Reducing the risk of Type 2 diabetes in people with intellectual disabilities: A three phase study

Volume I of II

Andrew Maine

BSc (Hons) in Psychology
BA History and English
SVQ4 Health and Social Care

School of Health and Social Care

EDINBURGH NAPIER UNIVERSITY

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List of abbreviations

ASD *Autistic Spectrum Disorder*

BMI *Body Mass Index*

CASP *Critical Appraisal Skills Programme*

CST *Common Sense Theory*

DESMOND *Diabetes Education and Self-Management for Ongoing and Newly Diagnosed*

DPT *Dual Process Theory*

EPHPP *Effective Public Health Practice Project*

HBM *Health Belief Model*

IPAQ *International Physical Activity Questionnaire*

ID *Intellectual Disabilities*

IDD *Intellectual and Developmental Disabilities*

IDF *International Diabetes Federation*

IPA *Interpretative Phenomenological Analysis*

JBI *Joanna Briggs Institute*

LAC *Local Area Coordinators*

NHS *National Health Service*

NICE *National Institute for Health and Care Excellence*

MRC *Medical Research Council*

PRISMA *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*

PIB *Positive Illusory Bias*

SCT *Social Cognitive Theory*

SELPA *Self-efficacy for Leisure Physical Activity*

SLT *Social Learning Theory*

SRT *Self-regulation theory*

SD *Standard Deviation*

T1D *Type 1 Diabetes*

T2D *Type 2 Diabetes*

TCS *Theory Coding Scheme*

TPB *Theory of Planned Behaviour*

TRA *Theory of Reasoned Action*

TTM *Transtheoretical Model*

UK *United Kingdom*

US *United States*

WHO *World Health Organisation*

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I would firstly like to thank my supervisors: Professor Michael Brown, Doctor Adele Dickson, my Director of Studies, Doctor Maria Truesdale, and Professor Thanos Karatzias, my Independent Panel Chair. All went the extra mile to bring a range of expertise, wisdom, and kindness that enabled me to progress successfully, and have acted as inspirational career role-models.

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Finally, I would like to thank my amazing wife, Eilidh for letting me swan off to do a PhD while she was doing the infinitely tougher job of parenting two toddlers; Arthur, for forgiving me for not being around 24/7 to build Star Wars Lego; and Sadie, for occasionally noticing when I wasn’t in the house.

Declaration

This work has not been submitted for any other degree or professional qualification, and is the result of my independent work. The word count in the main body of the text of this thesis is less than 80,000. The Walking Away program is the Intellectual Property of Leicester University and Leicester Diabetes Centre. The Three publications in the appendices are my independent work and are not a part of any collaborative project.

[redacted]

Abstract

Background:

People with intellectual disabilities (ID) remain at high risk of developing type 2 diabetes (T2D) due to lifestyle associated risk factors such poor diets and low physical activity levels. Interventions have been adapted which target ongoing T2D self-management. However, there are no adapted programmes which prevent T2D through reducing risk factors. The present research project addresses this gap through a three-phase study on the existing literature, theoretical basis, and process evaluation of a T2D prevention programme.

Methods:

Phase 1: The literature reviews identified that the support needs of people with ID with T2D are currently not being met. Appropriate training needs to be delivered so that people with ID can self-manage or reduce the risk of T2D effectively. Given the early onset of T2D in people with ID and their often shorter lifespan, there is rationale for a preventative agenda in T2D education. Four potential mainstream intervention programmes were identified, and the self-efficacy model was found to be the most prevalent successfully implemented theoretical model.

Phase 2: Nine sub-themes were identified following analysis of the data: 1) “Mastery through knowledge”; 2) “Mastery through tools and strategies”; 3) “Mastery through

autonomy”; 4) “Influence of social setting”; 5) “Positive social comparisons”; 6) “Positive and negative self-statements”; 7) “Feedback from Caregivers”; 8) “Adjustment experiences”; 9) “Symptom awareness”. These were mapped onto Bandura’s (1977) Four Sources of efficacy enhancement model and were consistent with its proposed mechanisms. The Four Sources model serves as a useful mode of enquiry for exploring people with ID’s experiences and perceptions of self-managing diabetes. It also confirms the appropriateness of ssself-efficacy as a potential intervention component for this population. However, additional support may be required for people with ID to reflect meaningfully on their experiences and thus have a sense of self-efficacy.

Phase3: 96% of invited students agreed to participate. The Walking Away programme was positively received, and some short-term impact was described, yet there were limitations to accessibility of the program due to the complexity of the language and materials. Suggestions for further adaptations regarding materials and content were provided, and there was perceived scope for a long-term implementation built into college curriculum.

Results:

Phase One: The literature reviews identified that the support needs of people with ID with T2D are currently not being met. Appropriate training needs to be delivered so that people with ID can self-manage or reduce the risk of T2D effectively. Given the early onset of T2D in people with ID and their often shorter lifespan, there is rationale for a preventative agenda in T2D education. Four potential mainstream intervention programmes were identified, and the self-efficacy model was found to be the most prevalent successfully implemented theoretical model.

Phase Two: Nine sub-themes were identified following analysis of the data: 1) “Mastery through knowledge”; 2) “Mastery through tools and strategies”; 3) “Mastery through autonomy”; 4) “Influence of social setting”; 5) “Positive social comparisons”; 6) “Positive and negative self-statements”; 7) “Feedback from Caregivers”; 8) “Adjustment experiences”; 9) “Symptom awareness”. These were mapped onto Bandura’s (1977) Four Sources of efficacy enhancement model and were consistent with its proposed mechanisms. The Four Sources model serves as a useful mode of enquiry for exploring people with ID’s experiences and perceptions of self-managing diabetes. It also confirms the appropriateness of self-efficacy as a potential intervention component for this population. However, additional support may be required for people with ID to reflect meaningfully on their experiences and thus have a sense of self-efficacy. Phase Three: 96% of invited students agreed to participate. The Walking Away programme was positively received, and some short-term impact was described, yet there were limitations to accessibility of the program due to the complexity of the language and materials. Suggestions for further adaptations regarding materials and content were provided, and there was perceived scope for a long-term implementation built into college curriculum.

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language and materials. Suggestions for further adaptations regarding materials and content were provided, and there was perceived scope for a long-term implementation built into college curriculum.

Conclusions:

The findings provide basis for a further trial incorporating the suggested adaptations. A self-efficacy informed prevention programme was highly acceptability to students and teaching staff. Further education colleges provided a supportive setting and yielded a rich sample.

Researcher background

This thesis will begin with a reflexive account to enable the reader to evaluate how my own personal background and experiences may have impacted upon my knowledge and beliefs of health in people with ID, and subsequently how these beliefs may have informed my decision-making process through the research project. I will revisit this reflective account again in Chapter Ten.

Prior to embarking upon my PhD, I worked for over ten years as a workshop leader in an outdoor day activities center for adults with ID. This involved designing and implementing gardening and conservation projects which were intended to provide meaningful and stimulating physical activity. There was a developmental and educational focus to this work. I worked with people with a range of levels of ID and developmental disorders, and those from diverse cultural and socio-economic backgrounds. Through this work I experienced that the overall health of these service users was poor, with limited knowledge of healthy diet, and it was evident that little physical activity took place outside of the day center. Despite this, service users responded well to tasks involving moderate physical activity, as well as participating in informal discussions during about nutrition mealtimes. The age within this group was mainly 20-30 years, although there were several older adults, some of whom had developed serious health complications such as cardiovascular disease and type 2 diabetes. More than one service user with comorbidities passed away before the age of 60 in the time of my employment.

Towards the end of this post, I also worked part time as a voluntary assistant psychologist in a community learning disability center. In this setting I learned about the application of evidence-based practice in a primary care setting, including the evaluations and guidance of clinical psychologists, dieticians, speech and language and occupational therapists. This also gave me an insight into the health and lifestyle of people with ID who were not in a structured care environment and who led predominantly inactive lifestyles. This insight was enhanced by the literature review on people with ID self-managing T2D, which is presented in Chapter Two.

These experiences closely relate to the issues identified and discussed within this thesis. In the full reflexivity section in Chapter Eleven, potential drawbacks are discussed, such as biases and preconceptions; together with benefits such as awareness of communicative tools.

Chapter One - Introduction

1.1. Background

Diabetes is a chronic health condition where the amount of glucose in a person's blood is too high. (Diabetes UK, 2017). This occurs when the pancreas does not produce any, or insufficient levels of insulin to enable the metabolism and entry of glucose into the body's cells. It can also occur when the insulin produced is ineffective, which is known as insulin resistance. Glucose, which is produced through digesting carbohydrate, is essential in providing the body with energy. Without insulin control, glucose cannot be used properly and instead leads to too much sugar in the blood, known as hyperglycaemia.

There are three major types of diabetes, each with differing aetiologies. Type 1 diabetes (T1D) occurs when insulin production is insufficient due to an autoimmune disorder, with a typical onset at a young age. T1D accounts for 10.9% of diabetes cases in Scotland (Scottish Public Health Observatory, 2013). Type 2 diabetes (T2D) is the instability of blood sugar levels due to the body's low or ineffectively used insulin. T2D starts with resistance to the action of insulin and is associated with older age, being overweight and obesity. Gestational diabetes occurs when high glucose levels develop during the third trimester of pregnancy, and typically resolves once the baby is born. In addition to these major types, Type 3 diabetes has been proposed as an alternative title for Alzheimer's disease, which results from resistance to insulin in the brain (de la Monte and Wands, 2008), and Type 1.5 is an unofficial term used to describe Latent Autoimmune Diabetes in

Adults (LADA), where there are characteristics of both T1D and T2D (Diabetes UK, 2017).

According to the International Diabetes Federation (IDF, 2018) 425 million people between the age of 20-79 years are living with diabetes, which is anticipated to rise to 629 million by 2045. The Scottish Public Health Observatory (2013) attributes this increase partly to higher levels of diabetes awareness in health professionals leading to increased diagnoses, and as a consequence of poor diet, low levels of physical activity and subsequent levels of obesity. There are complex and significant health risks associated with diabetes, including renal failure, blindness, amputation due to circulatory problems, and cardiovascular risks such as strokes and myocardial infarctions. If poorly managed, diabetes can lead to a reduced quality and duration of life (Balogh et al., 2015). In addition, there are major cost implications to health services from diabetes. Diabetes UK reported a cost of £23 billion in 2010/2011, of which 8.8 billion was for T2D (Hex et al., 2012), and a global cost of 727 billion US dollars (IDF, 2018). Risk factors for diabetes include poor diet, low levels of exercise, obesity, older age, comorbidities such as cardiovascular problems, family history and minor ethnicities. These specifically include groups whose poverty affects living conditions and restricts access to health services through transport and geographical locations (Taggart, 2013).

T2D is associated with lifestyle, for example diet and exercise, in addition to medication control and regular visits to health professionals for screening. Previous research has therefore focused on enhancing T2D self- management (Davies et al., 2008) or reducing T2D risk factors (Yates et al., 2009), although it should be noted that such behavioural changes are also beneficial to T1D. Self-management involves a combination of lifestyle adaptations, including diet, exercise, monitoring of HBa1c (blood sugar levels), foot care and adherence to medication regimes.

In addition to improving self-management, intervention programs have focused on identifying those at risk of developing T2D and providing education on behavioural changes to reduce these risks. There are several pre-diabetic conditions, which can progress to a full diagnosis of T2D. Impaired Fasting Glycemia occurs when blood glucose levels are raised during periods of fasting, though not high enough for a diagnosis of diabetes (Diabetes UK, 2017). Impaired glucose tolerance occurs when blood glucose levels are much higher than normal and places an individual at greater risk of progression to T2D than Impaired Fasting Glycemia. However, with dietary and physical activity adjustments these levels can be significantly reduced (Diabetes UK, 2017).

1.1.2. Intellectual Disabilities definitions and terminology

An intellectual disability is defined as a condition which affects development prior to the age of 18, leading to a need for assistance with understanding information, learning skills and living independently, as well as creating impairments in day-to-day functional skills (AAIDD, 2018). Sub-categories of disability are associated with an intelligence quotient score, with "mild" relating to a score of 50-69; "moderate" to 35-49; "severe" 20-34; "profound" less than 20.

There are several terms associated with the label “Intellectual Disabilities”, including “Learning Disabilities”, “Learning Difficulties” and “Special Needs”. In Scotland, the term Learning Disabilities is conventionally used in policy framework and practice procedures (NHS Education Scotland, 2014). However, the term “Intellectual Disabilities” is the recognised term used internationally. Schalock et al. (2010) discuss the evolution of terms from “Mental Retardation” to Intellectual Disability, including the rationale and criteria for ID, including empowerment, dignity and susceptibility to negative stigma, arguing ultimately that the term ID is non-static and semantically affords the possibility of learning. These values have led to the widespread adoption of the term. ID is therefore the term adopted throughout this thesis, in keeping with current international consensus. It should also be noted that Intellectual and Developmental Disabilities (IDD) is becoming an increasingly common term. Developmental disability refers to broader lifelong disabilities which can also be physical in nature; IDD acknowledges that both can be present alongside intellectual disabilities

1.1.3. Diabetes and people with intellectual disabilities

There are a number of factors which place people with ID at risk of developing T2D. Firstly, genetic conditions typical in people with ID such as Prader Willi and Down’s Syndrome are likely to cause obesity at a young age, severely increasing the likelihood of developing T2D later in life (O’Shea et al., 2018; Yang et al., 2017). Socio-economic inequalities exist between people with ID and the general population as a result of fewer educational and vocational opportunities (Emerson, 2005).

These can lead to poorer living conditions where there are reduced opportunities for engaging in physical activity, lower health literacy and less access to healthy diets (Melville et al., 2008). In addition to this, the use of psychotropic medications as a measure to control challenging behaviour in people with ID can lead to obesity and subsequently T2D (Trollor, Salomon, and Franklin, 2016).

In terms of T2D self-management in people with ID, primary care health services can further contribute to the situation by failing to make reasonable adjustments to care and support, such as providing longer appointment times and accessible, visually supported materials, that take account of and respond to the cognitive and communication impairments experienced by many of this population. These additional measures are not in place, despite being in accordance with the Adults with Incapacity Act (2000) and the Disability Equality Act (2010).

In addition, Brown et al. (2017) reported that there is a need for improved communication between primary healthcare and other diabetes and ID services, family members and paid carers. When coupled with low health literacy in people with ID, there are significant consequences in relation to making healthy lifestyle choices (Emerson and Baines 2010). Further research is therefore required to more fully understand how T2D interventions can be developed to improve health and facilitate self-management for people with ID.

Structured educational programmes have been adapted from mainstream educational programmes to suit the needs of people with ID, such as DESMOND ID (Taggart et al., 2017), or newly developed, such as OK Diabetes (Walwyn et al., 2015), and STOP diabetes (Dunkley et al., 2017). These programmes, although yet to be fully trialled, show potential for improving diabetes self-management and reducing risk. However, the pilot trial of Taggart et al. (2017), and a cross-sectional study by Coates et al. (2017) identified issues with recruitment and continued adherence, such as transport difficulties, motivation and setbacks due to life events. In addition to these issues, there has to date been no appraisal of the theoretical models embedded within these models in terms of their relevance and meaning to people with ID.

1.2. Research project aims

Despite the recent advancements described in the preceding section, the way forward in terms of addressing the needs of people with or at risk of T2D remains unclear, lacking systematic examination and theoretical underpinning. The overall aim of the research project is to identify the research, policy, and practice procedures which lead to the enhancement of the quality and duration of life in people with or at risk of T2D. This involved an evaluation of: i) the extant literature on T2D self-management in people with ID and the mainstream population; ii) the theoretical basis of intervention and prevention programmes; and iii) the appropriateness of existing mainstream programmes for use with people with ID.

These aims led to the design and implementation of three phases, which included i) two systematic reviews; ii) a qualitative exploration of people with ID's Self-efficacy experiences in self-managing T2D; and iii) a process evaluation of the implementation of Walking Away for people with ID in two further education colleges. These phases therefore addressed the following specific aims:

1.2.1 Study phases

Phase 1

1. To synthesise and evaluate the findings of studies which describe the T2D self-management experiences of people with ID
2. To describe the characteristics and appraise the quality of mainstream T2D intervention and prevention programmes in relation to the needs of people with ID

Phase 2

3. To explore the meaning and importance of theoretical basis in intervention and prevention programs for people with ID self-managing T2D

Phase 3

4. To evaluate the process of implementing an educational T2D programme for people with ID in a higher education setting

1.3. Structure of the thesis

This thesis consists of nine chapters. So far, the present chapter has introduced the thesis through providing a summary of the background on people with ID who have diabetes, the rationale for the study and an overview of the methodology. Following this, Chapter Two provides a detailed account of the issues around self-managing T2D for people with ID, first looking at prevalence rates identified in systematic reviews, then reporting a systematic review conducted by the author on the experiences and perceptions of people with ID and their caregivers on diabetes self-management.

Chapter Three provides a systematic review of mainstream T2D programmes used in the general population. The review evaluates the quality of study designs as well as the application of theoretical models. These are then discussed in terms of the needs of people with ID, identifying essential components for interventions aimed at this population. Chapter Four provides an account of the methodology for the second phase of the study, a qualitative exploration of a selected theoretical model used in intervention and prevention programs in terms of its relevance and meaning to people with ID, as indicated by their T2D self-management experiences. The chapter provides an overview of epistemological positions in research, highlighting the appropriateness of a qualitative approach for this phase. Following this, Chapter Five describes the results and discussion of the exploratory study. Chapter Six describes the methodology for the third phase of the study, the process evaluation of a T2D prevention program in a further education setting, as identified through the preceding phases. An overview of research methodologies is presented, which describes the appropriateness of a process evaluation. In Chapter Seven, the results of the process evaluation are described, which include the success of recruitment, participant demographics, ambulatory activity, and baseline questionnaire responses. Chapters Eight and Nine describe the acceptability of the programme through the results of four focus groups. Chapter Ten presents a discussion of the findings in relation to the background literature. Following this, Chapter Eleven concludes the thesis with the implications of these findings for further research, practice and policy.

Chapter Two – Background Literature on People with Intellectual Disabilities Self-managing Type 2 Diabetes

2.1. Introduction

This chapter presents an overview of the existing literature on people with ID who have diabetes. Firstly, recent systematic literature reviews are consulted which provide an account of the prevalence of diabetes in people with ID. Following this, a meta-aggregation is carried out which extracts and synthesizes the reported diabetes self-management experiences of people with ID and their caregivers. A rigorous approach is taken to evaluate the quality of the literature using the Elliot et al. (1999) guidelines for publication of qualitative research. This review has been published in the Journal of Intellectual Disabilities (Maine, Brown, Dickson, and Truesdale, 2018), a copy of which has been included in the appendices (Appendix 24, Volume II, p113)

An additional focus of the Macrae et al. (2015) review, and an earlier review by McVilly et al. (2014) was on T2D self-management in people with ID. In the mainstream population, self-management is considered as the most important and cost-effective approach towards T2D care (Davies et al., 2008). However, as these two reviews highlight, there are several issues for people with ID self-managing T2D regarding making lifestyle changes after diagnosis. A limited number of studies presented findings on the experiences of diabetes self-management in people with ID. Subsequent to these two reviews, several recent studies have offered further insight into the self-management experiences of people with ID and their caregivers, such as facilitated self-management and the discussion of findings in relation to theoretical models (for example Rouse and Finlay, 2016; Whitehead et al., 2016).

The findings from these, as well as from less recent studies, are important as the views and experiences of people with ID and their caregivers have the potential to inform and guide the development of intervention programmes aimed at assisting this population. Such interventions are urgently required, given the estimated global prevalence of T2D, inequalities, and the poorer management of long term health conditions in many people with ID (Cooper et al., 2018).

It is evident that there was a further need to provide a cohesive overview on how people with ID are managing their diabetes, in terms of adapting their lifestyles and adhering to diabetes management plans, and the level of support that is required to ensure effective compliance. A systematic review was carried out by the author to identify and appraise the scope and extent of the qualitative research studies which focus specifically on the diabetes self-management experiences and perceptions of people with ID and their caregivers, presenting the findings as themes using a meta-aggregative approach.

2.1.1. Prevalence

The most recent review of diabetes prevalence rates in people with ID was carried out by Macrae et al. (2015). A total of 22 studies reporting prevalence rates were identified and were conducted in the U.S. and Canada (*N* = 11), Europe-wide (*N* = 1) The Netherlands (*N* = 4), U.K. (*N* = 3), Sweden (*N* = 1), Hong Kong (*N* = 1), and China (*N* = 1). The average prevalence rate of diabetes in people with ID was reported as 8.3%

(Macrae et al., 2015). This is compared to a global prevalence rate of 8.5% in the general population (WHO, 2017). However, prevalence rates varied widely across the studies, ranging from 0.4% to 25%, reflecting several reporting issues in the studies. These included not reporting differences in type of diabetes and reliance on self-reports from people with ID, their family members or caregivers. In addition, a cross-sectional study by Axmon, Ahlström, and Höglund (2017) reported that people with ID are 20% more likely than the general population to have a diagnosis of diabetes. Therefore, evidence suggests that prevalence rates may be higher for people with ID than in the general population.

In an earlier review carried out by McVilly et al. (2014), the diabetes prevalence rate was reported as 8.7% in people with ID, ranging from 3.4 to 18.5% across 13 studies. However, similar issues were reported, such as a lack of distinguishing between types of diabetes and reliance on self-reports of diagnosis, rather than medical records. The concurrence of these two reviews suggests that prevalence rates are unclear due to methodological problems in studies, and that rates may be far higher than reported. The lack of demographic information, such as living arrangements, is important as this may elucidate for example whether people with ID who live in isolated situations are less likely to receive diabetes screening, and hence not receive a diagnosis. These findings report firstly that there is a lack of consistency over reporting details in studies about people with ID and diabetes. Secondly, the prevalence rates, although unclear, are likely to be higher than in the general population due to under-reporting and limited access to participants. Guidelines for conducting research, such as the CASP tools (CASP, 2017), provide guidelines and checklists to ensure consistency in data collection, which should be adhered to.

It therefore follows that there is a pressing need to understand how people with ID are managing their diabetes, in terms of adapting their lifestyles and following medical regimes, and the level of support that is required to carry this out. This leads to the next section, in which a review is carried out on the self-management experiences and perceptions of people with ID and their caregivers.

2.1.2. Literature review aims

1. To provide an overview of the common themes in qualitative studies in relation to the self-management of T2D in adults with ID.
2. To provide an appraisal of the theoretical application of the findings and describe the overall rigour of the literature.

2.2. Methodology

2.2.1. Search strategy

Elements of the Joanna Briggs Institute (JBI) approach of meta-aggregation were used to inform the methods of this review, following the guidelines provided by Lockwood, Munn, and Porritt (2015). This approach is phenomenological and pragmatic, enabling an in-depth synthesis of complex phenomena in a small body of literature, which retains the authors' original interpretation of the findings in the synthesis. The following inclusion criteria were applied: studies with a specific focus on people with ID self-managing type 2 diabetes; published in peer-reviewed journals; written and published in English.

Due to the paucity of the literature, searches were designed to be as broadly inclusive as possible. No restrictions were applied to the dates of studies or to further demographic restrictions such as age, gender and level of disability. The following exclusion criteria were implemented: studies which focused on specific learning difficulties, such as dyslexia and dyspraxia; studies which did not focus on self-management of type 2 diabetes; studies not published in peer reviews; studies not published in English.

2.2.2. Search terms and data sources

A review of the published literature focusing on self-management of T2D was carried out systematically using the key-words, “Intellectual Disabilities” OR “Learning Disabilities” OR “Mental Retardation” AND Type 2 Diabetes OR Diabetes Mellitus AND Self-management OR Self-care in the following databases: PUBMED; CINAHL; MEDLINE; PsychINFO; Psychology and Behavioral Sciences Collection. Further hand searches were carried out of study references.

2.2.3. Literature appraisal strategy and tools

Literature appraisal tools provide guidelines for evaluating the quality of studies (Thomas, Dobbins, and Micucci, 2004). The studies in this review are evaluated using the qualitative methodological guidelines by Elliot, Fischer, and Rennie (1999). These guidelines serve as a system for ensuring robust evaluation of qualitative studies by providing a set of evolving criteria. The CASP qualitative appraisal tool (2017) and Cochrane handbook (Higgins and Greene, 2011) were also considered as evaluative tools, however the Eliot et al. (1999) tools were selected based on flexibility across a range of qualitative approaches. The seven guidelines are as follows:

1. Owning one's perspective. The author explicitly states their own values, interests and assumptions to enable the reader to interpret the author's understanding of the data
2. Situating the sample: The author provides a detailed background description of the participants, so that reader can judge the meaning and importance of context
3. Grounding in examples: Examples of the data are provided, such as transcript excerpts. This enables the reader to judge the author's analysis of the data, and to potentially draw alternative conclusions
4. Providing credibility checks: The author verifies coding and analysis through checking them with the participants, a second analysist, comparing perspectives, or triangulating with external data
5. Coherence: The data is integrated into a coherent narrative, which describes clearly the sequential picture of the phenomena under investigation
6. Accomplishing general vs. specific research tasks: The authors state the limitations of the data in terms of generalizability when using limited samples or single case studies
7. Resonating with the readers: The manuscript is presented in a way that enables the reader to judge it as an accurate description of the phenomena when all guidelines are considered.

2.2.4. Data extraction

Elements of the JBI meta-aggregation approach were adopted for data extraction, where findings are appraised in terms of relevance. This involved a multi-phase process in which general data was first extracted, including study origins, participant demographics and methods (Lockwood et al., 2015). This process was verified by a second reviewer. Three of the studies were drawn from the same sample of people with ID (Hale et al., 2011; Trip et al., 2016; Whitehead et al., 2016). Trip et al. (2016) and Whitehead et al., (2016) supplemented this sample with support staff, which was also a shared sample. Therefore, to prevent overlap of reporting of demographic details, shared characteristics of these samples were not synthesised. However, as all three of these studies had a different focus and analysis yielding different results, each one was used in the later stages of synthesis described below.

2.2.5. Data synthesis

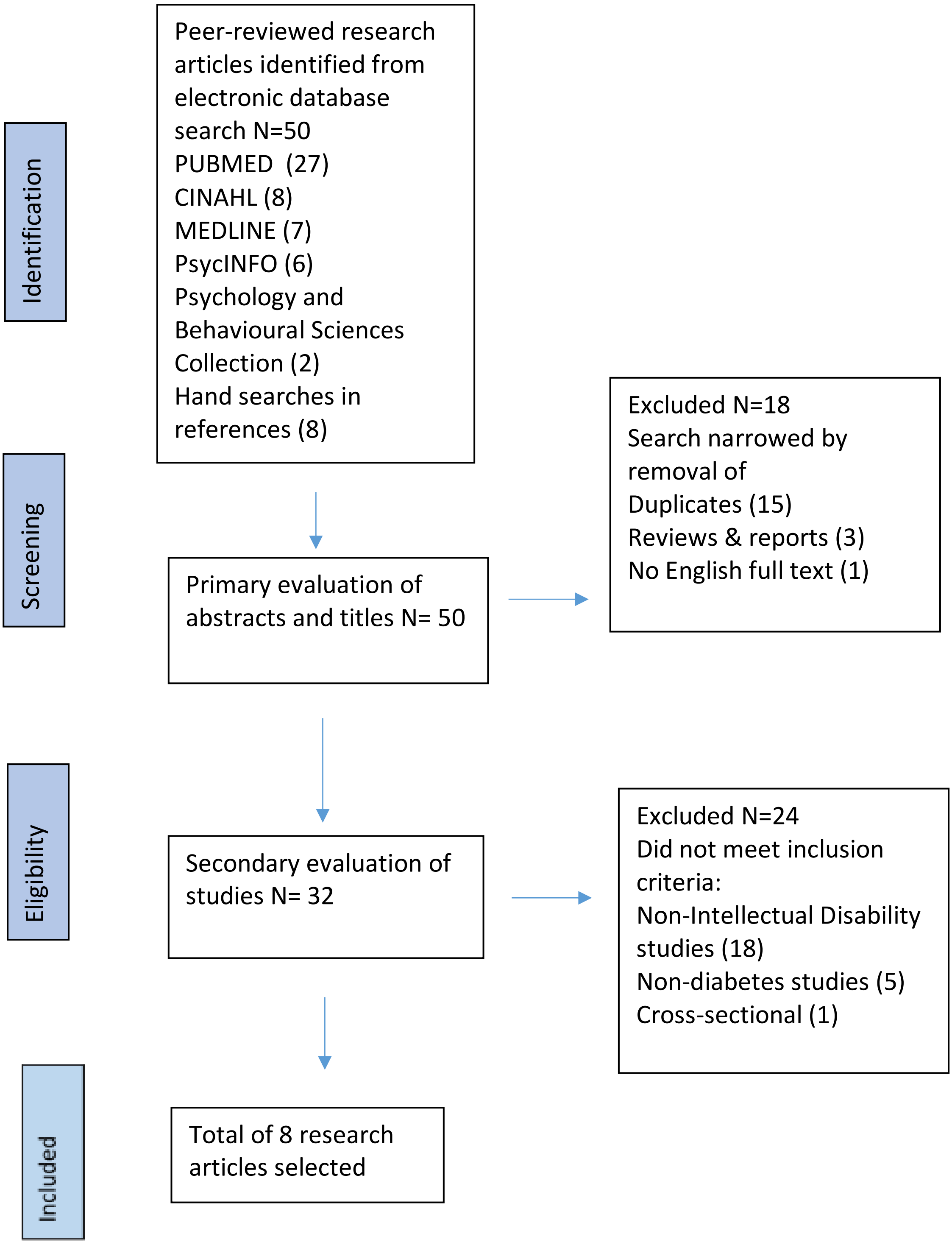
Following extraction, synthesis of the main findings of the studies was carried out. This involved extracting every finding from each study and accompanying this with an “illustration”, which included either a participant quotation in the form of a transcript excerpt, or an observation of the researcher supported by the number of participants. Ratings were then made based on the congruence of the finding and the “illustration” as i) “Unequivocal”; ii) “Equivocal”; iii) “Unsupported” (Lockwood et al., 2015). This stage of analysis was verified by the second reviewer, and differences between ratings were resolved through discussion. The final stage of the synthesis involved organising the

“Unequivocal” and “Equivocal” rated findings into categories. “Unsupported” findings were not included in the synthesis. Categories were then synthesised into themes. These themes were discussed and agreed with the second reviewer.

2.3. Results

A total of eight papers were identified and are presented in a PRISMA diagram (see *Figure 2.1: Flow chart of study selections* on the following page). Two of these were conducted in The Netherlands: Cardol, Rijken, and van Schrojenstein et al. (2012a); Cardol, Rijken, and van Schrojenstein Lantman-de Valk, (2012b); two in the UK: Dysch, Chung, and Fox (2012); Rouse and Finlay, (2016); three in New Zealand: Hale, Trip, and Whitehead (2011); Trip, Conder and Hale (2016); Whitehead, Trip, and Hale (2016); one in Australia: Rey-Conde, Lennox, and McPhee (2005).

Figure 2.1: Flow chart of study selections



2.3.1. Sample sizes and participant characteristics

Study characteristics are presented in *Table 2.1*, on the following page. Sample sizes ranged from N = 4 (Dysch et al., 2012) to N = 67 (Rey-Conde et al., 2005), mean 20.4. The range of sample sizes reflected the different aims and methodologies, with smaller samples in exploratory studies which recruited people with ID only (such as Dysch et al., 2012 and Hale et al., 2011), and larger studies which recruited people with ID and their supporters to evaluate theoretical constructs (Trip et al., 2016). Although the sample size of N = 4 in Dysch et al. (2012) was small compared to the other study sample sizes, IPA studies typically range from N = 1 to N = 15 (Pietkiewicz and Smith, 2016), therefore this was not necessarily an indicator of poor quality. However, recruitment of people with ID can present challenges, such as the ethical requirement to use third parties when approaching vulnerable adults, as highlighted by Hale et al., (2011). This issue led to the common approach across the studies of using a convenience sample, which may have resulted in a more homogenous selection than if a purposive sampling approach had been possible.

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Table 2.1: Summary of study characteristics

Study	Aims/design/method	Participant characteristics
Rey-Conde et al. (2005) Australia	Exploring perceptions from people with ID and caregivers. Qualitative study using focus groups	***N* = 67:** People with ID (*N* = 9); Family members (*N* = 8); Paid caregivers (*N* = 31); Service coordinators (*N* = 12); Health professionals (*N* = 6); Sector worker (*N* = 1); **Living status:** Living at home (*N* = 3); Supported accommodation (*N* = 6); **Further demographics not provided**
Hale et al. (2011) NZ	Exploring knowledge and understanding of people with ID self-managing T2D. Interviews analyzed using the General Inductive approach	***N* = 14** adults with ID Age: Mean: 51 years **Ethnicity:** Maori (*N* = 3); New Zealand European (*N* = 11) **Gender:** Female 43% **Level of disability:** Mild (*N* = 11); Moderate (*N* = 3) **Living status:** Residential care (*N* = 11); Supported independent living (*N* = 2); Independent living (*N* = 1)

		Diabetes type: Type 1 (*N* = 6); Type 2 (*N* = 8) **Management approach:** Not specified **Time since diagnosis:** 2-5 years (*N* = 3); 6-10 years (*N* = 4); 10+ years (*N* = 7)
Dysch et al. (2012) UK	Exploring experiences and perceptions of people with ID and diabetes. Qualitative study using IPA	**N = 4** Adults with ID **Age:** Mean 35 years **Ethnicity:** Not specified **Gender:** Female 75% **Level of disability:** Mild **Living Status:** Residential care (*N* = 2) With family (*N* = 1) Independent (*N* = 1) **Diabetes type:** Type 1 (*N* = 2); Type 2 (*N* = 2) **Management approach:** Not specified **Time since diagnosis:**

		Mean 17 years
Cardol et al. (2012a) Netherlands	Exploring T2D self-management experiences of PWID. Qualitative study using Leventhal's (1980) Illness Perception Framework and Thematic Analysis	**N = 17** adults with ID **Age:** mean 52 years **Ethnicity:** Not specified **Gender:** Female 53% **Level of disability:** Mild (*N* = 7); Moderate (*N* = 7); Unknown (*N* = 3) **Living status:** Independent living with and without support (numbers not given) **Diabetes type:** Not specified **Management approach:** Diet alone (*N* = 3) Medication (*N* = 6) Insulin (*N* = 8) **Time since diagnosis:** Under 5 years (*N* = 5); 5+ years (*N* = 12)
Cardol et al. (2012b) Netherlands	Exploring views of caregivers of people with ID who have T2D.	**N = 13** caregivers **Age:** Mean 52 years **Ethnicity:** Not specified

		Gender: 72% female
Trip et al. (2016) NZ	Exploring the role of key workers in supporting people with ID self-managing T2D. Qualitative study using Thomas' General Inductive Approach	***N* = 17** Support staff **Age:** 18-30 (*N* = 3); 41-50 (*N* = 1); 51-60 (*N* = 4); 60+ (*N* = 9) **Ethnicity:** New Zealand European (*N* = 14); Maori (*N* = 1); Australian (*N* = 1); African (*N* = 1) **Gender:** Female 88%
Whitehead et al. (2016) NZ	Exploring the experiences of people with ID and their caregivers self-managing T2D with a focus on the practice of autonomy	**N = 31** **PWID (*N*=14)** **Age:** Mean 51 years **Gender:** Female 43% **Ethnicity:** Not specified **Level of disability:** Mild (*N* = 11); Moderate (*N* = 3) **Living status:** Independent living (*N* = 1) Supported living (*N* = 2)

		Residential care (*N* = 11) **Diabetes type:** Type 1 (*N* = 6) Type 2 (*N* = 8) **Management approach:** Diet alone (*N* = 1) Medication (*N* = 8) Insulin (N = 5) **Time since diagnosis:** Not specified: **Caregivers (*N* = 17)** **Age:** 18-30 (*N* = 3); 41-50 (*N* = 1); 51-60 (*N* = 4); 60+ (*N* = 9) **Gender:** Female 88% **Ethnicity:** Not specified
Rouse and Finlay (2016) UK	Discourse analysis of the concept of responsibility in people with ID and their caregivers self-managing T2D	**N = 14** **People with ID (N=7)** **Age:** 20-54

		Gender: Female 71% **Ethnicity:** Not specified **Level of disability:** Mild-Moderate (N=7) **Living status:** Not specified **Diabetes type:** Type 1 (N =2) Type 2 (N = 5) **Management approach**: Not specified **Time since diagnosis:** “At least 6 months prior to interview” **Caregivers (N = 7)** **Age:** 44-51 **Gender:** Female 71% **Ethnicity** Not specified

A total of three studies recruited people with ID only (Cardol et al., 2012a; Dysch et al., 2012; Hale et al., 2011). There were two studies which recruited caregivers only (Cardol et al., 2012b; Trip et al., 2016). These focused on the experiences of support staff and keyworkers in supporting people with ID to self-manage T2D. Three studies recruited people with ID and support staff (Rey-Conde et al., 2005; Rouse and Finlay, 2016; Whitehead et al., 2016). Rey-Conde et al., and Whitehead et al., explored the experiences and perceptions of T2D self-management. This latter study used the data from Hale et al., (2011) and Trip et al., 2016). Rouse and Finlay (2016) explored the concept of responsibility for people with ID and their caregivers.

