 gift voucher is relatively small and is not thought to cause undue influence or act as a coercive inducement. In addition, within the participant information sheet and the parent/guardian information sheet, the incentive will be described as a thank you for the participant's time and for sharing their experiences. The adolescent's dignity will therefore not be compromised.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes  No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- Yes  No

#### NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

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 Yes  No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*

**PUBLICATION AND DISSEMINATION**

A50. Will the research be registered on a public database?

 Yes  No

*Please give details, or justify if not registering the research.*  
It is hoped the data will be published in an academic journal.

*Registration of research studies is encouraged wherever possible.*  
*You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on web site
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

A53. Will you inform participants of the results?

 Yes  No

*Please give details of how you will inform participants or justify if not doing so.*  
If participants request some feedback from the research, they will be given a brief outline of the findings and clinical implications in general terms.

**5. Scientific and Statistical Review**

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the*

researcher, give details of the body which has undertaken the review:

The research has been discussed and agreed by the research supervisors, Dr Liz Whitehead and Dr Renee Rickard.

The research proposal has been submitted to and authorized by the NWCPP research team (Professor Richard Hastings and Dr Vaso Totsika).

Throughout the study, the supervisors and members of the NWCPP will continue to review the scientific quality of the study.

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/institution.*

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 10

Total international sample size (including UK):

Total in European Economic Area:

Further details:

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

8-10 participants will be required for the study, which is believed to be the optimum number of participants based on methodological issues. Indeed, the qualitative research methodology, Interpretative Phenomenological Analysis (IPA), typically has a small number of participants to allow rich and detailed analysis of each participant's lived experiences to be explored. It is believed that 8 participants would be sufficient to achieve this in this investigation.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Data will be analyzed according to the principles of Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) as it allows in depth exploration of each participant's unique lived experience. IPA was chosen over other qualitative methodologies as the research question specifically investigates the lived experiences of adolescents who have diabetes mellitus and poor glycaemic control.

Indeed, IPA aims to explore how participants interpret and make sense of their own difficulties, which is compatible with the research aims of examining how adolescents believe that diabetes mellitus and poor glycaemic control may have affected their identity and relationships with others.

The audio-recorded interviews will be transcribed verbatim and it is hoped that a line-by-line analysis of the transcripts will be undertaken. The results will be presented as themes which have emerged from the data. The themes will be supported by direct quotations from the transcripts.

## 6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

|                |                       |                   |           |
|----------------|-----------------------|-------------------|-----------|
|                | Title                 | Forename/Initials | Surname   |
|                | Dr                    | Liz               | Whitehead |
| Post           | Clinical Psychologist |                   |           |
| Qualifications |                       |                   |           |

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|                |                                                                                      |
|----------------|--------------------------------------------------------------------------------------|
| Employer       | Betsi Cadwaladr University Health Board                                              |
| Work Address   | Minffordd Ward, Paediatric clinical psychology,<br>Ysbyty Gwynedd<br>Bangor          |
| Post Code      | LL57 2PW                                                                             |
| Telephone      | 01248 385488                                                                         |
| Fax            |                                                                                      |
| Mobile         |                                                                                      |
| Work Email     | liz.whitehead@wales.nhs.uk                                                           |
|                |                                                                                      |
|                | Title Forename/Initials Surname<br>Dr Renee Rickard                                  |
| Post           | Clinical Psychologist                                                                |
| Qualifications |                                                                                      |
| Employer       | Betsi Cadwaladr University Health Board                                              |
| Work Address   | North Wales Clinical Psychology Programme<br>Brigantia Building<br>Bangor University |
| Post Code      | LL57 2AS                                                                             |
| Telephone      | 01248 383778                                                                         |
| Fax            |                                                                                      |
| Mobile         |                                                                                      |
| Work Email     | r.rickard@bangor.ac.uk                                                               |

## A64. Details of research sponsor(s)

## A64-1. Sponsor

|                                                                                                       |                                         |
|-------------------------------------------------------------------------------------------------------|-----------------------------------------|
| Lead Sponsor                                                                                          |                                         |
| Status:                                                                                               | Commercial status:                      |
| <input type="radio"/> NHS or HSC care organisation                                                    |                                         |
| <input checked="" type="radio"/> Academic                                                             |                                         |
| <input type="radio"/> Pharmaceutical industry                                                         |                                         |
| <input type="radio"/> Medical device industry                                                         |                                         |
| <input type="radio"/> Local Authority                                                                 |                                         |
| <input type="radio"/> Other social care provider (including voluntary sector or private organisation) |                                         |
| <input type="radio"/> Other                                                                           |                                         |
| <i>If Other, please specify:</i>                                                                      |                                         |
| Contact person                                                                                        |                                         |
| Name of organisation                                                                                  | School of Psychology, Bangor University |
| Given name                                                                                            | Hein                                    |
| Family name                                                                                           | Francis                                 |
| Address                                                                                               | School of Psychology                    |
| Town/city                                                                                             | Bangor University                       |
| Post code                                                                                             | LL57 2AS                                |
| Country                                                                                               | UNITED KINGDOM                          |
| Telephone                                                                                             | 01248388339                             |

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Fax 01248382599  
E-mail h.francis@bsngor.ac.uk

Is the sponsor based outside the UK?

Yes  No

*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

A65. Has external funding for the research been secured?

- Funding secured from one or more funders  
 External funding application to one or more funders in progress  
 No application for external funding will be made

What type of research project is this?

- Standalone project  
 Project that is part of a programme grant  
 Project that is part of a Centre grant  
 Project that is part of a fellowship/ personal award/ research training award  
 Other

Other – please state:

DClinPsy

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes  No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

A68-1. Give details of the lead NHS R&amp;D contact for this research:

|              |                                                                      |                   |         |
|--------------|----------------------------------------------------------------------|-------------------|---------|
|              | Title                                                                | Forename/Initials | Surname |
|              |                                                                      | Rossela           | Roberts |
| Organisation | BCUHB                                                                |                   |         |
| Address      | Research and Development Office<br>Clinical School<br>Ysbyty Gwynedd |                   |         |
| Post Code    | LL57 2PW                                                             |                   |         |
| Work Email   | rossela.roberts@wales.nhs.uk                                         |                   |         |
| Telephone    | 01248483877                                                          |                   |         |
| Fax          |                                                                      |                   |         |
| Mobile       |                                                                      |                   |         |

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

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A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/06/2013

Planned end date: 31/07/2014

Total duration:

Years: 1 Months: 1 Days: 31

A71-2. Where will the research take place? (Tick as appropriate)

- England
- Scotland
- Wales
- Northern Ireland
- Other countries in European Economic Area

Total UK sites in study: 2

Does this trial involve countries outside the EU?

 Yes  No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:

- NHS organisations in England
- NHS organisations in Wales 2
- NHS organisations in Scotland
- HSC organisations in Northern Ireland
- GP practices in England
- GP practices in Wales
- GP practices in Scotland
- GP practices in Northern Ireland
- Social care organisations
- Phase 1 trial units
- Prison establishments
- Probation areas
- Independent hospitals
- Educational establishments
- Independent research units
- Other (give details)

Total UK sites in study: 2

A76. Insurance/indemnity to meet potential legal liabilities

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

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*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (NHS sponsors only)  
 Other insurance or indemnity arrangements will apply (give details below)

Bangor University has the appropriate level of insurance cover for this research project.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)  
 Other insurance or indemnity arrangements will apply (give details below)

Bangor University has the appropriate level of insurance cover for this research project.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)  
 Research includes non-NHS sites (give details of insurance/indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (NHS sponsors only)  
 Other insurance or indemnity arrangements will apply (give details below)

Bangor University has the appropriate level of insurance cover for this research project.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.



*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)  
 Other insurance or indemnity arrangements will apply (give details below)

Bangor University has the appropriate level of insurance cover for this research project.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)  
 Research includes non-NHS sites (give details of insurance/indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

## PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

Participants within the 12-16 years age group will be included. This is because the research is specifically focusing on the lived experiences of adolescents with diabetes mellitus and poor glycaemic control.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

There are no control participants as this is a qualitative design.

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

The adolescent will be required to read the participant information sheet and the parent/guardian will be required to read the parent/guardian information sheet.

If the adolescent and the parent/guardian are happy for the adolescent to take part, the adolescent and the parent/guardian will be required to complete and sign an opt-in form. Upon receipt of the opt-in form, Llinos Griffith will contact them via telephone to discuss the research and answer any questions. If the adolescent and parent/guardian are happy for the adolescent to take part, a date and time for the interview will be arranged.

Prior to commencing the interview, the adolescent and their parent/guardian will be required to read the information sheets again. If they are happy to take part, the adolescent will be asked to complete and sign a written consent form. The parent/guardian will also be asked to complete and sign a written assent form. The interview will only be conducted if both the consent form and the assent forms are completed.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

The participant information sheet, the opt-in form, and the participant consent form have been written according to the



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developmental appropriate level of young people between the ages of 12-15. The researcher will telephone all participants individually to explain the information in further detail, which can be repeated and simplified should a young person require this.

*Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.*

**PART C: Overview of research sites**

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

| Research site    |                                         | Investigator / Collaborator / Contact |          |
|------------------|-----------------------------------------|---------------------------------------|----------|
| Institution name | Betsi Cadwaladr University Health Board | Title                                 | Miss     |
| Department name  | Paediatric Psychology                   | First name/<br>Initials               | Llinos   |
| Street address   | Dewi Ward, Ysbyty Gwynedd               | Surname                               | Griffith |
| Town/city        | Bangor                                  |                                       |          |
| Post Code        | LL57 2PW                                |                                       |          |
| Institution name | Betsi Cadwaladr University Health Board | Title                                 | Miss     |
| Department name  | Paediatric Psychology                   | First name/<br>Initials               | Llinos   |
| Street address   | Ysbyty Glan Clwyd                       | Surname                               | Griffith |
| Town/city        | Bodelwyddan                             |                                       |          |
| Post Code        | LL18 5UJ                                |                                       |          |

**PART D: Declarations****D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
  - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
  - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
  - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
  - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
  - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication (*Not applicable for R&D Forms*)

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- Chief Investigator  
 Sponsor

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- Study co-ordinator  
 Student  
 Other – please give details  
 None

Access to application for training purposes (*Not applicable for R&D Forms*)

*Optional – please tick as appropriate:*

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: .....

Print Name: Lino S Griffith

Date: (dd/mm/yyyy)

## D2. Declaration by the sponsor's representative

*If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.*

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature: .....

Print Name: Mr Hein Francis

Post: School Manager, School of Psychology, Bangor University.

Organisation: Bangor University

Date: (d/d/m/yyyy)

## D9. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

## Academic supervisor 1

Signature: .....

Print Name: Dr Renee Rickard

Post: Clinical Psychology

Organisation: Betsi Cadwaladr University Health Board

Date: (dd/mm/yyyy)

## Academic supervisor 2

Signature: .....

Print Name: Dr Liz Whitehead

Post: Clinical Psychology

Organisation: Betsi Cadwaladr University Health Board

Date: (dd/mm/yyyy)

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Reference:  
13/MA/0155

IRAS Version 3.5

Date: 06/05/2013

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124901/443916/1/394

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.  
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



**Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin**  
**North Wales Research Ethics Committee - West**

Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor, Gwynedd  
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877  
Email: [Rossela.Roberts@wales.nhs.uk](mailto:Rossela.Roberts@wales.nhs.uk)  
Website : [www.nres.nhs.uk](http://www.nres.nhs.uk)

Miss Llinos Griffith  
North Wales Clinical Psychology Programme  
School of Psychology, Bangor University  
43 College Road,  
Bangor, Gwynedd  
LL572DG  
[pspefb@bangor.ac.uk](mailto:pspefb@bangor.ac.uk); [llinos.g@live.co.uk](mailto:llinos.g@live.co.uk)

17 May 2013

Dear Miss Griffith,

**Study title:** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?  
**REC reference:** 13/WA/0155  
**IRAS project ID:** 124901

The Research Ethics Committee reviewed the above application at the meeting held on 16 May 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Coordinator Dr Rossela Roberts, [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)

**Ethical opinion**

**Ethical issues raised by the Committee in private discussion, together with responses given by you when invited into the meeting**

Social or scientific value; purpose and need: scientific design and conduct of the study; patient /public representative involvement in study design

The Committee considered whether the objectives, design, methodology, and the conduct of the study are appropriately described in the protocol. The Committee congratulated you on a very valuable study and a well written protocol.

It was noted that from 1 October 2011 the way in which HbA1c results are expressed has changed. Results are now reported in the IFCC reference method of mmol/mol, rather than the DCCT units as a percentage. Guidance on the new values expressed as mmol/mol and the recommended targets in new units can be found at <http://www.diabetes.org.uk/Professionals/Publications-reports-and-resources/Tools/Changes-to-HbA1c-values/>

The Committee recommended that the protocol and participant information is updated to reflect this change.

The Committee concluded that the research design and the proposed analysis were deemed suitable for answering the research question. No further ethical issues were raised in relation to the scientific value and conduct of the study.



Independent review

The Committee discussed whether the study has been independently peer reviewed and whether the review is in scale of the research and risks involved. The Committee concluded that the review of the project by Bangor University School of Psychology Research Ethics and Governance Committee is sufficient evidence of peer-review for this type of project. No further ethical issues were raised regarding the peer-review.

Recruitment arrangements; fair participant selection

The Committee was satisfied that the selection of potential participants has taken into account their clinical care and sufficient details are provided in the protocol and the application form regarding the inclusion and exclusion criteria. The Committee raised no further issues.

Favourable risk benefit ratio; anticipated benefits/risks for research participants

The Committee discussed the anticipated benefits and potential risks to participants and were satisfied that the applicant has suitably identified the risks and benefits and highlighted them in the information given to potential participants. No further ethical issues were raised in relation to the risk/benefit for research participant.

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality

The Committee discussed the information governance aspects of the study. The Committee discussed where and for how long will data be stored, and clarified who will have access to the data.

The Committee agreed that there is adequate information regarding the potential need for breach of confidentiality in case of incidental disclosures, but requested a clarification of the actual process in place to deal with such occurrences. The Chief Investigator clarified that the first port of call would be the supervisor who would direct the appropriate action. The Committee suggested that GP would need to be informed. Dr Whitehead clarified that young people are seen in the Paediatric team, not in GP surgery and therefore this would not be appropriate. The Committee concluded that explicit consent needs to be sought to inform the healthcare team. No further ethical issues were raised in relation to data protection.

Informed Consent process; adequacy and completeness of Participant Information

The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The information is clear as to what the participant consents and there is no inducement or coercion.

The Committee agreed that the procedures described in the protocol have been addressed in the Information Sheet but felt that some minor corrections are needed to define "poor glycaemic control" in the first paragraph, and clarify the intention to use anonymised quotations from respondents in a future publication.

Suitability of the applicant and facilities

The Committee discussed the suitability of the applicant and concluded that you are sufficiently qualified and adequately supervised to carry out this research.

General comments/ missing information/ typographical errors/ application errors/ suitability of the study summary

The summary of the study as it appears in section A6-1 of the REC application form was deemed to be an accurate description of the study and suitable for publication on the NRES website.

The Chairman thanked you and Dr Whitehead for your availability to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.

**On the basis of the information provided, the Committee was satisfied with the following aspects of the research:**

- Social or scientific value; purpose and need
- Scientific design and conduct of the study
- Independent review
- Recruitment arrangements; fair participant selection
- Favourable risk benefit ratio; anticipated benefits/risks for research participants
- Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality
- Suitability of the applicant and facilities
- Suitability of the study summary

**The Committee identified issues with the following aspects of the research:**

- Informed Consent process; adequacy and completeness of Participant Information

The members of the Committee present 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.

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject the management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**The favourable opinion is subject to the following conditions being met prior to the start of the study:**

The Committee requested that the following amendments are to be made to the Participant Information Sheet and Consent Form

1. Explain/define 'poor glycaemic control' in the introductory paragraph.
2. Use the new IFCC reference method of mmol/mol, rather than the DCCT units as a percentage when describing normal ranges.
3. Clarify the intention to use anonymised quotations from respondents in a future publication; seek explicit consent.
4. Seek explicit consent to inform the healthcare team of any incidental disclosures.
5. The amended Participant Information Sheets and Consent Forms need translating and the Welsh language version made available to participants.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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. It is 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).

### Approved documents

The documents reviewed and approved at the meeting were:

| <i>Document</i>                                  | <i>Version</i> | <i>Date</i>   |
|--------------------------------------------------|----------------|---------------|
| REC application 124901/443916/1/394              |                | 06 May 2013   |
| Protocol                                         | 4              | 22 March 2013 |
| Participant Information Sheet                    | 2              | 19 April 2013 |
| Participant Information Sheet: Parent/Guardian   | 2              | 19 April 2013 |
| Interview Schedules/Topic Guides                 | 1              | 22 March 2013 |
| Participant Consent Form                         | 2              | 19 April 2013 |
| Participant Consent Form: Parent/Guardian        | 2              | 19 April 2013 |
| Other: Opt-in Form                               | 1              | 22 March 2013 |
| Other: Recruitment Information Sheet             | 1              | 22 March 2013 |
| Investigator CV                                  |                | 11 April 2013 |
| Other: Academic Supervisor CV (Dr Liz Whitehead) |                | 11 April 2013 |
| Other: Academic Supervisor Cv (Dr Renee Rickard) |                | 22 April 2013 |
| Letter from Sponsor                              |                | 19 April 2013 |
| Evidence of insurance or indemnity               |                | 09 July 2012  |

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

No declarations of interest were made in relation to this application.

### 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.

13/WA/0155

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**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 NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

|                   |                                                       |
|-------------------|-------------------------------------------------------|
| <b>13/WA/0155</b> | <b>Please quote this number on all correspondence</b> |
|-------------------|-------------------------------------------------------|

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



**Mr Derek James Crawford, MBChB, FRCS**  
Chair

E-mail: [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)

Enclosure: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

*"After ethical review – guidance for researchers"*



Copy: Sponsor: Dr. Charles Leek,  
School of Psychology, Bangor University  
Adeilad Brigantia, Penrallt Road  
Bangor, Gwynedd , LL57 2AS [e.c.leek@bangor.ac.uk](mailto:e.c.leek@bangor.ac.uk)

Academic Supervisor: Dr Renee Rickard  
School of Psychology,  
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Brigantia Building, Penrallt Road,  
Bangor, Gwynedd, LL57 2AS [r.rickard@bangor.ac.uk](mailto:r.rickard@bangor.ac.uk)

Dr Liz Whitehead  
Paediatric Clinical Psychology,  
Minfford Ward,  
BCUHB, Ysbyty Gwynedd  
Bangor, Gwynedd, LL57 2PW [liz.whitehead@wales.nhs.uk](mailto:liz.whitehead@wales.nhs.uk)

R&D Office: Mrs Lona Tudor-Jones  
Betsi Cadwaladr University Health Board  
Research and Development Office  
Holywell Community Hospital  
Holywell, CH8 7TZ [Lona.TudorJones@wales.nhs.uk](mailto:Lona.TudorJones@wales.nhs.uk)

**North Wales Research Ethics Committee West**  
**Attendance at Committee meeting on 16 May 2013**

**Committee Members**

| <i>Name</i>              | <i>Profession</i>                       | <i>Capacity</i> | <i>Present</i> |
|--------------------------|-----------------------------------------|-----------------|----------------|
| Dr. Karen Addy           | Clinical Psychologist                   | Expert          | No             |
| Dr. Swapna Alexander     | Consultant Physician                    | Expert          | Yes            |
| Ms Valerie Barcoft       | Volunteer Worker                        | Lay +           | Yes            |
| Mrs. Kathryn Chester     | Research Nurse                          | Expert          | Yes            |
| Dr. Christine Clark      | Consultant Obstetrician & Gynaecologist | Expert          | Yes            |
| Mr. Derek James Crawford | Consultant Surgeon (Chairman)           | Expert          | Yes            |
| Mrs. Gwen Dale-Jones     | Retired Personal Assistant              | Lay +           | Yes            |
| Mr. Hywel Lloyd Davies   | Solicitor (Alternate Vice-Chairman)     | Lay +           | No             |
| Ms. Gillian Jones        | Student                                 | Lay +           | Yes            |
| Dr. Mark Lord            | Consultant Pathologist                  | Expert          | No             |
| Dr. Neil McKenzie        | Retired Physicist                       | Lay +           | Yes            |
| Dr. Jason Walker         | Consultant Anaesthetist                 | Expert          | No             |
| Dr. Philip Wayman White  | General Practitioner (Vice-Chairman)    | Expert          | Yes            |

**Deputy Members**

| <i>Name</i>        | <i>Profession</i>                              | <i>Capacity</i> | <i>Present</i> |
|--------------------|------------------------------------------------|-----------------|----------------|
| Dr. Michael Cronin | Consultant Paediatrician (deputy to Dr. Clark) | Expert          | Yes            |

**Written comments received from**

| <i>Name</i>      | <i>Profession</i>       | <i>Capacity</i> | <i>Present</i> |
|------------------|-------------------------|-----------------|----------------|
| Dr. Jason Walker | Consultant Anaesthetist | Expert          | No             |

**In attendance**

| <i>Name</i>         | <i>Position (or reason for attending)</i> |
|---------------------|-------------------------------------------|
| Dr. Rossela Roberts | Committee Coordinator                     |

Miss Llinos Griffith  
North Wales Psychology Programme  
School of Psychology, Bangor University  
43 College Road  
Bangor  
Gwynedd  
LL57 2DG

North Wales Research Ethics Committee – West  
Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor  
Gwynedd  
LL57 2PW

06/03/2013

Dear Mr Derek James Crawford, MBChB, FRCS Chair,

**Study title:** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?

**REC reference:** 13/WA/0155

**IRAS project ID:**124901

As you are aware, following the Research Ethics Committee meeting held on the 16<sup>th</sup> May 2013, a favourable opinion subject to the following conditions being completed to the Information Sheet and Consent Form was made. I have outlined how each condition has been met and the relevant amended documents have been attached.

**1. Explain/define 'poor glycaemic control' in the introductory paragraph.**

'Poor glycaemic control' is now explained in the introductory paragraph of the participant information sheet and the parent/guardian information sheet.

