

**SELF-CARE IN YOUNG PEOPLE WITH DIABETES: A QUALITATIVE
EXPLORATION USING A SALUTOGENIC APPROACH**

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Abstract

This thesis investigates experiences of self-care amongst young people with diabetes using a qualitative salutogenic approach. Diabetes self-care includes injecting insulin, counting carbohydrates, attending hospital check-ups and other activities to maintain stable blood sugar levels. Optimal blood sugar levels are not always easy for young people with diabetes to attain, placing them at increased risk of health complications. A lack of self-care has been assumed traditionally to indicate a lack of knowledge. This exemplifies a ‘deficit’ approach whereby efforts to improve self-care focus heavily on diabetes education to increase knowledge. However, there is a lack of evidence that young people lack diabetes knowledge or that education-only interventions are effective.

This thesis applies salutogenesis as an alternative to the deficit approach in which young people are conceptualised as individuals and their capabilities are acknowledged. The empirical work undertaken includes: a meta-ethnography of the international qualitative literature, analysis of semi-structured interviews with young people living in a diverse urban area of the UK, defined as disengaged from diabetes self-care (N=14); and a qualitative study conducted with young people participating in novel salutogenic projects which focused on their capabilities rather than ‘correcting’ their deficits (N=5).

Across the studies it was found that ‘identity work’ underpins young people’s experiences with diabetes self-care. Identity work is the continual negotiation of diabetes into self-concept (‘being’ identity) and diabetes self-care into daily life (‘doing’ identity). This involves navigating threats to and validators of identity within the home, the diabetes clinic, the school and the social environment, to achieve a sense of normality. Identity work is fluid and comprises three types: ‘forgetting diabetes’, ‘diabetes as dominating’ and ‘diabetes as routine’, each of which are associated with different levels of engagement with diabetes self-care. Participating in salutogenic projects enabled young people to better navigate identity work and thus integrate diabetes into both ‘being’ and ‘doing’ identity. This thesis demonstrates that diabetes self-care is a manifestation of young people’s ongoing identity work and that this identity work is modifiable. Further research should explore the way in which salutogenic projects can enhance engagement with diabetes self-care on a larger scale.

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Contents

Chapter 1: Introduction

1.1	Introduction to this thesis	1
1.2	Content of this thesis	3
1.3	Context of this thesis	4
1.4	A definition of diabetes	6
1.5	The prevalence of diabetes	6
1.6	Health inequalities in diabetes	8
1.7	The costs of diabetes	10
1.8	A definition of disengagement	11
1.9	A definition of self-care	11
1.10	A definition of young people	13
1.11	A definition of salutogenesis.....	14
1.12	Area of enquiry	15
1.13	Concluding comments for this chapter	17

Chapter 2: Literature review

2.1	Overview of chapter	18
2.2	The conceptualisation of children and young people in research	18
2.3	The conceptualisation of children and childhood in theory	19
2.4	The conceptualisation of adolescence in theory.....	20
2.5	Young people with chronic conditions	21
2.6	Self-care in young people with chronic conditions.....	23
2.7	Self-care interventions in young people with chronic conditions.....	24
2.8	Education and diabetes self-care	25
2.9	Parents and diabetes self-care	28
2.10	Friends and diabetes self-care	31
2.11	Clinicians and diabetes self-care	33
2.12	Challenges with diabetes self-care	35
2.13	Identity and diabetes self-care.....	39
2.14	Self-care in young people defined as disengaged	44

2.15	Concluding comments for this chapter	48
Chapter 3: Methodology		
3.1	Overview of this chapter	49
3.2	A qualitative salutogenic approach	49
3.3	Stage 1: Qualitative systematic review	50
3.4	Research questions	50
3.5	Scope of the review	51
3.6	Inclusion criteria.....	51
3.7	Search strategy	52
3.8	Data management.....	52
3.9	Data synthesis	53
3.10	Review procedure.....	53
3.11	Stage 2: Qualitative interviews with young people with diabetes	60
3.12	Research questions	60
3.13	Aims.....	61
3.14	Interview participants.....	61
3.15	Interview sampling.....	61
3.16	Interview recruitment	62
3.17	Ethical issues.....	63
3.18	Location and timing of the interviews	63
3.19	Interview questions	63
3.20	Treatment of interview data.....	64
3.21	Data analysis	64
3.22	Stage 3: Interviews with young people involved in salutogenic projects.....	66
3.23	Research question	67
3.24	Interview participants.....	67
3.25	Interview recruitment	67
3.26	Ethical issues	68
3.27	Location and timing of the interviews	68
3.28	Interview questions	68
3.29	Treatment of interview data	68

3.30	Interview analysis.....	69
3.31	Ontology and epistemology of this thesis	71
3.32	My role as a researcher	71
3.33	Trustworthiness of data	74
3.34	Concluding comments for this chapter	75

Chapter 4: Findings from qualitative systematic review of young people's experiences with diabetes self-care

4.1	Overview of this chapter	76
4.2	Aims of the review	76
4.3	Research question.....	76
4.4	Number and characteristics of studies included in the review	76
4.5	Key findings of included studies.....	77
4.6	Identity	79
4.7	Disclosing (threat to identity)	81
4.8	Disruption (threat to identity)	83
4.9	Support (validator to identity).....	88
4.10	Independence (validator to identity)	92
4.11	Sense of control (threat and validator to identity).....	96
4.12	Normalisation.....	99
4.13	Concluding comments for this chapter	100

Chapter 5: Findings from qualitative interviews with young people with diabetes focusing on diabetes self-care

5.1	Overview of this chapter	101
5.2	Interview findings	104
5.3	Identity work	106
5.4	The context of identity work	127
5.5	Feeling intimidated.....	127
5.6	Feeling different	132
5.7	Feeling normal	136
5.8	Feeling supported	141
5.9	Concluding comments for this chapter	144

Chapter 6: Findings from interviews with young people with diabetes participating in salutogenic projects

6.1	Overview of this chapter	146
6.2	Interview findings	148
6.3	Developing a positive diabetes identity	149
6.4	Seeing behind the scenes of services	156
6.5	Learning to navigate boundaries	166
6.6	Concluding comments for this chapter	177

Chapter 7: Discussion of research findings

7.1	Overview of this chapter	178
7.2	Overview of principle findings	178
7.3	How do young people experience self-care?	178
7.4	How do different environments influence diabetes self-care?	184
7.5	How do support networks interact with diabetes self-care?	187
7.6	How does participating in salutogenic projects shape young people's perspectives and practice towards diabetes self-care?	190
7.7	Strengths and weaknesses of the research	195
7.8	Meaning of the research: possible mechanisms and implications for clinicians and policymakers	199
7.9	Unanswered questions and future research	204
7.10	Conclusion	207

Appendices

1.	Quality assessment tool for qualitative review by Rees et al (2011) (chapter 4)	236
2.	Data extraction criteria for qualitative review informed by Curtis-Tyler et al (2015) (chapter 4).....	239
3.	Table to demonstrate 2 nd and 3 rd order concepts from qualitative review (chapter 4)	240
4.	Parent information sheet for qualitative interviews (chapter 5).....	259
5.	Parent consent forms for qualitative interviews (chapter 5)	261
6.	Participant information sheet and assent form for qualitative interviews for young people aged 11-15 (chapter 5)	262
7.	Interview schedule for qualitative interviews (chapter 5).....	264
8.	Interview images for qualitative interviews (chapter 5)	266
9.	Ethics form for qualitative interviews (chapter 6)	275
10.	Participant information sheet for qualitative interviews (chapter 6).	279
11.	Participant consent form for qualitative interviews (chapter 6).....	282
12.	Optional parent information sheet for qualitative interviews (chapter 6).	283
13.	Interview schedule for qualitative interviews (chapter 6).....	286

List of figures

1.	Explanatory model of diabetes self-care from qualitative synthesis...	78
2.	Participant demographics (self-reported).....	102
3.	Overview of interview findings pertaining to diabetes self-care in participants	104
4.	Participant demographics (self-reported).....	147
5.	Overview of interview findings pertaining to the impact of participating in salutogenic projects.....	148

Chapter 1: Introduction

1.1 Introduction to this thesis

This thesis adopts a salutogenic approach to explore the experiences of diabetes self-care in young people defined as disengaged from diabetes services and/or diabetes self-care. In this chapter, I firstly introduce the focus of the thesis, highlighting the importance of diabetes as a public health issue and the importance of diabetes self-care in improving health outcomes. Secondly, I outline the context of this thesis. Thirdly, I provide an overview of the content of this thesis. Finally, I define the key concepts of this thesis: diabetes, self-care, young people and salutogenesis. Finally, I describe the research aims and questions addressed in this thesis.

Diabetes is a chronic condition. Improvements in both health care and health technologies have resulted in a substantial increase in the life expectancy of children and young people living with chronic conditions, such as diabetes (Aujoulat et al, 2017). It is estimated that up to 90% of children and young people with chronic conditions will survive into adulthood (Pai and Schwartz, 2011). Successfully coping with chronic conditions, such as diabetes, requires young people to take increasing responsibility for their care as well as engaging with health care services. Self-care includes activities such as injecting insulin and counting the number of carbohydrates in foods consumed, as well as attending to wider psychosocial needs. Young people, both with and without chronic conditions, are faced with a number of challenges as they transition towards adulthood. These challenges can be exacerbated by those inherent in living with a chronic condition (Aujoulat et al, 2017).

Studies conducted worldwide on children and young people with diabetes have documented glycaemic control levels placing them at heightened risk for developing diabetes-related complications (Danne et al, 2001). Research has also reported poorest glycaemic control in adolescence (Department of Health and Social Care, 2001; Royal College of Paediatrics and Child Health, 2017). The most recent national paediatric diabetes audit, conducted between 2016 and 2017, revealed that 16.4% of children and young people living in the UK have HbA1c levels which are considered very high, putting them at significant risk of developing future health complications. The audit also reported that more medically optimal glycaemic control is achieved in the first year

after diagnosis, after which time glycaemic control tends to worsen. Young people living in deprived areas tend to have poorer glycaemic control than those living in the least deprived areas (RCPCH, 2017). In order to improve health outcomes for all young people with diabetes, it is necessary to ensure that services meet the needs of young people and that young people feel able to integrate diabetes self-care into their daily lives.

Traditionally, a lack of engagement with diabetes self-care in young people has been conceptualised as being the result of a lack of knowledge about diabetes and diabetes self-care by researchers, policy makers and health care practitioners, indicative of a deficit approach (Scales and Leffert, 2004 and Rotegard et al, 2010). Although such approaches can be useful in identifying needs, they tend to define individuals and communities in negative terms, disregarding strengths and competencies (Morgan and Ziglio, 2007). As a result, recommendations to improve diabetes self-care have tended to focus heavily on the need for diabetes education (NICE, 2015). In research, this has resulted in a focus on gaps in knowledge about diabetes and diabetes self-care, attempting to address these gaps through education-based interventions (Boren et al, 2006 and Cooper et al, 2009). However, research has highlighted that differing levels of engagement are not associated with different levels of knowledge about diabetes and diabetes self-care (Boman et al, 2015, Huus and Eskar, 2007 and Damiao and Pinto, 2007). This explains why education-based interventions have been shown to improve knowledge but are not effective in increasing engagement with diabetes self-care (Boren et al et al, 2006 and Cooper et al, 2009). Interventions aimed to improve diabetes self-care are discussed further in chapter 2.

Research has suggested that young people may become resistant to health messages if they are perceived as telling them not to do something because of restricting freedom of choice (Wang et al, 2011). This could result in opposing reactions to the intended outcomes of interventions (Whitehead and Russell, 2004). Acknowledging young people's need for independence and autonomy is thus likely to be a more fruitful approach to improving health outcomes. A salutogenic approach (Antonovsky, 1996) frames these needs by viewing young people as competent social actors and agents able to make their own choices about their health, rather than as passive recipients of social forces and health care services. The approach also emphasises the capabilities and positive attributes of individuals and communities, rather than focusing on deficits.

Salutogenesis can be applied at a societal, group or individual level (Lindstrom and Eriksson, 2005). This thesis adopts the latter, focusing on the individual experiences of young people with diabetes with self-care. Antonovsky also stated the salutogenesis was not limited by the disciplinary borders of one profession but rather an interdisciplinary approach, with a focus on coherence between disciplines and the ideas that connect them (Lindstrom and Eriksson, 2005). This thesis thus adopts a psychosocial approach towards the exploration of diabetes self-care in young people.

Initially the application of salutogenesis in this thesis involved a focus on assets in young people with diabetes. Assets refer to attributes, skills and experiences of individuals and communities, which can be drawn upon to have a positive impact on health and wellbeing (Morgan, 2006). The research aimed to identify assets which could enhance engagement with diabetes self-care. However, when conducting data analysis, it became clear that this asset-based approach became reductionist and did not allow for the exploration of the challenges of diabetes self-care experienced by young people. Furthermore, it did not allow for the investigation of other important contributors to diabetes self-care which emerged during the data analysis. It was thus decided to move away from a narrower focus on assets and taking a broader salutogenic approach to allow for a holistic exploration of young people's experiences with diabetes self-care, which revealed identity work as being a particularly significant theme. A more in-depth definition of salutogenesis is provided in section 1.10 of this chapter.

1.2 Content of this thesis

Chapter 1 outlines the focus of this thesis, the key concepts relating to this thesis as well as the aims and research questions. Chapter 2 provides a discussion existing literature on diabetes self-care in young people with diabetes. Chapter 3 outlines the aims, design and methods of the research approach, which included a qualitative systematic review, interviews with young people with diabetes as well as interviews with young people involved in salutogenic initiatives. Chapter 4 presents the findings of the qualitative systematic review, which highlights the significance of identity work in diabetes self-care in young people from a worldwide perspective, which influences engagement with diabetes self-care. Chapter 5 presents findings from qualitative interviews with young people, living in North and East London, defined as disengaged from diabetes services and/or diabetes self-care, which highlights identity work as a typology that influences

engagement with diabetes self-care. Chapter 6 presents the findings from interviews with young people with diabetes living in East London involved with salutogenic initiatives, involving co-producing commissioning guidance on diabetes services for young people, attending task group meetings, site visits and participating in public speaking events. These interviews demonstrate the impact of participating on identity work and engagement with diabetes self-care. As part of my role in the CLAHRC project, I was a member of the task group and was therefore working alongside the young people in these roles. Chapter 7 provides a discussion of the findings on the role of identity work in diabetes self-care from the three stages of the research, including the strengths and limitations, as well as outlining the original contribution of research findings to the research literature and the implications for policy and practice.

1.3 Context of this thesis

There is increasing evidence, particularly from qualitative studies, that when people take responsibility for their healthcare, they are more likely to adopt healthier lifestyles, use services more appropriately, and make sufficient use of healthcare resources (Coulter and Ellins, 2006; Coulter and Ellins, 2007). For young people with chronic conditions, such as diabetes, dissatisfaction with healthcare can impact on their use of services, treatment, engagement with medical self-care and subsequently, health outcomes (Farrant and Watson, 2004).

Three different levels of patient involvement in healthcare services have been identified: micro, meso and macro (Russell and Kitt, 2014). Micro focuses on patient information, education and involvement in care decisions, and complaints. Meso focuses on the evaluation of services, information-sharing, planning changes to local services and local accountability. Macros focuses on influencing national health policy and government agenda and engaging members of parliament.

This thesis is embedded within a National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) funded project entitled 'Co-designing diabetes services responsive to the needs of children and young people.' It is an applied qualitative study and adopts a participatory salutogenic approach, working with young people to improve diabetes services in Newham in East London.

The purpose of the project was to bring together providers of diabetes care, with young people and their parents to produce recommissioning guidance for diabetes. It elicited the views of young people defined as disengaged from diabetes services and/or diabetes self-care to provide them with a voice in the research literature and an opportunity to influence change in their local area. To achieve these aims, the study adopted an ‘action research’ approach to systematically collect and review data in the interest of informing and shaping the development of the guidelines in real world conditions. The project therefore involved both micro and meso levels of patient involvement.

The CLAHRC study involved 3 inter-related stages. The first stage was a systematic review of reviews focusing on young people’s experiences with diabetes services worldwide. The second stage comprised qualitative interviews with young people living in North and East London to learn more about their experiences with their local diabetes services and their own diabetes self-care. North and East London are both ethnically diverse areas, which include high numbers of young people defined as disengaged from diabetes services and/or diabetes self-care. The findings from my analysis of these interviews is presented in chapter 6. The third stage involved work with four young Clinical Commissioners appointed by Newham Clinical Commissioning Group (CCG), to help produce recommissioning guidance. In line with a salutogenic approach, the young people received extensive training in relevant skills to their role, such as public speaking. They attended a number of different events in their role, including task group meetings with several diabetes care partners including an East London CCG, Diabetes UK, UCL Partners, Barts Health NHS Trust and Public Health England. The young people also undertook site visits to relevant diabetes organisations and presented at public speaking events. As mentioned earlier in this chapter, I interviewed these four young people about the experience of participating on their diabetes self-care as part of this thesis. The findings of these interviews is presented in chapter 7.

As part of my role in the CLAHRC project, I was involved in training these young people and worked alongside them. This allowed me to gain a comprehensive insight into diabetes services and diabetes self-care, from multiple perspectives. Furthermore, being involved throughout the project activities enabled me to view the development of the young Clinical Commissioners in their roles first hand. This experience was used to inform the data collection and data analysis of the qualitative interviews conducted with the young Clinical Commissioners for my PhD research. It allowed me to build a

stronger rapport with these young people and better understand the context of their experiences.

1.4 A definition of diabetes

Diabetes was initially described as the ‘too great emptying of urine’ in 1500 BC (MacCracken et al, 1997). Indian physicians referred to diabetes as madhumeha, which translates into ‘honey urine’ because of their observation that it attracted ants. Two types of diabetes were distinguished in 400-500BC, by an ancient physician named Sushruta and a surgeon named Charaka, which were later termed type 1 and type 2 diabetes (Frank, 1957 and Tipton, 2008).

Diabetes is one of the four main types of chronic conditions, along with cardiovascular diseases (such as heart attacks and stroke), cancers and chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma) (World Health Organisation, 2016). There are several types of diabetes but the two most common types are type 1 and type 2 diabetes (International Diabetes Federation, 2017). All types of diabetes cause people to have too much glucose in their blood. Type 1 diabetes develops when the body is unable to produce insulin. Insulin is a hormone enabling glucose to enter the cells to be used as fuel by the body. It is usually diagnosed before the age of 40. Type 2 diabetes develops when the body is unable to make sufficient insulin or when the insulin cannot be used properly by the body. This type of diabetes tends to be diagnosed in people over the age of 40, although it is increasingly being diagnosed in younger people (Farsani et al, 2013). A key marker of the health status of those living with diabetes is glycaemic control, which refers to the amount of glucose in the blood and is obtained from a blood test. Glycaemic control is expressed as an HbA1c value. Several factors affect glycaemic control, including genetic, socio-demographic and psychosocial factors as well as issues surrounding health care organisation and delivery.

1.5 The prevalence of diabetes

The estimated diabetes prevalence for adults aged 20-79 years is 425 million worldwide (IDF, 2017). This number increases to 451 million if the age is expanded to 18-99 years. If these trends in diabetes prevalence continue, by 2045, 693 million people aged 20-79 years will have diabetes (IDF, 2017).

North and East London, the context of the qualitative interviews with young people, presented in chapter 5, are characterised by high levels of migration from low and middle income countries. There has been a larger rise in diabetes prevalence in low-income and middle-income countries than in high-income countries. This is attributed to three main factors (NCD Risk Factor Collaboration, 2016). Firstly, a greater increase in obesity in low and middle-income countries compared to high-income countries. Being overweight or obese is considered to be the main modifiable risk factor for type 2 diabetes (Public Health England, 2014). It is hypothesised that obesity increases the risk because of fat cells releasing hormones which disrupt blood glucose regulation (Kahn et al, 2006). Secondly, differences in genetic susceptibility as a result of inadequate foetal and childhood nutrition and growth. Thirdly, there are better resourced health systems in high-income countries, which are able to target those at high risk for diabetes at an earlier age and implement dietary and lifestyle modifications to delay or prevent the onset of diabetes. Recent research has also highlighted weight stigma as a factor that may contribute to poorer health outcomes in those with obesity (Puhl et al, 2016). Individuals with obesity are vulnerable to stigma in multiple settings, including employment, educational institutions, health care facilities, as well in the media and broader society. Several decades of research demonstrate consistent weight bias expressed by healthcare professionals, which can impair quality of care to patients with obesity and diabetes (Puhl et al, 2016).

An estimated one million children below the age of 15 have a diagnosis of type 1 diabetes worldwide (IDF, 2017). There is also evidence from population studies that type 2 diabetes in children and young people is increasing worldwide. However, reliable data on the number of children worldwide who have a diagnosis of type 2 diabetes is lacking due to wide differences in population characteristics and study methods amongst existing data (Farsani et al, 2013). For example, some studies use estimates from health care professionals participating in a surveillance system, others use administrative databases or retrospectively review medical data to determine prevalence.

In the UK, there are an estimated 194.2 per 100,000 of the general population of children and young people below the age of 15 diagnosed with type 1 diabetes (Royal College of Paediatrics and Child Health, 2017). Similarly to worldwide data, prevalence rates of young people with type 2 diabetes cannot be accurately determined. This is due

to an unknown number of young people being treated for type 2 diabetes in primary care who are thus excluded from national audits. However, evidence suggest that the number of children and young people with type 2 diabetes is increasing each year (Balasanthiran et al, 2012; RCPCH 2017). The highest prevalence of type 2 diabetes in children and young people is found in Newham, in. This has been primarily attributed to high rates of obesity amongst young people in this area (Balasanthiran et al, 2012). However, as with adults, weight stigma may also play a key role in the relationship between weight and health outcomes (Palad et al, 2019). In addition, East London is characterised by high levels of ethnic diversity and social deprivation.

1.6 Health inequalities in diabetes

As with other health conditions, significant inequalities exist in the risk of developing diabetes, in access to health services, the quality of those services and in health outcomes. These inequalities begin early in life, resulting in wide inequalities in child health outcomes (Public Health England, 2018).

Within the context of diabetes, those with type 2 diabetes seem to be most affected by health inequalities. Existing literature suggests that people from South Asian, African, African-Caribbean and Middle Eastern backgrounds have a higher risk of developing type 2 diabetes, as well as people from more deprived backgrounds (Department of Health and Social Care, 2001). Diabetes tends to occur at younger ages in people from these ethnic groups and these groups have a greater risk of developing health complications.

In 2000, the first cases of type 2 diabetes in young people were diagnosed in the UK in girls between the ages of 9 and 16 from Pakistani, Indian or Arabic backgrounds It was reported in Caucasian adolescents in 2002 (Spinks and Mann, 2013). Deprivation is strongly correlated with physical inactivity and less nutritious diets, smoking and higher blood pressure. These factors contribute to an increased risk of developing type 2 diabetes and a higher risk of experiencing complications in either type of diabetes. In type 1 diabetes, there are no significant differences between ethnic groups in terms of prevalence (Oldroyd et al, 2005). However, those from ethnic minority groups are more likely to have poorer glycaemic control and experience complications related to their diabetes, particularly those from deprived backgrounds (National Paediatric Diabetes Audit, 2017).

Inequalities in young people with diabetes are well documented in the literature, both worldwide and in the UK. Young people of lower socioeconomic status (SES) and ethnic minorities tend to have poorer glycaemic control and are at increased risk for diabetes complications later in life (Carter et al, 2008; Deladoey et al, 2013 and Dabelea et al, 2014). However, other studies have not reported an association, highlighting the importance of avoiding definitive statements about particular social or ethnic groups and health outcomes (Baumer et al, 1998 and Thompson et al, 2013).

As highlighted by a number of researchers, it is important to acknowledge that health inequalities are driven by social and economic factors rather than genetic or cultural factors (Nazroo, 2014). Ethnic differences within diabetes and other health conditions are not causal and thus must be considered within a wider context, in research, policy and practice.

Social relations impact upon development of health and illness, experience of illness and healthcare seeking behaviour (Bradby and Nazroo, 2010). Ethnicity and racism play into these social relations in a nuanced and subtle way. Ethnicity can be conceptualised as an identity that is both self-ascribed and imposed by others. It thus influences both individual behaviour and context in which that behaviour occurs. Individual identities are a reflection of structural dimensions of society and thus range of choices for each individual is inevitably constrained.

As mentioned earlier in this chapter, this thesis focuses on the experiences of young people defined as disengaged from diabetes self-care and diabetes services. Sampling in both the qualitative review (chapter 4) and the qualitative interviews with young people (chapter 5) was based upon this criteria. The settings in which the interviews took place (North and East London) are ethnically diverse areas. Further details about the demographic characteristics of these areas can be found in chapter 5.

However, this thesis did not set out to explicitly study the relationship between ‘ethnicity’ and diabetes self-care. Instead, it but instead to explore the experiences of young people with their diabetes self-care, who were defined as disengaged.

This thesis acknowledges the inequalities that create and maintain health and illness statuses and that individuals do not have truly ‘free choice’ in their decisions about

diabetes self-care. However, the focus of analysis is on the way in which young people navigate their diabetes self-care as individuals within this context, rather than focusing on factors which have create and maintain this context. This is in line with the salutogenic approach applied at the level of the individual, which is discussed in more detail, later in this chapter. This approach also avoids the potential of causing a re-inscription of ethnic categories, which can occur in the explicit study of the relationship between ethnicity and health (Bradby, 2012).

1.7 The costs of diabetes

Diabetes and its complications are major causes of early death in most countries worldwide (IDF, 2017). 4 million people aged between 20 and 79 years were estimated to have died from diabetes in 2017. Diabetes-related deaths accounted for 10.7% of global all-cause mortality among people in this age group. In order to prevent these outcomes in adulthood, it is important to target young people with diabetes. This thesis addresses this need by focusing on young people between the ages of 10 and 25.

The estimated global economic costs of diabetes were 727 billion USD in 2017 for those aged 20-79 years (IDF, 2017). When using an expanded age range of 18 to 99 years, the costs are estimated to be 850 billion USD. Premature death and disability due to diabetes are also associated with an economic cost for countries, often referred to as the indirect costs of diabetes. These costs are expected to rise over the coming years. It is projected that the healthcare expenditure on diabetes will reach 776 billion USD by 2045 in ages 20-79, representing a 7% growth. When using the age group 18-99 years, total expenditure on diabetes is predicted to reach 958 billion USD.

The most recent UK National Diabetes Audit revealed that individuals with diabetes were 32% more likely to die than those without diabetes in the general population. The most common causes are vascular disease and cancer (NHS, 2017). The relative risk of death is increased at all ages. The relative risk is higher in younger people than older people and higher in type 1 diabetes than type 2 diabetes (NHS, 2017).

The most comprehensive analysis of the economic impact of diabetes in the UK to date concluded that the annual cost of diabetes to the NHS is approximately £9.8 billion with £1 billion for Type 1 and £8.8 billion for Type 2 (Hex et al, 2012). Around 80% of this

money is spent on treating complications of diabetes. The largest costs for complications are inpatient days, cardiovascular disease and damaged kidneys and nerves (Hex et al, 2012). The treatment costs of diabetes are approximately £2.1 billion. Additionally, the costs of reduced productivity at work, due to diabetes complications, are estimated at nearly £9 billion. The priorities for both improving physical health outcomes in individuals for diabetes and saving costs include preventing type two diabetes, ensuring services meet the needs of individuals and improving engagement with diabetes self-care. This thesis focuses on the experiences of diabetes self-care to improve health outcomes for young people. Implications of the findings of this thesis for improving health outcomes are presented in chapter 7.

1.8 A definition of disengagement

Disengagement has varying definitions in the research literature, which also differs from the way in which is defined by clinicians. For example, in the literature it is sometimes defined by HbA1c level (Leonard et al, 2005 and Scholes et al, 2013) or by self-reported engagement with diabetes self-care (Boman et al, 2015). Disengagement is defined by the NHS as when a young person or parent/carer does not respond to be cumulative and may include: disregarding health appointments, not completing health questionnaires/consent forms, not having a GP, not being home for professional visits, not allowing professionals into the home, agreeing to take action but never doing it, hostile behaviour towards professionals, manipulative behaviour resulting in no health care and actively avoiding contact with professionals (NHS, 2018). Issues associated with disengagement include bureaucratic problems leading to communication failures between young people and health care providers (Snow and Fullop, 2011). These authors reported that young people struggled to attend due to incompatible work hours and being worried about being judged for having ‘poor control’ of their diabetes.

1.9 A definition of self-care

The terms self-management and self-care are often used interchangeably in the scientific literature. Whereas self-management usually refers to developing autonomy in managing a condition from a purely medical perspective in daily life, self-care is a broader concept, including both autonomous self-care of condition-specific tasks but also the ability to attend to broader psychosocial needs (Pelican et al, 2015).

Condition-specific tasks have the goal of maintaining stable blood glucose levels, in order to prevent long term health complications (National Institute for Health and Care Excellence, 2015). This involves engaging in a number of technical skills, including capillary glycaemia, multiple daily intracutaneous injections, urinary surveillance testing and responding blood glucose levels (Pelicand et al, 2015).

There are a number of different insulin regimens that young people with type 1 diabetes may be ascribed to by health care professionals (National Institute for Health and Care Excellence, 2019). These include three types of insulin treatments: multiple daily injection basal-bolus insulin regimens, continuous subcutaneous insulin infusion (insulin pump therapy) and daily insulin injections. Young people with type 2 diabetes are typically prescribed medications such as metformin to regulate blood glucose levels (National Institute for Health and Care Excellence, 2019).

With the rapid evolution of technology, new opportunities have been provided to incorporate a variety of tools into diabetes self-care and services (Forlenza et al, 2016). Two of the most widely used technologies are the insulin pump and continuous glucose monitoring (CGM) system. Most of the research on technologies for diabetes has focused on clinical measures like glycaemic control, rather than being led by patient-centric measures and exploring experiences with these technologies (Mameli et al, 2013). However, evidence has shown that these technologies provide greater flexibility in daily life and information about glucose fluctuations. The increased flexibility provided by these technologies is associated with improved self-efficacy, treatment satisfaction and quality of life in children and young people (Hirose et al, 2012).

There are also challenges with such therapies, such as the increased level of skill required, which can be both emotionally and cognitively demanding. Research has shown that CGM systems these can be disruptive to daily life, due to the increased tasks required needed to manage them compared with insulin injections (Hirose et al, 2012). There are a number of psychosocial issues which have been documented with the use of insulin pump therapy, such as pump visibility and physical restrictions (Alsaleh et al, 2016). The huge volume of data generated by these technologies also have the potential to increase the burden placed upon young people (Prahalad et al, 2018). However, most of the research on technologies for diabetes has focused on clinical measures like

glycaemic control, rather than being led by patient-centric measures and exploring experiences with these technologies (Mameli et al, 2013).

Young people with diabetes are also recommended to count carbohydrate intake and adjust their insulin dose accordingly (National Institute for Health and Care Excellence, 2015). Multiple daily blood glucose testing is also advised for young people with both types of diabetes as well as engaging in physical activity. As a result, young people with diabetes are expected to make a vast number of decisions each day about what, when and how much food to eat, the physical activity to perform and when to incorporate the other condition-specific tasks required.

Condition-specific tasks are important to prevent both short term and long-term physical health complications (Shrivastava et al, 2013). The short-term complications can affect the kidneys, eyes and feet. The most common need for dialysis or kidney transplants is diabetic complications. Diabetes-related eye disease is the most common cause of blindness and diabetes-related foot disease increases the risk of ulcers and the need for amputation. Diabetes also heightens the risk of heart disease, stroke and dementia (NHS 2010). Preventing diabetes complications is therefore an important public health concern. This requires both optimising diabetes services to meet young people's needs and encouraging engagement with diabetes self-care.

However, this narrow and medicalised focus on diabetes self-care neglects young people's broader psychosocial needs. These are important to acknowledge because they not only influence their ability to perform condition-specific tasks but also play a key role in optimising young people's wellbeing. This holistic conceptualisation of health is central to the salutogenic approach adopted in this thesis. The programme of work explores young people's experiences with diabetes self-care in order to better understand how to support them. The methods used in this exploration are presented in chapter 3.

1.10 A definition of young people

This thesis focuses on young people who are between the ages of 10 and 25. This is the age group and term that is used throughout the thesis, in line with the Lancet commission on adolescent health and wellbeing (Patton et al, 2016). Adolescence is defined by the World health Organisation (WHO) as between the ages of 10 and 19

(WHO, 2001). Youth is defined as between 15 and 24 years. The term ‘emerging adulthood’ has been used to describe the stage from late adolescence to late twenties, a stage characterised by a gradual development into adult roles (Arnett, 2007).

Increasing acknowledgement of the rights of children and young people is apparent within policy in the UK, specifically with regards to their role in making decisions (Kirk, 2007 and Sharpe, 2009). This has arisen as a result of the United Nations Convention on the Rights of the Child (UNICEF, 1989) and the Children’s Act in 1989. The growing recognition of the importance of considering the views of children and young people is evident within policy and practice initiatives in health, social work and education (Department of Health, 2002 and Department of Health and Department for Education and Skills, 2004). Despite the increasing acknowledgement of the value of obtaining and considering the views of children and young people in research, policy and practice, there remains ambiguity about the way in which children and young people are conceptualised (Jans, 2004 and Kirk, 2007). In this thesis, young people are conceptualised as being able to make informed decisions about their diabetes self-care and to take an active role in participating in research.

1.11 A definition of salutogenesis

Salutogenesis proposes that researchers and practitioners ‘focus on salutary rather than risk factors, and always see the entire person (or collective) rather than the disease (or disease rate)’ (Antonovsky, 1996) and always see the entire person (or collective) rather than the disease (or disease rate)’ (Antonovsky, 1996). In comparison with concepts such as coping or resilience where the conditions and mechanisms are more rigid and contextual, salutogenesis is a dynamic approach with a focus on problem solving (Lindstrom and Eriksson, 2005)

A salutogenic approach makes two important contributions to this thesis. Firstly, a salutogenic proposes a holistic view of health, whereby young people are conceptualised as individuals rather than patients or diabetics. Secondly, the approach acknowledges the capabilities of individuals and thus young people are perceived as being capable of making informed decisions about their own diabetes self-care.

The concept of salutogenesis was developed in the 1970s by Antonovsky and was initially based on studies of women who survived the Nazi concentration camps. Antonovsky (1987) explored why some people in times of stress stay well whilst others do not. He described two key factors as being important in maintaining wellness, which are a sense of coherence and generalised resistance resources.

A sense of coherence is a personal and collective resource which promotes positive health and wellbeing. Individuals who have a strong sense of coherence experience comprehensibility, meaningfulness and manageability. Comprehensibility is the cognitive ability to understand and find meaning in their situation. Meaningfulness are the reasons that individuals find to improve their health. Manageability is the belief that individuals have the skills, ability, support and resources needed to take care of challenging situations and the sense that they have control over these elements. A sense of coherence is proposed to develop throughout the life course, being formed in young adulthood and stabilising around the age of 30 (Antonovsky, 1979).

Generalised resistance resources are found within individuals and in their environments. They can have both material and non-material qualities. These resources provide an individual with meaningful and coherent life experiences and are genetic, constitutional and psychosocial. A key aspect is the ability of individuals to use and reuse these resources for an intended purpose. Salutogenesis acknowledges the socioeconomic factors which influence access to these resources. However, the emphasis is not on what is available to individuals but rather the way they are used to influence health and wellbeing (Lindstrom and Erikson, 2005).

Salutogenesis can be applied at a community, group or individual level. Thesis adopts a salutogenic approach at on the individual level, with a focus on the way in which young people to develop and draw upon resources to navigate diabetes self-care. This approach considers the ecosystems in which young people live and the intersecting beliefs and values they are required to negotiate as part of their self-care. Salutogenesis helps to frame the complexities that can occur, internally and externally.

1.12 Area of enquiry

This thesis uses a salutogenic approach to explore young people's experiences with diabetes self-care. In particular it focuses upon young people who are disengaged from

diabetes self-care and services, whose voices tend to be underrepresented in the literature. The thesis methodology includes three stages. The first stage comprises a qualitative synthesis of studies on young people's experiences with diabetes self-care. The second stage entails an analysis of qualitative interviews with young people with diabetes living in North and East London. The third stage comprises interviews with young people with diabetes who have participated in salutogenic projects, which formed part of the CLAHRC study described earlier in this chapter. This thesis provides these young people with a voice in the research literature as well as proposing recommendations for research, policy and practice in relation to diabetes self-care in young people.

Research questions

In parallel with the transition in this thesis from a focus on assets towards applying salutogenesis more broadly, there was also a shift in my research questions. Initially, the primary research question was aiming to identify particular personal, social and cultural assets, which could enhance engagement with diabetes self-care. When it became clear that this research question and lines of enquiry were restricting the data analysis process, these were revised to have a broader focus. In light of the importance of the context of diabetes self-care in young people, informed by the literature presented in chapter 2, the lines of enquiry were revised to allow for exploration of these contextual factors. These revisions facilitated a more holistic perspective of diabetes self-care, in line with the salutogenic approach adopted in this thesis. These revised questions are presented below.

Primary research question:

How do young people experience diabetes self-care?

Lines of enquiry:

- How do different environments influence diabetes self-care?
- How do support networks impact diabetes self-care?
- How does participating in salutogenic projects shape young people's perspectives and practice towards diabetes self-care?

1.13 Concluding comments for this chapter

In this chapter, I have introduced the focus of the thesis on diabetes self-care in young people defined as disengaged from diabetes services and/or diabetes self-care. I have also outlined the content of this thesis. I have defined the key concepts of this thesis: diabetes, self-care, young people and salutogenesis. I have also outlined the research aims and research questions of this thesis. The following chapter (chapter 2) discusses existing literature on diabetes self-care in young people and demonstrates how this thesis addresses the gaps present within the literature.

Chapter 2: Literature review

2.1 Overview of chapter

This chapter explores the way in which young people have been conceptualised in research and within the clinic, highlighting what this might mean for their decision making around diabetes self-care. This will provide the context for how I've conceptualised young people in this thesis, which is balanced against gaps in literature and knowledge of young people's experiences of living with diabetes.

2.2 The conceptualisation of children and young people in research

Despite a long tradition of research focused on children and young people, the majority of research in this area has been conducted about them, rather than with them or by them (Hill, 1997 and Sharpe, 2009). Parents and carers have often been used as the source for seeking to understand more about the lives of children and young people or the children and young people are only considered as part of the whole family unit (Christensen and James, 2000). Kirk (2007) argues that there are two main reasons for the lack of research with children and young people. The first of these is the belief that data obtained from children and young people was unreliable. The second of these is the concern about ethical issues when conducting research with children and young people. In regards to the first reason, this idea arose from the belief that children and young people lacked the maturity to understand the world in which they live, and lacked the ability to articulate such understanding (Docherty and Sandelowski, 1999). In addition, it was argued that children and young people were suggestible and therefore incapable of distinguishing fantasy from reality (Punch, 2002a). However, there is an increasing body of research which challenges these assumptions, with the condition that researchers working with children and young people need to understand how to engage them and understand the way in which they communicate (Mauthner, 1997; Thomas and O'Kane, 1998 and Kirk, 2007).

In terms of ethical issues, adult proxies were frequently used by researchers because of the assumption that children and young people are vulnerable and open to exploitation in research (Beresford, 1997). However, there has been an increasing amount of literature addressing ethical issues when conducting research with children and young people, with good practice guidelines being developed specifically pertaining to children and young people (Alderson, 1995; Beresford, 1997; Morrow, 2008; Shaw et

al, 2011; Ward, 1998). This literature highlights that, as with all research, there are ethical issues when working with children and young people but this does not prevent research from being conducted with this population. As mentioned in chapter 1, this thesis involves qualitative interviews with young people with diabetes, the findings of which are presented in chapter 5. These interviews sought to learn directly from young people about their experiences with diabetes self-care and thus adult proxies were not used.

2.3 The conceptualisation of children and childhood in theory

The perspective of children and childhood was initially informed by socialisation theory and developmental psychology (Kirk, 2007). Socialisation, which describes the process whereby individuals become part of a social group, was the dominant framework employed by social scientists researching children (Waksler, 1991). This was later criticised for the assumption that children were empty and incomplete, needing to be filled with ideas from the society in which they were born, as well as neglecting to view children's experiences of the world as valid in their own right (Waksler, 1991 and James and Prout, 1997). Developmental psychology, drawing heavily on the theories of Piaget, proposed childhood as being characterised by a universal development process (James, 2001). This process was perceived as moving from simple to complex thinking and from irrational to rational behaviour (James and Prout, 1997). From this perspective, children were viewed as incompetent, unfinished and passive conformists to a one-way socialisation process (Waksler, 1991; James, 2001; James and Prout, 1997 and Kirk, 2007).

These ideas were later challenged, which occurred alongside an increasing interest in the experiences of childhood from the perspective of children (Mauhner, 1997 and Mayall, 1994). The new perception of children and childhoods was informed by interactionism and social constructionism as well as from developments in children's rights, which served to alter the perceived role of children in society (James, 2001; James and Prout, 1997). From this perspective, children and young people are seen as competent social actors and agents, rather than as passive recipients of social forces, dependent on adult control and care (Waksler, 1991; James and Prout, 1997; Christensen and James, 2000; Hutchby, 2005 and Skelton, 2008). In addition, children and young people are seen as playing an active part in both creating and interacting with their social environment and thus have different views and experiences, informed by the

social, cultural and historical context in which they live (James and Prout, 1997). This view complements the salutogenic approach adopted in this thesis where young people are conceptualised as being competent social actors and research participants.

2.4 The conceptualisation of adolescence in theory

The research on adolescence has grown exponentially over the past several decades (Furstenberg, 2000). Despite this growth, several key themes have remained prevalent in the literature. Hall (1904) is credited with establishing the field of adolescence research. Since this time, there has been a prevailing notion of adolescence as a problematic time period, both for the individuals themselves, as well as wider society (Furstenberg, 2000). The term ‘quarter life crisis’ has been coined to describe the alleged difficulties experienced by young people attempting to establish themselves in the adult world (Robbins and Wilner, 2001).

Adolescence only emerged as a discrete life stage in the middle decades of the twentieth century, when it was conceptualised as representing a transitional stage from childhood to adulthood (Furstenberg, 2000). This has been challenged by researchers, such as Arnett (2007), who proposed the theory of emerging adulthood. He proposes that this period of the life course has distinct developmental characteristics. In addition, Arnett argues that this period can be conceptualised as a separate period of the life course, rather than merely a transition.

The idea of emerging adulthood was put forward in response to the dominant theory of the life course in developmental psychology proposed by Erikson (1980). This theory proposed that adolescence was followed by young adulthood, which was subsequently followed by middle adulthood. Arguably such a conceptualisation was relevant in the middle of the 20th century when most individuals in industrialised societies married and entered full time employment by around age twenty. However, by the end of the twentieth century, this paradigm has shifted towards an extended phase of young adulthood. This time period is now characterised by individuals trying out new experiences and gradually transitioning into long term relationships and job roles (Arnett, 2007).

As a result of the new conceptualisation of childhood and adolescence, there has been increased questioning of the value of using adult proxies in research. Instead, it is

proposed that it is optimal to explore the views and experiences of children and young people by speaking to them directly (Mahon et al, 1996). This argument has been strengthened by the observation that the views and experiences of adults, children and young people tend to differ (Dixon-Woods et al, 1999). However, there remains debate about whether the same research methods should be used for children, young people and adults (Christensen, 2004 and Punch, 2002a). Some researchers have argued that a distinction between adults and children is not necessary when deciding upon the most appropriate research methods and that instead the decision should be based upon the characteristics of the population of interest, the social and cultural context and the particular research questions (Kirk, 2007).

Despite the conceptualisation of children and young people being ‘vulnerable’, ‘incompetent’ and ‘passive recipients of care’ being challenged in the research literature, it remains prevalent in medical practice (James, 2011). This results in children and young people facing a number of barriers to participating in decision-making processes (Beresford and Sloper, 2003; Carter, 2002; Coyne, 2006, Cox et al, 2007; Curtis et al, 2004, Hallstrom and Elander, 2004 and Tates and Meeuwesen, 2001). However, this does not mean that children and young people do not participate at all in clinical decision-making (Dedding et al, 2014). Research has demonstrated children and young people are social actors who construct their own meaning and direction in their lives, even in circumstances of coercion (Christensen and James, 2000; Giddens, 1984 and Prout, 2001). It is thus important to ensure that young people not only have a voice within the research literature but also within a clinical setting. This thesis provides young people with a voice in both contexts as a result of the application of a salutogenic approach. As mentioned in chapter 1, this thesis includes interviews with an ethnically diverse group of young people, a group typically underrepresented in the research literature, the findings of which are presented in chapter 5. In addition, this thesis also includes findings from interviews with a group of young people participating in salutogenic projects, which helped to provide them with a voice in the clinic. The findings from these interviews are presented in chapter 6.

2.5 Young people with chronic conditions

Successfully coping with chronic conditions, such as diabetes, requires young people to take increasing responsibility for their care as well as engaging with health care services. Young people, both with and without chronic conditions, are faced with

additional challenges as they transition towards adulthood. These challenges can be exacerbated by the challenges inherent in living with a chronic condition (Aujoulat et al, 2017).

This has been described as ‘meanings at risk’ by Bury (1991) whereby individuals continually test the meanings of their experience of living with a chronic condition against the reality of their everyday experience. Unlike adults, young people are in the process of developing their identity and thus negotiating their diabetes self-care occurs against this backdrop. I thus use the term ‘identity work’ to describe continual striving by participants to retain their desired sense of normality whilst navigating the role of diabetes as part of their identity. This work is fluid and includes managing validators and threats to identity. The nature and significance of identity work in diabetes self-care is the key contribution that my thesis makes to the literature, and is further discussed in chapters 4, 5, 6 and 7.

A particularly important time for young people with chronic conditions is the transition from paediatric to adult services. For young people with diabetes, this time is associated with a decline in clinic attendance, as well as less engagement with diabetes self-care activities, termed ‘non-adherence’ (Court et al, 2009). A paradox to non-adherence exists whereby such behaviours can increase the risk of both short and long term health complications but they make sense psychologically, as young people are in the process of developing their identity, which is distinct from their parents and one that is not dominated by their chronic condition (Aujoulat et al, 2017). Less engagement with services and self-care thus may be an inevitable aspect of this identity development process. The need to establish a coherent and valued sense of self has been acknowledged as being imperative for young people, both with and without chronic conditions (Luyckx et al, 2006). The importance of this identity work for diabetes self-care is further explored in chapter 4.

For young people with chronic conditions, such as diabetes, there is an additional challenge of integrating the condition into identity without it overshadowing other aspects. It has been suggested that diabetes self-care challenges arise as a result of the diabetes identity overshadowing other aspects of identity, which is referred to as illness centrality (Tilden et al, 2005; Helgeson and Novack, 2007). However, this remains a relatively unexplored area in the research literature, particularly from a qualitative

perspective. Illness centrality is associated with poorer wellbeing (Helgeson and Novack, 2007; Park et al, 2011), reduced psychosocial adjustment to the chronic illness (Morea et al, 2008) and the development of self-care abilities (Adams et al, 1997; Helgeson and Novack, 2007; Tilden et al, 2005). The integration of the chronic condition into identity thus appears to be important in relation to self-care for young people but requires further exploration. This thesis thus makes an important contribution to the literature in exploring the significance of identity work in diabetes self-care.

A salutogenic approach is particularly important in light of literature documenting higher levels of psychological distress in young people with diabetes, compared with their peers (Reynolds et al, 2011). This review also noted that young people with poorer glycaemic control were especially at risk, demonstrating the relationship between physical health and mental wellbeing. Similarly, studies have shown that depression scores are higher amongst those with poorer glycaemic control (Johnson et al, 2013). These depression symptoms were found to be predictive of experiencing depression later in life. Improving engagement with diabetes self-care is thus important for optimising both physical health and mental wellbeing in young people.

2.6 Self-care in young people with chronic conditions

The conceptualisation of young people as autonomous individuals is central to salutogenesis and is also fundamental to self-care in young people with chronic conditions (Beacham and Deatrick, 2013). The term self-care originates in the 1970s and was used in the context of people claiming self-determination within the health care system (Levin et al, 1975). Levin and colleagues defined self-care within a social theory that promotes participation and autonomy of individuals as a way to strengthen both individual and community ownership of health. An alternative use of the term ‘self-care’ emerged within nursing in the 1980s, where self-care was defined as being the responsibility of nurses’, who act as agents to boost people’s ability to manage their condition (Pelicand et al, 2015).

Despite its roots in health promotion, discourse on self-care in young people with chronic conditions has tended to adopt a deficit approach. For example, a review of strategies to support self-care reported that 25% of young people whose parents have low educational levels ‘presented a deficit in the capacity to manage their health’

(Fernandez et al, 2017, p. 1324). The review concluded that ‘limitations in parents’ education may affect their knowledge about health, adherence to treatment, understanding and following medical instructions, as well as the transition from paediatric to adult care’ (Fernandez et al, 2017, p. 1324). Similarly, a study on diabetes self-care in young people aged between 18 and 25 stated that ‘This transitional phase in life, which is defined as “emerging adulthood”, is characterised by anxiety, selfishness, conflicts, disappointments and emotional crises’ (Hilli et al, 2018, p.34).

Such a focus on deficits can lead to young people being labelled as problems to be fixed, with interventions targeted towards them being disempowering, ironically contributing to a disengagement with self-care and health services (Fenton, 2013). This thesis provides a challenge to the deficit approach through the application of salutogenesis, by acknowledging the capabilities of young people to make informed choices about their diabetes self-care in the context of their daily lives.

2.7 Self-care interventions for young people with chronic conditions

Interventions to enhance engagement with self-care have tended to focus only on medical management of chronic conditions, usually through education-based programmes (Bal et al, 2016; Kirk et al, 2012; Pelicand et al, 2015 and Sattoe et al, 2015). Interventions have rarely addressed social elements relating to self-care, such as communication, decision making, assertiveness and peer interaction (Sattoe et al, 2015). Similarly, few interventions have addressed emotional aspects pertaining to self-care, such as self-confidence, developing a positive body image, self-esteem, positive thinking, stress management or acceptance of the condition (Sattoe et al, 2015). Multicomponent interventions which have targeted emotional, social and family influences on self-care have been shown to be more effective than those targeting a direct, behavioural component (Hood, 2010). However, the notion that the social context of self-care requires consideration has only recently gained more attention (Bal et al, 2016 and Sattoe et al, 2015). The adoption of a salutogenic approach in this thesis allows for the social context of self-care to be explored. This will help to inform future self-care interventions.

Education-based interventions have provided mixed results in terms of improving knowledge (Kirk et al, 2012) and have shown even less success with improving

measures such as glycaemic control in young people with diabetes (Gage, 2004; Armour, 2005 and Boren, 2006). In addition, benefits were often only achieved in the short-term. Amongst education-based interventions, those using e-health seem to be the most effective in improving health status, psychosocial wellbeing and knowledge as well as being satisfactory to participants (Kirk et al, 2012). Interventions delivered in home, school or community settings also seem to be more effective than those delivered in a clinical setting (Edwards, 2014; Guljas, 2014; Kirk et al, 2012; Pansier, 2015 and Reynold, 2015). Furthermore, those demonstrating the inter-relatedness of different aspects of self-care also seem to be most effective (Hampson, 2001). This provides further support for the usefulness of a salutogenic approach towards diabetes self-care.