A total of three studies reported the level of ID (Hale et al., 2011; Dysch et al., 2012; Cardol et al., 2012a). The levels described were “Mild” (mean 7.33, SD 3.5), “Moderate” (mean 5, SD 2.82), and “Unknown” (*N* = 7: Cardol et al., 2012 only). Rouse and Finlay (2016) reported “mild or moderate” without specifying which of these levels applied to their seven participants yet detailing that two of these participants had autism and none had specific conditions such as Down’s Syndrome. The lack of inclusion of moderate and profound participants may reflect communication difficulties in this population which can lead to difficulties in giving consent and being able to give detailed responses. ID levels are based upon cognitive assessment of IQ, (NES, 2013) however it is unclear in these studies whether these groupings were based on formal cognitive assessment. This may detract from the validity of findings; however it is unlikely that participants who present with more severe learning disabilities are misdiagnosed as having mild disabilities rather than moderate. Future research should therefore, consider greater inclusion strategies through communication tools such as Talking Mats, a symbol-based communication assistance tool (Talking Mats, 2018).

The living status of people with ID was reported in three studies (Hale et al., 2011; Dysch et al., 2012; Cardol et al., 2012a). The reported living statuses were “residential care” (mean 5, SD 5.2), “supported independent” living (mean 3.3, SD 3.2), and “independent living” (mean 1, SD 0). The high number of participants in residential care, together with the high number of mild ID reported, suggests that across the studies most participants were receiving a high level of support, despite having low support needs. The data from these studies therefore may not be representative of the majority of people with ID self-managing diabetes, as the challenges for people with higher support needs who live in more isolated situations was not explored.

A total of three studies reported the number of participants with T1D or T2D (Hale et al., 2011; Dysch et al., 2012; Rouse and Finlay, 2016). There were slightly fewer participants with T1D (mean 3.3, SD 2.3) than with T2D (mean 5, SD 3.6). Although self-management was described in all of the studies, there were only two which specifically reported the self-management approaches of individual participants within the methods section (Cardol et al., 2012a, Whitehead et al., 2016). These included “diet alone” (mean 2, SD 1.4), “medication” (mean 7, SD 1.4), and “insulin” (mean 6.5, SD 2.1). Wider reporting of this information could have led to a greater understanding of the prevalence and efficacy of these approaches in people with ID.

The time since diagnosis was reported in three studies (Hale et al., 2011; Dysch et al., 2012; Cardol et al., 2012a). As there were differences in how these durations were presented, it is not possible to provide descriptive comparisons.

However, in each study there was a substantially greater number of participants with a long-term diagnosis than of those who had been diagnosed recently. This included over 5 years since diagnosis, (Cardol et al., 2012a) over 10 years since diagnosis (Hale et al., 2011), and mean 17 years (Dysch et al., 2012). This trend reflects the inclusion of T1D participants, for whom diagnosis would be more likely to be detected at an early age, as well as suggesting more progressed stages of T2D, where self-management would be typically dependent on medication or insulin. The small number of participants who were managing their diabetes through diet alone may reflect that there is a higher prevalence of T1D and advanced stage T2D, where medication and insulin control is a necessity. However, this may also reflect the struggle of the participants to adapt their lifestyle to diabetes; this is reflected in the themes described below.

2.3.2. Summary of participant characteristics

Given the small number of studies highlighted in this review, it is not appropriate to generalize findings. However, there are trends which suggest the following:

- Recruitment of people with ID who have diabetes can be challenging, as indicated by small sample sizes and higher prevalence of people with mild ID in residential care
- There is a lack of evidence on the diabetes self-management experiences of younger (<30) and older (>60) age groups in people with ID, as well as on those who have been recently diagnosed

- Few people with ID self-manage diabetes through lifestyle adaptations alone, and require the use of medication or insulin, though the inclusion of T1D participants makes this unclear
- The data is suggestive of a higher number of older caregivers, which may suggest gaps in training and qualifications, although this cannot be concluded as few of the studies reported duration of caregiver experience or education level

2.4. Themes highlighted through synthesis

Following the review and analysis of the eight studies, the following four themes were identified: i) “Frustration over lifestyle adjustments”; ii) "Limited understanding and inadequate educational resources"; iii) “Limited training and knowledge in staff”; iv) "Potential for effective diabetes self-management with appropriate support". The extracted findings, categories, and synthesis are presented in *Table 2.2* on the following page.

Table 2.2: Synthesis of findings

Author	Finding	Category	Synthesised finding
Rey-Conde et al., 2005	People with ID's perception of diabetes self-management (diabetes self-management) expressed as negative feelings (U)	Negative feelings regarding having diabetes	Frustration over lifestyle adjustments
Hale et al., 2011	Frustrations from some participants over lifestyle restrictions (E)	Frustration over diabetes related lifestyle changes	
Dysch et al., 2012	Frustration with lifestyle adjustments (E)		
Dysch et al., 2012	Struggling with adherence to diabetes self-management (E)		
Dysch et al., 2012	Participants struggle with the need for support (E)		
Cardol et al., 2012a	Feelings with loss regarding food and choice (E)	Feelings of loss following diabetes related lifestyle changes	
Cardol et al., 2012a	Feelings of loss of food choice through social comparison (E)		
Dysch et al., 2012	Social stigma of diabetes and diabetes self-management (E)	Impact of social setting	
Cardol et al., 2012a	Financial restrictions can impede diabetes self-management (E)		

Dysch et al., 2012	Social comparisons aid understanding of diabetes (E)		
	Finding	**Category**	**Synthesised finding**
Rey-Conde et al., 2005	Acknowledgement of dependence on families and support staff (U)	Limited competencies and dependence on caregivers	Limited understanding and inadequate educational resources
Rouse and Finlay, 2016	People with intellectual disabilities as lacking specific competence in relation to diabetes self-management tasks including organising, remembering and meal preparation (U)		
Hale et al., 2011	Diet awareness limited to avoiding sugar and difficult to monitor outside of residential care (U)		
Cardol et al., 2012b	Compassion but concern over competence in diabetes self-management (U)		
Dysch et al., 2012	Support from others required for diabetes self-management (E)		
Hale et al., 2011	Three levels of knowledge and understanding of diabetes in people with ID: good, limited and basic (U)	Understanding is limited leading to limited diabetes self-management skills	
Dysch et al., 2012	Confusion over diabetes (E);		
Rey-conde et al., 2005	Exercise is limited. Walking and bowling are most common (E)		
Cardol et al., 2012a	Medication control: mixed understanding and anxiety (E)		

Cardol et al., 2012a	Not feeling ill: diabetes only perceived as serious when insulin injections are required (E)		
Cardol et al., 2012a	Fear and uncertainty over diabetes consequences (E)		
Cardol et al., 2012a	Participant’s had practical but limited knowledge of dietary restrictions (E)		
Cardol et al., 2012a	Relationship between understanding of diabetes and diabetes self-management (E)		
Cardol et al., 2012a	Opportunities to build self-confidence were limited (E);	Appropriate resources are required	
Rey-Conde et al., 2005	More information on diet is needed (U)		
Hale et al., 2011	Information provision was limited or not in accessible formats (U)		
	Finding	**Category**	**Synthesised finding**
Rey-Conde et al., 2005	Staff training was a barrier to diabetes self-management (U)	Staff training was limited and this was a barrier to diabetes self-management	Limited training and knowledge in staff
Rey-Conde et al., 2005	Staff skills were mainly in observations and taking blood sugar levels (E)		
Cardol et al., 2012b	Caregivers did not perceive the seriousness of diabetes (U)		
Cardol et al., 2012b	Diabetes was not a prominent feature in care unless insulin injections required (E)		
Cardol et al., 2012b	Levels of training were varied: nurses were better qualified and caregivers sought help from doctors (E)	Staff training was varied and inconsistent	

Trip et al., 2016	Key-worker knowledge and understanding: diabetes management varied and limited (U)		
Cardol et al., 2012b	Differences between caregivers in level of support for autonomy (E)		
Trip et al., 2016	Key-worker knowledge and understanding: knowledge of impact of comorbidities was varied and limited (U)		
Trip et al., 2016	Frustration over lack of consistency in care (U)		
Trip et al., 2016	Lifestyle police: caregivers felt personally responsible for the health status of people with ID and focussed on controlling dietary intake (U)	Caregiver attitudes may reflect further training needs	
Rey-Conde et al., 2005	Fear and insecurity in staff over supporting diabetes self-management (E)		
Cardol et al., 2012b	Lack of motivation for DSM regarded as dispositional in people with ID (E)		
Rouse and Finlay 2016	Health care professionals are positioned as being competent in a broad sense, holding a higher level of diabetes knowledge (E)		
Rey-Conde et al., 2005	Lack of motivation and preferences are seen as barriers for people with ID (E)		

Trip et al., 2016	Dilemmas between enabling autonomy and safeguarding health-care (U)	Caregiver dilemmas	
Whitehead et al., 2016	Caregivers were aware of risks versus autonomy (E)		
Rouse and Finlay, 2016	Dilemmatic repertoires were presented regarding people with ID's independence (U)		
Rouse and Finlay 2016	Repertoires of risk management and control presented dilemmas against independence (E)		
Rouse and Finlay 2016	Responsibility and accountability are constructed as shared and problematic (E)		
Cardol et al., 2012a	Dilemmas between enabling autonomy and safeguarding health-care (E)		
	Finding	**Category**	**Synthesised finding**
Rey-Conde et al., 2005	People with ID spoke about practical diabetes self-management experiences and abilities (E)	Positive perceptions and statements of diabetes self-management abilities and awareness from people with ID	Potential for effective DSM with appropriate support
Rey-Conde et al., 2005	People with ID proud of skills, though these were limited (E)		
Rouse and Finlay, 2016	People with intellectual disabilities described themselves as competent in relation to diabetes self-management (U)		

Rouse and Finlay, 2016	Repertoires of confidence in relation to recognising symptoms (U)		
Rouse and Finlay, 2016	Constructing a positive identity: participants with ID described the needs for support but defended themselves against being seen as incompetent (E)		
Rouse and Finlay, 2016	People with ID construct themselves as ‘lazy’ to defend against being seen as disabled (E)		
Rouse and Finlay, 2016	Lack of competence was often described as due to external factors by people with ID, such as the attitudes of doctors (E)		
Rey-Conde et al., 2005	Positive comments about exercise from caregivers (U)		
Cardol et al., 2012a	Diabetes self-management is related to self-confidence (E)		
Rey-Conde et al., 2005	Concern and conflict in diet but some positive choices (E)		
Dysch et al., 2012	Participants showed understanding through language related to diabetes (E)		

Dysch et al., 2012	Participants described the fluctuating state of having diabetes (E)		
Dysch et al., 2012	Participants described the physical effects of diabetes (U)		
Dysch et al., 2012	Participants reported multiple health difficulties (U)		
Whitehead et al., 2016	Daily negotiated autonomy in relation to medication: Participants were almost fully independent with occasional support (E)	Examples of effective diabetes self-management with flexible and creative support from caregivers	
Hale et al., 2011	Blood Sugar Levels were not fully understood by people with ID but symptoms of blood sugar changes were recognised (U)		
Whitehead et al., 2016	Daily negotiated autonomy in relation to insulin injections: Participants were almost fully independent with occasional support (E)		
Cardol et al., 2012a	Diabetes self-management relaxed during special occasions (E)		
Whitehead et al., 2016	Daily negotiated autonomy in relation to insulin injections: Participants were almost fully		

	independent with occasional support (E)		
Whitehead et al., 2016	Renegotiation of autonomy in relation to goals: heathier diet (E)		
Whitehead et al., 2016	Renegotiation of autonomy in relation to goals: living arrangements (E)		
Whitehead et al., 2016	People with ID were supported to be autonomous during medication adjustments but control was sometimes increased during these times, then readjusted accordingly (E)		
Hale, 2011	Participants were good at remembering to monitor blood sugar levels but needed support (E)		
Haleet al., 2011	Participants were good at remembering to monitor blood sugar levels but needed support (E)		
Rey-Conde et al., 2005	Families and support staff felt that cognitive limitations were the biggest barrier but tailored education could help (E)		
Rey-Conde et al., 2005	Prompts, diet management and planning works well (E)		

Whitehead et al., 2016	Nurturing self-management skills: creating opportunities to check understanding and providing education on shopping, cooking and menu planning was limited by time (U)		
Whitehead et al., 2016	Dietary choices described as negotiated, ongoing and supported (E)		

2.4.1. Frustration over lifestyle adjustments

People with ID expressed negative feelings with regard to living with and self-managing diabetes, such as fear, insecurity, and being overwhelmed (Rey-Conde et al., 2005).

These were accompanied by a sense of frustration over changes to lifestyles, in particular dietary restrictions (Hale et al., 2011) medication regime adherence, and carer dependency (Dysch et al., 2012).

Participants also made statements which Cardol et al. (2012a) described as a sense of loss in relation to food choices. These feelings were occasionally accentuated by shared living situations in which social comparisons to others without diabetes were made, an issue also present in "Potential for effective DSM with appropriate support".

It is important that supporters of people with ID are aware of such feelings, as these may impact on mental wellbeing and long-term adherence to DSM behaviours. The social setting of the participants, rather than diabetes itself, appeared to contribute to frustration at times, and act as a barrier to DSM. Cardol et al (2012a) provided an example of a participant with ID who no longer engaged in physical activity due to lack of transport provision. A participant in Dysch et al. (2012) described experiencing social stigma around injecting insulin at work, which they were concerned would be seen as drug-use. This may have impacted on their sense of restricted lifestyle. However, it was reported by Dysch et al. (2012) that social comparisons could also facilitate understanding of diabetes self-management. People with ID’s understanding of diabetes is discussed in the following theme.

2.4.2. Limited understanding and inadequate educational resources

This theme synthesises categories in which the authors described limitations of diabetes self-management in people with ID, as described by their statements and the perceptions of caregivers. Dependence upon caregivers for diabetes self-management was either described directly by people with ID (Rey-Conde et al., 2005, Dysch et al., 2012 and Hale et al., 2011) or inferred by the authors' in their interpretation of people with ID's statements (Dysch et al., 2012). In addition, caregivers made statements which described limited self-management competence in the people they supported (Cardol et al., 2012b, Hale et al, 2011, and Rouse and Finlay, 2016). As is highlighted further below in "Attitudes, management of dilemmas and impact of social setting", these statements may be indicative of care attitudes as well as diabetes self-management competencies.

The studies indicated that overall people with ID had a limited understanding of diabetes, which sometimes impacted on self-management skills. Cardol et al., (2012a) reported that the consequences of having diabetes were only perceived as serious when injections of insulin were required, although it is important to acknowledge that this study included participants with T1D. Insulin injections are a necessity regardless of progression in T1D, whereas it is possible to control T2D with diet, exercise and medication. Therefore, there was a lack of clarity through not clarifying this distinction in relation to the participants' statements. However, Cardol et al.'s (2012a) conclusion that there was a relationship between understanding and diabetes self-management is a key-finding reflected throughout the themes, highlighting the need for diabetes education for people with ID.

Other findings indicated that where educational resources were available, they were not appropriate for people with ID due to being in formats that were not accessible (Hale et al., 2011). Rey-Conde et al. (2005) also reported that information on diet was insufficient leading to confusion. It is therefore important that educational resources are appropriately tailored for people with ID.

2.4.3. Limited training and knowledge in staff

Following on from the lack of knowledge of people with ID highlighted above, a lack of training and knowledge in staff was also described across the studies. Rey-Conde et al. (2005) reported that staff and families found limited staff training to be a barrier to effective self-management support. Rey-Conde et al. (2005) attributed some of these difficulties to high levels of staff turnover, exacerbated by limited training and experience. However, information was not provided about the level of training and qualifications of staff, or their duration of employment, making it difficult to conclude this finding.

Cardol et al. (2012b) reported that there were varying levels of knowledge according to whether participants were nurses, who had more specialist diabetes training, or care workers. Participants who were social workers reported that diabetes training often needed to be of their own volition, and that management occasionally impeded training. Care workers often did not perceive the seriousness of diabetes and, similarly to the views of the people they supported, diabetes care was not a prominent part of care unless administering insulin was required (Cardol et al., 2012b).

A limited awareness of available resources also appeared to reflect poor staff training; Hale et al. (2011) reported that some carers were unaware of diabetes management plans for an individual they supported. Cardol et al. (2012b) and Trip et al., (2016) reported an overall inconsistency in staff knowledge and training, and to some this was frustrating as they could not rely upon the competence of their colleagues (Trip et al., 2016). This inconsistency extended to training in supporting others to be autonomous in diabetes self-management (Cardol et al., 2012b).

Caregivers' descriptions of their role may be reflective of the barriers and challenges they face in supporting diabetes self-management in people with ID, however this may also describe attitudes which highlight a need for further training. Trip et al. (2016) reported caregivers who described themselves as "lifestyle police", who took a prohibitive approach to reduce the risk of unhealthy diets. Concern about this risk was also described by caregivers in Rey-Conde et al. (2005). People with ID were described as "lazy" and "passive" by caregivers in Cardol et al. (2012b), possibly reflecting a dispositional attribution. Whilst these caregivers may have been in an expert position to evaluate the characteristics of the people they supported, there were approaches reflected in the final theme, which describe viable and empowering alternatives to the prohibitive approach. It is notable however, that Rouse and Finlay (2016) reported people with ID describing themselves as "lazy". This was interpreted as a defensive repertoire against incompetence and dependency. In this case, caregiver training may also be required to support and enhance positive self-perceptions in people with ID.

Caregiver dilemmas also reflected a potential need for further training in caregivers. These dilemmas were between enabling autonomy and reducing risk, and were described in four studies (Cardol et al., 2012b; Rouse and Finlay, 2016;

Trip et al., 2016; Whitehead et al., 2016). As with the attitudes described above, a difference in caregiver approach was highlighted in how these dilemmas were resolved, and an absence of flexible, creative solutions may reflect a need for further training.

2.4.5. Potential for effective diabetes self-management with appropriate support

Although feelings of frustration were described by people with ID in the first theme, there were also descriptions of positive feelings which highlighted the potential for successful diabetes self-management. Cardol et al. (2012a) interpreted their findings to suggest that Self-efficacy in people with ID was linked to diabetes self-management. Self-efficacy is the confidence one has to achieve tasks and overcome barriers (Bandura, 1977). This confidence in diabetes self-management was also reported in Rey-Conde et al. (2005) and Rouse and Finlay (2016).

Dysch et al., (2012) interpreted that participants showed an understanding of diabetes though the language they used and through their awareness of physical symptoms, comorbidities and fluctuating states. This suggests a more sophisticated level of understanding than as was suggested above in “Limited understanding and inadequate educational resources”. In addition, Hale et al. (2011) described participants who were not only aware of the benefits of exercise to diabetes self-management, but also suggested a buddy-system as a potential exercise facilitator. People with ID may therefore potentially have the insight for understanding and subsequently self-managing diabetes, which could be enhanced through education.

Some studies highlighted the recognition of caregivers that whilst there were often limits to people with ID's competence in diabetes self-management, there were also areas of strength. Caregivers in Rey-Conde et al. (2005) reported that despite there being a need for concern, positive exercise and dietary and choices were made by people with ID. Similarly, Hale et al. (2011) reported caregivers who, despite the need for support, described the awareness of blood sugar change symptoms in the people they supported, and their awareness of recording times. Structured education was suggested as a solution to diabetes self-management barriers such as cognitive impairment, suggesting that change was perceived as possible. A potential for effective diabetes self-management was demonstrated through the flexible and creative support of caregivers. Whilst it was highlighted above in "Limited training and knowledge in staff" that there was a dilemma of protection versus enabling autonomy, some caregivers provided solutions to this dilemma. Whitehead et al. (2016) described a process of "negotiated autonomy", in which levels of support were adjusted in relation to the present needs of the people they supported. Participants were described as almost fully autonomous until situations such as medication adjustments or changes in living arrangements arose, presenting a need for higher support. However, as these situations passed, autonomy was restored where possible. Similarly, Cardol et al. (2012b) described a reduced restriction of dietary choices and provision of healthy alternatives on special occasions such as birthday parties. Although this may in part reflect a prohibitive approach in comparison to Whitehead et al. (2016), such a flexibility may reduce the frustrations of people with ID which were expressed above.

Finally, Rey Conde et al. (2005) described aspects of support which could facilitate independent self-management. These included providing prompts and supporting planning, which may potentially facilitate overcoming barriers and reducing relapses. Such strategies suggest that there are caregivers who look beyond controlling approaches and that this is sometimes reflected in practice. The importance of opportunities for shared knowledge of how to nurture independence was highlighted in Whitehead et al. (2016), although time was acknowledged as a barrier to this. However, investing in such approaches could potentially lead to a more consistent application of flexible and creative solutions.

2.6. Methodologies and quality

2.6.1. Introduction

This section describes the methodological approaches adopted by the studies, highlighting epistemological standpoints, theoretical frameworks and specific methods. A critique of the quality of studies is also provided.

2.6.2. Theoretical frameworks

Theoretical models provide a lens with which to organize and evaluate study findings (Crotty, 1998). In addition, they are commonly used to inform public health interventions (Michie et al., 2010). As well as informing specific methods, they shape and guide research questions, which can then structure methods, such as interviews or focus groups.

A total of 4 studies referred to a theoretical framework. These were Leventhal's Illness Perception theory (Cardol et al., 2012a); Phenomenology (Dysch et al., 2012) and Thomas' General Inductive approach (Hale et al., 2011; Trip et al., 2016). This range of approaches highlights a further positioning of the researchers as either inductive or deductive. Braun and Clarke (2006) discuss this positioning within the context of thematic analysis. Deductive approaches are informed by theory and subsequently shape the research questions and analysis. Inductive approaches are data-driven or ground-up, whereby the researcher attempts to avoid existing assumptions (Braun and Clarke, 2006). This latter approach is also characteristic of IPA, where the researcher attempts to bracket off their own assumptions and describe the unique experience of participants (Reid, Flowers and Larkin, 2005); Grounded Theory, where new theory is generated (Charmaz, 2006); and the General Inductive Approach. These approaches are further discussed in the Methodology chapter. Rey-Conde et al. (2005) did not explicitly state the use of a theoretical model. Rather, the authors employed thematic analysis with no reference to theory driven data, which may suggest an inductive approach.

Leventhal's Common Sense theory or Illness Perception Model, used by Cardol et al., 2012a) was the only deductive model used across the studies. The model is used to explain and predict health behaviours and is commonly used in public health interventions (Nutbeam and Harris, 2010). Cardol et al. (2012) was also the only study to discuss results within a theoretical framework. The Illness Perceptions Model makes use of the self-efficacy construct, used with Social Cognitive Theory (Bandura, 1977).

In the context of people with ID self-managing T2D, the studies which used deductive approaches were able to provide rich accounts of the experiences of service users and their caregivers and offered descriptions which may not have been possible under the restriction of a guiding theoretical framework. However, the analysis by Cardol et al. 2012a) helps to explain psychosocial behaviours such as social comparisons. Aligning responses with the Illness Perceptions theory also provided an explanation of the intentionality in behaviours and motivational factors. These insights may be useful in terms of providing strategies for enhancing self-management, as well as for potential theory-led interventions.

2.6.3. Study Quality

The studies are evaluated using the Elliot et al. (1999) guidelines. *Table 2.3* below summarizes the quality attributes of each study.

Table 2.3: Quality of studies

Study	Owning perspective	Situating the sample	Grounding in example	Credibility Checks	Coherence	General vs specific	Resonating with reader
Rey-Conde et al. (2005)	Yes: Clinical service for adults with ID Experience of poor diabetes management	Somewhat: Geographical and clinical setting, but some demographic information missing	Somewhat: Examples from interview transcripts provided for most, but not every theme, and lack sufficient detail to support themes	Yes: Triangulation through cross-checking written and audio data	Limited: Analysis process unclear Sub-themes not described	No: Does not describe limitations of the ID or caregiver sample population	Somewhat: Findings are generally negative, not fully evidenced and reflect researcher assumptions
Hale et al. (2011)	No: No information provided about researcher background or assumptions	Somewhat: Detailed demographics for participants was provided, but little about individual circumstances	Yes: Excerpts from transcripts provided which support themes	Yes: Discussion and debate of themes across researchers	Mostly: Sub-themes described within broad paragraphs – no figure to clarify structure	Yes: Acknowledges representation issues in recruitment and sample population	Somewhat: Difficult to judge the author position without reflexivity and lack of clarity in thematic structure

Dysch et al. (2012)	Somewhat: Background of one of the researchers but no research assumptions stated	Yes: Detailed demographics for participants was provided as well situational information about the participants	Yes: Excerpts from transcripts provided which support themes	Yes: 2 researchers compared and debated codes until consensus was reached	Yes: Clearly outlined sub-ordinate and super-ordinate themes	Yes: Acknowledges limitation of single geographical region, homogenous group	Mostly: Lacks researcher position and reflexivity
Cardol et al. (2012a)	Somewhat: Some background about wider study but no description of researcher assumptions	Somewhat: Detailed demographics for participants was provided, but little about individual circumstances	Yes: Excerpts from transcripts provided and themes are supported	Yes: 2 researchers compared and debated codes until consensus was reached	Yes: Clear structure of themes and sub-themes clarified by figure	Yes: Acknowledges that study must be considered exploratory	Mostly: Lacks researcher position and reflexivity
Cardol et al. (2012b)	No: No information provided about researcher background or assumptions	Somewhat: Detailed demographics for participants was provided, but little about individual circumstances	Yes: Excerpts from transcripts provided and themes are supported	Yes: 2 researchers compared and debated codes until consensus was reached	Yes: Clear structure of themes and sub-themes clarified by figure	Somewhat: Findings of the study are linked to other wider findings on carer training and qualifications, but limits of small, homogenous sample are not acknowledged	Mostly: Lacks researcher position and reflexivity
Trip et al. (2016)	Somewhat:	Somewhat:	Somewhat:	Somewhat:	Yes:	Somewhat:	Somewhat:

	No researcher information, through a constructivist approach is acknowledged	Detailed demographics for participants was provided, but little about individual circumstances	Excerpts from transcripts are brief and sparse	Transcripts read and reviewed but no evidence of triangulation/ verification from second coder	Clear structure of themes and categories, supported by figure	Findings of the study are linked to other wider findings on carers in residential settings, but limits of small, homogenous sample are not acknowledged	Lacks researcher position and reflexivity Limited examples of transcripts Robust coding procedure not described
Whitehead et al. (2016)	No: No information provided about researcher background or assumptions	Somewhat: Detailed demographics for participants was provided, but little about individual circumstances	Yes: Substantial transcript excerpts support themes	Yes: Analysis discussed within research team	Somewhat: Subthemes/categories not described. No supporting figure	Yes: Limitations of sample size and using cross-sectional data acknowledged	Mostly: Lacks researcher position and reflexivity
Rouse and Finlay (2016) UK	No: No information provided about researcher background or assumptions	Yes: Detailed demographics for participants was provided as well situational information about the participants	Yes: Substantial transcript excerpts support themes	No: No description of reviewing, triangulation or varication from additional author	Somewhat: Subthemes/categories not described. No supporting figure	Yes: Limitations of sample size and representativeness	Mostly: Lacks researcher position and reflexivity

There were several study overlaps in this review, where research was carried out as part of a wider team, with individual studies addressing different aspects of phenomena. The Cardol et al. (2012a&b) studies were two arms of a research project carried out by the same research team in The Netherlands. The majority of the studies in this review (*N* = 4) were carried out by a team in New Zealand, and Australia, comprising of Rey-Conde et al. (2005), Hale et al. (2011), Trip et al. (2016), and Whitehead et al. (2016). Despite the research overlaps, each study is reviewed in its own right. Therefore, lower quality ratings are given to studies which do not include information provided elsewhere in other studies carried out by the same research team, unless the study is explicitly referenced.

2.6.3.1. Owning perspective

This criterion describes the extent to which studies acknowledged the position of the researcher, including their background, theoretical beliefs and assumptions prior to data collection. Most of the studies did not include this information in the study, with the exception of Rey-conde et al. (2005), who described the research team as being part of a clinical service for adults with ID, and that expectations were low due to observing poor self-management. This positioning is useful in that the reader is able to judge what the impact of this may have been on the researcher's analytical approach and conclusions (Elliot et al., 1999). In this case, the negative findings supported the presuppositions. However, it was difficult to conclude whether this suggested a possibility of confirmation bias, as other aspects of evidence, such as transcript excerpts, were less well described (see below). This was despite the fact that the majority of the studies wrote in the first person, with the exception of Trip et al. (2016), and Whitehead et al. (2016), which can help with presenting a subjective stance (Elliot et al. 1999).

2.6.3.2. Situating the sample

This assesses the level of detail provided about the participants, such as the location and nature of the sample and demographics. Many of the studies provided detailed demographics, with the exception of Rey-Conde et al. (2005). However, situational information about individual participants was only provided in one study (Dysch et al., 2012). This omission made it difficult to judge the extent to which the surrounding context was relevant to data. Further personal, details such as recent life events or family circumstances may have enabled the reader to evaluate the accuracy of the themes. This can be explained by the fact that Dysch et al. (2012) had the smallest sample in the review (*N* = 4), which may have provided scope for greater detail on individual participants.

2.6.3.3. Grounding in example

This refers to the inclusion and depth of examples from raw data provided in the studies. The methodological approach in all of the studies included in this review involved analysis of transcripts; therefore, the examples were all transcript excerpts, where provided. All the studies provided examples. However, the richness of the examples varied across the studies; Whitehead et al. (2016) provided substantial transcript excerpts which supported the themes which were presented, whereas Rey-Conde et al. (2005) and Trip et al. (2016) provided sparse and brief examples which made it difficult to evaluate the accuracy of the analysis. In general, the transcripts of people with ID were better exemplified than representing caregivers. This is counterintuitive, given the communication difficulties of people with ID; richer examples could potentially have been provided from the caregivers.

2.6.3.4. Credibility checks

This describes the evidence in studies of checking credibility of analysis; including codes, categories, and themes. Many of the studies described credibility checks to some degree, except for Rouse and Finlay (2016). Rey-Conde et al. (2005) described triangulation, through checking transcripts against audio recordings. However, there was no mention of additional auditing, for example using a second researcher. Similarly, Trip et al. (2016) described multiple readings of transcripts, yet did not use triangulation or verification through another researcher. Hale et al. (2011), Dysch et al. (2012), Cardol et al (2012a&b) and Whitehead et al. (2016) described a review process where coding and themes were discussed until consensus was reached. The general adherence to this guideline across the studies gives credibility to the analyses.

2.6.3.5. Coherence

Coherence refers to the comprehensibility of the studies, including the presentation and structure. The Elliot et al. (1999) guidelines describe good examples of this as studies which include figure representations of the analytic procedure, including a description of the hierarchical relationship of categories and sub-categories. A total of four studies conformed to this guideline (Dysch et al., 2012; Cardol et al., 2012a&b; Trip et al., 2016). Rey-Conde et al (2005) and Whitehead et al. (2016) did not provide descriptions of the hierarchical structure or supportive figures. Hale et al. (2011) described sub-themes but did not support these with figures. These variations may reflect differences in journal stipulations, such as figure inclusions and word count. However, without a clear description of the analytic process it is impossible for the reader to evaluate whether the themes are accurate, or to be able to reach alternative conclusions.

2.6.3.6. Accomplishing general versus specific research tasks

This refers to the aims of the study in relation to generalizability and limitations, which are bound by factors such as sample size, homogeneity, and setting. The intention of qualitative studies is to understand and represent the experiences of individuals, rather than finding commonalities which can be generalized to wider populations (Elliot et al., 1999). In this sense, it is important for studies to acknowledge the restrictions of qualitative methodology when making claims about the generalizability of findings. The earliest two studies did not acknowledge the limitations of their sample sizes and nature (Rey-Conde et al. 2005; Lennox et al., 2009). Cardol et al. (2012b) and Trip et al. (2016) did not fully report the limitations of their sample in terms of generalizability, however they both reflected that their findings were consistent with other studies in the literature. The remaining studies reported limitations or stated that the study was to be treated as exploratory, whilst also highlighting the importance of their findings. This step was important to include, yet it was omitted in older and more recent studies, which was detrimental to their claims.

2.6.3.7. Resonating with the reader

This criterion asks the reader to make a conclusive judgment, weighing up the combined evaluation of the prior points to report a sense of the impression left by reading the study. In the present section, this is taken a step further, to evaluate the overall impression of the eight studies identified in this review. There were no studies which gave a strong sense of resonating with the reader, which was due to a variety of omissions across the criteria. The most commonly missed criterion was ‘’Owning perspective”, with only one study including this (Rey-Conde et al., 2005). The studies therefore lacked a sense of who the researchers were, as well as what their assumptions and expectations were, thus evoking an objective, scientific sense of detachment found, in quantitative studies. Other studies resonated less well due to sparse or brief transcript excerpts, unclearly described analytical procedures, or lack of description of thematic structure.

Despite these drawbacks, the findings in the studies were insightful, and the fact that the studies concur on many themes (see main findings above) strengthens their validity. What is missing is the sufficient detail for the reader to weigh up the position of the author and the supporting evidence of the data, against their conclusions, and to potentially be able to make additional or alternative conclusions. These omissions may reflect an adherence to the longstanding tradition of objectivity in research, which does not serve as an appropriate tool for evaluating standards in qualitative research (Elliot et al. 1999).

2.7. Chapter conclusion

This chapter has described the issues around diabetes self-management for people with ID, including a summary of prevalence rates followed by a review of the experiences and perceptions of people with ID and their caregivers self-managing diabetes. The review provided a detailed account of the participant demographics, a synthesis of the main findings, and an evaluation of the quality and theoretical application.