- 2. Use the new IFCC reference method of mmol/mol rather than the DCCT units as a percentage when describing normal ranges.**

As recommended in your letter, the research protocol has been amended to include the mmol/mol units (page 5).

- 3. Clarify the intention to use anonymised quotations from respondents in a future publication; seek explicit consent.**

The participant information sheet (page 6) and the parent/guardian information sheet have been amended to include information regarding the use of anonymous quotations. Explicit consent is also sought on the amended participant consent form and the parent/guardian assent form.

- 4. Seek explicit consent to inform the healthcare team of any incidental disclosures**

The participant information sheet (page 6) and the parent/guardian information sheet (page 6), have been amended to include this information. Explicit consent is also sought on the amended participant consent form and the parent/guardian assent form, which outlines that a member of the child's healthcare team will be informed.

- 5. The amended Participant Information Sheets and Consent Forms need translating and the Welsh language version made available to participants.**

All the information sheets and consent forms will be translated into Welsh following ethical approval.

#### Other amendments

During the Committee meeting, it was asked how participants will be informed of the research outcomes/given feedback about the research. This has now been made explicit on the participant information sheet (page 6), the parent/guardian information sheet (page 6), the participant consent form and the parent/guardian assent form. It is outlined that if the participant wants feedback, a general summary will be sent to them by post when the research has been completed and approved.

Yours Sincerely,

Llinos Griffith

Trainee Clinical Psychologist



Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.  
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



**Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin**  
**North Wales Research Ethics Committee - West**

Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor, Gwynedd  
LL57 2PW

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Website : [www.nres.nhs.uk](http://www.nres.nhs.uk)

Miss Llinos Griffith  
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43 College Road,  
Bangor, Gwynedd  
LL572DG [pspefb@bangor.ac.uk](mailto:pspefb@bangor.ac.uk); [llinos.g@live.co.uk](mailto:llinos.g@live.co.uk)

10 June 2013

Dear Miss Griffith,

**Study title:** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?  
**REC reference:** 13/WA/0155  
**IRAS project ID:** 124901

Thank you for your letter of 03 June 2013.

I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 17 May 2013

**Documents received**

The documents received were as follows:

| <i>Document</i>                                                               | <i>Version</i> | <i>Date</i>  |
|-------------------------------------------------------------------------------|----------------|--------------|
| Covering Letter: documents submitted in compliance with additional conditions |                | 03 June 2013 |
| Protocol                                                                      | 5              | 03 June 2013 |
| Participant Information Sheet: Young People                                   | 3              | 03 June 2013 |
| Participant Information Sheet: Parent / Guardian                              | 3              | 03 June 2013 |
| Participant Consent Form: Young People                                        | 3              | 03 June 2013 |
| Participant Consent Form: Parent / Guardian Assent Form                       | 3              | 03 June 2013 |

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

| <i>Document</i>                                                                  | <i>Version</i> | <i>Date</i>   |
|----------------------------------------------------------------------------------|----------------|---------------|
| REC application 124901/443916/1/394                                              |                | 06 May 2013   |
| Protocol                                                                         | 5              | 03 June 2013  |
| Participant Information Sheet: Young People                                      | 3              | 03 June 2013  |
| Participant Information Sheet: Parent / Guardian                                 | 3              | 03 June 2013  |
| Interview Schedules/Topic Guides                                                 | 1              | 22 March 2013 |
| Participant Consent Form: Young People                                           | 3              | 03 June 2013  |
| Participant Consent Form: Parent / Guardian Assent Form                          | 3              | 03 June 2013  |
| Other: Opt-in Form                                                               | 1              | 22 March 2013 |
| Other: Recruitment Information Sheet                                             | 1              | 22 March 2013 |
| Investigator CV                                                                  |                | 11 April 2013 |
| Other: Academic Supervisor CV (Dr Liz Whitehead)                                 |                | 11 April 2013 |
| Other: Academic Supervisor Cv (Dr Renee Rickard)                                 |                | 22 April 2013 |
| Letter from Sponsor                                                              |                | 19 April 2013 |
| Evidence of insurance or indemnity                                               |                | 09 July 2012  |
| Covering Letter:<br>documents submitted in compliance with additional conditions |                | 03 June 2013  |

You should ensure that the sponsor has a copy of the final documentation for the study.

It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

|                   |
|-------------------|
| <b>13/WA/0155</b> |
|-------------------|

|                                                       |
|-------------------------------------------------------|
| <b>Please quote this number on all correspondence</b> |
|-------------------------------------------------------|

Yours sincerely



**Dr Rossela Roberts**  
**Committee Co-ordinator**

E-mail: [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)

Copy: Sponsor: Dr. Charles Leek,  
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Academic Supervisor: Dr Renee Rickard  
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Dr Liz Whitehead  
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R&D Office: Mrs Lona Tudor-Jones  
Betsi Cadwaladr University Health Board  
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Holywell Community Hospital  
Holywell, CH8 7TZ [Lona.TudorJones@wales.nhs.uk](mailto:Lona.TudorJones@wales.nhs.uk)

file copy

Miss Llinos Griffith  
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LL57 2DG

R&D Internal Review Panel - West  
Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor  
Gwynedd  
LL57 2PW

08/07/2013

Dear BCUHB R&D Internal Review Panel - West,

**Study title:** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?

**REC reference:** 13/WA/0155

**IRAS project ID:**124901

As you are aware, following the meeting held on the 4<sup>th</sup> July 2013, it was outlined that all governance checks were not satisfied. I have therefore outlined the concerns raised and how I have addressed them. The amended documents have been attached.

- 1. The committee requested that both consent forms are re-designed to remove the 'YES/NO' response option and replace with boxes which the participants should initial.**

The opt-in form and both consent forms have been re-designed according to the above guideline.

- 2. The committee noted that in page 1 of the protocol the conversion of Hba1c results to be IFCC reference method is not correct (as 7% is now expressed as 53 mmol/mol, 7.5% is infact 58 mmol/mol. The committee suggested that this can be amended as a typographical error and the submission protocol version is not required.**

As recommended, this has been amended as a typographical error and the protocol has been attached for your information.

- 3. A further comment was made regarding the recruitment process, as it may be useful to account for the gender mix (to include proportionate representation of male/female participants). This is not conditions of approval.**

This comment will be further considered by the researchers.

Yours Sincerely,

Llinos Griffith

Trainee Clinical Psychologist



Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.  
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



**Pwyllgor Moezeg Ymchwil Gogledd Cymru - Y Orllewin**  
**North Wales Research Ethics Committee - West**

Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
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12 July 2013

Dear Miss Griffith,

**Study title:** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?  
**REC reference:** 13/WA/0155  
**IRAS project ID:** 124901  
**Amendment number:** AM01 (minor)  
**Amendment date:** 08 July 2013

Thank you for your letter of 08 July 2013, notifying the Committee of the above amendment.

The amendment has been considered by the Chair.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees.

The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

| Document                                  | Version | Date         |
|-------------------------------------------|---------|--------------|
| Notification of a Minor Amendment         | AM01    | 08 July 2013 |
| Protocol                                  | 6       | 08 July 2013 |
| Opt-in Form                               | 2       | 08 July 2013 |
| Participant Consent Form: Parent/Guardian | 4       | 08 July 2013 |
| Participant Consent Form                  | 4       | 08 July 2013 |

**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.

|                   |                                                       |
|-------------------|-------------------------------------------------------|
| <b>13/WA/0155</b> | <b>Please quote this number on all correspondence</b> |
|-------------------|-------------------------------------------------------|

Yours sincerely



**Dr Rossela Roberts**  
**Committee Co-ordinator**

E-mail: [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)

Copy: Sponsor: Dr. Charles Leek,  
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Academic Supervisor: Dr Renee Rickard  
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R&D Office: Mrs Lona Tudor-Jones  
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Research and Development Office  
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Holywell, CH8 7TZ [Lona.TudorJones@wales.nhs.uk](mailto:Lona.TudorJones@wales.nhs.uk)

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GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd Prifysgol  
Betsi Cadwaladr  
University Health Board

**Panel Arolygu Mewnol Y&D - Y Gorllewin  
R&D Internal Review Panel - West**

Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor, Gwynedd  
LL57 2PW

Miss Llinos Griffith  
42 Penrhos Road  
Bangor  
Gwynedd  
LL57 2AX

Chairman/Cadeirydd - Dr. Mike C Jackson, CPsychol, DClinPsych, DPhil  
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Tel/Fax: 01248 384 877

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05 July 2013

Dear Miss Griffith,

**Re: Notification that governance checks are not satisfied**

**Study Title** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control  
**IRAS reference** 124901

Thank you for submitting your R&D application and supporting documents.  
The above study was reviewed by the BCUHB R&D Internal Review Panel - West in its meeting of the 04 July 2013.

Below, please find a list of documents you have submitted for review:

| Document:                                    | Version | Date       |
|----------------------------------------------|---------|------------|
| R&D Checklist                                | -       | -          |
| R&D Form – 124901/464795/14/109              | -       | 17/06/2013 |
| SSI Checklist                                | -       | -          |
| SSI Form – 124901/463712/6/869/192441/274303 | -       | 12/06/2013 |
| Protocol                                     | 5       | 03/06/2013 |
| Participant Information Sheet                | 3       | 03/06/2013 |
| Parent/Guardian Information Sheet            | 3       | 03/06/2013 |
| Participant Consent Form                     | 3       | 03/06/2013 |
| Parent/Guardian Assent Form                  | 3       | 03/06/2013 |
| Opt-in Form                                  | 1       | 22/03/2013 |
| Interview Schedule                           | 1       | 22/03/2013 |
| Recruitment Information Sheet                | 1       | 22/03/2013 |
| REC Favourable Opinion Letter                | 1       | 17/05/2013 |
| University Ethics Approval                   | -       | 19/04/2013 |
| UMAL Insurance Certificate                   | -       | -          |
| CV of CI (L Griffith)                        | -       | 11/04/2013 |
| CV of Academic Supervisor (L Whitehead)      | -       | 11/04/2013 |
| CV of Academic Supervisor (R Rickard)        | -       | 22/04/2013 |

Unfortunately, we have been unable to satisfy all the governance checks for your study.  
Below are the details of the governance check(s) that we have been unable to satisfy:

The Committee considered the proposed consent process to ensure that any legal implications presented by the study are highlighted and considered the accuracy of the information provided.  
The following issues were raised:

- The committee requested that both consent forms are re-designed to remove the 'YES/NO' response option and replace with boxes which the participants should initial

The Committee considered whether the objectives, design, methodology, statistical considerations (or other methods of data analysis) and the organisation of the study are appropriately described in the protocol.

The following issues were raised:

- The committee noted that in page 1 of the protocol the conversion of Hba1c results to the IFCC reference method is not correct (as 7% is now expressed as 53 mmol/mol, 7.5% is in fact 58 mmol/mol. The committee suggested that this can be amended as a typographical error and the submission protocol version is not required.
- A further comment was made regarding the recruitment process, as it may be useful to account for the gender mix (to include proportionate representation of male/female participants). This is not conditions of approval.

If you are able to provide additional information or further clarification to resolve these issues, we will review the relevant local governance checks again.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chairman.

The Committee will issue a final opinion on the application within a maximum of 60 days from the initial receipt of application, excluding the time taken by you to respond fully to the above points.

The Committee expects to receive a response from you by no later than 25 July 2013 otherwise we shall consider the application to have been withdrawn.  
Should you decide not to proceed with this study, please inform us as soon as possible.

Please do not hesitate to contact us if you require any further information or assistance.

Kind regards



Dr. Rossela Roberts, MICR, CSci  
Clinical Governance Officer (R&D/Ethics)

Copy to:

Sponsor: Hefin Francis  
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LL57 2AS [h.francis@bangor.ac.uk](mailto:h.francis@bangor.ac.uk)

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---



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R&D Internal Review Panel - West  
Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor  
Gwynedd  
LL57 2PW

08/07/2013

Dear BCUHB R&D Internal Review Panel - West,

**Study title:** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control?

**REC reference:** 13/WA/0155

**IRAS project ID:**124901

As you are aware, following the meeting held on the 4<sup>th</sup> July 2013, it was outlined that all governance checks were not satisfied. I have therefore outlined the concerns raised and how I have addressed them. The amended documents have been attached.

- 1. The committee requested that both consent forms are re-designed to remove the 'YES/NO' response option and replace with boxes which the participants should initial.**

The opt-in form and both consent forms have been re-designed according to the above guideline.

- 2. The committee noted that in page 1 of the protocol the conversion of Hba1c results to be IFCC reference method is not correct (as 7% is now expressed as 53 mmol/mol, 7.5% is infact 58 mmol/mol. The committee suggested that this can be amended as a typographical error and the submission protocol version is not required.**

As recommended, this has been amended as a typographical error and the protocol has been attached for your information.

- 3. A further comment was made regarding the recruitment process, as it may be useful to account for the gender mix (to include proportionate representation of male/female participants). This is not conditions of approval.**

This comment will be further considered by the researchers.

Yours Sincerely,

Llinos Griffith

Trainee Clinical Psychologist



**Panel Arolygu Mewnol Y&D - Y Gorllewin  
R&D Internal Review Panel - West**

Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office  
Bangor, Gwynedd  
LL57 2PW

Miss Llinos Griffith  
42 Penrhos Road  
Bangor  
Gwynedd  
LL57 2AX

Chairman/Cadeirydd - Dr. Mike C Jackson, CPsychol, DClinPsych, DPhil  
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Tel/Fax: 01248 384 877

[pspefb@bangor.ac.uk](mailto:pspefb@bangor.ac.uk)

17 July 2013

Dear Miss Griffith

**Re: Confirmation that R&D governance checks are complete / R&D approval granted**

**Study Title** How do adolescents with Diabetes Mellitus experience having diabetes and poor glycaemic control  
**IRAS reference** 124901

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

Thank you for responding to the Committee's request for further information.

The R&D office considered the response on behalf of the Committee and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

**The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.**

The documents reviewed and approved are listed below:

| Document:                                               | Version | Date       |
|---------------------------------------------------------|---------|------------|
| R&D Checklist                                           | -       | -          |
| R&D Form – 124901/464795/14/109                         | -       | 17/06/2013 |
| SSI Checklist                                           | -       | -          |
| SSI Form – 124901/463712/6/869/192441/274303            | -       | 12/06/2013 |
| Protocol                                                | 6       | 08/07/2013 |
| Participant Information Sheet                           | 3       | 03/06/2013 |
| Parent/Guardian Information Sheet                       | 3       | 03/06/2013 |
| Participant Consent Form                                | 4       | 08/07/2013 |
| Parent/Guardian Assent Form                             | 4       | 08/07/2013 |
| Opt-in Form                                             | 2       | 08/07/2013 |
| Interview Schedule                                      | 1       | 22/03/2013 |
| Recruitment Information Sheet                           | 1       | 22/03/2013 |
| REC Favourable Opinion Letter                           | 1       | 17/05/2013 |
| University Ethics Approval                              | -       | 19/04/2013 |
| UMAL Insurance Certificate                              | -       | -          |
| CV of CI (L Griffith)                                   | -       | 11/04/2013 |
| CV of Academic Supervisor (L Whitehead)                 | -       | 11/04/2013 |
| CV of Academic Supervisor (R Rickard)                   | -       | 22/04/2013 |
| R&D Letter from L Griffith                              | -       | 08/07/2013 |
| SL31 Acknowledgement of NOMA 13-WA-0155-AM01 (Griffith) | -       | 12/07/2013 |

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009).  
An electronic link to this document is provided on the BCUHB R&D WebPages.  
Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the NISCHR CRP, please go to:  
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at:  
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

[http://www.crnc.nihr.ac.uk/about\\_us/processes/portfolio/p\\_recruitment](http://www.crnc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment).


Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.


If you need any support in uploading this data, please contact [wendy.scrase2@wales.nhs.uk](mailto:wendy.scrase2@wales.nhs.uk) or [sion.lewis@wales.nhs.uk](mailto:sion.lewis@wales.nhs.uk)

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Kind regards



 Dr. Mike C Jackson  
Associate Director of R&D  
Chairman IRP-West

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Bangor University  
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---

**Appendix 5B.**

**Research documents**



## Research Proposal

### 1. Project Title

The lived experiences of adolescents with Diabetes Mellitus who have poor glycaemic control.

### 2. Supervision

i). **Dr Liz Whitehead** (Clinical Psychologist)

The Heulwen Unit (Paediatric Outpatients)

Ysbyty Gwynedd

Bangor

LL57 2PW

Tel: 01248 385488

ii). **Dr Renee Rickard** (Clinical Psychologist) – Research and methodology supervision

Nant y Glyn Centre

Nant y Glyn Road

Colwyn Bay

Conwy

LL29 7RB

**And**

NWCPP

School of Psychology

Bangor University

Bangor

LL57 2DG

Tel: 01492 532164 & 01248 383778

### 3. Background

Diabetes Mellitus (DM1) or Type I Diabetes is a chronic disease whereby the immune system destroys the cells which produce insulin. This results with chronic insulin deficiency and increased blood glucose levels (Diabetes UK, 2010). The management of DM1 requires individuals to maintain blood glucose levels (HbA1C) of under 7.5% (NICE guidelines, 2004). However, it is important to note that since October 2011 HbA1c results in the UK are now reported in the IFCC reference method of mmol/mol. Therefore HbA1C levels of 7.5% are now expressed as 58 mmol/mol.

Successfully managing DM1 requires individuals to coordinate several insulin injections per day, regularly monitor blood-glucose levels, and also manage their weight, diet and exercise levels accordingly (Vesco et al., 2010).



Poor glycaemic control such as missing an insulin dose or consuming too many carbohydrates may result with abnormally high glucose levels, referred to as hyperglycemia. Prolonged hyperglycemia can lead to a serious condition called ketoacidosis, which is a life-threatening condition requiring hospitalisation (Diabetes UK, 2010). Alternatively, abnormally low levels of glucose (hypoglycaemia), which may be preceded by excessive exercise or under-eating, may result with semi-consciousness and the individual eventually going into a coma. DM1 is therefore a potentially life-threatening disease, which is associated with shorter life expectancy and poorer quality of life (American Psychological Association, 2012). Specifically, DM1 is the leading cause of end-stage renal failure, blindness in working-age adults, and non-traumatic lower-limb amputations (Centers for Disease Control and Prevention, 2005). Furthermore, the condition significantly increases the risk of cardiovascular mortality (Centers for Disease Control and Prevention, 2005).

Within the UK, 25,000 children and young people (under the age of 25) are thought to be affected by DM1 (Diabetes UK, 2010), with the peak age of diagnosis being between the ages of 10 and 14 (Department of Health, 2007). Indeed, following asthma and cerebral palsy, DM1 is the most common chronic illness affecting children in the UK (Ismail, 2008). Adolescents with DM1 not only have an increased risk of developing health complications but they are also at increased risk of developing emotional and behavioural problems (NICE guidelines, 2004). It is therefore recommended that adolescents with DM1 should have “timely and on-going access to mental health professionals” (NICE guidelines, 2004). Specifically, adolescents with DM1 may develop anxiety and/or depression, particularly if they are experiencing difficulties with managing their diabetes. Adolescents with DM1 are also at increased risk of developing conduct disorder and eating disorders (Rodin et al., 2002). Furthermore, NICE guidelines (2004) maintain that ‘non-adherence to therapy’ should be considered when adolescents have poor glycaemic control or recurrently present with diabetic ketoacidosis.

Considering the detrimental effect that poor glycaemic control may have on the health and wellbeing of adolescents with DM1, clinical psychologists are often asked to assess diabetes treatment-adherence and provide interventions to improve health-related behaviours (American Psychological Association, 2012). Indeed, it is maintained that “psychologists have a crucial role to play in helping children and their families manage Type I diabetes” (Schwartz, Axelrad, Cline & Anderson, 2011). Furthermore, considering that psychological factors are thought to significantly impact upon glycaemic control, it has been recommended that the “inclusion of a clinical psychology component in the integrated diabetes care team is desirable” (Leichter, Dreelin & Moore, 2004).

#### Poor glycaemic control during adolescence

Good diabetes management during adolescence is important to reduce the likelihood of long term complications (The Diabetes Control and Complications Trial; DCCT; 1993). However, it is widely recognised that a large proportion of adolescents have difficulty managing their diabetes, which is evidenced by “deteriorating metabolic control, poorer adherence, and heightened emotional distress” (Tran, Wiebe, Fortenberry, Butler & Berg, 2011). Indeed, global evidence suggests that

metabolic control deteriorates during adolescence, with only 15% of under-fifteens in the UK achieving recommended blood glucose levels (HbA1c) of 7.5% (Diabetes UK, 2010). In light of this, several studies have examined factors which may be associated with poor glycaemic control during adolescence.

Empirical studies have repeatedly demonstrated that poor psychosocial support is associated with negative outcomes for adolescents with DM1 (NICE guidelines, 2004). Indeed, adolescence is an important transition period in the management of diabetes with adolescents being expected to take increasing responsibility from caregivers in the management of their diabetes. Evidence suggests that transferring this responsibility prematurely can lead to poor self-care outcomes for adolescents, whilst those who feel supported by healthcare professionals, family and friends are more likely to have increased medication compliance and motivation (Kyngas & Rissanen, 2001). Contrarily, elevated family conflict and less parental monitoring are both risk factors for poor glycaemic control during adolescence (Vesco et al., 2010). Several other factors have also been associated with poor glycaemic control during adolescence, such as stressful life events (Helgeson, Escobar, Siminerio & Becker, 2010), diabetes-specific distress, longer disease duration and having to inject insulin rather than having insulin pump therapy (Hilliard et al., 2012).

Despite the usefulness of empirical studies, over recent years an increasing number of studies have sought to examine type 1 diabetes in adolescence using qualitative methodologies. A systematic review was undertaken by Spencer, Cooper and Milton (2010) which explored “the causal factors of deteriorating metabolic control in adolescents” (Spencer, Cooper & Milton, 2010). Twenty studies were included in the review and the authors concluded that four main themes emerged from the literature which were; independency and autonomy for diabetes self-care, living with DM1, family relationships and diabetes care. Specifically, intrusive parental input appeared to inhibit the development of diabetes management whilst parents who found a balance between providing support and ‘holding back’ facilitated this process. Furthermore, adolescents described feeling safe when their peers had knowledge of diabetes as they felt confident that they could cope in an emergency. However, over-involvement by peers was thought to be patronizing and intrusive. It was found that knowledge, experience and parental support facilitated self-care, whilst peer-difficulties often resulted with reduced glycaemic control and subsequent feelings of guilt.