2.8 Education and diabetes self-care

Research has identified the school environment as being challenging for maintaining diabetes self-care. A review by Marks (2013) reported that the majority of children were not receiving adequate diabetes treatment at primary school. Treatment was reported to occur away from the classroom, negatively impacting class attendance and glycaemic control. The review also reported that schools tended to restrict access of blood glucose testing equipment, resulting in delayed identification and treatment of hypoglycaemia. Children reported frequently missing school due to diabetes treatment issues that could not be managed at school. This highlights the importance of young people being adequately supported at school for both their physical health and educational attainment.

Friends have been highlighted as being particularly important within the school environment. Lewis (2007) used grounded theory methodology to explore the influence of the school environment on diabetes self-care in young people with type 1 diabetes between the ages of 11 and 16 in the UK. Similarly to the intervention research, self-care was conceptualised by the author as relating solely to the medical aspects of diabetes.

The study specifically focused on self-regulation, which pertained to both regulating blood sugar levels (biological self-regulation) as well as engaging in diabetes self-care behaviours. Friends played an important role in supporting diabetes self-care and were described as often advocating for young people with diabetes within the school environment, such as explaining the condition to others.

Other young people with diabetes in the school environment were cited by Lewis (2007) as being important in normalising diabetes, which improved young people's wellbeing. The importance of normalising for diabetes self-care in young people is further explored in chapter 4. Protective disclosure was also described as being helpful by some participants, where young people disclosed their condition to selected individuals who they trusted and would be able to provide help in a diabetes-related event, such as low blood sugar levels. For other participants, they avoided disclosing diabetes to others, which was described as being a threat to self-regulation. Some young people also attempted to conceal their diabetes self-care activities from others out of fear of unintended disclosure of diabetes. Stigma was a persistent theme amongst participants, which was both felt and enacted (Goffman, 1963). Some young people described derogative comments from others about their diabetes as well as fears about being perceived as a drug user by injecting themselves with insulin as part of diabetes self-care.

In light of Lewis's (2007) research being conducted on nine participants, it is possible that such findings are not representative of the experiences of other young people with diabetes. The use of theoretical sampling may also have resulted in the exclusion of certain aspects of young people's experiences at school with diabetes. However, such research highlights the potential significance of stigma, both felt and enacted, as well as the importance of friends in helping to mitigate these stigmas for the participants in this study. It is important to learn how to better support young people with diabetes in the school environment in order to optimise their physical health and wellbeing.

Further research on the school environment which widens the definition of self-care beyond medical aspects alone is needed to understand young people's experiences more holistically. This thesis addresses this gap through the application of a salutogenic approach. The qualitative interviews conducted as part of this thesis included an exploration of the influence of school on self-care. These interview findings are presented in chapter 5.

Little research has been conducted on the experiences of young people at university. However, studies have demonstrated the way in which the university environment can be disruptive for diabetes self-care. Balfe (2009) explored the role of the university environment in diabetes self-care in young people with type 1 diabetes between the ages

of 18 and 25 in the UK. Although a specific definition of self-care was not offered by the author, the behaviours used to manage the medical aspects of diabetes were likened to Foucault's ideas of 'disciplinary practices'. These are activities carried out to help individuals gain a sense of power, wellbeing and accomplishment by allowing them to regulate and normalise themselves.

Routines were described by participants in Balfe's study as being helpful in maintaining diabetes self-care. These routines not only served a biological function of maintaining balanced blood glucose levels but also had identity-producing benefits and thus appear to resemble disciplinary practices. Diabetes self-care routines served as a platform from which young people could engage in non-diabetes activities related to other aspects of their identity, such as sports. The more routinised that self-care was, the more easily young people were able to implement these activities into their lives. However, the university environment made it difficult for participants to maintain these routines because of the unpredictability of the university environment, in terms of lectures and stresses relating to their studies. Young people who had more recently been diagnosed with diabetes particularly struggled at university, especially in the first year. These young people also tended to be unwilling to create diabetes self-care routines for themselves. However, over time, young people's desire to create routines for their diabetes self-care increased.

As participants in Balfe's research were all white students attending elite universities, their experiences may not represent those from different backgrounds and universities. Nevertheless, such research highlights the significant role of diabetes self-care in allowing young people to engage in identity work, whereby they explore other non-diabetes aspects of their identity. This demonstrates the importance of exploring self-care in a holistic way, rather than focusing on only the medical aspects of the behaviours.

The study also highlights the significance of the university environment in disrupting this identity work. From a research perspective, it is important to learn about how to support young people from a range of different backgrounds to navigate these challenging environments that they experience, such as university. As mentioned earlier in this chapter, this thesis includes interviews with an ethnically diverse group of young

people living in North and East London, some of whom are close to the age at which they would attend university. These findings are presented in chapter 5.

2.9 Parents and diabetes self-care

Research has consistently shown the importance of social support in self-care for diabetes and other chronic conditions. The families and friends of young people with diabetes have been demonstrated to play an important role in their wellbeing, self-care and achievement of medically optimal glycaemic control (Modi et al., 2012). However, it is important to note that the association between social support and diabetes is bi-directional, with social support systems affecting diabetes self-care as well as diabetes self-care affecting social support systems. The importance of social support for diabetes self-care is further explored in chapter 4.

A diagnosis of diabetes or other chronic health condition has been highlighted as a potential cause of distress for the family (Goldstein, 2013; Melbourne, 2010 Sherifali, 2006 and Tseng, 2008). This is particularly problematic for families with a lower income and who lack social support (Melbourne, 2010; Swallow, 2012 and Tsiouli, 2013). However, research has highlighted that the effects of a diagnosis on the family can also be beneficial. For example, a diagnosis has been described as being a ‘catalyst for engagement’, leading to increased involvement in the care of the child or young person and a stronger parent-child relationship (Swallow, 2012). A key theme in adjusting to the diagnosis for young people and their families is striving for a sense of normalcy. The development of new routines has been described as critical in this process (Crespo, 2013 and Goldstein, 2013).

Relationships with family members have also been identified as being important in diabetes self-care by Auslander et al (2010). Authors studied young people with type 2 diabetes between the ages of 14 and 19 in the USA using a modified grounded theory approach. This study used the term ‘self-management’ rather than self-care and it is thus unsurprising that it focused only on the medical aspects of diabetes. The research reported that mothers tended to play a primary role in providing support for diabetes self-care. However, other family members with diabetes also played a significant role in helping young people recognise the severity of diabetes. Hearing stories from family members about diabetes-related complications was cited as being particularly helpful. Authors noted that the findings resemble those from studies of young people with type 1

diabetes, indicating that there not necessarily a need to separate the two in research. In this thesis, I chose to include young people with both types of diabetes as I was not working from the assumption that there would be inherent differences between the two groups.

Parental conflict has also been demonstrated to influence diabetes self-care. Weinger et al (2001) studied young people with type 1 diabetes between the ages of 13 and 15 in the USA and found that most participants reported experiencing conflict with their parents. It is worth noting that the authors used the term 'self-management' rather than self-care in their study and thus focused on the medical aspects of self-care only.

Three main sources of conflict were identified in the study: parental worry and intrusive behaviours, perceived parental lack of understanding and blaming behaviours as well as difference in perspectives with future and present concerns. In terms of parental worry and intrusive behaviours, young people reported that their parents were concerned about long term diabetes complications as well as typical adolescent behaviours, such as driving. These worries often manifested in behaviours which were perceived as being intrusive by young people. Lack of understanding and blaming behaviours occurred when young people felt that they were being blamed for mismanaging their diabetes. This was perceived as being due to a lack of understanding of the complexities of diabetes self-care. Some young people also reported food as being a source of conflict.

The difference in the value placed upon present compared with future concerns has also been described as a source of conflict (Weinger et al, 2001). Parents were described as being concerned about hyperglycaemia (high blood glucose levels) and preventing future complications. Young people were not as concerned with future complications and were more concerned with avoiding hypoglycaemic (low blood glucose levels). This research also identified two sources of parental support for diabetes self-care behaviours: parental understanding about the demands of diabetes and helping to maintain young people's wellbeing. As a result of the accumulated experience of diabetes in the family, parents were perceived as being understanding about daily blood glucose fluctuations. In situations where low blood glucose occurred, or other situations that were challenging, such as learning to drive, parents were described as being reassuring.

As Weinger et al's study used convenience sampling, it is possible that the views and experiences of parental conflict amongst participants differs from those who were not available to participate. Furthermore, the use of focus group methodology means that thoughts shared by participants may have been influenced by group dynamics. It is possible that different perceptions and experiences would have been captured with interview methodology, particularly in young people who may feel inhibited within a focus group setting. This thesis avoids this potential problem by implementing individual interviews with young people with diabetes to ensure that even young people who may be inhibited in a group setting are able to share their experiences with diabetes self-care. In addition, the adoption of a salutogenic approach involves a focus on the proactive ways that young people navigate self-care, rather than focusing on problems or deficits.

Nevertheless, Weinger et al's research highlights the difficulty of navigating relationships with parents whilst also negotiating the challenges of living with diabetes. This study also highlights the importance of acknowledging the non-diabetes related activities in which young people engage, such as learning to drive. Such activities are important to young people, both with and without diabetes but can place an additional stress on young people with diabetes who already face diabetes-specific challenges in their daily lives. The adoption of a salutogenic approach in this thesis allowed for the exploration of young people's experiences with diabetes self-care within the context of their daily lives.

The type of parental support has also been reported as being important in diabetes self-care. A study of young people between the ages of 12 and 16 with both type 1 and type 2 diabetes in Jamaica was conducted by Anderson et al (2013). This study defined self-care as including weight management, blood glucose monitoring, glycaemic control, and adherence.

It was found that most support from parents for these aspects of diabetes self-care was instrumental, such as preparing food, ensuring diabetes supplies were adequate and reminders about insulin injections. Young people appreciated this support but wanted it on their terms. Emotional support, particularly reassurance, was highly valued by participants. Food and glucose levels were the two biggest sources of conflict between parents and young people. The nature of the support provided seemed to be more

important than the amount of support provided. Shouting, criticism, threats and physical discipline were all poorly perceived by young people. However, collaboration between parents and young people tended to increase over time, which occurred alongside young people taking on greater responsibility for diabetes self-care.

In light of Anderson et al's study including only four participants, the results may not be transferable to other young people with diabetes. Furthermore, the use of focus group methodology, similarly to Weinger et al (2001) means that participants who felt inhibited within the focus group setting may not have had their perceptions and experiences represented. Nevertheless, the research makes an important contribution to the literature due to the limited number of studies conducted on the experiences of young people with diabetes living in countries outside of the UK and the USA. This thesis includes interviews with an ethnically diverse group of young people, including those from Jamaican backgrounds, to further add to this gap in the literature.

2.10 Friends and diabetes self-care

Friends have also been demonstrated to play an important role in diabetes self-care. Brouwer et al (2012) studied young people between the ages of 12 and 16 with type 2 diabetes in the USA and found four themes pertaining to the perception and experience of support from friends. These included: support for non-diabetes related behaviours, support for diabetes self-care behaviours, feelings of belonging and issues relating to disclosure. Support for non-diabetes related behaviours included participating in activities that were enjoyable together, such as swimming or cheerleading. Participants appreciated being able engage in 'normal' activities as a young person which were unrelated to diabetes and friends supporting them in this endeavour was highly valued. This demonstrates the importance of value of exploring the context in which diabetes self-care occurs as well as the non-diabetes aspects of identity and the important role of friends in both of these areas. Support for diabetes self-care included both practical and emotional support. Practical support was provided in the form of reminders about testing blood glucose levels. Emotional support included providing praise if blood glucose levels were within a healthy range as well as encouragement to improve blood glucose levels if they were not. Participants also appreciated friends accommodating diabetes food restrictions, such as not eating sugary foods around them.

Young people also expressed a feeling of belonging when they were around others with diabetes (Brouwer et al, 2012). They described being able to exchange healthy recipes, tips for diabetes self-care and emotional support for some of the challenges in living with diabetes. In terms of disclosure of diabetes, most young people reported telling close friends about their condition so that they would understand the diabetes self-care behaviours required and could provide help if a diabetes-related emergency occurred. Several participants had not told any friends about their condition. The reasons provided were that they felt it was a personal issue, that diabetes would be cured or that it would mark them out as being different from others. This research demonstrates that despite experiencing support from friends, there is still reluctance to disclose diabetes to friends. It is possible that these fears are particularly salient in young people with type 2 diabetes due to the associated societal stigma surrounding the condition. In light of the short time interval between diagnosis and being interviewed for this study, it is unclear if the issues of stigma are only problematic around the time of diagnosis or continue to be significant for young people.

Issues around disclosure towards friends were also reported by Lowes et al (2007), who studied young people with type 1 diabetes between the ages of 12 and 16 living in either England or Wales. Researchers did not offer a definition of self-care and used the terms self-care and self-management interchangeably throughout the paper. The research focused on the medical aspects of self-care and how young people were supported by their friends in relation to these behaviours.

Participants expressed a desire to take responsibility for their own diabetes self-care but mostly felt supported by their friends. Rather than disclosing to all friends, most young people disclosed to only best friends and also informed friends about the nature of diabetes. The amount of information provided was dependent on how comfortable participants felt about discussing diabetes and thus friends had varying levels of diabetes knowledge. However, most friends knew how to behave if the young person experienced an episode of hypoglycaemia. Diabetes was not perceived as playing a prominent role in interactions with friends although participants expressed sometimes feeling different or resentful around their friends. Participants also described feeling hurt by friends' misinterpretations of type 1 diabetes, such as a confusion with type 2 diabetes and thus an assumption that obesity was associated with type 1 diabetes. This highlights that stigma surrounding type 2 diabetes can be perceived as problematic for

young people with both types of diabetes. An information leaflet was suggested to be helpful to inform friends about diabetes, which would include experiences of young people living with diabetes pertaining to physical and emotional aspects of diabetes. As this study used telephone interviews for some of the data collection, rather than face-to-face interviews, it is possible that aspects of their experience were not captured. Nevertheless, this study highlights the significance of stigma for young people with type 1 diabetes and the potential of information provision to ameliorate this stigma.

2.11 Clinicians and diabetes self-care

Clinicians also influence diabetes self-care. Drotar (2009) reported positive as well as negative aspects of behaviour by clinicians from the perspective of young people with diabetes. Positive aspects included showing an interest in the person not just their condition, considering the life circumstances of the individual, being honest, encouraging good self-care and providing sufficient time for discussion. Negative aspects included being authoritarian, asking routine questions and being negligent. These behaviours were associated with less engagement in the medical aspects of self-care, which demonstrates the potential for clinicians to reduce to impact engagement in these behaviours in both directions.

A desire for positive interactions with clinicians in which clinicians demonstrate confidence in young people's capabilities has also been highlighted in previous research (Curtis-Tyler et al, 2015). The acknowledgement of individuals' capabilities is central to salutogenesis, an approach that can be applied within clinical practice as well as research. Young people have also described wanting opportunities to set the agenda in clinic appointments and have choices. As mentioned earlier in this chapter, this thesis includes interviews with young people involved in salutogenic initiatives which helped provide them with a voice in the clinic. The findings from these interviews are presented in chapter 6.

The importance of being treated as a young person rather than as a patient has been highlighted by Carroll and Marrero (2006). Authors studied young people between the ages of 13 and 18 with type 1 diabetes living in the USA. Participants felt that it was important for them to be seen by their clinician as an individual first and then as someone living with diabetes. This demonstrates the importance of adopting a holistic approach to diabetes care, as proposed by salutogenesis (Antonovsky, 1979).

Young people have expressed a desire to be able to talk about non-diabetes related issues with their clinician (Carroll and Marrero, 2006). Participants described wanting to be supported with the medical aspects of self-care within the context of their lives, rather than merely being fed information. Email communication with clinicians was valued because it enabled them to receive timely advice on how to carry out their medical self-care when challenging situations occurred, such as participating in a sporting event. They were also able to ask questions about how to approach self-care in the context of unusual blood glucose level readings. Young people who perceived having a positive relationship with their clinician reported being more careful about their medical self-care before and after their clinic appointment, demonstrating the significance of the clinic in providing a prompt for more engagement with these behaviours. Similarly to Anderson et al (2013) and Weinger et al (2001), this study used focus group methodology and thus the views and experiences of more inhibited participants may not have been captured. Nevertheless, the study highlights the importance of acknowledging the context of diabetes self-care by adopting a holistic approach. This is achieved in this thesis through the application of salutogenesis.

Collaboration with clinicians has been also been highlighted as particularly important for young people with diabetes (Hillis et al, 2018). Authors explored experiences of diabetes self-care in young people aged between 18 and 25. Findings highlighted the importance of clinicians creating a caring and supportive relationship with young people, where they were viewed as a whole person, rather than solely as a patient, as well as clinicians focusing on what young people were doing well in terms of diabetes self-care. Young people in this study valued joint decision-making with care providers.

Young people in this study also expressed finding diabetes self-care time consuming and mentally draining, emphasising the importance of receiving appropriate support from clinicians. They experienced a greater sense of control, and relief, when clinicians helped them develop a range of strategies to deal with the practical and emotional aspects of diabetes self-care. In light of these findings, researchers emphasised the need for clinicians to adopt an innovative and flexible approach, and for greater efforts to be made to engage young people with diabetes. Although this study was very small in scale, containing a total of 8 participants, it highlights the significance of clinicians in supporting young people with diabetes self-care from both a physical and psychological

perspective. Both these needs are acknowledged through the adoption of a salutogenic approach in this thesis.

2.12 Challenges with diabetes self-care

A range of challenges have been identified in diabetes self-care in young people. Davidson et al (2004) studied young people with type 1 diabetes between the ages of 12 and 20 living in the USA using content analysis. Authors defined self-care as pertaining to the medical aspects of diabetes only, in line with guidelines proposed by the American Diabetes Association (ADA). Researchers reported seven key stressors central to young people's experiences with diabetes self-care: nature of the condition, personal, care management, relationship, situational, situational, coping behaviours and dilemmas impacting self-care decisions and coping responses. Diabetes was described as being difficult, demanding and never ending although simultaneously participants expressed being currently or potentially able to manage the condition.

For young people in Davidson et al's study, diabetes represented a sense of difference in their lives, despite concerted efforts to maintain a sense of normality. Participants expressed ambivalence about the degree to which diabetes threatened this sense of normality. Although young people described attempts to view diabetes as one aspect of their lives, the condition was pervasive, affecting schedules, opportunities, emotions, relationships and situations. Participants conveyed difficulty with remaining optimistic and frustration in their perceived inability to control diabetes, both physically and psychologically.

Davidson and colleagues also reported that the provision of intensive therapies to manage diabetes exacerbated the challenges faced by young people. Ironically, the therapies served to worsen the same stressors that impacted decisions about diabetes self-care. Rather than engagement in the medical aspects of self-care being a binary decision, it represented a complex and evolving set of decisions that considered the personal, situational and relational context in which young people found themselves.

Both physical and emotional challenges have also been described by Damiao and Pinto (2007) who studied young people with type 1 diabetes between the ages of 12 and 18 living in Brazil using grounded theory methodology. Authors did not offer a definition

of self-care or use this term at all in the paper, instead they were guided by the language used by participants. They reported that young people were transformed by their experiences of diabetes. This transformation began when they were diagnosed, a time point that was memorable and highly significant for all participants. Young people tended to contrast their current knowledge with their lack of knowledge at the time of diagnosis. Awareness of having diabetes and the need for engagement in specific medical self-care behaviours were described as being a gradual adjustment process. Participants also expressed a simultaneous feeling of being normal yet also being different. Having a diagnosis of diabetes was something that made young people feel different to other young people, including their friends and was associated with a sense of awkwardness. However, participants expressed having similar preferences, expectations, and desires as their friends. The transformation of young people also included changes in diabetes self-care behaviour, with these activities becoming more routinized over time. This allowed them to maintain self-care whilst engaging in other non-diabetes related activities with identity-producing benefits, similarly to the young people described by Balfe (2009). Benefits of living with diabetes were also described by participants in Damiao and Pinto's study. Several young people felt that their physical health was better than before they had been diagnosed. Participants also expressed a belief that life with diabetes could be enjoyable, as long as diabetes remained under control.

Despite positive perceptions of living with diabetes, young people described living a 'prickly life' whereby they were required to manage ongoing diabetes-related challenges in this study. Hormonal changes of adolescence, which could influence blood glucose levels were frustrating for participants. There were also often fears around particular diabetes self-care activities, such as injecting insulin. Some young people were afraid that the needle would break or that they would hurt themselves. Physical symptoms of diabetes were also challenging for young people to deal with. Some participants used distraction techniques to manage these symptoms but others were unable to take their minds off diabetes. Although a greater understanding of the symptoms of diabetes was cited as being helpful, there were times when rationalising about the symptoms was not a useful coping strategy, demonstrating that knowledge is necessary but not sufficient in diabetes self-care. As quotations in this study were not attributed to individual participants it is not possible to determine the degree to which these findings were represented across the data set. However, this research makes an

important contribution to the literature by highlighting both the challenges and benefits associated with living with diabetes. Furthermore, it adds to the limited research conducted on young people with diabetes living outside of the UK or USA, where most research is conducted.

Emotional challenges of diabetes self-care were also reported by Huus and Enskar (2007) who studied young people with type 1 diabetes between the ages of 14 and 18. Participants described difficulties in being able to live a 'normal' life because they always had to be on time for meals and insulin injections so could not spend their time as freely as their friends. Young people felt that because of the demands of medical self-care activities that they could never relax and always had to think about diabetes when planning their activities. However, participants also described positive aspects of diabetes self-care. They described increased knowledge about their bodies, healthy foods and the importance of regular exercise. This research demonstrates the importance of exploring positive aspects of diabetes self-care, rather than adopting a deficit approach and focusing only on negative aspects. Further research of these positive aspects can help to determine how these can be drawn upon to better support young people with diabetes. This thesis explores these positive aspects through the application of a salutogenic approach.

Positive aspects of diabetes self-care were also been identified by Salamon et al (2012), who studied young people with type 2 diabetes between the ages of 11 and 16 living in the USA. Authors defined self-care as behaviours aimed at preventing hyperglycaemia and hypoglycaemia. Some participants described enjoying medical self-care activities because they knew that it helped their bodies. However, fears were also described of performing self-care in front of others, demonstrating the significance of felt stigma for young people with diabetes, as also described by Lewis (2007) and Lowes et al (2007).

Salamon and colleagues (2012) also found that participants perceived the changes made to their daily routines were positive. They described easily integrating blood glucose monitoring, dietary changes, insulin injections, medications and exercise in their lives. Adjustments were made over time, such as rotating injection sites, modifying needle depth and allocating more time in the mornings and evenings for these self-care activities.

A number of coping strategies were also described by participants, such as proactively managing their emotions so that it did not affect their blood glucose levels and continually learning about diabetes so that they had the adequate skills to be able to carry out medical self-care activities effectively (Salamon et al (2012)). In contrast with Weinger et al (2001), participants described being motivated by both immediate and long term consequences of diabetes self-care. Immediate consequences, such as high or low blood glucose levels were associated with health threats, such as needing to go to hospital or fainting. Long term consequences were also significant for participants, who were motivated to avoid diabetes-related complications. This was especially common amongst participants who had friends or family members living with diabetes. Similarly to Brouwer et al (2012), there was a short interval between the time of diagnosis and the time that the interview took place and thus findings may represent only initial views and experiences of the medical aspects of diabetes self-care. Nevertheless, such research highlights the importance of exploring both long and short term factors when exploring young people's experiences with diabetes self-care.

Coping and problem-solving skills pertaining to both emotional and physical aspects of diabetes self-care were also reported by Mulvaney et al (2008) who studied young people between the ages of 13 and 19 with type 2 diabetes living in the USA. Authors used the term 'self-management' rather than self-care and thus focused only on the medical aspects of self-care. Coping behaviours described in the study included taking notes at clinic appointments, showing friends how to carry out diabetes self-care activities and seeking diabetes-related information on the internet. When experiencing low blood glucose levels, young people described avoiding others in order to avoid conflict with them.

Participants also reported ways of coping that addressed their emotional needs but were associated with negative health consequences (Mulvaney et al, 2008). These behaviours included being untruthful about blood glucose reading to both parents and clinicians, deleting blood glucose readings and removing batteries from blood glucose meters and coming off medications to determine if diabetes-related symptoms were still present. This highlights the potential conflict with the emotional and physical aspects of diabetes self-care for young people. Psychological coping strategies were also discussed by participants, such as awareness and transformation of thoughts and feelings, distraction techniques to avoid thinking about diabetes, laughing at others who had previously

made fun of them, relaxation, remaining hopeful about a cure and realising that diabetes had not fundamentally changed their identities. These findings add to the existing literature which has acknowledged the importance of managing the role of diabetes within identity (Balfe, 2009 and Brouwer et al, 2012). Strengthening non-diabetes related aspects of identity seems to help to mitigate the emotional aspects of medical self-care but this remains an under investigated topic within the research literature (Aujoulat et al, 2017). The implications of young people participating in salutogenic projects for identity and diabetes self-care are discussed in chapter 6.

Planning strategies were also described as being helpful in diabetes self-care by Mulvaney et al (2008). Planning behaviours to optimise the physical aspects of diabetes self-care included determining what time to arrive home to check blood glucose levels, carrying extra medication and educating friends about how to help in a diabetes-related emergency. Mornings and evenings were described as being particularly challenging to navigate without sufficient planning. Young people felt they did not have enough time in the mornings, causing them to feel stressed, rushed and disorganised. Bedtimes were associated with forgetting about self-care activities or feeling too tired to perform them. Fridays were cited by participants as a day when they felt fatigued and was associated with less engagement in medical self-care activities. However, people described planned 'cheats' (eating unhealthy foods) as being helpful. The fatigue experienced on Fridays demonstrates the energy required to perform medical self-care activities, which builds up throughout the week. As this study used focus group methodology, similarly to Anderson et al (2013), Weinger et al (2001) and Carroll and Marrero (2006), inhibited participants' views and experiences may not have been represented. Nevertheless, this research highlights the importance of acknowledging both the emotional and physical aspects of diabetes self-care, which may sometimes conflict, rather than focusing on self-care from a purely medical perspective (Pelican et al, 2015).

2.13 Identity and diabetes self-care

Identity-related strategies have also been cited as important in diabetes self-care. However, as mentioned earlier in this chapter, this remains a relatively unexplored area in the research literature. Nevertheless, several studies have highlighted it as being significant, and thus this thesis makes an important contribution to the literature by

demonstrating the nature and significance of identity work in young people with diabetes defined as disengaged.

In a study of young people with diabetes between the ages of 16 and 22, living in the UK, using interpretative phenomenological analysis, Schur and colleagues (1999) reported that young people created identities which were separate from the condition. These identities were considered to be 'normal' and thus valued by others, particularly their peers. This was proposed to be a self-protective strategy to maintain a 'normal' identity, rather than one which was dominated by diabetes.

A desire to be 'normal' has been identified as being important for young people with a variety of chronic conditions, including diabetes (Taylor et al, 2008). The strive for normality has been described as comprising a range of strategies, including avoiding dwelling on the condition and its potential limitations, avoiding comparisons with others without chronic conditions and in some cases resisting aspects of chronic illness self-care that are seen to mark young people out as being different from their peers. The importance of normalising for diabetes self-care is further explored in chapter 4.

When asked about whether diabetes had impacted their overall identity, participants in Schur et al's study stated that it had not but acknowledged that aspects of their identity had been influenced by the condition (Schur et al, 1999). Interestingly, all of the aspects discussed by participants were positive and arguably socially acceptable. For example, working harder because of wanting to prove that diabetes did not hold them back from being successful. This relates to the public and private accounts discussed earlier in this chapter whereby young people with chronic conditions may provide a different public account of how their condition affects them, which contrasts with the way that it affects them privately (Kelly and Field (1996). This makes identity particularly challenging to study in young people with diabetes and other chronic conditions.

Schur and colleagues also found that participants often employed stigma management by not disclosing their condition to others, thus seeking to maintain their identity as a healthy person. Participants' fear of stigma caused them more anxiety than directly facing a situation in which their condition was revealed to others. Schur and colleagues suggest that this fear is so pervasive in young people with diabetes because it represents a fear of identity being discredited and thus experiencing the 'loss of self' described by

Charmaz (1983) in adults with chronic conditions. It is unclear, however, whether this fear of the 'loss of self' impacts upon self-care behaviour. Interestingly, not all participants perceived disclosing their condition as being a threat to their identity. For some young people, it served as a self-protective strategy because it ensured that the people who were closest to them were informed about the condition. As this research focused on young people who were white and in higher education, it is possible that the views of participants are not representative of young people from other backgrounds. Nonetheless, this research makes an important contribution to the limited literature on the role of identity within diabetes self-care.

Similarly to Schur et al (1999), Foster (2010) in a study of young people with type 1 diabetes between the ages of 12 and 15 living in the UK, using interpretative phenomenological analysis, also found that establishing a balanced relationship with diabetes was central to their experience in living with the condition. This was described by Foster as 'externalisation', encapsulated by the phrase 'the person is not the problem, the problem is the problem' (White and Epston, 1990). This involves distancing the self from the condition, to the extent that it is perceived as being a separate entity, rather than being part of identity. Instead of being a 'diabetic', participants considered themselves a 'person with diabetes' (Knight et al, 2003). Knight and colleagues found that externalisation, an aspect of narrative therapy, along with motivational interviewing techniques, helped young people reduce the threat of diabetes to their identity and feel that they were more in control.

In contrast to externalising, other research has highlighted the importance of incorporating diabetes into identity in young people with diabetes. Commissariat et al (2016) studied young people with type 1 diabetes between the ages of 13 and 20, living in the USA, using thematic analysis. Authors reported that participants who incorporated diabetes into their identity viewed self-care as being an active and necessary aspect of their daily lives. Mastery of medical self-care behaviours was cited as being an important catalyst in accepting diabetes and incorporating it into identity. This process was described as being important in managing the negative reactions from others towards diabetes. Young people who had incorporated diabetes into their identity took an active role in social situations, disclosing their diagnosis readily and educated others about their illness.

Results by Commissariat et al (2016) appear to conflict with those of Schur et al (1999) and Foster (2010) who reported that young people wished to distance diabetes from their identity in an attempt to maintain a sense of normality and mitigate stigma. However, Commissariat et al did not find all participants incorporated diabetes into their identity. Authors also reported that some participants attempted to place limits around diabetes. For these young people, diabetes was not fully integrated into their identity and instead diabetes was perceived as being a separate entity from their identity. Such participants described a struggle to accept diabetes and struggled to maintain consistent with diabetes self-care. In some cases, young people described deliberate medical self-sabotage by overeating and/or not correctly dosing their insulin. These participants were much less likely to disclose diabetes towards others and perceived diabetes as being a significant threat to their identity and sense of normality.

Interestingly, identity work has been found to be gendered (Commissariat et al, 2016). Authors reported that males were more likely to describe a containing approach, keeping diabetes outside their identity. In contrast, females were more likely to articulate integrating diabetes into their identity, disclose diabetes more readily to others and receive more support from friends and family. The participant sample was more diverse than most other studies of young people with diabetes, including those from black or African American backgrounds, White or Caucasian, Asian and Hispanic or Latino. This may also account for the finding of different types of identity work in participants. However, ethnicity of participants was not incorporated into the analysis and was not reported for each gender, it is thus unclear whether ethnicity was associated with different types of identity work.

Foster (2010) also reported that young people were engaged in a process of learning to live with diabetes, without making it 'the main thing' (Foster, 2010). This confirms the findings by Schur et al (1999) that young people felt diabetes should not become the top priority in their lives and those by Commissariat et al (2016) that diabetes should be contained within limits. The process of shifting the prioritisation of diabetes has been described as 'growing up as a diabetic' (Paterson and Sloan, 1994). When newly diagnosed, young people follow strict routines and allow diabetes to dominate their lives but over time adapt their medical self-care behaviour to better fit within their lives. The final stage in this process, termed 'adulthood', is proposed to occur once young people acknowledge that perfection is not possible because of the inherent

unpredictability of diabetes. This suggests that identity work may be a fluid process in young people with diabetes, rather than integrating or distancing being mutually exclusive.

Feeling different from peers was also described by Foster, a finding that remains consistent in the literature on young people with diabetes (Schur et al, 1999; Dickinson & O'Reilly, 2004). The young people in Foster's study attributed this sense of difference to self-care behaviour and to the way in which the condition required them to have a more responsible and adult perspective towards their lives. This sense of difference seems to impact sense of self, whereby being diagnosed with diabetes transforms young people from being 'normal' to becoming a 'diabetic' (Foster, 2010). This transformation is characteristic of the process of 'biographical disruption' that is described in adults with chronic conditions (Bury, 1982).

Participants in Foster's study also described a struggle with deciding about disclosing diabetes to others due to concerns about the perceptions of others. Similarly to Schur et al (1999), young people described a fear of being unacceptable to others, judged, or stigmatised if others knew about diabetes and were thus often reluctant to disclose their condition to others. An example of the stigma management strategies of 'information management' or 'covering' (Goffman, 1963). In contrast with Schur et al (1999), participants did not describe disclosure as being a self-protective strategy, which Foster suggests may be due to the younger age of participants in her study compared to Schur and colleagues.

Positive identity-related benefits of living with diabetes were also described by participants in Foster's study. Examples included becoming more organised, determined or confident. Focusing on these positives were helpful in making diabetes easier to live with for young people, a finding also reported by Schur et al (1999). This emphasises the importance of adopting a salutogenic approach to the study of diabetes self-care, people whereby there is an effort to explore both the positive and negative aspects for young people. Similarly to Schur et al (1999), participants were all white and thus findings may not be representative of young people from other backgrounds. There is thus a need to investigate the role of identity in diabetes self-care in young people from non-white backgrounds. This thesis addresses this gap in the literature by interviewing a

group of ethnically diverse young people living in North and East London, the findings of which are presented in chapter 5.

The idea of a tension between engaging in medical self-care behaviour and being a young person has been discussed by Fonte and colleagues (2017). Their research focused on young people aged between 12 and 17 with type 1 diabetes, living in France. Authors propose that the medical aspects of diabetes self-care demand an adult identity and that medical self-care education represents an emancipation from the identity of a young person. Engagement in medical self-care requires the adoption of a long-term perspective, one that is at odds with the hedonistic and instant gratification desires expressed by participants. For young people with chronic conditions, there is a need to integrate the illness into identity but also to assume aspects of an adult identity in order to maintain self-care of their condition. It is suggested that this represents a perceived obstacle to wellbeing by young people with chronic conditions who desire to build and maintain their identity as a young person (Fonte et al, 2017). Interestingly, a comparative study of young people with and without diabetes reported that young people with diabetes perceived themselves to be more adult than did those without diabetes (Luyckx et al, 2011). This suggests that living with diabetes is inextricably linked to the adoption of a more adult identity.

Fonte and colleagues described the difficulty participants experienced in expressing their views and experiences during the interviews. This may be due to the unconscious nature of identity work, which makes research on this topic particularly challenging. Authors suggest that the use of visual aids may be helpful in allowing participants to more easily express themselves, a technique which was used in the current research (see chapter 5). Nevertheless, in light of the limited research on the role of identity within diabetes self-care, this study makes an important contribution to the literature.

2.14 Self-care in young people defined as disengaged

A limited amount of research has explored diabetes self-care amongst young people defined as disengaged from diabetes self-care. Such research has tended to adopt a deficit approach, focusing on deficiencies in young people. This thesis provides an alternative to this dominant paradigm, and instead adopts a salutogenic approach to explore diabetes self-care in young people defined as disengaged, which acknowledges

the capabilities of young people and conceptualises them as autonomous agents, able to make informed choices about their diabetes self-care.

Boman et al (2015) explored perceptions of diabetes self-care in young people with type 1 diabetes between the ages of 13 and 18 living in Sweden using phenomenography.. Participants were defined as being 'adherent' or 'non-adherent' to the medical aspects of diabetes self-care based upon their interview responses. Knowledge of medical self-care did not vary amongst young people with differing levels of engagement with these self-care behaviours. Boman and colleagues reported that both 'adherent' and 'non-adherent' participants demonstrated a high level of knowledge about diabetes self-care and a desire to maintain medically optimal diabetes self-care practices. As this study used a clinically-based convenience sample, the views and experiences may not have represented those who are disengaged from diabetes services. Nevertheless, this research adds to existing literature which has suggested that knowledge is necessary but not sufficient to promote engagement with the medical aspects of diabetes self-care (Huus and Enskar, 2007 and Damiao and Pinto, 2007). This suggests that exploring self-care in a more holistic way may be a more fruitful endeavour than a narrow focus on the medical aspects of self-care. This is achieved in this thesis by the adoption of a salutogenic approach, which acknowledges the importance of both health and wellbeing and conceptualises people as individuals rather than patients.

Knowledge about diabetes was also found to be similar amongst young people with differing HbA1c levels by Scholes et al (2012) who studied young people between the ages of 11 and 22 with type 1 diabetes living in the USA. Participants demonstrated an awareness of future health complications associated with a lack of engagement in diabetes self-care. However, differences were found in the perceptions of the curability of diabetes. Those with lower HbA1c levels did not think that there would be a cure for diabetes whereas those with higher HbA1c levels envisaged a cure for diabetes within their lifetime.

Differences in engagement in diabetes self-care between young people with differing HbA1c levels were also reported by Scholes and colleagues. Those with high HbA1c levels reported avoiding diabetes self-care activities whereas those high low HbA1c levels described taking responsibility for their own diabetes self-care, which they had done since a young age. A particularly notable difference was the awareness of

carbohydrate counting between participants. Carbohydrate counting involves determining the amount of carbohydrates within a particular food in order to calculate the amount of insulin required. Young people with high HbA1c levels perceived carbohydrate counting as being unnecessary and instead guessed the amount of insulin needed by how their body felt. Those with low HbA1c levels reported that they had integrated carbohydrate counting into their daily routine and took it into consideration when planning and preparing meals. However, many participants described understanding how to count carbohydrates and calculate insulin in order to maintain stable blood glucose levels. The small sample size of 14 means that results should be interpreted with caution. Nevertheless, this research provides further evidence that knowledge is not significant in determining engagement in medical self-care and thus there is a need to consider the wider influences and context of self-care in young people (Boman et al, 2015; Huus and Enskar, 2007 and Damiao and Pinto, 2007).

Knowledge of both the short and long term consequences of diabetes self-care was also found to be unrelated to diabetes self-care behaviour by Leonard et al (2005), who studied young people with type 1 diabetes between the ages of 14 and 16 living in the USA using a qualitative content analysis approach. Similarly to Scholes et al (2013), authors compared young people with high and low HbA1c levels. It was found that despite knowledge of the consequences of not engaging in the medical aspects of diabetes self-care, including causing frustration to parents and increasing the risk of future health consequences, young people with high HbA1c levels regularly avoided diabetes self-care behaviours. This included avoiding testing their blood glucose levels as well as missing insulin injections and meals.

Differences were apparent in young people's desire to take responsibility for their condition (Leonard et al, 2005). Young people with low HbA1c levels were more positive about gaining freedom from their parents in terms of diabetes self-care and were enjoyed a sense of independence. Young people with high HbA1c levels felt less positive about taking on more responsibility for their diabetes self-care and described this as being a decision led by their parents rather than themselves. These participants also described experiencing conflict with their parents about diabetes self-care, which was not reported by participants with low HbA1c levels. It is unclear from this research whether parental conflict represents a cause or consequence of avoidance of medical self-care activities. Nevertheless, this study highlights the wide ranging consequences of

medical self-care behaviour, both for young people themselves as well as those around them.

The significance of identity work has been highlighted in studies comparing young people with differing levels of HbA1c levels and/or different levels of engagement with medical self-care. Scholes et al (2013) reported that the experience of being diagnosed also varied between participants. For those with low HbA1c levels, the diagnosis was readily accepted. Amongst participants with high HbA1c levels, the initial diagnosis was described as being traumatic and as something which had not been fully accepted. This highlights the significance of the time of diagnosis for beginning the process of identity work whereby the role of diabetes within identity is negotiated. The results of Scholes and colleagues suggest that such identity work has long-lasting consequences of the medical aspects of diabetes self-care behaviour and thus the risk of future health complications.

The significance of integrating diabetes into identity was also highlighted by Boman et al (2015). It was found that those who were 'adherent' had integrated diabetes into their identity whereas those who were 'non-adherent' tended to view diabetes as something external to themselves over which they had little control. These differences in perceptions translated into different approaches to medical self-care. Participants defined as 'adherent' had integrated this self-care into their daily lives. These young people attributed this to their responsible personality, their satisfaction in taking responsibility for their medical self-care and their inability to forget diabetes. The 'non-adherent' group perceived personality as limiting their ability to engage in medical self-care consistently. Furthermore, this group perceived that it was normal for young people to disengage from this self-care.

These results suggests that helping young people integrate diabetes into their sense of self plays an important role in promoting engagement with the medical aspects of diabetes self-care. This appears to be conflicting with the findings of Balfe (2009) and Brouwer et al (2012) who reported that strengthening non-diabetes aspects of identity and distancing from diabetes as being important to manage the emotional aspects of diabetes self-care. Identity work thus seems significant for young people disengaged from medical self-care and/or services but it is unclear how these different types of identity work relate to each other and the mechanisms by which they might influence

diabetes self-care. This thesis explores experiences of diabetes self-care in young people with diabetes defined as disengaged, including the role of identity work within their experiences. In light of the limited research which has investigated the significance of identity work in diabetes self-care in young people, and the deficit approach that has tended to be adopted when studying those defined as disengaged, this thesis makes an important contribution to the existing literature.

2.15 Concluding comments for this chapter

This chapter has outlined the traditional conceptualisation of children and young people in theory, research and practice, which is indicative of a deficit approach where young people's competencies are not acknowledged. In light of the lack of effectiveness of education-only interventions and research documenting the wide range of influences on diabetes self-care, it is clear that a more holistic approach towards diabetes self-care in young people is required.

This thesis offers this holistic approach through the adoption of salutogenesis, which aims to understand diabetes self-care in young people within the context of their daily lives. In particular this thesis focuses on those defined as disengaged from diabetes self-care and/or diabetes services. Some previous evidence suggests that issues surrounding identity may be particularly relevant to this population, which is further explored in chapters 4, 5 and 6. In addition, a large amount of research is focused on young people who are white, from affluent backgrounds and with type 1 diabetes only. This thesis adds to the literature through the inclusion of participants living in ethnically-diverse areas in London. The next chapter will describe the methods used in this thesis to explore diabetes self-care in young people from a salutogenic perspective.

Chapter 3: Methodology

3.1 Overview of this chapter

This thesis explores experiences of diabetes self-care in young people defined as disengaged from diabetes services and/or diabetes self-care. This chapter provides the methodology used in this exploration and the rationale for these methods. Firstly, this chapter outlines the qualitative approach of the research. This is followed by outlining the methods of the three stages of the research, including the sampling, data collection and analysis. Finally, the rationale for these methods is discussed.

As stated above, there are three stages of the research. The first stage comprises a qualitative systematic literature review on the experiences diabetes self-care in young people. The second stage involves qualitative systematic interviews of young people between the ages of 10 and 25 with either type 1 or type 2 diabetes living in North or East London in the UK who are defined as disengaged from diabetes services and/or diabetes self-care. The third stage entails qualitative interviews with young people with diabetes who participated in salutogenic projects.

As mentioned in chapter 1, this thesis is embedded within a larger National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) funded project applied study entitled ‘Co-designing diabetes services responsive to the needs of children and young people.’ This is an applied qualitative study and adopts a participatory salutogenic approach, working with young people to improve diabetes services in Newham in East London.

3.2 A qualitative salutogenic approach

In this thesis I explore the experiences of diabetes self-care in young people from a salutogenic perspective using qualitative methods. Salutogenesis (Antonovsky, 1979) is adopted in this thesis to investigate diabetes self-care in young people from a holistic perspective, acknowledging the context in which diabetes self-care occurs and conceptualising young people as individuals, rather than ‘diabetics’.

As mentioned in chapter 1, salutogenesis can be applied at the societal, group or individual level (Lindstrom and Eriksson, 2005). This thesis focuses on the latter, with an emphasis on the way in which young people use resources to continually navigate

decisions about diabetes self-care. Although salutogenesis acknowledges the societal forces that influence the availability of these resources, the focus is upon how they are used by young people in the context of diabetes self-care.

Antonovsky specified that salutogenesis should not be restricted by the disciplinary borders of one field (Lindstrom and Eriksson, 2005). Instead, there is a focus on bringing coherence between disciplines and the ideas that connect them. This thesis thus adopts a psychosocial approach, exploring the way in young people interact with their social environments, and draw upon resources in the context of diabetes self-care.

Social environments include the three primary settings where children and young people tend to stay within their daily lives: their homes, schools and recreational institutions.. However, it is also important to acknowledge the social relationships, and wider cultural and social contexts that sit in the background of these spaces (Rasmussen, 2004).

In line with this philosophy, qualitative research aims to understand phenomena within their context and understand links between behaviours (Bradley et al, 2007). A qualitative approach is thus most suitable for the current research, which seeks to understand young people's experiences with diabetes self-care in young people within the context of their daily lives. The following section outlines the methods used in the application of this qualitative salutogenic approach.

3.3 Stage 1: Qualitative systematic review

The qualitative review aimed to synthesise existing qualitative research on the experiences of young people with diabetes self-care, particularly young people defined as disengaged from diabetes self-care and/or diabetes services. These were used to inform the subsequent analysis of the qualitative interviews with children and young people with diabetes.

3.4 Research questions

Primary research question:

How do young people experience diabetes self-care?

Lines of enquiry:

- What is known about young people's experiences with diabetes self-care?

- How do different environments influence diabetes self-care?
- How do support networks impact diabetes self-care?
- How does participating in salutogenic projects shape young people's perspectives and practice towards diabetes self-care?

3.5 Scope of the review

This review of qualitative research sought to include papers which explored the experiences of living with diabetes in young people between the ages of 10 and 25, which mirrored the age group of the young people being interviewed about their experiences of diabetes self-care.

In order to explore the experiences of young people in different stages of identity development, a wide age range was used to allow for the investigation of young people who had lived with diabetes for different lengths of time, took varying levels of responsibility for their diabetes self-care and were at a range of stages in their transition from paediatric to adult diabetes services. However, this thesis does not explicitly seek to study the influence of age on diabetes self-care.

Studies conducted in any country were eligible for inclusion, as well as papers which were unpublished (grey literature). Particular efforts were made to include papers that included young people considered to be disengaged from diabetes services and/or diabetes self-care. As the focus is on the experiences of young people with diabetes self-care, the review excluded papers which used quantitative methods and studies which investigated experiences of interventions.

3.6 Inclusion criteria

1. Studies which focus on diabetes of any type (the studies may include other chronic conditions in addition to diabetes)
2. Studies which include young people as participants (ages 10-25)
3. Studies which use qualitative methods
4. Primary studies
5. Studies conducted in any country

Records identified from all searches were assessed by hierarchical exclusion criteria. The criteria were tested and amended after piloting it on a sample of the studies. Initially references were screened on the basis of the title and the abstract. Three reviewers conducted screening on a sample of 10% of the references and differences were resolved via discussion. Once a high level of reliability is achieved, defined as 80% agreement between reviewers, reviewers independently conducted screening on the remaining studies. The percentage of agreement is calculated by dividing the number of agreements by the total number of studies in the sample.

Following completion of coding on the basis of the title and abstract, full texts of included studies were acquired. Access to full text studies was provided by subscriptions to journals by the University of East London. The University of East London also sought to obtain full-text papers of references in journals that are not subscribed to, via an inter-library loan system. All full text references were screened by three reviewers, with disagreements resolved via discussion.

3.7 Search strategy

- Databases searched: Psychinfo, Academic Search Complete, CINAHL, Scopus, PubMed and Science Direct.
- Backward and forward citation searches were performed using Google Scholar in order to ensure extensive coverage of the evidence base.
- If necessary the authors were asked to provide a more thorough report of methodology/findings of their study.

3.8 Data management

EPPI-Reviewer 4 (ER4) (Thomas et al., 2010) was used for management, analysis and data extraction of the references. ER4 is a web-based systematic review program, which supports the review process. It enables bibliographic citations to be downloaded, inclusion and exclusion criteria to be applied, free text, categorical and numerical data to be recorded and stored and allows both statistical and qualitative synthesis of data. This program also contains functions to compare independent assessments of reports from multiple reviewers. The use of EP4 helped to assure both quality and transparency in the review.

3.9 Data synthesis

Meta-ethnography was used to synthesise the studies, informed by Noblit and Hare (1988). This method involves treating both original ideas from the researchers in the included studies and interpretations of these ideas as data. Noblit and Hare (1988) initially proposed seven steps to synthesising the studies. These include: getting started, deciding what is relevant to the initial interest, reading the studies, determining how the studies are related, translating the studies into one another, synthesising translations and expressing the synthesis. Schutz's (1962) notions of first, second and third order interpretations were also used, consistent with a number of published meta-ethnographies (Atkins et al, 2008). The term first order interpretations refers to the perceptions of the participants in research studies. Second order interpretations refer to the explanations of the researchers of research studies. Third order interpretations refer to interpretations of the author explanations. In this research, the third order interpretations are therefore generated myself. These third order interpretations are used to generate the final 'line of argument' synthesis of a meta-ethnography. The following section details the methodology of the meta-ethnography, structured according to Noblit and Hare's seven steps of meta-ethnography.

3.10 Review procedure

Step 1: Getting started

In preparation for the qualitative systematic review, I developed a protocol, informed by the literature on conducting qualitative systematic reviews and my experience in conducting a prior systematic review of reviews. The qualitative systematic review protocol specified the review aims and research questions, inclusion and exclusion criteria, data extraction criteria, synthesis methods and quality assessment criteria. The protocol was submitted to the information specialist to assist with the literature searches, along with sample papers to be included in the review, which fitted with the research questions and aims of the qualitative review. These papers included participants defined as disengaged from diabetes self-care or diabetes services, as the review specifically sought to include these individuals, who typically lack of voice in the research literature.

This involved discussion with an information specialist who carried out the literature searching, including the identification of sample papers which included this target population. The term disengaged was not always explicitly used in these sample papers.

Some papers used the terms ‘marginalised’ or ‘non-adherent’. As discussed in chapter 1, the focus of this thesis is on the experiences of young people defined as disengaged and thus ethnicity was not an explicit criterion for inclusion or exclusion in this qualitative review.

Step 2: Deciding what is relevant to the initial interest

Following the completion of the literature searches by the information specialist, the next stage of the qualitative systematic review involved screening on title and abstract using hierarchical inclusion and exclusion criteria. These ensured that the studies included in the review were able to address the aims and research questions of the review. The inclusion criteria included: studies which focused on diabetes of any type, studies which included children and/or young people as participants (ages 10-25), studies which use qualitative methods, primary studies and studies conducted in any country. Exclusion criteria included studies not focused on diabetes, studies where participants were all under the age of 12, studies which were not primary research, studies not utilising qualitative methods, studies not focused on experiences, studies and studies not available in English. A total of six databases were searched including: Psychinfo, Academic Search Complete, CINAHL, Scopus, PubMed and Science Direct. Specific search terms were used, which are detailed in the appendices. Backward and forward citation searches were performed using Google Scholar in order to ensure extensive coverage of the evidence base. Access to full text was provided by subscription to journals by the University of East London. The University was able to obtain full-text papers of references in journals that are not subscribed to, via an inter-library loan system.

There were initially 3385 references imported into Eppi reviewer following the searching of databases. Following screening on the basis of title and abstract, exclusions were made on health condition, population and research type, leaving 366 references remaining in the review. Screening on full text resulted in 93 studies being included in the review. At this stage it was clear that the number of studies eligible for inclusion in the review was remaining high. It was therefore decided that it was necessary to reduce the number of studies to a manageable number. The criteria were determined by considering which types of studies would be most relevant to the research questions of

the review and to the rest of my thesis. Three exclusion criteria were applied: studies where participants were all under the age of 12 and studies adopting a deficit approach.