The findings show that prevalence rates, although uncertain due to methodological inconsistencies, are likely to be higher in people with ID than in the general population (Axmon et al. 2017). This raises concern over self-management competence in this population, given the high number of people who may have limited cognitive capacities and hence difficulties in understanding consequences of potential long-term complications, thus struggling to adapt lifestyles and follow medication regimes. Additional concerns are raised regarding potential service utilisation and cost.

The review of the experiences and perceptions of people with ID and their caregivers provided an overview of the issues pertaining to research on diabetes self-management. Due to recruitment challenges, sample sizes predominantly included people with ID within certain age bracket (30-50), disability (mild ID) and living in residential care. There was also an over-representation of older, female caregivers, though this may reflect a wider demographic trend in care provision.

The following issues were highlighted as common across the findings from the studies: i) There is a lack of knowledge in people with ID around the characteristics of diabetes, including the severity of its consequences. This may be indicative of appropriate educational resources tailored to this population; ii) The adjustment to lifestyle change is experienced with difficulty by people with ID and is long term, often exacerbated by communal living situations such as shared mealtimes or celebrating special occasions; iii) People with ID required more support for managing medication and insulin injections than for diet adherence. This may reflect the attitudes of caregivers, who wish to support independence, but are often torn between this and safeguarding risks; iv) Training for caregivers supporting people with ID to self-manage diabetes is often inadequate, both in terms of medical competence and in supporting autonomy. This could potentially be improved through provision of accessible resources.

Regarding theoretical application, there was a lack of reflexivity in the studies which distanced the researchers from the presentation of their findings and left the reader unable to evaluate the researchers’ subjective impact. The themes presented across the studies were not always clearly evidenced in terms of coding structure, however the concurrence of findings across the studies suggests the analyses were accurate.

In terms of methodology and use of theoretical models, many of the studies took a data driven approach and thus assumed a deductive stance, though this is common in exploratory studies. Leventhal's Illness Perception model and the Self-efficacy construct were used in one study to guide, highlighting the potential for their application in theory-driven interventions for this population.

The above findings, although mainly restricted to people with mild ID living in residential care, highlight that people with ID are currently not sufficiently supported to self-manage T2D. To address this, tailored education needs to be developed and delivered to improve diabetes knowledge and health literacy. This education must be supplemented by theory-based psychosocial strategies which support adjustment to change and sustain this in the face of barriers and situational challenges.

In the general population there is a large body of diabetes intervention and prevention programmes which are designed to make education accessible and are informed by a range of psychosocial theoretical models. The following chapter presents a systematic review of these models, assessing quality and theoretical application with a view to potentially adapting programmes to meet the needs of people with ID. The themes identified through the meta-aggregation within the present chapter are used to guide a logic model in the following systematic review. This enables the theoretical models and programme components of mainstream T2D interventions and preventions to be evaluated alongside the needs of people with ID.

Chapter Three - Systematic Review of Mainstream Type 2 Diabetes Interventions

3.1. Introduction

This chapter follows on from the previous chapter, which identified the need for a systematic review of T2D interventions used in the general population. The purpose of this second review was to identify the study characteristics and theoretical models of successfully implemented interventions, and to critically appraise and evaluate these in relation the needs of people with ID self-managing T2D. The two reviews presented in this thesis comprise of distinct aims and methodologies, and have subsequently been presented in separate chapters. Although the efficacy of interventions is reviewed, there was a broad range of methodological approaches and measures utilised and, therefore a meta-analytical approach was not appropriate. Appraisal of quality is presented using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (1998), and of theoretical models using the Theory Coding Scheme (TCS), Michie and Prestwich (2010). The review in this chapter has undergone peer review in the Journal of Applied Research in Intellectual Disabilities and has been accepted for publication, subject to minor amendments (Maine, Brown, Dickson, Truesdale, 2018). The final submitted version is in the appendices (Appendix 25, Volume II, p.140).

There are a number of theoretical models which might inform diabetes prevention/management. A brief overview of each one will be presented here with applied examples to diabetes. The importance of giving strong a theoretical basis to intervention programmes is well documented (Gourlan et al., 2016; Michie and Prestwich, 2010). Furthermore, there is strong evidence to suggest that T2D self-management programmes which are based upon a theoretical framework can reduce the risk of complications (Krahn and Fox, 2015). Nutbeam and Harris (2010) provide a framework of models used in healthcare interventions, in which there are four major models aimed at lifestyle behavioural change: the Heath Belief Model (HBM), the theories of reasoned action and planned behaviour (TRA, TPB), the transtheoretical (stages of change) model (TTM), and Social cognitive theory (SCT). Within the HBM model (Becker, 1974) there are four factors which affect the likelihood of action being taken: perceived susceptibility, perceived seriousness, perceived benefits, and perceived barriers. In terms of T2D, these might mean perceiving susceptibility through risk factors such as family history or being overweight. Perceived seriousness may relate to an understanding of the consequences of developing diabetes, such as making necessary lifestyle changes and long-term complications. If benefits, such as healthy diet and exercise are perceived as important, behavioural changes may be made together with engagement in intervention programmes. Perceived barriers may include for example lack of transport to access exercise facilities or free time to commit to intervention programmes. While changes in these beliefs have resulted in behavioural change, the model has been less successful in addressing long term, socially influenced health behaviours, such as smoking (Nutbeam and Harris, 2010).

The TRA and TPB models (Ajzen and Fishbein, 1980, Ajzen, 1991) emphasise the importance of intention to act on behavioural change. For T2D, this could mean the intention to embark upon a physical activity programme or reduce saturated fats in diet. These intentions are governed by attitudes and subjective norms, as well as perceived control in relation to situations. An attitude in the present context could be seeing exercise as futile, or seeing oneself as static and unchanging and therefore unable to change dietary habits. In the T2D self-management context, identifying individuals' stages may aid with supporting behavioural change by tailoring support according to the present need, for example maintaining regular trips to health professionals when faced with sudden loss of mobility.

The Transtheoretical model (TTM) proposed by Prochaska and DiClemente (1983) presents a descriptive model of readiness to change, which includes the following stages: i) Precontemplation: People in this stage are not interested in making change in the near future, which may be due to their being uninformed about the consequences of a particular behaviour. In terms of T2D, this could describe a lack of interest in making dietary considerations; ii) Contemplation: This stage involves a higher awareness of the benefits of change, but also of the efforts involved in making change, which can lead to ambivalence and a reluctance to move beyond this stage. This awareness could, for example, include the benefits of increased levels of physical activity, such as reduced risk of cardiovascular disease. Reluctance may be driven by a perception of exercise as high intensity and unattainable; iii) Preparation: Those at this stage intend to take action for change soon. They are likely to have already engaged in some of the behaviours which will be a part of this change, and will have made a plan of action. This could include a plan to make a certain number of home-cooked meals per week; iv) Action: Action is described as making observable change over at least six months, and could include an increased daily step-count; v) Maintenance: After action has been initiated this must be maintained over time in the face of relapses. Relapses may occur in the form of life changes, such as a new job, pregnancy or bereavement, which could present barriers to a self-management programme.

SCT (Bandura, 1977) is based on the relationship between an individual and their environment, emphasising the interaction between social influence and cognition. For people with ID self-managing T2D, social influence could mean the support from paid caregivers and family members, as well as the influence of peers in shared living situations. The model has been successful in informing education programmes aimed at behavioural change (Nutbeam and Harris, 2010). In addition to these models, Leventhal's Self-Regulatory Theory (SRT) has been applied to interventions by focussing on individuals' representations of their illnesses, thereby providing a basis for behavioural change (Taggart et al. 2015).

The common focus across all the models is the individual, with a focus on beliefs, attitudes and responses to social influences. While there is a large body of evidence regarding the efficacy of the models within the general population (Davies et al., 2008; McCurley et al., 2017; Yates et al. 2009; Wu et al., 2011), little is known about their suitability for people with ID. The aim of this second review was therefore to systematically evaluate mainstream T2D interventions, with a view to informing the development of theoretically grounded interventions for the ID population. Studies were evaluated in terms of the quality of their design, with those that received a low rating discarded. Following appraisal, those detailing theoretical models were evaluated in terms of quality and clarity of evidence. The models were critically analysed and discussed in the context of the current literature regarding the self-management of T2D in people with ID.

3.1.2. Systematic review aims

1. To identify the core components of mainstream T2D intervention and prevention programmes and evaluate these alongside the needs of people with ID
2. To assess the quality of the evidence regarding the utilisation of the models and the translation and application as an intervention technique
3. To highlight potential implications for future interventions aimed at the ID population

3.2. Methodology

This systematic review is reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (Liberati et al., 2009).

3.2.1. Search Strategy

A systematic, comprehensive approach was taken using the following electronic data bases: PsychINFO, Psychology and Behavioural Sciences Collection, CINAHL, MEDLINE and PubMed. Search strategies were unique to each database according to suggested search terms, for example through MESH or Thesaurus. Systematic reviews of public health interventions present challenges due to database indexing issues (Tacconelli, 2010). With this in consideration, search terms, sub-headings and filters were designed to be as broadly inclusive as possible. These included "Type 2 Diabetes" OR "Diabetes Mellitus" OR "Non-insulin dependent diabetes" AND "self-management" OR "self-care", with sub-headings protection and control and filters set to quantitative only, and clinical queries set to Therapy: high sensitivity. An additional search was conducted with the preceding terms AND "Intellectual Disabilities" OR "Learning Disabilities" OR "Mental Retardation".

3.2.2. Inclusion and exclusion criteria

This review employed the following inclusion search criteria:

1) Type of paper: original, peer-reviewed research articles, excluding thesis, dissertations, books, reviews and government reports
2) Study Design: Quantitative studies employing randomized controlled trials (RCTs). Feasibility studies are also included as some of these expand the diversity of settings and participants
3) Theoretical model: only studies which included and make explicitly referenced to a theoretical model were included

The following were excluded:

1) Qualitative studies

2) Pseudo-experimental designs
3) Feasibility studies
4) Cross-sectional surveys
5) Follow-up studies
6) Studies not published in English
7) Secondary analyses of previously trialled interventions

3.2.3. Synthesis of programme components and outcomes

A logic model was developed to synthesise the components and outcomes of the interventions. Logic models are increasingly valued as a tool for evaluating complex interventions within a systematic review (Anderson et al, 2011). Elements of the Kneale, Thomas, and Harris (2015) guidelines were adopted for this iterative process, which comprised of the following:

1) Identifying the intervention programme core components and theoretical models
2) Identifying outputs: the mechanisms by which theoretical models and core components were operationalised
3) Identifying proximal significant outcomes: those which directly resulted in improved self-management or reduction of risk factors
4) Identifying intermediate significant outcomes: lifestyle modifications which could potentially lead to proximal outcomes
5) Identifying distal significant outcomes: social and psychological factors which could potentially support proximal outcomes

6) Linking proximal, intermediate, and distal outcomes to the needs of people with ID diagnosed or at risk of T2D. The meta-aggregation of the literature in the previous chapter provides a rigorous account of the needs of people with ID self-managing T2D, and was integrated into the logic model of the present review
Each stage of identification was validated by a second reviewer within the supervisory team

3.2.4. Quality Assessment

This review employed the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (1998). Other tools were considered such as CASP (2017), which employed similar criteria. However, the EPHPP was selected due to its healthcare research specificity. The tool comprises of eight components:

A. Selection bias: Representativeness of participants to the target population
B. Study design: ranging from RCT to “study not described”
C. Control of confounding factors: such as demographics
D. Blinding: of outcome assessors and participant
E. Data collection methods: reliability and validity
F. Withdrawals and drop-outs: attrition rates
G. Intervention integrity
H. Intervention analyses

The tool was developed to assess public health interventions and encompasses criteria for cross-sectional and clinical case studies, therefore not all assessment components were relevant to self-management interventions; “D”, and “G” were therefore not utilised in the current review, in line with previous work such as Macrae et al. (2015). In delivering educational programs, it is not possible to blind participants and assessors to outcomes as this awareness is central to components such as goal setting, where understanding of aims impact on potential success. Intervention integrity was not conventionally reported within studies unless, as fidelity in the case of studies adapted from previously implemented models. Therefore, this measure would not have served as a comparative criterion. The remaining five criteria comprised the “component ratings”, and were assigned the quality ratings of “Strong”, “Moderate” or “Weak”. The “Global rating” comprised of “component rating” scores including “Strong” (no “Weak” ratings), “Medium” (one “Weak” rating), “Weak” (two or more “Weak” ratings).

3.2.5. Theoretical Model Evaluation

Theoretical models used in studies given an EPHPP “Strong” and “Medium” rating were evaluated using Michie and Prestwich’s (2010) Theory Coding Scheme (TCS). The TCS questions whether the relevant theoretical constructs are targeted by intervention techniques, whether they are measured, how the intervention brings about behaviour change, and whether or not a single theory is used.

3.3. Results

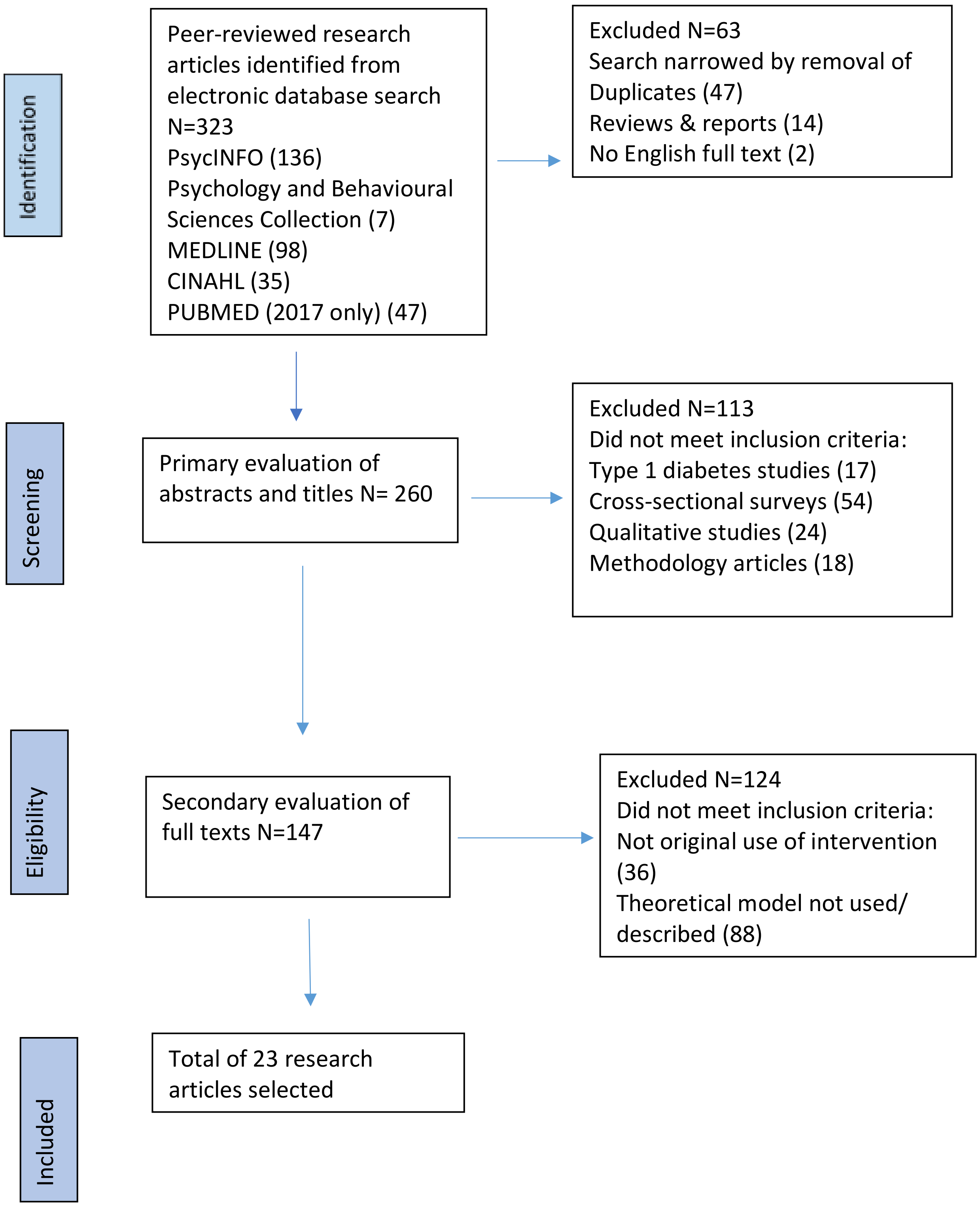
3.3.1. Study Characteristics

A total of 23 research articles were identified and are presented in *Table 3.1* below. The PRISMA diagram below, *Figure 3.1.* details the selection and elimination of studies at each stage of the review. Following this, *Table 3.2* provides an overview of included study characteristics.

Table 3.1 selected study list

1) Bradshaw et al. 2007	13) McCurley et al., 2017
2) Biddle et al., 2015	14) Miller, Kristeller, Headings, and Nagaraja, 2014
3) Contento, Koch, Lee, and Calabrese-Barton, 2010	15) Mohamed, Al-Lenjawi, Amuna, Zotor, and Elmahdi, 2013
4) Davies et al., 2008	16) Ramadas et al., 2015
5) Dutton, Provost, Tan, and Smith, 2008	17) Sacco, Malone, Morrison, Friedman, and Wells, 2009
6) Faro, Ingersoll, Fiore, and Ippolito, 2005	18) Saksvig et al., 2005
7) Glasgow et al., 2012	19) Taggart et al., 2017
8) Hartmann et al., 2012	20) Thoolen, de Ridder, Bensing, Gorter, and Rutten, 2007
9) Heiderman et al., 2015	21) Wu et al., 2011
10) Jennings, Vandelanotte, Caperchione, and Mummery, 2014	22) Yates et al., 2009
11) Laatikainen et al., 2007	23) Yates et al., 2016
12) Macedo, Cortez, dos Santos, Reis, Torres, 2017	

Figure 3.1: Flow chart of study selections



3.3.1.1. Study range

The included studies were published between 2005 and 2017. Although the search engines produced earlier results, 2005 was the first year in which inclusion criteria was fulfilled. Earlier reviews by Brown (1990) and Norris, Engelgau, and Narayan (2005) criticize the lack of application of theoretical models in diabetes intervention programmes, (thus the selection criteria resulted in the selection of studies from 2005, by which point theoretical models were more clearly demonstrated.

Table 3.2: Study characteristics table

Study	Design	Participants	Aims and setting	Measures	Outcomes	Delivery: Length of session(s), duration, and group or individual
Saksvig et al. (2005) Canada	Pretest/post-test, single sample Preventative	Sample size: 122 (Not Powered) Gender: females -45%; males 55% Age: Range 7-14 years) Ethnicity: not specified Diabetes status: At risk of T2	Pilot study of a culturally tailored intervention for Native Canadian Children	Height, weight, waist, BMI 24-h dietary recall CATCH Health Behaviors Questionnaire Kahnawake Schools Diabetes Prevention Programme classroom Questionnaire Developed parent/guardian questionnaire	Significant increases (*p* = .0001) for intention, dietary preference, knowledge, and dietary self-efficacy, curriculum knowledge scale Dietary knowledge (*p* = 0.05); Knowledge about curriculum concepts (*p* = 0.05) Dietary fiber intake (p = 0.1)	Delivered over academic year in curriculum Group

Faro et al. (2005) U.S.	Pretest/post-test, single sample Preventative	Sample size: 27 (Not powered) Gender: females – 44%; males – 56% Age: not specified Ethnicity: African American – 55%; Hispanic – 25%; White – 18%; Other – 2% Diabetes status: At risk of T2D	Pilot study conducting periodic diabetes care visits in school to reduce diabetes risk.	Self-Efficacy for Diabetes (SED) Tool Developed 15-item Survey for parents Developed physician or PNP survey	HbA1c levels: Not significant - Glycaemic control not significant Psychosocial: Student self-efficacy changes not significant.	Delivered over academic year in curriculum Group
Bradshaw et al. (2007) U.S.	RCT, Intervention and control Diabetes Self-management Programme	*N* = 67 (Powered) Gender: females 65%; males 35% Age: not specified Ethnicity: Hispanic - 3% & 0%; African American - 0% & 0% American Indian – 3% & 0%	Testing the efficacy of a resiliency training approach for people with T2D	Glycosylated haemoglobin (HbA1c) assay Waist measurement Purpose developed questionnaire	Physiological measures (not significant) Waist measurement (not significant) Eating and exercise habits ($p < .05$) Psychosocial measures (self-efficacy, locus of control, social	10 modules, 15 hours 6 months duration Group

		Asian – 7% & 0% Pacific Islander – 3% & 0% Caucasian – 83% & 100% Diabetes status: diagnosed T2D			support, and purpose in life, all *p* < .05)	
Laatikainen et al. (2007) Australia	Pretest/post-test, single sample Preventative	Sample size *N* = 237 (Not powered) Gender: females – 73%; males – 27%; Age: mean 57 years) Ethnicity: not specified Diabetes status: At risk of T2D	Examining effects of a T2D (with and at risk of) intervention (Greater Green Triangle (GGT) Diabetes Prevention Project)	HbA1c levels Kessler 10 Psychological Distress Scale (K-10) Hospital Anxiety and Depression Scale (HADS) General health assessed using Short Form 36 (SF-36v2) Height, weight, waist, BMI	Biochemical: Weight (not significant) Waist circumference reductions (95% confidence interval 3.48 to 4.87). Glucose Reductions (0.07 to 0.20)	6 modules, 90 minutes each 8 months duration Group

					Psychosocial: Reduced distress ($p = .002$)	
Davies et al. (2008) U.K.	RCT, Intervention and control Diabetes Self management Programme	Sample size $N = 824$ (Powered) Gender: females – 47%; males – 53%; Age: mean 59.5 years Ethnicity: not specified Diabetes status: diagnosed T2D	Effectiveness of the diabetes education and self-management for ongoing and newly diagnosed (DESMOND) programme for people T2D	HbA1c levels Summary of diabetes self-care activities questionnaire (lifestyle) International physical activity questionnaire World Health Organization’s quality of life instrument WHOQOL-BREF Illness perceptions questionnaire-revised Diabetes illness representations questionnaire	HbA1c levels: Weight loss ($p = .027$) Health behaviours: Smoking cessation ($p = .033$) Psychosocial: Illness belief scores ($p = .001$) directions of change were positive indicating greater understanding of diabetes Lower depression ($p = .032$)	One session of six hours (or 2 of 3 hours) One single session duration Group

				Problem areas in diabetes scale Hospital anxiety and depression scale	Positive association was found between change in perceived personal responsibility and weight loss at 12 months (β = .12; *p* = .008).	
Dutton et al. (2008) U.S.	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=85 (Not powered) Gender: females - 68.2%; males – 31.8% Age: mean 57.1 years Ethnicity: not specified Diabetes status: diagnosed T2D	Examining effects of a tailored, print-based intervention for promoting PA among patients with T2D	Self-report surveys and structured interviews with research staff HbA1c levels 7-day Physical Activity Recall (PAR) Stages of change	Non-significant PA levels, although Intervention group more likely to be in PA stage at 1 month (OR = 3.2, 95% CI 1.0 – 10.3) and in the Action or Maintenance stages (OR = 5.6, 95% CI 1.7 – 18.3)	No sessions delivered Individual
Thoolen et al. (2007) Netherlands	RCT, Intervention and control Diabetes Self-	Sample size *N*=180 (Powered) Gender: females – 35%; males – 64%	Evaluating an intervention for T2D self-management: addressing specific self-care issues with	Evaluation form Proactive Diabetes Management Inventory	Psychosocial: Self-efficacy and goal attainment (*p* = .001)	Eight 2 hour group sessions and two 1 hour individual sessions.

	management Programme	Age: mean 62 years Ethnicity: not specified Diabetes status: diagnosed T2D	proactive five-step plan to improve confidence and self-management .	Questionnaire adapted from Lorig et al.		12 weeks duration Group and individual
Yates et al. (2009) U.K.	RCT, Intervention and control Preventative	Sample size *N*=87 (Not powered) Gender: females – 38%; males – 62% Age: mean 64 years Ethnicity: White Europeans – 92%; South Asians – 8% Diabetes status: At risk of T2D	Evaluating a structured education programme promoting physical activity through increased ambulatory activity and improving glucose tolerance in those with impaired glucose tolerance (IGT).	Ambulatory activity through pedometer readings IPAQ Height, weight, waist, BMI Illness perceptions questionnaire Self-efficacy Likert Scale	Increased walking at 3, 6, and 12 months (95% CI: (576 – 3,150), p = .005; (989 – 3,426), p = 0.001; (945 – 2859) p = <0.001, respectively) Post-challenge glucose and fasting glucose (95% CI - 2.20 to -.43 and -.32 m-0.59 to -.03) Psychosocial: Walking self-efficacy (*p* = .01) .	One 3 hr Session 12 month duration Group

Sacco et al. (2009) U.S.	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=62 (Not powered) Gender: female – 58%; male 42% Age: mean 52 years Ethnicity: Caucasian - 77.4%; African–American – 45%; Hispanic – 8.1% Diabetes status: diagnosed T2D	Evaluating a telephone intervention by paraprofessionals for T2D targeting diabetes adherence, glycaemic control, diabetes-related medical symptoms, and depressive symptoms	Summary of Diabetes Self-Care Activities Questionnaire HbA1c levels Summary of Diabetes Self-Care Activities Questionnaire Nine Symptom Depression Checklist of the Patient Health Questionnaire (PHQ-9) Diabetes Knowledge Test Multidimensional Diabetes Questionnaire Self-Efficacy subscale Social support and self-care Likert Scales	Adherence to diabetes care regime (*p* = .001) Glycaemic control and BMI (non-significant) Diabetes Self-efficacy mediates effect of treatment on depressive symptoms (*p* = .05) Control and awareness of illness (*p* = .01)	Mean 16 sessions, 15-20 minutes long Average of 24 weeks duration Individual

Contento et al. (2010) U.S.	RCT, Intervention and control Preventative	Sample size = 1134 (Not powered) Gender: female – 49%; male – 51% Age: mean 12 years Ethnicity: Latino - 70%; African-American - 25%; Others - 5% Diabetes status: At risk of T2D	Examining effects of T2D prevention programme (Choice, Control, and Change (C3)) on diet and lifestyle in adolescents	Dietary and PA behavioural frequency measures, Personal agency (autonomy and competence)	Dietary behaviours: Decreases in poor diet (p = .001) Physical activity: Increases in intention to exercise (p = .001) Psychosocial: Increased self-efficacy for all targeted behaviours except eating more fruits and vegetables (p = .001)	Twenty four sessions of 45 minutes 8-10 weeks Group
Wu et al. (2011) China	RCT, Intervention and control Diabetes Self-management Programme	Sample size N=145 (Powered) Gender: female - 64.1%; male – 35.9% Age: mean 64 years Ethnicity: not specified	Exploring effectiveness of a Self-efficacy enhancing T2D intervention programme. The evaluation focused on improvements	Chinese version of the Diabetes Management Self-Efficacy Scale (C-DMSES) Chinese version of the Perceived Therapeutic	Efficacy expectations (p = 0.01) Outcome expectations (p = 0.01)	Four 1 hr sessions, follow-up calls at 8 and 16 weeks 16 weeks duration Individual

		Diabetes status: diagnosed T2D	in self-efficacy, outcome expectations, and self-care behaviours	Efficacy Scale (C-PTES) Chinese version of the Summary of Diabetes Self-Care Activities (SDSCA) scale	Self-care activities (p = 0.01)	
Hartmann et al. (2012) Germany	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=110 (Not powered) Gender: females – 22%; males - 78% Age: mean 59.5 years Ethnicity: not specified Diabetes status: diagnosed T2D	Exploring effects of a T2D intervention (HEIDIS) for reducing progression of nephropathy, depression and psychosocial stress, improving self-perceived health status	HbA1c levels Patient Health Questionnaire (PHQ) 12-item short-form health survey (SF-12)	Delayed progression of albuminuria (not significant) Lower depression in intervention (p = .71) and in health status (p = .54)	8 weekly sessions (session duration not provided) 8 weeks with booster session after 6 months duration Group
Glasgow et al. (2012) U.S.	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=463 (Powered) Gender: females – 50.4%, males – 49.6% Age: mean 58 years Diabetes status: diagnosed T2D	Internet based T2D self-management programme targeting changes in health behaviours (healthy eating, physical activity, and	Subjective health numeracy scale “Starting The Conversation” scale Lorig's eight-item Diabetes Self-Efficacy scale	Heaty eating, medication taking and physical activity (d for effect size = .09 – .16) Haemoglobin A1c, body mass index, lipids,	Internet programme self-administered. Additional support group received 2 follow-up calls and three 2 hour group sessions

			medication taking) plus biomedical and psychosocial issues (self-efficacy and diabetes distress)	HbA1c levels Positive Transfer of Past Experience from the Diabetes Problem Solving Scale of Hill-Briggs Chronic Illness Resources Survey (CIRS) EuroQol health status instrument Diabetes Distress Scale (DDS)	blood pressure (not significant) Reduced diabetes distress (*p* = .05).	12 months duration Individual and group
Mohamed et al. (2013) Qatar	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=430 (Not powered) Gender: not specified Age: mean 53.5 years Ethnicity: Arabic Diabetes status: diagnosed T2D	Culturally sensitive intervention for T2D targeting biomedical, knowledge, attitude and practice measure through T2D self-management education	HbA1c levels Adapted Diabetes questionnaire (previously used but not validated)	Improved HbA1C levels (*p* = .001) Diabetes knowledge (*p* = .0001)	Four sessions of 3-4 hours 12 weeks duration Group

Miller et al. (2014) U.S.	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=32 (Not powered) Gender: females 64%; males 36% Age: range 35-65 years) Ethnicity: Caucassian – 81.5%; Other - 18.5% Diabetes status: diagnosed T2D	Comparing a mindful-eating intervention to a DSME programme for improving dietary patterns	Food Frequency Questionnaire Outcome expectancies and self-efficacy questionnaire 25-item Eating Self-Efficacy Scale The Three-Factor Eating Questionnaire (TFEQ) The Five-Facet Mindfulness Questionnaire Height, weight, waist, BMI	Dietary knowledge (*p* = .05) Adherence to diet (F (1, 59) = 5.71, *p* = <.05 Depressive symptoms, outcome expectations, nutrition and eating-related self-efficacy and mindfulness (*p* = .0125) Weight change (non-significant)	8 weekly and 2 biweekly 2½ hour sessions, plus 1 and 3 month follow up sessions 2 years duration Group
Jennings et al. (2014) U.S.	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=397 (Powered) Gender: females - 47.6%; males 52.4% Age: mean 58 years	Evaluating a web-based physical activity intervention for adults with T2D targeting increased PA	International Physical Activity Questionnaire (IPAQ) HbA1c levels	Group-by-time interaction (X2 (df = 1) = 6.37, *p* = .05) for total physical activity	Internet programme self-administered. 12 weeks duration Individual

		Ethnicity: not specified Diabetes status: diagnosed T2D				
Heideman et al. (2015) Netherlands	RCT, Intervention and control Preventative	Sample size *N*=96 (Not powered) Gender: females - 67.7%; males - 32.3% Age: mean 55 years Ethnicity: Dutch – 80%; Suriname - 4.2%; Antilles - 2.1%; Netherlands East Indies - 4.2% Diabetes status: At risk of T2D	Examining effects of a low-intensive lifestyle educational T2D prevention programme (DiAlert) targeting weight loss	HbA1c levels International Physical Activity Questionnaire: IPAQ Health- related quality of life: EQ5D Kessler-10 scale (K10) for diabetes distress Self-efficacy (sum 20 scale)	Weight loss (*p* = .03) Waist circumference (*p* = .01) Self-efficacy and risk perception (non-significant)	Two sessions of 150 minutes plus newsletters 12 months duration Group
Biddle et al., (2015) U.K.	RCT, Intervention and control	Sample size *N*=187 (Powered)	Examining T2D prevention programme focussing on	Accelerometer-assessed sedentary behaviour	Reduced sedentary behaviour (non-significant)	One 3 hour session

	Preventative	Gender: females - 68.5%; males; 31.5% Age: mean 32.8 years Ethnicity: Unspecified majority – 80.2% Black and ethnic minority – 19.8% Diabetes status: At risk	sedentary time reduction	HbA1c levels l Height, weight, waist, BMI International Physical Activity Questionnaire (IPAQ) Total and Domain-Specific Sitting Questionnaire	HbA1c levels Height, weight, waist, BMI and psychosocial variables (all non-significant)	9 months duration Group
Ramadas et al., (2015) Malaysia	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=82 (Powered) Further demographics provided for intervention group only (*N*=59) Gender: Females 49.2%; males 50.8% Age: mean 49 years Ethnicity: “Malay community” 88%	Evaluating internet based diabetes intervention	Process evaluation for feasibility and acceptability Dietary Knowledge, Attitude, and Behaviour Questionnaire (DKAB-Q) HbA1c levels	Process evaluation Response rate 89% Dietary Knowledge, Attitude, and Behaviour score strongly correlated with content satisfaction (r=0.826, p<0.001)	12 Lessons Intended length not specified but participants logged in for a mean 12 minutes 6 months duration Individual

		Diabetes status: Diagnosed with T2D			Acceptability (r=0.793, p<0.001) and usability of website (r=0.724, p<0.001), and moderately correlated with frequency of log-in (r=0.501, p<0.05) and duration spent in the website (r=0.399, p<0.05).	
Yates et al., (2016) U.K.	RCT, Intervention and control Preventative	Sample size *N*=808 (Powered) Gender: Females 36%; males 64% Age: Mean 63.6 years Diabetes status: Pre-diabetic	Evaluating the efficacy of the “Walking Away from Diabetes” programme	Ambulatory activity through pedometer readings HbA1c levels Dietary Instrument for Nutrition Education food frequency questionnaire	Increased Physical activity [95% confidence interval (CI): 117, 704] and self-reported vigorous-intensity physical activity of 218 metabolic equivalent min/week (95% CI: 6, 425) at 12 months, however not beyond	One three-hour educational session followed by repeated measures 12 months duration Group

					Biochemical (not significant)	
Macedo et al., (2017) Brazil	RCT, Intervention and control Diabetes Self-management Programme	Sample size *N*=183 (Not powered) Gender: Females 62.5% Males 37.5% Age: Mean 59 years Diabetes status: Diagnosed with T2D	Evaluating adherence to a group based DSM educational programme	Adherence to self-care practices for diabetes mellitus (ESM) Diabetes Empowerment Scale-Short Form – DES-SF HbA1c levels	Significant decrease in glycated haemoglobin (P< 0.001) Significant increase in adherence to self-care and empowerment Scales (P< 0.001)	Seven group meetings, lasting around two hours 14 hours Group
McCurley et al., (2017) U.S.	RCT, Intervention and control Preventative	Sample size: N=61 (Not powered) Gender: Females 100% Age: Mean 47.8 years Diabetes status: At risk of T2D	Evaluating effectiveness, feasibility, and acceptability of a peer-led, culturally appropriate, Diabetes Prevention Programme (DPP) for Latina women at high-risk of T2	Height, weight, waist, BMI 9-item Rapid Assessment of Physical Activity University of California Cooperative Extension Food Behavior Checklist 8-item Patient Health	Mean reduction of 4.1% body weight at 6 months Significant improvements observed for dietary behaviors, stress, and depression symptoms (P<0.005)	Weekly 2-hour class for 12 weeks 6 Months Group

				Questionnaire (for depression) 9-item exercise barriers measure from the Healthy and Retirement Study 10-item Perceived Stress Scale (PSS) Intervention fidelity evaluation	Focus groups indicated that intervention content increased knowledge, was applicable, valued, culturally relevant, and would be recommended to others	
Taggart et al., (2017) U.K.	RCT, Intervention and control Diabetes Self-management Programme	Sample size: *N*=39 (Not powered) Gender: Females 56.4% Males 43.6% Age: Mean 54.7 years Diabetes status: Diagnosed with T2D	Pilot feasibility study of DESMOND-ID, and adaptation of the DESMOND (Davies et al., 2008) programme for people with ID.	Illness Perception Questionnaire-Revised (IPQ) The Diabetes Illness Representation Questionnaire (DIRQ) WHO quality of life questionnaire (WHOQOL-BREF)	Interaction between occasion (time) and condition, showed statistically significant results (P=0.04) for HbA1c Interaction between condition not significant in BMI IPQ shift (P = 0.00)	7 weekly sessions 12 week duration Group

	Focus group process evaluation Height, weight, waist, BMI HbA1c levels	DIRQ (not significant) WHOQOL-BREF (Not significant) Five major themes: 1) the user-friendly content and delivery of the programmeme; 2) the knowledge and skills of the educators; 3) the support of the carers; 4) social aspects; and 5) difficulties in understanding the nature of fats and carbohydrates.	