It should be noted that Spencer, Cooper and Milton (2010) highlighted some limitations within the literature as only one of the studies included in the review was conducted in the UK, whereas 18 were conducted in the USA. Indeed, the study conducted in the UK did not examine the lived experience of adolescents with DM1 as the study evaluated the effectiveness of a diabetes education programme (Waller, Eiser, Heller & Knowles & Price, 2005). The review therefore recommended that future research should examine the lived experiences of adolescents with DM1 in countries other than the USA. Furthermore, only six studies included in the review explicitly stated an epistemological viewpoint and only three of the studies applied a theoretical framework.

Indeed, several studies have used qualitative methodologies to examine the experiences of adolescents with DM1, such as examining adolescents' perception of healthcare professionals (Woodgate, 1998), parental conflict and diabetes (Weinger, O'Donnell & Ritholz, 2001), factors affecting decision-making (Viklund & Wikblad, 2009) and compliance (Jin, Sklar, Oh & Li, 2008), identity and adherence (Tilden, Charman, Sharples & Fosbury, 2005), experiencing of coping with diabetes (Schoor, Gamsu & Barley, 1999) and the management of diabetes through life transitions (Rasmusson, Ward, Jenkins, King & Duning, 2011).

However, very few qualitative studies have specifically examined the experiences of adolescents who have poor glycaemic control (Zin, 2008; Ivey, Wright & Dashif, 2009). A recent study by Maylani and Wahyu (2012), sought to do so by examining the experiences of adolescents who were identified as having difficulty in managing their diabetes and had suffered complications associated with poor glycaemic control. Interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009) was used to analyse the data, which revealed themes such as lack of understanding about diabetes and rejecting the diagnosis. However, a limitation of this study is that the participants were between the ages of 17 and 21, and therefore the perspectives of younger adolescents were not considered.

A similar study by Kyngas and Heimas (1995) compared the meaning attached with diabetes self-care amongst adolescents (between the ages of 14 and 17) with varying degrees of diabetes management. Using a grounded theory approach (Glaser and Strauss, 1967), it was found that adolescents who did not comply with diabetes medications tended to regard self-care with indifference and felt that neglecting their self-care allowed them to live freely, like their friends.

The proposed project therefore adds to the very limited research specifically examining the experiences of adolescents (between the ages of 13 and 17) who have been identified as having poor glycaemic control. Specifically, interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009) will be used to conduct in-depth explorations of adolescents' experience of DM1.

#### **4. Research question**

**Aim:** To explore the lived experiences of adolescents with Diabetes Mellitus who have poor glycaemic control.

#### **5. Overlap with previous assessments**

There is no overlap with previous assessments.

**MAP:** Is Dialectical Behaviour Therapy effective in reducing eating disordered behaviours? A meta-analysis.

**SSRP:** Factors contributing to first appointment non-attendance in a paediatric psychology service.

**Presentation:** Cognitive and emotional changes in Multiple Sclerosis.

**Essay:** Cognitive processes in Chronic Fatigue Syndrome.

## **6. Participant recruitment**

### Inclusion criteria

1. Adolescents between the ages of 12 to 17 years.
2. Adolescents with a diagnosis of Type 1 Diabetes Mellitus for a minimum of 1 year.
3. Adolescents identified as having poor glycaemic control defined as HbA1c levels of greater than or equal to 9% in their 2 most recent blood tests at the time of recruitment. It is important to note that HbA1C levels of 9% are now expressed in the UK as 74 mmol/mol.

This measurement gives an average of a person's blood glucose level over a period of time (approximately 6-8 weeks). For adolescents, NICE guidelines recommend that HbA1c levels of less than 7.5% (which is now expressed as 58 mmol/mol) is the long-term target for glycaemic control (NICE, 2004).

By setting the HbA1c levels of greater or equal to 9% (now expressed in the UK as 74 mmol/mol) over their two most recent blood tests as an inclusion criteria, this will ensure that participants have consistently had poor glycaemic control. Previous studies examining poor glycaemic control have used HbA1c levels of 9% as a cut-off score indicating poor glycaemic control (Igbal, Morgan, Maksoud and Idris, 2008; Juarez et al., 2012).

### Exclusion criteria

1. Adolescents with Type 2 Diabetes Mellitus.
2. Adolescents who have 'insulin pumps' to administer medications.
3. Adolescents with learning disabilities.

**Participants:** Approximately 8-10 adolescents will be recruited from the Paediatric Service in Ysbyty Gwynedd. Initial approval to access the participants has been provided by the Clinical Psychologist working in the paediatric service, Ysbyty Gwynedd, and the Specialist Diabetes Nurse, Ysbyty Gwynedd.

There are approximately 64 adolescents with diabetes (between the ages of 12 and 17) living in Gwynedd and Ynys Mon, who are being monitored by the paediatrics department, Ysbyty Gwynedd. Of these, the Specialist Diabetes Nurse has identified that approximately 45 adolescents meet the criteria for having poor glycaemic control. If we fail to recruit enough participants from Gwynedd and Anglesey, we will recruit participants from the Conwy and Denbighshire area by undertaking the same procedure in the paediatrics department, Ysbyty Glan Clwyd.

As a way of thanking participants for their participation, we would like to offer them a gift voucher of £5.

**Recruitment Process**

In the first instance, potential applicants will be recruited from the Paediatrics department, Ysbyty Gwynedd. Should it be necessary, participants will be recruited from the Paediatrics department in Ysbyty Glan Clwyd.

Adolescents participating in the study will be well known to clinicians in the Paediatrics department in Ysbyty Gwynedd or the Paediatrics Department in Ysbyty Glan Clwyd. Llinos Griffith will visit the sites to inform clinicians of the research and ask clinicians to ascertain whether any of the adolescents on their case-load fulfil the inclusion criteria. Clinicians will be given a recruitment information sheet outlining the purpose of the study and the inclusion/exclusion criteria. The clinician who will be a member of the adolescent's healthcare team will review their medical records to ascertain whether they meet the inclusion criteria.

The option of taking part in the research will first be raised with the adolescent by a clinician known to them, who is a member of their healthcare team. If the adolescent is interested in taking part, the clinician will give the adolescent a participant information sheet. The parent/guardian of the adolescent will also be given a parental/guardian information sheet.

If the adolescent wants to take part in the study and would like to talk to Llinos Griffith to discuss this and arrange an interview date and time, they will be given an opt-in form to complete. This form will ask for a telephone number for Llinos Griffith to contact them. The adolescent and their parent/guardian will be required to sign this opt-in form before any telephone contact is made.

Upon receipt of the opt-in form, Llinos Griffith will contact the adolescent via telephone and will speak with both the adolescent and their parent/guardian to discuss the study and answer any questions. If the adolescent and their parent/guardian are happy for the adolescent to take part, Llinos Griffith will arrange an interview date and time.

Prior to commencing the interview, the adolescent and the parent/guardian will be given the information sheets to read again. If the adolescent wants to take part, they will be required to complete and sign a consent form. The parent/guardian will also be required to complete and sign a parent/guardian assent form. Interviews will only be conducted if both the consent form and the assent form are completed and signed. The consents and assent forms will also include an agreement which will allow the trainee to extract information regarding their glycaemic control from the participants' health records.

**7. Design and procedures**

Qualitative methods are particularly recommended in areas where there is little existing research (Elliot et al., 1999). Approximately 8 to 10 individuals will participate in semi-structured interviews

which will be guided by an interview schedule (Smith, Flowers and Larkin, 2009). The participants will be offered a choice of interview location: either in a private clinic room in the Paediatrics Outpatient Department, Ysbyty Gwynedd; the Paediatrics Outpatient Department, Ysbyty Glan Clwyd, or at home.

### **8. Measures**

Semi-structured interviews of approximately 45-60 minutes duration will be conducted. Participants will be asked to discuss their experiences of living with diabetes with the following possible areas of focus:

1. What is your experience of living with diabetes?
2. What are the stages involved in managing your diabetes in a typical day? (medications, monitoring blood glucose, diet) Who does this? Where?
3. How do you feel about having to do this?
4. How do you think having to do this affects your life?
5. So as you know, I'm really interested in finding out what it's like for young people (like you) who have poor glycaemic control, can you tell me what this has been like for you?
6. In your experience, what do you think makes it difficult to manage your diabetes?
7. Is there anything that makes it easier?
8. How do you think other people think or feel about you having diabetes and poor glycaemic control?
9. Do you think that having poor glycaemic control has impacted on your relationship with others? (parents, friends, professionals).
10. Do you think that having poor glycaemic control affects the way you think or feel about yourself as a person?
11. Do you think you would think or feel differently about yourself if you did not have poor glycaemic control?

With written consent (obtained from the consent forms) Dr Liz Whitehead will identify the clinical files of participants. The files will then be passed to the trainee who will extract information regarding their diabetes and glycaemic control.

### **9. Data management and analysis**

**Data Management:** Data will be kept in accordance with Bangor University and BCUHB procedures. Recordings of interviews will be made using a digital audio-recorder and will be transferred from the audio-recorder to a password-protected (encrypted) data-storage device after each interview. The audio-files will then be deleted from the audio-recorder.

Interviews will be transcribed by the trainee. All transcripts will be fully anonymised as the participants will be assigned an identification number. The transcripts will be stored in a password-protected folder on the data-storage device. No identifiers such as address and name will be stored on the data storage device. Paper copies of participants details will be stored at a secure location (in a locked filing-cabinet in a locked office with restricted access) at the paediatric clinical psychology office, Minffordd ward, Ysbyty Gwynedd, and will only be accessed by the trainee and the clinical supervisor.

**Analysis:** IPA (Smith, Flowers & Larkin, 2009), which is a phenomenological approach will be used. IPA was chosen over other qualitative methodologies as it allows in-depth examination of how participants make sense of their own experiences. IPA has previously been used to examine the perspectives of young people (aged 16-22) with DM1, regarding their experience of living and coping with diabetes (Schur, Gansery & Barley, 1999).

#### **10. Diversity**

The researcher will aim to include both male and female adolescents who have been diagnosed with DM1 for varying lengths of time. The adolescents may also have varying degrees of diabetes control and may have different medication regimes to follow. Interviews will be conducted in either Welsh or English. All information sheets and letters will also be available in both English and Welsh.

#### **11. Proposed Journals**

Journal of Health Psychology, Sage Publications.

#### **12. Ethical/Registration Issues**

The interview will focus upon the experience of having Diabetes Mellitus and poor glycaemic control, which may be distressing for some participants. The interviewer will therefore emphasize that participants can withdraw at any time and can choose not to answer questions. At the end of the interview, all participants will be given the opportunity to discuss their experience of the interview and any distress they may have arisen. In addition, all participants will be asked to identify a supporting individual prior to the interview to ensure that they have support if they require it.

**Inconvenience:** Interviews will be arranged at a date and time which is convenient for participants. The interview times will also be sensitive to times of the year where participants may be sitting school examinations.

Approval will be obtained from the School of Psychology, Bangor University ethics board, approval will also be sought through a local NHS ethics committee and R&D registration will be established across all BCUHB sites used. This will be achieved via submission through the Integrated Research Application System (IRAS).



**13. Feedback**

As participants will be discussing their experiences of having Diabetes Mellitus and having poor glycaemic control, it is possible that individuals may become distressed. A comprehensive debriefing at the end of the interview will be conducted regardless of whether the participant is visibly distressed to ensure that the participant leaves the interview in a satisfactory state of well-being.

**14. Risk Assessment**

**Risk to Participants:** Discussing issues surrounding diabetes may be distressing for some participants. This information will be included in the information sheet, and will also be addressed when the study is explained to participants and consent sought. Full informed consent will be obtained. The researcher is a trainee clinical psychologist with experience of working with adolescents, and the interviews will be conducted with sensitivity. Dr Liz Whitehead has agreed to offer a follow up session if further support is needed.

**Risks to self:** It is expected that most interviews will be conducted in the Paediatric outpatient department, Ysbyty Gwynedd. All interviews on these premises will be held during working hours. Alternatively, if participants choose to complete the interviews at home, the trainee will undertake home-visits alone and full risk-assessments will be conducted. The trainee will adhere to the Bangor University and BCUHB lone-worker policies. The trainee will complete 'diary-tracking' and therefore locations and timings of visits will be known to Dr Liz Whitehead. The trainee will also telephone Dr Liz Whitehead prior to commencing interviews confirming the commencement time and expected departure time. The trainee will also telephone Dr Liz Whitehead when she has safely completed home-visits. If Dr Liz Whitehead is unavailable, safety checks will be carried out with another member of the Ysbyty Gwynedd Paediatric Department team.

**15. Data Storage**

Data protection legislation will be complied with in accordance with the Data Protection Act (1998) and BCUHB policy.

Anonymised transcripts of interviews will be stored on an encrypted pen drive which will be password protected. The participant's names and participant numbers will be kept in a locked cabinet in the psychology office in the paediatric clinical psychology office, Minffordd ward, Ysbyty Gwynedd.

**16. Financial Information**

- a. Postage = Second class stamps (36 pence x 80) = £28.80
  - c. Stationary = 1 box of A4 envelopes = £4.88
  - d. Photocopying. 1 pence per sheet (maximum of 200 sheets) = £2
  - e. Letterhead paper. 6 pence per sheet (maximum of 100 sheets) = £6
  - e. Travel expenses of participants (maximum of £100)
  - f. £5 gift voucher to each participant = maximum of £50
- Total = £191.68



**17. Timetable****Year 1**

| <b>Date</b>           | <b>Goal</b>                                                                                    |
|-----------------------|------------------------------------------------------------------------------------------------|
| October 2012          | Submit proposal                                                                                |
| October/November 2012 | Amend proposal as necessary and develop information sheets/consent forms & interview schedule. |
| December 2012         | Complete ethics proposal                                                                       |

**Year 2**

| <b>Date</b>             | <b>Goal</b>                                           |
|-------------------------|-------------------------------------------------------|
| January 2013            | Submit ethics proposal to University Ethics committee |
| April 2013              | Submit ethics proposal to BCUHB Ethics committee      |
| May 2013                | Start writing literature review                       |
| July 2013 – August 2013 | Recruit participants and arrange interviews           |
| August – December 2013  | Complete Data Collection and transcription            |

**Year 3**

| <b>Date</b>              | <b>Goal</b>                                                       |
|--------------------------|-------------------------------------------------------------------|
| January – February 2014  | Complete Analysis                                                 |
| March-April 2014         | Write up                                                          |
| 1 <sup>st</sup> May 2014 | Submit drafts to supervisors & training co-ordinator for feedback |
| June 2014                | Submit LSRP                                                       |
| July                     | Revise for Viva                                                   |
| August                   | Complete any revisions                                            |
| September                | Send report to participants                                       |

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**How do adolescents with Diabetes Mellitus experience having diabetes  
and poor glycaemic control?**

**Interview schedule**

**Demographic questions:**

How old are you?

How would you describe your ethnicity?

How old were you when you were told that you had diabetes?

**Interview schedule**

1. What is your experience of living with diabetes?
2. What are the stages involved in managing your diabetes in a typical day?  
(medications, monitoring blood glucose, diet) Who does this? Where?
3. How do you feel about having to do this?
4. How do you think having to do this affects your life?
5. So as you know, I'm really interested in finding out what it's like for  
young people (like you) who have poor glycaemic control, can you tell  
me what this has been like for you?
6. In your experience, what do you think makes it difficult to manage your  
diabetes?
7. Is there anything that makes it easier?

8. How do you think other people think or feel about you having diabetes and poor glycaemic control?
9. Do you think that having poor glycaemic control has impacted on your relationship with others? (parents, friends, professionals).
10. Do you think that having poor glycaemic control affects the way you think or feel about yourself as a person?
11. Do you think you would think or feel differently about yourself if you did not have poor glycaemic control?

Possible prompts

Can you tell me how this made you feel?

Can you tell me what you were thinking?

Can you tell me a bit more about that?

What happened? How did you cope?

What do you think that means?



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SCHOOL OF PSYCHOLOGY

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU  
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



**Young People's Experience of having Diabetes and poor glycaemic control**

**Recruitment Information Sheet**

Adolescents with Diabetes Mellitus not only have an increased risk of developing health complications but they are also at increased risk of developing emotional and behavioural problems (NICE guidelines, 2004). Specifically, adolescents with Diabetes Mellitus may develop anxiety and/or depression, particularly if they are experiencing difficulties with managing their diabetes. Indeed, it is recommended that adolescents with Diabetes Mellitus should have "timely and on-going access to mental health professionals" (NICE guidelines, 2004).

Considering the detrimental effect that poor glycaemic control may have on the health and well-being of adolescents with Diabetes Mellitus, we are interested in interviewing adolescents who have diabetes and poor glycaemic control. It is hoped that this information will inform future clinical interventions and therapeutic relationships with this client group.

**Recruitment Process**

We would like you to identify adolescents on your caseload who could potentially participate according to the following inclusion and exclusion criteria:

**Inclusion Criteria**

- Adolescents between the ages of 12 to 17 years.
- Adolescents with a diagnosis of Type 1 Diabetes Mellitus for a minimum of 1 year.
- Adolescents identified as having poor glycaemic control defined as HbA1c levels of greater than or equal to 9% in their 2 most recent blood tests.

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### **Exclusion Criteria**

- Adolescents with Type 2 Diabetes Mellitus.
- Adolescents who have 'insulin pumps' to administer medications.
- Adolescents with learning disabilities.

If you identify adolescents who meet the criteria, we would like you to provide them with a copy of the **Participant Information Sheet**. We would also like you to provide their parent/guardian with a copy of the **Parent/guardian information sheet**.

If the adolescent and their parent/guardian are happy for the researcher to contact them via telephone to answer any questions they may have and possibly arrange an interview date and time, please ask them to fill-in the **Opt-in form**. Contact will only be made if both the adolescent and the parent/guardian sign this form.

Participation in this study is completely voluntary and they have the right to withdraw at any point without giving a reason.

### **Contact Information**

If you require any further information or would like to clarify any information please contact the researcher, Llinos Griffith on 07717805611 or by email: [pspefb@bangor.ac.uk](mailto:pspefb@bangor.ac.uk).

**Thank you.**

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**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU  
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



## **Young People's Experience of having Diabetes and poor glycaemic control**

### **Participant Information Sheet: Part 1.**

My name is Llinos Griffith, I am a Trainee Clinical Psychologist at Bangor University and I work within the Betsi Cadwaladr University Health Board. I am inviting you to take part in a research project that is looking at how young people experience having Diabetes and poor glycaemic control. When I say 'poor glycaemic control' I mean that a person's blood glucose levels (commonly described as blood sugar level) has been higher than what the medical Doctors recommend it to be.

Before you decide if you want to take part, it's important to understand why the research is being done and what is involved for you. Please consider this leaflet carefully. Talk to your family, friends or a staff member from the Hospital if you want to.

#### **Why is the research being done?**

I am being supervised by Dr Liz Whitehead (Clinical Psychologist) and Dr Renee Rickard (Clinical Psychologist) and we are very interested in finding out what it is like for a young person, like you, to have diabetes and poor glycaemic control.

There is no medical procedure or medicine that we are testing - we simply want to find out what it's been like for you.

#### **Why have I been invited to take part?**

You have been chosen because you have experience of living with diabetes and poor glycaemic control. I am hoping to speak to between 8 and 10 other young people, like you, about their experiences.

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**Do I have to take part?**

**No, taking part is completely up to you.** I will ask for your consent and then ask you to sign a consent form. I will give you a copy of this information sheet and your signed sheet to keep.

If you do not want to take part, you do not have to give a reason and you will not be pressurised into taking part. Also, you are free to stop taking part at any point without giving a reason. Please note, **if you choose not to take part or withdraw from the research, this will not affect your current or future treatment in any way.**

If you participate in the interview, you will be given a £5 voucher as a thank you for your time and effort.

**What will happen to me if I take part?**

If you agree to take part, I will ask you to answer some questions. There aren't any right or wrong answers, I just want to hear your opinion about your experiences. The discussion should take between 60 and 90 minutes. You will be asked questions about what it's like to have poor glycaemic control and whether this has affected how you feel about yourself and your relationships with others.

**Is there anything to be worried about if I take part?**

It is possible you may become upset or unsettled during the interview, as you may discuss difficult topics. Before we start I will ask you to identify someone in your life who could support you if you feel upset. If you do become upset, I will spend some time with you either during the interview when you are upset or at the end of the interview to help you. I will also help you to access the person you identified as a source of support if you are still distressed when we are finished.

**What are the benefits of taking part?**

The interview will not be part of any intervention and it is not assumed that it will be of direct benefit to you. However, some young people may wish to have their views heard, and the interview may be a positive experience. It is hoped the research will give us ideas about how we can best work with young people who have diabetes and poor glycaemic control. We can then try to make services better for young people.

**In what language can I take part?**

You can choose to speak Welsh or English during the interview, it is completely up to you.

My contact details are:

Llinos Griffith, Trainee Clinical Psychologist  
School of Psychology  
Bangor University  
Brigantia Building  
LL57 2AS  
Telephone: 07717805611

**Thank you for reading this so far - if you are still interested,  
please read part 2.**

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## Young People's Experience of having Diabetes and poor glycaemic control

### Participant Information Sheet: Part 2.

This part of the information sheet contains more information that you need to know if you want to take part.

#### **What happens when the research stops?**

Nothing, once the interview is finished you will not be asked for anything further.

#### **What if there is a problem or something goes wrong?**

The only problem that might occur is that you may become distressed during the interview. We have tried to make sure that the questions will not make you upset, however if you do become upset the interview can be paused or stopped should you want. Also at the end of the interview you will be given a chance to discuss anything that may upset you and hopefully you will leave the interview feeling OK. However, if you still feel upset then I will help to find the person you identified at the start as someone who could provide you with more support.