Studies adopting a deficit approach were defined as studies which conceptualised young people as being passive and/or 'a problem'. This decision was made based upon the framing, language and assumptions made by the authors of the papers.

For example, a study which problematised young people's decision to consume alcohol, because of its potential to affect glycaemic control, rather than exploring its potential role in young people's social wellbeing. Another study was excluded which framed some of young people's responses to the challenges of living with diabetes as 'maladaptive'. A further example is a study that made the assumption that a diagnosis of diabetes in a female during adolescence will 'have disastrous effects on her life'.

It was felt that such studies did not fit with the adoption of a salutogenic approach in this thesis, which conceptualises young people as active agents, capable of making decisions about their own diabetes self-care. Furthermore, these studies were not deemed to be useful in determining how best to support young people with diabetes and thus these studies were excluded from the review. Following the application of these exclusion criteria, 45 studies remained in the review.

Purposeful sampling:

At this stage, it was decided to employ purposeful sampling strategies in order to reduce the number of studies included in the review to a manageable number and to ensure that a comprehensive understanding of the experiences of young people with diabetes could be obtained. Patton (2002, p.230) provided a definition of purposeful sampling as 'selecting information-rich cases for study in depth', which are chosen in order to facilitate 'in-depth understanding rather than empirical generalizations'. The current study employed one of these strategies: intensity sampling. Suri (2011) describes the aim of intensity sampling as developing a comprehensive understanding of the phenomena that has been researched in the synthesis. Intensity sampling was chosen for use in the current PhD project because of the consistency of the aims of these strategies with the aim of the qualitative systematic review. In the current qualitative systematic review, the aim was to gain a comprehensive and nuanced understanding of experiences of diabetes self-care in young people.

It was decided to implement purposeful sampling, informed by Benoot et al (2016). There are few examples in the literature of purposeful sampling in qualitative reviews and Benoot and colleagues is one of the few studies to provide a worked example of how to implement these strategies. Although the exact steps were not followed prescriptively in this thesis, the principles were used to inform the decisions made. Benoot and colleagues made clear that their intention of their paper was not to provide an exact recipe of how to conduct a meta-ethnography, but instead was to offer a worked example in order to help researchers make decisions about purposeful sampling in a more systematic and transparent way, which was the goal in this thesis. Benoot et al (2016) employed three purposive strategies sequentially, starting with intensity sampling, which was followed by maximum variation sampling. It was therefore considered appropriate to start with intensity sampling before applying any additional sampling strategies. The 45 articles remaining in the review were purposefully sampled, which involved selecting studies that were particularly rich examples of studies exploring the experiences of young people with diabetes.

Inclusion and exclusion decisions were informed by Benoot et al (2016) who propose a need to translate the theoretical definition of intensity sampling into concrete inclusion factors. The first inclusion factor was the amount of overlap between the research question of the particular article and the research questions of the current qualitative synthesis. This was to ensure that the article would provide relevant content for the meta-ethnography. For the current study, the article needed to provide a rich exploration of the experiences of young people with diabetes. The second inclusion factor was the conceptual clarity of the article (Toye et al, 2013). Conceptual clarity refers to the presence and transparency of concepts to enable translation across studies, which is an integral aspect of meta-ethnography. The concepts within the papers thus needed to be easily identifiable and well developed in order to be able to be summarised and compared with emerging concepts from other studies in the review. Studies lacking clarity and/or depth of concepts were thus excluded from the review.

Conducting the purposeful sampling strategies resulted in 32 articles being excluded from the review, leaving 13 studies in the review. This resulted in a feasible number of papers for data extraction to take place. The limited number of included studies also facilitated a thorough exploration of the phenomena of interest, namely the experiences

of diabetes self-care in young people. It was therefore deemed appropriate to stop sampling at this stage and move onto the data extraction process.

Data extraction was completed for the 13 included studies. Data on the characteristics of the study and the sample, the methods implemented by researchers and findings relevant to the review research questions were extracted. The form comprises an amended version of the data extraction form used by Curtis-Tyler and colleagues (2015) and can be found in appendix 2.

A quality assessment was also conducted on all included studies using criteria described by Rees et al (2011) in their qualitative systematic review. The assessment tool was selected because it is ideally suited to qualitative reviews of studies focusing on experiences. The quality assessment tool contains eight questions, with guidance provided for reviewers. The quality assessment tool assesses rigour (in sampling, data collection and analysis), whether the findings of the study were supported by the data, breadth and depth of the findings, extent that study privileged views of children and young people, perceived trustworthiness/reliability of findings and perceived usefulness of findings for the current qualitative review. Studies were rated as low, medium or high in quality after applying these criteria. The quality assessment was not intended to exclude studies but instead to inform the synthesis. However, as a result of the use of the inclusion factor of conceptual clarity in the purposeful sampling procedure, only those which were rated as being high in quality were included in the final synthesis. The quality assessment tool used can be found in the appendix 1.

Step 3: Reading the studies

Once the final number of studies to be included in the review was determined, the studies were re-read a number of times. It was initially intended to search for the first order interpretations in each of the included studies but in practice it became difficult to distinguish the first and second order interpretations from each other, a problem also described by Atkins et al (2008). It was therefore decided to first generate a list of second order concepts from each study and then to look for first order interpretations which were described by authors as representing each of the interpretations. A table was produced, detailing descriptive information about the studies, obtained from the data extraction in step 2, as well as the second and first order interpretations found within each study. This was important to clarify the findings of each of the studies as well as

preserving the context for these findings. A table of the second and third order concepts can be found in appendix 3.

Step 4: Determining how the studies are related

This involved comparing the second order interpretations across the studies, looking for both similarities and differences between them. The first order interpretations were used to help clarify the meaning of each second order construct, as well as clarify the relationship of the studies to one another. During this stage, there was frequent movement between the tables detailing the interpretations and re-reading the original studies to ensure that the interpretations were represented within the studies and to check for any further interpretations that had not been acknowledged when reading the studies previously. Similar ideas across the studies were highlighted to indicate that they were related to one another and could be subsequently translated into each other. During this stage, consideration was given to ideas which seemed oppositional to each other.

Step 5: Translating the studies into one another

This involved grouping the related second order constructs across the studies and considering which concept would best represent these related ideas. The first order constructs were used to help clarify the essence of the second order constructs. Papers were also re-read a number of times to ensure that the context of the studies was maintained. This process resulted in the identification of six concepts: identity, disclosing, disruption, support, independence and sense of control. All of these concepts were explicitly addressed in at least one of the studies, as described by Britten et al (2002). For example, disclosing was used in a number of studies to describe the process of young people telling others about their diagnosis of diabetes. However, sometimes different terminology was used to describe a concept. For example, within the concept of independence, some studies described 'taking responsibility', 'autonomy' or 'self-reliance'.

Step 6: Synthesising translations

This stage involved determining the key ideas, comprising the third order interpretations, within each of the six concepts. The second order interpretations and

corresponding first order constructs within each concept were read a number of times in order to determine the way in which they addressed the concept. A list of third order interpretations was then composed for each study within each of the six concepts. During this stage, reflection also took place about whether each of the second order interpretations belonged to that particular concept or whether it was more suited to another concept. First order interpretations were used to help clarify ideas both within and across the studies. Once the table was completed, consideration was given to whether the second order interpretations were refutations of each other (described contrasting ideas related to each concept) or were reciprocal (described the same idea related to a concept). It became clear that the relationships between the interpretations was reciprocal.

The next step involved highlighting the related third order constructs from each of the studies within each of the six concepts. From these related constructs, the essence of each of the concepts was able to be determined. This comprised two or three key ideas which were captured by the third order constructs, which clearly expressed a key component of the concept. For example, the concept identity was described as comprising two key ideas: 'being' identity and 'doing' identity.

Following the establishment of the concepts and the key ideas within each concept, it was necessary to determine how the concepts were related to one another. This process involved considering the third, second and first order interpretations generated from each of the studies within each concept and considering how they related to the other concepts. Whilst completing this task, it became clear that the dominant concept which seemed to be related to all of the other concepts was identity. Several different mind maps of all the concepts were drawn out to test various ways that the other concepts may have been related to the main concept. These different mind maps were then related back to the third, second and first order interpretations, to see which best fitted the data. At the end of this process it became clear that the five concepts were either threats to identity, validators to identity. Once this was determined, this was drawn out in a visual form and consideration was given to the line or argument which was expressed by the concepts and their relation to one another. The line of argument produced was 'Normalisation of identity is an ongoing process'. This characterises the ongoing process of 'identity work' whereby young people with diabetes seek to

integrate diabetes into their self-concept ('being' identity) and diabetes self-care ('doing' identity) into their daily lives.

Step 7: Expressing the synthesis

Chapter 4, which reports the findings of this meta-ethnography comprises one way of expressing the synthesis of this meta-ethnography. Potential audiences for this synthesis include practitioners (doctors, nurses and pharmacists), policy-makers and qualitative researchers. Practitioners may be interested in the clinical applications of the findings from this meta-ethnography, policy-makers in the potential generalisability of the findings and qualitative researchers in the methodology used for this synthesis as well as questions that are raised for future research studies.

3.11 Stage 2: Qualitative interviews with young people with diabetes

The second stage of the research comprised interviews conducted with young people with diabetes between the ages of 10 and 25. These interviews were carried out as part of the project in which this thesis is embedded entitled 'Co-designing diabetes services responsive to the needs of children and young people', funded by North Thames CLAHRC, as described in chapter 1. The CLAHRC project focuses on experiences of diabetes services in young people. The qualitative analysis of these interviews aimed to explore diabetes self-care in young people defined by clinicians as disengaged from diabetes services and/or diabetes self-care. These interviews investigated the influences upon their diabetes self-care and the way in which these findings can be used to better support young people with diabetes.

3.12 Research questions

Primary research question:

How do young people experience diabetes self-care?

Lines of enquiry:

- How do different environments influence diabetes self-care?
- How do support networks impact diabetes self-care?

3.13 Aims

The qualitative interviews aimed to explore diabetes self-care in young people defined by clinicians as disengaged from diabetes services and/or diabetes self-care. These interviews investigated the influences upon their diabetes self-care and the way in which these findings can be used to better support young people with diabetes.

3.14 Interview participants

Semi-structured qualitative interviews were conducted by the CLAHRC research team with young people between the ages of 10 and 25 who had a diagnosis of either type one or type two diabetes living within North or East London. The aim was to include participants from an age where they begin to take more responsibility for their own diabetes self-care through to an age where they are considered to be an adult. The transfer of responsibility for diabetes self-care from parents to young people typically occurs in parallel with the transition from paediatric to adult diabetes services. The age of at which both of these processes occur varies and thus the wide age span allowed for the exploration of a range of experiences with these significant time points.

3.15 Interview sampling

The CLAHRC project particularly sought to include those defined as disengaged from diabetes self-care and/or diabetes services. Purposive sampling was used, which is a non-random method of sampling designed to sample a group of individuals with particular characteristics (Bowling, 2002). Qualitative research primarily, although not exclusively, employs non-probability sampling techniques (Murphy et al, 1998). In this thesis, clinicians were asked to identify young people registered to their clinic that they would consider to be disengaged from diabetes services and/or diabetes self-care. The exact criteria used to determine disengagement was left for clinicians to decide, which allowed for a range of types of disengagement to be represented in the interview sample. For example, the inclusion of participants who did not regularly attend clinic but also those who did attend but did not take an active role during appointments.

All interview data collected as part of the CLAHRC project was included in the current analysis. However, in this thesis, the interview sample was split into two groups. Both groups contained young people living in North or East London, who were defined by clinicians as disengaged from diabetes services and/or diabetes care. The findings from the first group of interviews are discussed in chapter 5. The second group comprised a subset of these young people who had participated in salutogenic projects. The findings from the second group of young people are presented in chapter 6.

3.16 Interview recruitment

Recruitment for these interviews for the CLAHRC study took place following obtaining NHS Ethical approval by contacting two Diabetes Clinicians, one in East London and one in North London. Clinicians provided an information sheet for patients eligible to take part in the study. Eligibility criteria included living within North or East London, being between the ages of 10 and 25 and having a diagnosis of either type one or type two diabetes.

Clinicians were asked to approach those who they would define as disengaged from diabetes service and/or diabetes self-care. If the child or young person was interested in taking part, they provided permission for their details to be passed onto the CLAHRC research team. The research team then contacted the child or young person by telephone, to check eligibility, to provide more background information about the rationale and content of the interview before asking if the child or young person would be willing to take part. This was done in two batches: the first batch of interviews was conducted in East London and the second batch was conducted in North London.

Interviewees were provided with copies of the interview information sheet, consent form and interview schedule ahead of the interview, if requested. Participants were able to choose where the interview would be conducted: in their home, at the University of East London or at another location of their choosing. They also selected a time and date that was most convenient for them. Participants were also informed that they would receive a ten pound shopping voucher as an incentive for taking part and that the interview would last between one and one and a half hours.

3.17 Ethical issues

The CLAHRC research team obtained NHS Ethical approval for conducting these qualitative interviews. The team clearly explained to participants that participation was completely voluntary and that they were free to terminate the interview at any stage and withdraw completely if they choose. They were also assured that choosing to take part and the content of the interview would have no impact on the diabetes care that they receive. Informed consent was sought for all participants, as well as parental consent for participants below the age of 16. The interview sheets and consent forms were clearly explained to participants to ensure that they were fully informed about the nature of the interview and what would happen to the interview data. All participants also had the opportunity to ask any questions before deciding to participate. Participants were told that the interview data would remain confidential unless they disclosed information suggesting that either they or another child or young person was at risk of harm. In this case, appropriate support was sought by the CLAHRC research team to ensure safety and wellbeing of participants.

3.18 Location and timing of the interviews

All interviews took place either at the home of interview participants or at the University of East London. Participants decided both the time and location of the interview. This was to ensure that the participants were as comfortable as possible within the interview setting and that the timing of the interview was convenient for them. This also helped to

For some interviews conducted in family homes, parents requested to be present. Parental data did not form part of the interview analysis. Most interviews conducted took less than one hour.

3.19 Interview questions

The interview schedule used for the CLAHRC project involved a small number of open-ended questions, consistent with the description of semi-structured qualitative interviews by Willig (2013). The interview schedule included a total of 19 questions, which addressed demographic characteristics, perceptions of diabetes, support networks and experiences with diabetes services. The interview schedule can be found in appendix 7. This schedule was co-produced with young people working as young researchers within the CLAHRC project. The young people helped to develop and pilot

the interview schedule to ensure that questions were accessible for young people, including young people defined as disengaged.

Visual research methods were used in the interviews. These are methods which use visual materials in the data collection process to explore research questions. These methods are diverse in nature, both in terms of the types of visual materials used and the way in which they are used. Recent studies employing visual research methods have tended to use photographs (Gillian, 2014). Other methods have been used, including diagrams (Crilly et al. 2006), relational maps, timelines, self-portraits (Bagnoli 2009), films (Murray 2009; Pink 2007), video-diaries (Holliday 2000), collages (Mannay 2010), maps (Spencer 2011), memory books (Thomson and Holland 2005), drawings (Garner 2008), graphic novels (Galman 2009) and photo-diaries (Latham 2004). Participants in this research were given the option to use the images for particular interview questions, such as describing themselves and how they felt about their diabetes to help stimulate imagination and provide a way to aid communication. Two sets of images were utilised in the interviews, one set contained cartoon images and the other contained photographs. This enabled the research team to tailor the interview to the age and learning abilities of the participants. The images used in the interviews can be found in appendix 8.

3.20 Treatment of interview data

Interviews were audio-recorded with participant consent, which was supplemented by taking notes during the interviews. The recordings and transcripts of the interviews were kept in a secure place and were password protected to ensure confidentiality. Following transcription of the interview data, recordings were deleted. Before reporting the findings from the interviews for both the CLAHRC project and this thesis, data was anonymized to protect the identity of participants.

3.21 Data analysis

This thesis employed a ‘theoretical’ thematic analysis (Braun and Clarke, 2006), which means that the themes identified are driven by the focus of the research, which was diabetes self-care in young people. In addition, the thematic analysis employed in the current research identifies themes at the latent or interpretative level (Boyatzis, 1998). This means that the development of the themes involves interpretative work and goes

beyond merely describing the data, thus producing an analysis that is theorised (Braun and Clarke, 2006).

The thematic analysis in this research consisted of six stages, as described by Braun and Clarke (2006). The process was recursive rather than linear and entailed: familiarising myself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. Analysis involved continual movement between the entire data set (all of the interviews), the coded extracts that were being analysed (aspects of each interview highlighted as being most relevant) and the analysis being produced. Writing formed an integral part throughout the process and was used to 'test' the validity of themes as well as the relationships between themes (Braun and Clarke, 2006). In line with a 'theoretical' thematic analysis, engagement with the literature was conducted prior to beginning analysis. This entailed the general literature review, comprising chapter 2 of this thesis as well as the qualitative systematic review, the findings of which are reported in chapter 4.

The first phase involved reading and re-reading the data, noting down initial ideas. Although the focus of the current analysis was on diabetes self-care, care was taken to become familiar with all aspects of the data (Braun and Clarke, 2006). The second phase entailed generating initial codes from the data, which were ideas from the data which stood out as being most relevant to the research. This phase involved coding as many potential patterns/ themes as possible in order to prevent any aspects of the data being missed and coding extracts exclusively, which meant including the surrounding data to provide context (Braun and Clarke, 2006). During this phase, it became clear that the intended analytical framework, consisting of identifying assets in self-care became restrictive and did not allow for the coding of data articulating the challenges faced by young people. In addition, it did not allow for the investigation of other significant influences upon diabetes self-care which emerged during the data analysis. It was thus decided to apply a salutogenic approach more broadly, which allowed for a holistic exploration of young people's experiences with diabetes self-care, without being reductionist. This allowed for the emergence of themes around identity, which are discussed in chapter 5.

The third phase started when all the data was coded and collated, which resulted in a list of different codes identified across the data set (Braun and Clarke, 2006). The phase

involved analysing the codes and reflecting on how the different codes may combine to form an overarching theme (Braun and Clarke, 2006). This was achieved by grouping the codes into themes and ordering all the relevant coded data into these themes. It is also in this phase that the relationships between different codes and themes was considered, as well as the different components of each theme.

The fourth phase began after a set of candidate themes was produced (Braun and Clarke, 2006). Themes were then refined by rejecting themes that were not well supported by data, collapsing related themes into each other or breaking themes into two or more themes where appropriate. Patton's (1990) concepts of internal homogeneity and external heterogeneity were utilised during this phase. This ensured that all data grouped into one theme was meaningfully related and that there were clear distinctions between each different theme. This phase entailed two levels of reviewing and refining themes (Braun and Clarke, 2006). The first level involved reviewing at the level of the coded data extracts. This required reading all of the collated extracts for each theme and considering whether they seemed to form a coherent pattern. If not, this meant that some of the data may not have fitted within that theme or that the theme itself was problematic. Once the themes were finalised as accurately capturing the data, level two was conducted. This involved a similar process to the first level but across the entire data set. At the end of this phase, a thematic map was produced demonstrating the themes generated and their relationship to each other (Braun and Wilkinson, 2003).

The fifth phase began following the completion of a thematic map of the data. In this phase, the themes were clearly defined and refined in preparation for presentation of the analysis (Braun and Clarke, 2006). This involved determining the 'essence' of what each theme was about as well as determining which aspects of the data were captured by each theme. The relationship of the themes to the research questions were also articulated in this phase. The final phase involved producing a report of the analysis, which is detailed in chapter 5 of this thesis.

3.22 Stage 3: Interviews with young people involved in salutogenic projects

The third stage involved interviews with five young people involved in salutogenic projects, which formed part of the CLAHRC project in which this thesis is embedded. Involvement in salutogenic projects consisted of two roles. Participants were employed as either Young Clinical Commissioners or as a Youth Health Champion. One young

person was employed as a Youth Health Champion and the other four young people were employed as Young Clinical Commissioners. The Young Clinical Commissioners were appointed to help provide input to the recommissioning guidance for diabetes services in East London. The Youth Health Champion was recruited to co-ordinate a weekly peer diabetes youth group for young people in East London. Although the role of the Young Clinical Commissioners and the Youth Health Champion were different, all of the young people attended many of the same activities to help them develop in their respective roles. These activities included task group meetings, workshops, presentations and site visits. These interviews aimed to explore the impact of participating in salutogenic projects on diabetes self-care in young people.

3.23 Research question

- How does participating in salutogenic projects shape young people's perspectives and practice towards diabetes self-care?

3.24 Interview participants

A total of five young people were interviewed, four young Clinical Commissioners and one youth Health Champion. As the research sought to interview all young people in these roles, interview sampling was unnecessary.

3.25 Interview recruitment

Recruitment took place following obtaining approval from the Ethics committee at the University of East London (UREC). All the potential interview participants had already been recruited onto the CLAHRC project were thus already known to me. I also already had contact details for participants as a result of involvement in these projects.

All interviews were contacted by telephone to provide details about the rationale and content of the interviews and to ascertain whether they were interested in taking part. The young people were provided with information sheets and consent forms, sent via email, which they were able to read in their own time before providing consent to participate. The interview sheets and consent forms were clearly explained to participants to ensure that they were fully informed about the nature of the interview and what would happen to their interview data. Participants also had the opportunity to ask any questions before deciding whether to participate.

3.26 Ethical issues

All participants were over the age of 16 so were able to provide their own consent. It was made clear to the young people that their decision about whether to participate would have no influence on their diabetes care or their roles in the salutogenic projects. They were also informed that they were free to terminate the interview or withdraw from the research completely, without having to provide a reason. Participants were informed that they would receive a ten pound shopping voucher as an incentive for taking part and that the interview would last for no longer than one hour. Participants were also told that the interview data would remain confidential unless they disclosed information suggesting that either they or another child or young person was at risk of harm. In this case, appropriate support was sought by the research team to ensure safety and wellbeing of participants.

3.27 Location and timing of the interviews

The interviews took place at the University of East London (UEL) or a location of the participants choosing. The interviews lasted for approximately one hour each and were scheduled at a time and date that was most convenient for participants. This ensured that the interviews did not disrupt any work or education commitments.

3.28 Interview questions

These interviews adopted a semi-structured approach, where the ordering and wording of questions was altered in order to ensure the collection of relevant interview data and to allow for the exploration of new ideas that arose during the interview process (Willig, 2013). The interviews involved questions relating to their experiences of being involved in the project. The young people were asked to reflect on their reasons for choosing to become involved with the project, what they have learned/ gained from participating, the impact that participating has had in different areas of their lives and in their relationships as well as their reasons for choosing to leave/take time out of the role. The interview schedule consisted on 20 questions, which can be found in appendix 13.

3.29 Treatment of interview data

Interviews were audio-recorded with participant consent, which was supplemented by researcher making notes during the interview. The recordings and transcripts of the interviews were kept in a secure place to ensure confidentiality and were not passed on to anyone outside of the research team. Following transcription of the interview data,

recordings were deleted. Before reporting the findings from the interviews, data was anonymized in order to protect the identity of participants. However, due to the unique nature of their roles, participants were informed that anonymity was not guaranteed.

3.30 Interview analysis

Thematic analysis as proposed by Braun and Clarke (2006) was chosen as the analytic method for these qualitative interviews and followed the same process as stage two of the research. Similarly to stage two, this stage involved a ‘theoretical’ thematic analysis (Braun and Clarke, 2006), which meant that the themes identified were driven by the focus of the research, the experiences of participating in salutogenic project and the impact upon diabetes self-care. This approach meant that the development of the themes involves interpretative work and goes beyond merely describing the data, producing an analysis that is theorised (Braun and Clarke, 2006).

The six stages of thematic analysis described by Braun and Clarke (2006) were used for analysis of these qualitative interviews. These six stages included: familiarising yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report.

Similarly to stage two, analysis involved continual movement between the entire data set, the coded extracts being analysed and the analysis being produced. Writing formed a central part of the analytical process (Braun and Clarke, 2006). In line with a ‘theoretical’ thematic analysis, engagement with the literature was conducted prior to beginning analysis in order to sensitise the researcher to more subtle features of young people’s experiences with diabetes self-care (Tuckett, 2005). This thesis involved a general literature review, presented in chapter 2 as well as a qualitative systematic review, the findings of which are presented in chapter 4.

The first phase involved reading the data a number of times and noting down initial ideas (Braun and Clarke, 2006). The second phase entailed generating initial codes from the data, which are ideas that stood out as being most relevant to the focus of the research. This phase involved coding as many potential patterns/ themes as possible in order to prevent any aspects of the data being missed and coding extracts exclusively, which meant including the surrounding data to provide context (Braun and Clarke, 2006; Bryman, 2001). Extracts of data were sometimes also coded into several different

themes. Both similarities and differences in the data were acknowledged during this stage to include the range of experiences of participants and the impacts of participating in the projects on their diabetes self-care (Braun and Clarke, 2006).

The third phase began after all data was coded and a list had been produced of all codes across the data set (Braun and Clarke, 2006). This phase involved analysing the codes and reflecting on how the different codes combined to form an overarching theme (Braun and Clarke, 2006). This was achieved by grouping the codes into themes and ordering all the relevant coded data into these themes. During this stage, relationships between themes were also considered.

The fourth phase began after a set of candidate themes had been produced (Braun and Clarke, 2006). It was then necessary to refine the themes, excluding those not well supported by data, collapsing similar themes into each other and breaking complex themes into two or more separate themes. Similarly to stage two, Patton's (1990) concepts of internal homogeneity and external heterogeneity were used during this phase. This ensured that each theme included data which were meaningfully related to each other and that there were clear distinctions between each separate theme. This phase entailed two levels of reviewing and refining themes (Braun and Clarke, 2006). The first level involved reviewing at the level of the coded data extracts. This required reading all of the collated extracts for each theme and considering whether they seem to form a coherent pattern. If not, this meant that some of the data may not fit within that theme or that the theme itself is problematic. Once the themes were finalised as accurately capturing the data, level two was conducted. This involved a similar process to the first level but across the entire data set. At this stage, any aspects of the data which seem significant but were not yet been coded were included in the analysis. At the end of this phase, a thematic map was drawn up demonstrating the themes generated and their relationship to each other (Braun and Wilkinson, 2003).

The fifth phase began following the completion of a thematic map of the data. In this phase, the themes were clearly defined and refined in preparation for presentation of the analysis (Braun and Clarke, 2006). This involved determining the 'essence' of what each theme was about as well as determining which aspects of the data were captured by each theme. The relationship of the themes to the research questions were also

outlined in this phase. The final phase involved producing a report of the analysis, which comprises chapter 6 of this thesis.

3.31 Ontology and epistemology of this thesis

This thesis is located within a pragmatist paradigm. Issues of meaning and language form a central part of pragmatism, as well as an emphasis on the interactions that individuals use to negotiate these issues (Morgan, 2007). Rather than dictating specific research methods, pragmatism asserts that the most optimal methodology is dependent on the phenomena of study. As this thesis is embedded within a larger applied study, detailed in chapter 1, the methods selected needed to fit within this context. For example, qualitative interviews with young people involved in salutogenic initiatives were conducted at a time point in alignment with the commissioning cycle as well as being most suitable for the focus on the experiences of diabetes self-care in young people.

This thesis uses qualitative methodology, which is well suited for understanding phenomena within their context, understanding links between behaviours as well as generating and refining theory (Bradley et al, 2007). In this thesis, the focus is upon understanding the experience of diabetes self-care in young people, within the context of their lives and understanding the way in which environments and support networks and project participation interact with this experience. For this reason, a qualitative approach is most suitable for the research.

3.32 My role as a researcher

Through my involvement in the CLAHRC project, I was able to gain a comprehensive insight into diabetes services and diabetes self-care, from multiple perspectives. As part of the role, I was involved in producing a systematic review of reviews pertaining to diabetes services and self-care in young people. Results highlighted the importance of understanding young people's experiences with diabetes self-care within the context of their daily lives, which is achieved through the application of a salutogenic approach in this thesis. Furthermore, this review of reviews also helped to provide the context for the qualitative systematic review, which is presented in chapter 4.

In addition to being involved in the systematic review of reviews, I was involved in the recruitment and data collection for qualitative interviews with young people living in

North and East London. These interviews aimed to learn more about their experiences with their local diabetes services and their own diabetes self-care. I was able to see first-hand the challenges involved in recruiting young people who are disengaged from diabetes services and/or diabetes self-care.

Rapport building with participants is crucial within an interview setting. However, this can be challenging in light of the inherent power imbalances between researcher and participant. This can be heightened when there are demographic differences such as gender, socioeconomic status, ethnicity and professional background, and can also be influenced by the location of the interviews (Anyan, 2013).

The nature of qualitative research methods allows not only for the conversation to be participant-led but when conducted in the social spaces of participants, can complement the home environment, facilitating a more holistic discussion (Anderson et al, 2010). In addition, in the context of health research, the home environment also allows for participants to identify more as people than patients (Kendall and Halliday, 2014). This can also help with the rapport building process and overcome the power imbalances created by demographic differences (Sivell et al, 2019). Furthermore, by conducting interviews with young people in their homes, I was able to more clearly understand the context of their daily lives, which affected their diabetes self-care.

In the interviews with young people with diabetes living in North and East London, participants were given the choice about the interview location, with the majority choosing their home (see 3.18). Furthermore, in line with recommendations from Sivell and colleagues, informal conversation took place about the family and home environment (if the interview was conducted at home) or about the recent activities that the participant had been involved in (if the interview was conducted in the university setting). Informal dress by the researcher was also worn as a strategy to reduce power imbalances and improve rapport with participants. These strategies seemed effective as most participants appeared at ease in interviews, and were forthcoming with sharing their perceptions and experiences with diabetes self-care.

Participants seemed slightly more reserved when one of their parents was present (at the request of the parent). However, efforts were made to focus on the young person throughout the interview, including sometimes gently shifting the conversation away

from the parent, was helpful in keeping participants feeling comfortable and that their voice was important. The findings from these interviews are presented in chapter 5.

In being a member of the task group set up to produce recommissioning guidance for young people with diabetes living in Newham, I was able to learn more about the range of individuals and organisations involved in diabetes care. The group involved an East London CCG, Diabetes UK, UCL Partners, Barts Health NHS Trust and Public Health England as well as the four young Clinical Commissioners . In addition to my involvement in the task group, I attended training, public speaking events and site visits with the young people over the course of their year in the role. Being involved in these activities enabled me to view the development of the young Clinical Commissioners in their roles first hand. This experience was used to inform the data collection and data analysis of the qualitative interviews conducted with the young Clinical Commissioners people and better understand the context of their experiences.

Similarly, to the interviews with young people living in North and East London, participants were allowed to choose the location of the interview, with the majority selecting the University of East London (see 3.27). This highlights the degree of familiarity and comfort with the location that participants had acquired during the course of their involvement in the projects. The environment, as well as the researcher's existing relationship with participants also assisted in rapport building. Informal dress was worn to reduce power imbalances and help build rapport. In addition, informal conversation took place before the start of the interview to ensure young people felt comfortable.

Due to the existing relationship with participants, and the ease the young people had developed with speaking about their perceptions and experiences throughout the project, they seemed comfortable throughout the interview. In addition, because of their age, they were more knowledgeable about research more generally than the younger participants, and were interested in entering higher education, which also helped with maintaining strong rapport throughout. Participants also seemed enthusiastic about contributing to research so remained engaged and motivated throughout the interviews. The findings from these interviews are presented in chapter 6.

3.33 Trustworthiness of data

Several definitions and criteria of trustworthiness within qualitative research exist (Korstjens and Moser, 2018). However, the best-known criteria are credibility, transferability, dependability and confirmability as defined by Lincoln and Guba (1985). Each of these criteria will be defined, followed by a discussion of the way in which they have been addressed in this thesis.

Credibility

This is the confidence that can be placed in the validity of the research findings (Korstjens and Moser, 2018). Credibility establishes whether the research findings are plausible based on the data and reflect a valid interpretation of the participants' views. Prolonged engagement was used as a strategy to ensure credibility in this thesis (Lincoln and Guba, 1985 and Sim and Sharp, 1998). Prolonged engagement involved spending an extended period of time in the field, which was achieved through my role in the CLAHRC project. This involved interaction with young people with diabetes, health care professionals and organisations. This helped in understanding the context of the research but also in building trust with the young people being interviewed.

Transferability

This is the degree that findings can be transferred to other contexts or settings (Korstjens and Moser, 2018). Transferability was achieved through the production of a rich description of data thesis (Lincoln and Guba, 1985 and Sim and Sharp, 1998). This thick description involved describing young people's experiences with diabetes self-care but also the context surrounding these experiences.

Dependability and confirmability

Dependability refers to the stability of findings over time (Korstjens and Moser, 2018). Confirmability is the degree to which the findings are able to be confirmed by other researchers and thus ensures that interpretations are clearly derived from the data (Korstjens and Moser, 2018). Dependability and confirmability were achieved through the production of an audit trail describing the steps taken throughout the research, which is detailed earlier in this chapter. Dependability and confirmability were also achieved through ongoing feedback from my supervision team throughout the data analysis and write up stages of this thesis. Where appropriate, my interpretations of the data were challenged to ensure that findings were grounded within the data.

3.34 Concluding comments for this chapter

In this chapter I have outlined the aims, research questions and methods of the three stages of this thesis: the qualitative systematic review, a qualitative analysis of interviews with young people with diabetes living in North and East London and interviews with young people involved in salutogenic initiatives. I have also described the epistemological and ontological underpinnings of this thesis, which informed the decision to adopt a qualitative salutogenic approach to the study of diabetes self-care in young people. In addition, I have discussed my role as a researcher and the strategies used to ensure trustworthiness of the research data. The next chapter presents the findings from the first stage of the research, the qualitative systematic review.

Chapter 4: Findings from qualitative systematic review of young people's experiences with diabetes self-care

4.1 Overview of this chapter

This chapter explores what is known about young people's experiences with diabetes self-care from a worldwide perspective. A meta-ethnographic approach was used to synthesise the research studies. Firstly, the aims and research questions of the reviews are presented. Secondly, the number and characteristics of the included studies are outlined. Thirdly, the results of the meta-ethnography are presented, which highlighted the significance of identity work in diabetes self-care.

4.2 Aims of the review

This meta-ethnography aimed to synthesise worldwide qualitative research on the experiences of young people with diabetes self-care.

4.3 Research question

What is known about young people's experiences with diabetes self-care?

4.4 Number and characteristics of studies included in the review

13 studies were included in the meta-ethnography. Four were conducted in the UK (n=4), three in Sweden (n=3), two in the USA (n=2), one in Australia (n=1), one in Iran (n=1), one in Canada (n=1) and one in Taiwan (n=1). A range of ethnicities were represented across the studies but most studies focused on a single ethnic group. Three studies described all participants as being white/Caucasian (n=3), one study described participants as African American (n=1), one study described participants as being either Caucasian or First Nations/Metis (n=1), one study described participants as being either from or not from a Nordic country (n=1) and four studies did not provide any information about the ethnicity of participants (n=4).

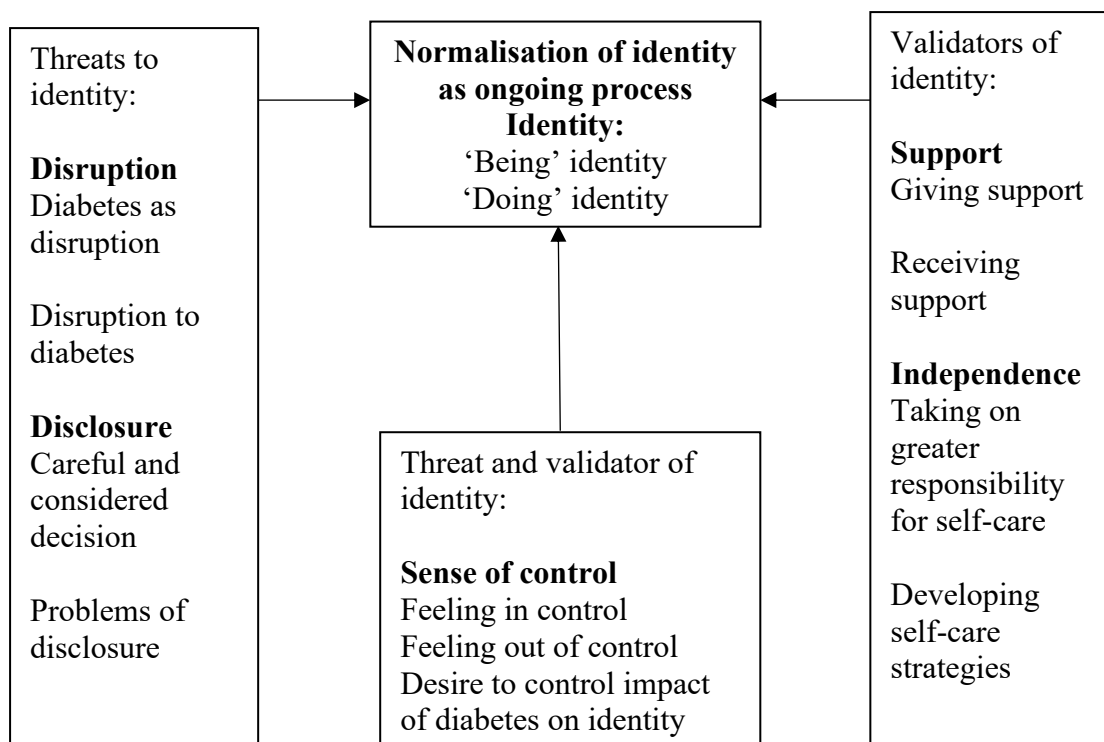
Approaches used within the studies included general qualitative (n=5), grounded theory (n=4) and phenomenological (n=4). Most studies used interviews only to gather data (n=11), with the remainder using interviews and focus groups (n=2). The vast majority of studies focused on young people with type 1 diabetes (n=11), with remainder focusing on type 2 only (n=2). Several studies used exclusion criteria of no other diagnosed mental or physical health problems (n=5).

Socio-economic characteristics of participants were rarely reported in studies. There was also considerable variation in format of this information amongst the studies reporting socio-economic information. Nine studies did not provide any information about socio-economic characteristics (n=9), one study reported that participants were 'middle-class' but did not collect this information from participants (n=1). One study reporting characteristics of the parents of participants, stating that the majority of parents earned between 51-75,000 dollars per year (36% of participants) and that the majority of parents has graduated from university (55% of mothers and 46% of fathers) (n=1). One study also reported the educational background of participants' families but did not disclose which family members the information referred to (n=1). One study reported the education or employment status of participants, describing four as in secondary education, four attending technical college, four in tertiary education, eight in postgraduate education, one employed on a casual basis, eleven employed full time, five employed part time and three as being full-time students who were also employed in part time (n=1). One study reported the average self-reported HbA1c level as 9.43%, which is above the recommended 7.5% level. No other studies reported information pertaining to glycaemic control levels of participants.

4.5 Key findings of included studies

Identity was a key concept which arose from the synthesis. 'Normalisation of identity' is an active process, which entails navigating both threats and validators of identity. Identity has two components: 'being' identity, which describes the young person's self-concept and 'doing' identity, which are the behavioural manifestations of identity. These threats and validators are socially mediated and serve to either reinforce or challenge a sense of normality for young people with diabetes. A sense of normality is achieved when there is a balance between the threats and validators to identity. The acknowledgement of the ongoing role of identity work in diabetes self-care behaviour is important in order to improve health outcomes for young people with diabetes.

Figure 1: Explanatory model of diabetes self-care from qualitative synthesis



Summary of figure 1

The line of argument produced from this meta-ethnography was 'Normalisation of identity is an ongoing process'. This characterises the ongoing process of 'identity work' whereby young people with diabetes seek to integrate diabetes into their self-concept ('being' identity) and diabetes self-care ('doing' identity) into their daily lives, whilst maintaining a sense of normality. The navigation of this identity work underlies young people's engagement with diabetes self-care activities. This process of identity work begins at the time of diagnosis, the point at which their identity is first threatened, and then continues throughout childhood and young adulthood.

Normalisation requires the negotiation of both threats and validators to 'being' and 'doing' identity. Threats and validators are influences from the environment which serve to either reinforce or challenge identity. The validators of identity arising from the synthesis were support and independence. The threats to identity arising from the synthesis were disruption and disclosure. Sense of control was found to act as either a validator or a threat. A sense of normality is achieved when there is a balance between these threats and validators to identity.

4.6 Identity

Identity is defined as a subjective sense of sameness and continuity in the self that is perceived and recognized by others (Erikson, 1980). It entails both psychological and sociological dimensions (Erikson, 1980). These different aspects correspond with ‘being’ identity and ‘doing’ identity respectively. ‘Being’ identity refers to a sense of self, for example, seeing oneself as a ‘diabetic’. ‘Doing’ identity refers to the behavioural manifestations of identity which are observable to others, such as the performance of diabetes self-care behaviours. This synthesis demonstrated that both ‘being’ and ‘doing’ identity are important to acknowledge in understanding young people’s engagement with diabetes self-care.

Identity work includes engaging in behaviours which may be harmful to physical health, such as avoidance of medical aspects of diabetes self-care but make an important contribution to ‘normalisation of identity’ and thus support young people’s wellbeing.

Erikson describes this identity work as characterising an ‘identity crisis’ (Erikson, 1970). For young people with diabetes, this identity crisis involves negotiating the role of diabetes within both ‘being’ and ‘doing’ identity whilst balancing it with the other non-diabetes aspects of identity (Erikson, 1970). This identity work is also important in the development of ‘ego strength’ (Erikson, 1963; 1964; 1968). Ego strength is built by individuals becoming more capable in different areas of life, which helps them with navigating identity work. The role of ego strength is further discussed in chapter 5.

a) Being identity

Being diagnosed with diabetes was described as a highly significant moment for ‘being’ identity and was an ongoing challenge. Being identity is exemplified through the following participant quotation: “I have shit days... really hate the fact that I need to be a diabetic sometimes but to sit and dwell on it doesn’t make it better, does it?” (female, pg 135, Sparud-Lundin, 2010).

Not all of the young people were at an age to remember their diabetes diagnosis. Those who did remember tended to recall the situation vividly. Frequently, such accounts contrasted the nonchalant way in which the message was communicated to them with their own reaction to hearing the diagnosis. Stark contrasts were also often present

between how young people felt just before being diagnosed to how they felt afterwards (Dovey-Pearce, 2007).

The time of diagnosis marks the start of the challenge to identity but being diabetic is described by participants in these studies as an ongoing threat to one's sense of self and a threat that can be variable from day to day (Sparud-Lundin, 2010). For some participants, diabetes was perceived as being a part of future identity but not something that represented a threat to identity (Sparud-Lundin, 2010). For other participants, diabetes was acknowledged as being a part of future identity but was perceived as being an ongoing threat to identity (Protudjer et al, 2014).

b) Doing identity

'Doing' identity was described as being highly challenging by participants in these studies. Diabetes demands a range of medical self-care activities to be undertaken on a daily basis, including injecting insulin or taking medication, frequent testing of blood glucose levels and controlling both food intake and exercise to maintain stable blood glucose levels. These behaviours play a role in physiologically managing diabetes but also have implications for managing identity, both in the present and in the future.

'Doing identity is demonstrated through the following participant quotation: "I think that's the thing really with avoiding complications and eating healthily. You're trying to make a better life for yourself in the future really. You're trying to preserve yourself for the future.'" (Lars, pg 143, Balfe, 2007).

For some participants, diabetes was sometimes forgotten because of a lack of physical symptoms. Feeling 'normal' was experienced as being incompatible with having diabetes, and thus diabetes could threaten young people's sense of normality (Protudjer et al, 2014). For other participants, the presence of diabetes symptoms served as constant reminders of their diabetes diagnosis and thus could not be forgotten. These symptoms were particularly difficult for some young people who had not yet fully accepted their diabetes diagnosis (Wang et al, 2013). For some other participants, a more positive association with diabetes was expressed, where diabetes was more integrated into identity. Some participants described a sense of freedom in terms of the

locations where they felt comfortable engaging in medical aspects of diabetes self-care (Spencer et al, 2014).

Several participants in the studies described diabetes as being a significant part of their identity, both in the present and in the future. This was described as being either neutral or negative in terms of its impact on identity by young people. Medical self-care activities were cited as being important in both avoiding diabetes-related complications but also in maintaining future identity. Other participants discussed strategies they used to manage the impact of diabetes upon their future identity. This included preventing diabetes from dominating identity (Babler, 2015). For some participants, engagement in medical aspects of diabetes self-care was important for maintaining future identity as well as maintaining future health (Balfe, 2007).

4.7 Disclosing (threat to identity)

This concept refers to the disclosure of a diagnosis of diabetes by the young people in these studies, which was perceived as a threat to both ‘being’ and ‘doing’ identity. Two key components of this concept emerged from the synthesis: a careful and considered decision and problems of disclosure. Concern about diabetes disclosure is characteristic of psychosocial development in young people, which places a high value on social relationships, particularly those with peers (Erikson, 1968).

The theme of disclosing is consistent with Goffman’s (1963) ideas of stigma, in terms of stigmatising attributes being ‘deeply discrediting’ because they serve to set individuals apart from others. Young people living with diabetes may be seen as having a potentially stigmatising attribute and if this is reinforced by others, their identity is threatened. Young people who were fearful of this stigma and chose not to disclose their condition may be seen as employing ‘information management’, ‘covering’ or ‘impression management’ in order to protect their identity (Giddens, 1959 and Goffman, 1963).

a) Careful and considered decision

A careful and considered decision to disclose diabetes was considered important by several participants in these studies. Those who were told were generally individuals close to the young person who were thus familiar with the non-diabetes aspects of their

identity. Young people described feeling more confident that they would be supported by these individuals and were often reluctant to disclose to other individuals. This concept is demonstrated through the following participant quotation: “I didn’t want to have to tell all these different people...I didn’t see the need to. I mean, half of those (classmates) I don’t even see. I haven’t really kept in touch with them, so there was not really much point in telling them” (Female, aged 16: pg 18, Dovey-Pearce, 2007).

Most participants did not feel it was necessary for everyone to know about their condition and were reluctant to tell people with whom they were not close (Dovey-Pearce, 2007). Participants described similar feelings about deciding about disclosure to work colleagues (Spencer et al, 2014). Other participants were not concerned if a fairly large group of people knew about their diabetes, such as other young people in their class at school. This occurred when participants felt that they could trust these individuals and they would not be perceived differently as a result of disclosing the diagnosis (Babler, 2015).

b) Problems of disclosure

Problems of disclosure occurred when young people felt that they were continually required to explain diabetes to others, when they were concerned about the negative perceptions of others, when they were unsure when to disclose their diagnosis to a partner, when an unexpected disclosure occurred during diabetes self-care or when they encountered a dangerous experience as a result of not disclosing the diagnosis. This concept is demonstrated through the following participant quotation: “I do not really like telling people. Telling people is like, eventually if I get to know them well enough, I do not really like talking about it, I think that if I told people they’d nearly see me as a pariah basically. Diabetes is quite hidden really. No one knows you’ve got it unless you tell people or they see you injecting or something.” (Male, 23, pg 782, Balfe and Jackson, 2007)

Several participants described the anticipated consequences following the disclosure (Babler, 2015). For some participants, disclosure was something that was actively avoided unless felt to be absolutely necessary. Similarly to other participants, disclosure is only considered to be needed when the individual is a close friend. Negative reactions

from those who are not close friends are often anticipating, contributing to this reluctance to disclose more readily (Balfe and Jackson, 2007).

Sometimes the negative reactions from others were not merely anticipated but were actually experienced by participants. This would often occur in individuals who did not know about the young person having diabetes but saw them carrying out diabetes self-care behaviours (Balfe, 2007). Disclosing the diabetes diagnosis to friends was also challenging, particularly when met with reactions that made the young person feel different. Young people appreciated types of support which demonstrated acceptance of diabetes and helped the young person feel more 'normal' (Dovey-Pearce, 2007). However, some participants described difficult interactions following disclosure of diabetes to friends. Sometimes this was a result of friends holding misconceptions about diabetes, which could serve as a threat to the identity of the young person with diabetes. Such misconceptions tended to dissipate over time as the friends of the young person became more knowledgeable about the condition and how to provide support (Karlsson, 2008).

The consequences of non-disclosure not only impacted identity but also had physical health implications, which were sometimes severe (Spencer et al, 2014). Romantic relationships were particularly problematic for some participants as they involved an inevitable degree of uncertainty. Deciding when was the best time to disclose diabetes was challenging, particularly because of the future implications for the relationship (Rasmussen, 2011). Disclosing to a partner was experienced as a difficult but inevitable decision to be made. In such situations, difficulty arose not only around the timing of disclosure but also in the knowledge that the disclosure would trigger several further conversations about the relationship and how diabetes would have an impact. Decisions about who, when and how to disclose diabetes are inherently difficult with consequences occurring both as a result of deciding to disclose but also as a result of deciding not to disclose. Consequences involve not only threats to identity but also threats to physical health.

4.8 Disruption (threat to identity)

This concept refers to diabetes as disruptive and factors which are disruptive to diabetes self-care, both of which serve as threats to identity. Erikson described the manifestations of such disruptions as conflicts, whereby there is a conflict between

different aspects of a person's identity (Erikson et al, 1970). For participants, this comprised a conflict between diabetes and another aspect of identity. These were described as being an inevitable aspect of navigating the 'identity crisis' of adolescence and young adulthood. Although such conflicts are potentially harmful from a physical health perspective, navigation of these conflicts serves an important role in the negotiation of the role of diabetes within identity (Aujoulat et al, 2017 and Erikson et al, 1970).

a) Diabetes as disruption

Several participants perceived 'doing' diabetes as being a disruption to their lifestyle, goals and activities. Due to the regularity and extent of medical self-care activities which are required to manage diabetes daily, maintaining engaged with these behaviours is onerous and particularly difficult when faced with other challenging events. Carrying out medical self-care behaviours was experienced not only as physically disruptive but also as psychologically disruptive, as these behaviours served as a constant reminder of having diabetes. Experiencing bouts of hypoglycaemia (low blood glucose levels) could also be disruptive, particularly as such events can be unpredictable and are associated with both physical and psychological changes. This concept is demonstrated through the following participant quotation "I could be doing a little bit better [managing diabetes] but I've got bigger issues at the moment. I've got to organise some things with my daughter. Just living at home in general, paying bills, that sort of stuff. At the moment that is more important than worrying about my diabetes." (Male, pg 1986, Rasmussen, 2011).

For some participants, the presence of equipment for diabetes self-care was inherently disruptive. These served as continual reminders of having diabetes and threatened the sense of being 'normal'. Despite having lived with diabetes for several years, this remained a challenge for many young people (Balfe and Jackson, 2007). Diabetes was experienced as being particularly disruptive when significant life events were occurring. These events were usually prioritised over diabetes because they were perceived as being more important urgent than maintaining engaged in the medical aspects of diabetes self-care. Such prioritisation was justified by participants when these situations were transient in nature (Rasmussen, 2011).

Diabetes was also experienced as being disruptive when in the presence of others without diabetes who were eating and drinking freely. This highlighted a sense of being different from peers, which had a negative effect on emotional wellbeing (Wang et al, 2013). Such situations are difficult for young people with diabetes because they are reminded of their diagnosis and the limitations that it can impose on their lifestyle. Such restrictions are heightened by being surrounded by others who are able to engage in desirable activities. Diabetes, therefore, has the potential to be experienced as disruptive because of challenging a young person's sense of normality and thus threatening identity.