3.3.1.2. Geographical origins of studies

A total of 23 studies were reviewed. Nine (39.1%) were conducted in the U.S. (Bradshaw et al., 2007; Contento et al., 2010; Dutton et al., 2008; Faro et al., 2005; Glasgow et al. 2012; Jennings et al., 2014; McCurley et al., 2017; Miller et al., 2014; Sacco et al., 2009). The remainder were published in the U.K. (five studies, 21.7%: Biddle et al., 2015; Davies et al., 2008; Taggart et al., 2017; Yates et al., 2009; Yates et al., 2016), the Netherlands (two studies, 8.7%: Heideman et al., 2015; Thoolen et al., 2007), Australia (one study, 4.3%: Laatikainen et al., 2007), China (one study, 4.3%: Wu et al., 2011), Germany (one study, 4.3%: Hartmann et al., 2012), Qatar (one study, 4.3%: Mohamed et al., 2013), Malaysia (one study, 4.3%: Ramadas et al., 2015), Brazil (one study, 4.3%: Macedo et al., 2017), and Canada (one study, 4.3%: Saksvig et al., 2005). The increased prevalence of U.S. studies may reflect the search platform (for instance, PsycINFO, indexes predominantly American Psychology Association research articles. All five U.K. studies were developed in collaboration with the NHS at Leicester Diabetes Centre and contain shared components of the core programme (Davies et al., 2008).

3.3.1.3. Sample size

Sample size ranged from N=27 (Faro et al. 2005) to N=1134 (Contento et al., 2010), mean 254.5.

3.3.1.4. Participant age and diabetes status

The majority (*N*=19) of studies provided the mean age of the participants, and the mean age was 53.6 years (SD 12.4). Mean age of the samples ranged from 12 years (Contento et al., 2010), to 64 years (Sacco et al., 2009; Yates et al., 2016). Indeed, the onset of Type 2 diabetes is more prevalent in those over 40 and can reduce life expectancy by ten years (Diabetes UK, 2017). This may account for such study characteristics.

With regard to diabetes status, the majority (*N*=14. 60.9%) of studies recruited were self-management programmes and hence recruited participants diagnosed with diabetes. (Bradshaw et al., 2007; Davies et al., 2008; Dutton et al., 2008; Glasgow et al., 2012; Hartmann et al., 2012; Jennings et al., 2014; Macedo et al., 2017; Miller et al., 2014; Mohamed et al., 2013; Ramadas et al., 2015; Sacco et al., 2009; Taggart et al., 2017; Thoolen et al., 2007; Wu et al., 2011). The remaining nine (39.1%) studies were preventative and recruited participants identified as ‘at risk’ of diabetes (Biddle et al., 2015; Contento et al., 2010; Faro et al., 2005; Heideman et al., 2015; Laatikainen et al., 2007; McCurley et al., 2017; Saksvig et al., 2005), with impaired glucose tolerance (Yates et al., 2009), and pre-diabetic status (Yates et al., 2016). The mean participant age of these studies was lower than that of the self-management programme studies (47.4 and 57.1 respectively), reflecting a strategy to target risk factors at a younger age. The mean age of participants with ID with or at risk of diabetes in a review by Macrae et al. (2015) was 40.06 years, suggesting that the onset of diabetes may be earlier in this population than in the mainstream population. This may be indicative of health inequalities such as people with ID being less physically active and having poorer diets. Thus, the importance of early intervention or preventative approaches for addressing diabetes in this population is apparent. As people with ID are likely to be at risk at an earlier age than this, preventative programmes should be aimed at younger adults accordingly.

3.3.1.5. Gender and ethnicity

All studies except Mohamed et al. (2013) reported gender demographics. There was a mean female participant rate of 54.9% (SD 16.6) and mean male rate of 44.9% (SD 16.5). Gender demographics were balanced at baseline in all studies, as described further below. The current literature does not highlight the necessity of a gender focussed T2D intervention programme for people with ID at this time.

3.3.1.6. Programme delivery and structure

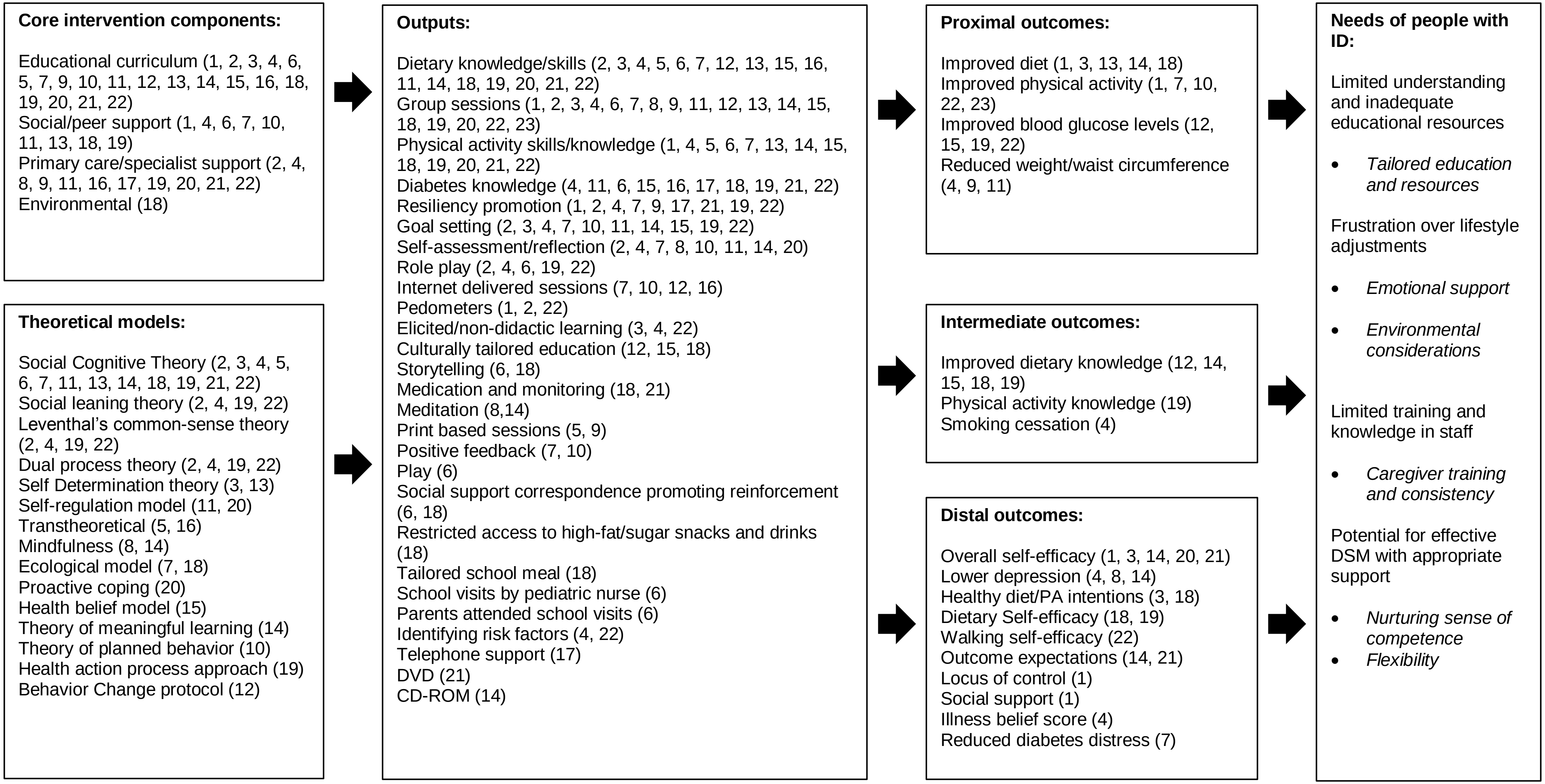
Programme duration was diverse, ranging from a single three-hour session (Yates et al., 2009) to delivery over a year within an academic curriculum (Faro et al., 2005; Saksvig et al., 2005. Sixteen (69.6%) studies were aimed at group level (Contento et al., 2010; Biddle et al., 2015; Bradshaw et al., 2007; Davies et al., 2008; Faro et al., 2005; Hartmann et al., 2012; Heiderman et al., 2015; Laatikainen et al., 2007; Miller et al., 2014; Macedo et al., 2017; McCurley et al., 2017; Mohammed et al., 2013; Saksvig et al., 2005; Taggart et al., 2017; Yates et al., 2009; Yates et al., 2016); five (21.7%) aimed at individual level (Dutton et al., 2008; Jennings et al., 2014; Ramadas et al. 2015; Sacco et al., 2009; Wu et al., 2011), and two (8.7%)

comprised both group and individual components (Glasgow et al., 2012; Thoolen et al., 2007). Group level interventions were typically structured education programmes, while those aimed at an individual level were delivered through one-one counselling sessions. Group based interventions may provide social support through shared learning. Further research into the psychosocial experiences of people with ID self-managing diabetes could elucidate whether the influence of social setting is important. A group, individual or mixed setting could be selected on this basis.

3.4. Impact and effectiveness: significant outcomes

A logic model is presented below (*Figure 3.2.*), which illustrates the relationship between the programme components and theoretical models, intervention techniques, significant outcomes and the needs of people with ID. Studies are presented hierarchically in order of frequency. Numbering corresponds to *Table 3.1* at the start of the results section.

Figure 3.2: Logic model of components, outcomes and needs



Core intervention components:

Educational curriculum (1, 2, 3, 4, 6, 5, 7, 9, 10, 11, 12, 13, 14, 15, 16, 18, 19, 20, 21, 22)
Social/peer support (1, 4, 6, 7, 10, 11, 13, 18, 19)
Primary care/specialist support (2, 4, 8, 9, 11, 16, 17, 19, 20, 21, 22)
Environmental (18)

Theoretical models:

Social Cognitive Theory (2, 3, 4, 5, 6, 7, 11, 13, 14, 18, 19, 21, 22)
Social leaning theory (2, 4, 19, 22)
Leventhal's common-sense theory (2, 4, 19, 22)
Dual process theory (2, 4, 19, 22)
Self Determination theory (3, 13)
Self-regulation model (11, 20)
Transtheoretical (5, 16)
Mindfulness (8, 14)
Ecological model (7, 18)
Proactive coping (20)
Health belief model (15)
Theory of meaningful learning (14)
Theory of planned behavior (10)
Health action process approach (19)
Behavior Change protocol (12)

Outputs:

Dietary knowledge/skills (2, 3, 4, 5, 6, 7, 12, 13, 15, 16, 11, 14, 18, 19, 20, 21, 22)
Group sessions (1, 2, 3, 4, 6, 7, 8, 9, 11, 12, 13, 14, 15, 18, 19, 20, 22, 23)
Physical activity skills/knowledge (1, 4, 5, 6, 7, 13, 14, 15, 18, 19, 20, 21, 22)
Diabetes knowledge (4, 11, 6, 15, 16, 17, 18, 19, 21, 22)
Resiliency promotion (1, 2, 4, 7, 9, 17, 21, 19, 22)
Goal setting (2, 3, 4, 7, 10, 11, 14, 15, 19, 22)
Self-assessment/reflection (2, 4, 7, 8, 10, 11, 14, 20)
Role play (2, 4, 6, 19, 22)
Internet delivered sessions (7, 10, 12, 16)
Pedometers (1, 2, 22)
Elicited/non-didactic learning (3, 4, 22)
Culturally tailored education (12, 15, 18)
Storytelling (6, 18)
Medication and monitoring (18, 21)
Meditation (8,14)
Print based sessions (5, 9)
Positive feedback (7, 10)
Play (6)
Social support correspondence promoting reinforcement (6, 18)
Restricted access to high-fat/sugar snacks and drinks (18)
Tailored school meal (18)
School visits by pediatric nurse (6)
Parents attended school visits (6)
Identifying risk factors (4, 22)
Telephone support (17)
DVD (21)
CD-ROM (14)

Proximal outcomes:

Improved diet (1, 3, 13, 14, 18)
Improved physical activity (1, 7, 10, 22, 23)
Improved blood glucose levels (12, 15, 19, 22)
Reduced weight/waist circumference (4, 9, 11)

Intermediate outcomes:

Improved dietary knowledge (12, 14, 15, 18, 19)
Physical activity knowledge (19)
Smoking cessation (4)

Distal outcomes:

Overall self-efficacy (1, 3, 14, 20, 21)
Lower depression (4, 8, 14)
Healthy diet/PA intentions (3, 18)
Dietary Self-efficacy (18, 19)
Walking self-efficacy (22)
Outcome expectations (14, 21)
Locus of control (1)
Social support (1)
Illness belief score (4)
Reduced diabetes distress (7)

Needs of people with ID:

Limited understanding and inadequate educational resources

- *Tailored education and resources*

Frustration over lifestyle adjustments

- *Emotional support*
- *Environmental considerations*

Limited training and knowledge in staff

- *Caregiver training and consistency*

Potential for effective DSM with appropriate support

- *Nurturing sense of competence*
- *Flexibility*

3.4.1. Proximal outcomes

Proximal outcomes were those which had a direct impact upon T2D progression risk factors, and included improvements in diet, physical activity, blood glucose levels and weight/waist circumference.

3.4.1.1 Improved diet

Improved diet was a significant outcome in five (21.7 %) studies. Two of these were T2D self-management programmes (Bradshaw et al., 2007; Miller et al., 2014) and three were prevention programmes (McCurley et al., 2017; Contento et al., 2010; Saksvig et al., 2005). Contento et al. 2010 and Saksvig et al. (2005) were aimed at adolescents in a secondary education setting, and the remaining studies were aimed at adults. Outcomes were achieved through an educational curriculum which taught dietary knowledge and skills, with support from primary care/specialist support, and additionally social support. The interventions were theoretically informed by Social cognitive theory; Self -determination theory; Mindfulness; Ecological model; Theory of meaningful learning. Intervention techniques included using group sessions; goal setting; self-assessment/reflection; elicited learning; cultural tailoring; story-telling; mediation; social support through correspondence; environmental factors such as a tailored school meal and reduced access to unhealthy snacks and drinks; use of a CD ROM.

3.4.1.2 Improved physical activity

Improved physical activity was a significant outcome in three (13%) T2D self-management studies (Bradshaw et al., 2007; Glasgow et al., 2012; Jennings et al., 2014) and two (8.7%) preventative studies, (Yates et al. 2009; Yates et al., 2016). Yates et al., 2009 trialled a structured educational programme, "PREPARE", which aimed to increase ambulatory activity. This was delivered in a primary care setting as "Walking Away from Diabetes" by Yates et al. (2016). Both programmes were developed from a wider diabetes educational programme called DESMOND (Davies et al., 2008), and hence shared core components, theoretical basis and outputs. Other programmes had core components which reflected those of "Improved diet" above. Theoretical basis was driven by SCT; SLT; Self-regulation/common sense theory; Dual process theory; Ecological model; the Theory of planned behaviour. Core components and theoretical models were operationalised using group sessions; resiliency promotion; goal setting; self-assessment/reflection; role play; internet delivered sessions; utilising pedometers; elicited learning; identifying risk factors.

3.4.1.3. Improved Glucose levels

Improving levels of blood glucose was significant in three (13%) T2D self-management programmes (Macedo et al., 2017; Mohamed et al., 2013; Taggart et al., 2017) and one preventative (Yates et al., 2009). Taggart et al. (2017) conducted a feasibility trial adapting DESMOND (Davies et al., 2008) for people with ID. All programmes were group based educational curriculum with support from primary care/specialist support. Interventions were informed by SCT; SLT; CST; DPT; the HBM. Intervention techniques which may have led to these outcomes were diet, diabetes, and physical activity knowledge and skills; group learning; resiliency promotion; goal setting; role play; utilising pedometers; elicited learning; identifying risk factors.

3.4.1.4. Reduced weight/waist circumference

Three (13%) studies achieved significant reductions in weight or waist circumference (Contento et al., 2010; Heiderman et al., 2011; Laatikainen et al., 2007), of which all were preventative. These studies also involved educational curriculum with primary care/specialist support and were theoretically informed by SCT; SLT; CST; DPT; SRT. Relevant intervention techniques included diet and physical activity knowledge; group learning; resiliency promotion; goal setting; self-assessment/reflection; role play; elicited learning; identifying risk factors.

3.4.2. Intermediate outcomes

Intermediate outcomes are those which impact upon healthy knowledge and behaviours, and subsequently have the potential to lead to or enhance the proximal outcomes described above. These included improved knowledge around diet and physical activity, and smoking cessation.

3.4.2.1. Improved dietary knowledge

Five (21.7%) studies yielded significant improvements in dietary knowledge (Macedo et al., 2017; Miller et al., 2014; Mohamed et al., 2013; Saksvig et al., 2005; Taggart et al., 2017). These outcomes unsurprisingly related to the programme components reported above in dietary improvements. However, the interventions were additionally informed by the Health belief model, HAPA and Behaviour change protocol. Intervention techniques also included goal setting and role play, which were not described in the interventions with proximal dietary improvements.

3.4.2.2. Improved Physical activity knowledge

A significant outcome in physical activity knowledge was reported in one (4.3%) study (Taggart et al., 2017). This was not matched with a proximal outcome of increased physical activity, which was not a measured outcome. Despite this, there were shared components, theoretical models, and intervention techniques with the studies which reported significant improvements in physical activity.

3.4.2.3. Smoking cessation

Smoking cessation was reported as a significant outcome in Davies et al. (2008), which is described above in "Improved physical activity". Other programmes with shared programmes and theoretical models, such as Taggart et al. 2017 and Yates et al. 2016 may also have yielded a significant result for smoking cessation where this was a measured outcome.

3.4.3. Distal outcomes

Distal outcomes included those which could potentially enhance intermediate outcomes, thus leading to behavioural change and improvements in health. These were primarily psychosocial, and reflected the theoretical models adopted. Overall, Self-efficacy was significant in five (21.7%) studies (Bradshaw et al., 2007; Contento et al., 2010; Miller et al., 2014; Thoolen et al., 2007; Wu et al., 2011). These studies were commonly informed by SCT, in which self-efficacy is a key construct (Nutbeam and Harris, 2010). Intervention techniques which may have led to these outcomes included resiliency training, goal setting, and self-assessment/reflection,
Related distal outcomes were dietary self-efficacy (Saksvig et al., 2005; Taggart et al., 2017), walking self-efficacy (Yates et al., 2009), Outcome expectations (Miller et al., 2014; Wu et al., 2011), Locus of control (Brashaw et al., 2007). Illness belief score reflected the use of Leventhal's CST in Davies et al. (2008), and lower depression the use of Mindfulness in Hartman et al. (2012), and Miller et al. (2014).

3.5. Quality Assessment

An overview of the quality assessment process is provided in Table 2, below. The EPHPP quality assessment tool (2008) was utilised to assess the quality of the studies. The researcher’s ratings were later verified by the second and third authors to ensure inter-rater reliability. In terms of the global ratings, seven (30.4%) studies were given a “strong” rating (Biddle et al., 2015; Contento et al., 2010; Davies et al., 2008; Hartmann et al., 2012; Heiderman et al., 2015; Macedo et al., 2010; Sacco et al., 2009). The remaining majority had one or more “weak” component ratings. Of these, 11 (47.8%) received a “moderate” global rating (Faro et al., 2005; Glasgow et al., 2012; Laatikainen et al., 2007; Miller et al., 2014; Mohammed et al., 2013; Ramadas et al., 2015; Taggart et al., 2017; Thoolen et al., 2007; Wu et al., 2011; Yates et al., 2009; Yates et al., 2016), and five (21.7%) received a “weak” global rating, with two or more “weak” component ratings (Bradshaw et al., 2007; Dutton et al., 2008; Jennings et al., 2014; McCurley et al., 2017; Saksvig et al., 2005).

The “local” category which contained the most “weak” scores was “representativeness” (12 studies, 52.2%). This was due to an absence of the description of the number of invited participants who continued to participate in the studies, or to the low number of participation after invitation. However, it should be noted that where powered samples required a high number of participants (such as Davies et al., 2008, Yates et al., 2009, and Yates et al., 2016), these sample targets were achieved, despite the low invited participant percentage (example for 20.7% in Yates et al., 2016). Nine (39.1%) studies used a powered sample calculation. In these studies, it is apparent that the recruitment drive required a very large, multiple-site approach, therefore the “representativeness” category was limited as an indicator of quality in these examples. It is important that quality reviews acknowledge the challenges of recruitment in this population, which are likely to be subject to low invitation-acceptance rates, so that high quality studies do not lose impact through low representativeness scoring.

Table 3.3: Quality Assessment of Papers

Author/year	Representativeness	Design	Confounders	Data Collection Method	Drop-outs	Global rating
Saksvig et al. (2005)	Strong	Moderate	Weak	Moderate	Weak	Weak
Faro et al. (2005)	Weak	Moderate	Weak	Weak	Strong	Moderate
Bradshaw et al. (2007)	Weak	Strong	Weak	Strong	Strong	Weak
Laatikainen et al. (2007)	Moderate	Strong	Strong	Strong	Weak	Moderate
Davies et al. (2008)	Moderate	Strong	Moderate	Strong	Strong	Strong

Dutton et al. (2008)	Weak	Strong	Weak	Strong	Strong	Weak
Thoolen et al. (2007)	Weak	Strong	Moderate	Moderate	Moderate	Moderate
Sacco et al. (2009)	Strong	Strong	Strong	Strong	Moderate	Strong
Contento et al. (2010)	Moderate	Strong	Strong	Moderate	Moderate	Strong
Yates et al. (2009)	Weak	Strong	Strong	Strong	Strong	Moderate
Wu et al. (2011)	Strong	Strong	Strong	Weak	Strong	Moderate
Hartmann et al. (2012)	Moderate	Strong	Strong	Strong	Moderate	Strong
Glasgow et al. (2012)	Weak	Strong	Strong	Moderate	Moderate	Moderate

Mohammed et al. (2013)	Weak	Strong	Strong	Strong	Moderate	Moderate
Miller et al. (2014)	Weak	Strong	Strong	Strong	Moderate	Moderate
Jennings et al. (2014)	Strong	Strong	Strong	Weak	Weak	Weak
Heiderman et al. (2015)	Strong	Strong	Strong	Strong	Moderate	Strong
Biddle et al. (2015)	Strong	Strong	Strong	Strong	Moderate	Strong
Ramadas et al. (2015)	Weak	Strong	Strong	Moderate	Strong	Moderate
Yates et al. (2015)	Weak	Strong	Strong	Strong	Strong	Moderate
Macedo et al. (2017)	Strong	Strong	Strong	Strong	Strong	Strong

McCurley et al. (2017)	Weak	Moderate	Strong	Moderate	Weak	Weak
Taggart et al. (2017)	Weak	Strong	Strong	Strong	Strong	Moderate

3.6. Theoretical Model Evaluation

Details of the Michie and Prestwich (2010) Theory Coding Scheme (TCS) evaluations are provided in *Table 3.4*. There were two studies (8.7%) which met all of the TSC criteria (Miller et al., 2014; Wu et al., 2011). Five studies (21.8%) were rated 5/6 (Contento et al., 2010; Hartmann et al., 2012; Heideman et al., 2015; Sacco et al., 2009; Thoolen et al., 2007). The remaining studies met 4/6 of the criteria or less.

All of the studies explicitly specified use of a theoretical model in the introduction or abstract, with the exception of Bradshaw et al. (2007), who described self-efficacy constructs but did not provide the wider theoretical model. The majority of the studies (*N*=17, 73.9%) provided evidence for the efficacy of theoretical constructs.

Fewer studies used a single theoretical model to inform an intervention (N=6, 26%). Michie and Prestwich (2010), suggest the efficacy of multiple model-based interventions can be unclear as it is not possible to tell which construct has affected an outcome. Therefore, theoretical comparisons cannot be drawn. Systematic reviews and meta-analyses (such as Gourlan et al., 2016) comparing the efficacy of single versus multiple theory-based interventions, have reported a higher impact on physical activity from single-theory interventions. However, the trend of multi-component interventions in the studies selected in the present review suggests that single model-based interventions may not be appropriate for addressing behavioural change in type 2 diabetes self-management, despite the difficulty of evaluating the efficacy of multiple-theoretical approaches.

In terms of the frequency of models, whether as standalone or alongside others, there were models which were utilized more recurrently than others. SCT was implemented in 15 (65.2%) multi-model studies and one single-model. The five U.K. studies were based on a core programme (Davies et al., 2008) and shared SCT, SLT, Leventhal's CSM, and DPT.

The construct most explicitly described as informing intervention technique was self-efficacy, which was used to inform intervention techniques in 10 (43.5%) studies. These techniques were associated with a range of successful outcomes, including physical activity (Yates et al., 2009), diet (Miller et al., 2014), and diabetes knowledge (Sacco et al. 2009). The prevalence of self-efficacy reflects on its practical applicability as a construct within SCT and also the Transtheoretical model (Nutbeam and Harris, 2010).

Many of the studies did not meet the criteria “Evaluation of theory and constructs in discussion”, with exception of six (26%), (Bradshaw et al., 2007; Miller et al. 2014; Sacco et al. 2009; Saksvig et al., 2005; Thoolen et al., 2007; Wu et al., 2011). These evaluations related to the promotion of Self-efficacy for self-directed care (Bradshaw et al., 2007; Wu et al., 2011), the usefulness of mindfulness as a measure for regulating eating behaviours, alongside diabetes self-management education (Miller et al. 2014), the potential for lower depression when correlated with higher self-efficacy (Sacco et al., 2009), and the application of proactive coping to self-management. The limitation of these evaluations were not discussed, for example whether models required adaptation, and were limited to advocating the models for future use.

From these findings and the logic model presented in *Figure 3.2*, it can be concluded that there are several consistently applied theoretical models which have led to significant distal outcomes, thereby furthering the potential for behavioural change. However, application of many models is limited due to the lack of clear description of how intervention techniques were informed by theoretical constructs, and of what the implications for models would be following outcome. The use of multiple-theories also limited the clarity of efficacy as single theories could not be examined in isolation. However, the frequency and diversity of the application of the self-efficacy construct highlight its potential for consideration alongside the needs of people with ID self-managing T2D.

Table 3.4: Evaluation of Theoretical Models

Author/ year	Theoretical model(s) Mentioned?	Efficacy of constructs evidenced in introduction?	Based on single theory?	Constructs explicitly inform intervention techniques?	Constructs measured?	Constructs/theory evaluated in discussion?	Score
Saksvig et al. (2005)	Yes SCT Ecological model	No	No	No	Yes Significant Self-efficacy	Yes	4/6
Faro et al. (2005)	Yes: SCT Developmental theory	Yes	No	No	Yes: Self-efficacy not significant	No	3/6
Bradshaw et al. (2007)	No (However, SCT constructs were used)	Yes	Unknown	Yes Self-efficacy	Yes	Yes	4/6
Laatikainen et al. (2007)	Yes: SCT Self-regulation model	Yes (referenced in Uutela et al., 2008)	No	Yes: Goal setting (Action-outcome expectancies), motivating progress from intention to change, using educational sessions	Yes: (Reduced diabetes distress $p<.002$)	No	4/6
Davies et al. (2008)	Yes: SCT, Common sense theory,	Yes	No	Yes: Educational session develops self-	Yes: Illness perceptions (*p*	No	4/6

	dual process theory, and self-regulatory model			responsibility through highlighting risk factors and choosing specific goals thus enhancing self-efficacy	= .001, correlated with weight loss (*p* = .008)		
Dutton et al. (2008)	Yes: Trans-theoretical Model and SCT	Yes	No	Yes: Stage of change-based counselling book addressing motivation, self-efficacy, goal-setting, social support, and problem-solving.	Yes: Intervention group in stages of change (OR=3.2, 95% CI=1.0, 10.3) Approximately 43% of intervention participants demonstrated stage Action or Maintenance stage	No	4/6
Thoolen et al. (2007)	Yes: Self-regulation theory & proactive coping	Yes	No	Yes: Goal setting as part of a 5 step plan to improve dieting, medication and physical activity	Yes: goal attainment (*p* = .001), self-efficacy (*p* = .005)	Yes, support for constructs used in measures	5/6
Yates et al. (2009)	Yes: SCT, Common sense theory,	Yes	No	Yes Structured educational	Walking self-efficacy (*p* = 0.01)	No	4/6

	dual process theory, and self-regulatory model			programme targeting self-efficacy, overcoming barriers and self-regulation. Goal setting for increased walking levels to improve physical activity.			
Sacco et al. (2009)	Yes: SCT Control Theory	Yes	No	Yes: Diabetes knowledge and self-efficacy, social support and reinforcement targeted through counselling sessions. Weekly goal-setting.	Yes: Self-efficacy, (*p* = .05); Reinforcement for self-care behaviour, (*p* = .001); Awareness of self-care goals, (*p* = .01)	Yes: Self-efficacy enhanced by intervention and acts as mediator for depression, therefore should be further explored	5/6
Contento et al. (2010)	Yes: SCT SDT	Yes	No	Yes	Yes: Increased self-efficacy for all targeted behaviours except eating more fruits and vegetables (*p* = .001)	No	5/6

Wu et al. (2011)	Yes: SCT	Yes	Yes	Yes: Pamphlet encouraging goal setting, DVD and counselling sessions enhancing self-efficacy skills	Yes: Efficacy expectations ($p = .01$); Outcome expectations ($p = .01$); Self-care behaviours ($p = .01$)	Yes: Advocates combined use of self-efficacy and outcome expectation	6/6
Hartmann et al. (2012)	Yes: Mindfulness	Yes	Yes	Yes: Mindfulness-based stress reduction (MBSR) through Group meditation practices	Yes: Lower levels of depression ($d = .71$) and improved health status ($d = .54$)	No	5/6
Glasgow et al. (2012)	Yes: SCT social-ecological theory	Yes	No	Yes: Internet based programme with and without additional support, comprising behaviour addressing motivation techniques for goal setting and problem solving	Yes: Self-efficacy and d scale (both not significant)	No	4/6
Mohamed et al. (2013)	Yes: Empowerment and health belief model	No	No	Yes: Self-support and illness awareness developed through	Yes: Attitude, ($p = .0001$);	No	3/6

				health education and counselling			
Miller et al. (2014)	Yes: Mindfulness SCT Theory of meaningful learning	Yes	No	Yes: Eating directed meditation and SCT component focussing on knowledge, outcome expectations, and self-efficacy	Yes: Depressive symptoms, outcome expectations, Eating Self-efficacy, (all *p* = .0125)	Yes: Constructs of SCT and mindfulness	6/6
Jennings et al. (2014)	Yes: Theory of Planned Behaviour	Yes (In methods)	Yes	Yes: Attitude, perceived behavioural control and subjective norm	No	No	3/6
Heideman et al. (2015)	Yes: Health Action Process Approach	Yes	Yes	Yes: Two stage behavioural change programme plus personal risk, outcome expectancies and self-efficacy components	Yes: Mostly not significant psychosocial results except diet and PA self-efficacy (*p* = .006 and *p* = .008 respectively)	No	5/6

Biddle et al. (2015)	Yes: SCT, Common sense theory, dual process theory, and self-regulatory model	Yes	No	Yes: As Davies et al. (2008) and Yates et al. (2009). Leaflet on illness perceptions. Workshop on diabetes knowledge, goal setting, self-management and self-awareness, social support and self-efficacy	Yes: (not significant psychosocial measures)	No	4/6
Ramadas et al. (2015)	Yes: Trans-theoretical Model (Abstract)	No	Yes	Yes: Dietary Stages of Change (DSOC) Dietary Knowledge, Attitude, and Behavior (DKAB)	Yes: Dietary Knowledge, Attitude, and Behavior score was strongly correlated with con- tent satisfaction (r=0.826, p<0.001), acceptability (r=0.793, p<0.001) and usability of the website (r=0.724, p<0.001), and moderately correlated with	No	4/6

					frequency of log-in (r=0.501, p<0.05) and		
Yates et al. (2016)	Yes SCT, Common sense theory, dual process theory, and self-regulatory model	Yes (In protocol)	No	Yes (Supplementary materials) And as Davies et al. (2008) and Yates et al. (2009)	No	No	3/6
Macedo et al. (2017)	Yes Behavioural change protocol	No	Yes	Yes	No	No	3/6
McCurley et al. (2017)	Yes: SCT SDT	No	No	Yes	No	No	2/6
Taggart et al. (2017)	Yes SCT, Common sense theory, dual process	No	No	Yes: As Davies et al. (2008) and Yates et al. (2009). Leaflet on	Yes: IPQ shift (P = 0.00)	No	3/6

	theory, and self-regulatory model			illness perceptions. Workshop on diabetes knowledge, goal setting, self-management and self-awareness, social support and self-efficacy	DIRQ (not significant) WHOQOL-BREF (Not significant)	
Totals (Yes)	**22**	**17**	**6**	**21**	**19**	**6**

3.7. Strengths and Limitations

This review has taken a rigorous approach to identifying and evaluating theoretically driven T2D prevention and intervention programmes, with a view to identifying potential areas for adaptation to the ID population. A rigorous search strategy was used which identified studies ranging in theoretical position, geographical origin and design quality. The use of the EPHPP quality assessment tool (2008) enabled a systematic and contemporary critique which can be used to inform subsequent studies.

A limitation was apparent in the search criteria around diabetes. Searching specifically for T2D excluded many physical activity studies, which may have provided further insight into application of theoretical models. However, as many of the studies in this paper were aimed at lifestyle change through increased physical activity or improving health literacy, it is likely that the models would have been similar. Therefore, by focussing on T2D studies, those relevant to the review questions were identified and analysed.

The inclusion criteria of explicitly described theoretical models may also have limited the scope of the review, as there may have been studies which successfully targeted a range of outcomes without explicit recourse to models. However, it was important to establish the dominant and successfully applied models so that these could be evaluated alongside the needs of people with ID who are diagnosed with or at risk of T2D, as such models have not been applied to this population in the context of T2D self-management.

3.8. Conclusions

Over the 12-year period focussed upon in this review, an internationally diverse range of prevention and self-management programmes were identified. These were critically analysed in the context of stringent criteria. The educational needs of people with ID at risk of or self-managing T2D may be met through existing programmes, although further modifications may be required for print-based resources to ensure accessibility. Facilitated self-reflection and elicited learning, underpinned by self-regulation theory and dual processing theory, may enable people with ID to reflect on and modify their current understanding of T2D risk factors and consequences. Further support for diabetes-related emotional distress in people with ID could potentially be provided using mindfulness. Goal setting and resiliency training, underpinned by SCT and delivered in a peer-shared environment, may enhance self-efficacy.