#### **Will anyone else know I'm doing this?**

All the information you share with me will be confidential - this means that no-one outside the study will know what we talked about.

**Confidentiality will only be broken in circumstances where you or other people may be at serious risk, and the researcher may have to tell the appropriate people, which will include a member of your healthcare team.**

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**What will happen to what I say?**

What we discuss with me in the interview will be recorded on a Digital recorder. This recorder will be kept by me and I will then type out everything we said onto a computer word document. Once your interview has been written up, I will delete your recording.

When your interview is written up, I will take out all the information that may identify you, such as your name. The written interviews will then be looked at by Dr Renee Rickard (Clinical Psychologist) and me. We will then look at the things that you spoke about and the things you felt were important. Whatever we find out from this research will be used as part of my training as a Clinical Psychologist. The findings may also be published in an academic journal (which is like a newspaper that reports new research). Any information in reports or journals would always be used in a way that would not allow you to be identified individually by anyone else. Anonymised quotations from your interview may be included in publications resulting from the research.

The written interviews will be kept at the Paediatrics department, Ysbyty Gwynedd for up to 12 months and then they will be destroyed. The information may be looked at again during this time by one of the researchers.

**Will I receive any feedback after the research has been completed?**

If you want, a summary of the research findings will be sent to you by post when the research has been completed and approved. This summary will include general feedback about the findings and will not include individual feedback about your interview. You will be asked whether you want this feedback on the participant consent form.

**Will you have access to my medical records?**

The consent form will ask you whether you are happy for me to access your medical records. If you decide that you want to take part in the study, I will access your medical records to gather information about your diabetes and glycaemic control.

**Who is organising and funding the research?**

Bangor University are organising and funding this research. It is forming part of my training on the North Wales Clinical Psychology Programme.

**Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure the research is fair. This project has been checked by the North Wales Research Ethics Committee.

**What do I do now?**

Think about the information on this sheet and ask any questions you may have.

If you agree that I can contact you via telephone to discuss the research and answer any questions you may have, please fill-in the 'opt-in form' with your parent/guardian.

**What will happen next?**

If you do not sign the opt-in form, you will not be contacted again.

If you do sign the opt-in form, I will contact you via telephone to discuss the research and answer any questions you may have. If after our discussion, you decide that you want to take part, we will arrange a time to meet which is convenient for you.

When we meet, you will be asked to read the information sheet again and I will ask you whether you still want to take part. **You can change your mind at any time.**

Before the interview, you will be asked to sign a consent form.

The opt-in form, the consent form and the assent form will be the only forms with your name on them and they will be filed separately from all other information.

**How do I make a complaint?**

If you wish to complain after reading this information sheet or at any point during the research the contact details are below.

If you have a complaint to the NHS you can write a letter to...

Concerns Team

Betsi Cadwaladr University Health Board

Ysbyty Gwynedd

Bangor

Gwynedd

LL57 2PW

Email... [ConcernsTeam.bcu@wales.nhs.uk](mailto:ConcernsTeam.bcu@wales.nhs.uk)



Or telephone...

Hospital and Community Services in Anglesey, Gwynedd, Conwy, Denbighshire,  
Flint and Wrexham - (01248) 384194

If you have a complaint to Bangor University you can write a letter to...

Isabel Hargreaves  
School of Psychology  
Bangor University  
Brigantia Building  
LL57 2AS

Email... [i.hargreaves@bangor.ac.uk](mailto:i.hargreaves@bangor.ac.uk)

Or telephone 01248 388365

**Thank you for your time**

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## Profiadau Pobl Ifanc o Glefyd Siwgr a Rheolaeth Glwcos Gwael

### Taflen Wybodaeth i'r Rhai sy'n cymryd Rhan: Rhan 1.

Fy enw i ydi Llinos Griffith. Rwyf yn Seicolegydd Clinigol dan Hyfforddiant ym Mhrifysgol Bangor ac rwyf yn gweithio ym Mwrdd Iechyd Prifysgol Betsi Cadwaladr. Rwyf yn eich gwahodd i gymryd rhan mewn prosiect ymchwil sydd yn edrych ar brofiadau pobl ifanc o glefyd siwgr a rheolaeth glwcos gwael. Pan rwyf yn cyfeirio at 'rheolaeth glwcos gwael' rwyf yn golygu bod lefel glwcos y gwæd yn uwch na'r hyn mae'r Doctoriaid meddygol yn argymhell iddo fod.

Cyn i chi benderfynnu os ydych eisiau cymryd rhan, mae'n bwysig eich bod yn deall pam bod yr ymchwil yn cael ei gynnal a beth fydd hyn yn ei olygu i chi. Felly ystyriwch y daflen hon yn ofalus. Siaradwch gyda'ch teulu, ffrindiau neu aelod o staff yn yr Ysbyty os hoffech chi.

#### **Pam fod yr ymchwil hwn yn cael ei gynnal?**

Rwyf i'n cael fy ngoruchwylio gan Dr Liz Whitehead (Seicolegydd Clinigol) a Dr Renee Rickard (Seicolegydd Clinigol) ac rydym eisiau darganfod pa fath o brofiad ydyw i berson ifanc, fel chi, i gael clefyd siwgr a rheolaeth glwcos gwael.

Tydym ni ddim yn profi unrhyw driniaeth feddygol neu feddyginiaeth - yn syml rydym am gael eich barn.

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### **Pam gefais i wahoddiad i gymryd rhan?**

Cawsoch eich dewis oherwydd eich bod gyda phrofiad o fyw gyda chlefyd siwgr a rheolaeth glwcos gwael. Rwyf yn gobeithio siarad gyda rhwng 8 a 10 person ifanc, fel chi, am eu profiadau.

### **Oes rhaid i mi gymryd rhan?**

**Na, eich dewis chi ydi cymryd rhan.** Byddaf yn gofyn i chi am eich cydsyniad ac yna'n gofyn i chi arwyddo ffurflen. Byddaf yn rhoi copi o'r daflen wybodaeth hon a'r daflen a arwyddwyd gennych i chi i'w cadw.

Os nad ydych chi am gymryd rhan, does dim rhaid i chi roi rheswm ac ni fydd pwysau arnoch i gymryd rhan. Rydych hefyd yn rhydd i roi'r gorau i gymryd rhan ar unrhyw adeg yn ystod yr ymchwil heb roi rheswm. **Sylwer, os ydych chi'n dewis peidio cymryd rhan neu'n tynnu'n ol o'r ymchwil, fydd hyn ddim yn effeithio ar eich triniaeth bresennol neu driniaeth yn y dyfodol o gwbl.**

Os ydych chi'n cymryd rhan yn y cyfweiliad, byddwch yn cael tocyn £5 i ddiolch i chi am eich amser a'ch hymdrech.

### **Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?**

Os ydych chi'n cytuno i gymryd rhan, byddaf yn gofyn i chi ateb rhai cwestiynau. Does dim atebion cywir nac anghywir, yr unig beth ydw i am ei glywed amdano yw eich profiadau a'ch barn. Dylai'r drafodaeth gymryd rhwng 60 a 90 munud. Byddwch yn cael cwestiynau am sut fath o brofiad ydi cael rheolaeth glwcos gwael ac os ydi hyn wedi effeithio ar sut rydych chi'n teimlo am eich hun ac ar eich perthnasau gyda eraill.

### **Oes yna unrhyw beth i boeni amdano os ydw i'n cymryd rhan?**

Mae'n bosib y byddwch chi'n anhapus neu'n ansicr yn ystod y cyfweiliad, gan y byddwch efallai'n trafod pynciau annodd. Cyn i ni ddechrau byddaf yn gofyn i chi enwi rhywun yn eich bywyd a allai'ch cefnogi os ydych chi'n teimlo'n anhapus. Os ydych chi'n anhapus, byddaf yn treulio ychydig o amser efo chi un ai yn ystod y cyfweiliad pan ydych chi'n anhapus neu ar ddiwedd y cyfweiliad i'ch helpu. Os

ydych chi'n dal i deimlo'n ddrwg ar ol i ni orffen, byddaf hefyd yn eich helpu i gysylltu a'r sawl a enwyd gennych i'ch helpu.

### **Beth yw manteision cymryd rhan?**

Ni fydd y cyfweiliad yn rhan o unrwy ymyrraeth ac ni honnir y bydd o fantais uniongyrchol i chi. Ond efallai y bydd rhai pobl ifanc yn dymuno mynegi eu barn ac efallai y bydd y cyfweiliad yn brofiad cadarnhaol. Y gobaith ydi y bydd yr ymchwil yn rhoi syniadau i ni am y ffordd orau o weithio gyda phobl ifanc gyda chlefyd siwgr a rheolaeth glwcos gwael. Yna gallwn geisio gwella gwasanaethau i bobl ifanc.

### **Ym mha iaith fedra' i gymryd rhan?**

Mi gewch chi ddewis siarad Cymraeg neu Saesneg yn ystod y cyfweiliad, mae hyn i fyny i chi yn llwyr.

Dyma fy manylion i:

Llinos Griffith, Seicolegydd Clinigol dan Hyfforddiant

Yr Ysgol Seicoleg

Prifysgol Bangor

Adeilad Brigantia

LL57 2AS

Ffon: 07717805611

**Diolch i chi am ddarllen hyd yma - os ydych yn dal i fod a diddordeb, yna darllenwch Rhan 2 os gwelwch yn dda.**

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## **Profiadau Pobl Ifanc o Glefyd Siwgr a Rheolaeth Glwcos Gwael**

### **Taflen Wybodaeth i'r Rhai sy'n cymryd Rhan: Rhan 2.**

Mae'r rhan yma o'r daflen wybodaeth yn cynnwys mwy o wybodaeth sydd angen i chi ei wybod os ydych am gymryd rhan.

#### **Beth sy'n digwydd pan fo'r ymchwil yn gorffen?**

Dim. Unwaith y bydd y cyfweiliad wedi gorffen ni fyddaf yn gofyn unrhyw beth arall i chi.

#### **Beth os oes problem neu os aiff rhywbeth o'i le?**

Yr unig broblem a allai ddigwydd ydi y gallech chi deimlo'n ddrwg yn ystod y cyfweiliad. Rydym wedi ceisio sicrhau na fydd y cwestiynau'n eich gwneud yn anhapus, ond os ydych chi'n anhapus gellir rhoi'r gorau iddi am ychydig neu'n gyfan gwbl os hoffech chi. Hefyd ar ddiwedd y cyfweiliad byddwch yn cael cyfle i drafod unrhyw beth a allai fod wedi'ch gwneud yn anhapus a'r gobaith ydi y byddwch yn gadael y cyfweiliad yn teimlo'n iawn. Ond, os ydych chi'n dal i deimlo'n anhapus yna mi wnaaf eich helpu i ddod o hyd i'r sawl a enwyd gennych ar y dechrau fel rhywun a allai roi mwy o genfnogaeth i chi.

#### **Fydd unrhyw un arall yn gwybod fy mod i'n gwneud hyn?**

Bydd yr holl wybodaeth y byddwch yn ei rannu gyda fi yn gyfrinachol - mae hyn yn golygu na fydd neb y tu allan i'r astudiaeth yn gwybod am yr hyn y buom yn siarad amdano.

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Yr unig adeg y caiff cyfrinachedd ei dorri ydi mewn amgylchiadau lle gallech chi neu bobl eraill fod mewn perygl mawr, ac bydd yn rhaid i'r ymchwilydd ddweud wrth y bobl priodol. Mi fydd hyn yn cynnwys aelod o'ch tim gofal iechyd.

#### **Beth fydd yn digwydd i'r hyn fyddaf i'n ei ddweud?**

Bydd yr hyn yr ydych yn ei drafod gyda mi yn y cyfweiliad yn cael ei recordio ar beiriant digidol. Mi fydd y peiriant recordio'n cael ei gadw gen i ac mi fyddaf i wedyn yn teipio popeth a ddywedwyd gennym ar ddogfen 'word' cyfrifiadur. Unwaith y bydd eich cyfweiliad wedi ei ysgrifennu, byddaf yn dileu'ch recordiad.

Pan fydd y cyfweiliad wedi ei ysgrifennu, byddaf yn tynnu allan yr holl wybodaeth a allai'ch adnabod, fel eich enw. Yna bydd Dr Renee Rickard (Seicolegydd Clinigol) a minnau'n edrych ar y cyfweiliadau ysgrifenedig. Byddwn yn edrych ar y pethau y buoch chi'n siarad amdanynt a'r pethau oedd yn bwysig yn eich barn chi. Bydd yr hyn y byddwn yn ei ddarganfod o'r ymchwil yma yn cael ei ddefnyddio fel rhan o'm hyfforddiant fel Seicolegydd Clinigol. Efallai hefyd y cyhoeddir y darganfyddiadau mewn cylchgrawn academaidd (sydd yn debyg i bapur newydd sy'n adrodd am ymchwil newydd). Byddai unrhyw wybodaeth mewn adroddiadau neu gylchgronau bob amser yn cael eu defnyddio mewn modd na fyddai'n galluogi i unrhyw un arall eich adnabod yn unigol. Mi fydd dyfyniadau o'ch cyfweiliad yn cael eu cynnwys mewn cyhoeddiadau o'r astudiaeth. Ni fydd y dyfyniadau yma yn cynnwys unrhyw wybodaeth a allai'ch adnabod yn unigol.

Cedwir y cyfweiliadau ysgrifenedig yng Ngwasanaeth Pediatrig, Ysbyty Gwynedd, am hyd at 12 mis ac yna cant eu dinistrio. Efallai y bydd un o'r ymchwilydwr yn edrych ar y wybodaeth eto yn ystod yr amser yma.

#### **Fydda i'n derbyn adborth wedi'r ymchwil gael ei gyflawni?**

Os ydych eisiau, bydd crynodeb o ddarganfyddiadau'r ymchwil yn cael ei yrru i chi yn y post wedi i'r ymchwil gael ei orffen a'i gadarnhau. Mi fydd y crynodeb yn cynnwys adborth cyffredinol ynglyn a'r darganfyddiadau ac ni fydd yn cynnwys adborth unigol am eich cyfweiliad chi. Mi fydd y ffurflen cydsynio yn gofyn os ydych chi eisio yr adborth yma.

#### **Fydd gennych chi fynediad at fy nghofnodion meddygol?**

Mi fydd y ffurflen cydsynio yn gofyn i chi gadarnhau eich bod chi'n hapus i mi gael mynediad at eich cofnodion meddygol. Os ydych chi'n penderfynnu eich bod eisiau cymryd rhan yn yr ymchwil, byddaf yn edrych ar eich cofnodion meddygol i gasglu gwybodaeth ynglyn a'ch clefyd siwgr ac eich rheolaeth glwcos.

**Pwy sydd yn trefnu ac yn ariannu'r ymchwil?**

Prifysgol Bangor sydd yn trefnu ac yn ariannu'r ymchwil. Mae'n rhan o fy hyfforddiant yn Rhaglen Seicoleg Glinigol Gogledd Cymru.

**Pwy sydd wedi adolygu'r astudiaeth?**

Cyn i unrhyw ymchwil fynd yn ei flaen mae'n rhaid i Bwyllgor Moeseg Ymchwil ei wirio. Maent yn gwneud yn siwr fod yr ymchwil yn deg. Cafodd y prosiect hwn ei wirio gan Bwyllgor Moeseg Ymchwil Gogledd Cymru.

**Beth ydw i'n ei wneud yn awr?**

Meddylwch am y wybodaeth ar y daflen hon, a gofynnwch i mi os oes gennych chi unrhyw gwestiynau.

Os ydych chi'n cytuno i mi gysylltu a chi dros y ffon i drafod yr ymchwil ac i ateb unrhyw gwestiynau sydd gennych, cwblhewch y 'Taflen Ymuno' gyda'ch rhiant/gwarcheidwad.

**Beth sydd am ddigwydd nesaf?**

Os ydych chi'n dewis peidio cwblhau'r 'Taflen Ymuno', ni fyddwn yn cysylltu a chi eto.

Os ydych chi'n dewis arwyddo'r 'Taflen Ymuno', byddaf yn cysylltu a chi dros y ffon i drafod yr ymchwil ac i ateb unrhyw gwestiynau sydd gennych. Os ydych chi'n dewis i gymryd rhan wedi ein trafodaeth, mi wnawn ni drefnu amser cyfleus i gyfarfod.

Pan fyddwn yn cyfarfod, mi fyddai'n gofyn i chi ddarllen y daflen wybodaeth eto a byddaf yn gofyn os ydych eisiau cymryd rhan. **Mi gewch chi newid eich meddwl ar unrhyw adeg.**

Cyn y cyfweiliad, byddaf yn gofyn i chi arwyddo ffurflen gydsynio.

Mi fydd eich enw yn cael ei gynnwys ar y 'Taflen Ymuno', y ffurflen gydsynio, a'r ffurflen cydsynio y rhiant/ gwarcheidwaid yn unig, a byddant yn cael eu cadw ar wahan i'r wybodaeth arall.



**Sut allai wneud cwyn?**

Os ydych chi'n dymuno cwyno ar ol darllen y daflen wybodaeth hon neu ar unrhyw adeg yn ystod yr ymchwil mae'r manylion cyswllt ar gyfer gwneud hynny ar gael isod.

Os oes gennych chi gwyn i'r *GIG* gallwch ysgrifennu llythyr at  
Adran Cwynion  
Bwrdd Iechyd Prifysgol Betsi Cadwaladr  
Ysbyty Gwynedd  
Bangor  
Gwynedd  
LL57 2PW

Ebost... [ConcernsTeam.bcu@wales.nhs.uk](mailto:ConcernsTeam.bcu@wales.nhs.uk)

Neu ffoniwch...

Gwasanaethau ysbytai a chymuned yng Ngwynedd, Sir Fon, Conwy, Dinbych,  
Fflint a Wrescam - (01248) 384194

Os oes gennych chi gwyn i Brifysgol Bangor gallwch ysgrifennu llythyr at...  
Isabel Hargreaves  
Yr Ysgol Seicoleg  
Prifysgol Bangor  
Adeilad Brigantia  
LL57 2AS

Ebost... [i.hargreaves@bangor.ac.uk](mailto:i.hargreaves@bangor.ac.uk)

Neu ffoniwch 01248 388365

**Diolch yn fawr am eich hamser.**



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**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU  
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



## **Young People's Experience of having Diabetes and poor glycaemic control**

### **Parent/Guardian Information Sheet: Part 1.**

My name is Llinos Griffith, I am a Trainee Clinical Psychologist at Bangor University and I work within the Betsi Cadwaladr University Health Board. I am inviting your child to take part in a research project that is looking at how young people experience having Diabetes and poor glycaemic control. When I say 'poor glycaemic control' I mean that a person's blood glucose levels (commonly described as blood sugar level) has been higher than what the medical Doctors recommend it to be.

Before you agree that your child can take part, it is important to understand why the research is being done and what is involved for your child. Please consider this leaflet carefully. Talk to your child, family, friends or a staff member from the Hospital if you want to.

#### **Why is the research being done?**

I am being supervised by Dr Liz Whitehead (Clinical Psychologist) and Dr Renee Rickard (Clinical Psychologist) and we are very interested in finding out what it is like for a young person to have diabetes and poor glycaemic control.

There is no medical procedure or medicine that we are testing - we simply want to find out your child's point of view.

#### **Why has my child been invited to take part?**

Your child has been selected because they have experience of living with diabetes and poor glycaemic control. I am hoping to speak to between 8 and 10 other young people about their experiences.

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**Does my child have to take part?**

**No, taking part is completely up to you and your child.** I will ask for your consent that your child can take part and then ask you to sign a form. I will give you a copy of this information sheet and your signed sheet to keep. Your child will also be asked to read an information sheet and sign a consent form.

If your child does not want to take part, they do not have to give a reason and they will not be pressurised into taking part. Also your child is free to stop taking part at any point during the research without giving a reason. Please note, **if your child chooses not to take part or withdraws from the research, this will not affect their current or future treatment in any way.**

If your child participates in the interview, they will be given a £5 voucher as a thank you for their time and effort.

**What will happen to my child if they take part?**

If your child agrees to take part, I will ask your child to answer some questions. There aren't any right or wrong answers. I just want to hear their opinion about their experiences. The discussion should take between 60 and 90 minutes. Your child will be asked questions about what it's like to have poor glycaemic control and whether this has affected how they feel about themselves and their relationships with others.

Please be aware that the sessions will be audio-recorded using a digital recorder and the recordings will later be written out on a computer.

**Is there anything to be worried about if my child takes part?**

It is possible that your child may become upset or unsettled during the interview, as they may discuss difficult topics. Before we start I will ask your child to identify someone in their life who could support them if they feel upset. If your child does become upset, I will spend some time with them either during the interview when your child is upset or at the end of the interview to help your child. I will also help your child access the person they identified as a source of support if they are still distressed when we are finished.

**What are the benefits of taking part?**

The interview will not be part of any intervention and it is not assumed that it will be of direct benefit to your child. However, some young people may wish to have their views heard, and the interview may be a positive experience. It is hoped the research will give us ideas about how we can best work with young

people who have diabetes and poor glycaemic control. We can then try to make services better for young people.

**In what language can my child take part?**

Your child can choose to speak Welsh or English during the interview, it is completely up to them.

My contact details are:

Llinos Griffith, Trainee Clinical Psychologist  
School of Psychology  
Bangor University  
Brigantia Building  
LL57 2AS  
Telephone: 07717805611

**Thank you for reading this so far - if you are still interested,  
please read part 2.**

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## **Young People's Experience of having Diabetes and poor glycaemic control**

### **Parental/Guardian Information Sheet: Part 2.**

This part of the information sheet contains more information that you need to know if your child wants to take part.

#### **What happens when the research stops?**

Nothing, once the interview is finished your child will not be asked for anything further.

#### **What if there is a problem or something goes wrong?**

The only problem that might occur is that your child may become distressed during the interview. We have tried to make sure that the questions will not make your child upset, however if your child does become upset the interview can be paused or stopped should they want. Also at the end of the interview your child will be given a chance to discuss anything that may upset them and hopefully they will leave the interview feeling OK. However, if your child still feels upset, I will help to find the person they identified at the start as someone who could provide them with support.