Sometimes diabetes was also experienced as being disruptive when diabetes-related events occurred, such as hypoglycaemia. In such instances, a range of physiological symptoms are experienced which prevent normal functioning. Despite the symptoms themselves being experienced as being disruptive, attending to them was not always desirable for young people (Spencer et al, 2014). Some participants also experienced other people perceiving diabetes as being disruptive. In such instances, diabetes was not something that was permitted to be disclosed or discussed, putting the young person at greater risk of harm in the case of a diabetes-related event occurring (Viklund and Wikblad, 2009). This highlights the potential for tension with the medical aspects of diabetes self-care and maintaining emotional wellbeing for young people.

b) Disruption to diabetes

Participants described factors which were disruptive to their ability to carry out self-care activities, including school, work and university environments and reactions of others. Experiencing a change in routine or being exposed to chronically unstructured environments, such as university, made maintaining consistency with the medical aspects of diabetes self-care highly challenging. Participants also described such situations being exacerbated by the reactions of others, who behaved in ways that were detrimental to engaging in these self-care activities. This concept is demonstrated through the following participant quotation: "I used to do it quite a lot, forget about my dinner time injection because I'd want to just go off to the music block for a practice, so I'd forget quite a lot and I'd come back from school in a mood because my blood would be about 20 from my dinner" (Male, aged 14, pg 27, Spencer et al, 2014).

Particularly problematic were situations where there was a lack of structure, making it more difficult to establish and maintain a regular routine with the medical aspects of diabetes self-care (Balfe, 2007). Several participants described the extreme lack of structure within the university environment and the continual changes to their schedule that occurred. This resulted in difficulties in knowing when and where to fit in diabetes self-care behaviours and thus diabetes self-care was disrupted (Balfe and Jackson, 2007). This lack of structure was described as being inherent to university life and as highly challenging to accommodate. For this participant, the constantly changing university timetable is particularly disruptive as it is seemingly unpredictably. Maintaining a regular routine with the medical aspects of diabetes self-care amongst this environment was thus incredibly difficult.

Aside from changing university timetables, a range of other factors inherent to the university environment were described by participants. However, despite the awareness of these influences and a strong intention to establish a routine, they were experienced as disruptive, resulting in a 'screw up' (Balfe, 2007). A lack of external reminders was also cited by participants as being disruptive to medical self-care activities. Despite previously establishing and maintaining a consistent routine, in the absence of accountability, remaining engaged in medical self-care activities was much more challenging. This was sometimes contrasted with experiences in the school environment, where reminders were more commonly provided by others (Balfe, 2007). In such instances, the lack of structure in the university environment combined with a lack of prompts to engage in medical self-care behaviours, was particularly disruptive. Maintaining a consistent the medical aspects of diabetes self-care was thus highly challenging.

School environments were also cited as being disruptive. Such environments could be busy, particularly if the presence of extra-curricular activities and thus medical self-care activities could be forgotten. This could result in either high or low blood glucose levels being experienced, along with their associated physiological symptoms (Spencer et al, 2014). Some participants also described teachers as exacerbating the disruptive nature of the school environment. In some instances, young people were prevented from leaving lessons to perform their medical self-care activities, even in the presence of accompanying evidence of the diagnosis (Spencer et al, 2014).

Other participants described having the medical aspects of diabetes self-care actively undermined by teachers. These instances involved enforcing changes onto the young person regarding their diabetes self-care. This was described as occurring even when participants felt confident about making decisions about their condition (Wang et al, 2013). Some participants also described negative reactions from peers at school as being disruptive to their medical self-care activities. This was often contrasted with the different responses they received in their home environment, which tended to be much more positive (Wang et al, 2013). In some participants, the negative reactions from peers were described as easing over time. The initial responses from peers were often attributed to curiosity, rather than having a negative intent. Nevertheless, these reactions had a negative impact on young people (Wang et al, 2013).

In addition to certain environments being chronically disruptive, a change in environment could also be disruptive for both medical self-care and identity. Work places were described as being inherently difficult to manage, due to the behaviour of both employers and fellow employees. As a result, some young people described transitioning between different work places, which could persist for several months (Rasmussen et al, 2011).

Parents were also sometimes described as being disruptive to the medical aspects of diabetes self-care and identity. Situations where parents were seen as failing to understand the complexities of medical activities were cited as being unhelpful (Viklund and Wikblad, 2009). Some participants described the reactions of parents as a result of performing these behaviours as being disruptive. Blood glucose tests where the reading was high could result in parents expressing frustration, which was detrimental to both emotional wellbeing and to subsequent engagement in such self-care activities (Viklund and Wikblad, 2009). In such situations, young people felt reluctant to perform medical self-care behaviours out of fear of the consequences of disclosing the outcome to parents. If they did carry out the activities and were met with anger from parents, they felt less inclined to take the necessary next step to stabilise blood glucose levels. Both reactions and anticipated reactions from others, such as parents can thus be disruptive to both medical aspects of diabetes self-care and emotional wellbeing.

4.9 Support (validator to identity)

This concept refers to both receiving support in managing diabetes and providing support to others with diabetes. The support given to and received by others validated both ‘being’ and ‘doing’ identity by helping participants feel more ‘normal’ and also feeling more capable of carrying out medical aspects of diabetes self-care consistently. Support thus helped participants to navigate the ‘identity crisis’ by allowing them to more easily reconcile diabetes with the other aspects of their identity (Erikson, 1970).

a) Receiving support

Receiving support involved practical support with diabetes self-care tasks and emotional support in helping to feel more ‘normal’. Both of these types of support help with the physiological management of the condition, by helping to maintain engagement in self-care tasks but also help to validate identity of the young person with diabetes. Several different sources of support were cited by participants in these studies, including parents, friends, teachers and health care professionals. This concept is demonstrated through the following participant quotation: “My family encourages me to take responsibility for my own medication management. Moreover, they have changed their own food to be compatible with my diet.” (Female, aged 14, Rostami et al, 2014)

School environments were generally not cited as being helpful but some participants described receiving support from teachers, or other school staff, which boosted wellbeing and confidence (Rostami et al, 2014). Friends were cited as particularly helpful within the school environment. Some participants described having one or two friends who they relied upon heavily, who knew about diabetes and what to do in a diabetes-related emergency. These friends had often learned about diabetes quickly and were confident about being able to provide support when needed (Babler, 2015 and Spencer, 2014).

Practical support was comforting to participants as even if a diabetes-related emergency had not yet occurred, they knew that friends who know how to support them in such an event. This served to maintain the physiological management of diabetes and emotional wellbeing in young people with diabetes. Furthermore, this support from friends played

a role in validating identity as young people were accepted and supported as a young person with diabetes.

Friends knowing how to provide help in a diabetes-related emergency was cited as being helpful but often time and space was appreciated by young people when carrying out daily medical self-care activities. This showed that friends accepted their diabetes and would ensure that they were not excluded from any activities. It also demonstrated a respect that young people were able to manage the condition independently most of the time (Spencer et al, 2014). Participants did not want to be helped with their condition unless it was deemed necessary but having their friends accommodate medical self-care activities was appreciated. Such behaviour served to validate identity by demonstrating acceptance of diabetes and its associated management but providing support in a way that helped the young person maintain a sense of normality.

Friends were described as also providing support in more subtle ways. Participants talked about friends understanding diabetes and the potential limitations that it placed upon their ability to engage in activities (Spencer et al, 2014). Although participants did not want to feel different from their friends, they appreciated friends understanding about how diabetes could impact them. This understanding helped to validate identity by demonstrating an acknowledgement and acceptance of diabetes and its influence on young people.

Parents were also described as being a key source of support by participants. They often attended diabetes clinic appointments with the young people and also provided frequent reminders for diabetes self-care activities (Sparud-Lundin, 2010). Parents were usually heavily involved in diabetes self-care and clinic appointments since diagnosis which meant they had accumulated a large amount of knowledge about the condition and its medical management. Support from parents helped in maintaining the medical aspects of diabetes self-care as well as the integration of diabetes into the young person's identity. Parental support thus served to validate identity of the young person with diabetes through normalising the condition and the associated self-care behaviours.

Reminders for medical self-care behaviours were also frequently described by participants in these studies. Such reminders these helped with the physiological management of the condition, they were sometimes met with negative reactions by

young people (Dovey-Pearce, 2007). Acceptance and accommodation of diabetes into family life was appreciated by participants as it helped them maintain a sense of normality and thus validated their identity. However, these supportive behaviours could also be difficult for young people because they served as a constant reminder of having diabetes and the medical aspects of self-care.

Health care professionals were also cited as being an important source of support by participants in these studies. Feeling involved in the decisions made about diabetes self-care was described as being helpful (Karlsson, 2008). Being directly involved in decisions made about their diabetes care helped young people feel validated by health care professionals. Participants appreciated being provided with information, advice and support but also wanted to maintain a sense of autonomy in how they managed their condition.

Meeting health care professionals for the first time was often daunting for young people as it involved navigating a lot of uncertainty. In such situations, extra support from health care professionals was appreciated as it helped young people to feel cared for and less alone in dealing with their diabetes (Rasmussen et al, 2011). Feeling both practically and emotionally supported by health care professionals was cited as being helpful not only for the medical management of diabetes but also in helping to maintain a sense of normality whilst living with diabetes. Such behaviour served to validate identity as it demonstrated an awareness of the inherent challenges of diabetes and also helped participants maintain emotional wellbeing. In addition to diabetes-specific support, participants also appreciated non-diabetes related support from health care professionals. This helped young people maintain a sense of normality in living with the condition (Spencer et al, 2014).

Some participants in these studies also discussed other young people with diabetes as being a source of support. Interactions with these individuals was usually either face-to-face, such as at a diabetes camp or was online, via a forum. Support received from other young people with diabetes was largely informational and therefore helped maintain the medical aspects of diabetes self-care. Such interactions also served to validate identity by helping young people feel normal (Rasmussen et al, 2011). Diabetes camps provided participants with the opportunity to meet and learn from other young people with diabetes in an informal way. Sometimes the information they

received was not necessarily new to them but was received much more favourably when it was relayed by another young person to whom they could relate. Interactions with other young people with diabetes served to maintain a sense of normality and thus information received was described as being much more impactful than other sources.

Interactions with other young people with diabetes also occur in online spaces. Similar to face-to-face interactions, support received was largely informational in nature. An advantage of online spaces is that it is possible to maintain a sense of anonymity and thus young people felt able to ask questions about their diabetes self-care that they may have been reluctant to ask in a face-to-face context (Rasmussen et al, 2011).

b) Giving support

Giving support refers to helping other young people with diabetes, either formally or informally. Such interactions served to increase acceptance of having diabetes, or 'being' identity as young people were able to draw on their own experiences of living with the condition in order to provide value to others. This concept is demonstrated through the following participant quotation: "It was amazing. He said, 'I'm just ringing to say thank you' and I said, 'that's okay, – what for.' And he said, 'thank you, thank you for identifying that it's a really hard time. Thank you for saying that there's hope and thank you for saying that dreams stay alive.' I got off the phone and I thought, 'it's been worth having diabetes for 19 years just to have spoken to that [person].'" ('Pump user', pg 1986, Rasmussen, 2011)

In addition to receiving support from a number of different sources, participants also described instances where they had provided support to other young people with diabetes. Interactions with other young people with diabetes usually occurred in formal mentoring opportunities and was something that was highly valued by participants. Often these mentoring roles involved providing emotional support to younger children with diabetes, thus helping to maintain their wellbeing (Babler, 2015).

Being a role model was commonly described by participants as being a key means of providing support to other young people with diabetes. Young people often felt that this was more impactful than providing oral information or support. Feeling able to help

other young people by relaying their own experiences was also highly valued because it helped to provide a sense of meaning for participants (Rasmussen, 2011).

Being a role model for other young people with diabetes was also self-motivating for participants. It encouraged them to maintain more consistency with their own medical self-care behaviour and seek out more opportunities where they could provide help to other young people (Babler, 2015).

4.10 Independence (validator to identity)

The concept independence refers to increasing responsibility for self-care behaviours to achieve a sense of normality and developing strategies to manage the emotional and practical elements of diabetes. Independence thus served as a validator to both 'being' and 'doing' identity. As young people with diabetes become older, they are expected to take on greater responsibility for their diabetes management and become more independent for their own self-care. At younger ages, young people typically receive a lot of support from family members, particularly mothers who tend to be more heavily involved in diabetes care.

The transition towards more independent management can be difficult for young people, particularly if they feel unprepared to take on greater responsibility. However, achieving more autonomy is necessary for young people to maintain a sense of normality and strong identity. The creation of a coherent identity represents a critical developmental task of adolescence, characterised by an attempt at reconciliation between 'the person one has come to be' and 'the person society expects one to become' (Erikson, 1970). In order to successfully navigate this 'identity crisis', participants developed an array of self-care strategies in order to manage the emotional and practical demands of diabetes. These strategies involved longer term planning for particular situations, such as work and social outings, but also reactive strategies in response to the current circumstances they were facing.

a) Taking on greater responsibility for self-care

Several participants contrasted the amount of involvement from family members at a younger age with their current state of greater independence. This was usually characterised by beginning to test blood sugar levels independently and take insulin or food if needed (Babler, 2015). For most participants, the move to greater independence occurred naturally over time as they became older. This concept is demonstrated through the following participant quotation: “when I was a child my mom mostly took care of it, so she was always watching my blood sugars, I think it was about when I was about 10-12 maybe between that time frame that I started doing it on my own” (Interview #4 p.1 pg 116, Babler, 2015)

Parents, particularly mothers, were usually heavily involved when young people were younger and kept a close eye on blood sugar levels. Becoming more independent was difficult for some participants as they felt that they lacked the same levels of knowledge as their parents about diabetes. If they were very young when they were diagnosed, health care professionals tended to direct information towards parents, who were usually taking responsibility for the management of diabetes. This resulted in young people feeling unprepared for a time when they were at an age where they were expected to begin taking greater responsibility for the medical aspects of their diabetes self-care (Karlsson et al, 2008). For some participants, learning about diabetes self-care from their parents was considered to be adequate and they did not express concern about their lack of knowledge. This meant that they did not actively seek out further information from health care professionals or other sources (Wang et al, 2013).

Some participants discussed sharing responsibility for the medical aspects of their diabetes with their parents. This allowed young people to manage the condition independently when they were by themselves but then allow parents to take over greater responsibility when they were at home. The oscillation between being autonomous and being supported was described as being something that occurred automatically (Karlsson et al. 2008).

Some young people described their family as actively encouraging them to take greater responsibility for the medical aspects of their diabetes self-care. This was experienced as being helpful, particularly when combined with other types of support, such as

dietary considerations Rostami et al, 2014). Despite participants generally feeling confident and capable of taking responsibility for their own medical self-care, achieving 'normal' blood glucose levels was often described as being highly challenging. This could result in young people feeling discouraged in their efforts and their sense of normality being threatened (Viklund and Wikblad, 2009).

Feeling able to manage diabetes independently was a validator to the identity of young people. However, their efforts could be undermined if external pressure was placed upon them by health care professionals to reach certain ranges of blood glucose levels. Having individualised targets could thus help to ensure that young people are empowered to continue to maintain responsibility for their condition, thus optimising the physiological management of their condition as well validating their identity work.

Taking on greater responsibility for the management of their diabetes provided young people with a sense of freedom. This was because they did not feel reliant on others to make decisions about their diabetes self-care. Several participants described this as being an empowering feeling (Karlsson et al, 2008). The perceived ability to manage the condition independently thus served as a validator to identity. Young people felt free to not only decide their own goals of their diabetes self-care but also the particular strategies that they would employ to achieve these goals. This involved considering both practical and emotional issues, as well as the physiological management of the condition to obtain their own balance between physical health and wellbeing.

b) Developing self-care strategies

When young people begin taking on greater responsibility for medical aspects of diabetes self-care, they also develop a variety of strategies which serve to manage the emotional and practical demands of diabetes and thus maintain a sense of normality. These strategies also lessen the impact that diabetes has on other activities and therefore reduces the threat of diabetes to identity. Planning ahead was a key strategy for participants, which could reduce subsequent worries about diabetes (Balfe and Jackson, 2007). This concept is demonstrated through the following participant quotation: "If you find yourself in a situation and don't know what to do, maybe others have had the same experience and know how to handle it." (Female, aged 13, pg 3266, Viklund and Wikblad, 2009)

Testing blood glucose levels before going out in the evening helped participants to determine their food and drink decisions whilst out, without the need to take diabetes-related equipment with them. This was helpful on both a practical and an emotional level as it avoided the equipment serving as a constant reminder of diabetes and thus being disruptive to identity. Some participants also discussed strategies they used when going out in the evening, such as eating beforehand and taking items to help in case a diabetes-related emergency occurred. This was described by some participants as being non-negotiable (Viklund and Wikblad, 2009).

Utilising these strategies allowed participants to enjoy their time out with friends without worrying about diabetes impacting them negatively. This meant that young people were therefore able to maintain a sense of normality as they were able to engage in the same activities as their friends. Such strategies also served to maintain the physiological management of diabetes as they preventing blood glucose levels from becoming too high or too low and thus diabetes-related events from occurring.

Participants who were in employment also discussed strategies that allowed them to manage diabetes more easily within the workplace, such as maintaining slightly high blood glucose levels. This was perceived as being particularly important when their jobs involved caring for children (Rasmussen, 2011). Maintaining slightly high blood glucose levels whilst arguably non-optimal from a physiological perspective, was helpful in a practical sense as it preventing episodes of low blood sugar from occurring, which was associated with risky behaviour. This highlights the need for young people to establish a balance between the emotional, practical and medical aspects of diabetes self-care.

Other participants also discussed using intuitive medical self-care strategies. This was described as being sufficient because of being aware of bodily symptoms linked to different blood glucose levels. For some young people, this meant that they did not feel the need to check their blood glucose levels regularly (Wang et al, 2013). Although a risky strategy from a physical health standpoint, this was a behaviour that served to help young people to feel more 'normal' as they avoided the use of equipment that could serve as a continual reminder of their diabetes, and thus a threat to their identity.

Several participants also discussed reactive strategies they used when a diabetes-related event occurred. In such instances, young people sometimes drew on their own past experiences as well as the experiences of others (Viklund and Wikblad, 2009). Being able to connect with other young people with diabetes, either virtually or face-to-face was extremely helpful in providing participants with a range of strategies they can employ in different situations. These strategies pertained to the medical aspects of diabetes self-care as well as the practical and emotional aspects of living with the condition. Such interactions were particularly useful for young people who were more recently diagnosed with diabetes and therefore had less experience in managing diabetes.

Young people also described sometimes forgetting about the medical aspects of diabetes self-care. In such instances, they would experience certain bodily cues that reminded them that they needed to perform particular tasks, such as injecting insulin (Dovey-Pearce, 2007). The ability to recognise bodily cues and understand the reasons for them occurring is something that young people with diabetes learn over time, particularly as they begin taking on more responsibility for their condition. Over time, the responses to such bodily symptoms can become habitual, minimising the impact of diabetes on daily life and thus allowing them to more easily maintain a sense of normality.

Some participants described an altered perspective in the importance of engaging in diabetes self-care behaviours. This was perceived as being a natural consequence of becoming older and more mature (Dovey-Pearce, 2007). Some young people described living with diabetes for a number of years as also changing their outlook to life generally, including acting proactively rather than reactively to situations. This was described as requiring constant vigilance to ensure to anticipate and prepare for future events.

4.11 Sense of control (threat and validator to identity)

This concept refers to feeling in control of both 'being' and 'doing' identity. Having balanced blood glucose levels provided young people with a sense of control, which was perceived in positive terms and in some cases a source of comfort. Balanced blood glucose levels and the associated sense of being in control are thus validators of identity because these helped to facilitate the integration of diabetes into identity, without it dominating over other aspects.

Conversely, imbalanced blood glucose levels led to a feeling of being out of control and thus represent a threat to identity. Erikson (1970) used the term 'negative identity' to describe such threats to identity, characterised by a struggle to integrate a perceived negative aspect of identity, in this context diabetes, within other aspects of identity. This is difficult for young people to navigate but forms a normative component of the 'identity crisis' characterising adolescence and young adulthood.

In addition to the desire to have balanced blood glucose levels, young people also seek to control the impact of diabetes on their identity, in an attempt to avoid feeling controlled by diabetes. The desire to control the impact of diabetes on identity is consistent with Goffman's (1963) ideas of stigma, whereby having diabetes is perceived as 'deeply discrediting' because it sets participants apart from others. Young people thus employ the strategies of 'information management', 'covering' or 'impression management' in order to protect their identity (Giddens, 1959 and Goffman, 1963). Although such efforts can potentially be harmful from a physical health perspective, if medical aspects of diabetes self-care activities are avoided, navigation of these events serve an important role in the negotiation of the role of diabetes within identity (Aujoulat et al, 2017 and Erikson et al, 1970).

a) Feeling in control

As part of diabetes self-care, young people are often required to take insulin injections or medication to help maintain stable blood glucose levels. Several participants discussed the helpfulness of these tools in maintaining their physical health but also in helping them to feel in control (Martin, 2011). Taking diabetes equipment around with them allows young people to more easily maintain stable blood glucose levels as they can respond to fluctuations in a more timely way. In addition to the physiological benefits of this, young people sometimes experienced the ability to quickly respond to imbalanced blood glucose as being emotionally comforting (Balfe and Jackson, 2007). This concept is demonstrated through the following participant quotation: "What's helpful to me is my medicine. That helps me feel better and gets you better when you feel sick." (Participant R, pg 111, Martin, 2011).

Having balanced blood glucose levels allowed young people to be able to engage in any activities they wanted, thus helping them maintain a sense of normality. In some cases,

optimising blood glucose levels throughout the day required a greater number of insulin injections each day. Rather than being an annoyance, this was sometimes experienced in positive terms because of the sense of control that the regime provided (Balfe and Jackson, 2007). Beginning insulin pump therapy also led to feelings of greater freedom as a result of more balanced blood glucose levels in some participants. This also could bring about positive emotional changes thus improving young people's sense of wellbeing (Rasmussen, 2011). Some young people also discussed enjoying having a sense of control over their bodies and the feeling that they were in charge of decisions made about their bodies. Input from others was not necessarily rejected but was interpreted as being suggestive, rather than directive (Viklund and Wikblad, 2009).

b) Feeling out of control

Imbalanced blood glucose levels have physical symptoms but can also be associated with emotional consequences, including a feeling of loss of control. Continued unsuccessful attempts to balance blood glucose levels sometimes led to feelings of hopelessness and poorer self-worth in young people (Karlsson et al, 2008). This concept is demonstrated through the following participant quotation: "It just feels hopeless like, you try and try but it still doesn't work. And sometimes it feels like you just want to forget the whole thing 'cause it doesn't matter, it doesn't get better anyway." (Female, aged 15, pg 657, Karlsson et al, 2008).

Despite efforts to balance blood glucose levels, this hard work was not always rewarded. This led to feeling out of control, disheartened and pessimistic about the future. Imbalanced blood glucose levels thus posed a threat to identity, resulting in young people wanting to cease further efforts to balance their blood glucose levels. The experience of high blood glucose levels was associated with a variety of both physical and emotional symptoms in some young people. These could be highly challenging to deal with, particularly because the desirable behaviour in response to these symptoms would lead to negative physiological consequences (Balfe, 2007). Attempts to lose weight could also be associated with feeling out of control. This was because such efforts often resulted in imbalanced blood glucose levels which needed to be remedied in ways that did not compliment their weight loss goals (Balfe, 2007).

c) Desire to control impact of diabetes on identity

In addition to balanced blood glucose levels serving to maintain a sense of being in control, young people also sought to control the impact of diabetes on their identity. For some participants this meant attempting to optimise the medical aspects of their diabetes self-care so that they could participate in desired activities. For others, it meant sometimes making decisions that were suboptimal from a physiological standpoint but which made them feel in control, rather than being controlled by their condition (Balfe, 2007). This concept is demonstrated through the following participant quotation: “I know that I am not like others can totally [be] free to eat what they want to eat and to do what they want to do. I need to test my sugar, adjust my insulin, and pay attention to my body carefully. Because I don’t want to be limited by this disease, I have been working hard to let others know I’m good and I’m doing well.” (Participant N, pg 237, Wang et al, 2013).

The potential negative impact of diabetes on other activities was acknowledged by several participants. Ensuring that blood glucose levels remained stable was cited as being integral to preventing this from occurring and thus provided a sense of control (Balfe, 2007). Controlling the perceptions of others was also cited as being important to maintain a sense of normality. Remaining engaged with the medical aspects of diabetes self-care whilst continuing to engage in normal daily activities was cited as being important in achieving this aim (Wang et al, 2013). In contrast, other young people chose to ignore their diabetes when making decisions in their daily life to avoid feeling controlled by their condition (Balfe, 2007).

4.12 Normalisation

Normalisation is an ongoing process for young people with diabetes, involving continual navigation of these threats and validators to both ‘being’ and ‘doing’ identity. It begins at the time of diagnosis and continues throughout childhood and young adulthood. Diabetes thus serves as both an acute and chronic threat to identity.

The normalisation process underlies young people’s engagement with diabetes self-care behaviour. Young people seek to maintain a sense of normality as they strive to integrate diabetes into their self-concept (‘being’ identity) and the medical aspects of diabetes self-care into their daily lives (‘doing’ identity). A sense of normality is

achieved when there is a balance between the validators and threats to identity and young people experience a sense of wellbeing. This is not necessarily optimal from a physical health standpoint but instead represents a balance between the physical, practical and emotional aspects of living with diabetes.

4.13 Concluding comments for this chapter

The chapter has presented findings from a meta-ethnography, synthesising qualitative research on the experiences of diabetes self-care in young people from a worldwide perspective. The line of argument produced from this meta-ethnography was ‘Normalisation of identity is an ongoing process’. This characterises the ongoing process of ‘identity work’ whereby young people with diabetes seek to integrate diabetes into ‘being’ and ‘doing’ identity whilst maintaining a sense of normality to achieve a state of wellbeing. Efforts to enhance engagement with medical self-care without acknowledging the emotional, practical and identity elements of living, are thus unlikely to be effective in optimising either physical health or wellbeing in young people.

The next chapter presents findings from qualitative interviews with an ethnically diverse group of young people living in North and East London, defined by health care professionals as disengaged from diabetes services and/or diabetes self-care. These interviews provide insight into the experiences of diabetes self-care in this group of young people, including the way in which identity work interacts with their diabetes self-care behaviour.

Chapter 5: Findings from qualitative interviews with young people with diabetes focusing on diabetes self-care

5.1 Overview of this chapter

This chapter describes the findings from qualitative interviews with young people with diabetes living in North and East London defined as disengaged from diabetes self-care and/or diabetes services by clinicians. These interviews aimed to explore experiences of diabetes self-care in this group of young people, who are underrepresented in the literature. Similarly to chapter 4, 'Identity work' emerged as a central theme from these interviews, which underpinned their engagement with diabetes self-care. This identity work was found to be a typology with three components: 'forgetting diabetes', 'diabetes as dominating' and 'diabetes as routine'. These refer to different ways that young people navigate the role of diabetes within their identity. This identity work was described as occurring in four different contexts: within the clinic, at school, with friends and within the family. These different contexts influenced participants' identity work, resulting in participants' 'feeling intimidated', 'feeling different', 'feeling normal' and 'feeling supported'.

The young people interviewed were between the ages of 11 and 19 and all had a diagnosis of type 1 diabetes. All were born in the UK, spoke English as their first language and were registered to a diabetes clinic in either North or East London (data not shown in table). They were interviewed as part of the larger CLAHRC project, described in chapter 1, which focuses on young people's experiences with diabetes services. As part of my role in the CLAHRC project I was involved in the recruitment and data collection for these interviews. Data from these interviews was used in the analysis presented in this chapter.

Participants were recruited from two ethnically diverse urban areas in North and East London : Barnet and Newham. Barnet is a borough in north London, with the second largest population of any London borough, with almost 380,000 residents, according to Trust for London (2018). This research found that approximately 4% of Barnet's working age people are unemployed, which is lower than the London average. However, 24% of employed residents in Barnet are low-paid, which is higher than the London average of 22%. Roughly 70% of 19-year-olds in Barnet have a Level 3 qualification, which is within the top five boroughs in London. Around 14% (9,700) of

children live in low income families and the poverty rates are below the London average (Public Health England, 2018). The health of people in Barnet is generally better than the average across England.

Newham is a borough in the Inner East of London, which experiences significant poverty and inequality. The latest local authority health profile for Newham highlighted the area as being one of the 20% most deprived areas in England (Public Health England, 2018). The health of people in Newham is varied compared with the average across England. Roughly 20% (14,800) children currently live in low income families. Trust for London (2018) found that 32% of residents living in Newham are low paid, which is the highest percentage in London. This research also revealed a 13% point gap in GCSE attainment between Newham's disadvantaged school children and those not facing disadvantage. Newham is within the top four boroughs in London in terms of this issue. The area has one of the youngest populations in the country, as well as having a high proportion of BME residents. According to the most recent census in 2011, 43% of residents in Newham are Asian. Demographic information pertaining to interview participants are presented in figure 2.

Figure 2: Participant demographics (self-reported)

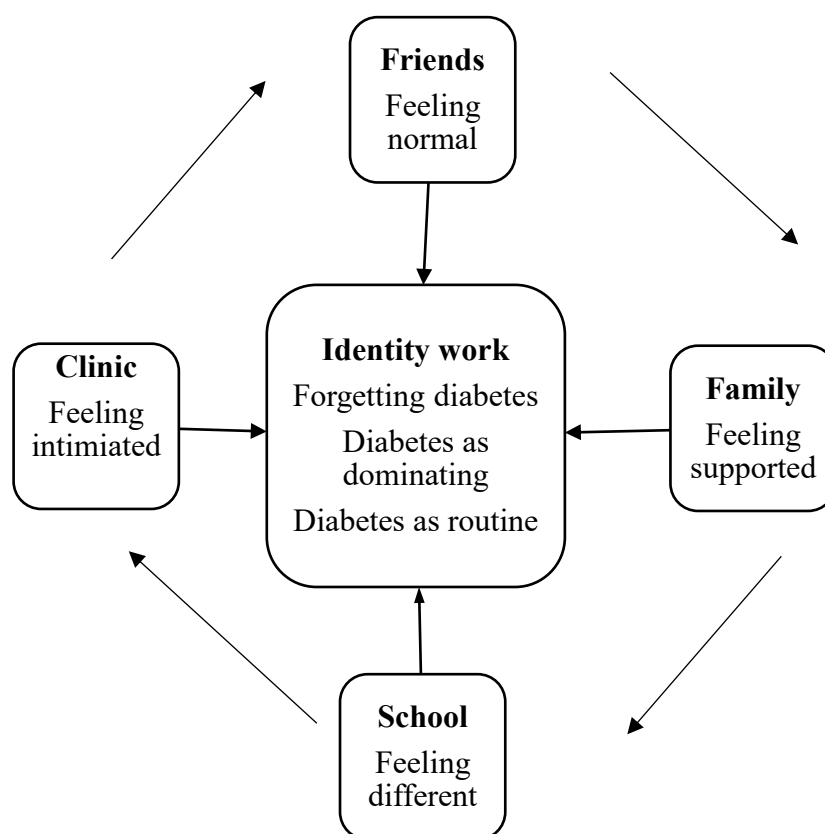
Participant name (pseudonyms have been used)	Gender	Age	Age diagnosed with type 1 diabetes	Ethnicity	Religion	Other family members with diabetes
India	Female	19	5	Mixed heritage (English and Jamaican)	Christian	None
Aaesha	Female	18	14	Asian	Muslim	Aunt, cousin, grandmother
Kai	Male	12	6	Mixed heritage (English and Bajan)	No religion	None

Eshal	Female	18	11	Asian	Muslim	Sister, Aunt, Grandmother
Kyron	Male	13	2	Mixed heritage (Greek and Sudanese)	Christian Orthodox	None
Tayvin	Male	15	2	Mixed heritage (English and Mauritius)	Catholic	Grandmother
Nadia	Female	18	13	Asian	Muslim	Aunts, Grandmother
David	Male	15	14	Mixed heritage (English and French)	No religion	None
Edward	Male	15	14	White (English and Scottish)	No religion	Uncle
Aabir	Male	11	2	Mixed heritage (English and Samalian)	Muslim	Mother
Mahir	Male	13	4	Asian	Hindu	None
Joshua	Male	17	3	White	No religion	None
Rachel	Female	18	4	White	No religion	None
Fiona	Female	13	6 months	White	No religion	Father and Aunt

5.2 Interview findings

The themes that emerged from the analysis of these interviews are summarised in figure 3.

Figure 3: Overview of interview findings pertaining to diabetes self-care in participants



Summary of figure 3

‘Identity work’ emerged as a central theme from the analysis of young people’s experiences with diabetes self-care, similarly to the qualitative review findings presented in chapter 4. ‘Identity work’ refers to the way in which participants navigated the integration of diabetes into self-concept (‘being’ identity) and diabetes self-care into their daily lives (‘doing’ identity). These correspond with the psychological and sociological dimensions of identity proposed by Erikson (1980). Furthermore, these interviews, similarly to the review also demonstrate the continuous nature of identity work, characterised by constant navigation of threats and validators of identity. This is a process that young people are constantly engaging in, which interacts with their diabetes self-care. The aim of this identity work, from young people’s perspective, is a sense of normality.

In addition to supporting the findings from the qualitative review in terms of the significance of ongoing nature of identity work in young people’s experiences with diabetes self-care, these interviews also demonstrated identity work to be a typology. This involves three different types: ‘Forgetting diabetes’, ‘Diabetes as dominating’ and

‘Diabetes as routine’. These refer to different ways that young people navigate the role of diabetes within their identity, and influence engagement with diabetes self-care.

‘Forgetting diabetes’ describes avoidance of the medical aspects of diabetes self-care, which characterises an attempt by participants to prevent diabetes from dominating their identity. For example, ignoring diabetes-related symptoms whilst engaged in an enjoyable activity.

‘Diabetes as dominating’ describes a sense of diabetes disrupting daily life, physically and mentally. For example, continually thinking about the medical aspects of diabetes self-care even when not engaged in these activities.

‘Diabetes as routine’ describes diabetes being fully integrated into both ‘being’ and ‘doing’ identity. It is characterised by a sense of control over diabetes and its impact upon identity. Diabetes self-care activities are thus not experienced as a threat to identity. This identity work occurs when young people experience a sense of normality, which is desirable to young people because they can manage their diabetes whilst pursuing non-diabetes related activities and life goals.

The other four themes, ‘feeling normal’, ‘feeling supported’, ‘feeling different’ and ‘feeling intimidated’, relate to the environments in which this identity work occurred: with friends, with family, at school and within the clinic respectively. These themes describe the impact of these different contexts on participants’ identity work, as a result of the threats and validators to identity within them. For example, an upcoming clinic appointment prompted young people to reflect on their recent medical self-care behaviour. If this was perceived as being suboptimal by young people, a sense of intimidation might be experienced because of the anticipated consequences within the next clinic appointment.

5.3 Identity work

Whilst earlier societies with a social order placed firmly in tradition would provide individuals with relatively fixed roles, such as a ‘farmer’, ‘baker’ etc, in post-traditional societies, we determine these roles for ourselves (Giddens, 1991). In the post-modern world, identity is thus not static but instead continually reshaped over time.

Nevertheless, the perception of a coherent identity is favoured both by ourselves and by

others. The creation of a coherent identity represents a critical developmental task of adolescence.

Erikson (1970) coined the term 'identity crisis', which describes the transition from childhood to adulthood whereby there is an attempt at reconciliation between 'the person one has come to be' and 'the person society expects one to become'. Recent demographic shifts over the past half century have resulted in identity development occurring over a protracted period, now forming a central task of both adolescence and young adulthood (Lugasi et al, 2013). This is a time period which has been referred to as 'emerging adulthood' (Arnett, 2007). During this stage, young people experience a number of transitional changes biologically, socially and psychologically (Holmbeck, 2002). These changes are universally experienced by young people but are nonetheless challenging and require adjustment.

In order to explore the experiences of young people in different stages of identity development, a wide age range was used for the interview sample. This also allowed for the investigation of young people who had lived with diabetes for different lengths of time, took varying levels of responsibility for their diabetes self-care at were at a range of stages in their transition from paediatric to adult diabetes services. However, this thesis did not explicitly set out to investigate the potential influence of age or length of diagnosis on diabetes self-care.

A diagnosis of a chronic condition represents an identity threat, which has been referred to as 'biographical disruption' (Bury, 1982) as described in chapter 2. Such significant life events have been argued to be critical in the development of psychological functioning and wellbeing (Erikson 1970). However, these are particularly demanding for young people to navigate because they are occurring against a backdrop of identity formation, rather than in the context of an established identity as in adults. In addition to the challenge associated with the diagnosis of diabetes for identity, the daily self-care activities required to manage diabetes serve as further disruption because they continually remind young people of having the condition.

Three types of identity work characterised the way participants discussed their diabetes: 'forgetting diabetes', 'diabetes as dominating' and 'diabetes as routine'. 'Forgetting diabetes' refers to identity work underlying the avoidance of the medical aspects of

diabetes self-care behaviour, which is often attributed to forgetting by participants and represents an attempt by participants to minimise the impact of diabetes on both their 'being' and 'doing' identity. 'Diabetes as dominating' refers to identity work occurring when both the illness and the associated medical self-care behaviours represent significant disruptors to daily life and thus maintaining self-care is mentally and physically taxing and thus may also be avoided. Both of these types of identity work are associated with disengagement from the medical aspects of diabetes self-care. It is thus unsurprising that these types of identity work emerged particularly strongly amongst a group of young people defined by clinicians as being disengaged from diabetes services and/or diabetes self-care. For young people, although this disengagement is suboptimal from a physical health standpoint, such behaviour represents an attempt to maintain a sense of normality and create a coherent identity.

'Diabetes as routine' describes a type of identity work where diabetes self-care activities are not experienced as disruptive to daily life or a threat to identity and thus diabetes is integrated fully into participants' identity. This type of identity work is also characterised by a sense that diabetes will not hold the young person back from achieving their non-diabetes related life goals. Identity work is also fluid, with participants transitioning between the different types frequently as they navigate threats and validators to their identity. This fluid movement between types manifests in fluctuating levels of engagement with the medical aspects of diabetes self-care.

Despite a wide age range in the sample, there were not significant differences between participants of different ages. Participants of a range of ages described experiencing each type of identity work ('forgetting diabetes', 'diabetes as dominating' and 'diabetes as routine'). Similarly, despite the varying lengths of time since the diabetes diagnosis, there were no notable differences between participants who had been recently diagnosed compared with those that had lived with the condition for a number of years.

All participants indicated that there were in the process of identity development, and were engaged in identity work, which interacted with their engagement in diabetes self-care. This is likely because of the range of factors influencing identity work, and the dynamic nature of the different settings in which it occurs.

For example, one participant cited that transitioning to pump therapy helped her establish a sense of ‘diabetes as routine’, while another described ‘diabetes as routine’ occurring naturally as a result of getting older, living with diabetes for longer and diabetes self-care behaviours becoming habitual.

In addition, although all participants transition from paediatric to adult diabetes services, there is no consistency about the exact age that this occurs. Two young people of the same age can therefore experience identity work, and the related contextual factors very differently. The significance of transitioning from paediatric to adult services for diabetes self-care is explored in greater detail in chapter 6.

‘Diabetes as dominating’ and ‘diabetes as routine’ types appear to be consistent identity work types in young people with diabetes. Participants in Clausi and Schneider’s study described a desire for greater freedom and a sense of normality, which relate to diabetes dominating identity. Some participants in the study also articulated a sense of diabetes as being part of themselves, which is synonymous with ‘diabetes as routine’ described in the current research. However, ‘forgetting diabetes’ was not reported by Clausi and Schneider (2017), which may be because this study did not specifically focus on young people defined as disengaged from diabetes self-care. This suggests that ‘forgetting diabetes’ may be unique to the experiences of young people struggling to integrate the medical aspects of diabetes self-care into their daily lives.

These three aspects of identity work described in this chapter reflect the tension in the literature between the importance of integrating diabetes into identity and creating identities which are separate from diabetes. These two positions have traditionally been positioned as being inherently contradictory (Commissariat et al, 2016). The current research suggests that both integrating and distancing are important in identity work. Integrating diabetes into both ‘being’ and ‘doing’ identity is necessary in order to remain engaged with diabetes self-care, characterised by ‘diabetes as routine’. In contrast, a lack of integration of diabetes into identity is characterised by ‘forgetting diabetes’. An intense focus on diabetes as part of identity can create a sense of being overwhelmed by diabetes, characterised by ‘diabetes as dominating’. This has been described in previous research as a process whereby young people learn to live with diabetes without making it ‘the main thing’ (Foster, 2010).

a) 'Forgetting' diabetes

'Forgetting diabetes' describes identity work involving the avoidance of the medical aspects of diabetes self-care, such as testing blood glucose levels regularly and injecting insulin before meals. This theme describes an attempt by young people to minimise the impact of diabetes on both 'being' and 'doing' identity and was present in around half of the account of participants. As mentioned previously, the task of integrating the different aspects of oneself into a coherent identity has been described as a central part of the 'identity crisis' characterising adolescence and young adulthood by Erikson (1970). It is thus something engaged in by young people with and without diabetes.

It has been argued that there is a paradox within the lack of engagement in the medical aspects of diabetes self-care in young people. The behaviour is physically dangerous but serves a psychosocial function as young people seek to develop an identity that is separate from their parents and one that is not dominated by their condition (Aujoulat et al, 2017). Inconsistent diabetes self-care, whilst risky from a clinical perspective, may thus be an important step in young people integrating diabetes into both their 'being' and 'doing' identity.

The notion of forgetting has been discussed in previous research on young people with diabetes and has been linked with diabetes self-care. However, this has rarely been characterised explicitly as identity work. Mulvaney et al (2008) reported that young people often forgot to perform diabetes self-care activities in the evenings, a time when they were mentally and physically fatigued. Conversely, Boman et al (2015) reported that young people defined as 'adherent' to diabetes self-care behaviours described being unable to forget about diabetes, which was cited as the reason for continuing to engage in diabetes self-care. Authors also found that those defined as non-adherent also reported forgetting about diabetes, which, similarly to the current research, was described in positive terms as an emotional strategy that prevented diabetes from dominating identity. Benefits of forgetting about diabetes have also been reported by Wicks (2011), who discussed the importance of exploring non-diabetes aspects of identity for young people, which allowed them to temporarily forget about diabetes. Such research highlights the problem with focusing solely on the medical aspects of

diabetes self-care, which neglects to acknowledge the important identity work in which young people are engaging and the psychosocial benefits of this work.

‘Forgetting diabetes’ was described as being an almost inevitable consequence of the invisibility of diabetes. India described only being reminded of the condition whilst engaging in medical aspects of diabetes self-care.

“I am only reminded that I have diabetes when I do my insulin injections, others don’t know that I have diabetes because it is not visible to others” (India, female, Mixed heritage, 19, diagnosed age 5)

For India, diabetes was hidden to others and thus was not something which of which she was constantly reminded of either. Performing insulin injections as part of her diabetes self-care was the only time that she was aware of living with diabetes and thus she remained mostly detached from diabetes, rather than perceiving it as forming a central part of her identity. India’s account demonstrates the significance of the characteristics of diabetes and the perceptions of others in influencing the ability to integrate diabetes into her identity.

‘Forgetting diabetes’ was sometimes discussed by participants in relation to personality; an inevitable consequence of being a ‘forgetful person’. This was described by Eschal who articulated a strong sense of challenge and obligation associated with her diabetes.

“I said responsibility and hard work. I think they kind of interknit together. It’s after you constantly remember to do it... Because I forget - I’m quite forgetful.” (Eschal, female, Asian, aged 18, diagnosed age 11)

For Eschal, needing to constantly perform medical self-care activities felt like an ongoing burden because she needed to continually remind herself of them, rather than them being habitual. This continual struggle resulted in these behaviours often being neglected, which she attributed to her forgetful nature. ‘Forgetting diabetes’ was thus considered to be an inevitable consequence of being a forgetful person. Her account demonstrates the conflict experienced between being forgetful (an aspect she considered to be part of her personality) with being consistent with the medical aspects of diabetes self-care. Experiencing conflicts whereby different aspects of identity seem

incompatible with each other are described as being a central part of the ‘identity crisis’ and form an important aspect of the identity development process (Erikson, 1970).

‘Forgetting diabetes’ also occurred in accounts describing the sequence of the medical aspects of diabetes self-care. Rather than taking insulin injections before meals, several participants would either take their insulin injections late or sometimes miss their insulin injections completely. This was especially apparent in participants who were more recently diagnosed, such as Edward, who had lived with diabetes for less than a year.

“No it was just me not injecting, or me eating first and forgetting to inject or something, I don’t know.” (Edward, White, aged 15, diagnosed age 14)

Edward acknowledged both forgetting and conscious avoidance of self-care as being influential in this behaviour. He described initially forgetting a medical aspect of diabetes self-care and then feeling reluctant to engage in these behaviours when he did remember at a later stage.

“I suppose a bit of both. So I forgot I suppose I wouldn’t really want to go and do it later on.” (Edward, White, aged 15, diagnosed age 14)

The simultaneous attribution of both forgetting and being unwilling to engage in a particular aspect of diabetes self-care, highlights the multiple influences on diabetes self-care experienced by Edward and the difficulty in integrating diabetes into his identity. Edward’s account also demonstrates the potential for these different influences to interact with each other, described when he initially forgot a medical aspect of diabetes self-care and then later avoided the behaviour.

The simultaneous attribution of forgetting and reluctance to engage in diabetes self-care activities was also described by Fiona who articulated her struggle to remain consistent with the medical aspects of diabetes self-care because it conflicted with her desire to have fun with her friends.

“Occasionally I do muck up and just forget about it because I can’t be bothered and I just want to enjoy myself. And, but apart from that I deal with it alright. I do all my

injections, some of them, not on time.'' (Fiona, female, White, aged 13, diagnosed age 6 months)

Being inconsistent with the medical aspects of diabetes self-care, specifically delaying or missing insulin injections, was not described as a regular occurrence by Fiona. Nevertheless, similarly to Eschal, Fiona experienced a conflict. She felt conflicted between wanting to have fun with friends and carrying out particular diabetes self-care activities, which were perceived as preventing her ability to experience that enjoyment. This conflict could cause her to 'forget' about diabetes and miss her insulin injections. Fiona's account demonstrates the struggle with integrating the different aspects of her identity: a conflict between being a person who likes having fun, and being a diabetic.

'Forgetting diabetes' could sometimes result in serious short-term health consequences for Fiona. Such events tended to occur when she was participating in enjoyable activities, such as singing in a choir. Despite knowing that she was experiencing low blood glucose levels, she described ignoring the symptoms, resulting in an emergency situation, made more serious by her 'forgetting' her glucose.

“...I start to get dehydrated but I just, sometimes I ignore it because if I'm doing something like choir, it's using my voice a lot and because like its movement it's well, I don't do an adjustment jab for it because last time, this was about two weeks ago, last time I did do an adjustment jab when my level was about 13, I went down that day, me being me stupid I forgot my [glucose] and my levels, and my phone died and I was on my way home. Luckily I got off the bus and a shop keeper let me erm, get a chocolate bar until a couple of days after.” (Fiona)

Although Fiona knew that singing affected her blood glucose levels and she was aware of the associated symptoms, she was reluctant to attend to her diabetes, an attempt to minimise the impact of diabetes on her identity. She describes sometimes ignoring the symptoms of low blood glucose levels and instead focus on her preferred activity, resulting in serious short-term consequences to her physical health. These negative consequences were exacerbated by her 'forgetting' her glucose tablets.

Fiona's account demonstrates the conflict she experienced between an activity she enjoyed (singing in a choir) and carrying out the medical aspects of diabetes self-care,

which can feel intrusive in such situations. This highlights the significance of such identity conflicts in influencing engagement with the medical aspects diabetes self-care. Furthermore, this conflict highlights the problem with the assumption in the literature that a lack of engagement with the medical aspects of diabetes self-care is the result of a lack of knowledge of the behaviours and the consequences. Instead, such behaviour represents an attempt to maintain a 'normal' identity and a sense of wellbeing by engaging in activities that are enjoyable.

Fiona also described 'forgetting diabetes' when she felt restricted with time. This occurred whilst she was working a job after school each day, for a total of 62 hours a month. Not finding time for herself was cited as causing Fiona to both forget and purposefully avoid medical aspects of diabetes self-care. She described initially postponing these activities until later in the day but then feeling reluctant to perform self-care at that later time.

‘Because of not finding any time for myself I was forgetting that I had diabetes and I was avoiding it. I would get home at half past eight, just finish my dinner by 9 o’clock and be in bed. And the injection would be sitting across the room and I’d think, I can’t even get out of bed and get that. And then it became a routine to not get out of bed and go and get that and I fell downhill from that point onwards.’ (Fiona)

Diabetes self-care was experienced as highly demanding in terms of both time and energy and thus was avoided in favour of other activities during the day. Once she was home in the evening, Fiona struggled between what she felt she 'should' do (a medical aspect diabetes self-care) and what she felt able to do. This presented a conflict between medical self-care and maintaining her wellbeing in light of all the other activities she was engaging in. Fiona also described the avoidance of medical aspects of self-care becoming habitual, which she perceived in negative terms, as evidence of her going 'downhill'.

Other participants described relying on reminders from others to perform medical aspects of diabetes self-care, including parents, teachers and friends. In addition to reminders, they would also provide practical help to ensure that these activities were completely correctly. This most commonly occurred in younger participants, such as

Kai who had lived with diabetes since the age of 6. Kai described the important role his teachers played in his medical self-care.

“And my tuition they help me a lot cos I have to test at the right time, and sometimes I forget so my tuition are there to help me if I’m doing it right or I’m doing it wrong.”

(Kai, male, Mixed heritage, age 12)

Kai relied on teachers, as well as his parents and friends, to ensure that he performed his blood glucose tests at the right times. He described otherwise struggling to be consistent with these activities even though he had lived with the condition for 6 years. These reminders were perceived as being helpful, rather than being intrusive, and thus he appreciated their involvement. For Kai, unlike other participants, the diabetes self-care aspects were not perceived as interfering with other non-diabetes related activities or as a threat to his identity.

‘Forgetting diabetes’ sometimes occurred in relation to clinic appointments, particularly when participants were busy and experienced conflicting priorities. Although she had lived with diabetes for 14 years, Rachel described struggling to attend these appointments regularly when she had important exams at school.

“And what with it being the, coming up to the end of school, coming up to exams it’s very difficult to remember why the hospital is so important.” (Rachel)

For Rachel, diabetes clinic appointments were difficult to prioritise because of her school exams, which were important to her. Similarly to Fiona, she experienced a conflict between knowing what she ‘should’ do (attend her clinic appointments) and what she wanted to prioritise (her school exams). Exams were described as being a more pressing issue, likely because the consequences of exams are seemingly more tangible and short term than the consequences of not attending a single diabetes clinic appointment. Nevertheless, such accounts demonstrate the variety of different challenges faced by young people in their daily lives which conflict with their ability and desire to maintain engaged with both the medical aspects of diabetes self-care and attend clinic appointments regularly. It is thus important to acknowledge such issues in the context of clinic attendance, rather than merely labelling young people who do not attend appointments regularly as ‘disengaged.’

‘Forgetting diabetes’ was also present in the account of David, who described self-harm behaviour relating to his diabetes self-care. David described restricting food intake and missing insulin injections because of the hyper-focused psychological state achieved by these activities. This self-harm behaviour suggests an attempt to attain a sense of being in control. Ironically, such behaviour resulted in increasing the potential for negative health consequences which would be out of his control as a result of the imbalanced blood glucose levels created by this self-harm behaviour. However, David did not see his behaviour as problematic and described having adequate diabetes supplies as being sufficient in allowing him to carry out the medical aspects of diabetes self-care regularly.