This review provides support for further randomized controlled trials of programmes for people with ID under development or having undergone feasibility studies. Rationale is also provided for the development/adaptation of a preventative programme based on similar components and theoretical models. This may achieve greater impact if delivered to younger adults or adolescents with ID, and an educational setting may provide an enhanced level of social support and reinforcement, thus leading to sustained behavioural change.

As exampled by the frequent deployment of SCT across the studies, it is a well-evidenced, flexible and clearly operationalised model. The ‘Four Sources’ model provides a clear framework for enhancing self-efficacy and subsequently confidence in diabetes self-management. SCT therefore stands as the most appropriate framework upon which to base future research regarding self-management of diabetes and people with ID. However, further work is required in order to assess the meaning and relevance of SCT constructs such as self-efficacy and outcome expectations to people with ID. These findings could inform and provide a theoretical basis for the advancement of research in the under-researched field of long term health conditions as experienced by people with ID.

The findings from this review lead to the following chapter, in which the relevance of the Self-efficacy construct is evaluated for people with ID self-managing T2D, and an outline for the methodology of this second phase is presented. The present chapter also provides rationale in part for the third phase, as components which target physical activity, dietary and diabetes knowledge and psychosocial support have been identified for use with younger people with ID.

Chapter Four – Phase 2 methodology

4.1. Introduction

This chapter describes the methodology for the first phase of the research, entitled: “An application of Bandura's ‘Four Sources of Self-Efficacy’ to the self-management of type 2 diabetes in people with ID: An inductive and deductive thematic analysis”. The chapter first outlines the overall epistemological standpoint which informed the methodology. An overview of qualitative methodology is presented, including the epistemological standpoint and range of methods typically employed in research focussed on behavioural change interventions. The strengths of qualitative approaches together with critique from the standpoint of quantitative research is also discussed in relation to the present aims and questions. This methodology informs the specific methods which follow, and include: recruitment participant demographics, recruitment procedures, ethical considerations, interview schedules, and analytical procedures.

4.2. Qualitative research design framework

It is recommended that prior to designing and conducting research, an overarching, guiding framework should be adopted (Creswell, 2003). This framework should address the following four facets of research (Crotty, 1998):

1. Epistemology: the theory of what constitutes knowledge
2. Theoretical stance: the philosophical position adopted by the researcher

3. Methodology: the guidelines for linking methods to the outcomes of the study
4. Methods: the techniques and procedures used to collect data

Creswell (2003), conceptualises epistemology and theoretical stances as “knowledge claims”. These claims enable researchers to begin a study with assumptions about what and how they will learn in its course. Four broad knowledge claims have been highlighted by Creswell (2003): “Post-positivist knowledge claims”; “Socially constructed knowledge claims; “Advocacy/participatory knowledge claims”; "Pragmatic knowledge claims”. These will be discussed in relation to the planning and design of the present study, highlighting the range of alternative methodological approaches and providing rationale for the select approach.

4.2.1. Post-positivist knowledge claims

Post-positivism challenges the earlier positivist stance of advocating absolute knowledge, where facts are empirically proven, to proffer instead that research can only refute or support theory, necessitating further testing (Creswell, 2003). The central characteristics of post-positivism are: i) determinism, where causal relationships are explored; ii) reductionism, where ideas are reduced into discrete variables in order to test hypotheses; iii) objectivism, where knowledge is obtained through observation of others and measures are taken to reduce bias as far as possible; iv) quantifiable, where data is numerical and must be counted; v) generalisable, where the findings taken from a sample can be generalised to a population.

The present phase of the study was exploratory and aimed to explore the meaning of self-efficacy for people with ID with T2D. There was arguably an element of determinism present, as the impact of self-efficacy on T2D self-management was investigated. Psychometric scales have been used to look at the effect of self-efficacy on physical wellbeing, such as the Self-efficacy for Leisure Physical Activity scale (Peterson et al., 2009). However, as the literature reviews in Chapters Two and Three highlighted, research into the experiences of people with ID self-managing T2D is limited, and these experiences have not been explored in relation to the Self-efficacy construct. It was therefore appropriate to take an approach which explored the richness and complexity of people with ID's self-management experiences subjectively and frame these experiences around the self-efficacy construct. Reducing responses into objective, measurable and generalizable data was therefore not an appropriate approach.

4.2.2. Socially constructed knowledge claims

Social constructivism holds that individuals seek to make meaning out of the world they live in through social interaction (Crotty, 1998). These meanings are subjective and varied, which leads the researcher to seek identification of the complexity of participants responses, rather than to reduce them into something quantifiable, as is the case with Post-positivism (Creswell, 2003). Researchers seek the subjective, rather than objective, and pose open-ended questions which generates ground-up data which builds the evidence base from the perspective of the participant, rather than starting with a theory to be tested. As knowledge is claimed to be socially constructed, the social context of participants is of key-importance.

These considerations make Social Constructivism a more suitable stance than Post-positivism. There is however a research aim in the present study which questions the appropriateness of this knowledge claim. As described in Chapters Two and Three, the success of an intervention is likely to be dependent on the application of a theoretical model, with Social Cognitive Theory highlighted as a model to be further evaluated. Therefore, one of the aims of the present study requires a theory-driven, rather than participant-driven approach. This presents a potential dilemma between taking a Post-positivist and Social Constructivist approach. However, as will be further discussed in the methods section of the first phase methodology, Braun and Clarke's (2006) Thematic Analysis provides a flexible approach which enables a data collection which is both deductive and inductive.

4.2.3. Advocacy/participatory knowledge claims

Whilst there are characteristics in the methodologies described above which would inform an appropriate methodology for the present study, more recent positions may be better posed to serve the participant sample group. The advocacy/participatory position which arose in the 1980's/90's saw prior positions as unsuited to addressing issues of social injustice for marginalized groups (Creswell, 2003). These groups have included race, class, gender, and disability. The assumptions within the advocacy/participatory position are summarised by Kemmis and Wilkinson (1998) and include: i) research should be action orientated and aimed at providing an agenda for change which benefits a marginalised group(s); and ii) research should be emancipatory in that it frees a social group from inequalities in society, such as workers' rights, education, and health; it should be collaborative in that the views of participants are actively sought in the research process.

The purpose of conducting the present research was to investigate Self-efficacy, with a view to informing future behavioural-change based intervention programmes. It was therefore aimed at contributing to a change beneficial to the participants, who are of a marginalised group. It is also collaborative, in that the views of people with ID self-management experiences are sought. The advocacy/participatory approach was therefore closely aligned to the aims of the study, and as such inform the study methods.

4.2.4. Pragmatic knowledge claims

Pragmatists, such as Cherryholmes (1992), advocate that in order to solve problems, such as the appropriateness of research methodologies, multiple philosophical standpoints may be taken. The following traits are observed by Creswell (2003): Pragmatic approaches may be mixed method and can therefore make use of quantitative and qualitative methodologies. Pragmatists agree with the advocacy/participatory position that research occurs in a social context and may therefore have social and political aims. An appropriate methodology must be flexible as it is subject to the practical requirements of the study, which may be influenced by contextual factors such as time, geography and resources. However, a strong rationale must be provided when mixing methods, to avoid an outwardly ad hoc approach.

It was necessary to adopt a mixed method approach in the present phase of the study as it was important to provide contextual demographic information, as per guidelines for conducting qualitative research (such as Elliot et al., 1999) which were discussed in Chapter Two. This approach is central to evaluating the process of implementing interventions, which is discussed in greater detail in Chapter Six.

4.2.5. Methodology informed by knowledge claims

The second phase of the study involved an evaluation of the relevance of a mainstream theoretical model for people with ID's diabetes self-management: Bandura's (1977) Four Sources of Efficacy Enhancement. To gain an insight into the appropriateness of using this model, the focus was to qualitatively explore the experiences and perceptions of people with ID. Experiences which were facilitators or barriers to self-management were explored using a deductive thematic analysis, which was guided by the constructs of Bandura's (1977) Four Sources model. The relevance and appropriateness of these constructs were evaluated in respect to the experiences. This phase informed the selection of the Walking Away programme as well as the setting for its delivery. The selection of this programme is discussed in Chapter Six.

4.3. Participants

Ten participants took part in this study. This sample is typical of similar studies in the literature (Macrae et al., 2015). The majority were male (*N*=7). Age range varied from 25 to 67yrs (mean = 49 years). Time since diagnosis of T2D ranged between two and 30 years (mean = 9 years). All names referred to herein are pseudonyms. Participant demographics are as described in *Table 4.1*, below:

Table 4.1: Participant demographics

Participant (Pseudonym)	Gender	Age at interview	Years since diagnosis (approximate)	Support to participate (High, medium, Low)		
Derek	M	45	15			Low
Ian	M	56	Unknown		Medium	
Annette	F	67	20		Medium	
Sam	M	60	30			Low
Gordon	M	44	Unknown		Medium	
Frankie	M	47	Unknown			Low
Daniel	M	53	2		Medium	
Mary	F	58	15			Low
Gavin	M	37	2		Medium	
Nicole	F	25	2	High		

4.4. Recruitment

Participants were recruited by the researcher through day and residential services, local authority social work centres and local area coordinators (LAC). Representatives from these organisations, including senior care staff, social workers and LAC's, acted as 'gatekeepers' and identified potential participants for the study, informally assessing their ability to reflect and communicate sufficiently for participation. Following this, easy-read information sheets and consent forms were sent out to participants via gatekeepers, with a minimum of a week to read. Consent was reviewed with participants prior to commencement of each interview as recommended by ethical guidelines for research with people with ID (National Disability Authority, 2009). Recruitment materials are presented in the appendices (Appendix 1-5, Volume II, p.1-15). Each interview was audio recorded, transcribed verbatim and coded, with the participants' permission. Ethical approval was obtained from Edinburgh Napier University ethical research governance.

4.5. Interview procedure

Participants were interviewed either at a day-centre (*N*=4) or a home/residential setting (*N*=6). Two of the participants were accompanied by carers for the interview. Interviews were semi-structured. This approach enabled flexibility to explore areas of interest to participants, which may have been less possible with a fixed schedule. Unstructured interviewing was also considered; however, it was necessary to follow a schedule based around the constructs of self-efficacy. Each lasted under one hour, which is typical for people with ID due to barriers to communication (Beail and Williams, 2014). The interview schedule was developed with questions structured around Bandura's (1977) Four Sources model. This model was selected based on its existing application to mainstream interventions such as the widely-implemented DESMOND programme (Davis et al., 2008), which has been adapted for people with ID (Taggart et al., 2015). Components of the model were contextualised for self-management of T2D and provided areas for enquiry. *Table 4.2*. below describes these contextualised components and provides examples of interview questions through which they were explored. A copy of the interview schedule is provided in the appendices (Appendix 5, Volume II, p.16).

Table 4.2: Self-efficacy component questions

Component	T2D context	Question example
Mastery of Experiences	Positive past T2D self-management experiences	*"I wondered if you could tell me about any changes that you've made in your lifestyle, and why you think you made those changes?"*
Vicarious Experiences	Learning how to self-manage T2D through observing peer experiences	*"So how does it feel, to have to make those changes around others who don't?"*
Verbal Persuasion	The importance of positive self-feedback, as well as from health professionals, regarding self-management of T2D	*"What do you think gave you the motivation to make those changes?"*
Emotional/ Physiological Arousal	Confidence from recognising symptoms of T2D	*"Would you be able to describe an experience where you've listened to what your body is telling you?"*

4.6. Analysis

The analysis was theoretically driven by Bandura's (1977) Four Sources model. A latent level of analysis was used as it was necessary to interpret some statements due to communication difficulties in some of the participants. An inductive method guides a data driven approach in which the participants' experiences are represented (Braun and Clarke, 2006). This approach guided the initial phases in which codes were generated to reflect these experiences. A deductive approach serves the purpose of evaluating an existing theory in a different population (Hsieh and Shannon, 2005; Vaismoradi, Turunen, and Bondas, 2013). This guided the latter phases in which coded themes were organised into the constructs of Bandura's (1977) Four Sources model.

Although Bandura's framework strongly guided the interviews and analysis, the researcher strived to accurately represent the views of the participants. To ensure this, a second coder (AD) reviewed the codes and early themes, prior to these being mapped onto the framework. In addition, themes were developed using codes which contradicted, as well as supported, Bandura's model. This balance helped avoid a bias towards aligning the participants' responses towards the model's mechanisms. Finally, the researcher drew upon his own background in social care to support participants in expressing their own experiences and opinions. Contextual background information from paid carers and family members was also sought by the researcher, separate to their interactions with participants. Analysis was carried out using Braun and Clarke’s (2006) coding procedure. This involved a six-phase guidance to analysis which included:

1. Familiarisation with data through transcription, multiple readings and note taking
2. Inductively generating initial codes from descriptions which were of importance to participants. This involved a degree of interpretation by the researcher to represent any experiences that participants had struggled to articulate
3. Searching for themes, where initial codes were grouped together by similarity, and organised into potential themes

4. Reviewing themes, which involved refining ‘candidate themes’ from the previous phase. At this stage, validity checks were carried out by the second author for accuracy, consistency and agreement of themes

5. Defining and naming themes, where analysis is organised into a narrative structure with accompanying descriptions. These themes are discussed individually as well as in relation to each other. At this deductive stage, the themes were mapped onto Bandura’s (1977) Four Sources model. Each of the model's constructs contained supportive or contradictory themes, which enabled discussion of their relevance to people with ID self-managing T2D

6. Producing the report which is described in the following chapter

Examples of the latter analytical phases described above are provided in the appendices (Appendix 7, Volume II, p.17).

4.7. Chapter conclusion

This chapter has firstly presented an overview of knowledge claims and evaluated each in relation to the aims of the present phase of the research project. A qualitative approach informed by the advocacy/participatory approach was selected. A small but representative sample was recruited. Because of the need for representing the participants’ subjective experiences and evaluating the Self-efficacy construct alongside this, an inductive and deductive analysis was carried out. The following chapter presents the results and discussion of this phase of the thesis.

Chapter Five – Results of Phase Two

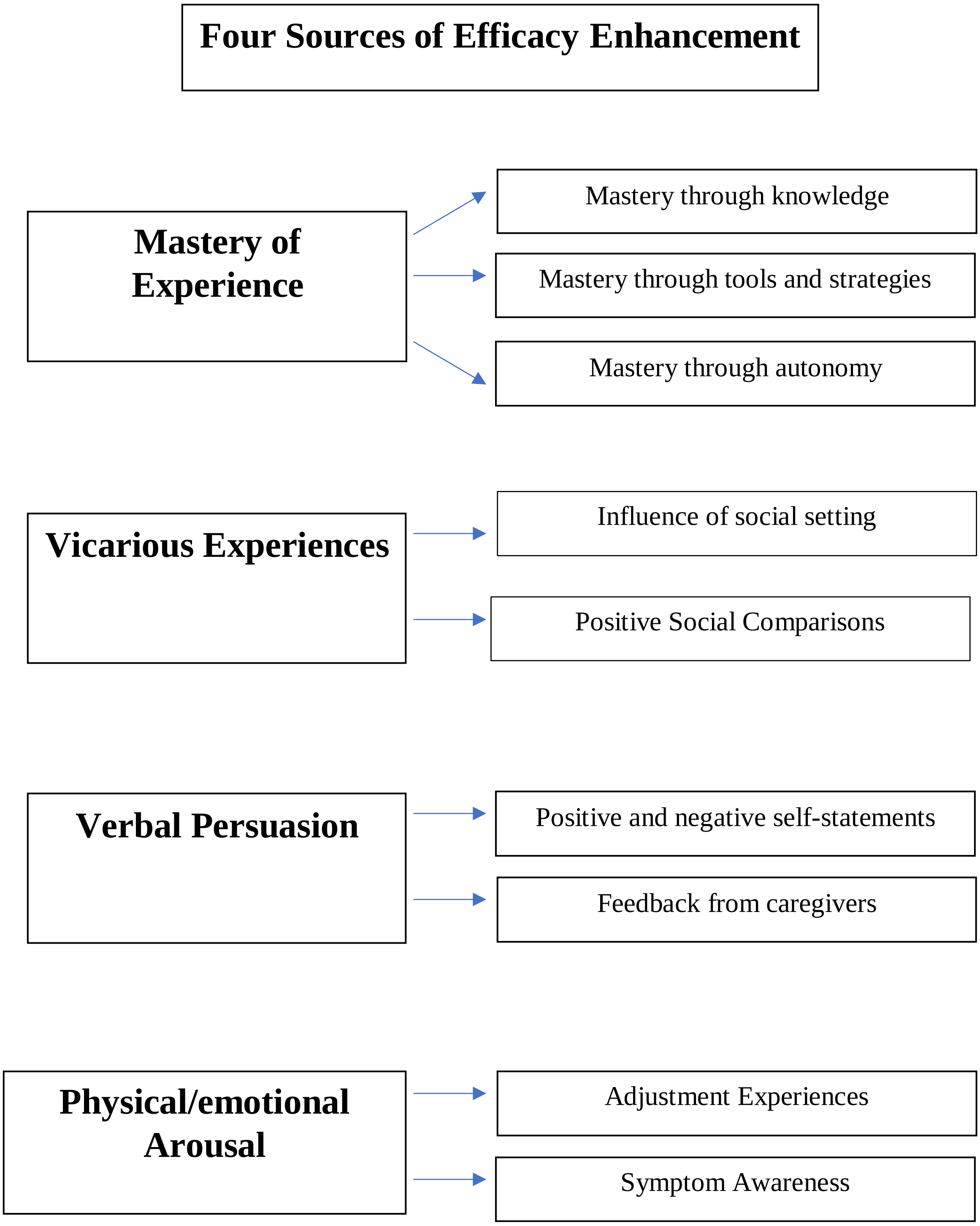
5.1 Introduction

This chapter presents the results of the second phase, an exploratory study on the T2D self-management experiences of people with ID. This phase of the study has undergone peer review and has been published in Research in Developmental Disabilities (Maine, Dickson, Truesdale, and Brown, 2017). A copy of the accepted paper is included in the appendices (Appendix 21, Volume II, p.106). A total of nine themes are presented through thematic analysis of ten semi-structured interviews, using Bandura's Four Sources of Efficacy Enhancement model. The model serves as a useful mode of enquiry for exploring people with ID's experiences and perceptions of self-managing diabetes. It also confirms the appropriateness of Self-Efficacy as a potential intervention component for this population. However, additional support may be required for people with ID to reflect meaningfully on their experiences and thus lead to self-efficacy.

5.2. Emerging themes and subthemes

Nine sub-themes were extracted from the data and mapped over Bandura's Four Sources of Efficacy model. These are presented in *Figure 5.1*. The "Mastery of Experience" sub-themes describe how a sense of competence in T2D self-management was obtained in the areas of knowledge, mastery through tools and strategies, and autonomy. “Vicarious Experiences” sub-themes describe the importance of social setting and social comparisons in regard to modelling the healthy lifestyle behaviour of others. “Verbal persuasion” includes sub-themes relating to the participants' positive self-feedback and feedback from others. The sub-themes included in “Physical/Emotional Arousal” describe the experiences of loss and symptom awareness.

Figure 5.1: Overarching themes mapped onto the Four Sources model



5.2.1. Mastery of Experience themes

The Self-efficacy sub-theme “Mastery of Experiences” describes confidence derived from successful past experiences (Bandura, 1977). In the context of the present study, the participants’ descriptions of T2D self-management experiences which they perceived to be successful are presented. Many of the participants (*N*=8, 80%) provided these descriptions. The experiences are organised into three sub-themes which include mastery though knowledge, tools and strategies, and autonomy.

5.2.1.1. Mastery through knowledge

Participants (*N*= 80%) expressed confidence regarding diet, medication and monitoring, and diabetes knowledge. Through achieving a level of competence in these areas, the participants could speak with confidence about self-management. This is exampled by Annette, a 67-year-old woman who had lived with T2D for approximately 20 years, and for whom dietary confidence appeared to have been enhanced through attending a diabetes educational programme. This had led to her seeking out a range of sugar free recipes, which she was keen to describe throughout the interview. The improvements in her diet had in turn led to weight loss, as well as to her leading a more active social life

> *Annette: …if it hadn’t been for [educational programme] I would’ve still been putting on more weight…*

Self-management confidence was enhanced through knowledge for Derek, a 45-year-old man with approximately 15 years of diabetes self-management history. In this time, Derek had used several different HbA1c readers, which measure glycated haemoglobin levels to reflect average blood glucose levels, and insulin pens, which provide a self-administered insulin injection. He seemed to enjoy that this was a domain in which he was an expert, and it was possible that this led to competence in reading and recording his blood sugar levels.

> *Derek: Now I've got a talking machine, so, you put your needles and things in there…it looks like a phone…*

In contrast, other participants demonstrated a lack of knowledge which reflected confusion over diet, a dependence on support staff for medication control, and a poor understanding of exercise. For example, Gordon, a 44-year-old male with an unknown duration since diagnosis, appeared to have a lack of knowledge regarding what constitutes exercise and appropriate levels of exercise. He described minimal amounts of walking when asked about exercise, however then later discussed friends from his Zumba class when describing social activities.

> *Gordon: Ohhh, well, I only do a wee bit of walkin' see as far as the door. But I, I'm ok ... I can always have a wee chat to my pals at Zumba…"*

5.2.1.2. Mastery through tools and strategies

This sub-theme describes the tools and strategies participants used to overcome barriers to self-management such as visual and memory impairments, typical in people with ID. These tools enabled some of the participants (*N*=6, 60%) to master self-management skills, particularly in the areas of medication control and keeping to medical appointments. For some participants, visual impairments and literacy issues were overcome by using large print. Derek had previously stated that he had poor eyesight, which he attributed to diabetes. His use of a large diary helped to offset this difficulty.

> *Derek: ...Some people got a really small diary ken, three times smaller than that. I like to keep it big so that I don't need a magnifying glass.*

Derek seemed proud of his ability to keep records and was keen to demonstrate pages from the diary. Other participants used tools to avoid forgetting appointments and medication routines. Annette and Frankie both emphasised the importance of using calendars, demonstrating this by presenting them and describing upcoming events. This is best illustrated by the following quote from by Frankie, who described overcoming difficulties in finding his way to the doctor for diabetes check-ups. By using a consistent route and building a sense of familiarity, he was able to overcome anxiety about getting lost.

> *Frankie: At first, I was wary at first. But, as the time went on, to me it's just a piece of cake.*

For other participants, strategies were used to overcome dietary frustrations. Having a weekly 'treat' seemed to help with the adjustment to dietary changes. For Iain, who expressed resentment over living with others who did not have a restricted diet, this involved having a weekly takeaway:

> *Iain: Always have my Chinese on a Saturday. I couldn't cut that out.*

These tools enabled the participants to overcome T2D self-management barriers such as cognitive impairments associated with having an ID, as well as coping with frustrations around loss.

5.2.1.3. Mastery through autonomy

The participants' (*N*=4, 40%) success of "Mastery through Autonomy" was dependent on relationships with those in support networks, including paid and unpaid caregivers, who could facilitate or control diabetes self-management. Autonomy was therefore achieved through both the acceptance and rejection of support from others.

Several participants described independently attained knowledge, including Sam, Frankie and Derek. Each stated that they were given little information following their diabetes diagnosis, and that they had needed to learn by themselves, through trial and error.

> *Frankie: Aye well I've sort eh. sort of learned through the hard way eh?*

For Sam, this was followed later with statements which suggested a rejection of professional support from doctors. Sam had experienced some difficulties in the past with medication adjustment. He described an experience where he felt that his stress levels interacted with his medication, leading to a hypoglycaemic episode, which occurs when blood glucose levels reach a low point resulting in sweating, dizziness and fatigue (Diabetes UK, 2017). He blamed this on the lack of information provided by his doctor at the time:

> *Sam: The only trouble is.. doctors. I wish they would give you more information about tablets…*

Sam also described situations involving discussions with his doctor. These were regarding smoking cessation and medication control, and in both areas Sam positioned himself as the expert, suggesting that he was better informed:

> *Sam: …the doctor was sayin', ah its ok, dinnae worry about it, just reduce it by 2 units for days blah blah blah. But, I looked at the figures and I knew what I needed.*

For Daniel, autonomy was facilitated by his support worker. Daniel was a 53-year-old man, who had also been diagnosed two years before. He described good intentions towards controlling his diabetes through diet and exercise, but also described this being a struggle for him. However, his support worker had helped him to make healthier decisions and choices, as the following example demonstrates:

> *Daniel: …we got some of these muesli bars, and we decided to put them in my safe, so I don’t eat them all in one go.*

These three areas of experience provided the participants with a sense of confidence in their ability to self-manage with independence. Confidence could also be attained through the influence of others, as the following theme suggests.

5.2.2. Vicarious Experiences sub-themes

“Vicarious Experiences" describes confidence from observing success in peers and modelling this behaviour (Bandura, 1977). The present sub-theme, which represents 4/10 of the participants, describes the limitations for social modelling opportunities in the participants' lives, as well as their descriptions of being a positive influence on others. Finally, there are descriptions of participants modelling people without ID, who are an influence on the participants' lifestyles.

5.2.2.1. Influence of social setting

The social settings of some participants in this study (3/10) were sometimes detrimental to self-management, particularly in regard to diet. Participants who lived in shared accommodation were often surrounded by other people with ID who did not have diabetes, and thus no dietary restrictions. This led to frustration, rather than providing positive examples for social modelling. Iain described finding this particularly difficult during special occasions, for example when cake was handed out. These occasions, where self-restraint was challenged by temptation, appeared to have had a negative impact on his acceptance of having developed diabetes:

> *Iain: …especially if somebody's got a birthday in here, ey, with a birthday cake. I [can't] take a bit cos of my diabetes*

However, in other areas of self-management the influence was more positive. Sam described a reciprocal caring relationship in which Mary, his wife, could recognise in him the early symptoms of a hypoglycaemic episode and Sam could subsequently adjust his insulin. In turn, he, could help with her own adjustment:

> *Sam: Well, looking after mine, and looking after hers, I'm able to help her, she knows roughly when I'm in the early stage of a hypo, I don't know how but she does. And um.. eh.. I'm able to adjust my insulin, plus I'm able to adjust hers… if it needs adjusting.*

The influence of setting was also described by several participants (5/10) in relation to exercise, such as Gavin who described going hillwalking as part of his day service activities, and Annette who had participated in a sponsored walk. Daniel described his caregivers supporting him to moderate his pace when going for walks so that he was able to do so without becoming fatigued:

> *Daniel: But eh, Ali and Pawel is getting me to walk at a pace which is comfortable. Because I used to go "wheesht wheesht," know what I mean?*

5.2.2.2. Positive social comparisons

Although the participants could not provide positive examples of social modelling from their peers, Annette's attendance at a structured education programme had enabled her to meet other people with ID who were self-managing T2D. She described a situation in which she was the positive influence on a fellow attender, who had expressed reservations about making dietary changes:

> *Annette: …I met a girl when I was at [training location], and she said I can't try anything like that, try and change my diet… then I said, I've got a sample with me, if you [want to] try it.*

Social modelling was also positive when comparisons were made by people with ID (2/10 participants) and their caregivers. In this sense, role models provided examples of healthy lifestyle approaches. Gavin's day service included cookery workshops and outdoor activities. It was evident that Gavin's workshop leader was a positive influence on his wellbeing, in terms of dietary choices and physical activities:

> *Gavin: I like making [healthy foods] with Stefano… It's [good for you] when you make it with Stefano! I just like going for walks with people.*

5.2.3. Verbal Persuasion sub-themes

Examples of "Verbal Persuasion", which describes confidence from positive feedback (Bandura, 1977), are presented below as self-statements from the participants (3/10) in relation to their T2D self-management, and of participants (3/10) who appeared to value feedback provided to them by their caregivers.

5.2.3.1. Positive and negative self-statements

This theme describes the self-statements participants gave, which offered insight into their self-perceptions and self-feedback. There were positive and negative statements, which reflected varying levels of confidence in regard to self-management skills. These were mainly related to dieting and exercise, highlighting the participant's beliefs about their ability to make changes. Derek, although using a humorous tone, described himself as a "bad diabetic" and unable to make dietary changes. In this sense, he seemed resigned to this being part of who he was:

> *Derek: I'm one of these bad diabetics that's what it is.*

These statements matched Derek's earlier descriptions of his struggle to control his diet, which may therefore suggest that his diet was influenced by his self-perception. In contrast, it was evident that Daniel believed in his ability to change, despite his being aware of how difficult the discipline of adhering to this could be. Daniel was accompanied by his support worker, who reminded him of the habits he might revert to, including excessive snack consumption, not exercising and forgetting medication:

> *Daniel: It is hard but I can do it. You know I'm gonnae try and do that…*

Mary, a 58-year-old woman with mild ID who had been diagnosed with T2D 15 years prior to interview, also saw herself as able to change. At the time of the interview Mary was in hospital due to several weight related complications. She was aware of the debilitating effect this was having on her life, mentioning that she was no longer able to put on footwear without assistance. However, she intended to use an earlier photograph of herself, as a motivator to lose weight:

> *Mary: … And I'm gonna have it framed and I'm gonna sit and look at it, and focus my mind onto losing the weight again.*

Having the intention to carry out this goal suggests that Mary gave herself positive feedback despite the difficulty of her present circumstances. She saw herself as capable of making dietary improvements, though it is unclear the extent to which Mary would overcome barriers to this, such as the habits which led to her weight gain. Similarly, it is not clear from Daniel's comment how he will accomplish change.

5.2.3.2. Feedback from caregivers

This theme describes *"Verbal Persuasion"* in the sense of taking encouragement from influential others, such as carers and health professionals, who had offered positive feedback. Many of the participants were able to recount experiences where they had taken encouragement from positive feedback, despite there being some ambivalent attitudes to health professionals, as highlighted in "*Mastery through Autonomy"*. Sam had described episodes where he was better informed than his doctor about his health. However, he valued the encouragement that his diabetes nurses could offer him regarding weight loss:

> *Sam: Yeah, it's quite a boost to my system, when they give me a positive feedback, from something that I've done.*

Frankie described himself as having a good relationship with the nurses he saw at his diabetic clinic. He expressed that keeping to these appointments were important to him because of this:

> *Frankie: Aye, aye… they make you happy some of the times and that, because they're cheerful.. and they're all right with me and I'm alright*

> *with them. And I think they're happy with me cos I, I turn up for my appointments and that eh?*

As many of the participants were independent, there were fewer examples of relationships with caregivers and their feedback. When Gavin was asked what he enjoyed about hillwalking, it appeared that the positive feedback from one of his caregivers was a motivational factor:

> *Gavin: I like walkin' up the hills...Sheona says I'm good at walkin'...*

5.2.4. Physical/Emotional Arousal sub-themes

"Physical/Emotional Arousal" describes confidence from physiological or emotional feedback (Bandura, 1977). The sub-themes below describe the emotional experiences of the participants (3/10) regarding their experiences of adjusting their lifestyles in order to self-manage their T2D. Accounts of physical feedback were also given in the form of symptom recognition for two of the participants.

5.2.4.1. Adjustment experiences

The emotionally turbulent experiences of some of the participants are reflected in this theme. These are in relation to the lifestyle adjustments they faced following their diabetes diagnosis. Some participants expressed frustration and resentment relating to a sense of loss in regard what they could do and where they could go. This may have impacted on a lower sense of Self-efficacy.

Sam's sense of loss was expressed regarding his no longer being able to drive certain vehicles and subsequently ability to work. This was due to the risk of having a hypoglycaemic episode. Following this he had tried to train as a mechanic but had suffered from a similar experience, leading to him being told he could not work. He recounted this, and described the frustration he experienced following it:

> *Sam: …We'll put you on long term unemployment. And ey it's a bit of a bugbear to me, it's like a thorn in the flesh.*

Sam also felt that his condition prevented him from being able to do exercise, which he was aware would be beneficial to his diabetes management, describing this situation as a "catch 22". Other participants such as Iain and Daniel expressed frustration at their dietary restrictions, and of no longer being able to eat the things they enjoyed:

> *Daniel: What I dinnae understand is.. I can.. I can stop the temptation of going to the chippie. But the sugar…*

However, despite being aware of the loss, some participants appeared to feel that they had moved on from this and had successfully adjusted to their new lifestyle. Janie was a 25-year-old woman who had been diagnosed two years before. Although she needed assistance from her support worker to participate in the interview, Janie was able to reflect on her experience of adjustment positively when asked if she had experienced it as difficult:

> *Janie: No it doesn't bother me. I'm used to it the now.*

Making these adjustments and thus reducing frustration may have enabled participants to have a great sense of Self-efficacy in their self-management.

5.2.4.2. Symptom awareness

Symptom recognition was also an important source of confidence in self-management for some participants, for example knowing how and when to respond to signs of a hypoglycaemic episode. For Frankie, this involved recognising the sensation of feeling tired due to low blood sugar levels:

> *Frankie: I know the uh, I know the symptoms. Oh aye, I know the symptoms. I know when to stop [to respond], I know when I feel like that.*

Mary and Sam had also described the importance of recognising and responding to symptoms. These sensations acted as trigger warnings for participants, and recognising them provided them with a sense of control over the physiological effects associated with having diabetes.

5.3. Conclusion

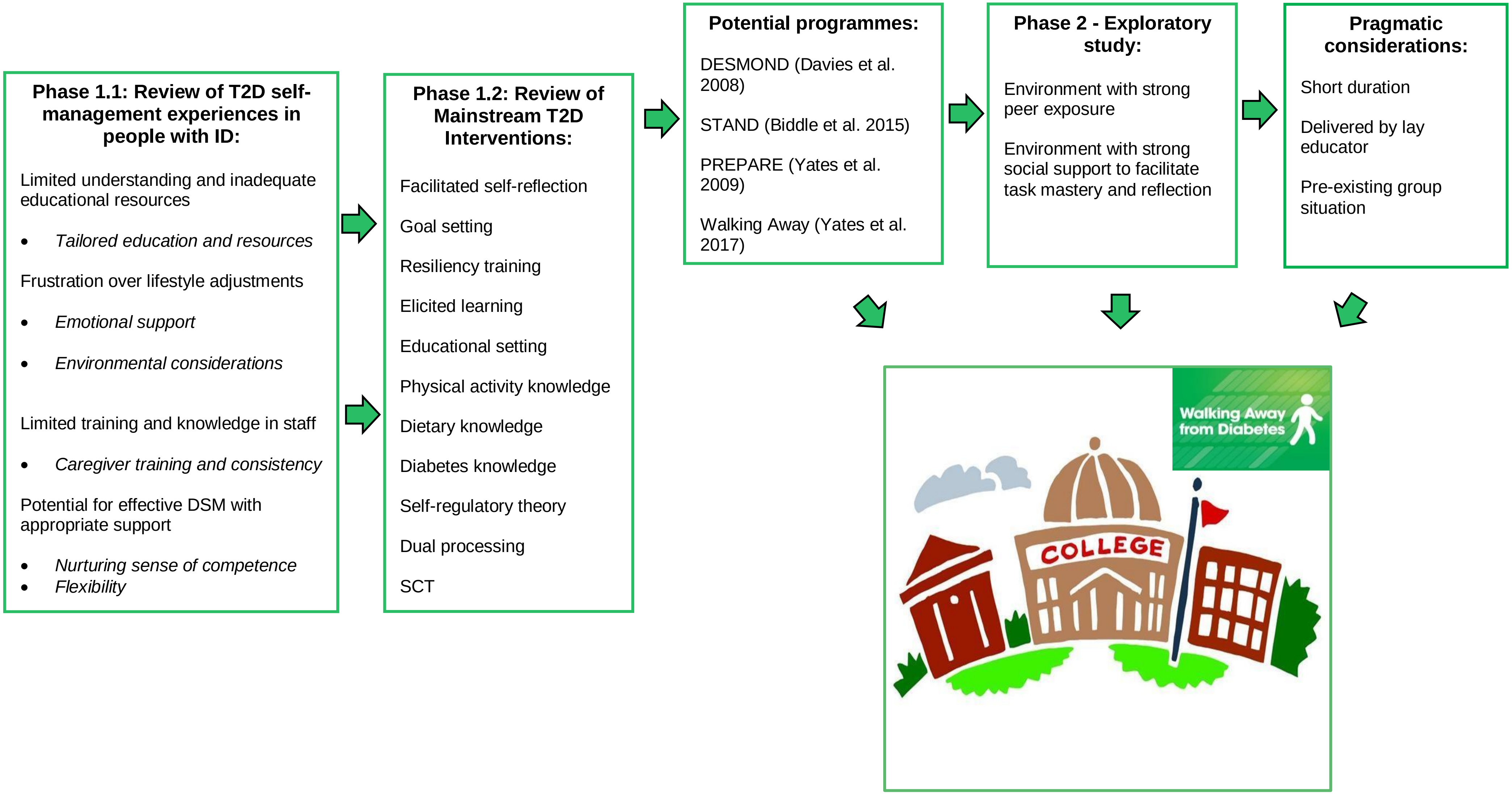
The Four Sources model provided a useful framework for enquiry in the present study on people with ID self-managing T2D. The important self-management experiences for the participants, were inductively represented, then organised into the four components of the model. However, for the model to be used as the theoretical basis for interventions or structured educational programmes aimed at people with ID, additional support is required, primarily in facilitating self-reflections. This may be achieved with proxies, or tools such as reflective diaries, thus enabling a clearer sense of where strengths are and how these can be developed further. Additionally, the environment in which a Self-efficacy-based programme is situated is of key-importance, as vicarious experiences requires a setting rich in peers. The following chapter engages with these caveats by providing a description of the selected T2D prevention programme, Walking Away from Diabetes, and the setting in which the programme is implemented.