#### **Will anyone else know that my child is doing this?**

All the information your child shares with me will be confidential - this means that no-one outside the study will know what we talked about.

**Confidentiality will only be broken in circumstances where your child or other people may be at serious risk, and the researcher may have to tell the appropriate people, which will include a member of your child's healthcare team.**

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**What will happen to what my child says?**

What your child discusses with me during the interview will be recorded on a Digital recorder. This recorder will be kept by me and I will then type out everything we said onto a computer word document. Once the interview has been written up, I will delete your child's recording.

When your child's interview is written up, I will take out all the information that may identify your child, such as their name. The written interviews will then be looked at by Dr Renee Rickard (Clinical Psychologist) and me. We will then look at the things that your child spoke about and the things they felt were important. Whatever we find from this research will be used as part of my training as a Clinical Psychologist. The findings may also be published in an academic journal. Any information in reports or journals would always be used in a way that would not allow your child to be identified individually by anyone else. Anonymised quotations from your child's interview may be included in publications resulting from the research.

The written interviews will be kept at the Paediatrics department, Ysbyty Gwynedd for up to 12 months and then they will be destroyed. The information may be looked at again during this time by one of the researchers.

**Will my child receive any feedback after the research has been completed?**

If they want, a summary of the research findings will be sent to your child by post when the research has been completed and approved. This summary will include general feedback about the findings and will not include individual feedback about their interview. Your child will be asked whether they want this feedback on the participant consent form. You will be asked whether you give your consent for your child to receive this summary on the parent/guardian assent form.

**Will you have access to my child's medical records?**

The consent form will ask you whether you are happy for me to access your child's medical records. If you agree that your child can take part, I will access your child's medical records to extract information about their diabetes and glycaemic control.

**Who is organising and funding the research?**

Bangor University are organising and funding this research. It is forming part of my training on the North Wales Clinical Psychology Programme.

**Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure the research is fair. This project has been checked by the North Wales Research Ethics Committee.

**What do I do now?**

Think about the information on this sheet and ask any questions you may have.

If you agree that I can contact you and your child via telephone to discuss the research and answer any questions you may have, please fill-in the 'opt-in form' with your child.

**What will happen next?**

If you do not sign the opt-in form, you will not be contacted again.

If you and your child do sign the opt-in form, I will contact you and your child via telephone to discuss the research and answer any questions you may have. If after our discussion, you and your child are happy for your child to take part, we will arrange a time to meet which is convenient for you and your child.

When we meet, your child will be asked to read the information sheet again and I will ask them whether they still want to take part. **Your child can change their mind at any time.**

Before the interview, your child will be asked to sign a consent form and you will be asked to complete a parental/guardian assent form.

The opt-in form, the consent form and the assent form will be the only forms with your child's name on them and they will be filed separately from all other information.

**How do I make a complaint?**

If you wish to make a formal complaint after reading this information sheet or at any point during the research the contact details are below.

If you have a complaint to the NHS you can write a letter to...

Concerns Team

Betsi Cadwaladr University Health Board

Ysbyty Gwynedd

Bangor



Gwynedd  
LL57 2PW

Email... [ConcernsTeam.bcu@wales.nhs.uk](mailto:ConcernsTeam.bcu@wales.nhs.uk)

Or telephone...

Hospital and Community Services in Anglesey, Gwynedd, Conwy, Denbighshire,  
Flint and Wrexham - (01248) 384194

If you have a complaint to Bangor University you can write a letter to...

Isabel Hargreaves  
School of Psychology  
Bangor University  
Brigantia Building  
LL57 2AS

Email... [i.hargreaves@bangor.ac.uk](mailto:i.hargreaves@bangor.ac.uk)

Or telephone 01248 388365

**Thank you for your time**

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## Profiadau Pobl Ifanc o Glefyd Siwgr a Rheolaeth Glwcos Gwael

### Taflen Wybodaeth i Riant/Gwarcheidwaid: Rhan 1

Fy enw i ydi Llinos Griffith. Rwyf yn Seicolegydd Clinigol dan Hyfforddiant ym Mhrifysgol Bangor ac rwyf yn gweithio ym Mwrdd Iechyd Prifysgol Betsi Cadwaladr. Rwyf yn gwahodd eich plentyn i gymryd rhan mewn prosiect ymchwil sydd yn edrych ar brofiadau pobl ifanc o glefyd siwgr a rheolaeth glwcos gwael. Pan rwyf yn cyfeirio at 'rheolaeth glwcos gwael' rwyf yn golygu bod lefel glwcos y gwaed yn uwch na'r hyn mae'r Doctoriaid meddygol yn argymhell iddo fod.

Cyn i chi gytuno bod eich plentyn yn cael cymryd rhan, mae'n bwysig eich bod yn deall pam bod yr ymchwil yn cael ei gynnal a beth fydd hyn yn ei olygu i'ch plentyn. Felly ystyriwch y daflen hon yn ofalus. Siaradwch gyda'ch teulu, ffrindiau neu aelod o staff yn yr Ysbyty os hoffech chi.

#### **Pam fod yr ymchwil hwn yn cael ei gynnal?**

Rwyf i'n cael fy ngoruchwyllo gan Dr Liz Whitehead (Seicolegydd Clinigol) a Dr Renee Rickard (Seicolegydd Clinigol) ac rydym eisiau darganfod pa fath o brofiad ydyw i berson ifanc gael clefyd siwgr a rheolaeth glwcos gwael.

Tydym ni ddim yn profi unrhyw driniaeth feddygol neu feddyginiaeth - yn syml rydym am gael barn eich plentyn.

#### **Pam gafodd fy mhentyn wahoddiad i gymryd rhan?**

Cafodd eich plentyn ei (d)dewis oherwydd fod ganddi/ganddo brofiad o fyw gyda chlefyd siwgr a rheolaeth glwcos gwael. Rwyf yn gobeithio siarad gyda rhwng 8 a 10 person ifanc am eu profiadau.

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**Oes rhaid i fy mhlentyn gymryd rhan?**

**Na, eich dewis chi a'ch plentyn ydi cymryd rhan.**

Byddaf yn gofyn i chi am eich cydsyniad i'ch plentyn gymryd rhan ac yna'n gofyn i chi arwyddo ffurflen. Byddaf yn rhoi copi o'r daflen wybodaeth hon a'r daflen a arwyddwyd gennych i chi i'w cadw. Byddaf hefyd yn gofyn i'ch plentyn ddarllen taflen wybodaeth ac arwyddo ffurflen gydsynio.

Os nad ydi'ch plentyn eisiau cymryd rhan, does dim rhaid iddo/iddi roi rheswm ac ni fydd pwysau arno/arni i gymryd rhan. Mae eich plentyn yn rhydd i roi'r gorau i gymryd rhan ar unrwy adeg yn ystod yr ymchwil heb roi rheswm. **Sylwer, os ydi'ch plentyn yn dewis peidio cymryd rhan neu'n tynnu'n ol o'r ymchwil, ni fydd hyn yn effeithio ei driniaeth/thriniaeth bresennol neu ei driniaeth/thriniaeth yn y dyfodol o gwbl.**

Os ydi'ch plentyn yn cymryd rhan yn y cyfweiliad, bydd ef/hi yn cael tocyn £5 i ddiolch iddo/iddi am ei (h)amser a'i (h)ymdrech.

**Beth fydd yn digwydd i'm plentyn os ydi ef/hi yn cymryd rhan?**

Os ydi'ch plentyn yn cytuno i gymryd rhan, byddaf yn gofyn iddo/iddi ateb rhai cwestiynau. Does dim atebion cywir nac anghywir, yr unig beth ydw i am ei glywed amdano yw ei b/phrofiadau a'i b/farn. Dylai'r drafodaeth gymryd rhwng 60 a 90 munud. Bydd eich plentyn yn cael cwestiynau am sut fath o brofiad ydi cael rheolaeth glwcos gwael ac os ydi hyn wedi effeithio ar sut mae ef/hi yn teimlo am ei hun ac ar ei b/pherthnasau gyda eraill.

Cofiwch y caiff y sesiynau eu recordio ar beiriant digidol ac yn ddiweddarach bydd y recordiau'n cael eu hysgrifennu ar gyfrifiadur

**Oes yna unrhyw beth i boeni amdano os ydi fy mhlentyn yn cymryd rhan?**

Mae'n bosib y bydd eich plentyn yn anhapus neu'n ansicr yn ystod y cyfweiliad, gan y bydd ef/hi efallai'n trafod pynciau anodd. Cyn i ni ddechrau byddaf yn gofyn i'ch plentyn enwi rhywun yn ei f/bywyd a allai ei g/chefnogi os ydi o/hi'n teimlo'n anhapus. Os ydi'ch plentyn yn anhapus, byddaf yn treulio ychydig o amser gydag ef/hi unai yn ystod y cyfweiliad neu ar ddiwedd y cyfweiliad i helpu'ch plentyn. Os ydi'ch plentyn yn dal i deimlo'n ddrwg ar ol i ni orffen, byddaf hefyd yn helpu'ch plentyn i gysylltu a'r sawl a enwyd ganddo/ganddi.

**Beth yw manteision cymryd rhan?**

Ni fydd y cyfweiliad yn rhan o unrwy ymyrraeth ac ni honnir y bydd o fantais uniongyrchol i'ch plentyn. Ond efallai y bydd rhai pobl ifanc yn dymuno mynegi eu barn ac efallai y bydd y cyfweiliad yn brofiad cadarnhaol. Y gobraith ydi y bydd

yr ymchwil yn rhoi syniadau i ni am y ffordd orau o weithiau gyda phobl ifanc gyda chlefyd siwgr a rheolaeth glwcos gwael. Yna gallwn geisio gwella gwasanaethau i bobl ifanc.

**Ym mha iaith caiff fy mhlentyn gymryd rhan?**

Mi gaiff eich plentyn ddewis siarad Cymraeg neu Saesneg yn ystod y cyfweiliad, mae hyn i fyny i'ch plentyn yn llwyr.

Dyma fy manylion i:

Llinos Griffith, Seicolegydd Clinigol dan Hyfforddiant  
Yr Ysgol Seicoleg  
Prifysgol Bangor  
Adeilad Brigantia  
LL57 2AS  
Ffon: 07717805611

**Diolch i chi am ddarllen hyd yma - os ydych yn dal i fod a diddordeb, yna darllenwch Rhan 2 os gwelwch yn dda.**

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## **Profiadau Pobl Ifanc o Glefyd Siwgr a Rheolaeth Glwcos Gwael**

### **Taflen Wybodaeth i Riant/Gwarcheidwaid: Rhan 2.**

Mae'r rhan yma o'r daflen wybodaeth yn cynnwys mwy o wybodaeth sydd angen i chi ei wybod os yd'ch plentyn am gymryd rhan.

#### **Beth sy'n digwydd pan fo'r ymchwil yn gorffen?**

Dim. Unwaith y bydd y cyfweiliad wedi gorffen ni fyddaf yn gofyn unrhyw beth arall i'ch plentyn.

#### **Beth os oes problem neu os aiff rhywbeth o'i le?**

Yr unig broblem a allai ddigwydd ydi y gallai'ch plentyn deimlo'n ddrwg yn ystod y cyfweiliad. Rydym wedi ceisio sicrhau na fydd y cwestiynau'n gwneud eich plentyn yn anhapus, ond os yd'ch plentyn yn anhapus gellir rhoi'r gorau iddi am ychydig neu'n gyfan gwbl os yw'ch plentyn yn dymuno hynny. Hefyd ar ddiwedd y cyfweiliad bydd eich plentyn yn cael siawns i drafod unrhyw beth a allai fod wedi ei (g)wneud yn anhapus a'r gobaiith ydi y bydd eich plentyn yn gadael y cyfweiliad yn teimlo'n iawn. Ond, os yd'ch plentyn yn dal i deimlo'n anhapus, mi wna'f ei helpu i ddod o hyd i'r sawl a enwyd ganddo/genddi ar y dechrau fel rhywun a allai roi cefnogaeth iddo/iddi.

#### **Fydd unrhyw un arall yn gwybod bod fy mhientyn yn gwneud hyn?**

Bydd yr holl wybodaeth y bydd eich plentyn yn ei rannu gyda mi yn gyfrinachol - mae hyn yn golygu na fydd neb y tu allan i'r astudiaeth yn gwybod am yr hyn y buom yn siarad amdano.

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Yr unig adeg y caiff cyfrinachedd ei dorri ydi mewn amgylchiadau lle gallai'ch plentyn neu bobl eraill fod mewn perygl mawr, ac bydd yn rhaid i'r ymchwilydd ddweud wrth y bobl priodol. Mi fydd hyn yn cynnwys aelod o dim gofal iechyd eich plentyn.

**Beth fydd yn digwydd i'r hyn fydd fy mhentyn yn ei ddweud?**

Bydd yr hyn y bydd eich plentyn yn ei drafod gyda mi yn y cyfweiliad yn cael ei recordio ar beiriant digidol. Mi fydd y peiriant recordio'n cael ei gadw gen i ac mi fyddaf wedyn yn teipio popeth a ddywedwyd gennym ar ddogfen 'word' cyfrifiadur. Unwaith y bydd y cyfweiliad wedi ei ysgrifennu, byddaf yn dileu recordiad eich plentyn.

Pan fydd y cyfweiliad wedi ei ysgrifennu, byddaf yn tynnu allan yr holl wybodaeth a allai adnabod eich plentyn, fel ei (h)enw. Yna bydd Dr Renee Rickard (Seicolegydd Clinigol) a minnau'n edrych ar y cyfweiliadau ysgrifenedig. Byddwn yn edrych ar y pethau y bu'ch plentyn yn siarad amdanynt a'r pethau oedd yn bwysig yn ei f/barn o/hi. Bydd yr hyn y byddwn yn ei ddarganfod o'r ymchwil yma yn cael ei ddefnyddio fel rhan o'm hyfforddiant fel Seicolegydd Clinigol. Efallai hefyd y cyhoeddir y darganfyddiadau mewn cylchgrawn academiaidd (sydd yn debyg i bapur newydd sy'n adrodd am ymchwil newydd). Byddai unrhyw wybodaeth mewn adroddiadau neu gylchgronau bob amser yn cael eu defnyddio mewn modd na fyddai'n galluogi i unrhyw un arall adnabod eich plentyn yn unigol. Mi fydd dyfyniadau o'r cyfweiliad yn cael eu cynnwys mewn cyhoeddiadau o'r astudiaeth. Ni fydd y dyfyniadau yma yn cynnwys unrhyw wybodaeth a allai adnabod eich plentyn yn unigol.

Cedwir y cyfweiliadau ysgrifenedig yng Ngwasanaeth Pediatrig, Ysbyty Gwynedd, am hyd at 12 mis ac yna cant eu dinistrio. Efallai y bydd un o'r ymchwilydd yn edrych ar y wybodaeth eto yn ystod yr amser yma.

**Fydd fy mhentyn yn derbyn adborth wedi'r ymchwil gael ei gyflawni?**

Os ydi'ch plentyn eisiau, bydd crynodeb o ddarganfyddiadau'r ymchwil yn cael ei yrru iddo ef/hi yn y post wedi i'r ymchwil gael ei orffen a'i gadarnhau. Mi fydd y crynodeb yn cynnwys adborth cyffredinol ynglyn a'r darganfyddiadau ac ni fydd yn cynnwys adborth unigol am ei g/chyfweiliad. Mi fydd y ffurflen cydsynio yn gofyn i'ch plentyn os ydi o/hi eisio yr adborth yma. Mi fydd ffurflen gydsynio'r rhiant/gwarcheidwaid yn gofyn i chi os ydych yn cydsynio i'ch plentyn dderbyn yr adborth yma.

**Fydd gennych chi fynediad at gofnodion meddygol fy mhlentyn?**

Mi fydd y ffurflen cydsynio yn gofyn i chi gadarnhau eich bod yn fodlon i mi gael mynediad at gofnodion meddygol eich plentyn. Os ydych chi'n penderfynnu eich bod yn caniatáu i'ch plentyn gymryd rhan yn yr ymchwil, byddaf yn edrych ar ei g/chofnodion meddygol er mwyn casglu gwybodaeth ynglyn a'i g/chlefyd siwgr a rheolaeth glwcos.

**Pwy sydd yn trefnu ac yn ariannu'r ymchwil?**

Prifysgol Bangor sydd yn trefnu ac yn ariannu'r ymchwil. Mae'n rhan o fy hyfforddiant yn Rhaglen Seicoleg Glinigol Gogledd Cymru.

**Pwy sydd wedi adolygu'r astudiaeth?**

Cyn i unrhyw ymchwil fynd yn ei flaen mae'n rhaid i Bwyllgor Moeseg Ymchwil ei wirio. Maent yn gwneud yn siwr fod yr ymchwil yn deg. Cafodd y prosiect hwn ei wirio gan Bwyllgor Moeseg Ymchwil Gogledd Cymru.

**Beth ydw i'n ei wneud yn awr?**

Meddyliwch am y wybodaeth ar y daflen hon, a gofynnwch i mi os oes gennych chi unrhyw gwestiynnau.

Os ydych chi'n cytuno i mi gysylltu gyda'ch plentyn dros y ffon i drafod yr ymchwil ac i ateb unrhyw gwestiynnau sydd ganddo/ganddi, cwblhewch y 'Taflen Ymuno' gyda'ch plentyn.

**Beth sydd am ddigwydd nesaf?**

Os ydych chi'n dewis peidio cwblhau'r 'Taflen Ymuno', ni fyddwn yn cysylltu a chi eto.

Os ydych chi a'ch plentyn yn dewis arwyddo'r 'Taflen Ymuno', byddaf yn cysylltu gyda chi a'ch plentyn dros y ffon i drafod yr ymchwil ac i ateb unrhyw gwestiynnau sydd gennych. Os ydych chi a'ch plentyn yn hapus i'ch plentyn gymryd rhan wedi ein trafodaeth, mi wnawn ni drefnu amser cyfleus i gyfarfod.

Pan fyddwn yn cyfarfod, mi fyddai'n gofyn i'ch plentyn ddarllen y daflen wybodaeth eto ac byddaf yn gofyn iddynt os ydynt eisiau cymryd rhan. **Mi gaiff eich plentyn newid ei f/meddwl ar unrhyw adeg.**

Cyn y cyfweiliad, byddaf yn gofyn i'ch plentyn arwyddo ffurflen cydsynio ac byddaf yn gofyn i chi arwyddo ffurflen cydsynio rhiant/ gwarcheidwaid.

Mi fydd enw eich plentyn yn cael ei gynnwys ar y 'Taflen Ymuno', y ffuflen gydsynio, a'r ffurflen cydsynio y rhiant/gwarcheidwaid yn unig, a byddant yn cael eu cadw ar wahan i'r wybodaeth arall.

### **Sut allai wneud cwyn?**

Os ydych chi'n dymuno cwyno ar ol darllen y daflen wybodaeth hon neu ar unrhyw adeg yn ystod yr ymchwil mae'r manylion cyswllt ar gyfer gwneud hynny ar gael isod.

Os oes gennych chi gwyn i'r GIG gallwch ysgrifennu llythyr at  
Adran Cwynion  
Bwrdd Iechyd Prifysgol Betsi Cadwaladr  
Ysbyty Gwynedd  
Bangor  
Gwynedd  
LL57 2PW

Ebost... [ConcernsTeam.bcu@wales.nhs.uk](mailto:ConcernsTeam.bcu@wales.nhs.uk)

Neu ffoniwch...

Gwasanaethau ysbytai a chymuned yng Ngwynedd, Sir Fon, Conwy, Dinbych,  
Fflint a Wrescam - (01248) 384194

Os oes gennych chi gwyn i Brifysgol Bangor gallwch ysgrifennu llythyr at...

Isabel Hargreaves  
Yr Ysgol Seicoleg  
Prifysgol Bangor  
Adeilad Brigantia  
LL57 2AS

Ebost... [i.hargreaves@bangor.ac.uk](mailto:i.hargreaves@bangor.ac.uk)

Neu ffoniwch 01248 388365

**Diolch i chi am eich hamser.**



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NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



**Young People's Experience of having Diabetes and poor glycaemic control**

**Opt-in form**

**Participant number (to be completed by researcher): .....**

Please initial all boxes

I confirm that somebody has explained this research project to me.

I confirm that I have read and understand the information sheet.

I am happy for Llinos Griffith to contact me via telephone to discuss the research and answer any questions I may have.

I understand that it is ok for me to change my mind at any time.

I understand that if I decide to take part after speaking with Llinos Griffith, she will arrange an interview date and time with me over the telephone.

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If you are happy for Llinos Griffith to contact you via telephone, please provide a contact telephone number: \_\_\_\_\_

If any answers are “no” or you don’t want Llinos Griffith to telephone you, don’t sign your name! If you do want Llinos Griffith to telephone you, you can write your name below:

**Participant signature** ..... **Date** .....

**Print Name** .....

**Parent/guardian assent**

If you are happy for Llinos Griffith to contact you and your child on the above telephone number, please write and sign your name below.

**Signed** ..... **Date** .....

**Print Name** .....



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**Profiadau Pobl Ifanc o Glefyd Siwgr a Rheolaeth Glwcos Gwael**

**Taflen Ymuno**

**Rhif yr un sy'n Cymryd Rhan (i gael ei gwblhau gan yr ymchwilydd): .....**

Nodwch eich llythrennau cyntaf (initials) ym mhob blwch os gwelwch yn dda

Rwyf yn cadarnhau bod rhywun wedi egluro'r prosiect hwn i mi.

Rwyf yn cadarnhau fy mod wedi darllen a deall y daflen wybodaeth.

Rwyf yn fodlon i Llinos Griffith gysylltu a mi dros y ffon i drafod yr ymchwil ac i ateb unrhyw gwestiynau sydd gennyf.

Rwyf yn deall ei bod hi'n iawn i mi newid fy meddwl ar unrhyw adeg.

Rwyf yn deall os byddaf yn dewis cymryd rhan wedi i mi siarad a Llinos Griffith, y bydd hi'n trefnu amser a dyddiad y cyfweiliad gyda mi dros y ffon.