‘Not really. For me I just see diabetes as just another thing, it’s not a problem really. It would be a problem if I did not have a supply. But right now it’s no problem.’
(David, male, Mixed heritage, aged 15, diagnosed age 14)

David did not describe diabetes as a threat to his identity despite regularly avoiding certain medical aspects of self-care. Diabetes was perceived as being ‘no problem’ because of having access to diabetes equipment, which meant that medical self-care was physically possible. The short length of time since David’s diagnosis meant that he had not had the opportunity to engage in as much identity work or had as much opportunity to experience the longer-term consequences of avoiding the medical aspects of diabetes self-care. Therefore unlike other participants, he did not perceive diabetes as being a threat to his identity but nevertheless avoided certain medical aspects of diabetes self-care in order to maintain a desirable psychological state. This account also highlights the potential for tension between medically optimal diabetes self-care and maintaining a sense of wellbeing for young people.

b) Diabetes as dominating

‘Diabetes as dominating’ was an aspect of identity work which occurred in several participant accounts. For these participants, diabetes the illness and its management served as significant disruptors to their daily lives, physically and mentally. Physically, the medical aspects of diabetes self-care dominated because they were time consuming and painful. Diabetes self-care was thus perceived as negatively interfering with other

areas of life which were important to participants in maintaining their wellbeing and their identity as a ‘normal’ young person. This created a conflict between participation in these life activities and being consistent with the medical aspects of diabetes self-care.

Diabetes was also described as being mentally disruptive. Diabetes tended to dominate participants’ thoughts and thus could feel mentally draining, making medical self-care difficult to sustain because it was perceived as adding to this burden. When diabetes dominates identity, the developmental task of integrating the different aspects of oneself into a coherent identity is particularly challenging. Erikson (1970) used the term ‘negative identity’ to describe such challenges, in which the young person struggles to integrate a perceived negative aspect of identity, in this context diabetes, with the other aspects of identity. Such tensions can underlie a lack of engagement with the medical aspects of diabetes self-care.

‘Diabetes as dominating’ is synonymous with a high level of illness centrality, a concept which describes the extent to which the illness experience plays a central role in an individual’s identity (Helgeson and Novak, 2007). Research has demonstrated that illness centrality is associated with poorer psychosocial adjustment to illness (Morea et al, 2008) as well as with reduced wellbeing and development of self-care capabilities (Helgeson and Novak, 2007). It is thus important to support young people in reducing the perceived threat of diabetes and helping them integrate the condition into their identity whilst maintaining their wellbeing.

For Tayvin, the medical aspects of diabetes self-care were not always physically difficult to perform but were nevertheless draining, which could create the temptation to avoid them. Knowing that he needed to remain engaged in medical self-care in order to maintain his health was a further weight on his mind. This knowledge contributed to a mental battle between what he felt he should do and what he wanted to do, a battle that cannot easily be resolved for those living with diabetes.

“I want to say [diabetes] has a very direct impact or can have...I guess the amount of food I eat, the amount of activities I do.” (Tayvin, male, Mixed heritage, age 15, diagnosed age 2)

Tayvin articulated an acute awareness of the impact of diabetes on a variety of factors. The pervasiveness of this impact meant that diabetes was perceived as dominating. Interestingly, this influence was not deemed to be inevitable but was seen as being a likely consequence of living with diabetes. Although Tayvin had lived with diabetes for 13 years, diabetes continued to have a significant influence on his daily life and he felt constrained by the limitations that it placed upon him.

Kai described the time and effort required to perform the medical aspects of diabetes self-care, which created a sense of 'diabetes as dominating'. Determining the amount of carbohydrate he was ingesting and the corresponding insulin dose required was difficult even though he had lived with diabetes for 6 years. Needing to check the accuracy of calculations was a further difficulty, resulting in such activities being even more onerous to undertake.

“Erm, calculating all the stuff, it’s really hard. You can’t just do it like snap I’ve got the answer, like cos, say erm, at lunchtimes at school I have to do my carb counting but at the same time I have to use my maths skills at it and I have to work out, like going through it and everything and I have to double check my answer, cos make sure that it’s the right insulin I’m taking. So say I take a bit too much I might go to , a bit too less go a bit high so you have to be like right.” (Kai, male, mixed heritage, aged 12, diagnosed age 6)

For Kai, diabetes dominated due to the both the nature of the medical self-care behaviours themselves and the severity of the consequences. Such accounts demonstrate the interaction between the physical and the mental aspects of the medical aspects of self-care, which serve to dominate daily life physically but also serve as an ongoing reminder of having diabetes and thus can be a threat to identity.

Diabetes could dominate at times when participants were not engaging in medical self-care activities. Aaesha, described diabetes as continually pervading her everyday thoughts.

“Diabetes is always on your mind even when you’re not injecting.” (Aaesha, female, Asian, aged 18, diagnosed age 14)

For Aaesha, this continual presence of diabetes on her mind made it more difficult for her to focus on other areas of her life. She felt as though she was either carrying out medical aspects of self-care or thinking about these activities all of the time. Despite having lived with diabetes four years, the impact of diabetes on her daily thoughts had not dissipated. Diabetes thus dominated her identity, overshadowing other aspects and threatening her sense of normality. Such struggles are characteristic of ‘negative identity’, whereby a particular aspect of identity is hard to integrate into the self and form a coherent identity (Erikson, 1970).

The sense of ‘diabetes as dominating’ could result in avoidance of medical self-care activities as an emotional coping mechanism. Eschal described missing insulin injections, mainly when she was with her sister, who also had diabetes. For Eschal and her sister, skipping insulin injections was described as being a form of mutual emotional support. This prevented diabetes from physically and mentally dominating their lives.

‘A lot of people - well, some people that I do know that have diabetes, like me and my sister - I’m not going to lie – sometimes we don’t do our injection because it gets really stressful, and we get frustrated because, you know, it hurts, it bruises, we bleed, and it just gets really annoying. After a while you just don’t want to do it.’ (Eschal, female, Asian, aged 18, diagnosed age 11)

Eschal described missing insulin injections as being a common practice amongst young people with diabetes with the aim of easing both the physical pain and emotional burden of diabetes self-care, thus reducing the dominance of diabetes. Avoidance of these aspects of self-care were thus perceived as normal. Despite having lived with diabetes for seven years, the pain, frustration and stress of performing insulin injections had not dissipated for Eschal and such experiences were reinforced by her sister.

Eschal also cited being diagnosed at a young age as contributing to an increased sense of ‘diabetes as dominating’. She contrasted her knowledge of diabetes currently to when she was first diagnosed. The lack of awareness about diabetes and its consequences at diagnosis was described as leading to an overestimation of the impact of diabetes on her life.

“Yeah, when I was diagnosed I didn’t know what diabetes was. No one told me. I didn’t learn about it. So in my head I was thinking I have this condition I have no idea what it is. I was never taught about it. So I thought it was something really big and I thought, okay, my entire life is going to change – you know, the way I eat and the way I look at everyone. It was just a really big impact on me because I was so young at the time and I didn’t know anything.” (Eschal)

Diagnosis was described as an overwhelming time for Eschal. She anticipated that diabetes would have a large impact on her, both in terms of her daily life and her perceptions of others. The lack of knowledge about diabetes meant that it was an unknown entity and thus impossible to integrate into her identity. Such experiences are characteristic of the ‘biographical disruption’ that is experienced when being diagnosed with a chronic condition, such as diabetes, where young people are confronted with a threat to their identity (Bury, 1982).

The sense of ‘diabetes as dominating’ could also have significant and ongoing effects on young people’s wellbeing. Rachel described an ongoing struggle with negative thoughts relating to her diabetes, which contributed to her feeling negatively about herself.

“... diabetes is very mentally draining. There are from books that I’ve read based on diabetes and blogs that I’ve read and stories that I’ve read, depression that comes with diabetes. It’s very easy to feel disappointed in yourself, and to blame yourself and to dislike yourself because of your diabetes. You’re disappointed you’ve failed to do better at improving it. Or you’re doing worse than you was doing the three months ago. Or you know you hate yourself because you’re forever worried that you’re going to lose an arm or a leg or you’re going to go blind and obviously that’s very scary. So I think being reassured, being able to communicate is a very important thing.” (Rachel, female, White, aged 18, diagnosed age 4)

The mental struggles articulated by Rachel were perceived as being normal for a person with diabetes to experience but were nonetheless mentally taxing for her to deal with on a daily basis. Rachel’s account demonstrates the continued impact that living with diabetes can have, both in terms of emotional wellbeing and in influencing a young person’s identity. For Rachel, diabetes was so dominant that it overshadowed other

aspects of her identity and disrupted her everyday life. Establishing an identity which was not dominated by diabetes was thus a struggle. Such accounts highlight the ongoing identity work in which young people are engaging and the importance of supporting young people's wellbeing, rather than a narrow focus on their physical health.

'Diabetes as dominating' could also arise after experiencing negative consequences as a result of avoidance of the medical aspects of self-care. Rachel described such events as providing prompts for her to become more focused upon these self-care activities in the future. Such situations heightened her awareness of the severity of diabetes-related health consequences and thus she became more adamant in her efforts to prevent them.

'Erm, I mean things that have worked for me, are really bad things that have happened... And because of that I fixed up, and I was doing my testing more than I should have been doing. I was OCD every time I saw my testing gear I'd do a test, I mean seconds after I'd do it. And I get a bit focussed and really improving from that point onwards. But the routine of testing and injection does get boring and quite repetitive very quickly. And because of that I soon grew out of that routine and got bored very quickly basically.' (Rachel)

Despite the severity of the health consequences, these were perceived positively by Rachel because they were catalyst for boosting her engagement with the medical aspects of diabetes self-care. However, as she was motivated by fear, these activities were engaged in more frequent than necessary. This demanded a high degree of both time and effort, resulting in a sense of diabetes dominating her daily life, which was difficult to sustain. Nevertheless, without such serious events occurring, Rachel struggled to stay consistent with these behaviours, which she attributed to boredom. The medical aspects of her diabetes self-care thus oscillated between intense engagement and non-engagement, with diabetes either dominating her daily life or being completely avoided. Her account demonstrates the fluid nature of identity work as young people negotiate the role of diabetes within their identity.

The sense of 'Diabetes as dominating' was described as being ameliorated by participating in activities unrelated to diabetes. Fiona described benefitting from external support networks, such as charities. These charities were helpful in lessening

the dominance of diabetes in her identity because they providing the opportunity to focus on non-diabetes related activities.

“There are, like charities that have helped, because there has been periods where it’s been really stressful and they’ve helped out so like, they’ve helped like with clothing, or spending money, so I could just like release stress for a day, and that has been a really big help.” (Fiona, female, White, aged 13, diagnosed age 6 months)

For Fiona, participating in non-diabetes related activities allowed the condition to fall into the background, perhaps even temporarily forgotten, which improved her emotional wellbeing. This highlights the significance of engaging in non-diabetes related activities in helping to mitigate the dominance of diabetes on identity for young people. Such activities help to reinforce the other non-diabetes related aspects of identity, helping to create an identity which is not dominated by diabetes.

c) Diabetes as routine

‘Diabetes as routine’ was an element of identity work present in the majority of participants’ accounts. For these participants, diabetes was fully integrated into their identity and was not experienced as being disruptive, physically or mentally. Diabetes did not dominate their lives but instead was woven into their habits so that it did not detract from other aspects of their identity. Participants described a sense of control over their diabetes and a perception that diabetes would not prevent them from engaging in enjoyable activities or from achieving non-diabetes related life goals that were important to them. This is the identity work occurs when young people perceive a sense of normality, as described in chapter 4.

The majority of participant accounts describing ‘diabetes as routine’ also made reference to at least one of the other types of identity work in their accounts: ‘forgetting diabetes’ or ‘diabetes as dominating’. This suggests that identity work is fluid, whereby participants are continually negotiating the role of diabetes within their identity as part of the ‘identity crisis’ (Erikson, 1970). However, other research has described this process as being more linear (Paterson and Sloan, 1994). Authors described ‘growing up as a diabetic’ as being characterised by an initial tendency to follow strict routines. This is by a gradual adaption over time towards ‘adulthood’ where young people no

longer strive for perfection because of the inherent unpredictability of diabetes. It is plausible that identity work is more fluid in the short term (such as during adolescence and young adulthood) but more linear over the long term (during adulthood).

The importance of ‘diabetes as routine’ for identity work has been discussed by Balfe (2007). Young people in this study described routines as serving both a biological function (maintaining stable blood glucose levels) but also providing benefits to identity. Medical self-care routines served as a platform from which young people could engage in non-diabetes activities related to other non-diabetes related aspects of their identity. Taken together with the findings of the current research, this suggests that diabetes self-care routines are both a cause and a consequence of identity work. The integration of diabetes into identity allows for such self-care routines to be created and the creation of these routines allows for other non-diabetes related aspects of identity to be explored.

The sense of ‘diabetes as routine’ was demonstrated in accounts describing habitual diabetes self-care behaviour. For Edward, these habits were sometimes as simple as eating similar foods each day.

“Well I’m kind of a fussy eater so, I suppose I eat mostly the same thing most of the time, so it’s quite easy to manage.” (Edward, male, White, aged 15, diagnosed age 14)

Maintaining a consistent diet was helpful in making diabetes less intrusive in Edward’s everyday life. This allowed him to minimise time spent deciding on what to eat, how many carbohydrates the foods contained and how much insulin was required. The extra time and energy obtained could be used towards engagement in other activities, which prevented a sense that diabetes dominated his daily life.

Acceptance of diabetes and its consequences was cited as being particularly important in facilitating a sense of ‘diabetes as routine’. Fiona described this as occurring naturally over the time that she had lived with diabetes. Knowledge that diabetes was not curable was particularly important for helping Fiona integrate diabetes into her identity because there was not a conceivable alternative.

‘‘over time I’d just get used to it, you know what you’ve got it you can’t get rid of it, there’s no cure, just get on with it.’’ (Fiona, female, White, aged 13, diagnosed age 6 months)

For Fiona, knowing that diabetes could not be cured was empowering. Her account demonstrated an acceptance that a life without diabetes was impossible and thus integrating diabetes into identity was compulsory. The integration process was described as occurring slowly over time, demonstrating the ongoing nature of identity work (Erikson, 1970). The protracted influence of diabetes on identity described by Rachel characterises the concept of ‘biographical disruption’, whereby there is both an acute and chronic threat to identity following a chronic condition diagnosis. (Bury, 1982).

India described the importance of feeling similar to others without diabetes as helping her to become more comfortable with the diagnosis. This allowed her to be more open about living with diabetes and increased her willingness to provide information to others.

‘‘I now enjoy showing and teaching others about diabetes but I used to keep it a secret from others, now getting older I have realised that diabetes doesn’t make me different from anybody else, at age 14-15 I became more comfortable with my identity.’’ (India, female, Mixed heritage, aged 19, diagnosed age 5)

Despite having lived with diabetes for 14 years, the acceptance of her diabetes diagnosis had only occurred relatively recently for India. Her account highlights the importance of young people becoming comfortable with their own diagnosis before feeling able to disclose to others. Furthermore, her account demonstrates the potential for sharing information about diabetes to become something that is enjoyable for young people with diabetes.

The impact of a lack of acceptance of diabetes was described by Rachel, who described an initial struggle to come to terms with having the condition, a time which was also characterised by avoidance of the medical aspects of self-care. Interestingly, she did not seem to connect her lack of acceptance with her avoidance, demonstrating the unconscious nature of identity work.

‘Erm my childhood with diabetes was quite bad. I’ve never really accepted it. I’ve never really controlled it very well either.’ (Rachel, female, White, aged 18, diagnosed age 4)

Rachel highlights the importance of accepting the diabetes diagnosis in determining her engagement with medical self-care activities and thus facilitating a sense of ‘diabetes as routine’. As a result of not accepting diabetes, diabetes self-care was avoided, resulting in difficulty achieving stable blood glucose levels, described as diabetes not being ‘controlled’. Medical self-care activities serve as a continual reminder of having diabetes and thus when the condition is not fully accepted, these activities are experienced as being a threat to identity. When young people, such as Rachel, are diagnosed at such a young age, it is long before they begin to formally develop an identity. This age of diagnosis is thus not a time period characterised by engagement with identity work (Erikson, 1970).

Although Rachel struggled to accept her diabetes diagnosis at a younger age, the identity threat of diabetes was described as lessening over time in her account. This allowed the medical aspects of diabetes self-care to become habitual because they were not experienced as disruptive to her identity, which facilitated a sense of ‘diabetes as routine’.

‘Yeah its faded in to now obviously having been like that since I was young it’s become a habit to then do it as I get older. So yeah the diagnosis and the stages of having it from a young age are having an effect on me now I would say.’ (Rachel)

Rachel described a gradual and organic acclimatisation to her diabetes diagnosis and integration of diabetes into her identity, characterises the experience of an ‘identity crisis’ (Erikson, 1970). Rachel’s account suggested that this identity work occurred in stages, with earlier stages continuing to have an impact on her currently. Rachel’s account demonstrates the importance of identity work in learning to accept the condition and its implications and thus helping young people navigate medical self-care in their daily lives. It is only when young people reach adolescence that this identity work begins and the ability to integrate diabetes into identity is possible, resulting in a sense of normality and ‘diabetes as routine’.

Increasing experiential knowledge of the consequences of fluctuating blood glucose levels was also cited as being helpful by Rachel in facilitating a sense of 'diabetes as routine'. Diabetes-related symptoms, although both physically and mentally unpleasant, reminded her of the importance of engaging in the medical aspects of self-care. Becoming increasingly aware of these effects, along with a lack of attention from others towards diabetes self-care, helped Rachel remain more engaged in self-care.

'because obviously I'm totally in control of it now and as soon as my sugars have gone up, I'm the one that feels rough. And I'm moody and people don't like to be around me and it gets a bit uncomfortable. So I do it for my own wellbeing now rather than other people's wellbeing, you know. No one really asks me anymore so I don't get any attention from it or anything.' (Rachel)

The experiential knowledge of the physical and psychological effects of changes in blood glucose levels was described as being valuable by Rachel. Although such effects could be physically harmful to her health, they served an important role in providing her with a sense of control because she was aware of the consequences of her behaviour. As Rachel no longer received a high amount of attention from others when she experienced blood glucose fluctuations, the benefits of engaging in medical self-care activities outweighed those gained from avoiding them. 'Diabetes as routine' was thus rewarding because it allowed Rachel to maintain a sense of wellbeing.

Nadia cited a recent change in diabetes equipment, the transition to an insulin pump as being important in facilitating a sense of 'diabetes as routine'. Pump therapy was described as being physically helpful in maintaining stable blood glucose levels but also as being beneficial psychologically because it lessened the time taken for medical self-care and was not visible to others.

'Very much. Cos before it was like writing out everything, you can't really tell I'm wearing a pump right now because everything is electronic blue tooth, I know within a certain range of space the pump and the meter will connect automatically vibrated so I will know the insulin will get delivered so I will know I won't need to do something specifically like take it out or anything. Whereas with the pen I have to pick up my clothes, to open this, put a needle in the pen, do this, it's like a big long procedure

before I actually give myself the injection whereas this is, I do my blood, put in my carbohydrate and that's it. You can't even tell. And the noise is so quiet you can't even tell. Unless it's like really pin drop silence probably then. I've never actually tried it I must say, but probably then you would know that something electronically is going on. Otherwise, generally you can't tell.'' (Nadia, female, Asian, aged 18, diagnosed age 13)

The physical and psychological advantages of the insulin pump meant that diabetes was not experienced as being disruptive and thus was not a threat to Nadia's identity. The reduced time, effort and visibility of pump therapy compared to insulin injections allowed diabetes to fall into the background, allowing her to focus on non-diabetes aspects of her identity. Nadia's account demonstrates the role of diabetes equipment in influencing identity work and engagement in the medical aspects of self-care.

A consequence of the sense of 'diabetes as routine' was that Nadia felt empowered to reach her non-diabetes related goals, without fear of the condition holding her back. Being able to pursue goals similarly to those without diabetes was cited by Nadia as being highly valuable because it provided her with a sense of freedom. Being able to conceal her diabetes from others was described as further reinforcing this sense of freedom.

"No nothing stops me not in that way, it doesn't stop me from doing anything. Like it was today when I had a questionnaire, it says erm, do you feel that erm, you have your diabetes is preventing you to be like a normal person. I said no because no one can actually tell, if I was to walk on the streets like that no one could actually tell that I had diabetes, unless I actually, actually do something for example a blood test, or take out something from, or even actually not even drinking Lucozade because people drink Lucozade anyway but something in that category of doing something like that, only then will someone find out oh so and so, this child has, or this guy has diabetes.'" (Nadia)

For Nadia, being able to conceal her diabetes from others prevented diabetes from being a threat to her identity because it allowed her to feel like a 'normal person', which was important for her wellbeing. Nadia thus avoided telling anyone outside her family about her diabetes. Although this non-disclosure increased the risk for negative health consequences if a diabetes-related emergency was to occur, it prevented the condition from posing a threat to Nadia's identity and thus allowed her to maintain a sense of

normality. This highlights the potential tension between optimising the medical aspects of diabetes self-care and maintaining a sense of wellbeing for young people.

5.4 The context of identity work

It is important to acknowledge that identity work in young people with diabetes does not occur within a vacuum but is influenced by both the personal and social context surrounding young people (Erikson, 1956). This has been described by Radley (1994, p.39) who states that ‘chronic illness means living with illness in a world of health’. The four other themes which emerged from these interviews: feeling intimidated, feeling different, feeling normal and feeling supported, represent these different contexts relevant to participants’ identity work: the clinic, the school, friends and family respectively.

5.5 Feeling intimidated

‘Feeling intimidated’ was described participant accounts describing experiences with clinic appointments. Young people with diabetes are expected to attend four clinic appointments per year, where they see a doctor and diabetes specialist nurse, as well as other health professionals occasionally, such as a dietician and a psychologist. This comprises the multidisciplinary health care team which is recognised as optimal diabetes care (NICE, 2015). At the clinic appointments, health measures are taken, including a measure of HbA1c, which represents the average blood glucose level over the previous three months. Young people are encouraged to attend clinics on a regular basis because regular attendance is associated with improved blood glucose control (NICE, 2015).

Attending clinic appointments was described as intimidating when participants perceived their recent medical self-care to be inconsistent and thus worried about the consequences of this at their upcoming appointment. This was such behaviour is likely to result in a less favourable HbA1c measure, which participants worried would dominate the conversation in the clinic appointment. The context of the clinic appointments could also be intimidating for participants, in terms of the hospital setting and the particular health care professional with whom they were interacting. This resulted in young people feeling intimidated and thus were more reluctant to ask for help and support for the medical aspects of self-care. Consequently, participants could

be trapped in a cycle where they struggled to maintain consistent medical self-care in their daily lives but felt too intimidated to discuss their struggles within the clinic environment.

Previous research has suggested that clinic appointments, with their tendency to focus on diabetes education about diet and exercise, are ineffective in improving medical self-care because they serve to emphasise diabetes identity, which subsequently reduces the likelihood in engaging in medical self-care (Tilden et al, 2005). This means that rather than helping to support young people to integrate medical self-care into their daily lives and allow it to become routine, clinics can actively contribute to the sense of diabetes dominating daily life and an avoidance of these behaviours.

Previous research has also suggested that a strong focus on diabetes education emancipates young people from their membership to an adolescent group because optimal self-care from a medical perspective is associated with the adoption of an adult identity (Fonte et al, 2017). This idea is supported by research reporting that young people with diabetes consider themselves as being more adult than young people without diabetes (Luyckx et al., 2011). Previous research has also demonstrated young people's preferences for being seen as an individual first and then as someone living with diabetes (Carroll and Marrero, 2006). This highlights the value of adopting a salutogenic approach within the clinic, which allows for young people to be conceptualised as individuals rather than 'diabetics' by health care professionals, which includes the acknowledgement of non-diabetes related aspects of their lives and the bidirectional relationship between those aspects and medical aspects of diabetes self-care.

Upcoming clinic appointments provided a prompt for participants to reflect on their recent medical self-care behaviour. If this was perceived as being inconsistent, this increased anxiety and made young people less likely to want to attend an appointment.

Joshua described being worried when a clinic appointment was approaching if he had experienced a 'bad week' of medical self-care, despite knowing that the appointment aimed to be a source of help and support.

“For some reason I get nervous whenever I’m going to go to one. I don’t know if I’ve had a bad week of blood sugars and then I might get lectured of how I’m doing stuff wrong. Which is obviously for my benefit it’s to help me but I don’t know, it can be quite scary sometimes.” (Joshua, male, White, aged 17, diagnosed age 3)

For Joshua, clinic appointments represented an assessment of his recent medical self-care, which was intimidating. He nervously anticipated the consequences of this behaviour, expecting to be scolded by his health care team. Previous research suggests that being ‘lectured’ during a clinic appointment makes it more likely that young people will be dishonest about their recent diabetes self-care behaviour (Mulvaney et al, 2008). Behaviours reported included being untruthful about blood glucose readings to both parents and clinicians, deleting blood glucose readings and removing batteries from blood glucose meters (Mulvaney et al, 2008). This highlights the importance of healthcare professionals in taking a compassionate approach to young people with diabetes and exploring the reasons behind struggling with the medical aspects of diabetes self-care.

The intimidation that Joshua felt also resulted in a reluctance to ask questions which were important to him. He described being interested in learning more about the effect of alcohol on his blood sugar levels. Joshua hoped his health care team would raise the issue because he was worried about how they would react to him initiating the conversation.

“I don’t think I’d discuss that with anyone yet. I’ve had discussions with my parents about it and they’re just like be safe. And I know the general idea is obviously go mental erm, because it does affect your blood sugars, as I said it makes you go low. They haven’t had a talk with me about it yet. I don’t know if that’s because they want me to address it or them to address it. Erm, I’d kind of like them to bring it up because I don’t want to sound like an alcoholic when I’m not.” (Joshua)

Joshua knew that alcohol influenced his blood glucose levels but did not know how to drink without causing imbalanced blood sugar levels. Although the topic of alcohol consumption had been on Joshua’s mind for a while, the anticipated reaction from his health care team meant that he had refrained from asking any questions about drinking alcohol in his appointments. This emphasises the importance of considering the non-

diabetes related activities in which young people might be engaging which can both directly and indirectly affect their diabetes and medical self-care.

Clinic appointments were much less intimidating for participants when health care professionals acknowledged the identity work in which participants engaged. Rachel described appreciating her health care team understanding of the different aspects of her lifestyle which impacted her medical self-care. This awareness was reflected in their communication with her, to which Rachel responded positively.

“My relationship with the doctors has improved a lot. Because they sort of talk to me in a way that they understand the typical lifestyle of my age group, so going out clubbing or learning to drive and they really do try to work around all the difficult stages I’m going through.” (Rachel, female, White, age 18, diagnosed age 4)

Rachel’s account demonstrated the identity work in which she engaged in, including the conflicts she experienced between different aspects of her identity as a young person, which were challenging to navigate. Having such identity work acknowledged allowed Rachel to be more open with her health care team and discuss the current difficulties she was facing. This in turn helps facilitate the integration of the medical aspects diabetes self-care into her daily life, whilst engaging in activities which were important for her identity development as a young person.

Certain health care professionals could be more intimidating than others. Eschal contrasted the interactions with her nurse compared to those with her doctor.

“She’s more easy to talk to. I can’t really explain. I guess it’s because she’s easy to talk to. I can ask her questions that I want to be answered and she will, you know, give me any relevant information that’s needed, even extra information that, you know, I probably would have thought about before. Whereas my diabetic doctor he would just... So I’m going for an appointment. He’d talk about what’s needed to be talked about and that’s it.” (Eschal, female, Asian, aged 18, diagnosed age 11)

Eschal found the nurse less intimidating than the doctor and thus Eschal felt more able to talk openly with her and receive necessary information and support to help her more easily navigate diabetes self-care in her daily life. This was in stark contrast to her

appointments with her clinician, which focused on the medical aspects of diabetes self-care without acknowledgement of the context in which it was occurring. Eschal's account highlights the significance of the nurse in helping Eschal feel more equipped to navigate identity work and thus remain more engaged in medical self-care.

Other participants did not feel intimidated by their clinic appointments, even if multiple health care professionals were present. Mahir described being eager to ask questions about his newly fitted insulin pump, which he had written down prior to his upcoming appointment. He took these questions out during the interview to show what he had written.

‘I ask them cos like sometimes I’ll probably leave on this table, like when I go I can take with me, but then knowing me I’ll probably forget. So when I give them my pump they’ll go oh what’s this? And then I’ll take it out, these are my questions.’ (Mahir, male, aged 13, diagnosed age 4)

Similarly to other participants, Mahir was keen to learn more about diabetes and self-care, particularly his new insulin pump. However, unlike other participants, he felt very comfortable with his health care team and was thus very willing to ask questions that were important to him, despite being amongst the youngest of the participants. Mahir's account demonstrates the importance of creating a comfortable clinic environment so that young people feel able to be open with their health care team and request the information and support they need to help integrate diabetes into their identity and navigate diabetes self-care in daily life.

5.6 Feeling different

‘Feeling different’ was described by several participants in reference to how they felt within the school environment. This sense of difference occurred as a result of the unwanted attention gained from performing medical aspects of diabetes self-care, the treatment by school staff and the behaviour of other young people with diabetes within the school environment who behaved differently to participants. In addition, the fear of feeling different could prevent some participants from disclosing their diabetes to others in the school environment. Findings support previous research which has reported that

young people often feel uncomfortable with performing medical self-care activities at school because of the behaviour marking them as being different from others (Wang et al, 2013).

The sense of feeling different from others is characteristic of psychosocial development in young people, which places a high value on social relationships, particularly those with peers (Erikson, 1968). The sense of feeling different is also consistent with Goffman's (1963) ideas of stigma, in terms of stigmatising attributes being 'deeply discrediting' because they serve to set individuals apart from others.

Young people living with diabetes may be seen as having a potentially stigmatising attribute and if this is reinforced by others, their identity is threatened. Young people who were fearful of this stigma and chose not to disclose their condition may be seen as employing 'information management', 'covering' or 'impression management' in order to protect their identity (Giddens, 1959 and Goffman, 1963). As mentioned earlier in this chapter, the reinforcement of a diabetes identity has been also been shown to reduce young people's likelihood to engage medical aspects of self-care (Tilden et al, 2005).

Several participants, such as Rachel, felt very self-conscious about performing medical self-care in front of others at school because it marked her out as being different. She described the unwanted attention she received from other students, which included staring and asking lots of questions about diabetes.

"...I had to hide when I did my injections, I got very embarrassed if I was low and I had to leave the classroom and I got to drink Lucozade and all the kids would be looking at me while I drank Lucozade for example. And I would drink the Lucozade to make it go up quicker. I think that probably, that was the starting point where all the kids were watching me or were aware when I left the classroom what I was doing that led me to know where I can sometimes find it quite embarrassing. I find it a bit of an inconvenience, I find that people start asking questions and their attention is on me and I don't like it." (Rachel, female, White, aged 18, diagnosed age 4)

For Rachel, even performing medical self-care out of the classroom environment was difficult because of the reactions of the other students. Such behaviour made her feel uncomfortable because of the sense of difference it fostered. Their reactions exacerbated

the perceived inconvenience of the medical aspects of diabetes self-care and made it more practically and psychologically challenging for Rachel to engage in at school.

Rachel's account characterises 'extreme identity consciousness', whereby young people are particularly self-conscious of their behaviour and highly concerned with the reactions of their peers (Erikson, 1956). Although feeling self-conscious is both a transient and normative part of the 'identity crisis' (Erikson, 1970), it is exacerbated for young people with diabetes because of the nature of medical self-care activities, which foster a sense of 'feeling different' because of the reactions of others. These findings support previous research which reported that young women with diabetes were keen to fit in with others (Kay et al, 2009). These young women strongly disliked being seen as a diabetic and that overshadowing other aspects of their social identity. Participant's concerns about how others perceived them was found to be strongly linked to their perceptions of themselves.

School staff could also contribute to the sense of feeling different. Rachel described being sent home when she had low or high blood glucose levels, rather than treating the issue at school. This was frustrating because Rachel knew how to treat the problem and did not want to miss school unnecessarily. Such situations occurring repeatedly led to her missing large amounts of school, leading to further issues.

“There was a phase where every time I said I was high or low they would phone my mum and say could you come and collect [Rachel] please because her diabetes is out of control. And really it just needed me to sit there for 15 minutes, but they wouldn't let me sit there they wanted me to go home. And again that was an inconvenience, because then my attendance went down which was another issue. It's only been since year 11 where the schools kind of attitude towards the students change a bit and they treat you a bit more like an adult.” (Rachel)

The treatment by school staff served to reinforce the sense of diabetes as 'negative identity', whereby the condition is seen as a threat to identity and thus difficult to integrate it into identity (Erikson, 1970). As mentioned earlier in this chapter, the reinforcement of diabetes identity has paradoxically has been shown to reduce young people's consistency with the medical aspects of self-care (Tilden et al, 2005). Interestingly, Rachel found the behaviour of school staff changed as she became older,

where she felt that she was treated as an ‘adult’, which she appreciated because she felt she was treated more similarly to the other students.

Knowing others with diabetes at school could also contribute to the sense of feeling different. The awareness that these young people were more open about their diabetes caused resentment because Rachel felt unable to be equally open.

‘I know a few people, or at least I know of a few people that have diabetes. There was a few people in my year actually that were very open and very ‘I have diabetes’. And that kind of for me, I began to dislike those people because I do believe that I was jealous that they could be so open about it.’ (Rachel)

For Rachel, knowing and meeting others with diabetes was not helpful in mitigating her feelings of being different from others because she could not relate to them. Their ability to be open about having diabetes was something that Rachel did not feel capable of doing. This further contributed to the sense of being different from other young people, both those with and without diabetes. Rachel’s account highlights the potential for the school environment to contribute to the sense of being different in a number of different ways and thus served to exacerbate the ‘identity crisis’ of adolescence and young adulthood (Erikson, 1970).

Rachel’s account contrasts with previous research which reported that participants did not feel understood by others and found it helpful to speak to others who also had diabetes because they could share experiences and gain support (Kay et al, 2009). Similarly, previous research has reported other young people at school with diabetes as being helpful for participants because it helped to normalise diabetes (Lewis, 2007). For young people, such as Rachel, interacting with other young people with diabetes may be more desirable in other settings, such as online networks (Rasmussen et al, 2007a).

Meetings between the school, the diabetes health care team, parents and young people could be helpful in improving the treatment of diabetes within the school environment, thus preventing feelings of difference in participants. Joshua, White, aged 17, who had lived with diabetes for 14 years, described the proactive approach taken by his health care team whereby any problems were swiftly handled, avoiding unnecessary disruption to education and preventing wellbeing being compromised.

‘But if there is ever a slight problem with the schools way of dealing with it, one of the assistants or herself will get in touch with the school. And say look this isn’t right, this needs to be changed. I’ve had a couple of meetings with erm, the school like the teacher and Dr H just to try and sort things, just me and my mum and them two to try and sort things out. So they’re quite firm about how they want the school to be running things in terms of diabetically speaking. I’m not sure why, but they really put time in to that.’
(Joshua)

Joshua’s account highlights the importance of the diabetes health care team in liaising with the school to avoid problematic treatment by school staff. The knowledge that his diabetes health care team were quick to address problems provided Joshua with a sense of comfort, knowing that he would not be prevented from carrying out medical aspects of self-care whilst at school. Furthermore, this approach from his health care team prevented him from feeling different from other students because it helped prevent diabetes becoming a threat to his identity in the school environment and thus causing experience of a ‘negative identity’ (Erikson, 1970). Furthermore, it avoided conflicts from occurring between diabetes and his education, thus helping to support identity development, where young people seek to integrate the different aspects of their self into a coherent identity (Erikson, 1970).

Some participants were so fearful of the reactions of others to disclosing diabetes that they refrained from telling others as much as possible. Kyron was so nervous that disclosing diabetes to one individual would result in several others also finding out, which he wanted to avoid. This was due to a fear of being treated differently by others.

‘Because the next day the whole school would know.’ (Kyron, male, Mixed heritage, age 13, diagnosed age 2)

For Kyron, the idea of telling anyone at school was met with a significant amount of anxiety. He did not trust that his disclosure would be kept secret and instead expected it would result in everyone knowing about his diabetes, marked him out as being different from others. Kyron had not had any prior negative experience of disclosing diabetes but nevertheless remained reluctant about disclosure because of the anticipated consequences. This highlights the importance of the anticipated consequences of

disclosing diabetes for young people, which may not necessarily reflect the reality but nevertheless is a source of worry.

Nadia also described fears about the reactions of others to disclosing diabetes. Nadia was particularly concerned about the judgments that people would make in response to learning she had diabetes so avoided telling anyone about her condition.

‘‘Probably because people maybe be judgemental about me. I don’t know it’s just that thing in me like I don’t like it when other people find out things I have diabetes or anything.’’ (Nadia, female, aged 18, diagnosed age 13)

Similarly to Kyron, the potential of being perceived differently was enough to prevent Nadia from disclosing her condition to anyone other than family members. The interview was the first time that she had openly discussed diabetes with anyone outside of her immediate family and health care team. Nadia’s fears of feeling different are consistent with Goffman’s (1963) ideas of stigma, in that diabetes was perceived to be a threat to her identity and thus ‘deeply discrediting’ because it set her apart from others. Her reluctance to disclose her diabetes was a thus behaviour she chose in order to protect her identity (Giddens, 1959 and Goffman, 1963).

5.7 Feeling normal

‘Feeling normal’ was described as by participants as feeling similar to other young people without diabetes. Friends played a particularly important role in facilitating this feeling. The desire to obtain a sense of normality was described in chapter 4 and is a central aspect of psychosocial development in young people (Erikson, 1968). During psychosocial development, young people place a high value on social relationships, particularly those with peers. Successfully navigating the ‘identity crisis’ requires an assimilation of all of aspects of identity but also a reconciliation of an individual’s identity with the community’s recognition of that self (Erikson, 1970). Participants are thus faced with the challenge of integrating diabetes into their identity whilst striving to have their identity validated by their friends.

Participants described disclosing diabetes to a few select friends with whom they felt most comfortable, rather than disclosing to all friends. This has been described as ‘protective disclosure’ (Lewis, 2007). Not being treated differently by friends despite

having diabetes was instrumental in allowing participants to feel ‘normal’, which was highly valued. This behaviour prevented emphasising the diabetes identity of participants. Furthermore, treatment by friends meant that participants felt more comfortable in performing the medical aspects of self-care around their friends because they did not worry that this would threaten their sense of normality.

The role of friends in validating identity has been reported in previous research on young people with diabetes by Schur et al (1999). Authors reported that young people created ‘normal’ identities that were separate from diabetes, in order to be valued by other young people. Previous research has also highlighted the importance of participating in non-diabetes related activities with friends in terms of identity work (Balfe, 2007 and Brouwer et al, 2012).

Feeling normal around others without diabetes was described as being unexpected for some participants. Kai was pleasantly surprised by the reaction of his friends at his new school to his diabetes diagnosis. He described anticipating a negative reaction but instead found that diabetes was not deemed to be at all problematic by others and thus he was treated similarly to other young people without diabetes.

“They’re important to me because they don’t want, the way they like me, is like, cos when I came to [School] I thought no one would like me cos I’ve got a medical problem, cos my old school everyone likes me, every treats me the same ways as they would treat their other friends, so I thought no one would treat me like cos no one would like me but everyone straight away just likes me cos I basically, just to say this way everyone thinks I’m the clown cos I make everyone laugh. Like that’s my thing, yeah.” (Kai, male, Mixed heritage, age 12, diagnosed age 6)

Despite Kai’s expectation of being disliked by others upon learning that he had diabetes, this was not his experience. Contrary to his prediction, he was not treated differently for having diabetes and was liked by others, which made him feel normal. Kai’s fears of feeling different are consistent with Goffman’s (1963) ideas of stigma, in that diabetes was perceived to be a threat to his identity and thus ‘deeply discrediting’ because he worried it would distinguish him as being different from others. In addition to his friends accepting diabetes, his friends served the important role of highlighting

his sense of humour, a non-diabetes aspect of his identity, which prevented diabetes from dominating his identity. This enhanced Kai's ability to feel like a 'normal' young person and prevented experiencing 'negative identity', whereby diabetes is perceived as a threat to identity (Erikson, 1970).

Although Kai's friends helped reinforce feeling 'normal', experiencing diabetes-related events could threaten these feelings. Such situations, as well as being physically uncomfortable, emphasised diabetes identity because they marked him as being different from his friends. Needing to perform medical self-care activities in response to these situations further reinforced this sense of difference.

‘It’s terrifying when I get hypo. Yeah really terrifying and it’s kind of weird having diabetes er, because er, I find it really weird that I’m the one that tests myself, injects myself, and no one else does it, none of my friends does that. They’re ordinary like, normal kids like do what they need to do and stuff.’ (Kai)

Despite having lived with diabetes for six years, experiencing low blood glucose levels was still frightening for Kai. These events also reminded him of having diabetes, making him feel abnormal compared to his friends who did not have diabetes. Kai's account demonstrates the interaction between physical symptoms of diabetes and identity work, whereby the medical manifestation of diabetes provided a threat to identity, further reinforced by the perceived need to respond to these symptoms, which also marked him out as being different. This highlights the ongoing 'biographical disruption' experienced by young people with diabetes whereby they continually experience threats to their identity (Bury, 1982).

Being able to do 'normal' activities with friends was highly valued by participants. This took their minds off diabetes, preventing it from feeling as though it dominated their lives. Aaesha described moving away to university as being difficult because it meant she had to form new friendships and disclose her diagnosis to more people. The feelings of normality were thus threatened by this change in circumstances.

‘My close friends know all about my diabetes and have been great in the sense they just treat me as normal. We do the normal things like shopping and the cinema but I see

them less now because of University. Instead, I am having to make new friends where I am. Nobody knows I am diabetic at University.'' (Aaesha, female, Asian, age 18, diagnosed age 14)

For Aaesha, similarly to Kai, having close friends who knew about her diabetes and did not treat her differently was helpful because it allowed her to feel 'normal'. Furthermore, seemingly simple activities typically enjoyed by young people were appreciated because they served to reinforce this sense of normality. However, a change in environment was difficult because it demanded new relationships to be made and diabetes disclosure to be re-navigated, posing a potential threat to normality. Aaesha had refrained from disclosing diabetes to her new friends at university, a strategy of 'information management', 'covering' or 'impression management' in order to protect her identity (Giddens, 1959 and Goffman, 1963). Although putting her health at risk, this served to maintain her sense of normality and wellbeing.

Modifying the environment to accommodate diabetes also helped participants to feel 'normal'. Joshua described how friends modified their activities to ensure that he was able to participate, such as refraining from drinking alcohol around him. Similarly to Kai, Joshua was pleasantly surprised by the support he received from his friends, which also included providing reminders for medical self-care when he was with them. This helped him to remain consistent with these behaviours when he was with his friends whilst maintain feelings of being 'normal.'

“Actually yeah surprisingly my friends are pretty good. They tell me to test more than I tell myself to test. Erm, so if we were going out for a meal or something, they would generally be the first ones to say afterwards well you need to test. I can do it myself...I'm kind of making myself sound bad here. But erm, they yeah they're generally very supportive they don't try and force anything on me, they don't say no you can't eat this or you can't eat that because they like expect me to kind of know what I can and can't do. They will remind me a lot and they are always conscious of the fact that I'm diabetic so they won't do anything that I can't do if that makes sense.” (Joshua, male, White, age 17, diagnosed age 3)

Joshua's friends cultivated a comfortable environment for him which facilitated a sense of normality when he was with them. Gentle but frequent reminders from friends were useful in helping Joshua feel comfortable performing medical aspects self-care around his friends without fear of it threatening this sense of normality. Their behaviour thus supported Joshua in integrating diabetes into his identity, thus helping him with navigating his 'identity crisis' (Erikson, 1970). This highlights the significance of friends in supporting young people's identity work.

Sometimes participants did not feel normal whilst spending time with their friends. Fiona described feeling left out when her friends were eating foods that she was not able to immediately eat without testing her blood glucose levels. Unlike Joshua, reminders by Fiona's friends to test her blood glucose levels threatened her feelings of normality by marking her out as different to them. Fiona described the reminders as being more authoritative than those described in Joshua's account and thus they were perceived as being intrusive rather than supportive. However, Fiona had another friend with diabetes who was able to provide moral support during these times by helping mitigate the threat to Rachel's feelings of normality.

"They help when, say if they're having sweets or crisps or whatever they're eating, I'm like oh can I have some and they're like no, your sugar levels high or you need to test and I have a diabetic friend as well. She's type 2 so we kind of help each other out, yeah." (Fiona, female, White, age 13, diagnosed age 6)

Although Fiona's friends were trying to be supportive by providing reminders for her medical self-care, these reinforced a sense of her being different from them. Their behaviour served to emphasise her diabetes identity, thus contributing to the feeling of 'negative identity' (Erikson, 1970). However, having a friend who also had diabetes helped Fiona navigate such situations whereby her identity was threatened because it served to normalise diabetes. This friendship was described as being mutually beneficial whereby they provided each other with both emotional and practical support. Such accounts highlight the value of meeting other young people with diabetes in helping young people cope with situations that might threaten their feelings of normality.

5.8 Feeling supported

The family provided a very strong support system for many participants. Both practical and emotional support from families and siblings was described by participants. The nature of support changed as participants became older and took more responsibility for the medical aspects of their diabetes self-care. The increased independence was welcomed by participants but resulted in diabetes self-care being more difficult to manage and thus being less consistent than when they were younger.

Theories of adolescence typically suggest that a central task is for young people to move from a state of dependence on parents to a state of independence (Schur et al, 1999). However, other research has suggested that this stage is better characterised as moving from dependence towards interdependence, rather than seeking to maintain complete freedom from parents (Anderson, 1994). Findings from this research suggest the latter as young people expressed a desire for more independence whilst still receiving emotional and practical support from their parents with medical self-care.

Participants valued the support they received from their families but also described a desire for increased independence from their parents as they became older and were able to take on greater responsibility for their medical self-care. India described enjoying the increasing independence because it provided her with more freedom to make different decisions with regards to her diabetes but could heighten the risk of physical health complications.

‘‘It hasn’t always been under control. It was when my mother took responsibility for me that my diabetes was more controlled, more freedom means less control. I had a DKA (diabetic ketoacidosis) over Ramadan. My mother was away and I was at home with my older sister. I wanted to experience fasting and the feast at the end. However, I ended up in hospital. I had a lapse due to death in the family and dealing with course work. This resulted in missing meals and taking insulin.’’ (India, female, Mixed heritage, age 19, diagnosed age 5)

The increased independence made it more challenging for India to be more consistent with her medical self-care, particularly whilst she was dealing with other challenges in her life. India described choosing to fast during Ramadan, an activity in which she had not previously participated. India’s account highlights the difficulty in navigating an ‘identity crisis’, whereby there is an attempt to balance diabetes and non-diabetes

related aspects of identity, in this case a struggle between balancing being a Muslim and being a diabetic (Erikson, 1970).

Rachel described being given greater responsibility for the medical aspects of her self-care at a young age, which provided her with the ability to make her own decisions. She realised that she was able to be dishonest about her medical self-care, without her mother immediately finding out. Rachel articulated the benefits she experienced of avoiding these activities, which allowed her to imagine and behave as if she did not have diabetes.

“Because I was given so much freedom of a young age and because I was trusted so much of a young age I found it easy, to, not do it and get away with it. And because I wasn’t doing it I could avoid having diabetes, and pretend I didn’t have diabetes.”

(Rachel, female, White age 18, diagnosed age 4)

Rachel articulated the short-term emotional benefits of avoiding medical aspects of self-care, which were rewarding to her. Avoidance of these behaviours provided her the opportunity to experience her life without diabetes, which was enjoyable. This demonstrates the fluid nature of identity work, whereby the role of diabetes within identity is continuously negotiated (Aujoulat et al, 2017 and Erikson et al, 1970). Furthermore, Rachel’s account highlights the difficulty in balancing the medical aspects of diabetes self-care whilst maintaining wellbeing.

A variety of creative supportive strategies were employed by Rachel’s family to encourage her to be more consistent with the medical aspects of diabetes self-care. Although such strategies helped Rachel feel supported and were initially effective in changing her behaviour, this strategy did not result in long term consistency.

“So yeah, when I came out of the hospital I remember my sister use to do something with me which was, every time that I injected in front of her she would use a tiny little sewing needle, that she would sterilise she put in a glass of salty water and then she would either prick her finger or prick her tummy so that we did the same thing. Erm, now I think about it, it probably wasn’t the most normal way to encourage me to do my

diabetes but in, I think maybe mentally I thought well she's got to do the same as me now and that lasted not very long, it was about a month'' (Rachel)

‘‘I mean my mum went through a phase where she tried to encourage me with money because I'm very money minded. And my mum said right if you do your injections and I can see on your meter, that your testing results, cos I said I could write them down it could be a complete lie, I can see on your meter your results. I will give you 10 pound a month but I have to see a months' worth of results. And I was like okay, and it worked for about two months and then as I say I got bored and went off again. ’’ (Rachel)

Despite the innovative strategies used by both her mother and her sister, which made Rachel feel supported, Rachel struggled to remain consistent with her medical self-care. Rachel described being ‘bored’ by these activities, demonstrating the desire for identity work exploration. Such identity work is characterised by a continual negotiation of the role of diabetes within identity, including situations in which medical self-care activities are avoided (Aujoulat et al, 2017 and Erikson, 1970).

Rachel described a rift with her mother that had resulted in a significant change to their relationship. It had also caused her mother and her sister to take a much less active role in Rachel's medical self-care and clinic appointments. Although Rachel had largely resisted all previous attempts of support, she described negative feelings towards her mother's current lack of involvement.

‘‘Yeah. Erm, me and my mum had a bit of a falling out, well quite a big falling out about two years ago and I haven't really made up since. And it's actually affected our relationship if anything. It kind of offends me when my family, especially my mum and my sister have grown up with me having it, don't say [Rachel] how's your diabetes going? It's very independent now I go to clinics on my own which I don't like. Yeah so it's kind of all [Rachel] now and not many other people. ’’ (Rachel)

Rachel desired having support from her family although she had not responded to their previous attempts to help. She described feeling resentful that she was no longer asked about the medical aspects of her diabetes self-care and was not accompanied to her clinic appointments. This demonstrates the challenge associated with balancing support and independence. Furthermore, Rachel's account highlights the complexity of identity

work, whereby diabetes can pose a threat to identity and medical self-care is avoided but simultaneously there is a desire to have the diabetes identity confirmed by family members through tangible forms of support.

One participant described feeling so well supported by her family that she did not look for any other sources of support. Nadia felt very confident about the diabetes knowledge held by her parents and her wider family so felt she was always safe. This meant she did not disclose diabetes outside of her family because she did not deem it to be necessary.

‘I already know I have people there to support me like my mum, my dad, the rest of my other family so I don’t need to be assured or anything because I know 100% there is always someone or another there to support me because if there was an emergency and like that there’s always someone there, to help me.’ (Nadia, female, age 18, diagnosed age 13)

When asked about the different sources of support for her diabetes, Nadia described highly valuing the support provided by her family and felt that it was adequate for her needs. Although she was not always with her family, and thus was increasing the risk of health complications by not disclosing to others, she did not perceive this as being problematic. Nadia’s account demonstrates the different preferences for sources of support amongst young people with diabetes.