Chapter Six – Phase Three methodology

6.1. Introduction

The literature reviews in chapters two and three, together with the findings from the first phase of the study described in the previous chapter, evidenced the need for a tailored programme focusing on diabetes education for young adults with ID. Delivery is necessary in a setting where social support can be provided to facilitate full participation. On this basis, the Walking Away from diabetes programme (Yates et al., 2016) was selected for a feasibility study in a further education college attended by people with ID. On the following page, *Figure 6.1.* models the decision process for selecting this programme and setting. The model first describes the key findings of Phase 1.1, a review of the T2D self-management experiences in people with ID. This review identified the needs of people with ID self-managing T2D, which were used to inform Phase 1.2, a review of mainstream T2D interventions. Core components and theoretical models relevant to these needs were highlighted and four potential programmes were identified (Biddle et al., 2015; Davies et al., 2008; Yates et al., 2009; Yates et al., 2016). Following this, the key findings of Phase 2 are presented, which explored the meaning and relevance of the Self-efficacy construct for people with ID, a central theoretical model in the potential programmes. Finally, several pragmatic considerations were made, such as recruitment, duration and resources. These, alongside the preceding stages, led to the selection of the Walking Away programme in a further education setting.

Figure 6.1: Programme selection decision flow chart



Phase 1.1: Review of T2D self-management experiences in people with ID:

Limited understanding and inadequate educational resources

- *Tailored education and resources*

Frustration over lifestyle adjustments

- *Emotional support*
- *Environmental considerations*

Limited training and knowledge in staff

- *Caregiver training and consistency*

Potential for effective DSM with appropriate support

- *Nurturing sense of competence*
- *Flexibility*

Phase 1.2: Review of Mainstream T2D Interventions:

Facilitated self-reflection

Goal setting

Resiliency training

Elicited learning

Educational setting

Physical activity knowledge

Dietary knowledge

Diabetes knowledge

Self-regulatory theory

Dual processing

SCT

Potential programmes:

DESMOND (Davies et al. 2008)

STAND (Biddle et al. 2015)

PREPARE (Yates et al. 2009)

Walking Away (Yates et al. 2017)

Phase 2 - Exploratory study:

Environment with strong peer exposure

Environment with strong social support to facilitate task mastery and reflection

Pragmatic considerations:

Short duration

Delivered by lay educator

Pre-existing group situation

This chapter describes the methodology that was used to evaluate the feasibility of implementing this programme in larger trial. The framework and guidelines advocated by Creswell (1994) and Crotty (1998), described in Chapter Five have also been adopted in this phase of the study. A brief summary of each knowledge claim is presented below, and discussed in relation to the aims of the present phase. The claims are also discussed in relation to the findings of the first phase of the study which, together with the literature reviews in Chapters Two and Three, provide the rationale for the second phase. Following this the methods are described in detail, which include a process evaluation and thematic analysis of focus groups.

6.1.1. Post-positivist knowledge claims

Post-positivist knowledge claims are as follows: i) Determinist: where causal relationships are explored; ii) Reductionist: Ideas are reduced into discrete variables to test hypotheses; iii) Objectivist: Knowledge is obtained through observation, bias is avoided; iv) Quantitative: Data is numerical and must be counted v) Generalizable: Findings taken from a sample can be generalised to a population.

The present study could have taken a deterministic approach, whereby the effects of a structured education programme on people with ID were explored. In such approaches, these effects are typically tested through a randomized controlled trial (RCT) and reduced into discrete and quantifiable measures. As described in the review of mainstream diabetes intervention programmes in Chapter Three, such measures have included dietary changes (Contento et al. 2010), glycated haemoglobin (Davies et al., 2008) and ambulatory measures (Yates et al., 2009).

Indeed, these were key components in the PREPARE study which informed the Walking Away programme (Yates et al., 2009). Ambulatory measures would have therefore been appropriate for the present study, had a post-positivist position been adopted. Some numerical data was recorded, for example baseline measures and participant demographics, and the feasibility of asking people with ID to wear and record pedometers was partly reflected by numerical data describing these recordings as this demonstrated the extent to which they could participate.

However, a RCT requires a demanding level of resources in order to be successful in terms of statistical significance (Thabane et al. 2010). It is therefore important to determine the potential success of a RCT by first conducting a feasibility and acceptability study, where study processes such as participant recruitment and retention, engagement, and accessibility and acceptability to the studied population are evaluated (Craig et al., 2008). The measures involved in this kind of evaluation lend themselves in part to a post-positivist approach, yet in the case of the present study were more adequately informed by the further “knowledge claims” discussed below.

6.1.2. Socially constructed knowledge claims

Socially constructed knowledge claims are that: i) Individuals seek to make meaning out of the world they live in through social interaction; ii) Meanings are subjective and varied, leading the researcher to seek out complexity; iii) Researchers seek the subjective, rather than objective, and pose open-ended questions which generates ground-up data; iv) Knowledge is socially constructed and the social context of participants is of key-importance.

An important element in the first phase of the study was that structured education programmes may be more effective if opportunities for enhancing Self-efficacy through “Mastery of experience”, “Vicarious experiences” and “Verbal persuasion” are provided, so that self-reflection and learning can be supported and reinforced by peers and supporters. Social setting is therefore of key-importance. The social context in the present study includes the participants’ age, intellectual disability and associated potential for poor physical health, and attending a further education College course for people with ID. Furthermore, social context encompasses the participants' social support.

In the present study, assessing the acceptability and accessibility of the Walking Away programme to people with ID were primary research aims. The issues around delivering a non-tailored programme to people with ID for the first time were likely to be complex. Seeking the subjective experiences of people with ID was therefore an appropriate manner of capturing this complexity, and elucidating participants’ experiences and perceptions of participating in the programme was an appropriate starting point in the process.

6.1.3. Advocacy/participatory knowledge claims

Advocacy/participatory knowledge claims are that: i) Research should be action orientated and aimed at providing an agenda for change which benefits a marginalised group(s); ii) Research should be emancipatory in that it frees a social group from inequalities in society; iii) Research should be collaborative in that the views of participants are actively sought in the research process.

The wider aims of the present study are concerned with reducing potential health inequalities between people with ID and their non-disabled peers. The literature reviews in Chapters Two and Three, together with the results of the first phase of the study, suggest that these aims may in part be realised through developing a tailored educational programme delivered in a setting which offers a high level of social support. These aims are therefore aligned with the position of the advocacy/participatory approach. Furthermore, the views of the participants are integral to the study as these provide insight into the acceptability and accessibility of the materials. The inclusive/participatory stance is common in research with people with ID (Kaehne and O'Connell, 2010). This suitability however does not diminish that of the social constructivist position. It is therefore necessary to consider more than one position, which is discussed further in the following philosophical stance.

6.1.4. Pragmatic knowledge claims

Pragmatic knowledge claims are that: i) Multiple philosophical standpoints may be taken; ii) Approaches may be mixed method, and can make use of quantitative and qualitative methodologies; iii) Research occurs in a social context and may therefore have social and political aims; and iv) Methodologies must be flexible due to the practical requirements of the study, which may be influenced by contextual factors such as time, geography and resources.

The present study required predominantly qualitative but also quantitative, data to evaluate the processes involved in recruiting participants, implementing, the programme and carrying out data collection with measures used in a previous study (Yates et al. 2016). A position which acknowledges social context and the perspective of participants was required, and so social constructivist and advocacy/participatory positions were adopted. Finally, the broader aims of the study were to generate behavioural change through reducing the risk of diabetes for people with ID, and subsequently reducing health inequalities, again drawing upon social constructivist and advocacy/participatory positions.

6.1.5. Methodology informed by knowledge claims

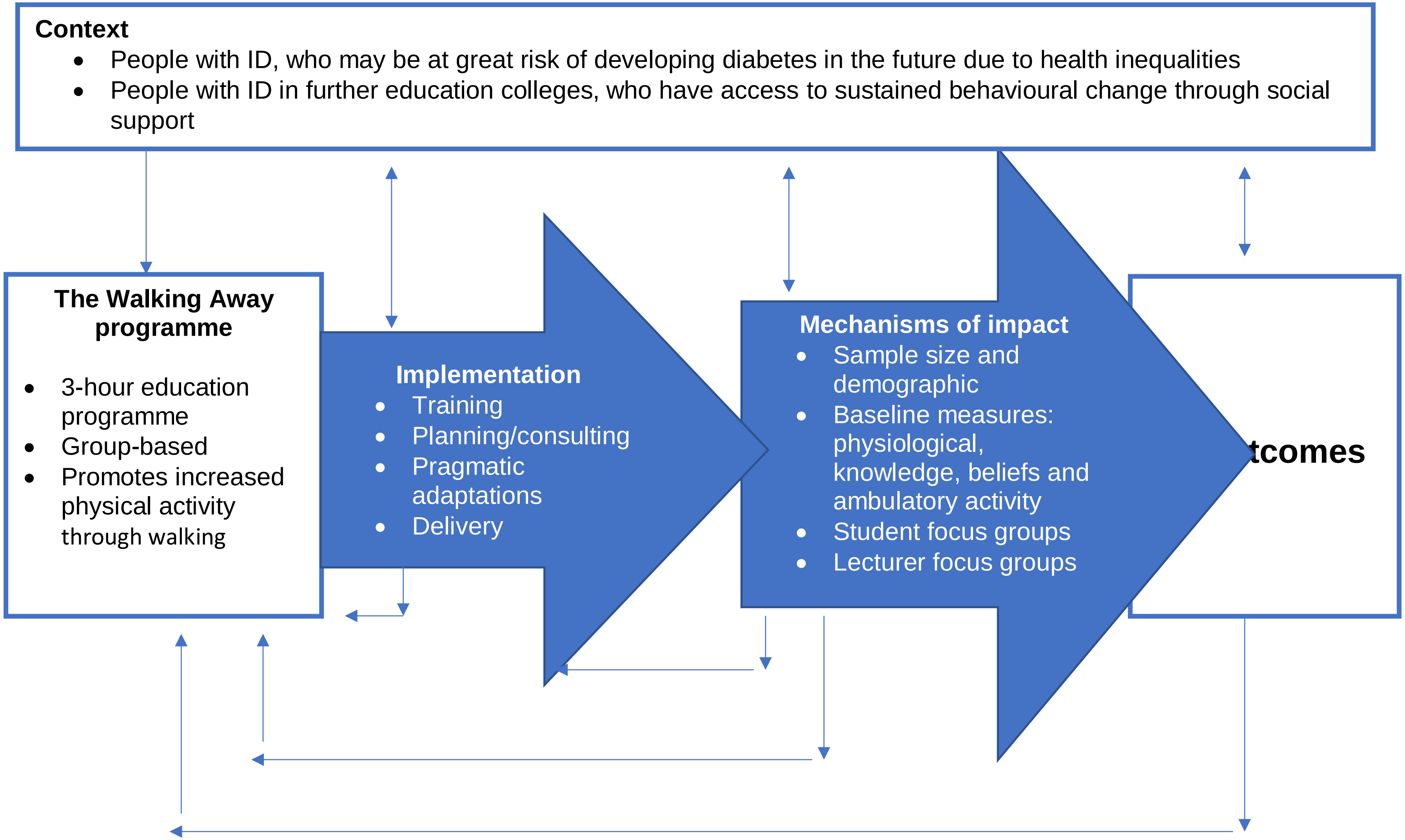
Following the discussion above, a rationale has been provided for selecting a philosophical position for the present element of the study. A predominantly qualitative position was adopted, underpinned by both social constructivist and advocacy/participatory positions. This helped guide the investigation into issues regarding i) the relevance of the theoretical model(s) which informed the original Walking Away programme; ii) the recruitment and consent process; iii) the participation and engagement of the students in the programme; iv) the acceptability and accessibility of the materials and delivery. A quantitative methodology would be inappropriate as numerical data could not capture the complexities of these issues or prioritise the subjective experiences and perspectives of the participants. However, a pragmatic position has also been adopted as it was necessary to use quantitative methods to describe data which pertained to the process of the study. This methodology therefore informs the specific methods utilised, as described below.

6.2. Process evaluation

The Walking Away programme has multiple-components, including the increase of physical activity, improved dietary knowledge and improved diabetes knowledge. It can therefore be described as a complex intervention (Craig et al., 2008). The Medical Research Council (MRC) has developed guidelines for evaluating complex interventions. The first stage of the development and evaluation process is feasibility and piloting, which encompasses testing procedures, recruitment and retention, and determining sample size. This stage describes the present study. The process evaluation of the Walking Away programme used the updated MRC guidelines (Moore et al., 2014). The evaluation comprised of the following i) Recruitment: The number of potential participants, those invited to participate, those who accepted invitation, and retention rates; ii) Implementation: How the delivery of Walking Away was carried out, including training, planning, consistency, pragmatic adaptations, delivery, and measures; iii) Mechanisms of impact: How the participants interacted with the programme, as indicated by their feedback on the acceptability and accessibility of the materials and content.

Figure 6.2 below presents the core functions of a process evaluation. The figure has been adapted from the model provided by Moore et al. (2014), and contextualized for the present study. The figure illustrates that a process evaluation is cyclical and iterative, where later stages subsequently inform the revision of earlier stages. The context informs every stage of the process and is therefore pivotal. In turn these processes may impact upon the context. In the present study, the context of people with ID in a further education setting shapes is shaped by the Walking Away programme, its implementation, and mechanisms of impact.

Figure 6.2: Core functions of process evaluation



6.2.1. The Walking Away programme

This section describes the components of the original Walking Away course, which is a three-hour structured educational programme aiming to encourage participants to increase physical activity through walking and to improve diet through increased awareness of saturated fats. Walking Away is adapted from the DESMOND (Davies, 2008) and PREPARE (Yates, 2011) programmes. DESMOND (Diabetes Self-management for Ongoing and Newly Diagnosed) is the core programme developed by Leicester Diabetes Centre and is currently delivered through the NHS throughout the UK. Values and philosophies of the DESMOND programme have been applied to its associated programmes, such as Walking Away.

6.2.1.1. Structure and content

The structure and content of the programme is outlined on the following page in *Table 6.1:*

Table 6.1: Structure and content of Walking Away

Session	Description
Session A: Introduction and Housekeeping (5-10 minutes)	Brief overview of the course. General health and safety points. Patient handbook handed out and contents described. Participants invited to provide question about course, which will be revisited at the end of the sessions.
Session B: Participant Story (25 minutes)	Participants invited to describe their own T2D experiences, including diagnosis and impact.
Session C: Blood Glucose (20 minutes)	Describes insulin resistance, levels of blood glucose, and personal risk factors. Magnetic board depicts outline of human body and magnet images of anatomical parts related to diabetes demonstrate process of digestion and glucose metabolism. Magnetic timeline used to demonstrate level of diabetes risk.
Session D: How Could Being at Risk of Diabetes Affect My Health? (15 Minutes)	Risk associated T2D presented: cardiovascular, cholesterol and renal complications. Magnetic images of these complications used in conjunction with magnetic timeline and personal risk profiles.

Session E: Risk Story (25 minutes)	Analogy of overloaded tray demonstrate multiple risk factors. Cards with images such as age, saturated fats and family history describe risks. Participants encouraged to reflect on their own personal risks.
Session F: Physical Activity (55 minutes)	Health benefits of physical activity described using images. Physical activity cards present a range of everyday options. Participants use their physical activity diary and pedometer to plan and record activity. Step count cards presented to convey number of steps in relation to activities. Magnetic diagram of a cycle of change is used to demonstrate motivation and overcoming barriers to change.
Session G: Food Choices (20 minutes)	Saturated, poly-unsaturated, and mono-unsaturated fats described and participants organise laminated card images of food into each of these groups.
Session H: Questions and Future Care (5 minutes)	Participant questions from Session A are revisited and discussed. Further questions invited.

6.2.1.2. DESMOND philosophy

Several principals inform the DESMOND approach to diabetes education. These are described in the DESMOND training manual (DESMOND Collaborative, 2011), and are as follows.

1. *"People are ultimately responsible for their own self-management":* Daily self-management decisions and choices are made by the individual with or at risk of diabetes. Therefore, educators are responsible for: providing them with up-to-date diabetes information; making them aware of risks and how to reduce them; supporting them to make their own self-management plan.
2. *"People want to maximise their quality of life":* People are motivated to maximise their quality of life. However, this may not always be in accordance with the educator’s view. Therefore, the educator must: treat every patient with respect, regardless of their approach to self-management; ensure that patients are supported to understand and information; ensure that patients have access to resources, such as medication and technological support.
3. *"The barriers to self-management are in the person's world":* Barriers tend to be personal and social, such as poor social support or depression. Educators must therefore: provide empathy and warmth; provide opportunities for reflection on barriers; support patients to develop self-management skills.
4. *"The consequences of Type 2 diabetes are experienced by the person with or at risk of developing Type 2 diabetes.":* Patients should be allowed to make their own self-management choices as it is they who experience the consequences of having Type 2 Diabetes. Educators must therefore: provide a space for discussing the experience of being diagnosed with or being at risk of diabetes;

ensuring patients are supporting in their emotional responses to the impact of diabetes.

6.3. Expert Panel Consultation

An initial aim of the study was to assemble an expert panel to review the Walking Away materials prior to delivery of the intervention. Individuals known to the researcher from their social care background were informally approached and expressed an interest in assembling as a panel. This included a clinical psychologist, a team of learning disability dietitians, and a speech and language therapist. However, a delay in accessing the materials meant that collecting data for this consultation would not have been feasible in the timescale of the research project. Therefore, ethical approval for this potential arm of the study was not applied for, and the members of the expert panel were not contacted for this purpose again.

6.4. Recruitment and procedure

Recruitment initially began in tandem with the ethics procedure. The researcher engaged in preliminary discussions with Edinburgh College to identify any concerns they anticipated should the study take place there. Lecturers expressed interest in taking part at this stage and were contacted again after ethical approval was obtained.

To take a systematic approach to recruitment, a list of colleges across Scotland providing life skills classes for people with Intellectual Disabilities was obtained from the Family Advice and Information Resource (FAIR), and the Supporting You at College guide for students with additional needs. Responses were positive, although only Glasgow College agreed to participate. Other Edinburgh College campuses were contacted, but only the initial campus (Sighthill) agreed to participate. This may have been due to the time of year, as the college's summer break was approaching. At this stage, each Site suggested that approximately 25-30 participants would be available and likely to participate. This number was suitable for a feasibility study, according to guidelines provided by Lancaster, Dodd, and Williamson, (2003).

Initial meetings with lecturers took place during April and May 2016. Aims of the study and expectations of the participants were outlined at this point. Support and involvement from the colleges was strong, with the assurance of support to engage participants during the delivery of the educational programme, and to encourage continued programme adherence in terms of increased physical activity and recording of pedometer levels.

Recruitment of student participants began at the start of the first trimester, in September 2016. At each college, the researcher gave a verbal presentation of the study. This included an introduction to consent, an overview of the Walking Away programme and its structure, and a brief description of the measures. An accessible information pack was handed out and verbally presented. These materials are presented in the appendices (Appendices 8-13, Volume II, p.20-45). It was emphasised that although the Walking Away sessions would take place at the college during study hours, participation was optional. Teaching staff added that alternative activities, such as computer time, would be available. Participants were invited to ask questions at this stage. The pack included an accessible consent form, which was left for the participants to read and sign. This recruitment approach was aligned to the stages of Foster et al.'s (2011) framework.

Recruitment of lecturers and support staff took place at a later point, during the second trimester. Because of the possibility of timetable changes, it was necessary to take a pragmatic approach, in which lecturers who were able to attend the majority of the Walking Away units were recruited to focus groups to evaluate the content, materials, and process.

6.5. Measures

6.5.1. Anthropometric

To provide a physiological indication of the student participants' health, anthropometric measures were recorded by the researcher. These included height, weight, body mass index (BMI), and waist circumference. Participants removed shoes and any outer bulky clothing. BMI was calculated using the following formula: BMI = weight/height 2 (kg/m2). These measures were in accordance with the International Standards for Anthropometric Assessment (Stewart, Marfell- Jones, Olds & De Ridder, 2011).

6.5.2. Questionnaires

To provide a detailed account of the extent to which the student participants were engaged in physical activity, as well as their attitudes towards it, two baseline questionnaires were conducted prior to delivery of the Walking Away programme. The first of these, the International Physical Activity Questionnaire (IPAQ) asked participants about their moderate and vigorous activity across several contexts. The questionnaire comprises a total of 27 items across the domains of overall physical activity, transport, household, recreational, and sedentary time. Data are a self-report of the last seven days of activity. Volume of activity is measured continuously in MET-minutes (multiples of the resting metabolic rate), which are computed by multiplying the MET score by the minutes performed. The questionnaire has been validated across 12 countries, with Spearman's *rho* clustered around 0.8 (Craig et al., 2003) and across varied populations including ethnic minorities (Wolin et al., 2008), and age groups of 18-84 (Wanner et al., 2016).

A pilot study by McKeon, Slevin and Taggart (2013) confirmed the IPAQ as a practical tool to use with people with ID in conjunction with measures of ambulatory activity. However, prior to this study, the tool had not been psychometrically validated for people with ID, and adaptations had not been made. Since this study was conducted, the IPAQ has been adapted and validated for people with ID in the DESMOND-ID study (Taggart et al., 2017). The present study evaluated the process for replicating the Walking Away study (Yates et al. 2016) for people with ID in the context of further education using the IPAQ without adaptation. Therefore, the results in the following chapter consider the strengths and limitations of this measure.

The second questionnaire, Self-efficacy for Leisure Physical Activity (SELPA) comprises of 31 items across the domains of occupation, social support from family, and social support from health. The questionnaire was developed and validated specifically for people with ID by Peterson et al., (2009), using path analysis. However, as with the IPAQ, it was beyond the scope of the present thesis to develop an adapted version. This measure was therefore used to assess the usability of the unadapted tool, and to further evaluate the relevance of the self-efficacy construct to people with ID by examining their self-efficacy beliefs in regard to physical activity. Schedules for both questionnaires are included in the appendices (Appendices 14 and 15, Volume II, p.47-58).

6.5.3. Ambulatory activity

The participants were provided with pedometers at the start of the study in September 2016 and were also given recording sheets. The aims of collecting this data were twofold: firstly, to replicate the process used for the primary measure in the PREPARE and Walking Away study (Yates et al. 2009, and Yates et al. 2016, respectively) and secondly to ascertain if any adaptations or additional supports are required for people with ID. The measure recorded by the participants provided an indication of how many participants were able to successfully wear and record the pedometers, and how many days per week were successfully recorded. Temple and Stanish (2009) suggest that a measure of 3 days per week is sufficient to record walking activity in people with ID. The focus group discussions provided further insight into the barriers and facilitators experienced by the students and their supporters in engaging in this activity.

The second aim was to further describe the health status of the participants by providing a mean weekly step count. Tudor-Locke et al. (2011) reported that in normative trends, step-counts in adults range from 4000-18,000 per day, and that 10,000 steps per day is reasonable. However, it was acknowledged that trends may vary in subpopulations. Temple and Stanish (2009) reported an average step count of 6508 steps per day (SD 3296) in adults with ID. This number was used to predict the sample in the trial of a programme called Walk Well (Melville et al., 2015), which aimed to increase the steps of 102 people with ID by 3000 a day following a 12-week intervention programme. The baseline step count was 4780 steps per day. This mirrors the Walking Away curriculum manual, which suggests that 10,000 steps per day may be difficult to achieve for an individual at risk of diabetes and recommends an increase from 4000 steps per day to 7000. It was therefore useful to compare the mean step count of the participants in the present study to that reported in the literature.

The pedometers used in this study were the Yamax SW-200. This is a well validated and cost-effective model (Schneider, 2003), recommended by Leicester Diabetes Centre. Melville et al. (2015) and Yates et al. (2016) used the Actigraph GT3X. This is a newer model than the SW-200, highly regarded for accuracy (Lee et al. 2014). However, as ambulatory activity was not a primary measure in the present study, a cost-effective option was deemed more appropriate.

6.6. Focus Groups

Focus groups are a form of qualitative data collection where multiple participants meet to discuss a research topic. This can enable learning from one another through exchanging and building on one another's views (Marshall et al., 1999). The guidelines of Moore et al. (2014) advocate the use of collecting qualitative data to identify the strengths and weaknesses of an intervention’s implementation. As the Walking Away sessions were delivered in a group setting and involved collaborative learning, focus groups were an appropriate method of capturing this dynamic. As lecturing staff were in the expert position of being able to evaluate the impact of the programme on the students and had experienced a range of issues and strategies, they were also invited to participate in focus groups. Due to the distance between the two study locations it was necessary for there to be two separate sets of focus groups at each site. The focus group topic guides are presented in the appendices (Appendices 16 and 17, Volume II, p.59-62).

Kaehne and O'Connell (2010) provide guidelines for planning and conducting focus groups with people with ID. These contain four aspects, which discussed below in relation to the present study.

6.6.1. Abilities versus key methodological requirements

This aspect describes the challenges of overcoming communication difficulties in a focus group setting. Participants in a focus group are required to not only reflect on their own experiences but also listen to and engage with fellow participants. For people with ID, this can be challenging, and Kaehne and O'Connell (2010) highlight that there are several factors which contribute to variability in communication skills, including age, level of ID and social background. Because of these difficulties, responses can often be more reflective of the individual as opposed to the group. This can lead to a one to one interview style rather than focus group. Kaehne and O'Connell (2010) suggest that for people with ID, additional time and resources may be required to achieve a focus group style of communication, and that this interaction must be clearly demonstrated through transcript quotations in subsequent reporting. In the present study, materials from the Walking Away programme were used as prompts to help facilitate discussion. In addition, teaching staff were recruited to the focus groups to facilitate students to reflect on and articulate experiences. This is further discussed in the following aspect.

6.6.2. The role of advocates

Kaehne and O’Connell (2010) highlight that there is a lack of literature on the role of advocates for people with ID in focus groups. However, a few authors such as Fraser and Fraser (2001) praise the usefulness of advocates, who can not only assist with helping participants to reflect and articulate experiences, but also offer a facilitative role due to their close relationship with the participants. The potential drawback for this is highlighted by Kaehne and O’Connell (2010) who suggest that in entering into a facilitative role, advocates may step out of a neutral position, which in some cases may go as far as leading participants. Teaching staff were invited to participate in the focus groups as advocates to ensure that all participants were able to contribute. Elspeth (pseudonym), a Glasgow teaching staff member who had attended all of the units attended, actively participated in the group, supporting the students to vocalise their experiences and clarifying certain statements. At Edinburgh College, a complication arose as the results of the industrial strikes, which meant that no member of the teaching staff was available to attend the session. This may also have led to differences between the sites, as Elspeth's support enhanced the students' discussion. This was not possible in Edinburgh. A carer attended the Edinburgh Group, however this was in a non-participatory role. Therefore, it is possible that at the Glasgow focus groups, student responses were better facilitated, although as described above there may have been potential for leading, which could have detracted from the validity of the findings.

6.6.3. Research, policy and research saturation

In this aspect the danger of leading participants is further explored. Kaehne and O'Connell (2010) point out that the aims of research using focus groups with people with ID may overlap as these are likely to tie in with broader policy aims, such as inclusion and empowerment. This likelihood is further increased if focus groups are selected from pre-existing groups who have been previous been recruited for research. In the present study, participants were recruited from a class where students in a previous year had participated in a focus group study (not published) on the Human Papillomavirus and people with ID. Although the students in the present were recruited from a later academic year, there was a risk of the staff carrying an awareness of the aims of this study and leading the students to provide answers which reflected commonalities between the two studies, such as illness awareness. However, as described above, the teaching staff were briefed on this. In addition, the researcher was prepared to probe further into responses which appeared to be students giving the ‘right answer’, as recommended by Kaehne and O’Connell (2010).

6.6.4. Ethical problems

The final aspect of Kaehne and O’Connell’s (2010) criteria follows on from the previous concerns over recruiting from existing groups. Here it is highlighted that re-recruitment may be common in research with people with ID due to the limited population size, which is further narrowed when health concerns such as chronic illnesses as are added as inclusion criteria. It follows that participants who have previously been recruited to studies may consequently relive sharing traumatic experiences associated with the study topic (Kaehne and O’Connell, 2010). A second ethical concern is that the path from research to changes in policy and practice is slow, and apparent lack of change to participants who repeatedly engage in research may be distressing. As the participants in the present study had not been diagnosed with diabetes, there is very little risk that the topic has been previously discussed in relation to a study. However, with sensitivity to the possibility of this occurring in the future, the participant debrief sheets handed out at the end of this study emphasised the long transition from research to change. Although this final aspect may relate to general ethical guidelines in research rather than focus group-specific, these are important considerations for conducting research with people with ID.

6.7. Student focus group recruitment and procedure

Towards the end of the delivery of the Walking Away units, the researcher described the aims and nature of the focus groups to students who had attended thus far. Several expressed interest at this point and were later approached by the teaching staff who reiterated that the groups would be taking place. The staff then aided the researcher with selecting participants. This selection was based on the participants' interest in joining the focus groups as well as their engagement in the programme, as observed by the researcher and staff. The guidelines by Kaehne and O'Connell's (2010) described above were considered, and eight student participants per site were selected. The limited size of this group enabled many of the participants to make contributions without feeling inhibited.

These students received information sheets and consent forms, which reiterated the overall purpose of the study and the focus groups. Support was provided by the staff and researcher to ensure these forms were understood. As two of the recruited participants did not speak throughout the main section of the focus group, they have not been listed in the participant table below and were not included in the analysis.

The focus groups lasted approximately one hour and took place in college classrooms familiar to the students. The groups each began with a warm-up exercise, where photographs of celebrities were placed on a table and the participants were invited to choose a celebrity, about whom they could describe something they either liked or disliked. This was a successful method for engaging the participants as a lively conversation took place in both sites, although some students who engaged in the warm-up exercise did not actively participate in the rest of the discussion. Topics were provided by the researcher (see Focus Group Schedule in appendices). These covered each of the units, the overall delivery and materials, recruitment and consent, and the pedometers.

6.7.1. Staff focus group recruitment and procedure

The researcher described the focus groups to the teaching staff during planning meetings and reminded senior staff towards the end of the programme delivery that these would take place. All staff who were involved in the study participated. This involvement included attending the Walking Away sessions, supporting the students to wear and record pedometers, collecting demographic data, and recruitment. From Edinburgh College there were five participants, and there were four from Glasgow College.

The Staff focus groups lasted approximately one hour and took place in un-used classrooms. A similar schedule was used to the student focus groups (see appendices), however there was a focus on the teaching staffs' perceived impact of the programme on the participants

6.8. Analysis

As with Phase 2, there was likely to be limited communication in some participants and there would be theory-driven data collection. Therefore, alternative methods such as Interpretative Phenomenological Analysis or Grounded Theory, which both require rich, detailed responses from participants and are data-driven, were not selected. Instead, analysis of the focus groups used Braun and Clarke's six stage guidelines, as described in the methodology for the first section. The flexibility guidelines of this method matched the pragmatic epistemological standpoint, described at the start of the present chapter. The following amendments were incorporated:

1. At the fifth stage, where higher order themes are defined and named themes, there was no deductive evaluation as with the first phase, which evaluated the findings alongside a theoretical model. This current stage was purely inductive, and the themes were therefore developed from subordinate themes extracted from the data into superordinate themes.
2. The entire analytical process was carried out with the student focus group, then with the staff. Once the staff focus group analysis had been completed, the student focus group was repeated in full and compared with the original. This provided a fresh perspective on the student coding and enabled the researcher to evaluate the analysis alongside the perspectives of the teaching staff.

Stages of the analysis are presented in the appendices (Appendices 18 and 19, Volume II)

6.9. Chapter conclusion

This chapter has described the epistemological standpoint and subsequent knowledge claims which inform the methodology of the second phase of the thesis. This stage involved a process evaluation and thematic analysis of a feasibility study, which implemented the Walking Away programme in two further education colleges. The processes described above have described this implementation. The following chapter describes the mechanisms of impact, which includes the recruitment, demographic reach, and measures. The chapters which follow this present the findings of the focus group analysis.

Chapter Seven: Phase Three results – process evaluation

7.1. Introduction

This chapter presents the process evaluation of the Walking Away programme for people with ID in a further education setting. First, recruitment is discussed, including the strengths and limitations of the approach taken. Following this, the demographics of the participants are presented, which give an indication of how successful the study was in terms of reaching the targeted population in line with the study rationale. Baseline questionnaires are then evaluated in terms of their suitability for students with ID. Finally, the feasibly of obtaining measures of ambulatory activity through students wearing and recording pedometers is discussed.

7.2. Success of recruitment

At Glasgow College, 22 (92%) students agreed to participate in the study. One of the students who did not wish to participate had physical disabilities and saw the programme as unsuitable. Edinburgh College were able to offer 26 potential participants. All students agreed to participate. Therefore, a total of 48 students participated in the study. A further recruitment drive was taken which made secondary requests to colleges in the surrounding counties. Contacts provided by teachers at Edinburgh and Glasgow Colleges were also followed up. However, although additional information was requested by one college, the drive was unsuccessful as no requests to visit or discuss the study were returned.