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Os ydych chi'n hapus i Llinos Griffith gysylltu a chi dros y ffon, ysgrifennwch eich rhif ffon os gwelwch yn dda: \_\_\_\_\_

Os ydych chi wedi nodi 'na' fel ateb i unrhyw un o'r cwestiynau uchod, neu os nad ydych chi am i Llinos Griffith eich galw ar y ffon, yna pheidiwch a arwyddo'ch enw! Os ydych chi am i Llinos Griffith eich galw, yna gofynnir i chi arwyddo isod:

**Llofnod yr Un sy'n Cymryd Rhan** ..... **Dyddiad** .....

**Printiwch eich Henw** .....

### **Rhiant/Gwarcheidwad**

Os ydych chi'n fodlon i Llinos Griffith gysylltu gyda chi a'ch plentyn dros y ffon gan ddefnyddio'r rhif uchod, ysgrifennwch ac arwyddwch eich enw isod os gwelwch yn dda.

**Llofnod Rhiant/ Gwarcheidwaid** ..... **Dyddiad** .....

**Printiwch eich Henw** .....

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**Young People's Experience of having Diabetes and poor glycaemic control**

**Participant Consent Form**

**Participant number (to be completed by researcher): .....**

Please initial all boxes

I confirm that somebody has explained this project to me.

I understand what this project is about.

I have asked all the questions that I want.

All questions have been answered in a way that I understand.

I understand that it is OK for me to stop taking part at any time.

I am happy to take part.

I agree to being audio-recorded as part of the research.

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I am happy for anonymised quotations from my interview to be included in publications resulting from the research.

I am happy for Llinos Griffith to access my medical records to extract information about my diabetes and glycaemic control.

As explained on the participant information sheet, all the information you share with Llinos Griffith will be confidential – this means that no-one outside the study will know what you talked about.

I understand that **confidentiality will only be broken** in circumstances where I or other people may be at serious risk and Llinos Griffith will have to tell the appropriate people, which will include a member of my healthcare team.

Please initial the box if you would like to receive general feedback by post outlining the findings of the research when it has been completed and approved. This will not include individual feedback about your interview.

If you would like to receive a summary of the findings, please write the address you would like it to be sent to:

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---

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Please do not sign your name below if you do not want to take part!

If you do want to take part in the research, you can write your name below:

**Participant signature** ..... **Date**.....

**Print Name** .....

**Signed on behalf of the researchers**

**Signed** ..... **Date**.....

**Print Name** .....

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**Profiadau Pobl Ifanc o Glefyd Siwgr a Rheolaeth Glwcos Gwael**

**Ffurflen Gydsynio I'r Un sy'n Cymryd Rhan**

**Rhif yr un sy'n Cymryd Rhan (i gael ei gwblhau gan yr ymchwilydd): .....**

Nodwch eich llythrennau cyntaf (initials) ym mhob blwch os gwelwch yn dda

Rwyf yn cadarnhau bod rhywun wedi egluro'r prosiect hwn i mi.

Rwyf yn deall beth yw pwrpas y prosiect hwn.

Rwyf wedi gofyn yr holl gwestiynau sydd gennyf.

Atebwyd yr holl gwestiynau mewn ffordd roeddwn yn ei ddeall.

Rwyf yn deall ei bod hi'n iawn i roi'r gorau i gymryd rhan ar unrhyw adeg.

Rwyf yn fodlon cymryd rhan.

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Rwyf yn fodlon cael fy recordio ar beiriant sain fel rhan o'r ymchwil.

Rwyf yn fodlon i ddyfyniadau o'r cyfweiliad gael eu cynnwys mewn cyhoeddiadau o'r astudiaeth. Ni fydd y dyfyniadau yn cynnwys unrhyw wybodaeth fyddai'n galluogi i unrhyw un arall fy adnabod yn unigol.

Rwyf yn fodlon i Llinos Griffith gael mynediad at fy nghofnodion meddygol i gasglu gwybodaeth am fy nghlefyd siwgr a rheolaeth glwcos.

Yn unol a'r hyn esbonwyd yn y 'Daflen Wybodaeth i'r Rhai sy'n Cymryd Rhan', bydd yr holl wybodaeth y byddwch yn ei rannu gyda Llinos Griffith yn gyfrinachol – mae hyn yn golygu na fydd neb y tu allan i'r astudiaeth yn gwybod am yr hyn y buom yn siarad amdano.

Rwyf yn deall **mai'r unig adeg y bydd cyfrinachedd yn cael** ei dorri ydi mewn amgylchiadau ble gallwn i neu bobl eraill fod mewn perygl mawr, a bydd yn rhaid i Llinos Griffith ddweud wrth y bobl priodol. Mi fydd hyn yn cynnwys aelod o fy nhim gofal iechyd.

Nodwch eich llythrennau cyntaf (initials) yn y blwch os ydych eisiau derbyn adborth cyffredinol yn y post fydd yn amlinellu darganfyddiadau'r ymchwil wedi iddo gael ei orffen a'i gadarnhau. Ni fydd hyn yn cynnwys adborth unigol am eich cyfweiliad.

Os ydych chi eisiau derbyn adborth, ysgrifennwch y cyfeiriad yr hoffech i'r adborth gael ei yrru iddo os gwelwch yn dda:

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Os nad ydych chi am gymryd rhan, yna pheidiwch a arwyddo'ch enw!

Os ydych chi am gymryd rhan, gallwch ysgrifennu'ch enw isod:

**Llofnod yr Un sy'n Cymryd Rhan ..... Dyddiad .....**

**Printiwch eich Henw .....**

**Arwyddwyd ar ran yr ymchwilwyr**

**Arwyddwyd ..... Dyddiad .....**

**Printiwch eich Henw .....**



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**Young People’s Experience of having Diabetes and poor glycaemic control**

**Parental/Guardian Assent Form**

**Participant number (to be completed by researcher): .....**

**Name of Child: .....**

Please initial all boxes

I confirm that somebody has explained this project to me.

I understand what this project is about.

I have asked all the questions that I want.

All questions have been answered in a way that I understand.

I understand that my child can stop taking part at any time.

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I am happy for my child to take part.

I agree that my child can be audio-recorded as part of the research.

I am happy for anonymised quotations from my child's interview to be included in publications resulting from the research.

I am happy for Llinos Griffith to access my child's medical records to extract information regarding their diabetes and glycaemic control.

As explained on the parent/guardian information sheet, all the information your child shares with Llinos Griffith will be confidential – this means that no-one outside the study will know what they talked about.

I understand that **confidentiality will only be broken** in circumstances where my child or other people may be at serious risk and Llinos Griffith will have to tell the appropriate people, which will include a member of my child's healthcare team.

Please initial the box if you are happy for your child to receive general feedback by post outlining the findings of the research when it has been completed and approved. This will not include individual feedback about their interview. If you are happy for your child to receive feedback, a summary will be sent to the address provided by your child.

Please do not sign your name below if you do not want to take part!

If you are happy for your child to take part, you can write your name below:

**Parent/Guardian Signature .....** **Date .....**

**Print Name .....**

**Signed on behalf of the researchers**

**Signed .....** **Date .....**

**Print Name .....**

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**Ffurflen Gydsynio Rhiant/ Gwarcheidwaid**

**Rhif yr un sy'n Cymryd Rhan (i gael ei gwblhau gan yr ymchwilydd): .....**

**Enw'r plentyn:.....**

Nodwch eich llythrennau cyntaf (initials) ym mhob blwch os gwelwch yn dda

Rwyf yn cadarnhau bod rhywun wedi egluro'r prosiect hwn i mi.

Rwyf yn deall beth yw pwrpas y prosiect hwn.

Rwyf wedi gofyn yr holl gwestiynau sydd gennyf.

Atebwyd yr holl gwestiynau mewn ffordd roeddwn yn ei ddeall.

Rwyf yn deall y gall fy mhlentyn roi'r gorau i gymryd rhan ar unrhyw adeg.

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Rwyf yn fodlon i fy mhlentyn gymryd rhan.

Rwyf yn fodlon i fy mhlentyn gael ei recordio ar beiriant sain fel rhan o'r ymchwil.

Rwyf yn fodlon i ddyfyniadau o'r cyfweiliad gael eu cynnwys mewn cyhoeddiadau o'r astudiaeth. Rwyf yn deall na fydd y dyfyniadau yn cynnwys unrhyw wybodaeth fyddai'n galluogi i unrhyw un arall adnabod fy mhlentyn yn unigol.

Rwyf yn fodlon i Llinos Griffith gael mynediad at gofnodion meddygol fy mhlentyn er mwyn casglu gwybodaeth am ei g/chlefyd siwgr a rheolaeth glwcos.

Yn unol a'r hyn esbonwyd yn y 'Daflen Wybodaeth i Riant/Gwarcheidwaid', bydd yr holl wybodaeth y bydd eich plentyn yn ei rannu gyda Llinos Griffith yn gyfrinachol – mae hyn yn golygu na fydd neb y tu allan i'r astudiaeth yn gwybod am yr hyn y buom yn siarad amdano.

Rwyf yn deall **mae'r unig adeg y bydd cyfrinachedd yn cael** ei dorri ydi mewn amgylchiadau ble gallai'ch plentyn neu bobl eraill fod mewn perygl mawr, ac bydd yn rhaid i Llinos Griffith ddweud wrth y bobl priodol. Mi fydd hyn yn cynnwys aelod o dim gofal iechyd eich plentyn.

Nodwch eich llythrennau cyntaf (initials) yn y blwch os ydych chi'n fodlon i'ch plentyn dderbyn aborth cyffredinol yn y post, fydd yn amlinellu darganfyddiadau'r ymchwil wedi iddo gael ei orffen a'i gadarnhau. Ni fydd hyn yn cynnwys adborth unigol am ei g/chyfweiliad. Os ydych yn fodlon i'ch plentyn dderbyn adborth, bydd crynodeb yn cael ei yrru yn y post i'r cyfeiriad a nodwyd ganddo/ganddi.

Os nad ydych chi am i'ch plentyn gymryd rhan, yna pheidiwch a arwyddo'ch enw!

Os ydych chi'n fodlon i'ch plentyn gymryd rhan, gallwch ysgrifennu'ch enw isod:

**Llofnod Rhiant/ Gwarcheidwaid ..... Dyddiad .....**

**Printiwch eich Henw .....**

**Arwyddwyd ar ran yr ymchwilwyr**

**Arwyddwyd ..... Dyddiad .....**

**Printiwch eich Henw .....**

**Appendix 5C.**

**Section of an Annotated Transcript**

| Emergent Themes | Original Transcript                                                                                                                      | Exploratory comments                                                                                    |
|-----------------|------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|
|                 | I: It's on... ok cool. So the first question is... how old are you?                                                                      |                                                                                                         |
|                 | P: I'm seventeen                                                                                                                         |                                                                                                         |
|                 | I: Seventeen ok, and how would you describe your ethnicity?                                                                              |                                                                                                         |
|                 | P: ... umm... normal? [laugh]                                                                                                            |                                                                                                         |
|                 | I: [laugh] ok, ok so I'd describe myself as white British                                                                                |                                                                                                         |
|                 | P: ye same thing, that thanks                                                                                                            |                                                                                                         |
|                 | I: that's alright... and how old were you when you were told that you had diabetes?                                                      |                                                                                                         |
|                 | P: Seven                                                                                                                                 |                                                                                                         |
|                 | I: Seven ok ... ok great, so the first question is... umm what is your experience or what has it been like for you living with diabetes? |                                                                                                         |
|                 | P: Rubbish [laugh]                                                                                                                       | First answer to describe diabetes is 'rubbish'                                                          |
|                 | I: Rubbish [laugh] ok, so tell me a bit more about that what...                                                                          |                                                                                                         |
|                 | P: I hate it... I just... umm it's just been really like h... really hard                                                                | Appears hesitant initially, is it difficult talking about it? Strong emotions 'I hate it' 'really hard' |



|                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                         |
|-------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                   | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                         |
| Feeling different                                                 | P: Umm not in the sense that there's been no one to support me or anything cos there has, I've got so much support... but it's just umm... like being the only child in my family to have it                                                                                                                                                                                                                | It's not difficult because there's no support, she emphasises that she has support, but it's difficult because she's the only child in the family to have diabetes. Does it make her different?                                                                                                                                                                         |
|                                                                   | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                         |
| Wanting to hide diabetes                                          | P: Umm and... it's just like it's not something discrete, it's so... like... you <i>have</i> to tell people, it's not like you can just keep it... quiet, so it's like it really sets you apart                                                                                                                                                                                                             | She has no option but to tell people, she can't 'keep it quiet'. Indicates that she possibly might like to do so? Wants it to be a secret? Indication that she is different, 'It sets you apart'. Echoes previous comment, she's the only child in her family to have diabetes.                                                                                         |
|                                                                   | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                         |
| Burdensome                                                        | P: Umm and it's just... remembering to do it every day... umm... and it's like...remembering to do homework, sometimes you remember                                                                                                                                                                                                                                                                         | Appears hesitant but is willing to elaborate without prompt. It's difficult to remember to do it every day, which may imply it's a burden? Monotonous? Says 'remember' twice. Compares it to doing homework, reflecting her age.                                                                                                                                        |
|                                                                   | I: Ye                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                         |
| Changing motivation – rejecting diabetes<br><br>Changes over time | P: and you'll be like oh I really really want to get into this and like finish it and then sometimes you're like... just you just wanna just go to sleep and you just wanna forget about it and you don't want to do it...and that's just... I think you go through like different stages... umm and I definitely have, like it's just... like the stage where you don't want to do it are just really hard | Continues with the comparison. Things change, sometimes she really wants to do it and sometimes she wants to forget about it. Feelings and motivation change. Repetition of 'really' to indicate that she sometimes really wants to do it. Describes going through definite 'stages', it changes over time. The stage where she doesn't want to do it is 'really hard'. |

|                                                              |                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|--------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                              |                                                                                                                                                                                                                                                                                                                                                                                      | Also used these words at the beginning. Indicates a struggle with her diabetes? Although her motivation changes her diabetes doesn't.                                                                                                                                                                                                                                                                                                                                                                   |
|                                                              | I: Ok                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| Rejecting diabetes<br>Wanting to be normal<br>Poor adherence | P: and ... cos you go... there's a definite stage... umm where you just don't want it anymore and you'd do anything to just not have it... umm and you just don't inject... you don't test... you don't wanna listen to advice from anyone, you don't wanna take support from anyone, you just want to cut everyone off, you just wanna, you just, you just want to be normal again. | Repetition of 'definite stage' and 'don't want it anymore and you'd do anything not to have it'. Possibly providing insight into her inner dialogue? The struggle of living with diabetes. Is she trying to reject it? Repetition and listing highlighting all the things she doesn't want to do. These feelings make her not want to adhere to her regime and accept support. She wants to be 'normal again'. Similar to her describing earlier that diabetes sets her apart. Impact on sense of self. |
|                                                              | I: Ok                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| Relationship with parents                                    | P: umm... and especially going from when it was, when I was seven and my mum and dad got told everything... they did it for me                                                                                                                                                                                                                                                       | It's changed from her being seven and people doing it for her. Have things changed as she has developed? Have the expectations placed upon her changed?                                                                                                                                                                                                                                                                                                                                                 |
|                                                              | I: Ok                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| Changes over time                                            | P: and going from being seven... to being fifteen, sixteen, seventeen, and having to start doing it by myself                                                                                                                                                                                                                                                                        | Repetition and listing of ages underlines that diabetes is a constant in her life. However, her management of it has changed.                                                                                                                                                                                                                                                                                                                                                                           |
|                                                              | I: Ye                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |

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| Transferring responsibility                              | P: was even harder cos you have to start all the way from the beginning and do it all again ... so it's like being diagnosed twice... and that was crap... and I didn't it's just really hard... but umm... I'm <i>sort of</i> figuring it out a bit more now... | Doing it herself was harder, compares this to being 'diagnosed twice', so was it possibly traumatic? Responsibility transitioning from parents to her was 'crap' and 'really hard'. Continuing to struggle with it 'sort of figuring it out'. Is it ever a finished process? |
|                                                          | I: Ok                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                              |
|                                                          | P: But overall it's... it's rubbish [laugh]                                                                                                                                                                                                                      | Summarizes that it is overall 'rubbish', which is the first word she used.                                                                                                                                                                                                   |
|                                                          | I: [laugh] so overall rubbish ok... so you said, it sounded like, you felt like you'd been diagnosed twice                                                                                                                                                       |                                                                                                                                                                                                                                                                              |
|                                                          | P: Twice ye                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                              |
|                                                          | I: So when was it when you started having to do it all yourself?                                                                                                                                                                                                 |                                                                                                                                                                                                                                                                              |
|                                                          | P: Umm when I was about... fifteen                                                                                                                                                                                                                               | Hesitant, possibly she's not sure when she started to manage her diabetes, approximately aged 15. Is this transition complete?                                                                                                                                               |
|                                                          | I: Ok                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                              |
| Relationship with parents<br>Transferring responsibility | P: They started like saying, you know try and get more independence and umm... do it, do more things yourself... y my mum was like still doing stuff                                                                                                             | This transition was instigated by other people, use of 'they' telling her to get more independence. Mum still doing 'stuff'. Is transition a difficult process/handing over responsibility?                                                                                  |
|                                                          | I: Ye                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                              |

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| It changes over time<br>Negotiating parent role              | P: but she backed off a lot... but then like I'd go through stages where I'd do it loads by myself, do everything and she's only be reminding me... to... not then, like totally changing it and mum would do everything again and then we would like, it was like... keep swapping                                                         | Indicating a lot of change, use of 'totally changing' and 'stages'. Her and mum 'keep swapping' roles. The transition of responsibility not straight forward. 'backed off' – indicating conflict between her and mum? Possibly a difficult process for both of them?                                                                               |
|                                                              | I: Ok so it changed a lot then?                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                    |
|                                                              | P: Ye ye                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                    |
|                                                              | I: Ok                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                    |
| Relationship with mother                                     | P: and umm... and it was just it's re like, really confusing like... so now... I've totally said to my mum this is me doing it by myself now ok, no messing around, but she still does like... have you been doing your injections? Have you done this, have you done your test? What was your test today? Why don't you show me your test? | Hesitation. 'really confusing'. She's now told mum that she's doing it herself, taking control? Possibly Imitating dialogue between them here - 'doing it by myself now ok, no messing around'. But mum still checks on her asking lots of questions. Repetition of questions indicating the repetitiveness of this, how much she is checked upon. |
|                                                              | I: How does that make you feel?                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                    |
| Relationship with mother – wanting help but not wanting help | P: ... Like she doesn't... it makes me feel nice... in a way like 'cos she still wants like to look after me but                                                                                                                                                                                                                            | Conflicting feelings about mum. 'Nice in a way'. She likes that mum wants to look after her.                                                                                                                                                                                                                                                       |
|                                                              | I: Ok ye                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                    |

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| Not feeling trusted                                               | P: I just want her to let me do it like otherwise I'm never going to do it and it makes me feel a bit like... umm like she doesn't trust me...                                                                                                                                                                                                                                                                           | However, she wants to learn to do it herself. Seeking independence? Hesitation when describing feeling that her mum doesn't trust her.                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|                                                                   | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Not feeling trusted<br>Being told what to do                      | P: and like the... the umm you don't feel trusted at home and in school sometimes cos... umm in school and they were like... oh yes ok when you've done your test go report it to reception ... go tell them when you've done your injection, when you've done your test, what your test was and then we can send them off home... and it was a bit like well if I'm trying to do this myself why why am I doing this... | Describing not feeling trusted at home or at school. Repetition of instructions 'go' indicating that people are constantly telling her what to do.                                                                                                                                                                                                                                                                                                                                                                                                                            |
|                                                                   | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Not feeling trusted<br>Difficult relationships with professionals | P: to send home for them to look over and it didn't feel like it was... it felt like it was... a test, like it was all like one big like test and if I didn't go and report it then they're going to get mad at me and... umm people are going to shout at me... and it feels a bit like that for, it used to feel like that to me with clinic                                                                           | Appears to be a conflict between being told to be independent and then being told to report her tests to reception. Realisation of 'why am I doing this?'<br>Conflicting messages.<br><br>'Felt like it was a test' 'one big like test'. Repetition here. Powerful imagery, is diabetes a test that she's failing? Similar to homework imagery earlier. People checking up on her. Difficult interactions if she doesn't do as she's told 'they're going to get mad at me, shout at me'. She describes that the clinic is similar. Appears isolated with adults scolding her. |
|                                                                   | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |

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| <p>Impact on sense of self</p> <p>Being criticized</p>                                                               | <p>P: and... cos it was just a bit... umm sometimes it can just be a bit... umm too much... and like I know they're only doing it for my own benefit but I don't... I didn't like... the negative ...side of it, like the criticisms</p>                                                                                                                                                                                                                                                                                                                                                                                                             | <p>Hesitation, is it difficult to talk about clinic? Is she nervous to do so? Starts sentence four times. Acknowledges that attending clinic is for her benefit but dislikes the 'negative side', criticisms' 'too much'. Is the whole process overwhelming?</p>                                                                                                                                                                                                                                                                                                                                                                                       |
|                                                                                                                      | <p>I: Ye, so tell me more about that, the negative side, the criticisms of it</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <p>Difficult relationship with professionals</p> <p>Negative feelings about the self</p> <p>Disappointing others</p> | <p>P: Umm... it's just like for clinic, when they, when you come in like it's just like this horrible like sick feeling you get before clinic... and then it feels like... it feels like I'm going to let them down, like I don't want to let them down...</p>                                                                                                                                                                                                                                                                                                                                                                                       | <p>Hesitation, 'horrible sick feeling' before attending clinic. Indication of anxiety? Anticipation? Physical symptoms. Repetition of 'let them down' doesn't want to do so. Impact on sense of self, is she feeling guilty? Has she failed? Echoing previous comparison of it being a test.</p>                                                                                                                                                                                                                                                                                                                                                       |
|                                                                                                                      | <p>I: Ok</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <p>Difficult relationship with professionals</p> <p>Negative feelings about the self. Being criticized</p>           | <p>P: I hate public humiliation, I hate umm... failing things... so like when umm...when I came, when I come to clinic... when I used to come, just used to feel like when my mum and dad were in there with me, if I didn't have a good sugar reading... I'd like failed them and they were going to shout at me and like my dad would go away and he'd be like well you need to do better at this, you need to do better at that and... umm I used to sort of like, I always thought that [name of Paediatrician] and [name of diabetes nurse] like be like really umm... sort of like they'd they'd be unhappy with me and angry at me... umm</p> | <p>Strong imagery 'public humiliation'. Is it a shaming experience? Repeats 'failing' and 'failed them', possible negative impact on sense of self.</p> <p>Feelings spill over from clinic to the home when parents went in to the clinic with her. Repeats 'shout at me' here. Her father was angry with her about her poor control. Again, use of repetition 'need to do better' indicates how often people tell her what to do or what she isn't doing right. Impact on parent-child relationship. Hesitation when describing that healthcare professionals were unhappy and angry with her. Appears that her perception of adults thus far are</p> |