5.9 Concluding comments for this chapter

This chapter has discussed the findings from qualitative analysis of interviews with young people with diabetes living in North and East London, defined as ‘disengaged’ from diabetes self-care and/or diabetes services by health care professionals. Similar to chapter 4, ‘Identity work’ emerged as a central theme from these interviews, which young people engaged in to achieve and maintain a sense of normality. In addition to supporting the findings from the qualitative review, the interviews discussed in this chapter demonstrated that identity work is a typology with three aspects: ‘forgetting diabetes’, ‘diabetes as dominating’ and ‘diabetes as routine’, all of which were associated with different levels of engagement with the medical aspects diabetes self-care. Disengagement from diabetes services and or diabetes self-care, whilst suboptimal

from a physical health perspective, represents an attempt by young people to maintain a sense of normality and create a coherent identity.

This chapter also highlighted the different contexts in which identity work occurs: within the clinic, at school, with friends and within the family. These different contexts influenced participants' identity work, resulting in participants' 'feeling intimidated', 'feeling different', 'feeling normal' and 'feeling supported'. Such contexts demanded young people to make difficult decisions about their medical self-care whilst striving to maintain their wellbeing and sense of normality. The next chapter presents findings from qualitative interviews with young people who participated in salutogenic projects. Findings highlight the way in which participating in these projects impacted upon identity work and their diabetes self-care.

Chapter 6: Findings from interviews with young people with diabetes participating in salutogenic projects

6.1 Overview of this chapter

This chapter discusses the impact of participating in salutogenic projects on identity work and diabetes self-care. These interviews aimed to explore the experiences of young people participating in these salutogenic initiatives to determine if it influenced their diabetes self-care behaviour. As a consequence of being involved in salutogenic projects, participants built competencies, referred to as 'Ego strength' by Erikson (Erikson, 1963; 1964; 1968). Involvement in the salutogenic projects provided young people with the tools to better navigate identity work and negotiate the role of diabetes self-care in their daily lives.

Participation resulted in three main consequences for young people: developing a more positive diabetes identity, gaining a broader perspective of diabetes services and self-care as well and gaining confidence in their ability to overcome diabetes and non-diabetes related boundaries in the projects, in the clinic and in their social environment. These consequences of participating in the salutogenic projects correspond to the three aspects of a sense of coherence: meaningfulness, comprehensiveness and manageability (Antonovsky, 1993). A higher sense of coherence has been associated with processes of identity development in young people with diabetes in quantitative research (Luyckx et al, 2008) but has not yet been explored qualitatively

Involvement in salutogenic projects consisted of two roles. Participants were employed as either Young Clinical Commissioners or as a Youth Health Champion. Although the role of the Young Clinical Commissioners and the Youth Health Champion were different, all of the young people attended many of the same events to help them develop in their respective roles. The Young Clinical Commissioners were appointed to help re-commission the paediatric diabetes pathway for East London. In their role as young Clinical Commissioners, the participants were involved in a number of different activities. For example, following recruitment and training they prepared and delivered a series of workshops which were attended by children and young people with diabetes, parents and health care professionals. Themes arising from the workshops formed a basis for their subsequent work in contributing to the re-commissioning guidance and presenting their findings to a number of different audiences. As part of their roles,

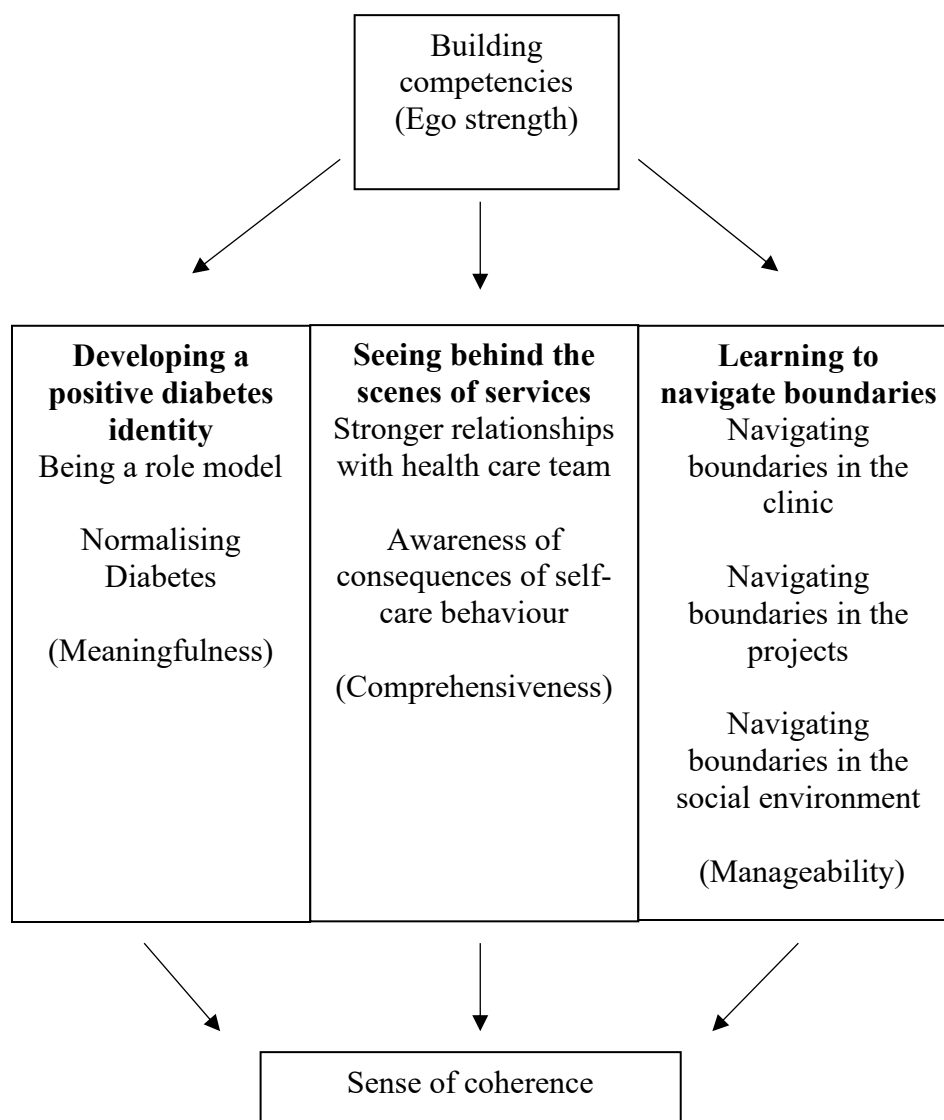
participants were also part of a task group, which held regular meetings and was comprised of individuals and organisations relevant for diabetes care in young people. In addition, participants completed site visits to diabetes organisations to obtain a wider perspective of diabetes care and to exchange ideas in how to better support other young people with diabetes in London. In parallel to the employment of the young Clinical Commissioners, a Youth Health Champion was recruited in the same period to co-ordinate a weekly peer diabetes youth group for young people in London. As described in chapter 3, as part of the CLAHRC project I was involved in training these young people and worked alongside them in the task group and in the other activities as part of the projects. I was thus able to see them develop in their roles, gained an understanding of the context in which they were working and was more easily able to build rapport with them during the qualitative interviews.

Figure 4: Participant demographics (self-reported)

Participant name (pseudonyms have been used)	Gender	Age	Diabetes type	Age diagnosed	Ethnicity	Religion	Other family members with diabetes
Kali	Female	18	2	12	Asian	Muslim	Mother and father
Stephanie	Female	19	2	16	West Indian	Christian	Mother and father
Saara	Female	18	1	13	Asian	Muslim	Mother and father
Taanish	Male	18	1	12	Asian	Muslim	Grandmother, multiple Aunts and Uncles
Haadee	Male	25	1	21	Asian	Hindu	None

6.2 Interview findings

Figure 5: Overview of interview findings pertaining to the impact of participating in salutogenic projects



Summary of figure 5

The salutogenic projects in which participants were involved, aimed to develop competencies, referred to as ‘ego strength’ (Erikson, 1963; 1964; 1968). Ego strength is built by individuals becoming more capable in different areas of life, which helps them navigate identity work. The concept of ego strength is considered to be a ‘generalised resistance resource’ in salutogenesis (Antonovsky, 1979; 1987). Generalised resistance resources refer to characteristics which facilitate the individual’s abilities to cope effectively with stressors (such as diabetes) and thus achieve a greater sense of coherence. A sense of coherence entails three aspects: meaningfulness, comprehensiveness and manageability.

The interview themes describe the consequences of participating in the projects in relation to diabetes self-care: ‘Developing a positive diabetes identity’, ‘Seeing behind the scenes of services’ and ‘Learning to navigate boundaries’. These correspond to meaningfulness, comprehensiveness and manageability respectively. Participation in the projects impacted upon participants’ identity work, including both ‘being’ identity (sense of self) and ‘doing’ identity (behavioural manifestations of identity which are observable by others). This facilitated greater engagement with the medical aspects of diabetes self-care in participants and an enhanced ability to navigate both diabetes and non-diabetes related boundaries in the projects, the clinic and in their wider social environment, contributing to a heightened sense of coherence. These findings therefore demonstrate that identity work is modifiable and can be targeted as a way to enhance engagement with diabetes self-care.

6.3 Developing a positive diabetes identity

Developing a positive diabetes identity describes going beyond an acceptance of diabetes towards a positive perception of having diabetes, as a result of the project activities. This facilitated an enhanced ability to integrate diabetes into participant’s both ‘being’ and ‘doing’ identity, which was reflected in greater engagement with medical self-care activities. Developing a positive identity included two aspects: ‘Being a role model’ and ‘Normalising Diabetes.’ The activities, such as running workshops and public speaking, contributed to the sense of being a role model and consequently provided a sense of motivation and accountability for participants to remain engaged with their own medical self-care. The interaction with other young people with diabetes as part of their roles facilitated a normalisation of living with diabetes, which prevented diabetes from posing a threat to identity. Developing a positive identity thus helped to

mitigate the identity work types ‘Forgetting diabetes’ and ‘Diabetes as dominating’, described in chapter 5, instead helping to facilitate a sense of ‘Diabetes as routine’.

‘Developing a positive diabetes identity’ corresponds to the sense of meaningfulness, described by Antonovsky (1993) as comprising part of a sense of coherence. A sense of coherence reflects an individual’s view of life and ability to respond to stressful situations. As mentioned earlier in this chapter a sense of coherence consists of three elements: meaningfulness, comprehensibility and manageability. It was defined by Antonovsky as:

“a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli from one’s internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.”
(Antonovsky, 1987 p. 19)

Results appear to conflict with previous research highlighting the importance of distancing diabetes from identity in young people (Schur et al, 1999). Schur and colleagues reported that young people distanced diabetes from their identity as a self-protective strategy; a way to maintain identity as a ‘normal’ person. However, in these salutogenic projects, young people were surrounded by others with diabetes, which served to reduce the threat of diabetes to identity because it was perceived as being ‘normal’ and was valued by others. Distancing diabetes from identity was thus unnecessary because it was no longer perceived as being a threat to identity. However, previous research has also reported that young people feel a sense of belonging when surrounded by others with diabetes (Brouwer et al, 2012).

a) Being a role model

All participants expressed a perceived importance of being a ‘role model’, in terms of providing a good example for other young people with diabetes. Being a role model was described as being both an individual and a group responsibility by participants. The project roles provided a strong sense of accountability for maintaining high levels of engagement with the medical aspects of self-care, which was described as being an ongoing process for participants. The participants’ current commitment to improving

diabetes self-care was often contrasted with their behaviour prior to becoming involved in the project.

Being a role model was described as being an individual responsibility by Kali, female, aged 18, who had lived with diabetes for six years. She described her feelings of anxiety early on in the role when she was aware that she was not prioritising her own diabetes self-care. This was contrasted with her subsequent dedication to improving engagement with her own self-care, which was described as being a gradual process that was largely cognitive in nature.

“And maybe at first I was a bit like, oh okay I don’t want to really tell these people like how I’m not even managing it right now. How I’m going to be commissioner to these people and I’m not even a role model to myself like how can I do all this? And then I think it was just that gradual process of getting in to that mind set of that’s it, you’re gonna be like a role model for these people, you need to get on yourself and this and that and I just, yeah.” (Kali)

For Kali, the project role caused her to confront her own diabetes self-care behaviour. She described a strong sense of obligation to set a good example for other young people with diabetes in terms of the medical aspects of self-care. Although this responsibility weighed heavily on her, Kali described the process of becoming a role model as being a slow transition. Kali’s account demonstrates the navigation of an ‘identity crisis,’ characterised by an attempt during adolescence and adulthood to reconcile ‘the person one has come to be’ with ‘the person society expects one to become’ (Erikson, 1970). As a result of participating in the projects, Kali felt compelled to reconcile being a young commissioner with her own diabetes self-care behaviour.

Haadee, male, aged 25, who had lived with diabetes for four years also described a strong sense of obligation in being a good role model for other young people with diabetes. This was described as being a compulsory aspect of being involved in the projects and was taken very seriously.

“You kind of have to be a role model in a way. So you have to make sure you’re controlling your sugar levels to a good level as well so.” (Haadee)

For Haadee, participation in the projects not only required a high level of engagement with medical self-care but also the achievement of ‘good’ blood glucose levels. This demonstrates the extent of the perceived commitment required as part of the project roles. Similarly to Kali, Haadee articulates navigating an ‘identity crisis’, involving matching his own diabetes self-care behaviour with the perceived expectations of others.

Despite a strong sense of commitment to achieving optimal diabetes self-care from a medical perspective, participants struggled with achieving this in their daily lives but felt that had made progress following their role in the project. Saara, female, aged 19, who had lived with diabetes for three years, described the positive change that had occurred since being involved.

“...I have to take care of myself. So it’s like, in a way, I’m a role model as well to these young people, so I would say it’s improved and it’s gone better. In a way, not 100% fully but getting there.” (Saara)

Similarly to Kali and Haadee, the project role was described as providing a sense of obligation to be more engaged with the medical aspects of diabetes self-care by Saara. Despite this sense of obligation, carrying out the daily medical self-care activities was described as being an ongoing effort. Saara’s account demonstrates the difficulty in navigating an ‘identity crisis’ and balancing the perceived expectations of others with her own self-care perceptions and behaviour.

In addition to being an individual responsibility, being a role model was also described as being a group responsibility by Saara. The other young people working on the projects were cited as being helpful and supportive throughout the process.

“So like, we’re all role models, because it’s everyone there trying to help out one another who need support. There’s always there someone who you can talk to.” (Saara)

Saara described viewing both herself and the other young people in the project as being role models. The strong levels of support shared between the young people meant that they helped each other to fulfil this responsibility. This was described as being a mutual and ongoing process throughout the project. Saara’s account demonstrates both the

individual and shared aspects of identity work, whereby support from others helps to facilitate successful navigation of the ‘identity crisis’, namely the balance between being a young commissioner and maintaining her own diabetes self-care (Erikson, 1970).

b) Normalising diabetes

A desire to feel normal is a central aspect characterising psychosocial development in young people, which places a high value on social relationships, particularly those with peers (Erikson, 1968). A sense of normality was described by participants as being important in both chapters 4 and 5. Chapter 4 described the ongoing process of normalisation of identity which characterised the experiences of young people with diabetes self-care. Chapter 5 discussed ‘Diabetes as routine’ which is the identity work associated with this sense of normality.

For young people in these interviews, feeling ‘normal’ was perceived as being particularly positive consequence of being involved with the projects. This occurred due to being surrounded by other young people with diabetes, resulting in the creation of strong friendships, which went far beyond sharing a diagnosis of diabetes. Interacting with other young people with diabetes was perceived as being helpful in feeling more able to talk about diabetes. Together these experiences served to normalise diabetes and thus lessen the potential threat of diabetes to their identity.

Kali, female, aged 18, who had lived with diabetes since the age of 12, described a strong sense of mutual support amongst the other young people involved in the projects. Although they all shared a diagnosis of diabetes, their friendship went far beyond this similarity.

“Yeah it’s more like, forget about diabetes, it’s like let’s just be friends and stuff.”
(Kali)

For Kali, diabetes was normalised because all the young people involved in the projects had the condition. This prevented diabetes from being seen as threat to identity, or ‘negative identity’ (Erikson, 1970) and as something which needed to be navigated in

the relationship with the other young people working on the project. Diabetes was therefore able to fall into the background, which served to prevent diabetes from dominating over aspects of her own identity but also allowed strong friendships to be established which were based on non-diabetes aspects of identity.

In addition to working directly with other young people with diabetes, the projects provided the opportunity to interact with other young people with diabetes living in the local area. Taanish, male, aged 18, who had lived with diabetes since the age of 12, described valuing being able to discuss diabetes with people who would understand what it was like to live with condition. Such discussions helped to further normalise living with the condition because it removed the need for disclosure of diabetes to be navigated.

“Erm it felt, I guess it felt normal cos everyone else had the same condition like, cos you’ve got someone like here, you could just talk to them about it. Whereas if I go up to someone who doesn’t have diabetes...oh my god you were diagnosed and then that starts. It’s just nice to see like that everyone else is in the same position as you.”
(Taanish)

Taanish described feeling normal when surrounded by other young people with diabetes. This provided him with a sense of freedom to be able to discuss diabetes freely because it was not something that posed a threat to his identity. There was therefore no need to employ the strategies of ‘information management’, ‘covering’ or ‘impression management’, in order to protect his identity (Giddens, 1959 and Goffman, 1963). This was contrasted with his interactions with others who did not have diabetes which marked him out as being different and served to emphasise his diabetes identity.

A sense of normality could also be facilitated even in the absence of conversation. Taanish described attending a support group where diabetes wasn’t necessarily openly discussed but diabetes self-care tasks were organically built into the social setting when the group visited a restaurant. This highlights the two normalisation effects of being surrounded by other young people with diabetes: feeling able to talk about diabetes openly and feeling able to perform medical self-care tasks without them posing a threat to identity.

“Well no one said anything about it to begin with, so we did the activity but erm, we were all sitting down and everyone was doing their blood tests and insulin, that’s when it came up. So they were trying to integrate it like that. ” (Taanish)

Taanish’s account demonstrates the important role of interacting with other young people in serving to normalise diabetes. Such interactions this help to facilitate acceptance of diabetes and the integration of diabetes into identity because in mitigates the threat of diabetes to identity. Furthermore, such interactions can help to facilitate greater engagement with the medical aspects of self-care because the behaviours are normalised.

Despite the normalisation of diabetes as a result of interacting with other young people with the condition, Taanish described an ongoing feeling of being isolated. This was a feeling he described as experiencing prior to becoming involved but as something he expected to be ameliorated throughout the project activities.

“When we started talking about the project, we talked about we want to raise diabetes and remove that isolation of you know how a diabetic feels and I guess like sometimes at work that’s how it feels. ” (Taanish)

For Taanish, the project activities were expected to reduce his feelings of being isolated as a person with diabetes but this was not what he experienced. It is worth noting that this participant became disengaged from the project role for an extended period of time, so this feeling of isolation may have been either a cause or consequence of this disengagement. Nevertheless, the normalisation of diabetes created through the project activities did not reduce his feelings of isolation. This demonstrates that despite sharing a diagnosis of diabetes, this was not sufficient to feel connected to other young people with the condition.

As Kali described, the friendships she built with other young people in the project were based upon characteristics other than diabetes. It is possible that when diabetes is normalised and thus is a less dominant aspect of identity, other aspects of identity are emphasised. This can result in connecting with others if these aspects are shared and

feeling disconnected if these aspects are not shared. This may account for the different experiences of Kali and Taanish respectively.

Taanish described feeling different to the other young people involved in the project particularly when there were difficulties with communication. This was encountered when there were different interpretations of what message was trying to be conveyed.

‘I guess we’re just different, as in, when I say something, or when someone else says something, I think cos everyone interprets it different, like the main message is lost.’
(Taanish)

Taanish’s account highlights the importance of communication in being able to connect with other young people with diabetes. Despite being in an environment in which diabetes was normalised, feelings of difference were facilitated by the struggles with communicating, which likely further contributed to his feelings of isolation. This demonstrates the interaction between the ‘being’ and ‘doing’ aspects of identity whereby the reactions of others (‘doing’ identity) influence the sense of self (‘being’ identity) (Erikson, 1970). For Taanish, the interpretations of others to his message emphasised his sense of being different.

6.4 Seeing behind the scenes of services

It is important to acknowledge that identity work in young people with diabetes is influenced by both the personal and social context surrounding individuals (Erikson, 1956). For young people with diabetes, one of the most significant contextual influences is the clinic, a place they regularly visit for health care appointments. One of the unique aspects of the project roles was the opportunity for participants to see ‘behind the scenes’ of diabetes services, in contrast with their prior experiences as health service users. During the time working in the projects, participants interacted heavily with a range of individuals involved in the delivery of diabetes health care services through public speaking engagements, workshops, site visits, meetings and a range of other events. Exposure to this side of diabetes services resulted in two significant consequences for participants: an enhanced understanding of the perspective of the health care team as well as a greater awareness of the consequences of their own diabetes self-care behaviours.

‘Seeing behind the scenes of services’ corresponds to the sense of comprehensiveness described by Antonovsky (1993) as contributing to a strong sense of coherence. In being able to see diabetes services from a new perspective, participants developed a greater understanding of the condition and its associated consequences as well as the range of individuals involved in diabetes care. This constituted a comprehensiveness of knowledge that was instrumental in developing better relationships with their health care team and in boosting motivation to remain engaged with diabetes services and the medical aspects of self-care.

Results appear to conflict with previous research which reported that knowledge of diabetes self-care did not vary amongst young people with differing levels of engagement with the medical aspects of self-care (Boman et al, 2015). Boman and colleagues found that both ‘adherent’ and ‘non-adherent’ participants demonstrated a high level of knowledge about medical self-care. However, it is likely that the process of acquiring information about diabetes was empowering in these salutogenic projects because it enhanced the ability of participants to contribute positively to the projects. Furthermore, the knowledge built did not just pertain to medical self-care but also to diabetes services and thus the knowledge was contextualised. As participation in the projects was voluntary, the information is also likely to have been more positively received by young people than in other settings.

a) Stronger relationships with the health care team

Participants interacted with a range of individuals involved with diabetes services during their time working in the projects, including members of their own health care team. Such interactions enabled young people to more easily understand the views of their health care team and therefore the reasons that the team continually encouraged high engagement with the medical aspects of diabetes self-care. This was often contrasted with the way in which participants viewed this behaviour prior to becoming involved in the projects. The improved understanding of the perspective of the health care team led to better relationships between the young people and their health care team, particularly enhanced reciprocity within these relationships.

When asked about whether they felt that they were being listened to by these individuals with whom participants interacted, most participants described an evolution over the course of the project. Initially, young people did not feel that they were taken

seriously by the other adults working on the project. This was something that the participants felt changed over time, as a result of remaining committed and demonstrating a strong drive to engage with health care professionals as well as other relevant individuals and organisations whilst in their role.

One of the key priorities identified by participants for diabetes services in community workshops was the need for a gradual transition from paediatric to adult diabetes services. Kali, female, aged 18, who had lived with diabetes for six years, described this being particularly visible in her current experiences of diabetes services.

‘I think, at first I don’t think they really did, cos then it was just like oh they’re just kids and stuff and then slowly I think it was just that thing of putting forward that we belong here as much as you do. Especially like if we’re talking to doctors and nurses and then I think when they see like our determination its making them realise okay we’ve got to do this and that. And obviously it’s evident to how the clinics are now. There’s more like gradual processes of being transf- transitioning and all that stuff. So I think yeah, I think they do take us seriously now.’ (Kali)

Erikson (1980) emphasises that identity is a subjective sense of sameness and continuity in the self that is perceived and recognized by others. Interactions with others therefore serve to either validate or threaten identity. The ‘identity crisis’ of adolescence involves the reconciliation of oneself and the community’s recognition of self (Erikson, 1970). Being taken seriously by adults working on the project was thus important in providing recognition for Kali as a young person with diabetes in the role of young clinical commissioner. This recognition allowed Kali to feel able to have a voice throughout the project and subsequently to have her ideas drawn upon to improve diabetes services. A stronger relationship between Kali and her diabetes health care team was also evident as a result of being involved in the projects. She described receiving consistent positive feedback about her work as part of the project from her diabetes health care team and the subsequent impact on both her physical health and wellbeing. This was perceived as being a natural consequence of being involved with the project and was just one of many beneficial outcomes that had arisen from her role.

‘I think now it’s always mentioned now, and it’s kind of like their way of showing that yeah they’re proud of me. I think my recent one, (Lauren), even, (Katie), my dietician,

and (Dr Mital), they've always just been constantly been saying like how proud they are. Like everything I'm doing, they can see the effect that it's having on my actual wellbeing. And that obviously I agree with them definitely, I mean it's just something that's happened, and it's worked out everything for the better to be honest.' (Kali)

Kali's account highlights the further reinforcement she received from members of her health care team who had been involved in the projects. These not only served to validate her identity but also emphasise the improvement in her wellbeing since becoming involved in the project. Furthermore, Kali's experience demonstrates the value in building ego strength, through developing competencies and the subsequent development of a sense of comprehensiveness and then impact upon wellbeing. Comprehensiveness forms a central aspect of the sense of coherence as proposed by Antonovsky (1993), which has been associated with improved health outcomes and wellbeing (Eriksson and Lindstrom, 2006).

For Kali, being involved with the projects also facilitated a greater understanding of the perspective of her diabetes health care team, which also contributed to an improved relationship with them. This understanding was contrasted with her view before becoming involved with the project.

"Yeah I think it made me understand from their point of view now. Because I think before I was just like, oh why are they always on my back? I know what I'm doing, I'll fix up don't worry and then I don't do it. And now this, I realise you have to be on it, like you can't just leave it for later on to just work out later. You have to be on it so it works out on the later." (Kali)

Kali described feeling frustrated with the continual encouragement by her health care team to maintain consistent medical self-care before becoming involved in the project. She didn't see the importance of such reminders and thus largely ignored them. However, through her involvement in the project, she developed a greater understanding of the reasons that her health care team encouraged self-care and thus was more receptive to this in subsequent clinic appointments. Kali's account demonstrates the importance of interacting with her health care team outside the clinic in developing a comprehensive understanding of both diabetes services and the medical aspects of self-

care. This facilitated an improved relationship with her health care team and a greater motivation to be more engaged with medical self-care.

Saara, female, aged 18, who had lived with diabetes for five years, described developing a more reciprocal relationship with her health care team as a result of being involved in the projects. Saara cited working towards a shared goal and greater awareness of the needs of young people with diabetes as being particularly beneficial in fostering this more reciprocal relationship.

‘‘I’d say it’s stronger because you know they get to see us outside of just clinic times, and you know they’re on the project with us, on the same project and trying to achieve the same thing as us. So they’re like you know what us lot want. ’’ (Saara)

For Saara, the project activities which took place outside the clinic had a direct and observable impact on her relationship with her health care team in the clinic, which was perceived to be stronger and more reciprocal. Being listened to by her health care team as part of the project also served to validate her identity and allow her to have a voice throughout the project. Similarly to Kali, such interactions helped Saara to navigate the ‘identity crisis’ by having her role in the project acknowledged and positively reinforced by her health care team (Erikson, 1970).

A stronger relationship with the health care team was also exemplified through assistance by the health care team with non-diabetes related issues. Taanish, male, aged 18, who had lived with diabetes since the age of 12, described the help offered by his clinician with regard to his future career.

‘‘Even with (Dr Mital) I saw yesterday he erm, he emailed me yesterday saying if you need any help with your career plans, because we were speaking about my university options, and stuff like that... it doesn’t have to do with my diabetes or anything, we were just talking like colleagues or friends like so, which is very nice.’’ (Taanish)

For Taanish, being able to discuss topics which were unrelated to diabetes was seen as particularly valuable and as symptomatic of a strengthened and more reciprocal relationship. This approach of Taanish’s clinician prevented diabetes identity from being emphasised and thus serving to threaten his identity. This therefore helped to

support the integration of diabetes into his identity, a central component of the navigation of the 'identity crisis' of adolescence (Erikson, 1970).

Despite feeling that his time in the role in the projects had contributed to an improved relationship with his diabetes health care team, Taanish did not express positive experiences of task group meetings which he was required to attend as part of his role. In contrast to the way in which he described the equal relationship with his clinician, he described feeling treated as a child by the other task group members during meetings.

“I guess it would just be the team in general. As in like you could definitely feel, as in like we're the children in the room. So when we're in the room with other commissioners you can definitely tell we're not treated differently, but it's not the same” (Taanish)

Taanish's experiences demonstrate the importance of interactions with others in either validating or threatening identity (Erikson, 1980). The perceived behaviour of the other adults working on the project served to threaten his identity and thus he became increasingly absent in project activities, including task group meetings and site visits over the course of the projects.

During this period of disengagement, he also became more distant from the other participants and became harder to contact, which highlights the importance of threats to identity in feeling connected with others. It is interesting that despite some of his negative experiences with the projects, he perceived a positive impact on his relationship with his health care team. This suggests that challenges to identity have the potential to have both positive and negative consequences. Negotiating such challenges plays an important role in navigating the 'identity crisis' of adolescence and young adulthood and subsequently building ego strength (Erikson, 1963; 1964; 1968).

b) Awareness of consequences of self-care behaviour

All participants had lived with diabetes for a number of years and often had several family members who also had diabetes. Despite their experiences, most felt they were lacking in knowledge about the diabetes prior to becoming involved in the projects. This included a lack of knowledge about diabetes itself, as well as the potential future consequences arising from a lack of engagement in the medical aspects of self-care.

Developing a more comprehensive knowledge was empowering for participants and motivated them to become more consistent with their own medical self-care.

A lack of knowledge about diabetes was expressed particularly strongly by Kali, female, aged 18, who had lived with diabetes since the age of 12. She described an enhanced understanding about the different types of diabetes as well as the various treatments available. This was perceived as being particularly valuable because of a lack of prior exposure to individuals taking openly about diabetes. The absence of discussion about diabetes was seen as particularly surprising in light of the high prevalence of diabetes in East London.

‘I think even being a diabetic myself, I didn’t really understand the difference really between the two. I just thought there’s maybe just one and there’s other ones that you’re born with. Or I didn’t know that there’s different types of medication that you can get out there or anything like that. And I didn’t even know that it’s actually really common, cos you don’t really see a lot of people talking like they have diabetes or anything like that. And then to find out that it’s actually the most common place to have diabetes, it’s quite shocking to be honest.’ (Kali)

Seeing ‘behind the scenes’ of services during the project allowed Kali to access information of which she had previously been unaware. The lack of discussion about diabetes despite its prevalence highlights the potential stigmatising nature of a diagnosis of diabetes, whereby talking about having diabetes can be ‘deeply discrediting’ (Goffman, 1963). Individuals with diabetes thus may choose not to disclose their condition in order to protect their identity (Giddens, 1959 and Goffman, 1963).

One of the impacts of this ‘information management’, ‘covering’ or ‘impression management’ is that it contributes to a lack of knowledge about diabetes and its treatments, both in wider society and in others with diabetes, such as Kali. Although Kali had lived with diabetes for 6 years, her knowledge about the different types of diabetes and the treatments was limited because she had not been exposed to conversations about diabetes and its treatments. Her involvement in the projects thus facilitated greater comprehensiveness of knowledge with regards to both diabetes and its treatments.

Kali also described an enhanced awareness of the wide-ranging effects that diabetes could have upon the body from being involved in the projects. This contributed to an increase in the perceived severity of the condition as well as a greater ability to more accurately attribute bodily symptoms to diabetes.

“Yeah, I think I’m more aware of that, obviously diabetes has an effect on everything, everything in the body. So now when I realise that I’m fainting maybe it’s more to do with my sugar than to do with something else. So I think, like even with this role I think it’s helped me to kind of realise the seriousness of it. “(Kali)

For Kali, involvement in the projects had provided her with a new awareness of diabetes and its implications. Although such awareness had the potential to facilitate a sense of diabetes dominating her identity, it also allowed her to more easily recognise her own diabetes-related symptoms and thus attend to them appropriately. Her role in the project had also increased her awareness of the consequences of not attending to such symptoms for her long term health. This increased awareness translated into more engagement with her own medical self-care.

In addition to learning more about diabetes itself, Kali also described an increased knowledge of medical aspects of self-care, especially carbohydrate counting, which is recommended maintain balanced blood glucose levels.

“I actually didn’t know about carb counting at all. I didn’t really know what it was until I remember talking about in our like, training sessions. And I was thinking what is that?” (Kali)

Despite having lived with diabetes for 6 years, Kali had not encountered information about carb counting prior to becoming involved in the project. Through the training sessions as part of the projects, carb counting was discussed and she was able to learn more about the role of carb counting for blood glucose control. Her participation in the projects thus facilitated greater comprehensiveness of knowledge with regards to both diabetes and medical self-care behaviours.

Through involvement in the projects, Kali also developed a greater knowledge of diabetes services and the different individuals that comprise the recommended

multidisciplinary health care team. Although this information was deemed to be useful, it caused frustration because these recommendations did not fit with her previous and current experiences of diabetes services.

“And then obviously learning from this project apparently you have to see a psychologist, dietician and everything and it just made me wonder why wasn’t it there at the time?” (Kali)

For Kali, being previously denied access to a multidisciplinary health care team provoked feelings of anger and frustration. Being involved in the projects had provided her with knowledge about the recommendations for diabetes services as well as the importance of these recommendations. Although she had lived with diabetes since the age of 12, she had not been provided access to this multidisciplinary health care team and because she was unaware that she should have had access, she was unable to advocate for herself in the clinic. Kali’s account demonstrates the potential for increased comprehensiveness of knowledge to cause negative emotions, including anger and frustration, when such knowledge reveals past inadequacies in diabetes services.

Saara, female, aged 19, who had lived with diabetes for since the age of 16, also described an increased knowledge of diabetes services as a result of being involved with the project. She had previously been offered a psychologist when she was considering transitioning from insulin injections to pump therapy. Saara expressed a lack of prior awareness that a psychologist was something that she could request and that support was available for her family members, as well as herself.

“I did actually see a psychologist once when I was going on to a pump. So I had a pump session thing. But I didn’t know you can request to see one. I didn’t know there was a psychologist for people with diabetes. Only when I got in to the role I found out you can request it and there is a service out there for people with diabetes, for families and not just for the individual as well.” (Saara)

Similarly to Kali, Saara also gained knowledge of diabetes services that she had not had prior to becoming involved in the project. Although Saara had lived with diabetes for 3 years, her knowledge about the different individuals comprising multidisciplinary care team was limited. This meant that although she had received one-off access to a

psychologist, she was not aware that she could request this help at other times, not only for herself but also for her family members. Saara's account highlights the significance of the comprehensiveness of knowledge gained for both herself and her family members, also affected by her diabetes.

Learning about the financial implications of diabetes was also described by Saara as a consequence of being involved in the projects. This heightened her awareness of the consequences of her own medical self-care decisions for herself but also for the health care service as a whole.

“She brought in someone and they were talking about A & E and the statistics and you know when you go in to A+E it costs money and stuff. So again knowledge, not just about the project but like other health you know problems out there, like long term conditions, and the effects it has on people and like, benefits it can have of you know like, your services and going to appointments and such.” (Saara)

For Saara, the knowledge gained about the costs associated with treating diabetes-related complications was eye-opening. Particularly memorable were the financial implications of an A & E admission, found to be approximately £1000 per night, which would be the consequence of a serious diabetes-related event. This increased comprehensives of knowledge prompted reflection of her own clinic attendance and medical self-care, prompting her to become more engaged.

The range of individuals and organisations involved in diabetes services was also enlightening for participants. Stephanie, female, aged 19, who had lived with diabetes since the age of 16, expressed surprise that did not have this knowledge before becoming involved in the projects. This was described as being a unique benefit of the project role but was perceived as being knowledge that should be more readily available to other young people with diabetes.

“Why doesn't everybody know who they are? They are the one providing the services, everyone should know the CCG, but I think that's the biggest thing for me learning what the CCG was.” (Stephanie)

Stephanie was particularly surprised that she had no knowledge of the primary organisation involved in delivering her diabetes services despite being a service user for the past 3 years. She felt that this knowledge was important in order to appreciate the range of individuals and organisations affected by attendance to clinic appointments. Stephanie's account highlights the comprehensiveness of knowledge gained through seeing 'behind the scenes' as part of the projects. This experience was unique to the young people involved in these projects and had a significant impact on their engagement with both their own medical self-care and their engagement with diabetes services. This impact occurred as a result of an increased awareness of their decisions about self-care and clinic attendance, not only for themselves but also for a range of other individuals and organisations involved in diabetes care.

6.5 Learning to navigate boundaries

Feeling able to manage diabetes, requires not only adequate information about the condition and its implications but also the ability to navigate challenges within a variety of settings. This allows for diabetes self-care to be maintained whilst pursuing other non-diabetes life goals (Aujoulat et al, 2017). I use the term 'identity work' to describe the continual striving by participants to maintain a balance between the different components of one's self whilst navigating diabetes self-care.

Previous research has demonstrated the importance of the creation of identities which are independent of diabetes in young people living with the condition (Schur et al, 1999). Acknowledging the social context surrounding young people with diabetes is thus important because it influences identity work and subsequently self-care behaviour (Erikson, 1956). This has been described by Radley (1994, p.39) who states that 'chronic illness means living with illness in a world of health'.

Learning to navigate boundaries describes the enhanced ability of participants to acknowledge, challenge and overcome barriers in the projects themselves, the clinic and the wider social environment. The boundaries experienced by participants pertained to both diabetes-specific and non-diabetes issues. The theme of learning to navigate boundaries corresponds to the sense of manageability, described by Antonovsky (1993) as contributing to a strong sense of coherence. In learning to navigate boundaries in a

variety of settings, participants felt more confident in negotiating their own diabetes self-care and advocating for themselves both inside and outside the clinic.

The importance of exploring non-diabetes related aspects of identity has been identified in previous research on young people with diabetes (Brouwer et al, 2012 and Balfe, 2007). Strengthening non-diabetes related aspects of identity seems to help to mitigate the emotional aspects of medical self-care (Aujoulat et al, 2017). The development of work-related aspects of identity may be particularly beneficial because of the association with an adult identity, which has been argued to be a requirement for engaging in the medical aspects of self-care (Fonte et al, 2017). In exploring adult aspects of identity, including the associated constraints and responsibilities, young people are more likely to take responsibility for their own diabetes self-care in an attempt to embody a more adult identity.

a) Learning to navigate boundaries in the project

For most participants, being involved in the projects was their first experience of paid employment and exposure to a work environment. During their time in their roles, participants described learning about the boundaries inherent within a work setting, as well as the importance of communication and time management to help navigate this environment. Gaining 'ego strength' (Erikson, 1963; 1964; 1968) via the accumulation of knowledge and skills relevant to the work environment was described as being highly valuable by participants because it helped them more feel prepared to enter the workplace in the future. Furthermore, their experiences in the projects allowed them to explore and develop a non-diabetes aspect of their identity, their future employment. This in turn helped them navigate the 'identity crisis' whereby there is an attempt at reconciliation between 'the person one has come to be' and 'the person society expects one to become' (Erikson, 1970).

Haadee, male, aged 25, who had lived with diabetes for four years, described the positive impact of being involved with the project on his ability to manage his time more effectively. His experiences prompted him to purchase a diary and ensure that he used it regularly as a way to enhance his time management.

‘‘So I guess time management skills as well has been quite, within this as well because I manage my time better, get myself a diary. Although I used one but I use it a lot more now.’’ (Haadee)

For Haadee, despite already being in employment before the role described the benefit of his involvement in the projects in improving his time management. Although he already had purchased a diary, his experiences had encouraged him to use it more frequently because he had seen the benefits of doing so. Feeling more confident in being able to manage his time meant that he could not only be more organised in work-related tasks but also could ensure that he allocated sufficient time for his diabetes self-care activities. This served to support his identity work by helping him navigate both diabetes and non-diabetes demands in his daily life.

Haadee also described developing enhanced communication skills as a result of his experiences with the projects. Project activities included attending task group meetings, preparing presentations and organising events, all of which demanded the ability to work with others. The improved communication skills involved feeling more able to listen to the views of others, which was a skill he felt he lacked before becoming involved with the projects.

‘‘There’s another thing I might have picked up as well is listening to other people’s opinions.’’ (Haadee)

Developing improved communication skills not only helped him as part of the projects but was a skill he felt confident in being able to take forward when the projects had finished. These communication skills serve an important function within identity work, which involves not only negotiating the different components of one’s own identity but also navigating the behavioural manifestations of identity that are observable to others. These characterise the ‘being’ and ‘doing’ aspects of identity described in chapter 4.

Taanish, male, aged 18, who had lived with diabetes for six years, described feeling the adults he interacted with in the projects as having low expectations of him. This provided him with the opportunity to overcome a barrier by proving himself and speaking up for what he believed in. Taanish described being pleasantly surprised that he was listened to by others and that this contributed to a productive conversation.

‘Erm, well I got there late. And I don’t think, when I went in there I don’t think anyone was expecting anything of me. Or they didn’t really think, I was there but didn’t really think I had much to say. And when I did start speaking erm, I don’t know, I think everyone just took it on board and we were able to have like a nice discussion about what we was speaking. And it just felt you know, well we might not be implementing that but at least we’re discussing it. So trying to take the best bits out of it.’ (Taanish)

Despite arriving late at the meeting and feeling that others did not expect anything from him, Taanish was keen to contribute and make his voice heard. This was rewarded when his views were acknowledged and a fruitful discussion took place. Although he felt frustrated that these ideas were not been implemented into diabetes services in the way he expected he appreciated being able to have a voice in the conversation. Feeling able to have a voice characterises ‘ego strength’ (Erikson, 1963; 1964; 1968) whereby becoming more competent in communicating ideas allowed him to feel more important and thus able to contribute in a meaningful way to important discussions about diabetes services.

Taanish also described other barriers he perceived in the projects, such as perceived lack of responsibility. He expressed his frustration at being treated in a way that made him feel like a child and was different to the way in which he expected to be treated during the projects.

‘I still feel yeah I still feel like a child basically. So when I took the role I thought you know we’d be given more responsibility, we’d be taken more seriously. And sometimes I don’t think it feels that way like, we do get respect, and we do get responsibility, but I think I prefer er, more.’ (Taanish)

For Taanish, the projects had provided him with a new level of responsibility that he had not previously experienced but this did not match with his expectations or desires of the project roles. Participating in the projects involved a lot of interaction with adults involved in diabetes services and Taanish was acutely aware of the way in which he was treated in comparison to the other adults. This perceived barrier was frustrating to him because he felt limited in the ability that he could make a positive difference to diabetes services during his time working in the projects.

When reflecting on his behaviour in the projects, Taanish described a lack of discipline with regards to his role. Despite this acknowledgement, Taanish did not feel that this behaviour should have impacted upon the way he was treated by other, primarily adult members of the task group.

‘‘I’m not the best employee in the world. I guess I would have to be more erm, disciplined in the way I go about the role. But also erm, with the task group I think erm, they need to like realise as in, we’re not erm, you know we shouldn’t be treated like, the way, we’ve started working in the same field as adults so we should be treated the same’’ (Taanish)

For Taanish, being treated the same way as other adults despite behaving differently was a difficult barrier for him to face. Although he admitted that he lacked discipline in his approach to the role, this was not perceived as something which should contribute to this barrier. Taanish’s account emphasises the impact of others on identity work, whereby there is a need to negotiate the different components of one’s own identity but also to navigate the behavioural expressions of identity that are observable to others. These characterise the ‘being’ and ‘doing’ aspects of identity work respectively, which are discussed in chapter 4.

Taanish also described not being able to interact with individuals in positions of power as part of the projects. He expressed disappointment that the project activities had not been as impactful as he had hoped, which he attributed to this lack of interaction. This was perceived as a barrier to improving the lives of other young people living with diabetes in East London.

‘‘So it would be like, so the work I’ve done is great, but I think I just kind of hope we’d be able to take it a bit further as in erm, we need more people where you engage with people higher up there, people who actually have the power to you know make the changes and help those living with the condition.’’ (Taanish)

Although Taanish appreciated the contribution that he and the other young people working in the projects had been able to make, he felt frustrated that more action was not taken towards improving diabetes services. Taanish described the barrier of not only

lacking power himself but also the ability to communicate with people in positions of power. However, despite these experiences, Taanish valued the experience of being exposed to such barriers.

‘‘It’s still quite hard cos, erm I’m quite impatient but erm, I guess that’s what makes you more mature, as in you don’t always get your way. Sometimes you have to just play by the rules’’ (Taanish)

Taanish described struggling to accept these power boundaries but felt that they had taught him an important life lesson. He felt more able to manage similar boundaries in future employment settings because he understood them to be inherent in the work environment. Taanish’s account demonstrates the importance of gaining ‘ego strength’ (Erikson, 1963; 1964; 1968) via the accumulation of knowledge and skills relevant to the work environment. The project experiences had allowed him to explore a non-diabetes related aspect of his identity, being an employee, which had helped him to feel more prepared for future employment positions. This in turn helped him to navigate the ‘identity crisis’ of adolescence and young adulthood whereby young people attempt to reconcile ‘the person one has come to be’ with ‘the person society expects one to become’ (Erikson, 1970).

b) Learning to navigate boundaries in the clinic

Participants interacted with a range of individuals involved with diabetes services during their time working in the projects, including members of their own health care team. Such interactions helped participants understand the perspective of their health care team but also to better advocate for themselves within their clinic appointments. The feeling of having a voice, making a difference and taking ownership in their project roles helped participants take a more active role in their clinic appointments. This active role in clinic appointments included feeling more able to ask questions and to negotiate about the way in which they would fit self-care into their daily lives.

Taking ownership over the projects was described as being particularly valuable by participants. This was because young people are not often provided with platforms whereby they can express their views and have them acknowledged and addressed. Kali, female, aged 18, who had lived with diabetes for six years described this as being a unique, positive and empowering experience.

‘I think that’s the one thing that I really liked. It was us taking charge.’ (Kali)

Being able to ‘take charge’ during the project was a unique experience for Kali and something which played a large role in her enjoyment of the projects. This highlights the importance of participating in activities which build ‘ego strength’ (Erikson, 1963; 1964; 1968). Such activities, which allow participants to become more competent in a variety of areas, including being able to take responsibility, provide a sense of being important and thus serve to validate identity. This therefore provides young people with diabetes the confidence to better navigate barriers because they feel able to ‘take charge’ when approaching them.

In addition to taking ownership, Kali also described feeling that she had made a positive impact whilst working in the projects. She perceived the time spent in the roles as being effective in bringing about change to diabetes services as well as within her own life. Kali articulated the satisfaction in being able to enact on her desire for change, rather than merely contemplating desirable changes.

‘But no I’m glad that I went forward for it. Because so much has happened, like positive things like you know people say that they want to make a difference in the NHS and so on, whereas I’ve actually just done something rather than just sitting there thinking about it. So I think that was one of the rewarding things.’ (Kali)

For Kali, being able to take meaningful action in the projects was empowering, particularly because she perceived her action as making a difference to diabetes services. Feeling able to make a difference in a way that would potentially improve diabetes services not only for herself but for other young people with diabetes in East London was highly rewarding. Despite the time in the roles being limited, and encountering barriers during the project, Kali felt that she had contributed towards many ‘positive things’ which made her time working in the projects seem worthwhile. This also served to boost her ‘ego strength’ (Erikson, 1963; 1964; 1968) as it made her feel capable of making a difference in her own life, including the improved ability to navigate boundaries she encountered.

This enhanced ability to navigate boundaries in her own life came to fruition when she attended a clinic appointment without a parent being present for the first time. The confidence gained from the project allowed her to more easily advocate for herself in the clinic appointment and negotiate with her health care team about diabetes self-care activities.

“then erm, I think my recent appointment was my first time ever I went without my mum, and then I think that was so much better for me because I could talk to them about it and we came to an agreement like oh maybe just have tablet in the day and do your injection at a certain unit and stuff. And I think that helped me a lot.” (Kali)

Before becoming involved in the project, Kali had not attended an appointment without her mother being present. The boost in ‘ego strength’ (Erikson, 1963; 1964; 1968) as a result of the project helped to increase her confidence in being able to attend a private clinic appointment and to better advocate for herself within the clinic. This allowed her to discuss the challenges she faced with implementing medical self-care activities in her daily life and to come to an agreement with her health care team about how best to navigate these challenges.

Advocating for themselves in the clinic also involved participants feeling more able to ask questions to the health care team. Stephanie, female, aged 19, who had lived with diabetes for three years, described being more confident about asking questions, which she attributed to her involvement in the projects. This enabled Stephanie to ensure that her concerns relating to diabetes or diabetes self-care could be addressed, allowing her to feel more able to manage her diabetes in her daily life.

“I’m not afraid to ask questions anymore.” (Stephanie)

Advocating in clinic was also facilitated by the experiences of being listened to by individuals and organisations involved in diabetes care as part of the projects. This was a unique experience for participants such as Saara, female, aged 18, who had lived with diabetes for 3 years. She described feeling disempowered before participating in the projects and feeling that young people did not have a voice. Her experiences with the projects provided an opportunity to have her views listened to by others, including her own health care team.

“Well compared to before to now, so before it was probably little...but now it’s just like, knowing that there are actually people out there, they are willing to listen, but then, whereas before I’d be like do you know what young people don’t have a voice, whatever it is we want to say, whatever it is that we want, you know there’s no one there to listen. Whereas now working for the CCG you know that there are people out there trying to support you who are willing to help.” (Saara)

For Saara, being involved in the projects provided her with the opportunity to have her perceptions of the individuals and organisations involved in diabetes care challenged. She described feeling empowered by being able to have a voice and have her views acknowledged by others with influence, including her own health care team. Learning that these individuals and organisations were not only willing to listen but were also keen to provide help and support, allowed her to feel more able to advocate for herself because she trusted that her perspective would be acknowledged and acted upon. Saara’s account highlights the importance of others in enhancing ‘ego strength’ (Erikson, 1963; 1964; 1968) and thus providing young people with confidence to negotiate boundaries both inside and outside the clinic.

c) Learning to navigate boundaries in the social environment

Participants also described experiencing boundaries within their wider social environment. Such barriers involved disclosing their diabetes diagnosis to friends as well as addressing the lack of awareness about diabetes within their wider social network. As a result of learning more about the potential complications of diabetes in their project roles, participants described feeling more willing to disclose their diabetes to their friends who they spent time with regularly.

Participants also described feeling more inclined to discuss diabetes openly with others as a result of being involved in the projects, which was perceived as being important due to the lack of awareness about diabetes within the general population. Successfully navigating the ‘identity crisis’ of adolescence and young adulthood requires an assimilation of all of aspects of identity but also a reconciliation of an individual’s identity with the community’s recognition of that self (Erikson, 1970). For young people with diabetes, in addition to negotiating the role of diabetes within their identity, they are also required to navigate the way in which their diabetes identity is expressed

towards others. These characterise the ‘being’ and ‘doing’ aspects of identity discussed in chapter 4.

Heightening awareness about the potential consequences of diabetes as part of being involved in the projects provided added motivation for participants to disclose their diabetes to others. Saara, female, aged 18, who had lived with diabetes since the age of 13, specifically attributed her role to feeling more inclined to tell significant others about her diabetes. The potential negative consequences of them not knowing and thus not being able to help was cited as being a key driving factor.

“But like since I got in to this role I feel like, you know what I should let them know, I should be more like aware of what would happen if they didn’t know.” (Saara)

For Saara, becoming increasingly aware of the potential for negative health implications as a result of not disclosing her condition strongly influenced her decision to tell others about her diabetes. Due to the stigma associated with diabetes, Saara had previously chosen to avoid disclosing diabetes and thus was employing the strategies of ‘information management’, ‘covering’ or ‘impression management’, in order to protect her identity (Giddens, 1959 and Goffman, 1963). Being involved in the project allowed Saara to overcome the barrier of perceived stigma and thus played an important role in her identity work around diabetes but also served to help maintain her physical health.