The recruitment process took place over 2 months. Some students at Edinburgh College seemed reluctant at first to commit to participation, which was attributed by the lecturers to confusion over what would be entailed, despite the information sheet and class discussions. To overcome this, a game was devised by the researcher and lecturers to demonstrate the wearing and recording of pedometers. These were provided to the students, who were invited to guess how many steps it would take to complete a short, designated circular route around the campus. After completing this walk, students were then supported to read out their pedometer readings and compare these to their estimates. This game seemed to encourage participation as students returned signed consent forms during the following week. The focus groups later revealed that the students and lecturers found this a valuable process, which also assisted students with learning to correctly wear and record the pedometers. Two students at Edinburgh College had reservations about taking part due to what they perceived as risks related to diabetes. The focus group discussions highlighted that this was partly due to an introduction provided by the lecturing staff, prior to the first researcher visit and dissemination of participant information sheets. Further discussions between these students and the researcher and teaching staff helped to reduce anxieties about taking part.

7.3. Participants

A total of 48 participants consented to participate. The table below, *Table 7.1*, provides an overview of measures which give an indication of the health status of the participants. Following this, *Table 7.1.1.* illustrates the raw data.

Table 7.1: Participant demographics summary

Age (Mean, SD)	**Gender**	**Height (Mean, SD)**	**Weight (Mean, SD)**	**BMI Classification (%)**	**Waist circumference (Mean, SD)**
20.9 years, 5.0	Female: 37.5% Male: 62.5%	167.1cm, 11.3	81.6kg, 22.9	Obese: 37.5% Overweight: 27% Healthy weight: 29.1%	98.3cm, 21.3

Table 7.1.1. Participant demographics raw data

Participant number	Age	Gender	Height (CM)	Weight (KG)	BMI	Waist (CM)
1	21	Male	172	93	31.4 Obese	112
2	19	Male	178	102	32.1 Obese	116
3	19	Female	158	101	40.4 Obese	119
4	19	Female	148	68	31 Obese	100
5	19	Male	180	115	35.4 Obese	143
6	22	Male	162	60.7	23.1 Healthy weight	100
7	19	Male	158	74.4	29.8 Overweight	101
8	19	Male	178	77	24.3 Health weight	101
9	22	Male	178	95	29.9 Overweight	110
10	18	Female	156	53	21.7 Healthy weight	80
11	18	Male	171	53.4	18.2 Underweight	76
12	22	Male	173	108	36 Obese	108
13	21	Male	184	142	41.9 Obese	132
14	18	Female	174	100	33 Obese	103
15	23	Female	153	105	44.8 Obese	130
16	19	Female	150	90	40 Obese	102
17	25	Female	169	104	36.4 Obese	103
18	26	Male	180	64	19.7 Health weight	100

19	22	Female	174	74	24.4 Healthy weight	63
20	18	Male	177	74	23.6 Healthy weight	104
21	21	Female	145	69	32.8 Obese	96
22	21	Male	168	82	29 Overweight	104
23	20	Male	191	120	33.8 Obese	111
24	18	Female	164	120	44.6 Obese	120
25	18	Male	175	55	17.9 Underweight	72
26	19	Female	146	55	25.8 Overweight	85
27	18	Male	167	75	26.8 Overweight	91
28	19	Male	182	120	36.2 Obese	124
29	19	Male	180	85	26.2 Overweight	85
30	18	Male	176	60	19.3 Healthy weight	90
31	18	Female	162	52	19.8 Healthy weight	71
32	18	Male	165	70	25.7 Overweight	92
33	19	Male	176	72.5	23.4 Healthy weight	72
34	19	Male	171	82	28 Overweight	95
35	20	Male	173	65	21.7 Healthy weight	79
36	19	Female	168	75	26.5 Overweight	161
37	21	Male	176	74	23.8 Healthy weight	96
38	19	Male	167	45	16.1 Underweight	79
39	16	Male	185	88	25.7 Overweight	54
40	18	Female	160	50	19.5 Healthy weight	18
41	21	Male	179	70	21.8 Healthy weight	86
42	44	Female	155	85	35.5 Obese	106
43	19	Male	183	124	37 Obese	122
44	29	Female	67	101	224.9 Obese	120
45	27	Male	184	71	20.9 Healthy Weight	90

46	20	Female	172	61	20.6 Healthy Weight	77
47	39	Female	148.5	64	29 Overweight	89
48	19	Male	165	75	27.5 Overweight	62

7.3.1. Sex and age

There were 18 (37.5%) female participants and 30 (62.5%) male. The age range was 18-39 years, mean 20.9 (SD 5.02). The mean female age was 22.7 (SD 7.5), male 19.9 (SD 2.3). The literature reviews presented in Chapters Two and Three highlighted the need for diabetes education aimed at younger adults with ID. The age group in this sample demonstrates that recruitment in further education colleges may be an appropriate strategy for accessing this demographic.

7.3.2. Height

Overall height ranged from 145-191cm, mean 169.2cm (SD 11.3). The mean female height was 153.8cm (SD23.7), male 175.1cm (SD 7.5).

7.3.3. Weight

Overall weight ranged from 53-124kg, mean 81.6kg (SD 22.7). The mean female weight was 79.2kg (SD 21.9), male 83kg (SD 23.4).

7.3.4. Waist circumference

The overall waist circumference ranged from 54-161cm, mean 98.3cm (SD 21.3). The mean female was waist circumference was 96.8cm (SD 30.5), male 96.9 (SD 20.1).

7.3.5. Body Mass Index

Based on the age, mean height and weights reported above for each gender, the mean BMI was 33.3 (obese) for females and 27.1 (overweight) for males. Seventeen (35%) of the participants were in the obese category. 10 (59%) of these were female and seven (41%) were male. 12 (25%) of the participants were in the overweight category. Three (25%) of these were female and nine (75%) were male. 15 of the participants were in the healthy weight category. Four (27%) of these were female and 11 (73%) were male. Three of the participants were underweight, all of these were male.

The physiological data above suggests that the overall health of the majority of participants placed them at higher risk of illnesses and chronic diseases such as diabetes. According to NHS guidelines, a waist circumference of 94cm and above for men and 80cm and above for women is indicative of a higher risk of cardiovascular disease and T2D. 102cm for men and 88cm for women is considered very high risk. According to the mean participants' waist circumferences, males are at high risk (96.9cm) and females at very high risk (96.8). Although participants were not recruited on the basis of individual diabetes risk factors, these findings support the extant literature on the health of people with ID, and further highlight the need for the evaluation, adaptation and application of such programmes as the Walking Away programme, which is discussed in the following sections.

7.4. Educator training

Training for the educator to deliver the programme for was provided over two days. The first of these involved generic DESMOND training (Diabetes Education for Ongoing and Newly Diagnosed), which entailed an overview of the programme's philosophies and theoretical frameworks. The researcher attended a group training session for this by two DESMOND trainers in Dublin.

The second part of the training was module specific and thus contained the components unique to Walking Away. This was delivered one-to-one to the researcher, by one of the Dublin trainers. This enabled the researcher to discuss and plan structural adaptations, such as dividing the programme into smaller sessions and the ethical consideration of removing personal risk content.

A limitation of the present study is that the researcher undertook the educator training and delivered the sessions. Subsequently, it was not possible to objectively evaluate the quality of these processes. In the DESMOND-ID study (Taggart et al., 2017), fidelity was assessed through the extent to which trained educators were able to implement the programme whilst retaining the core values and philosophy. As the values of Walking Away are drawn from DESMOND, it was not necessary for a repetition of this appraisal, and instead there was a focus on the accessibility of the materials within an educational setting. Educators were provided with reflection sessions and provided feedback in focus groups. This was not possible, as it was beyond the scope of the present study to recruit and provide Walking Away training for diabetes educators. However, the quality of the programme delivery is discussed in the focus groups in the following chapters.

7.5. Pragmatic adaptations

The aim of this phase of the study was to evaluate the Walking Away programme in terms of any potential changes required to tailor to the needs of people with ID. This evaluation was chiefly guided by the student participants' experiences of engaging with the original programme, prior to adaptation. There were however several pragmatic and ethical adaptations which were decided upon prior to delivery. These were discussed with i) with lecturing staff at the further education colleges; ii) Edinburgh Napier University ethics committee; iii) the Walking Away developers at the University of Leicester as part of the Memorandum of Understanding with Edinburgh Napier University; iii) the Walking Away educator trainer. The adaptations are described in the following subsections.

7.5.1. Ethical considerations and risk identification

The original Walking Away programme was designed to be delivered to individuals who had been clinically identified as at risk of T2D. This identification involves either i) a blood glucose test, where fasting blood glucose levels and/or HbA1c results were in the range of 5.5 - 6.9 mmol/l; HbA1c 6.4% or ii) a high number of risk factor symptoms identified by a GP. In the present study, it was anticipated that there may have been ethical issues because of this identification, including distress to the participants' understanding of the consequences, and the potential for insensitive comments from peers in the group setting of the programme.

As highlighted in the literature review in Chapter Two, people with ID are at higher risk of diabetes than their non-disabled peers, are more likely to struggle to adjust to diagnosis at an older age and would benefit from structured education delivered in a setting with strong social support. There is therefore rationale for assessing the feasibility and acceptability of delivering a preventative structured education programme to adolescents with ID in a further education college. Potential participants were therefore not recruited based on being identified as at risk of diabetes, but of having an intellectual disability and attending a further education college. This reduced the potential risk of distressing social stigma from being identified as at risk.

During the educational sessions, risk factors were described to participants, and they were directed to look at a risk score profile in their handbook materials. However, a group discussion of the participant's risk factors was not facilitated, as with the original programme. As an additional consideration, lecturing staff had been alerted to the potential distress of identifying risk factors and had agreed with the researcher to signpost to local GPs for further information and support.

7.5.2. Division and length of sessions

Through discussion with the college lecturers, the 3-hour duration of the programme was deemed to be unsuitable for the students, whose lessons were typically around 1 to 1 and a half hours. Given the students capacity for maintaining attention and remembering content, the staff agreed upon four parts of 45 minutes to 1 hour in length. During the educator training, the eight Walking Away sessions were arranged into these four parts. This is described in *Table 7.2* on the following page.

There were differences between the two sites in the timespan of delivery. At Glasgow College, the four parts were delivered over two weeks. For logistical reasons, the classes at Glasgow were merged into groups of up to 25, which was greater than the Walking Away recommended group size and had some impact on delivery, as described in the focus groups. At Edinburgh College, participants were divided into three classes due to timetabling differences, which resulted in there being smaller groups of 5-10. This meant that 12 visits were required to deliver the full programme. Further to this, many of the sessions had to be cancelled and rearranged due to a series of industrial strikes which were carried out over that month. This significantly lengthened the programme, with gaps of at least 1 week between each session. The focus groups show that there were differences between the two sites in terms of how well the programme was received and understood. Unanticipated events such as this, together with organisational differences between conferences may be important factors to consider in the planning of a study delivered to multiple further education settings, as these may be difficult to control yet nonetheless result in key-differences between sites and conditions.

Table 7.2: Summary of session divisions

Session	**Description**
Part 1: *Session A: Introduction and Housekeeping (5-10 minutes); Session B: Participant Story (25 minutes); Session C: Blood Glucose (20 minutes).*	The main content of this session was drawn from *Session C*, which described the process of glucose metabolism in a healthy and pre-diabetic person. Introductions and housekeeping were less important to emphasise as this was an established classroom setting, and the participants had met the educator several times before. The participant story was also less relevant, as students had not been identified as at risk of diabetes and therefore could not describe this experience. However, students were able to ask questions about diabetes which would be revisited at the end of the programme.
Part 2: *Session D: How Could Being at Risk of Diabetes Affect My Health? (15 Minutes); Session E: Risk Story (25 minutes).*	These two sessions fitted well into the designated length and the content could be delivered at a comfortable pace.
Part 3: *Session F: Physical Activity (55 minutes).*	This session contained the core messages of the Walking Away programme and was rich in content, requiring a fast pace of delivery. Due to the high support needs of some students in making action plans, there was not sufficient time to do this on an individual basis. Instead, example action plans were described. There was scope for spending an additional session on individualised action plans which became apparent during delivery, and the teaching staff expressed interest in continuing this beyond the study.
Part 4: *Session G: Food Choices (20 minutes); Session H: Questions and Future Care (5 minutes)*	These two sessions could be delivered at a comfortable pace. An initial idea for adaptation which had been agreed between the researcher and educator trainer had been to invite participants to bring along food packaging items from home, which could be used to learn to identify types of fat. However, following discussion with the college teaching staff, it was highlighted that this may have been difficult for some students and furthermore placed additional expectations on parents and carers. Instead, the researcher sourced examples of food labels from used recyclable packaging. Participants were given these during the session and additional support was provided by the researcher and teaching staff to identify fat types and quantities. This part was shorter overall, which provided additional time for the researcher to conclude the programme and describe the forthcoming focus groups.

7.6. Baseline Questionnaires

7.6.1. International physical activity questionnaire

Raw data for the IPAQ is presented in the appendices (Appendix 19, Volume II, p.65). Validity and reliability of the tool for people with ID is described in Chapter Six (section 6.5.2.). The IPAQ was divided into five sections: Job related physical activity; Transportation physical activity; Housework, house maintenance, and caring for the family; Recreation, sport, and leisure-time physical activity; Time spent sitting. The questions, apart from Question One which asked for either “yes” or “no”, asked about the number of days per week or number of hours per week in the last seven days. To collate and present this data, median MET units per week are presented, as per the reporting guidelines in Craig et al., (2003). The table below, *Table 7.3: IPAQ summary*, is divided into the five sections and each are discussed. Immediately after this, *Table 7.3.1.* presents the raw IPAQ data

Table 7.3: IPAQ summary

Domain	Median MET	High activity %	Moderate activity %	Low activity %
General physical activity	598	0%	21/48 (43.8%)	22/48 (45.8%)
Transport	165	0%	4/48 (8.3%)	40/48 (83.3%)
Household	150.75	0%	8/48 (16.7%)	36/48 (75%)
Recreational	224.75	0%	6/48 (12.5%)	41/48 (85.4%)

Table 7.3.1: IPAQ raw data

											Total MET	
Particpant	Question			MET			MET			MET	Total MET PW	SCORE
	1	2: Vig days	3: Vig mins		4: mod days	5: mod min		6: Walk days	7: Walk mins			
1	Yes	3	30	720	3	20	240	3	30	297	1257	MODERATE
2	Yes	3	20	480	4	30	480	3	10	99	1059	MODERATE
3	Yes	3.5	30	840	3	9	108	1	10	33	981	MODERATE
4	Yes	3	15	360	3	20	240	1	20	66	666	MODERATE
5	Yes	3	40	960	3	30	360	1	30	33	1353	MODERATE
6	Yes	3	20	480	3	20	240	3	30	99	819	MODERATE
7	Yes	3	20	480	3	10	43	3	10	99	1582	MODERATE
8	Yes	3	15	360	3	30	360	1	20	66	786	MODERATE
9	Yes	3.5	10	280	3	30	360	3	30	297	937	MODERATE
10												
11	Yes	0	0		4	40	640	1	30	99	739	MODERATE
12	Yes	0	0		4	50	800	2.5	10	82.5	882.5	MODERATE
13	Yes	0	0		4	30	480	4	40	528	1008	MODERATE
14	Yes	0	0		4	30	480	4	60	792	1272	MODERATE
15	Yes	0	0		4	40	640	1	50	165	805	MODERATE
16	Yes	0	0		3	20	240	3	20	198	438	LOW
17	Yes	0	0		3	20	240	3	40	396	636	MODERATE
18	Yes	0	0		3	30	360	0	0	0	360	LOW
19	Yes	0	0		3	10	120	0	0	0	120	LOW
20	Yes	0	0		3	30	360	1	20	67	427	LOW
21	Yes	0	0		3	20	240	3	45	445.5	685.5	MODERATE
22	Yes	0	0		3	15	180	3	20	198	378	LOW
23	Yes	0	0		1	30	120	3	30	297	417	LOW
24	Yes	0	0		1	30	120	4	30	396	516	LOW
25	Yes	0	0		4	30	480	3	15	148.5	628.5	MODERATE
26	Yes	0	0		3	20	240	3	15	148.5	388.5	LOW

The majority of the students stated that they had a job or carried out unpaid work outside of home (92%). The students perceived this as attending college, or additional employment. The second question on vigorous physical activity was understood by the students as walking up and down the stairs at college. However, the students may have misunderstood this question as it is unlikely that this would have taken place for 10 minutes at a time. This estimation was made despite the guidance of the researcher and teaching support, which reflects on the difficulty experienced by some of the students in judging levels of exercise and time periods. Questions Four and Five were explained to the students as carrying light loads, which could mean carrying their bags to and from college. For questions six and seven, it appeared that the students did little in the way of walking as part of college activities, with 0.8 hours on 1.5 days describing walking associated with gardening activities.

Regarding transport, the students' answers related to their journeys to and from college (mean 3.5 days, 0.8 hours per day). Cycling was not a common activity for the students (mean 0.39 days per week, 0.1 hours per day). Walking, either to or from college or as part of other journeys was more common (3.16 days per week, 0.5 hours per day). As walking appeared to already be a part of the students' lives, there was potential for the messages and aims of the Walking Away programme to be integrated into their weekly activities.

Few students were able to describe vigorous household activities they had engaged in during the last seven days (mean 0.46 days per week, 0.11 hours per day). Moderate activities were more common, and these included household chores. This happened on more days (mean 2.28) but for fewer hours per day (mean 0.04 hours). The final two questions in this section may have confused the students due to their similarity to the two preceding questions. The different answer (mean 1.63 days, 0.61 hours per day) suggests that the students may have been drawing on different activities to estimate their physically active time.

The section above contains questions on recreational physical activities. Walking was not a common activity throughout the week (mean 1.41 days, 0.62 hours per day). Few hours were spent on vigorous physical activity (mean 0.58 days, 0.27 hours per day). The students were supported to answer this question by being prompted about any examples of sport activities, some of which the teaching staff were aware of and could remind the students. However, there were few students who saw these activities as "vigorous". The following two questions on moderate recreational physical activity yielded similar answers (mean 0.52 days, 0.41 hours), suggesting that the students may have been drawing on the same activity examples for their answer. From this it is possible to estimate that some of the students engaged in 1-2 activities, once or twice per week, which may not have been sufficient to maintain or improve their physical health, placing them at higher risk of developing chronic diseases like diabetes.

The final question of the IPAQ contains questions on the amount of time spent sitting down during the week and during weekends. The students found it difficult to estimate this, and support was provided from the teaching staff and researcher to enable them to reflect on activities in which they were more likely to be sedentary. At 4.27 hours on weekdays and 5.20 hours on weekends, the students appeared to spend a significant part of their days being physically inactive. Studies such as Biddle et al. (2015) have trialed the use on intervention programmes for reducing sedentary behaviour as this has been highlighted as a risk factor for the development of type 2 diabetes (Edwardson et al., 2014).

To conclude, the IPAQ in its unadpated format was not suitable for young adults with ID in a college setting. Questions required a high level of support and contextualization to be understood by the participants. However, the responses provide some guidance for future adaptation, and synthesizing these findings with the adapted and validated version (Taggart et al. 2017) may enable development of an appropriate tool for assessing levels of physical activity in young adults with ID who attend college.

7.6.2. Self-efficacy for Leisure questionnaire

Validity of the SELPA tool for people with ID is described in Chapter Six, (section 6.5.2). The questionnaire was divided into three sections: 1) self-efficacy for physical activity, which assessed participants' self-efficacy towards physical activity barriers; 2) social support from family for leisure physical activity, which assessed the influence of family social support on self-efficacy; 3) social support from staff for leisure physical activity, which assessed the influence of staff social support on Self-efficacy. It was agreed with the college teaching staff that they would be considered in relation to the staff social support section, as this context was relevant to the delivery of the Walking Away context. Several questions had to be explained to the students as they would otherwise have been irrelevant to a college setting; these are described further below. *Table 7.4* below lists the questions together with the participant responses in percentages.

Table 7.4: Self-efficacy for leisure physical activity questionnaire

Section 1: Self-efficacy for physical activity			
Question	**Yes**	**No**	**Maybe**
1) Do you think that you can make time for physical activities almost every day?	32(64%)	5(10%)	13(26%)
2) Do you think that you can do physical activities even when someone important in your life wants you to spend more time with them?	19(38%)	17(34%)	14(28%)
3) Do you think that you can do physical activities even when you are very busy?	27(54%)	10(20%)	13(26%)
4) Do you think that you can do physical activities even when you are feeling sad or depressed?	18(35%)	24(48%)	8(16%)
5) Do you think that you can do physical activities even after a long, hard day at work?	27(54%)	19(38%)	4(8%)
6) Do you think that you can do physical activities on days when you are tired or don't have much energy?	15(30%)	28(56%)	7(14%)
7) Do you think that you can do physical activities even when you feel lazy?	9(18%)	35(70%)	6(12%)
8) Do you think you can do physical activities by yourself when you can't find other people to do them with?	29(58%)	17(34%)	4(8%)
9) Do you think you can find a place to do physical activities if you don't have a ride when you need one?	24(48%)	22(44%)	4(8%)
Section 2: Social support from family for leisure physical activity			
Question	**No**	**Yes- Sometimes**	**Yes- A lot**
1) Does anyone in your family remind you to do physical activities?	11(22%)	37(74%)	2(4%)
2) Does anyone in your family do physical activates with you?	20(40%)	23(46%)	7(24%)
3) Does anyone in your family plan physical activities when you spend time with them?	17(32%)	28(56%)	6(12%)
4) Does anyone in your family show you how to do physical activities?	19(38%)	26(52%)	5(10%)
5) Does anyone in your family tell you that you are good at physical activities?	7(14%)	34(68%)	9(18%)

6) Does anyone in your family pay for you to do physical activities somewhere or buy you things that you need to do physical activities?	19(38%)	23(46%)	8(16%)
7) Does anyone in your family drive you somewhere to do physical activities when you need them to?	19(38%)	25(50%)	6(12%)
8) Does anyone in your family tell you not to do physical activities?	41(82%)	6(12%)	3(6%)
9) Does anyone in your family tell you that physical activities will hurt you?	34(68%)	16(32%)	0
10) Does anyone in your family tell you that you are bothering them when you do physical activities?	44(88%)	5(10%)	1(2%)
11) Does anyone in your family ever tease you or make fun of you when you do physical activities?	47(88%)	3(6%)	0
Section 3: Social support from staff for leisure physical activity			
1) Does your staff remind you to do physical activities?	9(18%)	32(64%)	9(18%)
2) Does your staff do physical activities with you?	11(22%)	24(48%)	15(30%)
3) Does your staff plan physical activities for you, or help you to plan physical activities?	12(24%)	29(58%)	2(4%)
4) Does your staff show you how to do physical activities?	12(24%)	29(58%)	9(58%)
5) Does your staff ever tell you that you are good at physical activities?	9(18%)	32(64%)	9(18%)
6) Does your staff pay for you to do physical activities somewhere or buy you things that you need to do physical activities?	19(39%)	29(58%)	2(4%)
7) Does your staff drive you somewhere to do physical activities when you need them to?	29(58%)	20(40%)	1(2%)
8) Does your staff tell you not to do physical activities?	42(84%)	8(16%)	0
9) Does your staff tell you that physical activities will hurt you?	45(90%)	5(10%)	0
10) Does your staff tell you that you are bothering them when you do physical activities?	48(96%)	2(4%)	0
11) Does your staff ever tease you or make fun of you when your do physical activities?	50(100%)	0	0

7.6.2.1. Self-efficacy for physical activity

The participant responses to the first section indicated that overall there was a moderate to high self-efficacy towards physical activity, with 64% stating that they had time to do physical activity every day. The second question which presented the idea of spending time with someone as a potential barrier to physical activity seemed to confuse some of the participants, as they were unsure of who this would be or why they would prevent them from exercising. Other potential barriers such as a long day at “work”, which was presented to the participants as “college”, did not appear to lower self-efficacy (19% no), although feeling tired (56% no) or in a lazy mood (70% no) were stronger barriers. This may potentially suggest that the students saw external factors as being unlikely to reduce their engaging in physical activity, but that their mind-states probably would.

7.6.2.2. Social support from family for leisure physical activity

Many of the student participants appeared to receive some support from their family to engage in physical activity, with 74% saying that their family sometimes reminded them to engage in physical activities, and 18% saying this happened a lot. However, if the students were financially supported to engage in physical activity they were less aware of this, with 38% saying that their family did not buy them physical activity equipment or driving them to places to do physical activity. This may reflect the students being over 18 years of age and receiving benefits, such as Personal Independence Payments, and being supported to use these towards physical activities. Students may therefore see themselves as paying for physical activities, rather than their parents paying. However, the students may also be unaware of additional financial support from their parents which may be used towards physical activities.

Many of the students (82%) said "No" to members of their family telling them not to undertake physical activity. However, it is notable that 32% said that their family sometimes told them that doing physical activity would hurt them. Students may have interpreted this question as parents cautioning them when engaging in vigorous activities which may put them at risk. People with Down's Syndrome are likely to have heart conditions (Emerson and Baines, 2010), and subsequently families may safeguard against perceived risk factors. One student with epilepsy stated that they were reminded to not engage in vigorous physical activity as this was a seizure risk. Overall, it can be concluded that family social support was not a barrier to physical activity.

7.6.2.3. Social support from staff for leisure physical activity

The students had been asked to consider the college teachers as "staff" in this section. Many of the students (64%) said that they were sometimes reminded by staff to do exercise, and 48% said that staff did physical activity with them. This reflected the fact that not all students were enrolled in college activities which involved physical activity, such as light walking or gardening. This difference was reflected in other questions, such as showing how to do physical activity and financially supporting it. The final four questions were consistent amongst the students, with majorities stating that staff did not tell them not to do physical activity or tease them about engaging in it. Overall the staff social support did not appear to have a strong impact on the students' engagement in physical activity. Were the Walking Away programme to be trialed over an extended period, this questionnaire may yield different results as the social support of staff would be intrinsic to the implementation and sustained engagement in the programme's goals.

The SE for leisure activity questionnaire may serve as a useful measure quantitatively evaluate Self-efficacy in young adults with ID in a further education setting. However, as with the IPAQ, contextualization and adaption, such as visual aids, is required. The responses above provide guidance for a future adaptation.

7.7. Ambulatory activity measures

This section presents the findings of the student pedometer recordings. As discussed in the methodology, the purpose of this activity was not to measure the effects of The Walking Away programme as indicated by ambulatory activity. Instead, the intention was to ask students with ID in a further education setting to wear pedometers and successfully record a minimum of three days per week of step counts, thus assessing the feasibility of obtaining this measure in a larger trial. Temple and Stanish (2009) suggest that three days of pedometer recordings is sufficient to predict average weekly steps among ambulatory adults with intellectual disability. A different approach was taken between the colleges towards recording. The pedometers were handed out to both colleges in September 2016, and the researcher advised that notice would be given when the educational sessions were due to commence. The lecturers were to then ask the students to wear and record the pedometers for a minimum of three days in one week, prior to the sessions. Following this initial instruction, lecturers at Glasgow College asked if they could begin taking measures, as the students were keen to start using the pedometers and increase their walking. This was unanticipated, yet it seemed unethical to dissuade the students from their enthusiasm, and provided broader and therefore potentially richer data. Edinburgh college lecturers were advised that this was taking place at another college, and that it was optional to start using the pedometers at an earlier point. To sustain the students' interest in participating, the Edinburgh College lecturers invited students to use the pedometers and developed a game where students predicted their own step count for trips around the college. However, measures were not obtained earlier than prior to the educational sessions.

The measures are presented below in *Table 7.5*, and provide an indication of how far the students were able to consistently remember to wear and record the pedometers. The focus group discussions in the following chapters provide an insight into the barriers and facilitators experienced by the students, and by the lecturers who supported them in this activity. *Table 7.5.1* illustrates the raw ambulatory data.

Table 7.5: Ambulatory activity

Site	**Participants (*N*)**	**Days recorded (mean days per week, SD)**	**Step count (mean, SD)**
Glasgow	12/22 (55%)	1.8, 1.1	4323, 858.4
Edinburgh	10/26 (38.5%)	2.8, 0.4	5461.5, 2150
Combined	22/48 (45.9)	1.96, 1.1	4485.7, 3211

Table 7.5.1 Raw Ambulatory data

Site A (*N*=12)	24/10/16		7/11/16		21/11/16		5/12/16		9/1/17	
	Days recorded	Mean Steps	Days recorded	Mean Steps	Days recorded	Mean Steps	Days recorded	Mean Steps	Days recorded	Mean Steps
Participant 1	3	4228.5	3	1714	2	5948	2	4397	0	0
Participant 2	3	6307	3	3693.5	2	4656	2	5063	0	0
Participant 3	1	1553	3	1675	1	5919	0	0	3	2890
Participant 4	3	9212	2	3284	2	7949	0	0	1	9464
Participant 5	0	0	2	11839	0	0	0	0	0	0
Participant 6	1	485	3	8820	0	0	2	5455.2	2	3540.5
Participant 7	3	9088.75	2	5313.5	2	8920	3	8405	2	7738
Participant 8	0	0	3	11074	0	0	0	0	0	0
Participant 9	1	5354	3	2785	0	0	2	7214	2	5060
Participant 10	3	5771	3	8277.5	2	7556	3	5967	3	4888
Participant 11	2	766	3	5024	2	7023	3	2135	3	2981
Participant 12	2	5444	3	5038	2	6701	3	6023	3	6743
Mean (SD)	1.83 (1.19)	4017.4 (3388.3)	2.75 (0.45)	5711.5 (3495.9)	1.25 (0.96)	4556 (3530.1)	1.7 (1.3)	3721.6 (3128.3)	1.58 (1.58)	3608.7 (3273.9)

Site B (*N*=10)	24/10/16	
	Days recorded	Mean Steps
Participant 1	3	5067
Participant 2	3	4055
Participant 3	3	8999
Participant 4	3	4340
Participant 5	2	3099
Participant 6	3	6612
Participant 7	3	3096
Participant 8	3	4675
Participant 9	3	9002
Participant 10	2	5670
Mean (SD)	2.8 (0.42)	5461.5 (2150)

As *Table 7.5* illustrates, usable measures were obtained from 12/22 (55%) students at Glasgow college, and 10/26 (38.5%) students at Edinburgh college.

Glasgow College provided measures for five weeks out of four months, and Edinburgh College provided one week. The overall mean number of days per week recorded at Glasgow College was 1.8 (SD 1.1). This ranged from a mean of 1.25 to 2.75 days per week. The lecturers noted that on occasion, events such as public holidays or field trips meant that it was not possible to obtain a third day. The overall mean step count at Glasgow College was 4323.04 steps (SD 858.4, range 3721.6-5711.5).

At Edinburgh College, the mean number of days obtained from one week was 2.8 (SD 0.4). This may have been higher than Glasgow College due to data being collected from fewer participants and who had lower support needs. Both data sets were comprised of students from “supported learning” classes and “skills for employment”, which reflected higher and lower support needs respectively. The mean step count at Edinburgh college was 5461.5 (SD 2150, range 3099-9002), which suggests that there were some students at Edinburgh College who were either more able to wear and record pedometers, or more physically active, or a combination of both.

The mean number of steps per week from the combined sample was 1.96 (SD 1.1, range 0-3). This suggests that overall, the students and lecturers experienced difficulties in obtaining a consistent weekly count. The suggested minimum of three days per week appeared difficult to achieve, however it is possible that if the suggested minimum was five days per week, the students may have recorded more days overall. The levels of wearing and recording may also have increased post-intervention, in which case the data presented above would have served as a useful baseline measure. However, the discussions in the focus groups suggested that there were substantial areas of difficulty and barriers which could not be overcome, chiefly due to unsuitability the materials in their present format.

The combined mean number of steps was 4485.7 (SD 3211). Melville et al. (2015) reported a baseline step count of 4780 (SD 2432) steps per day in a sample of 102 people with ID which took place in a similar geographical region, and a t-test found the difference between this and the findings above to be non-significant (p = 0.6287, d = 0.103). Therefore, although the validity of the present data is questionable due to the number of days per week, it is likely that this level of activity is representative of people with ID. However, it is notable that the mean age of the participants was 46.3 years (SD 12.9), compared to mean 20.9 years (SD 5.02) in the present study. The similar level of activity between samples is therefore counterintuitive, as it would be reasonable to predict a higher level of activity in a younger age group. It is therefore possible that either the data in the present study did not accurately represent the participants' level of physical activity, or that the participants undertook a similar level of activity to their elder peers, which highlights an urgent need for change.

7.8. Chapter Conclusion

The study was successful in identifying, targeting and recruiting an appropriate and sufficient sample in terms of the stated aims of this part of the study, which were to assess the feasibility of trialing the Walking Away programme in a further education setting. Further work is required to assess the potential wider impact of the study however, as only 2/6 colleges responded to invitation to participate. Alternative recruitment strategies should be explored, such as presenting findings at teaching staff conferences and liaising with central educational bodies, which could lead to national implementation.

The health status and health literacy of the participants in the present study indicated by the demographics, questionnaire responses, and pedometer recordings suggests that this sample was appropriate for the aims of the study, however measures need to be adapted to the communication needs of people with ID in a college setting. Collaborative work with those conducting similar research could lead to consistently validated measures and appropriate materials. The following chapters qualitatively explore the experiences of the students and lecturers in participating in the study and educational sessions.

Chapter Eight: Student's Focus Group Report

8.1. Introduction

This chapter presents findings from the analysis of the student focus groups. Three themes emerged from the data, including: 1) "Acceptability and Impact", 2) "Understanding Course Content and Procedure", and 3) "Issues and Solutions". These themes encompass representations in relation to attending the Walking Away sessions, to wearing and recording the pedometers, and to aspects of the wider study process such as recruitment. Each theme begins with an overview of the Master theme. Related sub-themes are then presented in figure-form. Focus Group One and Focus Group Two represent Edinburgh and Glasgow, respectively. The participants in these groups are listed as pseudonyms in *Table 8.1,* below. Transcript excerpts are provided within each subtheme, to evidence Elliot et al.'s (1999) guidelines on 'grounding in examples'. It was necessary to include excerpts from the researcher, as these provide context for the reader to some of the participant responses. Further demographic details for participants are presented in the previous methodology chapter. The findings were positive overall, reflecting the students' acceptability of the study processes, materials and content. However, parts of the content were not accessible for all, posing implications for potential adaptations or sample targets.