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|                                           |                                                                                                                                                                                                                                                             | angry/negative with her - school, parents and professionals.                                                                                                                                                                                                                                                                            |
|                                           | I: And did you think they were angry with you?                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                         |
|                                           | P: Ye                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                         |
|                                           | I: Ok, ok how how did you know that or what made you think that?                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                         |
| Difficult relationship with professionals | P: It was just like how they spoke to me, it was a bit like... they were... they were like dismissive and... umm very umm authoritative... rather than like... they'd always see like the negative... side of things rather than the what I'm doing... good | Professionals spoke to her in a 'dismissive', 'authoritative' way and 'always see like the negative'. Use of 'rather than' indicating that she would have liked them to see 'what I'm doing... good'. Doesn't appear to be balanced. Is it all negative? Is the responsibility/blame placed solely on her? Possibly shaming experience. |
|                                           | I: Ok                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                         |
| Diabetes being used as a weapon by others | P: Umm and like at home, my mum and dad like used my test as like a threat to me like if I was angry... just like normal anger                                                                                                                              | Parents used her test as 'a threat', when she experienced 'normal anger'. Is she not allowed to feel normal emotions? Diabetes being used against her.                                                                                                                                                                                  |
|                                           | I: Ye                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                         |
|                                           | P: My mum would be like right go do a test you're obviously high and...                                                                                                                                                                                     | Mother attributing normal anger to blood sugars being high. Invalidating her feelings?                                                                                                                                                                                                                                                  |
|                                           | I: Ok                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                         |

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| Emotional impact<br>Diabetes being used against her                                | P: like she'd use it as a threat but like she'd never do it any other time, it would just be like... a threat to me, like cos [name of sister], my sister doesn't have it, and it would be like a direct hit to <i>me</i>                                                                                                                                                                                                                                                    | Repetition of 'threat' twice here. Use of words 'direct hit' evoking imagery of war-fare and conflict, with her being the target. Mother using diabetes against her, comparing how different she is to her sister.                                                                                                                                                                                                                                                         |
|                                                                                    | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|                                                                                    | P: She couldn't do that to [name of sister]... and it was like, it's umm... it was a lot more personal...                                                                                                                                                                                                                                                                                                                                                                    | Repetition of comparison with her sister, are people using diabetes against her? Diabetes is personal to her.                                                                                                                                                                                                                                                                                                                                                              |
|                                                                                    | I: How did it make you feel when she when she said that?                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| Emotional impact                                                                   | P: I used to hate it, it made me so angry                                                                                                                                                                                                                                                                                                                                                                                                                                    | These conflicts create intense feelings 'hate it, it made me so angry'.                                                                                                                                                                                                                                                                                                                                                                                                    |
|                                                                                    | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| Emotional impact<br>Wanting to be normal<br>Rejecting diabetes as part of the self | P: I used to get so... frustrated and angry with her and umm upset, it used to make me really upset... umm cos it was like why why use it like that... it's umm... like I can, I am a normal person as well, I do have... normal emotions, diabetes doesn't affect my... emotions... I know it's... like frustrating that like that she, it felt like I wasn't being taken seriously, it felt like diabetes was just like something that people could like... use against me | Repetition here of 'frustrated' and 'angry'. First time indicates 'upset' and then 'really upset'. Repetition of 'why' indicating that she's trying to make sense of why diabetes is used against her. Is it seen as her weakness? Similar to earlier, repeats that she is normal. Is she trying to distance herself from diabetes? Repeating that it doesn't affect her emotions. She sounds isolated, are her emotions reduced to the effects of diabetes? Invalidating? |
|                                                                                    | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |



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|                                                          | P: and manipulate... and it felt a bit... umm intrusive                                                                                                                                                                                                                                                                                                                                                           | Use of 'manipulate' and 'intrusive', does the diabetes give people permission to tell her what to do or interpret her emotions? Indicating a lack of privacy?                                                                                                 |
|                                                          | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                               |
| Diabetes as a weakness                                   | P: like umm people like just trying to get at me through my diabetes and it's like my weakness...                                                                                                                                                                                                                                                                                                                 | Again, indicating here that diabetes makes her a target or a victim. 'people like trying to get at me through my diabetes and it's like my weakness'. Does diabetes makes her vulnerable?                                                                     |
|                                                          | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                               |
| Rejecting diabetes                                       | P: and I just... hate it so much...                                                                                                                                                                                                                                                                                                                                                                               | 'hate it so much', she dislikes how diabetes is used. Hate is a word previously used.                                                                                                                                                                         |
|                                                          | I: ok, so it sounds like... or did it change the way people were towards you?                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                               |
|                                                          | P: Ye, like when... when you're... umm a teenager, obviously like you know there's all the normal teenage like things, like getting a boyfriend and friends and stuff, and I used to have the pump                                                                                                                                                                                                                | Describes 'normal teenage' things and introduces the fact that she used to have an insulin pump. Again referring to 'normal'.                                                                                                                                 |
|                                                          | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                               |
| Relationship with professionals/parents<br>Non-adherence | P: and umm... I was sort of, I was forced in to it mostly about my dad... but I felt a bit forced by the doc, like doctors and nurses and stuff, cos they were all like, this is what you need to have, it's gonna make everything better... and like people would be like... like when I'd have it in at school and people would be like www what's this, what's that, and like you've got like this tube coming | Repeats 'forced' by her dad, the doctors and nurse to have the pump. Strong imagery. Repetition of 'they were all like' and use of listing indicating that people bombarded her. People told her the pump would make 'everything better' but they were wrong. |

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| Impact on her social self<br><br>Non-adherence | out of you and oh that's so weird and... it was just so, it was like, it was like a pressure... and I used to take it off like unclip it... and I just used to like... still put it in my pocket but just unclip it for the whole day... | Pump drew attention to her in school, made her different, impact on her sense of self/social self? 'that's so weird', peers asking lots of questions was a 'pressure' so she unclipped it – non-adherence with medication. Was the social pressure of being different not worth adhering? Reflecting developmental age. Did people warn her about this? |
|                                                | I: Where you meant to do that or... sorry I don't really understand about those things                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                         |
|                                                | P: No, like when it was a canular on my back or stomach                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                         |
|                                                | I: Ye                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                         |
|                                                | P: and the pump had a line coming from it with a little umm thing that connected on to the top of the canular                                                                                                                            | Describing pump.                                                                                                                                                                                                                                                                                                                                        |
|                                                | I: Ok                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                         |
| Poor adherence                                 | P: and... it looked a bit like umm like a fencing sword... umm and it just used to connect on and I just used to take it off                                                                                                             | Pump was unsightly, maybe scary? Strong imagery 'like a fencing sword'. Similar to earlier imagery of war-fare. Minimizing non-adherence with the use of 'just' or is she indicating how easy it was not to adhere to the regime?                                                                                                                       |
|                                                | I: Ok, why why do you think you took it off?                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                         |
| Diabetes drawing attention to her Social self  | P: it was just, people used to just look at it                                                                                                                                                                                           | Confirming that she took it off as people used to look at it. Dislike of drawing attention to herself and of being different.                                                                                                                                                                                                                           |

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|                                                 | I: Ok                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                         |
|                                                 | P: and be umm... like when I'd tell them, they'd be like, oh you're diabetic, oh do you have to do this, do you have to do that, do you have to do this, and it's like I understand like people wanna ask questions and stuff but it was just like... it was embarrassing and it's like... something you don't want people to know about | Describing how people react when they find out that she's diabetic, people change. It appeared to give them permission to ask questions/be intrusive. Use of 'oh' to indicate people's exaggerated responses. She understands that people want to ask questions, but 'it was embarrassing'. Echoes previous statements 'you don't want people to know'. |
|                                                 | I: Ok                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                         |
| Wanting to be normal – wanting to hide diabetes | P: Umm because they treat you different, they treat you like... you need to be looked after and... oh you're always ill and bla bla bla and it's like I just want to be treated like a normal person...                                                                                                                                  | People treat her differently, like 'you need to be looked after', people make assumptions, which appears to make her angry 'oh you're always ill bla bla bla'. Again, repeats that she wants to be 'treated like a normal person'. Conflict between how she wants to be treated 'normal' and how people actually treat her.                             |
|                                                 | I: Ok, cos you've mentioned that a couple of times now, wanting to be treated like like a normal person                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                         |
|                                                 | P: Ye                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                         |
|                                                 | I: so could you tell me a bit more about that or how how diabetes affects that?                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                         |
| Relationship with parents – restrictions        | P: ye like people, like my mum and dad are always sort of like... you can't do, you can't do this... because you're diabetic, you can't do...                                                                                                                                                                                            | Because of diabetes people tell her 'you can't', she repeats this. Diabetes and her parents stop her from doing things. People telling her what to do. Restrictions placed on her.                                                                                                                                                                      |

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|                                             | I: like, like what?                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                                   |
|                                             | P: I was going to go on a trip to [name of country]                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                                   |
|                                             | I: Ok                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                   |
|                                             | P: and they were like, well there's not really like any hospitals like around where you're going that's close enough so if something happened then you'd be in the middle of nowhere...                                                                                                                                                                          | School trip not close enough to a hospital so she can't go. Restricting the activities she can do.                                                                                                                                                                                                                                                |
|                                             | I: Ok                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                   |
| People asking intrusive questions           | P: and... like... it's just like people always ask me questions and things like... umm what about when you have kids, when you when you want children, can you, can you still do that like with diabetes... and it's like ye I can... and can you, can you still go to [name of country], and like ye I can do it, it it's like it doesn't stop me from doing it | People asking intrusive questions. Diabetes resulting in a lack of privacy? Three questions about her ability to have children. Future orientated. She says here that it doesn't 'stop' her. She appears to be in a conflict with her diabetes, positioning herself against it. Indication that diabetes is something that is trying to stop her. |
|                                             | I: Ye                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                   |
| Rejecting diabetes. Impact on sense of self | P: people like have this perception that diabetes is this thing where it's like... like loads of things get cut off and you're only allowed to take one certain path in life and choose certain things                                                                                                                                                           | Describes other people's perception of what diabetes is 'things get cut off', 'only allowed one path in life', 'choose certain things'. She disagrees, which contradicts her earlier description that it does stop her.                                                                                                                           |
|                                             | I: Ok                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                   |
| Impact on sense of self                     | P: umm and it's just like... it like when you're, when you're talking to people and like you have like a cert, like you get angry or you                                                                                                                                                                                                                         | Repetition here that people attribute her emotions to her being diabetic. Are people being                                                                                                                                                                                                                                                        |

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| Establishing a self which is separate to diabetes                                                     | get upset or you just don't feel well, people are always like oh is it your diabetes? And it's just like no it's just me                                                                                                                                                                     | patronizing/dismissive? 'ohh is it your diabetes?'. Seems like a struggle with her trying to form her own identity and be seen as a person rather than her diabetes 'no it's just me'. Is she not taken seriously?                                                                                                                         |
|                                                                                                       | I: Ok                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                            |
| Impact of poor glycaemic control<br><br>Emotional impact<br>Sense of self – diabetes not part of self | P: being a person who gets angry or upset or I'm just ill, like it does affect those things sometimes but it doesn't mean it changes me as a person... and then people have described like my boyfriend and my mum and my dad, they say like when I'm high, I'm I'm like a different person. | Recognition that diabetes may sometimes affect her emotions 'but it doesn't change me as a person', her sense of self, trying to form an identity which is separate from her diabetes. However, introduces here that her boyfriend, mum and dad say that she is 'like a different person' when she's high. Contrast here. Does she change? |
|                                                                                                       | I: ok, so you say high, is that your your blood sugars?                                                                                                                                                                                                                                      | Poor glycaemic control                                                                                                                                                                                                                                                                                                                     |
|                                                                                                       | P: Ye                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                            |
|                                                                                                       | I: Ok, so what what do they mean by different person?                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                            |
|                                                                                                       | P: Like they... cos like I tend to get angry and umm... like my all my emotions are heightened                                                                                                                                                                                               | Describes her emotions are effected when she's high. Emotional impact of poor glycaemic control.                                                                                                                                                                                                                                           |
|                                                                                                       | I: mmm                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                            |
| Sense of self – impact on identity formation                                                          | P: and it feels like any little tiny thing can like just throw me totally off... umm it's like... they think of me as a like an angrier person or a nastier person, but it's like they... I'm not angry when I'm not high but I'm still the same... person                                   | Contradiction here with earlier where she rejected people attributing her emotions to diabetes. She is angrier/nastier when she's high 'but I'm still the same... person'. Echoing earlier – grappling with who she is and how diabetes fits with it.                                                                                      |

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| Emotional impact of poor glycaemic control                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|                                                                                          | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Rejecting impact of diabetes – not a part of who she is                                  | P: when I'm high, it's just diabetes affects my emotions but it doesn't affect, it doesn't change me physically                                                                                                                                                                                                                                                                                                                                                                           | Trying to differentiate that whilst diabetes may affect her emotions it doesn't change who she is – her sense of self. Seems to be a conflict between the two. She rejects that it affects her sense of self.                                                                                                                                                                                                                                                                                                                                                                                        |
|                                                                                          | I: Ye                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Negative sense of self                                                                   | P: and it's like when they say I'm like a different person, it's like makes me feel umm... bad about myself                                                                                                                                                                                                                                                                                                                                                                               | When people say that she's 'like a different person' it makes her feel bad about herself. Shame? Guilt? Powerful emotions. Similar to earlier when she said that she 'failed'. Impact on sense of self.                                                                                                                                                                                                                                                                                                                                                                                              |
|                                                                                          | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Rejecting diabetes<br>Social self – impact on peer relationships<br>Wanting to be normal | P: umm like... I don't know, I just don't want it anymore, like I wish I could do all the normal things, eat what I want, just not have to like, like when you're around people that like are the same like, different from you, like don't have diabetes, it's like you don't wanna... you don't want to... do it like you don't want to get you're insulin out and be like oh I've got to do an injection now... or I'll do a test now or I can't eat that umm... cos it's embarrassing | Rejection again of diabetes 'I just don't want it anymore, like I wish I could do normal things'. Again here grappling with whether she can be 'normal', describes people without diabetes as 'different from you'. Repetition 3 times of 'you don't wanna', 'you don't want to', 'you don't want to', describing the intensity of her feelings about adherence. Rejecting it.<br><br>Use of 'ohh I've got to do an injection now' to indicate that it's a charade? Repetition of what she has to do, sounds overwhelming. Use of 'embarrassing' again here. Is she worried what people might think? |

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|                                                             | I: Ok tell me a bit more about embarrassing, how is it embarrassing?                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                                             | P: It's just like, in class, I used to umm, I started doing my test in class and like the tester would like beep when it was ready                                                                                                                                                                                                       | Describes the practicalities, testing in class. Machine beeps.                                                                                                                                                                                                                                                                                                                                                                                                        |
|                                                             | I: Mhm                                                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Social self – impact on peer relationships                  | P: or beep when it was done, I'd press a thing and everyone would be turning round like oh it's fire alarm, it's a fire alarm and I'd have to be like no it's ok it's just my testing kit                                                                                                                                                | Would draw attention to her. Exaggerated/dramatic responses by peers 'ohh it's a fire alarm'. She then reassures them.                                                                                                                                                                                                                                                                                                                                                |
|                                                             | I: Mm                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| How peers perceive diabetes<br>Impact on peer relationships | P: and like everyone would be like, once I explained it, they'd be turning round like www so what do you have to do, what do you have to do and like can you do it again, do it again like, show us how you do it and like can you inject yourself, can you inject yourself and like it was like a... like something to entertain people | Once people know she's faced with a barrage of questions. Repeats seven questions here in quick succession, highlighting the intensity of it. Peers want her to demonstrate 'do it again, do it again'. Seeing it as 'something to entertain people'. Similar to exaggerated language previously used. Seems like she's the focus of all the attention because of her diabetes. Must be difficult when she's rejecting it/ maintaining it's not a part of who she is? |
|                                                             | I: Ok                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                                             | P: umm and it was, it was just... I... I sort of like wanted everyone to know so they were aware of it                                                                                                                                                                                                                                   | Contrast to earlier where she said she didn't want people to know. Here she says she wants everyone to know.                                                                                                                                                                                                                                                                                                                                                          |

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|                                                                              | I: Ye                                                                                                                                                                          |                                                                                                                                                                                                                     |
| Conflicting feelings – wanting people to know yet not wanting people to know | P: but at the same time, I didn't want them to know because I hate being... not questioned about things just embarrassed                                                       | There seems to be a struggle here, she wants them to know but also does not want them to know as she gets embarrassed.                                                                                              |
|                                                                              | I: Ok, drawing attention, so what would be good about them knowing like you said like you wanted them to know                                                                  | Does she want people to get used to her testing?                                                                                                                                                                    |
|                                                                              | P: umm... like say like in the future they'd be like oh she's just doing her test                                                                                              |                                                                                                                                                                                                                     |
|                                                                              | I: Oh ok ye                                                                                                                                                                    |                                                                                                                                                                                                                     |
|                                                                              | P: she's just diabetic it's ok... umm or like if I if something happened to me everyone would be like she's type 1 diabetic, like they'd know what to do                       | Future orientated. People knowing will keep her safe, 'they'd know what to do' if something happened. Indication that she is aware of health risks.                                                                 |
|                                                                              | I: Ok                                                                                                                                                                          |                                                                                                                                                                                                                     |
| Sense of safety in people knowing                                            | P: Like it's a sense of safety                                                                                                                                                 | First time described that other people knowing can keep her safe 'like it's a sense of safety'. Does she feel scared or unsafe?                                                                                     |
|                                                                              | I: Ok                                                                                                                                                                          |                                                                                                                                                                                                                     |
| Social identity – shaped by diabetes                                         | P: And but at the same time like I, at the same time I didn't, I hated it, I just, like I don't want to have to be like a... the diabetic one, cos I'm the only one in my year | A struggle seems evident again here. On the other hand 'hated it'. Sense of self and identity – 'I don't want to have to be like a... the diabetic one'. Is that what defines her? Is she nothing more? Echoes what |



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| Impact on sense of self                                                         |                                                                                                                                                                                                                                                                                                                                             | she said earlier about her feelings being reduced to the effects of diabetes.                                                                                                                                                                            |
|                                                                                 | I: Ok                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                          |
| Rejecting diabetes<br>Feeling different<br><br>Impact on sense of self/identity | P: so it's like... oh ye it's [participants name], she's diabetic, it was like that's how people... like explain me to other people... and it's like the defining factor it's not like oh [participant's name] she's got [colour] hair or [participant's name], she's really funny... umm it's like [participant's name] she's got diabetes | Describes that nothing else defines her, no personal characteristics. Diabetes is the 'defining factor'. Contradiction between how she sees herself as separate from the diabetes and how she thinks others perceive her, with diabetes being the focus. |
|                                                                                 | I: How does that make you feel?                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                          |
| Emotional impact                                                                | P: Horrible                                                                                                                                                                                                                                                                                                                                 | Horrible. Short answer. Intense feelings.                                                                                                                                                                                                                |
|                                                                                 | I: Ok                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                          |
| Negative impact on sense of self                                                | P: It's just like... like it makes me feel bad about myself cos it feels like there's nothing else that defines me in a way that it defines someone else... umm                                                                                                                                                                             | Repeats here 'makes me feel bad about myself'. Impact on sense of self and self-esteem, 'there's nothing that defines me in a way that defines someone else'. Diabetes defines her. Is she by rejecting it trying to fight against this?                 |
|                                                                                 | I: Do you think that's true?                                                                                                                                                                                                                                                                                                                | She's not sure if she's accurate.                                                                                                                                                                                                                        |
|                                                                                 | P: I don't know                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                          |
|                                                                                 | I: Ok                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                          |

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|                                                      | P: Like, I haven't heard anyone explain me in any other way, apart from like if I like, my friends if I ask them they'd be like oh no we wouldn't explain you like that                                                                                                                                | Is her belief based on reality? Possibly not but disregards her friends reassurances. Not heard anyone describe her this way. Is she projecting her own self-image onto others?                                                                   |
|                                                      | I: Ok                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                   |
| Social self/value<br>Impact on identity              | P: but then you just know that if they were to go up to someone they'd be like oh ye it's [participant's name] she... she's got [colour] hair, but she's got diabetes as well and they'd know cos like everyone knows there's a diabetic girl in year [school year] cos it's like everyone has to know | Repetition of earlier. She's 'the only diabetic girl' in her school year. Indication of a lack of privacy. Repetition of 'everyone' knows. Nothing else defines her. Struggling with how she thinks people perceive her – conflicting identities. |
|                                                      | I: Oh ok                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                   |
| Impact on sense of self –wrestling with the diabetes | P: and it's like that's it's like the defining factor of me... and I just don't, I want it to be the opposite way around, I want me to be the defining factor of me rather than the the diabetes                                                                                                       | Repetition and contrast 'it's like the defining factor of me' and 'I want me to be the defining factor of me' Struggle here.                                                                                                                      |
|                                                      | I: Rather than it being the diabetes, ok... so sounds like there are lots of conflicting things going on then?                                                                                                                                                                                         |                                                                                                                                                                                                                                                   |
|                                                      | P: Ye                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                   |
|                                                      | I: So you mentioned about umm the food and what you could eat, what do you have to do in a typical day to manage your diabetes?                                                                                                                                                                        |                                                                                                                                                                                                                                                   |
| Burdensome - Restrictions                            | P: Umm... well like on the food and drink bit, I sort of just... like when like when you first get diagnosed, they're always like well                                                                                                                                                                 | When asked about food, she lists the things she was told when diagnosed that she couldn't have. Repeats 'you can't' four times.                                                                                                                   |