In addition to feeling more able to disclose their diabetes diagnosis to others, participants also described being more willing and able to discuss diabetes with other people within their social network as a result of being involved in the projects. Haadee, male, aged 25, who had lived with diabetes since the age of 21, described the difference in the amount that he spoke about diabetes with others in comparison to before his involvement in the project.

“Speaking about diabetes more as well with people I meet as well.” (Haadee)

For Haadee, being involved in the projects had provided him with more confidence in discussing diabetes with others. Similarly to Saara, participation helped to reduce concerns about the stigma surrounding diabetes and thus lessened the threat of diabetes to his identity. This meant that he felt more able to disclose and discuss diabetes when

deemed necessary but also was more inclined to instigate conversations with others about diabetes.

Taanish, male, who had lived with diabetes since the age of 12, described feeling particularly motivated to discuss diabetes with others to help counter the negative media messages pertaining to diabetes. He described feeling that diabetes lacked exposure within the media and where messages were communicated, they were predominantly pertaining to type 2 diabetes, rather than type 1. This was perceived as contributing to a lack of awareness about diabetes as a whole and particularly the differences between type 1 and type 2 diabetes.

‘I guess it’s to do with awareness. So not much in the media or just in general is done with diabetes. And if it is, it’s to do with type two and not type one.’ (Taanish)

For Taanish, the perceived stigma of diabetes, causing a boundary towards disclosure, was exacerbated by the media portrayal of diabetes. This was described as resulting in a lack of awareness about diabetes generally but particularly about type 1 diabetes. However, his involvement in the project, which built his knowledge base about diabetes allowed him to feel more able to effectively communicate messages about diabetes to others.

‘I guess I’m just taken more seriously because I’m working in it, I think more people when I say something they erm, they not believe more but they understand more, they want to hear it more. Whereas if I didn’t have the role, they’re oh how would you know? How, do you have any evidence to back it up? I’d say you know what, I work in it, I see this every day erm, I like give facts and statistics to back up my arguments as well, which is cool.’ (Taanish)

Involvement in the projects had allowed Taanish to feel more confident in being able to discuss diabetes with others. This was attributed both to his larger knowledge base about diabetes but also due to the reactions of others. Taanish’s account demonstrates the importance of the projects in reducing the threat of diabetes to his identity but also in empowering him to disclose and discuss diabetes more readily with others, these characterise the ‘being’ and ‘doing’ aspects of identity discussed in chapter 4.

The boost to ‘ego strength’ (Erikson, 1963; 1964; 1968) as a result of being involved in the projects thus allowed him to feel more capable and thus overcome the boundaries in his social environment. The reactions of others, in terms of taking him more seriously, subsequently served to validate his identity, thus helping him to navigate the ‘identity crisis’ of adolescence and young adulthood (Erikson, 1970).

6.6 Concluding comments for this chapter

This chapter has described the effects of participating in two salutogenic projects in relation to diabetes self-care via building ego strength (Erikson, 1963; 1964; 1968). The themes pertaining to these consequences are ‘Developing a positive diabetes identity’, ‘Seeing behind the scenes of services’ and ‘Learning to navigate boundaries’. These themes correspond to the three aspects of a sense of coherence: meaningfulness, comprehensiveness and manageability respectively (Antonovsky, 1993). Participation in the projects provided young people with the tools to better navigate identity work. This in turn helped them to integrate diabetes into their self-concept (‘being’ identity) and diabetes self-care into daily life (‘doing’ identity). Results highlight the potential for salutogenic projects to promote greater engagement with the medical aspects of self-care by influencing young people’s identity work. The next chapter discusses findings across all three stages of my research, about the role of identity work in diabetes self-care in young people, including the implications for research, policy and practice.

Chapter 7: Discussion

7.1 Overview of this chapter

In this chapter, the findings of the research are considered in relation to the research questions, existing theory and literature. Firstly, the principle findings of the research on the role of identity work in diabetes self-care are discussed in relation to the research questions. This will be followed by a discussion of the strengths and weaknesses of the research. A discussion of the meaning of the findings for diabetes self-care, including the implications for both policymakers and clinicians will then be presented. The chapter will conclude with a discussion of the unanswered questions about identity work and diabetes self-care, including suggestions for future research.

7.2 Overview of principle findings

This sections below discuss the main findings on the research in relation to the research questions, which were:

- How do young people experience diabetes self-care?
- How do different environments influence diabetes self-care?
- How do support networks impact diabetes self-care?
- How does participating in salutogenic projects shape young people's perspectives and practice towards diabetes self-care?

7.3 How do young people experience self-care?

The findings of the research presented in this thesis has identified identity work as significant in shaping young people's experiences of diabetes self-care, particularly for those young people defined as disengaged from diabetes services and/or diabetes self-care. Identity work describes the continual negotiation of the role of diabetes into self-concept ('being' identity) and diabetes self-care into daily life ('doing' identity). These are synonymous with the psychological and sociological aspects of identity discussed by Erikson (1980). Rather than merely being part of the experience in living with diabetes, this research has demonstrated that identity work underpins young people's engagement with diabetes self-care. This is a fluid process, with young people oscillating between different types of identity work.

This research has confirmed previous findings that a diagnosis of diabetes represents an identity threat, which has been referred to as ‘biographical disruption’ in research on adults with chronic conditions (Bury, 1982). The response to such significant life events have been argued to be critical in the development of psychological functioning and wellbeing (Erikson 1970). However, such events are extremely demanding for young people to navigate because they occur against a backdrop of identity formation. The diagnosis has been described as transforming young people from being ‘normal’ to becoming a ‘diabetic’ (Foster, 2010).

In light of this ‘biographical disruption’, the identity work engaged in is aimed at achieving a sense of normality for young people with diabetes. This refers to diabetes being integrated into a young person’s ‘being’ and ‘doing’ identity in a way that does not dominate over other aspects of identity. A sense of normality occurs when there is a balance between the threats and validators of identity.

Previous research has highlighted the desire for normality in young people with diabetes (Schur et al, 1999, Foster, 2010 and Commissariat et al, 2016) although this has not been explicitly described as identity work. The desire to be ‘normal’ has also been identified as being important for young people with a variety of other chronic conditions (Taylor et al, 2008). This suggests that results pertaining to identity work may be transferable beyond young people with diabetes.

For young people defined as disengaged from diabetes services and/or diabetes self-care, two other types of identity work form an important part of their experiences with diabetes self-care: ‘forgetting diabetes’ and ‘diabetes as dominating’. ‘Forgetting diabetes’ describes a type of identity work underlying the avoidance of the medical aspects of diabetes self-care, which represents an attempt by young people to minimise the impact of their condition on their identity. Young people engaging in this type of identity work were struggling to integrate diabetes into their sense of self (‘being’ identity) and diabetes self-care into their daily lives (‘doing’ identity). When engaging in activities that were enjoyable for them, such as singing in a choir, diabetes was more likely to be ‘forgotten’ because it was perceived as being an inconvenience.

Furthermore, when events occurred that were important to them, such as school exams, young people also described difficulty in prioritising clinic appointments. This highlights the importance of considering the context in which diabetes self-care occurs and the competing priorities that young people with diabetes are negotiating on a daily

basis. Optimal self-care from a purely medical perspective can thus differ significantly from optimal self-care from the perspective of young people with diabetes.

‘Diabetes as dominating’ describes a type of identity work occurring when diabetes and diabetes self-care serve as significant disruptors to young people’s identity. In terms of ‘doing’ identity, diabetes self-care dominated because it was time consuming and sometimes painful to carry out for young people. The medical aspects of diabetes self-care were also perceived as interfering with other non-diabetes areas of young people’s lives which were important to them.

In terms of ‘being’ identity, diabetes tended to dominate participants’ thoughts and thus could feel mentally draining, making medical self-care difficult to sustain because it was perceived as adding to this burden. Although the avoidance of the medical aspects of self-care can be dangerous due to the heightened potential for negative health consequences, such behaviour makes sense psychologically as young people seek to develop an identity that is not dominated by diabetes (Aujoulat et al, 2017). Similarly, a lack of engagement in these aspects of self-care can represent an attempt by young people to maintain their emotional wellbeing. Young people are thus tasked with a ‘trade-off’ when navigating decisions about their self-care.

Traditionally, a lack of engagement with the medical aspects of self-care in young people has been conceptualised as being due to a lack of knowledge about the condition and its management within research, policy and practice. This is symptomatic of a deficit approach, where there is a focus on what is perceived to be lacking in individuals and communities. Recommendations to improve the medical aspects of self-care have thus tended to focus heavily on the need for diabetes education (NICE, 2015).

As noted in chapters one and two of this thesis, previous research has highlighted that differing levels of engagement with the medical aspects of self-care are not associated with different levels of knowledge about diabetes or medical self-care (Boman et al, 2015, Huus and Eskar, 2007 and Damiao and Pinto, 2007). This thesis provides evidence that identity work, rather than knowledge can explain different levels of engagement with the medical aspects of diabetes self-care. This work involves navigating both diabetes and non-diabetes aspects of identity, which highlights the importance of conceptualising young people as individuals, rather than as ‘diabetics’ in research, policy and practice, an idea that is integral within a salutogenic approach.

The three types of identity work described in this thesis ('forgetting diabetes', 'diabetes as dominating' and 'diabetes as routine') reflect the tension in the literature between the importance of integrating diabetes into identity and creating identities which are separate from diabetes. These two positions have traditionally been positioned as being inherently contradictory (Commissariat et al, 2016).

This thesis has shown that both integrating and distancing are important in identity work. The process is fluid, with young people oscillating between the different types of identity work as they negotiate the role of diabetes into their identity. These findings were elucidated through the application of a salutogenic approach, whereby there is a focus on the problem-solving capacities of individuals and the dynamic nature of this behaviour.

Integrating diabetes into both 'being' and 'doing' identity is necessary in order to engage with medical self-care activities, whilst maintaining a sense of normality, characterised by 'diabetes as routine'. A lack of integration of diabetes into identity is characterised by 'forgetting diabetes'. However, an intense focus on diabetes as part of identity can create a sense of being overwhelmed by diabetes, characterised by 'diabetes as dominating'.

In this thesis, most participant accounts describing 'diabetes as routine' also made reference to at least one of the other types of identity work in their accounts: 'forgetting diabetes' or 'diabetes as dominating'. This suggests that identity work is fluid whereby young people are continually negotiating the role of diabetes within their identity as part of the 'identity crisis' of adolescence (Erikson, 1970). This can be likened to a process described as young people learning to live with diabetes without making it 'the main thing' (Foster, 2010).

The identity work types 'Diabetes as dominating' and 'Diabetes as routine' are consistent with findings from Clausi and Schneider (2017), who explored the impact of the medical aspects of self-care on identity in young people with diabetes. However, rather than conceptualising medical self-care as merely impacting upon identity, this thesis has highlighted a closer connection between self-care and identity. It has demonstrated that identity work underpins diabetes self-care, with different types of identity work being associated with different levels of engagement with the medical aspects of diabetes self-care. Clausi and Schneider (2017) did not report identity work

which could be characterised as ‘forgetting diabetes’, which suggests that this type of identity work may be specific to young people defined as disengaged from diabetes services and/or diabetes self-care. For these young people, avoiding the medical aspects of self-care represents an attempt to maintain their sense of normality, prevent diabetes from dominating their identity and maintaining their emotional wellbeing.

The notion of forgetting has been discussed in previous research on young people with diabetes although has not been explicitly described as identity work by authors. Mulvaney et al (2008) reported that young people often forgot to perform medical self-care activities in the evenings, a time when they were mentally and physically fatigued. Conversely, Boman et al (2015) reported that young people defined as ‘adherent’ to medical self-care behaviours described being unable to forget about diabetes, which was cited as the reason for continuing to engage in these self-care activities. Authors also found that those defined as non-adherent also reported forgetting about diabetes, which was described in positive terms as an emotional strategy that prevented diabetes from dominating identity.

Benefits of forgetting about diabetes have also been reported by Wicks (2011), who discussed the importance of exploring non-diabetes aspects of identity for young people, which allowed them to temporarily forget about diabetes. Taken together, these findings suggest that ‘forgetting diabetes’ is an inevitable aspect of identity work as negotiate the role of diabetes within their identity whilst striving to maintain a sense of normality. Although this ‘forgetting’ may result in less engagement in the medical aspects of self-care and thus compromise physical health, ‘forgetting’ serves an socioemotional function in preventing young people from feeling that diabetes dominates their identity. Optimal diabetes self-care from a medical perspective is thus often at odds with young people’s wellbeing. Diabetes self-care for young people thus represents a ‘trade-off’ between these conflicting influences.

The sense of diabetes as dominating relates to Erikson’s conceptualisation of ‘negative identity’, whereby the young person struggles to integrate a perceived negative aspect of identity with the other aspects of identity. ‘Diabetes as dominating’ is synonymous with a high level of illness centrality, a concept which describes the extent to which the illness experience plays a central role in an individual’s identity (Helgeson and Novak, 2007). This concept has largely been explored quantitatively with research reporting an

association between illness centrality and poorer psychosocial adjustment to illness (Morea et al, 2008). Studies have also found higher illness centrality to be associated with reduced wellbeing and development of self-care capabilities (Helgeson and Novak, 2007). It is thus important to support young people in reducing the perceived threat of diabetes and helping them integrate the condition into both their ‘being’ and ‘doing’ identity to help facilitate engagement with the medical aspects of self-care whilst maintaining their sense of normality.

In addition to highlighting the significance of identity work in diabetes self-care in young people, this thesis has also demonstrated that identity work is modifiable. Participation in salutogenic projects, allowed young people to develop competencies, defined as ‘ego strength’ (Erikson, 1963; 1964; 1968). These competencies provided young people with the tools to more confidently navigate identity work within their daily lives. Consequently, this helped them to integrate diabetes into their self-concept (‘being’ identity) and the medical aspects self-care into their daily lives (‘doing’ identity).

It is important to highlight that young people’s self-care is dependent on the competing priorities within their lives and the resources available to them. Diabetes self-care decisions made by young people are not necessarily optimal from a purely medical perspective but is a reflection of young people’s desire to balance the diabetes and non-diabetes aspects of their identity, maintaining their socioemotional wellbeing.

Salutogenesis (Antonovsky, 1996) proposes a holistic view of health and acknowledges the autonomy and capability of individuals to make choices about their health and wellbeing. In line with a salutogenic approach, this thesis highlights the importance of considering diabetes self-care within the context of the lives of young people and conceptualising young people as individuals, rather than patients, capable of making their own decisions about self-care.

This thesis makes an important contribution to the literature on identity in young people with diabetes, a topic which has not been extensively studied. Within this limited evidence base, most studies of identity in young people with diabetes have been quantitative in nature. Such research has tended to use questionnaires, such as the ‘Illness Perception Questionnaire’ (Weinman et al, 1996), ‘Illness Identity Questionnaire’ (Oris et al, 2016) and ‘Illness Self-Concept Scale’ (Luyckx et al, 2014).

This thesis has highlighted the significance of identity work in young people's engagement with diabetes self-care behaviours. It has explored the way in which young people experience this identity work, the different types of identity work, the threats and validators to identity, the context in which identity work occurs and how identity work influences diabetes self-care. Furthermore, the research focused particularly upon young people defined by clinicians as disengaged from diabetes self-care and/or diabetes services, whose voices tend to be underrepresented in the literature. 'Forgetting diabetes' was a type of identity work identified in this thesis, which may be unique to this population.

The findings presented in this thesis have emphasised the importance of identity work within the experience of diabetes self-care in young people, particularly those defined as disengaged. It has also provided evidence that identity work is modifiable, which is a unique contribution to the research literature. Young people's involvement in salutogenic projects gave them confidence in being able to navigate this identity work within their daily lives, and thus have greater autonomy in decisions about their self-care.

7.4 How do different environments influence diabetes self-care?

This thesis has highlighted the importance of acknowledging the context of identity work in young people with diabetes. The contexts which were particularly significant for participants' identity work were the clinic and the school. The significance of such contexts for individuals with chronic conditions has been described by Radley (1994, p.39) who states that 'chronic illness means living with illness in a world of health'. The acknowledgement of the context of young people's experiences is central to the salutogenic approach applied throughout this thesis (Antonovsky, 1979).

The clinic was described as being intimidating by participants, which meant that young people felt less able to ask for help and support with the medical aspects of self-care. Feelings of intimidation were particularly heightened when young people were anxious about their upcoming clinic appointment, due to their recent lack of engagement with medical self-care. This could contribute to a sense of 'diabetes as dominating'. Young people described expecting to be 'lectured' by clinicians if their blood glucose readings

were evaluated as being poor. The perceived likelihood of being ‘lectured’ during a clinic appointments is associated with more dishonesty about recent medical self-care behaviour by young people. Previous research has reported that young people are sometimes untruthful about blood glucose readings to clinicians, delete blood glucose readings and remove batteries from blood glucose meters (Mulvaney et al, 2008). Not all young people described feeling intimidated by clinic appointments. When young people felt that health care professionals understood the other non-diabetes related issues they were facing, they felt more at ease. This enabled them to be more open during clinic appointments so that they could receive the advice and support they needed to integrate diabetes self-care into their daily lives (‘doing’ identity) whilst maintaining a sense of normality, characterised by the identity work ‘diabetes as routine.’

Participants tended to describe having stronger relationships with nurses than clinicians, with the latter focusing solely on diabetes-specific issues in contrast with nurses who tended to adopt a more holistic approach. Previous research has also reported young people’s preferences for being seen as an individual first and then as someone living with diabetes within the clinic (Carroll and Marrero, 2006). This highlights the value of a salutogenic approach within the clinic, which allows for young people to be conceptualised as individuals rather than ‘diabetics’ by health care professionals.

It has been suggested that when clinic appointments focus heavily on diabetes education about diet and exercise, they are ineffective in improving medical self-care (Tilden et al, 2005). This is suggested to be the result of emphasising diabetes identity, akin to ‘diabetes as dominating’, which reduces young people’s likelihood of engaging in medical self-care behaviours. Other research has suggested that a strong focus on diabetes education emancipates young people from their membership to an adolescent group. This is because optimal self-care, from a medical perspective, is associated with the adoption of an adult identity (Fonte et al, 2017). This idea is supported by research reporting that young people with diabetes consider themselves as being more adult than young people without diabetes (Luyckx et al, 2011). Being treated as a young person rather than a diabetic in the clinic is thus important to support young people’s identity work and support them to make their own decisions about diabetes self-care.

Independence was important in young people taking on greater responsibility for their diabetes self-care to achieve a sense of normality. This process also involved the development of diabetes self-care strategies to manage the emotional and practical elements of diabetes. Independence served as a validator to both 'being' and 'doing' identity. Support thus helped participants to navigate the 'identity crisis' by allowing them to more easily reconcile diabetes with the other aspects of their identity (Erikson, 1970). However, the transition towards more independent self-care was often challenging for young people, particularly if they felt unprepared to take on greater responsibility. This could occur in young people who were diagnosed with diabetes at a young age and thus most information about diabetes and diabetes self-care had been directed towards their parents.

The school environment was described as making young people feel different. Carrying out medical aspects of diabetes self-care could result in unwanted attention from others, making young people reluctant to carry out these behaviours at school. These findings support previous research which has reported that young people often feel uncomfortable performing medical self-care at school because of the behaviour marking them as being different from others (Wang et al, 2013). The feeling of difference in the school environment characterises 'extreme identity consciousness', whereby young people are particularly self-conscious of their behaviour and highly concerned with the reactions of their peers (Erikson, 1956). Avoiding medical self-care in these situations thus represents an attempt by young people to maintain a sense of normality and wellbeing.

Some participants were so fearful of the potential reactions of others that they avoided disclosing their condition others, putting their health at risk if a diabetes-related event was to occur. Avoidance of disclosure has been reported in previous research on young people with diabetes (Lewis, 2007). These fears are consistent with Goffman's (1963) ideas of stigma, in terms of stigmatising attributes being 'deeply discrediting' because they serve to set individuals apart from others. Young people who were fearful of this stigma thus chose not to disclose their condition in an attempt to protect their identity (Goffman, 1963).

Treatment by school staff could also reinforce the sense of difference from others, which was particularly detrimental because it resulted in young people missing school,

thus having their education disrupted. The treatment by school staff reinforced the sense of ‘diabetes as dominating’, akin to ‘negative identity’, whereby the condition is seen as a threat and is thus difficult to integrate it into identity (Erikson, 1970). As mentioned earlier in this chapter, the reinforcement of a diabetes identity reduces the likelihood of young people engaging in diabetes self-care (Tilden et al, 2005).

The sense of difference in the school environment could also be facilitated by other young people with diabetes. If other young people had dissimilar attitudes towards their diabetes, this highlighted the sense of difference for others felt by participants. This supports findings by Kay et al (2009), who reported that young people with diabetes wanted to fit in with others and strongly disliked diabetes overshadowing other aspects of their identity. However, other research has reported other young people at school with diabetes as being desirable because of helping to normalise diabetes (Lewis, 2007). Other young people at school with diabetes thus interacts with identity work but this may be perceived positively or negatively, depending on the perceived similarity of the other young person with diabetes.

The school environment was not always associated with negative experiences or the sense of being different from others in participants. Strong communication between the diabetes health care team, young people, parents and the school was helpful in ensuring that participants were adequately supported at school. This resulted in young people being able to remain consistent with the medical aspects of diabetes self-care, minimised disruption to their education and thus promoted a sense of normality.

7.5 How do support networks interact with diabetes self-care?

The family provided a strong support system for participants. The family provided both emotional and practical support for participants, which has also been found in previous studies (Anderson et al, 2013). The nature of support changed as participants became older and began to take on more responsibility for the medical aspects of their self-care.

Findings demonstrated that the transition towards more independence is difficult for young people, particularly if they feel unprepared to take on this greater responsibility. Although participants enjoyed having more freedom, it also resulted in medical self-care being harder to manage and thus these self-care behaviours were less consistent than

when they were younger. The reduced engagement with medical self-care resulted in more frequent diabetes-related complications. This demonstrates the explorative nature of identity work, whereby the role of diabetes within identity is continuously negotiated by young people, which manifests in fluctuating levels of engagement with medical self-care (Aujoulat et al, 2017 and Erikson et al, 1970). Although not necessarily optimal from a physical health perspective, such exploration is an important aspect of young people's development.

The creation of self-care strategies helped young people to navigate this transition towards independence more easily. The strategies drawn upon included planning ahead, using intuitive diabetes self-care techniques, drawing on the experiences of others with diabetes, being attuned to signs of unbalanced blood glucose levels and taking a proactive approach to their diabetes self-care. These strategies enabled participants to manage both the emotional and practical demands of diabetes, preventing the sense of 'diabetes as dominating', thus helping them successfully navigate their 'identity crisis' (Erikson, 1970). However, such strategies sometimes required a compromise of physical health in order to maintain emotional wellbeing, such as keeping blood glucose levels slightly high to prevent them from becoming low whilst at work.

The importance of diabetes self-care strategies has been reported in previous research by Mulvaney et al (2008). Planning diabetes self-care helped young people to address the physical and emotional aspects of diabetes self-care. Similarly to the findings of this thesis, authors reported that the emotional and physical aspects of diabetes self-care were sometimes conflicting, such as having 'cheats' (eating unhealthy foods), which helped to ameliorate the emotional fatigue from living with the condition.

Young people did not always feel supported by their families. Conflicts could occur over medical self-care behaviour. Participants also described experiencing a tension between wanting parents to be involved in medical aspects of self-care and wanting to have more independence. Theories of adolescence typically suggest that a central task is for young people to move from a state of dependence on parents to a state of independence (Schur et al, 1999). However, other research has suggested that this stage is better characterised as moving from dependence towards interdependence, rather than seeking to maintain complete freedom from parents (Anderson, 1994). Findings from this thesis suggest the latter as young people expressed a desire for more independence

whilst still receiving emotional and practical support from their parents for medical self-care.

Friends played an important role for young people in helping them to feel normal. This normality was characterised by a sense of being similar to other young people without diabetes. Participants described disclosing diabetes to a few chosen friends with whom they felt most comfortable, rather than disclosing to all friends. This has been described as 'protective disclosure' (Lewis, 2007) because it ensures that young people are protected if a diabetes-related emergency occurs. Not being treated differently by friends despite having diabetes was instrumental in allowing participants to feel 'normal' and thus maintaining a sense of 'diabetes as routine'. This prevented emphasising the diabetes identity of participants, characterised by 'diabetes as dominating.'

Being treated 'normally' also meant that young people felt more comfortable performing medical self-care when with their friends because they did not worry that self-care would threaten their sense of normality. This conflicts with previous research which has reported friends of young people with diabetes as lacking knowledge about diabetes which can serve to threaten a sense of normality (Lowes et al, 2007). Authors found that young people were sometimes resentful towards friends who misunderstood diabetes or who misinterpreted type 1 and type 2 diabetes. This highlights the role of diabetes knowledge amongst friends of young people with diabetes in helping to facilitate an environment where young people feel normal and thus comfortable in carrying out medical aspects of self-care when with their friends.

Participants also described the importance of engaging in non-diabetes related activities with their friends, which helped them to feel normal. Such activities allowed young people to explore non-diabetes aspects of their identity and thus prevented the perception of diabetes dominating identity. Previous research has also highlighted the importance of participating in non-diabetes related activities with friends in terms of identity work (Balfe, 2007 and Brouwer et al, 2012).

The desire to feel normal is a central aspect of psychosocial development in young people, whereby a high value is placed upon social relationships, particularly those with peers (Erikson, 1968). The role of peers in validating identity has been reported in previous research on young people with diabetes by Schur et al (1999). Authors

reported that young people created ‘normal’ identities that were separate from diabetes, in order to be valued by peers. Taken together, these findings demonstrate the significance of friends in impacting upon young people’s identity work and helping to facilitate a sense of normality in young people.

7.6 How does participating in salutogenic projects shape young people’s perspectives and practice towards diabetes self-care?

As a result of actively participating in salutogenic projects, young people developed competencies, referred to as ‘Ego strength’ (Erikson, 1963; 1964; 1968). Salutogenesis (Antonovsky, 1996) involves conceptualising young people as individuals and acknowledging their capabilities. Ego strength is built by individuals becoming more capable in different areas of life, which helps them navigate identity work. Ego strength is considered to be a ‘generalised resistance resource’ in salutogenesis (Antonovsky, 1979; 1987). Generalised resistance resources are characteristics help individuals more effectively cope with stressors (such as diabetes) and thus achieve a greater sense of coherence. A sense of coherence entails three aspects: meaningfulness, comprehensiveness and manageability.

Participation in the salutogenic projects impacted upon participants’ identity work, including both ‘being’ identity (sense of self) and ‘doing’ identity (behavioural manifestations of identity which are observable by others). This facilitated an enhanced ability to navigate both diabetes and non-diabetes related boundaries in the projects, the clinic and in their wider social environment, contributing to more confidence in making decisions about diabetes self-care and a heightened sense of coherence.

The salutogenic projects in which the participants were involved share many characteristics with positive youth development programmes (Eccles et al, 2002). Positive youth development focuses on developing strengths in young people, rather than focusing on risk behaviours as a way to promote positive outcomes including competence, confidence, character, social connectedness and compassion (Maslow et al, 2013). These attributes are proposed to be inherently important for improving the health and wellbeing of young people but also in fostering healthy adult development. For young people with chronic conditions, such as diabetes, positive youth development may contribute to greater confidence in making decisions about self-care as well as the ability to advocate for themselves in the clinic (Chung et al, 2010).

There is currently limited evidence for positive youth development in young people with chronic conditions but there are indications that this approach can facilitate beneficial educational, vocational and health care outcomes (Maslow et al, 2013). Furthermore, research has suggested there are no significant differences between young people with chronic conditions than those without that would alter the effectiveness of positive youth development for each of these groups. Positive youth development and related approaches may thus be equally effective for young people both with and without chronic conditions such as diabetes (Maslow et al, 2016).

In this research, young people described having a more positive diabetes identity as a result of participating in the salutogenic projects. This corresponds to the sense of meaningfulness, described by Antonovsky (1993) as comprising part of a sense of coherence. The more positive diabetes identity facilitated an enhanced ability for participants to integrate diabetes into their identity, which was reflected in greater engagement with the medical aspects of diabetes self-care. Positive youth development interventions have reported a trend in increasing engagement with medical self-care in the short-term but this has not tended to reach statistical significance (Maslow et al, 2013). Similarly, interventions aiming to improve diabetes knowledge or improve problem-solving skills have failed to produce long-term improvements with diabetes self-care (Grey, 2000; Gage et al, 2004; Murphy et al, 2009 and Hampson et al, 2001). However, as highlighted in this thesis, optimal self-care from a medical perspective often conflicts with optimal self-care from a young person's perspective. From a salutogenic perspective, it is thus preferable to focus on supporting young people's identity work, empowering them to make their own decisions about self-care, which includes balancing both their physical health with socioemotional wellbeing.

Developing a positive identity included two aspects for participants: being a role model and diabetes being normalised. The project activities, such as running workshops and public speaking, contributed to the sense of being a role model and consequently provided a sense of accountability for young people to remain engaged with their own medical self-care. This supports previous research by Manning et al (2018), which reported that participation in diabetes camp as a counsellor improved glycaemic control and engagement with medical self-care. Being nominated as being a good role model

was particularly effective in promoting greater engagement with the medical aspects of self-care.

The interaction with other young people with diabetes as part of their roles facilitated a normalisation of living with diabetes, which prevented diabetes from posing a threat to identity and thus contributed to a more positive diabetes identity. This supports previous research which has reported that young people feel a sense of belonging when surrounded by others with diabetes, (Brouwer et al, 2012). However, other research investigating an online peer mentoring programme for young people defined as having poor glycaemic control failed to produce any significant positive effects in terms of glycaemic control, quality of life or other outcome measures (Suh et al, 2014). This suggests that face-to-face interaction with other young people with diabetes is important in producing positive outcomes with regards to identity work.

The more positive diabetes identity reported by young people as a result of participating in the salutogenic projects appears to conflict with previous research highlighting the importance of distancing diabetes from identity in young people (Schur et al, 1999). Schur and colleagues reported that young people distanced diabetes from their identity as a self-protective strategy; a way to maintain identity as a 'normal' person. However, in these salutogenic projects, young people were surrounded by others with diabetes, which served to reduce the threat of diabetes to identity because it was perceived as being 'normal' and was valued by others. Distancing diabetes from identity was thus unnecessary because it was no longer perceived as being a threat to identity.

In this thesis, young people described becoming more organised, determined and confident as a result of living with diabetes. Focusing on these positive aspects was perceived as being helpful in making diabetes easier to deal with in everyday life. The importance of developing a positive diabetes identity has also been highlighted in previous research by Foster (2010). These findings emphasise the importance of adopting a salutogenic approach, including the focus of positive aspects of living with diabetes for young people. Participation in salutogenic projects provides a useful application of this approach because young people are able to use their experiences of living with diabetes in a positive way.

A unique aspect of the salutogenic projects was the ability for young people to gain a different perspective of diabetes services compared to merely being a health service user. Whilst being involved in the projects, participants interacted with a variety of health professionals and organisations involved in diabetes services. Exposure to a new side of diabetes services facilitated an enhanced understanding of the perspective of the diabetes health care team as well as a greater awareness of the consequences of participants' own medical self-care for both themselves and other individuals and organisations. As participants were of an age associated with reduced clinic attendance (Court et al, 2009), this increased understanding was particularly timely and will help to decrease the risk of clinic non-attendance. 'Seeing behind the scenes of services' corresponds to the sense of comprehensiveness described by Antonovsky (1993) as contributing to a strong sense of coherence.

The enhanced understanding of the perspective of the health care team resulted in improved relationships between the young people and their health care team. This included more reciprocity within these relationships as well as an ability to discuss non-diabetes related issues with clinicians. As mentioned earlier in this chapter, previous research has reported that young people wish to be seen by health professionals as an individual first and then as someone living with diabetes, highlighting the importance of being able to discuss non-diabetes related issues for young people (Carroll and Marrero, 2006). Carroll and Marrero also found that young people did not want to be merely fed information by clinicians, demonstrating the importance of reciprocity in clinician-patient relationships for young people. Salutogenic projects thus provide a useful platform for young people to develop stronger relationships with clinicians, have improved interactions with them in clinic appointments and thus receive the necessary support for their diabetes self-care.

Seeing behind the scenes of services also had a direct impact on the medical aspects of self-care in participants. Developing a more comprehensive knowledge of the characteristics of diabetes, diabetes self-care and diabetes services was empowering for participants and motivated them to become more consistent with their own medical self-care. These results appear to conflict with previous research which reported that knowledge of the medical aspects of diabetes self-care did not vary amongst young people with differing levels of engagement with these activities (Boman et al, 2015). Boman and colleagues found that both 'adherent' and 'non-adherent' participants

demonstrated a high level of knowledge about the medical aspects of self-care. Other research has also highlighted knowledge as being necessary but not sufficient to enhance engagement with medical self-care (Gage et al, 2004). However, it is likely that the process of acquiring information about diabetes was empowering in these salutogenic projects because it enhanced the ability of participants to contribute positively to the projects as well as make informed decisions about their own self-care. Furthermore, as participation in the projects was voluntary, the information is likely to have been more positively received by young people than in other contexts.

Learning to navigate boundaries was another consequence of participating in the salutogenic projects for participants. Young people described an improved ability to acknowledge, challenge and overcome diabetes and non-diabetes related boundaries within the projects, the clinic and their wider social environment. Within the projects, participants learned about the boundaries inherent within a work setting, as well as the importance of communication and time management to help navigate this environment. This was perceived as being highly valuable because it helped them to more feel prepared to enter the workplace in the future. This supports the goals of positive youth development programmes, which strive to prepare young people for adulthood in a holistic way (Maslow et al, 2013).

Participation in the salutogenic projects also facilitated the exploration and development of a non-diabetes aspect of their identity, their future employment. As mentioned earlier in this chapter, the importance of exploring non-diabetes related aspects of identity has been identified in previous research on young people with diabetes (Brouwer et al, 2012 and Balfe, 2007). Strengthening non-diabetes related aspects of identity seems to help to mitigate the emotional burden

of medical self-care (Aujoulat et al, 2017). The development of work-related aspects of identity may be particularly beneficial because of the association with an adult identity, which has been argued to be a requirement for engaging in the medical aspects of self-care (Fonte et al, 2017). In exploring adult aspects of identity, including the associated constraints and responsibilities, young people are more likely to become more engaged with their own medical self-care in an attempt to embody a more adult identity.

In terms of the clinic, the interactions with health care professionals as part of the project activities helped young people to advocate for themselves within their clinic appointments. Being able to advocate is another goal of positive youth development programmes which are aimed at young people with chronic conditions (Chung et al, 2010). The feeling of having a voice, making a difference and taking ownership in the projects helped young people take a more active role in their appointments. This included feeling more able to ask questions and to negotiate about the way in which they would fit diabetes self-care into their daily lives. The desire to have support from health care professionals in integrating medical self-care into daily life has been identified in previous research (Carroll and Marrero, 2006). Salutogenic projects thus provide a way for young people to gain confidence in managing clinic appointments to ensure that they are sufficiently supported in their diabetes self-care.

In the wider social environment, participants described feeling more able to overcome barriers such as the disclosure and discussion of diabetes with friends and others in their social environment. Stigma has been identified as a barrier to disclosing and discussing diabetes in previous studies on young people with diabetes (Brouwer et al, 2012; Lewis, 2007 and Lowes et al, 2007). Participating in a salutogenic projects can thus help young people to overcome these stigmas and disclose diabetes to others, which will ensure that young people can maintain self-care when with others and can be helped in a diabetes-related emergency. Furthermore, in light of previous studies highlighting a lack of knowledge even amongst friends of young people with diabetes (Lowes et al, 2007), feeling more inclined to discuss diabetes with others can improve knowledge of the condition in young people's social networks.

7.7 Strengths and weaknesses of the research

The use of meta-ethnography for the qualitative review allowed for a rigorous approach to synthesising literature. Meta-ethnography includes explicit sampling, data extraction, analysis and quality assessment steps, which allow for a new understanding to be developed, which goes beyond the findings of individual studies. Despite the small number of studies included in the meta-ethnography (n=13), there were a range of countries represented (UK, Sweden, USA, Australia, Iran, Canada and Taiwan). There was also diversity in terms of ethnicity (white/Caucasian, African American and First Nations/Metis). However, four studies in the review did not provide any information

about the ethnicity of participants, limiting the ability to determine the mix of ethnicities across the whole of the meta-ethnography.

A meta-ethnography requires a careful balance between homogeneity and heterogeneity of studies (France et al, 2019). This is because a central aim is to develop a comprehensive understanding of a phenomenon (such as diabetes self-care in young people), which demands sufficient studies to elucidate the different aspects, whilst maintaining a manageable amount for a meaningful synthesis.

The meta-ethnography detailed in this thesis specifically sought to include young people defined as disengaged from diabetes services and/or diabetes self-care. Disengagement can occur for a variety of reasons and thus a certain level of heterogeneity was inevitable. However, because the focus was relatively narrow, focusing on experiences with diabetes self-care, rather than more general, studies were sufficiently homogenous in order to conduct a synthesis. The consistency of the importance of identity in diabetes self-care that emerged from the included studies confirms this homogeneity.

With regards to the findings, the meta-ethnography revealed the significance of identity work in diabetes self-care in young people, which had not been previously been made explicit in the research literature. Through my involvement within the CLAHRC project, in which this thesis is embedded, I conducted a systematic review of reviews on young people's experiences with diabetes services, which helped to provide valuable experience and context for the qualitative review.

In light of the limited amount of existing meta-ethnographies in the literature, particularly within healthcare (Goodson and Vassar, 2011), this thesis makes an important contribution to this evidence base. The search strategy of the meta-ethnography specifically sought out young people considered to be disengaged from diabetes self-care or diabetes services. The meta-ethnography was thus able to synthesise experiences of young people who typically lack of voice in the research literature. In writing up the findings of the meta-ethnography, the latest guidance currently being developed for meta-ethnography reporting was drawn upon (France et al, 2015). The approach to the meta-ethnography thus allowed for validity to be maximised at all stages of the meta-ethnography.

My role in the CLAHRC project also allowed me to gain insight into both diabetes services and diabetes self-care, from multiple perspectives. Involvement in the CLAHRC project also allowed for relationships to be built with clinicians, allowing access to young people with diabetes defined as disengaged from diabetes services or diabetes self-care by these clinicians. I was involved in the recruitment and data collection for qualitative interviews with young people living in North and East London. I was thus able to observe the challenges associated with recruiting young people who are disengaged from diabetes services and/or diabetes self-care. Furthermore, by conducting interviews with young people in their homes, I was able to more clearly understand the context of their daily lives, including the competing priorities they were facing, which influenced their engagement with diabetes self-care.

Involvement in the CLAHRC project also provided me with the opportunity to be involved with training the young people in their roles, participate in task group meetings with them as well as observing them in public speaking events and site visits. I was thus able to view the development of the young Clinical Commissioners in their roles over the course of the projects. This involvement enhanced both the interview process by more easily establishing rapport but also the interview analysis as the context of the salutogenic projects was fully understood.

The recruitment strategy used to gather data for the qualitative interviews presented in chapter 5 was a limitation, which involved recruitment from only two diabetes clinics in London. This excluded other young people with diabetes living in the area who were not currently registered to either of these clinics. It also prevented young people who were previously registered to these clinics but had transferred to another clinic for university or employment reasons from participating.

A further limitation was the potential for selection bias amongst those choosing to participate. It is possible that the experiences of those choosing not to participate were different to those taking part. Clinicians were asked to identify young people who were disengaged from diabetes self-care and/or diabetes services. However, it is possible that those who were the most disengaged from diabetes services and/or diabetes self-care were less likely to be willing to participate in research discussing their experiences with diabetes. In order to mitigate the potential of this occurring, potential participants were

informed that anything shared in the interview would not be attributed to them individually and would not affect the diabetes care that they would receive.

The small sample size of young people interviewed who had participated in salutogenic projects, presented in chapter 6, was another limitation. Due to the unique nature of the initiatives, a total of only five young people were able to be interviewed about the way in which participating influenced their diabetes self-care. However, these interviews sought to achieve depth rather than breadth and were thus preceded by a period of extended engagement with participants. Findings demonstrated the potential for participation in salutogenic projects to promote engagement with diabetes self-care though impacting upon identity work. These findings need to be explored in a larger study, such as a trial testing the effectiveness of a salutogenic approach to improve diabetes self-care in young people.

Another important consideration is the settings in which the qualitative interviews took place. Participants were interviewed at home, at the University of East London or in a public setting of their choosing. Amongst those interviewed at home, parents were sometimes present during the interview or were in the next room. It is possible that this may have influenced participant accounts as they may have felt restricted in what they felt able to disclose. However, interviewing the young people at home provided a relaxed and familiar atmosphere. Such an environment was likely much less anxiety-provoking than if interviews had taken place in a hospital setting. In light of the intimidation surrounding the clinic described by participants in the interviews, the clinic would not have been a suitable setting for the current research.

Although every attempt was made to be rigorous and transparent throughout analysis and interpretation, it is important to emphasise that what is presented is the researcher's interpretation and thus other researchers may have highlighted different aspects. However, every effort was made for the research to be trustworthy. Several definitions and criteria of trustworthiness exist (Korstjens and Moser, 2018). However, the best-known criteria are credibility, transferability, dependability and confirmability as defined by Lincoln and Guba (1985). Each of these components was addressed in this thesis to ensure trustworthiness of findings.

Credibility is the confidence that can be placed in the validity of research findings (Korstjens and Moser, 2018). Prolonged engagement was used as a strategy to ensure credibility in this thesis (Lincoln and Guba, 1985 and Sim and Sharp, 1998). This involved spending an extended period of time in the field, which was achieved through my ongoing involvement in the CLAHRC project. This entailed interaction with young people with diabetes, health care professionals and organisations, which helped in understanding the context of the research but also in building trust with the young people I interviewed.

Transferability is the degree that findings can be transferred to other contexts or settings (Korstjens and Moser, 2018). This was achieved through the production of a rich description of young people's experiences with diabetes self-care but also the context surrounding these experiences (Lincoln and Guba, 1985 and Sim and Sharp, 1998). This is the degree that findings can be transferred to other contexts or settings (Korstjens and Moser, 2018).

Dependability is the stability of findings over time (Korstjens and Moser, 2018).

Confirmability is the degree to which the findings are able to be confirmed by other researchers, which ensures that interpretations are clearly derived from the data (Korstjens and Moser, 2018). Dependability and confirmability were achieved through the production of an audit trail describing the steps taken throughout the research process. Dependability and confirmability were also achieved through ongoing feedback from my supervision team throughout the research process and write up stages of this thesis. Where appropriate, my interpretations of the data were challenged to ensure that all reported findings were grounded within the data.

7.8 Meaning of the research: possible mechanisms and implications for clinicians and policymakers

This thesis has demonstrated the importance of providing adequate support for young people in both the school and university environments. Both environments are associated with disruption to medical self-care due to a lack of support from others and concerns about being marked out as different. It is important that young people are able to carry out the medical aspects of diabetes self-care in a way that minimises intrusion

to their education and avoids distinguishing them from others to allow them to maintain a sense of normality.

Training should be provided to all members of staff in schools and universities about how to support young people with diabetes, both in terms of physical health and wellbeing. This can be facilitated through the adoption of a salutogenic approach by school staff, in which young people being are treated as individuals, rather than as diabetics and thus are supported to balance both the diabetes and non-diabetes aspects of their daily lives (Antonovsky, 1979). Maintaining a salutogenic approach towards young people with diabetes helps them to more easily navigate identity work and be able to engage with their diabetes self-care whilst pursuing their educational goals.

Strong communication is also needed between schools, universities, the diabetes health care team and the young person to ensure that young people receive adequate support for diabetes in all settings. Regular meetings, virtually or in-person, would help to make sure that any issues experienced by young people are able to be addressed in an efficient and timely way. Currently, it is recommended that Diabetes health care teams should liaise regularly with school staff with a focus on diabetes education and practical information (NICE, 2015). However, there is no explicit recommendation for young people to be involved in these meetings or the need to discuss non-education based issues, such as the minimisation of stigma for young people within the school environment. There are also no current recommendations about the way in which health care teams should communicate with universities. Expanding existing recommendations to ensure that young people's health and wellbeing can be optimised within the school environment is key.

Similarly to school and university environments, young people described the desire to be treated as individuals in the clinic, rather than as patients with an intense focus on their current blood glucose levels. Currently, recommendations about providing holistic care are relatively vague. It is suggested that young people should receive an integrated package of care from a multidisciplinary paediatric diabetes team (NICE, 2015). No explicit guidance is provided on which specific health care professionals should be involved, except that the health care team should include members with training in clinical, educational, dietetic, lifestyle, mental health and foot care aspects of diabetes for young people (NICE, 2015). More explicit guidance on the content of clinic appointments would help to ensure that young people receive the holistic, individualised

care that they require. This includes acknowledging the non-diabetes aspects of their lives, which not only impact diabetes self-care but are an important part of young people's psychosocial development.

In light of the rapid development of technology, new opportunities have been provided to incorporate a variety of tools into diabetes self-care and services (Forlenza et al, 2016). However, existing research and practice has tended to focus on clinical measures like glycaemic control, rather than being led by patient-centric measures and experiences with these technologies (Mameli et al, 2013). Although such tools can provide increased flexibility, they can also be emotionally and cognitively demanding. It is therefore imperative that young people take an active role in decisions about technology. The findings of this thesis highlighted the potential of pump therapy to help in reducing the threat of diabetes to identity due to it lessening the time needed for medical self-care and not being visible to others. Choices about technology therefore should consider benefits and risks to both physical health and wellbeing, including an acknowledgement of the impact of these tools on identity work.

The findings of this thesis have also highlighted the importance of directly addressing identity work in the diabetes clinic, particularly in young people defined as disengaged from diabetes self-care and/or diabetes services. This is not currently part of diabetes care recommendations (NICE, 2015). Health care professionals need to discuss disclosure of diabetes to others, recognising that this represents a threat to young people's identity. They can help young people to determine who to disclose to and how this should be navigated. This could be addressed by a Psychologist. Although it is recommended that young people should have access to mental health professionals, this is currently framed as an option only if young people are experiencing psychological problems, rather than being part of standard care (NICE, 2015). Findings from this thesis suggest that young people would benefit from having access to psychological support from the time at which they are diagnosed with diabetes to help them navigate the integration of diabetes into both 'being' and 'doing' identity. This would help young people negotiate diabetes self-care within the context of their daily lives, including navigating the competing priorities they face, such as social, academic and health variables.

Clinicians should avoid an intense focus on HbA1c levels in clinic appointments and instead address issues which are important to young people, which may seem unrelated to diabetes but impact upon their identity work. Currently, guidance emphasises the importance of all young people reaching a target HbA1c level of less than 7.5%, which is recommended to be tested at every clinic appointment (NICE, 2015). A more holistic approach, in line with salutogenesis, would avoid creating a sense of 'diabetes as dominating' and also prevent young people from feeling intimidated about attending clinic appointments. Instead, this would help to support young people navigate identity work and thus integrate diabetes into their self-concept ('being' identity) and diabetes self-care into their daily lives ('doing' identity). Addressing issues that are important to young people also ensures that clinic appointments are individualised and meet the unique needs of each young person at their particular life stage.

Guidance suggests that education is the solution to suboptimal glycaemic control levels, despite a lack of evidence of knowledge being significant in medical self-care (Boman et al, 2015, Huus and Eskar, 2007 and Damiao and Pinto, 2007). An intense focus on diabetes education has also been suggested to be ineffective in improving the medical aspects of self-care because it serves to emphasise diabetes identity, reducing young people's likelihood to engage in these behaviours (Tilden et al, 2005). However, this thesis has provided evidence for the effectiveness of learning more about diabetes self-care within the context of diabetes services, which helped young people better understand the perspectives of health care professionals. Providing knowledge about diabetes services may thus be helpful for young people but it is important that this does not dominate clinic appointments. Furthermore, the information should be contextualised, rather than abstract, which is likely to be better received by young people and allows them to more easily integrate it into their daily lives.

In addition to clinic appointments being more suited to young people's needs, findings from this thesis also suggest there would be value in young people contributing to the design of patient-reported outcome measures. This would ensure that the quality of services are assessed in ways that are meaningful to them, rather than being narrowly focused on clinical markers. This has not yet been explored in young people but has been tentatively investigated in adult patients (Wiering et al, 2016).

The experiences of participants in salutogenic projects has suggested that opportunities for young people with diabetes to take on mentoring roles may be helpful. This is not

currently offered as part of standard care for young people with diabetes (NICE, 2015). However, peer support groups are sometimes offered for young people with diabetes, which are attached to diabetes clinics. For example, in the current research, a Youth Health Champion was interviewed who was involved in a peer support group for young people with diabetes in East London. Opportunities where young people can become role models to others, are likely to be particularly beneficial. Such roles not only allow young people to help others with diabetes and spread awareness about the condition and its management but also support young people's identity work and help them feel empowered to make choices about their diabetes self-care.

The notion of young people being more heavily involved in service design and delivery is not new. However, despite the array of resources, reports and government statements promoting its value, the role of the patient as an active participant in their care is insufficiently acknowledged and supported by healthcare professionals (Russell and Kitt, 2014).

This thesis has provided evidence for the value of young people with chronic conditions, such as diabetes, taking an active role in their care, as well as being heavily involved in the design of services at a local level, corresponding to the micro and meso levels of patient involvement that have been identified (Russell and Kitt, 2014). Although the focus of this thesis is the perceptions and experiences of young people involved in salutogenic projects, the positive response from healthcare professionals was evident. This suggests that experiences with young people in such initiatives, may be necessary in order to shift attitudes about the value of patient involvement amongst healthcare professionals.

To build on the current findings and ensure that young people's participation is fully embedded into healthcare at the micro, meso and macro levels, there is a need for cultural changes in four key areas (Weil et al, 2015). This includes greater dissemination of available guidance in order to demystify the process of participation and ensuring that it is conducted to a high standard.

The current research provides a successful example of young people defined as disengaged from diabetes services and/or diabetes care successfully participating. It also entails greater evaluation of the lessons learned from initiatives and the long-term

changes that are made. Interviewing young people following their participation in the salutogenic projects provided evidence of the impact on their own diabetes self-care.

There is also a need for sufficient training, structures and procedures in place to support young people and the organisations involved. This was covered extensively in the salutogenic projects and was likely a key factor in its positive influence on participants. In addition, there must be adequate resources within healthcare systems to fully implement patient participation. The Young Clinical Commissioner initiative was not continued after the initial year due to a lack of long-term funding.

More broadly, it is also important to reinforce the conceptualisation of professional practice as including patients as providing valuable knowledge, which supplements, rather than replaces professional knowledge (Aagaard, 2017). This helps avoid the problem of the ‘professionalisation’ of patient involvement. Young people should feel empowered to share their perceptions and experiences with healthcare but not pressured to use medical terminology or have extensive medical knowledge.

Some researchers have raised the issue of ‘proto-professionalism’, whereby patients become familiar with medical language and culture, and may perceive that they have an understanding of the processes occurring within the clinic (Dent and Pahor, 2015). This can be particularly common in young people, or adults, with chronic conditions who are required to attend clinic appointments regularly. Although this familiarity can result in patients feeling more engaged in their care, there is the potential for this to be tokenistic in nature, and for a paternalistic doctor-patient relationship akin to a soft system of control to be maintained. It is therefore important to encourage young people to use their own language when advocating for themselves individually at a micro level, or on behalf of other young people at a meso level, as well as ensuring that involvement is meaningfully integrated into processes and practices.