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|                                              | you can't eat cake, you can't eat biscuits, you can't eat sweet things, you can't drink fizzy drinks... umm but like I don't like really fizzy drinks anyway and that's sweet, I don't have a sweet tooth                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|                                              | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Burdensome - Restrictions                    | P: but I still like... cakes and sweets and chocolate... but I sort of like... as I've grown up with it, I've sort of... like it's... like when you first get diagnosed, it's like this thing that, there's like a set of guide rules                                                                                                                                                                                                                                                                                            | She still likes those foods, but says she has grown up with it, has she adjusted to it then?                                                                                                                                                                                                                                                                                                                                                                                       |
|                                              | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Burdensome - Restrictions                    | P: that... that defines diabetes for every single person                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Rules that define 'diabetes for every single person'. Use of the word 'define' again. Dislikes living by 'diabetes' rules?                                                                                                                                                                                                                                                                                                                                                         |
|                                              | I: Oh ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Ambivalence<br>Rejecting diabetes management | P: and... but what I like try to explain to people is that, it doesn't like... things might work for me that don't work for someone else or I might be able to eat cake... and be ok with it and someone else might not, it might throw their sugars off by loads but it would be ok for me, but I just think what what's the point of of... why let the diabetes define what I do and what I eat... when like I should be just be able to eat what I want and if I have to inject I have to inject, that's like, it's my choice | She tries to explain that people with diabetes are different from one another and she may be able to eat things that other people can't, 'things that might work for me that don't work for someone else'. Repeats 'but it would be ok for me'. Is she in denial? Is it really ok for her or is she not adhering? 'why let the diabetes define what I do and what I eat... when I should be able to just eat what I want' 'it's my choice'. Indication she is fighting against it. |

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|                                             | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                             | P: umm be ye like in the mornings like I have to wake up and I usually have to wake up earlier... umm than my sister because I have to test, I have to inject, I've got to make sure I eat properly, I have a full like breakfast like porridge or ... I just can't run out of the door with an apple                                                                                                                | However, the reality is that she does have to eat differently. Wakes up earlier than sister to test, inject and eat properly. Needs to have a full breakfast in the morning. 'can't run out the door with an apple', is this what other girls her age are doing? Is her life more regimented?                                                                                                                                               |
|                                             | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Burdensomeness – adhering to the regime     | P: or like... like a piece of toast, I have to sit down and eat like an omelette or something, umm and then like you... you go to school and, and after like break time you have to test and inject again, like I've only just realised that I have to inject for things like an apple                                                                                                                               | Monotony of her life 'I have to sit down and eat'. Has to inject after everything, still learning about diabetes 'only just realised' indicates that her management and understanding changes with time and is developing.                                                                                                                                                                                                                  |
|                                             | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Burdensomeness of managing diabetes herself | P: or a packet of crisps or like a drink of tea or orange juice or anything like that and it's it's really strange to have going from mum and dad doing that for me to me... to realising I have to inject after every single little thing, it's it's annoying it's like a pain in the backside... and umm then like for lunch I have to inject and test again and... and then when I go home... I do the same again | Reflecting on the difference between her parents doing it for her and her doing it herself 'really strange'. Monotony and extent of what she needs to do, has to inject 'after every single little thing', 'after lunch I have to inject and test again... and then when I go home... I do the same again'. Constant management of it, all day every day. She appears frustrated with it, 'it's annoying it's like a pain in the backside'. |
|                                             | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                             |

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| <p>Burdensomeness</p> <p>Feeling different</p>                          | <p>P: and then for dinner... and like I have to make sure I'm eating regularly... I can't like do a diet... I can't like just go without for like... a few hours... and like I can't just, can't like maybe eat how other people eat, like when I'm with my boyfriend, he's like oh we'll be having dinner in like three hours and I'd be like well I need something before that</p> | <p>Repetition here of what she can't do, how her life is different to 'other people'. Repetition of 'I can't' four times here. She has to eat regularly. Has to constantly manage it. Seems to be a nuisance, makes her different. She can't wait for food like other people.</p>                                                                                                                  |
|                                                                         | <p>I: Ok</p>                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                    |
| <p>Demonstrating knowledge of diabetes</p> <p>Forgetting the regime</p> | <p>P: umm cos the more structured I eat, the better my sugars are going to be, umm... so then at night time I'll do my lamptis before I get into bed, umm... but it's hard doing the lamptis now by myself cos I forget cos I just fall asleep really early</p>                                                                                                                      | <p>Demonstrating awareness of how she needs to eat 'the more structured I eat, the better'. Contrast with her saying earlier 'why let the diabetes define what I do and what I eat'. Conflicted, shifting perspectives. Describes that it is difficult doing her lamptis by herself before going to bed as she forgets. Is remembering difficult then? Life gets in the way, she falls asleep.</p> |
|                                                                         | <p>I: Ok</p>                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                    |
| <p>Forgetting the regime</p>                                            | <p>P: happens a lot, but that affects my sugars as well if I fall asleep early, ye mum will ask me if I've done it and like, or I'll wake up, get up at three a clock in the morning to go to the toilet and then I'll be like oh I didn't do it and I'll do it then</p>                                                                                                             | <p>Admits that poor management happens 'a lot' and that affects her sugar levels. Indicates that this happens accidentally, she falls asleep and then she remembers when she gets up. Typical of real life? People forget things but she has responsibilities.</p>                                                                                                                                 |
|                                                                         | <p>I: And how does it make you feel when you remember that you've not done it?</p>                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                    |
| <p>Poor adherence - negative impact on sense of self</p>                | <p>P: ... like I've... like I've let myself down, like cos I want to be able to have kids and I I want to be healthy... but then like at the same time it's just so hard it's like people are like why why do you not</p>                                                                                                                                                            | <p>Hesitant. Repeats here again 'like I've let myself down'. Indicative of shame? Has it affected her self-esteem, sense of self? Recognises how conflicted she is 'I want to be healthy... but then like at the same time</p>                                                                                                                                                                     |

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| <p>Guilt – scolding herself</p> <p>Thinking about the future</p>                                                                                  | <p>inject, like don't you want to, don't you want to have kids, don't you want to be healthy like you'll... people are always telling me like these horror stories about like people with diabetes losing their legs</p>                                                                                                                                          | <p>it's just so hard' Seems like it's difficult to follow the regime yet she wants to be healthy.</p> <p>People constantly asking 'why' 'why don't you want to have kids, don't you want to be healthy'. Seems conflicted in herself and pressurised by others. People telling her 'horror stories' about the medical complications. Oscillating between extremes.</p>                                                                                                                                                                                                                      |
|                                                                                                                                                   | <p>I: Ok</p>                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <p>Oscillating feelings</p> <p>Ambivalence vs Guilt</p> <p>Cannot maintain good control</p> <p>Constantly changing</p> <p>Oscillating control</p> | <p>P: Or their eyesight and things and it's sort of like... it hasn't like sunk in, it just sort of washes over me and I don't really care... but then at the same time I do, like if I think, if I sit down and think about it... like I sort of like go ye, I do want to do it but then... like I do it really good for a few days and then I'll lose it...</p> | <p>Recognition of the potentially serious health complications 'hasn't sunk in, it just sort of washes over me and I don't really care'. Is she in denial? Is the future to distant? Yet she is conflicted, 'I do, like if I think, if I sit down and think about it'. Does this indicate that she manages to avoid thinking sometimes? But when she does think 'I do want to do it'.</p> <p>Thinking about the complications makes her 'do it really good for a few days and then I'll lose it' Appears that the effect doesn't last long. Does she get scared and then it dissipates?</p> |
|                                                                                                                                                   | <p>I: Ok, what do you think happens when you lose it, what happens, what happens then?</p>                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <p>Forgetting, bargaining with self</p>                                                                                                           | <p>P: I'll just like just keep forgetting to do it like for lunch I'll sit down and I'll have lunch and then... I just won't... and I'll say to myself, ok inject, but then I'll be like ok inject in ten minutes and then I'll like totally forget</p>                                                                                                           | <p>Indicates again here that she forgets to do it. She delays injecting and then forgets. Possibly representing inner dialogue of arguing with herself 'I'll say to myself, ok inject, but then I'll be like ok inject in ten minutes'. Is this to avoid the embarrassment of</p>                                                                                                                                                                                                                                                                                                           |

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|                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | injecting? She appears to know what she's meant to do.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                                                                                                                     | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <p>Motivation to adhere wains with burdensomeness</p> <p>Ambivalence vs wanting to adhere</p> <p>Poor adherence</p> | <p>P: and it's just like my structure and my routine just goes out of the window and it just totally like... I'll be injecting like this bit here and this bit there and... I sometimes I'll go for like... two weeks without doing a test... because it's just a waste of time... like it's like it's some sometimes to me it seems like a waste of time but then I see the point in it and it's like you know you need to do it but it just takes so long to do it... that like doing it in class, if I do a test I miss... like five minutes of someone talking</p> | <p>Importance of structure and routine. Describes what happens when she has poor control, structure 'goes out of the window'. 'I'll be injecting this bit here and this bit there'.</p> <p>Does she simply have enough and then rejects the whole diabetes management and avoids it altogether? 'because it's just a waste of time... like it's like it's some sometimes to me it seems like a waste of time but then I see the point in it and it's like you know you need to do it but it just takes so long'. Conflict between rejecting/avoiding diabetes and knowing that she should do it. Oscillating between the two extremes.</p> |
|                                                                                                                     | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <p>Burdensomeness</p> <p>Peer relationships</p>                                                                     | <p>P: and then to do an injection... like if I'm wearing like a skirt and tights... I can't just pull down my tights and do it in class, I have to go out to the toilet to do it... so then I miss like ten minutes... but if I'm with a friend, they'll do it in my arm for me</p>                                                                                                                                                                                                                                                                                    | <p>It gets in the way of her lessons. Practical difficulties of it, can't pull her tights down in class, missing lessons. Friends will inject for her.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                                                                                                     | I: so your friend would do it for you?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|                                                                                                                     | P: Ye                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |

|                                                                                      |                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                   |
|--------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                      | I: Ok                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Burdensomeness<br>Diabetes holds her back<br>Poor adherence                          | P: but if I'm wearing trousers I do it through my trousers which I'm not supposed to but I do it anyway because I think it's better than losing ten minutes of my lesson... umm so it's just I think it's something that holds me back... umm                             | Will not do her injections like she's supposed to as it makes her miss lessons. Which is more important to her? Does she not prioritise diabetes? Sees diabetes as something that 'holds me back'. Similar to earlier describing it as something which stops her from doing things.                                                                                                                               |
|                                                                                      | I: So sounds like on the one hand you know about the ill effects but then sometimes it's really difficult to do it?                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Oscillating control and motivation over time.<br>Conflicting feelings<br>Ambivalence | P: Ye sometimes I say to myself I really really want to do it, I want to be good at it, I want to be healthy, I really want to be good at it... but on the other side I just can't be bothered                                                                            | Conflicting feelings. Motivation and feelings change. Typical of adolescence? Constantly oscillating between the two extremes, seems to change all the time. Not straight forward. Repetition of 'really' three times indicating how much she sometimes wants to do it. 'I really want to be good at it... but on the other side I just can't be bothered'. Too much effort? Too much involved? Motivation wanes. |
|                                                                                      | I: Ok                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                   |
|                                                                                      | P: but I think that's like the epitome of every teenagers life [laugh] just can't be bothered                                                                                                                                                                             | She normalises this feeling of 'can't be bothered' as being typical of teenagers. Maybe this will be different in the future? Is it a way of rebelling?                                                                                                                                                                                                                                                           |
|                                                                                      | I: OK, so sounds like there are lots of things involved in managing it... and you know I'm really interested in finding out what it's like to have poor glycaemic control and talking to young people who have poor glycaemic control, so is there anything that makes it |                                                                                                                                                                                                                                                                                                                                                                                                                   |



|                                               |                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                                                                                                                          |
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|                                               | easier to have good control or anything that makes it more difficult?                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                          |
|                                               | P: Umm... no                                                                                                                                                                                                                                                                                                    | Denies that anything makes good control easier or more difficult. Definite answer.                                                                                                                                                                                                                                                                       |
|                                               | I: Ok                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                          |
|                                               | P: it's just like it just depends on... on on me as a person and if, if, like it's the same as exercise, if one day I'll come home and be like really really wanting to do exercise, and then another day I'll come home and I'll be like all I want to do is lie in bed, drink tea, watch tv and eat chocolate | It comes back to her 'as a person'. Similar to describing it to homework earlier, she describes it to exercise here. Perhaps trivialising it a little? Does she realise or believe that diabetes has more serious implications for her? Describes motivation changes from one day to the next.                                                           |
|                                               | I: Ye                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                          |
| Motivation and adherence changes over time    | P: That's all I want to do... and it's the same with my diabetes, it's like one month I can just be like, I just don't want to do it... and it's... nothing affects it... like nothing will make that happen and... it's just the way... it just happens...                                                     | Indicates here that she has no control over her change in motivation 'it just happens', varies from one month to the next 'nothing affects it'. Lack of insight perhaps? Minimizing the effect of other things? Indicating that she's a passive recipient? Is it too overwhelming?                                                                       |
|                                               | I: Ok                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                          |
| Difficult life experiences impact on diabetes | P: umm and then one month I'll be... like say if I... maybe it's organizing it... like the more organized I am with everything else, the more organized I am with my diabetes, umm maybe things like... umm my life, like my life in general, if they're in turmoil then my diabetes will go into turmoil       | Describing perhaps more insight here. Importance of organisation 'like the more organized I am with everything else, the more organized I am with my diabetes'. Similarly 'if life in turmoil then my diabetes will go into turmoil'. Management of diabetes reflecting what is happening in her life, the better things are, the better her management. |

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|                         | I: ok, tell me a bit more about that                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                    |
|                         | P: If I'm just having a hard time like with... with school work, or with my boyfriend, or my mum and dad... umm then... if if something's off... it it changes something else, so it will affect my diabetes... my control of my diabetes, like I'm behind in essays because... my relationship with my... mum and dad at the moment isn't so good | Wider factors affect her glycaemic control. If she's having a difficult time with her school work or relationships 'it will affect my diabetes, my control of my diabetes'. Her diabetes does not exist in isolation, it is affected by other aspects of her life. |
|                         | I: Ok                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                    |
|                         | P: so it's like a knock on affect, it's like if I'm not... if I'm not having a good time in my personal life                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                    |
|                         | I: Ye                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                    |
| Impact on sense of self | P: it affects... my diabetes, it affects me which affects my diabetes                                                                                                                                                                                                                                                                              | Differentiating here between 'me' and 'diabetes'. Awareness that if she is having a difficult time this will affect her which in turn will affect her diabetes. She knows what contributes to good or bad control. Diabetes is just one aspect of her life.        |
|                         | I: Ok ye                                                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                    |
|                         | P: like a like a cold... like if I have a cold it will affect my health which will affect my diabetes...                                                                                                                                                                                                                                           | Gives more examples, such as being ill, her relationships and academic work. They all affect her diabetes. It's complicated.                                                                                                                                       |
|                         | I: so like a knock on affect then                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                    |

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|-------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                               | P: ye                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                                                                               | I: Ok... is there anything you quite like about having poor glycaemic control?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Likes having poor glycaemic control                                           | P: ... it... it's like I know... like <i>I've</i> done that...                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | She does sometimes <i>like</i> having poor control – knowing that <i>she's</i> done it.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                                                               | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                                                                               | P: it makes me feel like... I've got... I've got the control to be able to make it go really bad or really good... and sometimes when there's total loss of control in other parts of my life, knowing that I have control... over my diabetes... makes it better.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | She likes the control, repeats the word 'control' three times here. She has the power 'to make it go really bad or really good 'when there's total loss of control in other parts of my life, knowing that I have control... over my diabetes... makes it better'. But it appears that this is in the context of having poor control? Exercising control in a dangerous way. Self-destructive?                                                                                                                                                                                                                      |
|                                                                               | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Negative impact on sense of self<br>Wanting to be normal<br>Feeling different | P: and sometimes... I want to make it bad... because I don't want to be... a nice person, sometimes I just want to be a really horrible awful person, that doesn't want to get on with people, that just wants to shout at everyone all the time, and be really grumpy... and like... it's like I missed out on like... this like... how every other teenager has got this space... like where their parents can just go oh it's just hormones, they're just going through that teenage phase, like I missed out because it was like no she's not going through that hormonal stage, she's got diabetes that's what it is, its her diabetes, that's what's wrong... and it's like if... I can just maybe make my diabetes... make me a horrible person | Associates having poor control with not being a nice person. 'sometimes... I want to make it bad... because I don't want to be... a nice person'. Does it give her permission not to be nice? Rebellious? Describes that she 'missed out' (repeats this twice) on having a teenage phase where teenagers are given space and 'parents can just go oh it's just hormones'. Instead they say to her 'no she's not going through a hormonal stage, she's got diabetes'. Is she not allowed to be a normal teenager? Similar to earlier, describing that her behaviour and emotions are all attributed to her diabetes. |

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|                                                           | then they'll be like oh she's just maybe going through a teenage growing up thing... cos I missed out on it...                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|                                                           | I: so is it a sort of way of getting that back almost?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Impact on social self/how she is perceived                | P: Ye                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Having poor control is her attempt to be seen as a normal teenager. Misguided? Surely poor control increases people's emphasis on her diabetes? Unclear. 'if... I can just maybe make my diabetes... make me a horrible person then they'll be like oh she's just going through a teenage growing up thing'. Real sense of loss of 'teenage' experience, emphasising how other people perceive her.                                                                                      |
|                                                           | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Wanting to be normal                                      | P: It's umm, it's childish, but it works.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Describes herself as 'childish, but it works'. Secondary gains? Poor control gives her something that she won't otherwise get? Allowing herself to be a teenager?                                                                                                                                                                                                                                                                                                                        |
|                                                           | I: Ok                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Diabetes draws attention to her<br><br>Rejecting diabetes | P: And umm... my diabetes has always been umm... like a source of attention... umm but it wasn't like... people always say to me umm like my sister's a brat and I hate her... and I always tell people that I don't like her and she's so like, she gets everything her way and... they're always like maybe she... it's just because you had lots of attention when you were younger when you got diagnosed, that she's maybe missed out a bit... and that makes me so angry cos it's like I didn't <i>ask</i> for it, I didn't, I would have rather them give me attention because I did well in school | Describes difficult interactions with sister. The effect of diabetes on her sibling. She got a lot of attention for her diabetes, people indicating that her sister is a 'brat' because 'she's maybe missed out a bit'. Appears very angry at this 'makes me so angry'. Repeats that she didn't want or ask for diabetes. She would rather receive attention for something positive. Is diabetes the only thing she gets attention for? Does she feel blamed for her sister's behaviour? |

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|                                                                                    | I: Ye                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                |
| Physical changes associated with diabetes<br><br>Rejecting diabetes                | P: Because I really did well from being athletic, because I <i>was</i> athletic, and the diabetes totally screwed that up for me and I suppose I hated, hate diabetes because it's screwed up so many things, like I was su- I was such an athletic person, but umm                                                                                                                                                                                                                                                                         | Diabetes has taken things away from her – athleticism. Repeats that diabetes 'screwed that up', 'screwed up so many things'. Anger at diabetes 'I hated, hate diabetes'. Rejection of diabetes. Does not seem to have accepted it.                                                                             |
|                                                                                    | I: So how how did that change?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                |
| Physical changes associated with diabetes                                          | P: It's like with... one month I can... be say eight stone... in weight and then another month I can put on one and a half, two stone... but I'll be eating the same things, it's just the control of my diabetes                                                                                                                                                                                                                                                                                                                           | Recognition that her glycaemic control affects her physically. It affects her weight, which can vary from one month to the next. She can gain a lot of weight whilst eating the same things. How much is she concerned about this?                                                                             |
|                                                                                    | I: ok, so how does that work?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                |
|                                                                                    | P: it's like if my, if my diabetes are constantly low                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                |
|                                                                                    | I: Ye                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                |
| Blaming diabetes for things she has lost/rejecting it<br><br>Knowledge of diabetes | P: then I've obviously I've got to eat more... to bring them up or if they're... if they're just like it's like my hormones are like heightened... from the diabetes... but then it also like makes me... if I put on weight it takes me twice as much effort and hard work than it would take for you or someone who hasn't got diabetes to lose the weight.... Umm so like when I was having like a really good athletic period in my life, umm and I put on a bit of weight and I wasn't as fast anymore... and so I stopped training... | Shows understanding of what she needs to do with regards to food, but is there a conflict here between her knowing that she needs to eat when her sugars are low and her maybe not wanting to eat more because it's so difficult for her to lose weight?<br><br>Did she give up athletics because of diabetes? |

**Appendix 5D.**  
**Statement of Word Count**

## Statement of word count

### Main documents

|                                                       |               |
|-------------------------------------------------------|---------------|
| Thesis abstract                                       | 276           |
| Literature review                                     |               |
| Abstract                                              | 149           |
| Main text (excluding abstract, tables and references) | 5459          |
| Empirical paper                                       |               |
| Abstract                                              | 150           |
| Main text (excluding abstract, tables and references) | 6221          |
| Contributions to theory and clinical practice         |               |
| Main text (excluding references)                      | 4790          |
| <b>Total</b>                                          | <b>17,045</b> |

### Appendices

|                                               |               |
|-----------------------------------------------|---------------|
| Literature review                             |               |
| Tables 1, 2 & 3                               | 2982          |
| Figure 1                                      | 156           |
| References                                    | 1398          |
| Empirical paper                               |               |
| Tables 1 & 2                                  | 157           |
| Figure 1                                      | 128           |
| References                                    | 1306          |
| Contributions to theory and clinical practice |               |
| References                                    | 1041          |
| Section of an Annotated Transcript            | 9,897         |
| <b>Total</b>                                  | <b>17,065</b> |