7.9 Unanswered questions and future research

As interviews were only conducted at one point in time, it is unclear how diabetes self-care perceptions, influences and behaviour might have changed over time. Conducting multiple interviews with young people over time would have enabled for this exploration. Furthermore, due to the small nature of the salutogenic projects, there is a need to explore the impact of salutogenic projects in influencing both identity work and

diabetes self-care on a larger scale. This would help to determine who and who does not benefit from salutogenic projects and which aspects of the projects are most effective for young people.

It is also unclear whether other types of initiatives and interventions might impact upon identity work. This research suggests that interventions for young people with diabetes need to be diabetes-specific but it is unclear whether more generic interventions may be effective in influencing identity work and navigating diabetes self-care. In light of the importance of developing non-diabetes aspects of identity, it is possible that generic interventions may be effective in lessening the threat of diabetes to identity. As mentioned earlier in this chapter, positive youth development programmes are likely to be equally effective for young people with and without chronic conditions (Maslow et al, 2016). However, one of the benefits of the salutogenic projects in the current research was the ability for young people to meet others with diabetes. Generic interventions would clearly not allow for this type of peer support, although it is possible that young people with diabetes might benefit from interacting with young people with other chronic conditions. Further research is needed comparing the merits of targeted and generic approaches for young people's identity work and self-care.

More research is also needed investigating the role of identity work in young people with type 2 diabetes and how these experiences might differ from those with type 1 diabetes. Although this thesis included both types of diabetes, there was a large discrepancy between the number of participants diagnosed with type 1 diabetes and type 2 diabetes. This discrepancy is representative of the general population as it is estimated that 95% of young people with diabetes have type 1 diabetes (RCPCH, 2017). However, the discrepancy in this thesis, as well as in the diabetes literature as a whole, means that much more is known about the experiences of those with type 1 diabetes than those with type 2. In light of the significance of stigma in the experiences of young people with diabetes, it is possible that this may be heightened in young people with type 2 diabetes, which may impact upon their identity work and diabetes self-care differently to young people with type 1.

Future research should seek to develop interventions for young people with diabetes based upon notions of identity work. To date, interventions have tended to focus on diabetes education, which have not been shown to be effective (Murphy et al, 2006).

Tentative evidence exists of the effectiveness of motivational interviewing and mentoring roles for young people. For example, 'Externalising' and motivational interviewing interventions have been effective in improving self-concept in young people with diabetes (Knight et al, 2003). Externalising is a component of narrative therapy and aims a person to separate diabetes from identity by relating to diabetes as an external entity to the individual. Motivational interviewing is a technique designed to encourage people to change their behaviour by invoking intrinsic motivation to change based upon the values of the individual. Knight and colleagues reported that young felt less threatened and expressed a greater sense of control after an intervention which combined these techniques.

A review of interventions based upon motivational interviewing found that such interventions improved glycaemic control in young people with diabetes although it is unclear how identity work was influenced (Gregory and Channon, 2009). Further research is required to determine the range of outcomes from such interventions, as well as the optimal mode, frequency and length of sessions. In addition, future research should explore whether externalising and motivational techniques are equally effective, or whether combining them results in improved outcomes for young people with diabetes.

Further research should also explore the potential of mentoring roles to impact positively on young people with diabetes because these allow young people to become role models. Manning et al (2018) reported positive outcomes in medical self-care engagement after participating in a diabetes camp as a camp counsellor. However, due to the small sample size and lack of a control group, further research is required on the potential effectiveness of diabetes camp counsellor programmes for both identity work and diabetes self-care.

This thesis has highlighted the value of adopting a salutogenic approach towards young people with diabetes. In order to maintain this perspective in research, interventions should measure wellbeing, identity work and engagement in diabetes self-care behaviour, rather than the traditional narrow focus on glycaemic control. Ye et al (2016) explored outcomes important to young people with diabetes and found that interactions with peers, emotional well-being, physical well-being, education and motivation of others, family interactions, academic achievement, and interactions with important others such as teachers were most significant for young people. This highlights the

importance of acknowledging the non-diabetes aspects of young people's lives in the study of their diabetes self-care and ensuring that the outcomes that are important to them are adequately addressed in research, policy and practice.

7.10 Conclusion

This thesis has adopted a qualitative salutogenic approach to explore young people's experiences with diabetes self-care, which has included both a systematic review and semi-structured interviews. Findings highlighted that diabetes self-care is a manifestation of the ongoing identity work engaged in by young people as they navigate the role of diabetes within their identity. Identity work is the continual negotiation of the role of diabetes into self-concept ('being' identity) and diabetes self-care into daily life ('doing' identity). These are synonymous with the psychological and sociological aspects of identity discussed by Erikson (1980). It is important to acknowledge the context of this identity work

Identity work is a fluid process, with young people oscillating between three different types: 'forgetting diabetes', 'diabetes as dominating' and 'diabetes as routine'. This identity work involves the continual navigation on both threats and validators to identity. It aims to achieve a sense of normality, which is created when there is a balance between the threats and validators to identity.

The threats to identity identified in this thesis were disclosure and disruption. Disclosure refers to the disclosure of a diagnosis of diabetes by young people, which was perceived as a threat to both 'being' and 'doing' identity. Concern about diabetes disclosure is a central aspect of psychosocial development in young people, which places a high value on social relationships, particularly those with peers (Erikson, 1968). Disruption refers to diabetes as disruptive and factors which are disruptive to diabetes self-care, both of which pose threats to identity. Erikson described these as conflicts, whereby there is a conflict between different aspects of a person's identity (Erikson et al, 1970). For young people, this represents a conflict between diabetes and another aspect of their identity. Navigating such conflicts are described as being an inevitable aspect of the 'identity crisis' of adolescence and young adulthood. Although these conflicts are potentially harmful to physical health, navigation of such conflicts serve an important role in the

negotiation of the role of diabetes within identity (Aujoulat et al, 2017 and Erikson et al, 1970).

Validators to identity were independence and support. Independence refers to increasing responsibility for self-care behaviours and developing diabetes self-care strategies. Independence thus served as a validator to both 'being' and 'doing' identity. As young people with diabetes become older, they are expected to take on greater responsibility for their diabetes management and become more independent for their own medical self-care. At younger ages, young people typically receive a lot of support from family members, particularly mothers who tend to be more heavily involved in the medical aspects of diabetes care.

Support also served as a validator to both 'being' and 'doing' identity. This included both receiving support in managing diabetes and providing support to others with diabetes. The support given to and received by others validated by helping participants feel more 'normal' and also feeling more capable of carrying out the medical aspects of diabetes self-care in their daily lives. Support therefore helped participants to navigate the 'identity crisis' by allowing them to more easily reconcile diabetes with the other aspects of their identity (Erikson, 1970).

A sense of control was found to act as both a validator and threat to 'being' and 'doing' identity. Balanced blood glucose levels provided young people with a sense of control, which perceived positively and sometimes as a source of comfort. Balanced blood glucose levels and the associated sense of being in control are thus validators of identity because these helped to facilitate the integration of diabetes into identity, without it dominating over other aspects. This thesis has highlighted the importance of understanding the context of the identity work of young people with diabetes, which includes the home, the school, the clinic and the wider social environment. These are the environments in which the threats and validators to identity exist, which young people are required to continually navigate.

Findings demonstrated that this identity work comprises three different types: 'forgetting diabetes', 'diabetes as dominating' and 'diabetes as routine'. Both 'forgetting diabetes' and 'diabetes as routine' represent struggles with integrating diabetes into both 'being' and 'doing' identity. These types of identity work are thus characterised by less engagement with the medical aspects diabetes self-care in young

people. Findings suggest that identity work is thus a particularly important consideration in young people defined as disengaged from diabetes services and/or diabetes self-care. 'Diabetes as routine' is a type of identity work that occurs when young people experience a sense of normality. This identity work is characterised by a sense of control over diabetes and a perception that diabetes will not prevent young people from engaging in enjoyable activities or from achieving non-diabetes related life goals.

This thesis has also demonstrated that identity work is modifiable. Through the participation in salutogenic initiatives young people were able to develop competencies, referred to as 'ego strength' (Erikson, 1963; 1964; 1968). These facilitated a greater sense of coherence in young people, which is comprised of meaningfulness, comprehensiveness and manageability (Antonovsky, 1993). This allowed young people to more easily navigate identity work, which helped them to integrate diabetes into both 'being' and 'doing' identity. As a result they felt empowered to make decisions about their own diabetes self-care, which represented a 'trade-off' between optimising physical health and maintaining wellbeing.

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Appendix 1: Quality assessment tool for qualitative review by Rees et al (2011) (chapter 4)

Rate all items as low, medium or high.

Criteria used to appraise study quality (with guidance for reviewers)

1. Were steps taken to increase rigour in the sampling?

Consider whether:

- *the sampling strategy was appropriate to the questions posed in the study (e.g. was the strategy well reasoned and justified?);
- *attempts were made to obtain a diverse sample of the population in question (think about who might have been excluded; who may have had a different perspective to offer);
- *characteristics of the sample critical to the understanding of the study context and findings were presented (i.e. do we know who the participants were in terms of, for example, basic socio-demographics, characteristics relevant to the context of the study, etc.).

2. Were steps taken to increase rigour in the data collected?

Consider whether:

- *data collection tools were piloted (and if quantitative) validated;
- *(if qualitative) data collection was comprehensive, flexible and/or sensitive enough to provide a complete and/or vivid and rich description of people's perspectives and experiences (e.g. did the researchers spend sufficient time at the site/with participants? Did they keep 'following up'? Was more than one method of data collection used?);
- * steps were taken to ensure that all participants were able and willing to contribute (e.g. processes for consent, language barriers, power relations between adults and children/young people).

3. Were steps taken to increase rigour in the analysis of the data?

Consider whether:

- * data analysis methods were systematic (e.g. was a method described/can a method be discerned?);
- *diversity in perspective was explored;

* (if qualitative) the analysis was balanced in the extent to which it was guided by preconceptions or by the data);

*the analysis sought to rule out alternative explanations for findings (in qualitative research this could be done by, for example, searching for negative cases/exceptions, feeding back preliminary results to participants, asking a colleague to review the data, or reflexivity; in quantitative research this may be done by, for example, significance testing).

4. Were the findings of the study grounded in/supported by the data?

Consider whether:

*enough data are presented to show how the authors arrived at their findings;

*the data presented fit the interpretation/support claims about patterns in data;

*the data presented illuminate/illustrate the findings;

*(for qualitative studies) quotes are numbered or otherwise identified and the reader can see that they don't just come from one or two people.

5. Please rate the findings of the study in terms of their breadth and depth.

Consider whether:

(NB: it may be helpful to consider 'breadth' as the extent of description and 'depth' as the extent to which data has been transformed/analysed);

*a range of issues are covered;

* the perspectives of participants are fully explored in terms of breadth (contrast of two or more perspectives) and depth (insight into a single perspective);

*richness and complexity has been portrayed (e.g. variation explained, meanings illuminated);

*there has been theoretical/conceptual development.

6. To what extent does the study privilege the perspectives and experiences of children?

Consider:

* whether there was a balance between open-ended and fixed response options;

*whether children were involved in designing the research;

* whether there was a balance between the use of an a priori coding framework and induction in the analysis;

*the position of the researchers (did they consider it important to listen to the perspectives of children?);

* whether steps were taken to assure confidentiality and put young people at ease.

7. Overall, what weight would you assign to this study in terms of the reliability/trustworthiness of its findings?

Guidance:

Think (mainly) about the answers you have given to questions 1 to 4 above.

8. What weight would you assign to this study in terms of the usefulness of its findings for this review?

Guidance:

Think (mainly) about the answers you have given to questions 5 and 6 above and consider:

*the match between the study aims and findings and the aims and purpose of the synthesis;

*its conceptual depth/explanatory power.

Appendix 2: Data extraction criteria for qualitative review informed by Curtis-Tyler et al (2015) (chapter 4)

- Study characteristics
 - Type of diabetes
 - Aims/ Research questions
 - Rationale
 - Location of study
- Type of diabetes
 - Type 1 only
 - Type 2 only
 - Both types of diabetes
- Aims/ Research questions
- Rationale
- Location of study
 - UK
 - European country
 - USA
 - Other country
- Methods
 - Design
 - Recruitment

Appendix 3: Table to demonstrate 2nd and 3rd order concepts from qualitative review (chapter 4)

Study author	2 nd order concepts	3 rd order concepts
Babler (2015)	<p>Recognising recognising life is changing</p> <p>Taking action learning to balance blood sugar levels</p> <p>Disclosing disclosing diabetes diagnosis to others</p> <p>Engaging others enlisting support from others</p> <p>Taking responsibility independently managing condition</p> <p>Accepting learning to cope with diabetes</p> <p>Helping sharing with others to improve their lives</p>	<p>Identity recognising life is changing (realising diabetes is a long term condition) acceptance of diabetes sense that have lost a 'normal life' desire to restore sense of normality</p> <p>Disclosing disclosing diabetes diagnosis to others to engage support more likely to disclose to close friends young people do not feel everyone needs to know about diabetes</p> <p>Support sharing with others to improve their lives sharing own experiences with other young people with diabetes teaching others with diabetes about their condition</p>

		<p> motivating others to engage in self-care sharing with others ways to accept diabetes acting as a role model for others showing compassion to others with diabetes planning a career helping other young people with diabetes </p> <p> Independence independently managing condition learning to cope with diabetes believing it is possible to manage diabetes making diabetes a priority making diabetes a part of daily routine setting and achieving goals recognising high and low blood sugars demonstrating competency to others self-encouragement evaluating effects of actions </p>
Balfe (2007)	Identity diabetes self-care (eating healthily) as helping to maintain both current and future identity	Identity maintenance of current and future identity through self-care eating healthily as serving to construct moral self

		<p>disciplinary practices allowing for identification with desired, gendered subject positions</p> <p>Control</p> <p>self-care provided sense of mastery where diabetes could be controlled</p> <p>disciplinary practices as linked with moral control of the self</p> <p>imbalanced blood sugar as being out of control</p> <p>eating for comfort when feeling 'out of control' (high blood sugar)</p> <p>refusal to engage in disciplinary activities to maintain control over diabetes rather than being controlled by diabetes</p> <p>tension between desire for control and lack of structure within university environment</p> <p>failure to achieve weight loss as triggering feeling of loss of control over body</p> <p>failure to achieve weight loss as triggering feeling of loss of control over body</p> <p>rebellion against disciplinary practices in order to avoid feeling controlled by others</p> <p>control via exercise creates feeling of moral empowerment</p>
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		<p>food as helping to maintain control by preventing hypoglycaemia</p> <p>Disruption</p> <p>maintaining self-care to reduce possibility of future biographical disruption</p> <p>disruption as a result of engaging in multiple body projects</p> <p>desire to maintain normal student identity as disruptive to self-care</p> <p>lack of routine within university environment as disruptive to engagement in moral disciplinary practices</p> <p>inability to actualise goals of disciplinary activities as disruptive to emotional wellbeing</p>
Balfe and Jackson (2007)	<p>Flexibility</p> <p>technology provides social and spatial flexibility</p> <p>technology allows for engaging in disciplinary practices (dieting and exercising)</p> <p>Identity</p> <p>technology minimises risk to health and identity</p>	<p>Control</p> <p>technology providing social and spatial flexibility (control of lifestyles)</p> <p>technology allowing to engage in disciplinary practices (control of bodies) to preserve desired sense of self</p> <p>more control of diabetes as providing more freedom</p>

	<p>technology is potentially stigmatising</p> <p>Disruption</p> <p>frequent use of technology as disruptive</p> <p>university environment as barrier to diabetes self-care</p>	<p>controlling risk by testing blood sugar more frequently</p> <p>Identity</p> <p>technology minimising risk to identity</p> <p>use of technology as stigmatizing</p> <p>technology serving as constant reminder of diabetes identity</p> <p>older adolescents as disassociating from 'normal' student identity</p> <p>Disruption</p> <p>frequent use of technology as disruptive to lifestyle</p> <p>lack of routine in university environment as disruptive</p> <p>stress as disruptive to glycaemic control</p> <p>use of technology as form of biographical disruption (reminder of diabetes identity)</p> <p>technology as disruptive to desire to remain invisible</p> <p>Support</p> <p>friends helping to redefine injecting insulin as normal</p> <p>friends could also stand in front of young person whilst injecting to privatise act</p>
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<p>Dovey- Pearce (2007)</p>	<p>Disclosing disclosing to others as careful and considered decision</p> <p>Taking responsibility occurs alongside integration of diabetes into self-identity</p> <p>Identity: diabetes diagnosis as causing threat to identity and redefinition of: relationship with others, current and future identity goals</p> <p>Sense of difference: friends helped young person feel less different if treated them the same as before diagnosis drawing attention to self-care by friends reinforced feelings of difference</p> <p>Independence: family provide 'safe base' for young person to become increasingly independent</p> <p>young person becoming more independent from family as difficult for both parties</p>	<p>Disclosing: disclosing diagnosis as careful and considered decision</p> <p>Independence: taking responsibility family provide 'safe base' young person becoming more independent from family as difficult for both parties balancing daily life with future health threats taking responsibility for life- long management of condition balance between engagement and avoidance of self-care needed to manage practical and emotional demands of diabetes engaging with long-term consequences of diabetes and own mortality</p> <p>Identity: diagnosis as threat to identity and redefinition of: relationship with others, current and future identity goals</p> <p>Support: friends helping with feeling less different drawing attention to self-care highlighting sense of difference</p>
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Karlsson et al (2008)	<p>Transition: transition towards autonomy as hovering between individual actions and those of others</p> <p>Self-reliance: individual self-reliance: characterised by self-determination through making one's own decisions</p> <p>Cognitive maturity: psychological maturity as creating possibilities for increased responsibility and freedom</p> <p>successful self-management as increasing motivation</p>	<p>Independence: self-reliance and self-determination through making own decisions</p> <p>psychological maturity as enabling independence</p> <p>successful independent self-management increasing motivation</p> <p>balance between individual actions and help from others</p> <p>failure to achieve target glycaemic control due to indifference or non-compliance</p> <p>Support: support from diabetes health care team strengthens self-esteem</p> <p>peer acceptance facilitates incorporation in daily self-management activities</p> <p>parental acceptance boosts self-confidence</p>
Martin (2011)	<p>Identity comparison of life before diagnosis to current identity (body and abilities)</p> <p>self-care (taking medication) as allowing identity to be maintained (being normal)</p>	<p>Identity comparison of past to present body and abilities</p> <p>self-care as maintaining identity</p> <p>future identity influencing current self-care</p> <p>others with diabetes as providing evidence of future identity</p>

	<p>perceptions of future identity influenced current engagement with self-care</p> <p>Experiences provided other experiences of diabetes for young people (potential future consequences)</p>	
Protudjer et al (2014)	<p>Balancing self-care as achieving a balance between individual and social factors which gets easier over time</p> <p>Identity diagnosis as uncomfortable and provided threat to cultural identity</p> <p>Perceptions of control forgetting deliberate avoidance of self-care</p> <p>Supportive relationships provided support when making behavioural changes those struggling with self-care cited lack of support from friends and family</p>	<p>Identity diagnosis as threat to cultural identity</p> <p>Control perceptions of control influencing self-care failure to achieve target glycaemic control attributed to indifference towards diabetes or conscious noncompliance</p> <p>Support importance of supportive relationships with family and friends when making behavioural changes</p> <p>lack of support as detrimental to self-care</p> <p>Independence self-care as balance between individual and social factors which gets easier over time</p>

		<p>Disclosure</p> <p>fear of social prejudice or exclusion as a result of diagnosing condition</p>
Rasmussen et al (2011)	<p>Transition:</p> <p>transitions as significant life events which permanently change perspective on life and diabetes (include both diabetes and non-diabetes related transitions)</p> <p>life changes are stressful and influencing glycaemic control and wellbeing</p> <p>Cognitive maturity</p> <p>self-negotiating to maintain blood glucose balance (weighing pros and cons)</p> <p>managing diabetes using previous experiences (developing intuitive management strategies)</p> <p>connecting with others with diabetes (exchanging emotional support)</p> <p>actively seeking information to patch knowledge (boosted sense of autonomy and confidence in managing condition)</p> <p>putting diabetes into perspective (not letting the condition take over)</p> <p>Disruption:</p> <p>work environment as stressful</p>	<p>Disruption</p> <p>hospital appointments as disruptive to education</p> <p>engaging in risky behaviours as disruptive to diabetes self-care</p> <p>maintaining friendships as stressful and thus disrupting glycaemic control and emotional wellbeing</p> <p>prioritising health of children over self as disruptive to glycaemic control</p> <p>relocating as disruptive to diabetes self-care and accessing health services</p> <p>ignorance and discrimination from co-workers as disruptive to emotional wellbeing</p> <p>work environment as disruptive to self-care routine</p> <p>Independence</p> <p>self-negotiating to maintain blood glucose balance</p> <p>developing intuitive management strategies</p> <p>managing diabetes using previous experiences</p> <p>actively seeking to patch knowledge gaps</p>

	<p>potential negative consequences of disclosing their diabetes</p> <p>employers and co-workers ignorance about diabetes</p>	<p>putting diabetes into perspective</p> <p>Support</p> <p>exchanging emotional support with others with diabetes</p> <p>meeting others with diabetes as helping to feel less isolated</p> <p>inspired by other young people with diabetes managing well</p> <p>maintaining peer group relationships as challenging due to discrimination and peer pressure</p> <p>Control</p> <p>not letting the condition take over</p> <p>entering motherhood as demanding vigilant control of blood sugar levels</p> <p>stabilised blood sugar levels as a result of being on pump</p> <p>providing sense of control</p> <p>weighing up pros and cons of strategies to feel safe and in control</p> <p>development of intuitive management strategies from recognising body cues to maintain control</p> <p>Disclosing</p>
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		<p>fear of disclosing diagnosis due to fears of discrimination/losing job</p> <p>difficult to decide how and when to involve a new partner in their diabetes management</p>
Rostami et al (2014)	<p>Supportive relationships</p> <p>financial support</p> <p>assistance with balancing blood glucose levels</p> <p>mutual understanding</p> <p>being sensitive to symptoms</p> <p>rallying support from school</p> <p>encouragement of independence in young person</p> <p>treating diabetes as normal</p> <p>avoiding conflict with young person</p>	<p>Support</p> <p>economic support from parents</p> <p>practical support from parents</p> <p>emotional support from parents</p> <p>parents leveraging school support</p> <p>emotional support from friends</p> <p>practical support from friends</p> <p>educational support from health care team</p> <p>psycho-spiritual consultations</p> <p>medication management by health care team</p> <p>school staff boosting confidence and wellbeing</p> <p>encouragement to participate in social and educational activities</p> <p>parents treating diabetes as normal</p> <p>Independence</p> <p>close communication with school boosts self-reliance</p> <p>conscious management of resources to achieve normalisation</p>

		being sensitive to diabetes-related complications
Sparud-Lundin et al (2010)	<p>Identity</p> <p>reconsidering self by becoming aware of identity threats</p> <p>growing acceptance of identity over time</p> <p>Supportive relationships</p> <p>Parents:</p> <p>Acting as driving agents for young person</p> <p>Relinquishing responsibility over time</p> <p>Concerns of parents causing conflict</p> <p>Partners:</p> <p>Concern from perceived unqualified partners</p> <p>Friends:</p> <p>Need to manage involvement of friends</p> <p>Key idea= Ongoing definition of identity and relationships with others in relation to diabetes self-care in emerging adulthood</p> <p>These processes intersect as self and identity is challenged or confirmed in interactions with others</p>	<p>Identity</p> <p>awareness of identity threats</p> <p>growing acceptance and stronger identity over time</p> <p>needing help as challenging self-identity</p> <p>involving partners too much seems to be related to a refusal to adopt an illness identity</p> <p>impulsive personality as inappropriate characteristic for a diabetic</p> <p>Control</p> <p>feelings of failure when blood glucose levels not controlled</p> <p>Support</p> <p>parents as driving agents</p> <p>mothers as mainstay in providing diabetes-related support</p> <p>parents relinquishing responsibility over time</p> <p>concern from parents and partners causing conflict</p> <p>active management of friend support needed</p> <p>partners and friends as transferring strength</p> <p>communication with family and friends as harsh</p>

		<p>parents as guiding agents by sharing own experiences and enabling young person to become more confident in own ability</p> <p>siblings having a 'stand by' role</p> <p>reluctance to be with others where diabetes is only common denominator</p> <p>feeling connected by diabetes when exchanging support with another young person with diabetes</p>
Spencer et al (2014)	<p>Confidence</p> <p>Confident in carrying out insulin injections in public</p> <p>Sense of difference</p> <p>feeling different from friends as a result of receiving attention due to self-management behaviours</p> <p>fear of reactions of others if injecting insulin in public</p> <p>forgetting</p> <p>preference for time and space to undertake self-care activities without having to talk about it</p> <p>Supportive relationships</p> <p>Family:</p> <p>setting up injections</p> <p>recording blood glucose results</p> <p>collecting prescriptions</p>	<p>Identity</p> <p>confidence in carrying out insulin injections in public spaces vs fear of reactions of others if injecting insulin in public spaces</p> <p>feeling different from friends as a result of attention due to self-management behaviours</p> <p>Support</p> <p>preference for time and space to deal with diabetes</p> <p>preference to avoid discussion about diabetes</p> <p>family and friends as providing practical support</p> <p>positive relationships with nurses who showed an interest for non-diabetes life</p>

	<p>administering injections</p> <p>other family members with diabetes meant that diabetes routines were an accepted part of family life</p> <p>Both parents:</p> <p>provided reminders about self-management (sometimes annoying and sometimes helpful)</p> <p>involved in provision of adequate meals</p> <p>minimal involvement from siblings</p> <p>Friends:</p> <p>careful decision to disclose diagnosis to friends (only long-term friends)</p> <p>interested in condition</p> <p>provided help in emergencies</p> <p>Clinic:</p> <p>positive relationships with nurses who were friendly and showed an interest in life outside of diabetes</p> <p>adult healthcare series seen as daunting and unknown by young people</p> <p>School:</p> <p>school environment as barrier to diabetes self-care</p>	<p>other family members with diabetes normalised diabetes routines</p> <p>leaving friends to inject insulin as making young people feel different</p> <p>injecting around friends if diabetes is perceived as accepted by friends</p> <p>school providing lunch pass so young person did not have to queue</p> <p>putting photograph of young person in school staffroom so staff aware of diabetes</p> <p>support from friends as boosting adherence to diabetes self-care</p> <p>friends knowing how to help in an emergency</p> <p>Disclosure</p> <p>careful decision to disclose to closest friends</p> <p>Disruption:</p> <p>diabetes as disruptive to family routine</p> <p>diabetes self-care as disruptive to desirable school activities</p> <p>school detentions as barrier to self-care</p> <p>being asked to talk at school about diabetes</p>
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	<p>Disruption</p> <p>performing insulin at school was difficult</p> <p>differences in preferences for where to perform insulin injections</p> <p>Sense of difference</p> <p>being tasked to talk to class about diabetes</p> <p>being sent home for hypoglycaemia</p> <p>being unable to participate in certain activities</p> <p>having to eat in class</p>	<p>being unable to participate in school activities</p> <p>having to eat in class at school</p> <p>ignorance from teachers as disruptive to self-care</p> <p>concentration in school disrupted by hypoglycaemia</p>
Viklund and Wikblad (2009)	<p>Cognitive maturity</p> <p>being able to make abstractions (immediate and long-term consequences)</p> <p>trusting in own capabilities (taking initiative and seeking knowledge when needed)</p> <p>having self-knowledge (insight and conscientiousness)</p> <p>Self-reliance</p> <p>courage to follow through with decisions</p> <p>Self-strength</p> <p>feeling in control and desire to make own decisions</p>	<p>Independence</p> <p>ability make abstractions (short and long term consequences)</p> <p>having self-knowledge (insight and conscientiousness)</p> <p>trusting in own capabilities (taking initiative and seeking knowledge when needed)</p> <p>being able to be flexible (making adjustments)</p> <p>using both own and others experiences to solve problems</p> <p>trust in own knowledge</p> <p>courage to make and defend decisions</p> <p>Control</p>

	<p>Knowledge of diabetes: own experiences (reflecting on mistakes and successes) and experiences of others (could help with problem solving)</p> <p>Supportive relationships: Family: family helping to create a safe environment for diabetes self-care teamwork involving shared knowledge and responsibility helped with problem solving provided reminders only when needed creating safe environment for young person where they feel understood and supported also help to inform significant others about diabetes diagnosis lack of involvement/concern/knowledge control of parents inhibits independent self-management fear of diabetes complications and making others fearful of diabetes</p>	<p>feeling in control and desire to make own decisions parental need for control as detrimental to self-care</p> <p>Support: family creating a safe space for diabetes self-care (practically and emotionally) family teamwork where knowledge and responsibility is shared family helping with problem solving family informing others about diabetes meeting others with diabetes providing inspiration meeting others as helping to recognise problems and finding solutions</p> <p>Disruption: parental fear of diabetes as disruptive to emotional wellbeing authoritarian parenting style as detrimental lack of involvement as disruptive to self-care lack of empathy from parents as detrimental</p>
Wang et al (2013)	The same yet different:	Identity:

	<p>unsure how similar or different to classmates</p> <p>used coping strategies such as describing self as ‘normal’</p> <p>did not want special treatment at school</p> <p>Covert and overt: dilemma about diabetes disclosure often wanted to hide diagnosis at school fear of consequences of disclosure knowledge of diabetes symptoms to others as important testing of disclosure to see reaction did not want others to know if had low blood sugar as might be labelled a ‘problem’</p> <p>Limitations and freedom: knowledge of long term consequences physical symptoms as reminder of diabetes limitations at school (long walks, limited food choices, hard to bring supplies each day) developed strategies to feel more comfortable (ignoring others, not thinking about it, getting used to it)</p>	<p>symptoms as uncomfortable reminder of having diabetes</p> <p>symptoms as reminder than not ‘normal’</p> <p>sense of difference to others reinforced when with others</p> <p>Independence: reliant on parents for diabetes self-care and education lack of support from teachers as barrier to independence use of intuitive diabetes self-care strategies</p> <p>Sense of control: felt lack of control because of diabetes desire to be seen as ‘normal’ by others</p> <p>Disruption: diabetes self-care as disruptive to school life</p>
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	<p>sometimes avoided self-care if felt was unnecessary (felt could trust body signals)</p> <p>teachers often misunderstood diabetes (would prevent participation in school activities)</p> <p>more restricted at school than home because of perceptions of others</p> <p>Dependent and independent: realised need for independence, autonomy and responsibility dependent on parents for self-care and education</p> <p>arguments with parents about diabetes self-care when not at home</p> <p>lack of support at school makes it harder to be independent</p> <p>Derailing and being on track: lot of temptations to manage at school</p> <p>hard when others are still eating to stop eating</p> <p>lots of unpredictable situations</p> <p>Disease identity and denial: negative emotions about having diabetes</p> <p>emotions reinforced by treatment by teachers</p>	
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	<p>felt more mature than peers</p> <p>without diabetes</p> <p>wanted to be nurses when older to</p> <p>help others with diabetes</p>	
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Appendix 4: Parent information sheet for qualitative interviews (chapter 5)

Collaboration for Leadership in
Applied Health Research and Care

North Thames


**National Institute for
Health Research**



Dear Parent/Carer,

Hello, my name is Professor Angela Harden, Professor of Community and Family Health, Institute for Health and Human Development (IHHD), based at the University of East London (UEL). I am the principle investigator on a project entitled ‘Co-designing community-based diabetic services responsive to the needs of children and young people’.

The project aims to gain insight into the experiences of young people living with diabetes and their experiences of diabetes care via interviews. Co-designed workshops are also being conducted with young people with diabetes, their families, health professionals and other key stakeholders to share ideas and prioritize solutions to diabetes care. Young people with diabetes are also invited to play an active role in designing and participating in workshops which aim to share ideas about how to optimize diabetes care for young people living in London.

A report summarising findings from the interviews and the workshops will be completed. This will involve conclusions and recommendations for optimizing diabetes care for young people living in London. The results of this project will help to inform new developments in diabetes services for children and young people, ensuring that they are responsive to the needs of children and young people.

The project is being funded by the NIHR CLAHRC North Thames. The NIHR CLAHRC North Thames is a collaboration between universities, the NHS, UCLPartners, local authorities, patients, the public, industry and charities. The NIHR CLAHRCs conduct applied health research.

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Contact details for further information about the project:

Professor Angela Harden

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IHHD, UH250

Stratford Campus

University of East London

Water Lane

London, E15 4LZ

Appendix 5: Parent consent forms for qualitative interviews (chapter 5)

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Parent/Carer consent form: Interview

The purpose and details of this study have been explained to me. I understand that this project is designed to collect data from my son/daughter to gain insight into their experiences in their role as Young Clinical Commissioner.

Please **initial** the following statements before signing the form:

I have read and understood the information sheet and this consent form.

I have had an opportunity to ask questions about my child participating in the interview.

I understand that they are under no obligation to take part in the project.

I understand that the decision for my child to take part will not affect their diabetes management or their role as Young Clinical Commissioner.

I understand that I have the right to withdraw my child/children from the project at any stage for any reason, and that I will not be required to explain my reasons for withdrawing.

I understand that all the information my child/children provide will be treated in strict confidence.

I agree to my child/children to participate in this project.

I agree to my child/children to be tape recorded and to use direct/anonymized quotations (if required)

I understand that my child/childrenis willing to take part in this study and I give permission for child/children to participate in this study.

Your name (Parent/Carer) _____

Your signature _____

Date _____

Signature of investigator _____

Date _____

Appendix 6: Participant information sheet and assent form for qualitative interviews for young people aged 11-15 (chapter 5)

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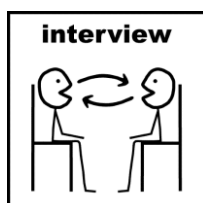
Title of the project: Co-designing community-based diabetic services responsive to the needs of children and young people



We are asking you to take part in a research study because we are trying to learn more about how children and young people manage living with diabetes and how you use diabetes services in your local community.



If you agree to be in this study we will interview you about your experience of living with diabetes which will last no longer than one hour.



No one outside of the research team will know what you have said and we will not share details of this conversation with your diabetic nurse or doctor or anyone else, unless you are at risk of harm. We will have to inform the responsible adult at the University to get you or another child help if we felt you were at risk of harm.



You will be given a £10 shopping voucher as well as travel expenses for taking part in the study and the information you provide will help the NHS design new local services to help improve the way children and young people control their diabetes.



Please talk this over with your parents before you decide whether or not to participate. We will also ask your parents to give their permission for you to take part in this study. But even if your parents say “yes” you can still decide not to do this.



If you don't want to be in this study, you don't have to participate. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.



You can ask any questions that you have about the study. If you have a question later that you didn't think of now, you can call me 0208 223 2167 to talk with a member of the research team.



If you agree to be in the study we will ask to tape record the interview and to use direct/anonymised quotations (if required).



Signing your name at the bottom means that you agree to be in this study. You and your parents will be given a copy of this form after you have signed it.

Name of Participant _____

(To be written by child/adolescent)

Printed Name of Researcher

Signature of Researcher

Date

Time

Appendix 7: Interview schedule for qualitative interviews (chapter 5)

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Section 1: The individual

1. If you could use five words to describe your diabetes what would they be?
(Prompt cards used to answer question)
2. How old were you when you were diagnosed with diabetes?
3. What has changed since your diagnosis?
4. What is it like to be living with diabetes today?

Section 2: Others

5. What works/doesn't work for you in terms of your diabetes management?
(Prompt cards to be used to answer question)
6. Could you rank these the health professionals in terms of the importance you think that they have in your diabetes management? (Prompt cards used to answer question)
7. How do your family impact upon the management of your diabetes?
 - a. Is there anything you would like them to do differently?
8. What role do your friends play in your diabetes management?
 - b. Is there anything you would like them to do differently?
9. Are there any other individuals/ organisations which play a significant role in your diabetes management?
 - c. Is there anything you would like them to do differently?
10. Do you use any online support resources?
 - d. If yes: How do these resources impact upon your diabetes management?
11. Do you use any other technology to help manage your diabetes?
 - e. If yes: What do you use this technology for?

Section 3: The future

12. How do you think diabetes services for young people could be modified in order to help you manage your diabetes in the best way possible?

Section 3: Demographic information

13. What is your age?

14. What type of diabetes do you have?
15. What is your ethnicity?
16. What is your position in your family?
17. What is the history of diabetes in your family?







Appendix 8: Interview images for qualitative interviews (chapter 5)









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Health Research**



Image	Relevant questions
<p>Figure 1- Gym</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 2- Fruit and vegetables</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 3- Injecting insulin</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 4- Running</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 5- Swimming</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 6- Meditating</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>

<p>Figure 7- Reading</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 8- Drama</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 9- Music player</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 10- Doing homework</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 11- Mother looking after child</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 12- Hiking</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 13- Social Media</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 14- Dinner</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>

<p>Figure 15- Concert</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 16- Happy person</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 17- Friends playing together</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 18- Thinking</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 19- Park</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 20- Sports</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 21- Watching a musical</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 22-Shopping centre</p>	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>

	
<p>Figure 23- Church</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 24- Paint palette</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 25- Shopping</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 26- Jewish temple</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 27- Coffee bar/café</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 28- Place of worship</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 29- Group of friends</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>






































<p>Figure 30- Family</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
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Image	Relevant questions
<p>Figure 1- Book</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 2- Giving someone medicine</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 3- Patient in Hospital</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 4- Using laptop</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 5-Climbing mountain</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 6- Laboratory experiment</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 7- Group of friends</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>

<p>Figure 8- Meditating</p> 	<p>5 . (h)What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 9- Running</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 10-Gym</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 11- Swimming</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 12- Fruit and vegetable basket</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?</p>
<p>Figure 13- Giving insulin injection</p> 	<p>5 (h) What works/doesn't work for you in terms of your diabetes management?.</p>
<p>Figure 14- Group holding hands n/a</p>	<p>n/a</p>
<p>Figure 15- Social media</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 16- Friends</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>

<p>Figure 17- School</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 18- Family</p> 	<p>3 (a) Please take a look at the images in front of you and select one or two which best shows the people who support you.</p>
<p>Figure 19- People holding hands n/a</p>	<p>n/a</p>
<p>Figure 20- Music player</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 21- Park</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 22-Concert</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 23- Bedroom</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 24- Café</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 25- Paint palette</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>

<p>Figure 26- Shopping</p> 	<p>1 (a) Please take a look at the images in front of you and select one or two which best shows how you see yourself and explain why.</p>
<p>Figure 27- Restaurant</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 28- Shopping centre</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 29- Sports</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 30- Drama</p> 	<p>2 (a) Please take a look at the images in front of you and select one or two which best shows what you like to do in your spare time.</p>
<p>Figure 31- Pharmacist</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>
<p>Figure 32- Consultant</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>
<p>Figure 33- Diabetes specialist nurse</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>

<p>Figure 34- Psychologist</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>
<p>Figure 35- Optometrist</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>
<p>Figure 36- Dietician</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>
<p>Figure 37-GP</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>
<p>Figure 38- Podiatrist</p> 	<p>5 (g) Please take a look at the photographs and can you rank the health professionals in terms of the importance you think that they have in your diabetes management?</p>

Appendix 9: Ethics form for qualitative interviews

Collaboration for Leadership in
Applied Health Research and Care

North Thames

NHS
National Institute for
Health Research



13 June 2016

Dear Emma,

Project Title:	An exploration of an asset-based approach to the
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	management of diabetes in young people: a qualitative participatory approach
Principal Investigator:	Professor Angela Harden
Researcher:	Emma Green Dr Darren Sharpe
Reference Number:	UREC 1516 134

I am writing to confirm the outcome of your application to the University Research Ethics Committee (UREC), which was considered by UREC **on Wednesday 18 May 2016.**

The decision made by members of the Committee is **Approved**. The Committee's response is based on the protocol described in the application form and supporting documentation. Your study has received ethical approval from the date of this letter.

Please note the UREC Application Form for ethical approval has been revised. For future applications please use the revised application form which can be found on:

<https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Pages/Ethics.aspx>

The Committee would like to commend you on the presentation of this application for ethical approval. Should you wish to make any changes in connection with your research project, this must be reported immediately to UREC. A Notification of Amendment form should be submitted for approval, accompanied by any additional or amended documents:

<http://www.uel.ac.uk/wwwmedia/schools/graduate/documents/Notification-of-Amendment-to-Approved-Ethics-App-150115.doc>

Any adverse events that occur in connection with this research project must be reported immediately to UREC.

Approved Research Site

I am pleased to confirm that the approval of the proposed research applies to the following research site.

Research Site	Principal Investigator / Local Collaborator
University of East London and by telephone	Professor Angela Harden

Approved Documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
UREC application form	3.0	3 June 2016
Participant Information Sheet	3.0	3 June 2016
Consent Form	3.0	3 June 2016
Interview schedule for interviews with peer educators	3.0	3 June 2016

Approval is given on the understanding that the [UEL Code of Practice in Research](#) is adhered to. The University will periodically audit a random sample of applications for ethical approval, to ensure that the research study is conducted in compliance with the consent given by the ethics Committee and to the highest standards of rigour and integrity.

Please note, it is your responsibility to retain this letter for your records.

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

Yours sincerely,

Catherine Fieulleteau

Research Integrity and Ethics Manager

University Research Ethics Committee (UREC)

Email: researchethics@uel.ac.uk

Appendix 10: Participant information sheet for qualitative interviews (chapter 6)

Collaboration for Leadership in
Applied Health Research and Care

North Thames


**National Institute for
Health Research**



13 June 2016

Dear Emma,

Main Project Title: Co-designing community-based diabetic services in response to the needs of children and young people

Purpose and value of study:

This project is examining the co-design of community-based diabetes services in London in response to the needs of children and young people. The results of this project will help to inform new developments in diabetes services for children and young people, ensuring that they are responsive to the needs of children and young people. The research team for this project includes Professor Angela Harden (Principal Investigator), Dr Darren Sharpe (Research fellow) and Emma Green (PhD student). For more information about this project please visit <http://www.clahrc-norththames.nihr.ac.uk/co-designing-young-peoples-diabetic-services/>.

Emma Green's PhD project forms part of this larger project and aims to gain insight into the experiences of the young people who have taken an active role in youth-participation initiatives, including the young people who have taken an active role in influencing diabetes commissioning guidelines in their role as Young Clinical Commissioners.

Invitation to participate:

We are seeking to individually interview you and the other Young Clinical Commissioners to gain insight into your experiences in the role and the impact that it has had upon you. The interview will be conducted by Emma Green and will last between 1 and 1 ½ hours and will take at the University of East London. The interviews will be audio recorded with your permission.

Incentive for participating:

If you choose to participate, travel expenses will be provided.

If you are interested in participating:

Please inform the person who gave you this information sheet that you are interested in taking part in the project. You will then receive telephone call from Emma Green to arrange a time and date that is convenient for you for the interview to take place.

Whether you accept to take part: If you decide not to take part in the project you will not be asked to explain why. Your decision to participate or not will not influence your role as Young Clinical Commissioner in any way.

Whether you can withdraw at any time, and how:

If you do agree to take part, you retain the right to withdraw from the study at any stage for any reason. You just need to tell the researcher of your decision. You will not be asked to explain your reasons for withdrawing. Withdrawing will have no impact on your role as a young Clinical Commissioner.

What will happen if you agree to take part (brief description of procedures/tests):

If you agree to participate in the interview you will be asked to sign a consent form and return it to the researcher along with the parent/guardian consent form (if you are under the age of 16).

Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety:

Interviews will be scheduled around you and will not disrupt your education, training or work commitments. The topics that will be discussed in the interviews should not involve any risks (physical or psychological). However, if information is provided during the interview which suggests that you or another young person is at risk of harm, details will be provided to the safeguarding officer at the University of East London who will seek to provide further help.

What will happen to any information/data that are collected from you:

The recordings and transcripts of the workshops and interviews will be kept in a secure place to ensure confidentiality and will not be passed on to any third parties. Before sharing results of the study, data will be anonymized in order to protect your identity.

Who is organizing the research: The research team is based at the University of East London. The team consists of Professor Angela Harden, Dr Darren Sharpe and Emma Green.

Details of the Principal Investigator:

Professor Angela Harden

0208 223 2167

a.harden@uel.ac.uk

What will happen to the results of the project:

The results of the PhD project will form part of Emma Green's PhD thesis, which will be submitted to the University of East London as part of the PhD assessment process.

Source of funding for the research:

The project is being funded by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) in North Thames London.

Research Ethics:

This study has been reviewed and received favourable opinion by South East Coast-Surrey Research Ethics Committee.

If you have any queries regarding the conduct of the project in which you are being asked to participate, please contact:

**Catherine Fieulleateau, Research Integrity and Ethics Manager, Graduate School,
EB 1.43 University of East London, Docklands Campus, London E16
2RD(Telephone: 020 8223 6683, Email: researchethics@uel.ac.uk).**

YOU WILL BE GIVEN A COPY OF THIS TO KEEP,
TOGETHER WITH A COPY OF YOUR CONSENT FORM

Appendix 11: Participant consent form for qualitative interviews (chapter 6)

Collaboration for Leadership in
Applied Health Research and Care

North Thames


**National Institute for
Health Research**



Main Project Title: Co-designing community-based diabetic services in response to the needs of children and young people

NAME OF PARTICIPANT:

Title of the project: Co-designing community-based diabetes services responsive to the needs of children and young people

Main investigator and contact details: Professor Angela Harden

IHHD, UH250

Stratford Campus

University of East London

Water Lane

London, E15 4LZ

0208 223 2167

a.harden@uel.ac.uk

Please tick the following statements before signing this consent form:

- ☐ I agree to take part in the interview. I have read the Participant Information Sheet which is attached to this form. I understand what my role will be in the project, and all my questions have been answered to my satisfaction.
- ☐ I understand that I am free to withdraw from the interview at any stage, for any reason and without prejudice.
- ☐ I agree for the interview to be audio-recorded
- ☐ I have been informed that the confidentiality of the information I provide will be safeguarded.
- ☐ I have been provided with a copy of this form and the Participant Information Sheet.

Name of participant

(print).....Signed.....Date.....

Participant consent form

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of Project: Co-designing diabetes services responsive to the needs of children and young people

I WISH TO WITHDRAW FROM THIS STUDY

Signed: _____ Date: _____

Appendix 12: Optional parent information sheet for qualitative interviews (chapter 6)

Collaboration for Leadership in
Applied Health Research and Care
----- North Thames


**National Institute for
Health Research**



Dear Parent/Carer,

My name is Emma Green, I am a PhD student based at the University of East London. I am part of the project team on a project entitled 'Co-designing community based diabetes services responsive to the needs of children and young people'. The research team for this project includes Professor Angela Harden, Dr Darren Sharpe and Emma Green. My PhD project forms part of this larger project and aims to gain insight into the experiences of young people who have taken part in youth-participation initiatives. The interviews aim to explore their experiences in the role and the impact that the role has had upon them.

The interviews be face-to-face and will take place at the University of East London, or via telephone, and will last between 1 hour and 1 ½ hours. Emma Green (PhD student) will be conducting the interview with your son/daughter. The interviews will be audio recorded with your child's permission. Consent to participate is entirely voluntary and your/son or daughter will be able to terminate the interview at any time, without providing a reason. The decision of whether or not to participate will have no impact on the diabetes care that your child receives or their role as a peer educator. If your child does decide to take part, he/she will be provided with travel expenses as well as a £10 shopping voucher to thank them for giving up their time to take part. Data from the interviews will be anonymized in order to protect the identity of your child. However, if information is provided during the interview which suggests that your child or another young person is at risk of harm, details will be provided to the safeguarding officer at the University of East London who will seek help.

Findings from the interview will form part of Emma Green's PhD thesis, which will be submitted to the University of East London as part of the PhD assessment process. The project will provide insight into the experiences of young people with diabetes who choose to take on peer educator roles and the impact that it has upon them.

If your child is interested in taking part and you are happy for them to do so, they will receive a telephone call to schedule a time and date for the interview to take place. The project is being funded by the NIHR CLAHRC North Thames. The NIHR CLAHRC North Thames is a collaboration between universities, the NHS, UCLPartners, local authorities, patients, the public, industry and charities. The NIHR CLAHRCs conduct applied health research.

This study has been reviewed and received favourable opinion by South East Coast-Surrey Research Ethics Committee. If you have any queries regarding the conduct of the project in which you are being asked to participate, please contact:

**Catherine Fieulleateau, Research Integrity and Ethics Manager, Graduate School,
EB 1.43 University of East London, Docklands Campus, London E16 2RD
(Telephone: 020 8223 6683, Email: researchethics@uel.ac.uk).**

Contact details for further information about the project:

Professor Angela Harden

0208 223 2167

a.harden@uel.ac.uk

IHHD, UH250

Stratford Campus

University of East London

Water Lane

London,

E15 4LZ

Appendix 13: Interview schedule for qualitative interviews (chapter 6)

Collaboration for Leadership in
Applied Health Research and Care
North Thames



Section 1: Demographic information

1. Tell me about yourself?
 - a. What were you doing before you were a peer educator?
 - b. How did diabetes/ health fit within your life at this time?
 - c. Why did you decide to apply for the role?
 - d. What did you know about the role?
 - e. What did you expect of the role?
 - f. Has the role fitted in with your expectations?

2. Tell me about what you like doing
 - a. What do you enjoy doing in your spare time?
 - i. How does diabetes/health fit into this?
 - ii. Are there particular strategies you use during these activities to help manage your diabetes/ maintain good health?
 - b. What else do you do when you are not taking part in activities relating to being peer educators?
 - i. How does diabetes/health fit into this?
 - ii. Are there particular strategies you use during these activities to help manage your diabetes/ maintain good health?
 - c. Could you tell me about a recent activity that you have taken part in as part of your role?
 - i. What do you feel you contributed to this activity?
 - ii. How do you think this activity was perceived/ received by other people?
 - iii. Did you feel that you have an active role in preparing for and delivering this activity?

Section 2: Tell me about your diabetes/ health/ role as a peer educator

3. Has your role influenced the way in which you perceive diabetes?
 - a. How has it changed your view?
4. Has your role influenced your diabetes self-management/ health care?
 - b. If so, what has changed?
5. Has your role influenced your relationship with your health care team?
 - c. If so, what has changed?
6. What skills or experiences did you bring to the role?
7. What have you learned or gained so far since being a young clinical commissioner/ a young researcher?
8. What has been most beneficial/significant/ influential for you?
9. Has your role influenced the way in which you perceive diabetes?
 - a. How has it changed your view?

10. Has your role influenced your diabetes self-management/ health care?
 - a. If so, what has changed?
11. Has your role influenced your relationship with your health care team?
 - a. If so, what has changed?
12. Has your role as young Clinical Commissioners / young researchers influenced the way in which you see yourself?
 - a. How has it changed your view?
13. Has your role influenced other aspects of your life?
 - a. How and what has been influenced by your role?
14. Have you felt that your voices are being heard whilst you have been in your role?
 - a. Who has listened?
 - b. Who would you like to listen to you?

Section 3: Tell me about other people in your life

15. Do/did your friends know about your role? What have you told them about your role?
 - a. What do they think about your role?
 - b. What role do your friends play in your diabetes management generally/ health care?
 - c. What do they do for you?
16. What do your parents think about your role?
 - a. What role do your parents play in your diabetes management/ health care generally?
 - b. What do they do for you?
17. Do your health care team know about your role?
 - a. What have you told them about your role?
 - b. What do they think about your role?
 - c. Is there anyone/anywhere else you have discussed your role with?
 - i. What do they think about your role?

Section 4: The future

18. What do you hope to achieve during the rest of your time in the role?
19. Would you be interested in be involved in similar roles in the future?
 - a. Why/ why not?
20. What do hope to be doing after your role?