Table 8.1: Focus group participants

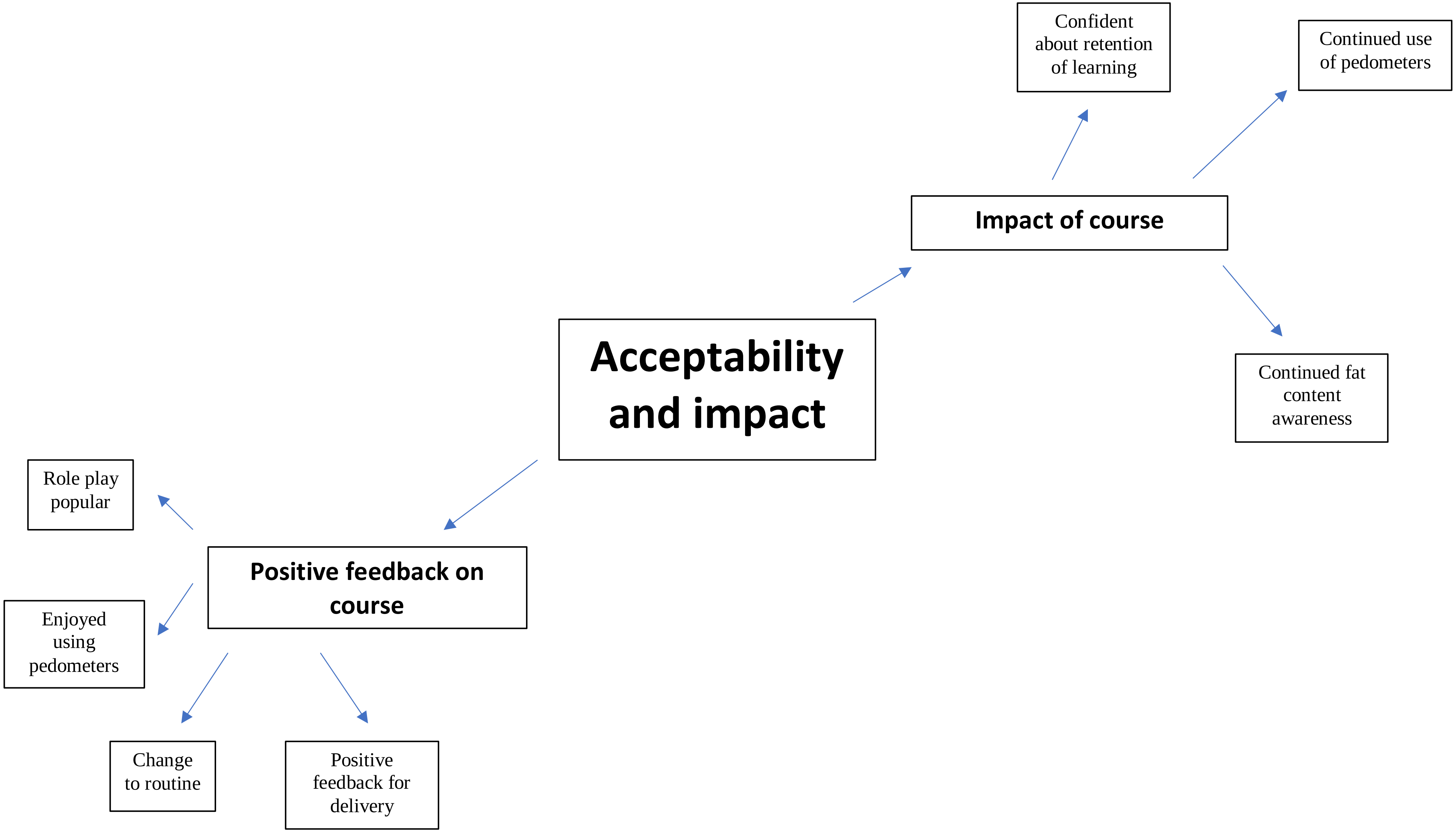
Edinburgh College	**Glasgow College**
Focus Group 1	Focus Group 2
Ali Steven Kerry Emily Beth David	Catriona Anita Nick Sean Lucy Michael Elspeth *(Teaching Staff)*

The names above are pseudonyms to preserve participant anonymity.

8.2. Theme 1: "Acceptability and Impact"

The first theme emerging from the student focus groups was "Acceptability and Impact". The first part of this, "Positive feedback on the course", represents statements which reflect the students' positive perceptions of the Walking Away programme. The examples highlight areas of the programme which stood out favourably for the students, as reflected by consensus, within and between the two focus group discussions. In “Impact of the course”, the theme also represents examples of the apparent impact of key-messages on the participants, which were reflected by descriptions of behavior change following the delivery of the programme. An overview of the theme’s subordinate and superordinate themes, structured in accordance with the guidelines of Braun and Clarke (2006), is presented in *Figure 8.1*, on the following page

Figure 8.1: Theme 1) Acceptability and impact



8.2.1. “Positive feedback on the course”

When the discussion focused on the overall impression of the Walking Away sessions, there was a general agreement that it had been an enjoyable experience. Students appeared to value the importance of learning about their bodies, and ways in which they could maintain a healthy lifestyle. Students appeared to value the importance of learning about their bodies, and ways in which they could maintain a healthy lifestyle. Ali, an articulate 19-year-old man in Group One, spoke about his learning experience:

> Ali: “They were quite brilliant, ‘cause you learned all about your body … and how you can keep on doing regular exercise...”

Students in Group Two also positively described their experience of attending the sessions, particularly in relation to components involving role play. One session involved a demonstration of increased risk of diabetes due to multiple risk-factors using an analogy within role play. Students discussed their reasons for appreciating this activity:

> Steven: “..it helps when it’s fun…”

In this statement, Ali described his appreciation of learning about behaviours which could reduce the long-term risks associated with developing diabetes, and his opinion was affirmed by the group, though no other participant spoke individually about this. The extent to which these messages were understood is discussed further in “Theme 2: Understanding Course Content and Procedure”, however these students appeared to perceive their learning experience positively.

The participants in Group Two also positively described their experience of attending the sessions and stated what they enjoyed about them:

> Catriona : “Um, learning, learning how to not get diabetes”
>
> Anita: “And how to be healthy, how to be very good and healthy all the months of the year.”
>
> Nick: “Well, I liked the taking part and being healthy.”

The above example shows that when asked further about enjoying the sessions, participants valued the messages around reducing the risk of diabetes and improving general health. Catriona, a 23-year-old woman whose weight currently increased her risk of developing diabetes, attributed her enjoyment of the sessions to learning how to reduce this risk. Anita, a 25-year-old woman, and Nick, a 19-year-old man, were both overweight and appeared to value the importance of staying healthy.

The possibility that the sessions were enjoyed as a novelty for some may be of importance for future delivery of the programme. If integrated into existing modules, it is possible that the programme would become part of the perceived norm and potentially lose impact. This topic was further discussed in the teaching staff focus groups.

The importance of relationships prior to delivery of the sessions was highlighted in both focus groups. The researcher had visited the participants in their classrooms on several occasions prior to the delivery of the sessions. These visits were made with the purpose of introducing the study and programme, then later taking baseline measurements. On these occasions, there were opportunities for informal conversations about the study and the participants' interests, which they appeared keen to share as a way of getting to know the researcher. The value of this relationship building was reflected in Group One, and participants reflected positively on why the perceived this to be helpful:

> Ali: "Just to give us some ideas"
>
> Steven: "Of what you're like and that."

In the above example, Ali's statement was endorsed by Steven's elaboration which suggested that they found the process of getting to know the researcher helpful. Steven had some initial reservations about participating, which will be discussed in "Theme 3: Problems and Suggestions". These reservations may have been reduced through relationship building, which in turn increased the acceptability of the programme.

The participants in Group Two echoed the importance of relationship building with a strong consensus when the researcher asked if he had been sufficiently trained to deliver the programme:

> Group: [Unanimously] "Yes!"
>
> Anita: "Yes you were."

Sean: “You definitely were.”

The students’ relationship with the researcher, and subsequent confidence in training, was later noted and confirmed in the staff focus group. This may have had an impact on the students’ acceptability of the programme and increased their likelihood to engage in learning.

Other positive feedback was in relation to a role play-based session. This involved a demonstration of increased risk of diabetes due to multiple risk-factors using the analogy of a tray overloaded with drinks. With the help of a member of the teaching staff, the plastic cups were loaded onto the tray to demonstrate the increased likelihood of dropping something. The students in Group One discussed their reasons for appreciating this activity:

Kerry: “Mhm yeah that bit”

Steven: “Yeah I liked that one”

Researcher: “What do you think you enjoyed about it?”

Ali: “It gave us a wee laugh”

Several voices: “Yeah, funny”

The participants’ understanding of the message behind this activity was less clear, and it is possible that the appeal of this was limited to humour. However, this may also have impacted on their general engagement in the programme, potentially leading to increased learning in other areas.

8.2.2. "Impact of the course"

An area which was popular with the students was utilizing pedometers to record walking. These were issued several weeks before the educational sessions were delivered, so that participants had adequate time to familiarize themselves with wearing and recording them. Despite there being several difficulties with this, as reported further below (in Theme 3: Problems and Suggestions), student participants reported that they enjoyed using them and continued to do so. Anita and Nick had brought theirs along to the focus group and were currently wearing them. Both discussed what they enjoyed most about using pedometers:

> Anita: “I got mine's on.”
>
> Nick: “I've got mine on too”
>
> Researcher: “What’s good about wearing them?”
>
> Anita: “Because it's good exercise, [Nick: “Aye”] how many steps you walk to bus stop and college”

Anita and Nick’s enjoyment of using the pedometers therefore appeared to have had some potential impact on their lifestyles as it was evident that they were continuing to use them beyond the requirements of the study, which highlights the necessity of an external reinforcer to prompt and sustain change. Kerry, an 18-year-old woman who had a part-time job in a nursery as well as attending college, also appeared to enjoy using her pedometer:

> Researcher: "Has anyone else done more walking since they got the pedometers?"

> Kerry: "I wear it at my work. I look after children and I work in a nursery."

Kerry had integrated wearing and recording her pedometer into her daily life, which reflected that the unit on physical activity may have had an impact upon her. For one student, the session on Food Choices appeared to have made an impact. When asked by Elspeth, a member of the teaching staff who supported students to engage in the focus group, Anita appeared to have remembered and acted upon an activity where food labels were checked for fat types and content:

> Anita: "I have a healthy stuff now."
>
> Elspeth: "You remember when you looked at the back of the packs."
>
> Anita: "I look at the back of my prawns and my salad."
>
> Elspeth: "So you've been looking at it since Anita to be [Michael it's the higher contents and the lower contents] healthy."
>
> Anita: "Yes"

Anita's apparent healthy eating awareness was confirmed in the teaching staff in the Focus Group 4 discussions, and it was highlighted that other students had engaged in this awareness during break-times. However, not all students were responsible for grocery shopping, and this may have detracted from the relevance of this unit:

> Kerry: “Well, I don't buy the stuff from the shops, I do sometimes, to get the stuff that I like. My Dad goes to Tesco's to get food for dinner and things”

Beth, a 44-year old woman in Group Two, also appeared to have used the pedometer to increase her walking, and had decided to walk rather than take the bus to college to increase her daily step count:

> Beth: "…I walk every day. I walk into the college in the morning and I walk home… now I walk round the shops to get here instead of the bus."

Beth's continued use of the pedometer together with her efforts to walk instead of taking the bus suggests that participating in the programme may have led to an increase in physical activity. It was unclear however whether this was due to messages of the programme, the use of the pedometer alone, or a combination of both. Beth's weight and age may have put her at higher risk of developing diabetes than some of the other students, and it is possible that learning that these were risk factors during the programme may have influenced her motivation to increase her physical activity. The session on physical activity contained messages on how to increase activity within daily routines, which also may have been an influence on her change of route. However, Beth was unclear about this element of the session during the focus group discussion and could not recall the session when asked:

> Beth: "I think I'm not sure about that. I remember the other bit more."

Beth's difficulties recalling this session may reflect wider problems experienced by the group, rather than her individual difficulty with recall. These will be discussed in the third theme: "Issues and solutions".

Overall acceptability of the programme was reflected by the students' attitude to the efficacy of their learning experiences. In both groups, there appeared to be a perceived confidence about their ability to retain the information they had been given over time. There was a consensus from the students in Group One when they were asked whether they would recall information from the sessions after a year. Students in the second focus group also seemed to be positive about their learning. However, they were less confident about recall over time and were receptive to the idea of a refresher session, responding with consensus to the suggestion.

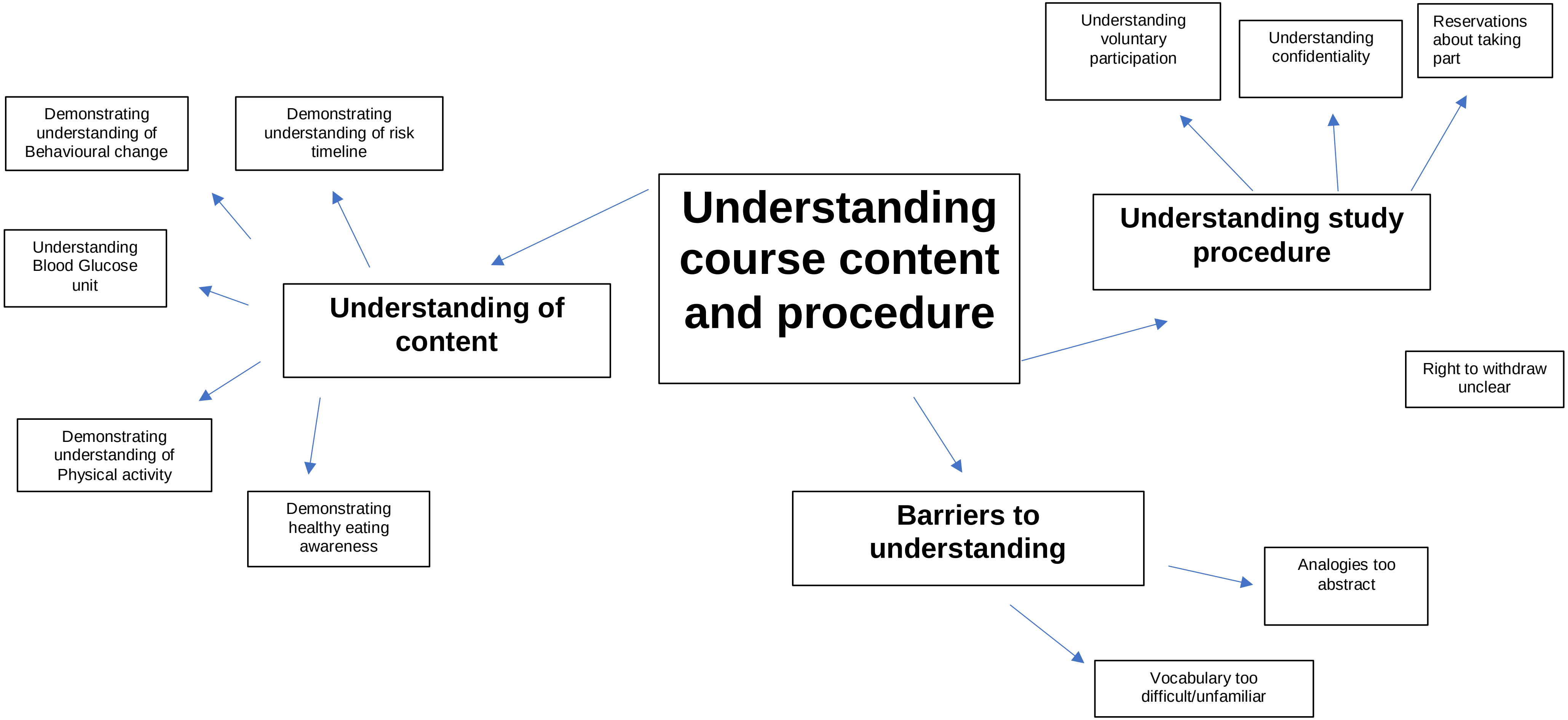
8.2.3. “Acceptability and Impact conclusion”

This theme represented the areas in which students spoke positively about attending the Walking Away sessions or suggested that they had acted upon the programme's key-messages. From the participant statements is it possible to conclude that there was an overall sense of enjoyment and acceptability of the programme together with a willingness to take on board some of the key-messages and act upon them, although this was only represented by individuals and may not have been reflective of the whole group. Furthermore, it is less clear whether the enjoyment and acceptability was held regarding the key-content of the programme, or towards more superficial elements such as changes to routine, new relationships and humour. This is further elucidated in the following theme, "Understanding course content and procedure", where the level of the students' understanding of the programme is represented.

8.3. Theme 2: “Understanding Course Content and Procedure”

This theme begins by representing the students’ understanding of the course content, including its key-messages and information. In addition, a representation of the understanding of the process of being involved in the wider study is provided, which details aspects such as the recruitment procedure, confidentiality, and consent. These are highlighted through statements which demonstrate varying levels of understanding, where the potential for engagement with the programme is highlighted but with limitations, and are presented in the sub-themes "Understanding of Content", and "Understanding of Study Procedure". Alongside this, barriers are discussed which resulted in limitations to the students' level of comprehension in "Barriers to Understanding". *Figure 8.2* on the following page illustrates these themes and subthemes

Figure 8.2: Theme 2) Understanding of course content and procedure



8.3.1: "Understanding of Content"

The following examples cover each unit of the Walking Away programme and are presented in the order that they were delivered. The first module, "Blood Glucose", covered the process of glucose control and glucose impairment, using a magnetic board with a human body outline and magnets to demonstrate the process of glucose metabolism. A key and lock analogy were used to describe the process of insulin entering cells, whereby the locks were rusted as the risk of type 2 diabetes increased. One participant demonstrated some understanding of this by recalling parts of anatomy:

> Researcher: "So we had this bit to start with." [shows magnetic board]
> Ali: "Oh yeah! The stomach, the muscles, the pancreas and all that."

Ali appeared to have been able to recall some of the information given during this unit. However, it is possible that this information was already known to him. Other students in Ali's group were not forthcoming about their recollection of this information, and none appeared to understand the analogy, which is discussed further below in the sub-theme "Barriers to understanding". However, some students in the second focus group did appear to have a recollection and understanding of this and could recognize key concepts such as insulin resistance and glucose metabolism, as well as phrases such as “keys to the door” and “glucose” when the researcher pointed to their location on the magnetic model.

The students demonstrated that they could recall vocabulary relevant to the learning activity, potentially reflecting an understanding of the messages. Cues were offered by the researcher to assist with naming insulin, however no participant managed this, except for Sean who appeared to recognise the term afterwards. Sean, a 19-year old man, had been diagnosed as prediabetic and was likely to have been aware of the term prior to attending the sessions, though had not attended a structured diabetes education programme. Catriona appeared to demonstrate some understanding of the rusty key analogy by saying that the "doors" mentioned by Nick and Sean were cells. Catriona was a 23-year-old woman who showed a high level of engagement throughout the educational sessions and had been able to answer many of the questions throughout. In comparison however, other students seemed less able to understand this analogy. This is also discussed further in the subtheme "Barriers to understanding".

The students in this group also demonstrated an understanding of the latter part of the first Walking Away unit, which used a timeline diagram on the magnetic board to show a progression starting from "no diabetes", moving to "at risk of diabetes", and ending at "diagnosed with diabetes". Sean, Nick, and Michael appeared to understand this progression:

> Sean: "No diabetes."
>
> Michael: "No diabetes. If we hit that, good!"
>
> Nick: "And then - at risk."
>
> Elspeth: You're moving towards diabetes-
>
> Michael: "And then at the red you've got it."

Michael appeared to understand that the coloured bar, which moved from green to red, indicated the increased risk of diabetes. The key-message of the activity is that by increasing physical activity and making healthy food choices, it is possible to reduce the risk of further diabetes and to move back from "at risk", to "no diabetes". Michael indicated an understanding of this by saying it would be good to "hit" the "no diabetes" area, although it is not clear if he understood that this could be achieved through reducing risk factors. The potential issue of representative diagrams and analogies such as this is discussed further in "Barriers to understanding.

The second Walking Away unit focused on the risks associated with developing diabetes, first using activity cards to encourage thinking about risk factors such as family history, physical inactivity and obesity, then using a role play activity to demonstrate that multiple risk factors can lead to increased risk of diabetes. The participants appeared to enjoy the role play activity, as described above in "Acceptability and Impact". However, participants did not seem able to recall risk factors when asked by the researcher:

> Catriona: "Yeah, eating more healthy stuff."
>
> Anita: "No eating – cakes are not healthy."

The students appeared to have understood a general health message about healthy eating yet had not been able to draw upon the examples of potential causes of diabetes highlighted in the unit when asked by the researcher about risk factors. This may have had an impact on the depth of their understanding of the role play activity, as there was not a clearly apparent connection for them between the loaded tray and diabetes risk factors.

The programme then moved onto physical activity, which contained the core message of reducing diabetes risk though walking and was therefore the most important unit. The participants were given the opportunity to learn about the benefits to health of physical activity, ways of integrating moderate physical activity into daily life, using pedometers and making activity plans using the Walking Away resource booklets. The unit did not appear to have made a strong impact on the students in Group One and did not seem to recognise it when given cues. However, the students in focus group 2 appeared to have understood the message concerning the benefits of physical activity, and provided different examples of moderate activity:

> Catriona: "Walking."
>
> Anita: "Yoga's good for your exercise."
>
> Michael: "Swimming."
>
> Anita: "Some people do exercise for their gardening."

The participants in this example showed a clear recognition of this part of the unit in comparison to those in Group One. It was unclear whether this difference was due to cognitive differences between the groups or other potential factors, such as prior influences on the students' interest in physical activity. As highlighted in the Methodology, no teaching staff were able to attend Group One as advocates. It is possible that the students were less able to communicate their understanding without this support. Regarding the pedometers, the students had engaged with wearing and recording their steps for several weeks before the educational sessions commenced, as Beth's example highlighted in "Acceptability and Impact". Anita also demonstrated an enthusiasm for using the pedometer when asked why it was important to be aware how many steps she had achieved:

> Anita: "Because it's good to see how many steps you've done for every month of the year."

Anita appeared to understand that the purpose of wearing the pedometers could encourage further engagement in physical activity. This was not the case for every participant however, and several difficulties with wearing and recording the pedometer are discussed further below in "Issues and solutions" (such as physical discomfort and reading the display screen), and in the lecturer and support staff focus groups.

The final element of the "Physical Activity" unit presented the diagram of a behavioural model, which represented different cyclical stages of motivation. Students in both groups recalled this enthusiastically and appeared to have some understanding of its messages. Steven and Kerry were particularly drawn to this model:

> Steven: "Yeah, yeah I liked that one … it's a bit like motivating yourself."
> Kerry: "I also felt the same."
> Steven: "Not being glued to the TV and that, you know what I mean like. Get yourself out of bed in the morning and go out for a walk you know what I mean?"

Steven and Kerry had both actively engaged in this activity during the unit, offering contributions to the conversation. The message of motivation appeared to resonate with Steven and Kerry acknowledged her agreement and this may potentially have been linked to a perception of having agency in regard to health. It is unclear from their statements whether it was just this aspect of the model that was understood, or whether they understood the model's message of reflected and acting upon past barriers before re-attempting goals. However, it may be that they found the complexity of the model difficult to communicate.

The final session focused on food choices. Participants were encouraged to consider different types and quantities of fats and were given food packaging labels to read and discuss. There appeared to be a mixed understanding of this, as reflected by some participants' difficulty with recalling the content:

> Catriona: "We were talking about Glucose."
>
> Michael: "About diabetes."
>
> Anita: "We were talking about butter had fat in it. And sugar."
>
> Nick: "About what's in it. Bad for your diet and health."

In this example, Catriona and Michael, who had shown understanding of earlier parts of the programme, appeared unable to recall that fats were the main subject of the unit. Anita did mention fats, but also sugar, which was not a focus throughout the programme. However, this session appeared to have had some impact on Anita, as described in "Acceptability and Impact". Once the group had been reminded what the unit was about, Michael also showed an understanding of carrying an awareness of fat content:

> Michael: "It's the higher contents and the lower contents. Healthy."

Michael appeared to understand that an awareness of higher and lower fat content could lead to being healthy. There were some difficulties with this unit, which are discussed in problems and suggestions, and may have contributed to a limited understanding of the messages and content. Overall, the statements of the students suggested that there was some recollection and understanding of the Walking Away programme, but there were barriers which led to this understanding being limited. This leads on to the next sub-theme, in which these barriers are explored in further depth.

8.3.2. "Barriers to Understanding"

A difficulty which seemed to be present for students throughout the programme was the use of analogies to explain concepts. The two main examples of these are the "rusty key" explanation of insulin resistance, and the overloaded tray depicting multiple risk factors. Ali appeared to recollect and enjoy the session describing blood glucose, as described in "Acceptability and Impact". However, when the group were asked about rusty keys, he and Steven were clearly unaware of the link:

> Ali: “No.”
> Steven: “Not a clue.”
> Ali: “Don't have a scoobie.”

The analogy was returned to throughout the units which should have made it easier to learn and subsequently remember. The strong statements against this may suggest that the analogy did not make sense to them. The teaching staff believed this to be the case, as is discussed further below in their focus group report. This was not the case for everyone however, as Catriona did appear to have understood the door-cell analogy, as reported above in the "Understanding of Content" subtheme. There may have differences between students due to ASD and Asperger traits, whereby literal interpretations could lead to difficulties with the use of metaphors and interpretations, as was also discussed in the teaching staff focus groups. There may have also been differences due to the presence of an advocate in Focus Group 2, as highlighted above, who may have been able to provide cues for the students to recall their experiences more easily.

The overloaded tray roleplay activity also asked participants to understand that one thing represented another. The activity was popular and well received, but as has been pointed out, there were evident limitations to the student participant's understanding. The following extract provides an example of a student making a literal interpretation of the activity:

> Elspeth: "Where we had to put things on the tray? Remember?"
>
> Anita: "You need to carry one things at a time."

In this extract, Anita appears to remember the role play session. However, rather than linking the activity the drinks on the tray to diabetes risk factors, she states that the drinks should be healthy, suggesting that she instead is possibly remembering and repeating a general health message about dietary choices. Following this she then stated that the tray should not be overloaded, suggesting that she had understood a health and safety message rather than the analogy. However, for some students an understanding of the link may have been present, but the concept too difficult to articulate. The issue of the student participant's potential linguistic limitations extends to other areas of the programme. As suggested above in "Understanding of content", "insulin" was a difficult word for the students to learn:

> Catriona: "That word, whatever that word was"
>
> Researcher: "Insulin?"
>
> Catriona : "Yeah"

During the educational sessions, Catriona had appeared to learn the word Insulin, recalling when prompted. However, by the time the focus groups were conducted, she struggled to recall it. This was also the case in the other focus group:

> Kerry: "I hadn't heard a lot of Glucose"
>
> Researcher: "And then, what was the "in" word we were talking about a lot" before? Insu-
>
> David: "Insulation?"

As with Sean, in the example provided in "Understanding of content", David had answered "Insulation" in response to the "In-" cue offered by the researcher. This may have been the result of attempting to assimilate new information into existing knowledge. The unfamiliarity of certain words and phrases may have been a barrier for the students and future adaptations may benefit from reducing complexity or simplifying concepts. This was discussed further by the teaching staff, who had a stronger awareness of the students' pre-existing knowledge and the limits of their vocabulary. The "Blood Glucose" unit was particularly rich in biological content and contained complex terms and concepts, which may have been too difficult for the students to follow. This was reflected by Ali when he was asked about the blood glucose session:

> Ali: "I think that there were some bits which were very, very ultra-hard"

Ali stated this difficulty, despite earlier describing learning about the body as "quite brilliant". Both Ali and Steven were unsure why they found the Blood Glucose session difficult. This may have been because they found it difficult to articulate which aspects of the unit they found difficult. However, the earlier comments of participants and the teaching staff feedback suggests that the vocabulary or the concepts were too complex, and that this may have been a barrier to successful learning. The teaching staff later discussed that the recruitment process could have involved a tighter selection of participants, so that only those who were likely to be able to fully understand the content were recruited. An alternative explanation is that the there was an appreciation of the content in terms of learning about how the body works, regardless of the technicalities of the vocabulary. This leads to the final part of the "Understanding Content and Procedure" theme, which explores the student participant's understanding of the recruitment process.

8.3.3."Understanding study procedure"

This subtheme represents the student participant's understanding of the study procedure, including recruitment, consent, right to withdraw and confidentiality.

There appeared to be a strong understanding of consent, with several voices speaking in unison that they had understood that participation was voluntary:

> Sean: "Yeah we felt like it was out choice, definitely."
>
> Researcher: "OK. Did anyone feel like they had to do it?"
>
> Catriona : "No."

The students had received an easy-read introductory sheet (see appendices) with pictorial support. In addition, the researcher had given an introductory talk to the class, which had been reinforced by the teaching staff. In one location, the teaching staff had made their own introduction prior to the dissemination of the information sheets and made their own introduction to the study. This caused some confusion for the students, which is reported in more detail below in "Problems and Suggestions", and in the report of the teaching staff focus groups. Perhaps in part due to this, the students appeared to have understood that participation was voluntary, but not their right to withdraw from the study. When the researcher asked whether this had been understood, David and Ali reflected that they hadn't:

> David: "No, I didn't realise that."
>
> Ali: "I didn't know you could stop taking part."

Students who attended the focus groups, including David and Ali, were given updated information sheets which also stressed the right to withdraw, and signed consent forms to indicate that they understood this. However, these were received several months after the initial information sheets which were given prior to commencement of the study. It may be that David and Ali had read and understood about their right to withdraw but had forgotten this by the time the focus groups took place, therefore only focusing on new information on the second information sheet such as information about the focus groups.

Another problem which appeared to have been related to the introduction delivered by the teaching staff was the students' negative perception of what the study was going to be about and how it might impact upon them. Steven and Kerry were both anxious that they might "get" diabetes if they were to take part:

> Steven: "In case I got it."
>
> Kerry: "I'm the same – I'm the same as Steven"
>
> Kerry: "So for me the difficulty was going to be like, hearing it and then like,
>
> Steven: "Aye. In case you found out something that you had."

In this extract, Steven and Kerry both clarify that what they mean by "getting" diabetes, was finding out that they had diabetes symptoms, and that they might therefore already have the disease. This had happened directly after the staff introduction, which is discussed in the staff focus group report, and Steven was reluctant to participate at this point, telling the teaching staff that he didn't want to get diabetes. Following this, Steven had met with the researcher and a member of the teaching staff to reassure him that this would not be the case, and it transpired that Steven had a relative with diabetes, which may have contributed to this anxiety. This meeting clarified for Steven that attending the course would not lead to him getting diabetes, but that it might be helpful to learn about symptoms and learn more about how to reduce the risk factors, and this seemed to reassure him:

> Steven: "Just like, talking about it and things like that, know what I mean?"

Following this, Steven stated that he wanted to participate in the study. The researcher and teaching staff were alerted to the possibility of Steven becoming distressed if he were to learn that he did have risk factors, though this did not turn out to be the case. Measures were in place in the event of a participant becoming distressed in this situation, as discussed in Chapter Four. It is important to acknowledge that these considerations are carried forward in future deliveries. Kerry's anxiety was related to the possibility of her having an illness in addition to epilepsy:

> Kerry: Well for me I was worried cos I've got epilepsy. That's why I was worried. Cos I've got epilepsy. I take seizures. Cos I had one on Saturday.

Unlike Steven, Kerry had not mentioned these concerns prior to or during the study, and it was only during the focus group that she expressed them. However, Kerry seemed to enjoy participating, as the examples in "Acceptability and Impact" demonstrated. It is important however to acknowledge that such concerns may exist for participants, and that clear information as well as opportunities for reassurances are provided upon introduction and implementation.

Students appeared to have understood and retained their understanding of confidentiality. The students required some prompting to remember what was meant by anonymous but appeared to understand what this meant in relation to the study when asked by the researcher:

> Ali: "Is it because it's got some private information in it?"

> David: "Means no one knows like who you are or that."

In Group Two, Catriona seemed clear about the meaning of confidentiality:

> Catriona: "It means, no-one knows. It's all secret and hush hush …
> "That only the people that are in it know."

Catriona appeared to speak for the rest of the group and when pressed further about the meaning in the context of the study was able to provide a clear explanation. With the exception over right to withdraw, the students seemed to have an overall strong understanding of the study procedure. The pictures and format in the information sheets had been used successfully in previous studies with people with ID, and the verbal explanations by the researcher and teaching staff helped to reinforce this information and assist the students with their understanding. The staff and some of the students had also been involved in previous research and may therefore have had some familiarity with study procedures.

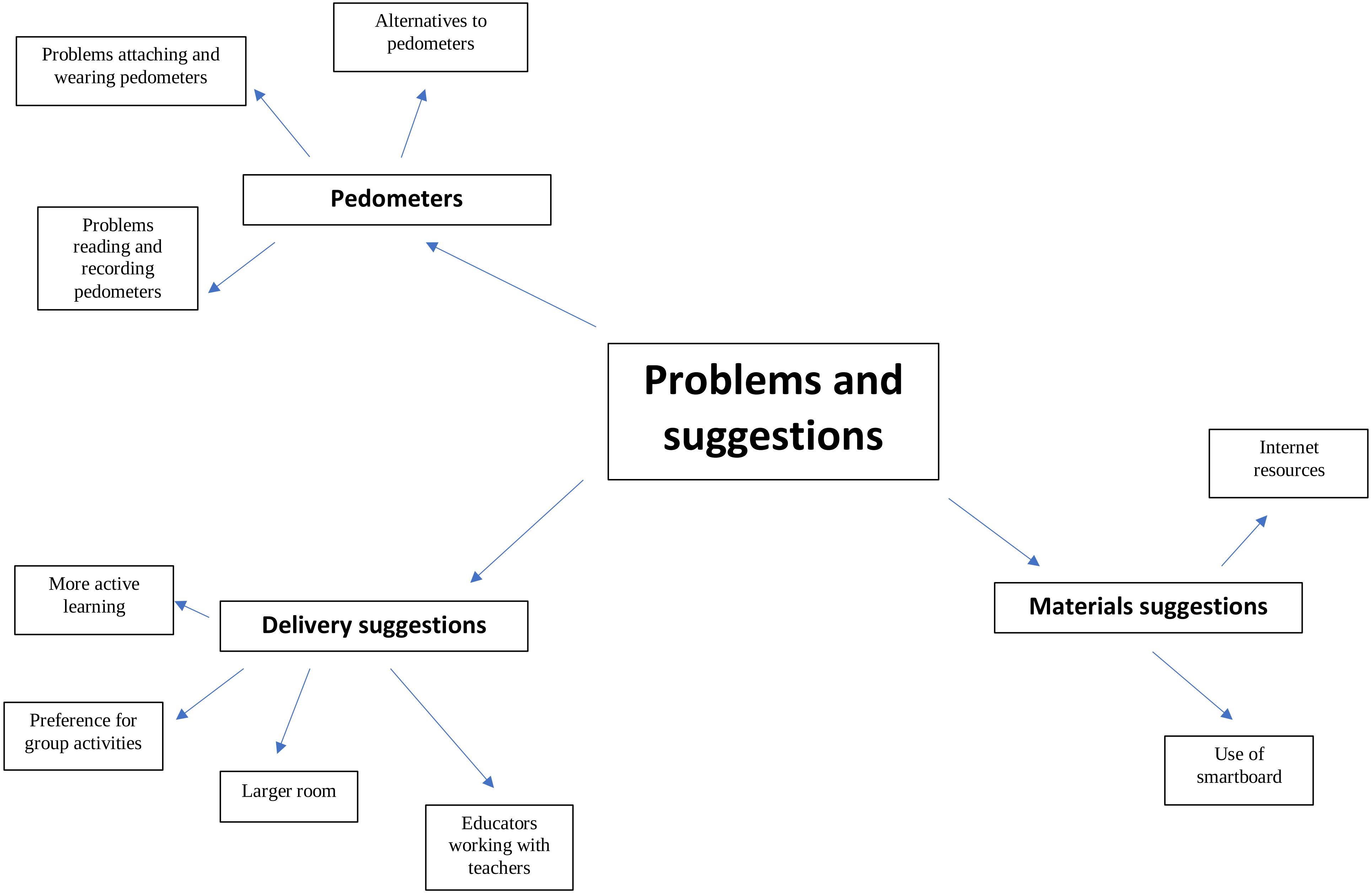
8.3.4. "Understanding Course Content and Procedure" Conclusion

The student's overall understanding of Walking Away was limited, highlighting that adaptations would need to be made were the programme to be implemented on a wider scale. Difficulties due to limited vocabulary and literal interpretations meant that additional learning aids would be required, and that some aspects of the course may not be suitable for people with Asperger's Syndrome or ASD without modifications. The expert position of the teaching staff led to some useful considerations and suggestions for these adaptions and are discussed in the staff focus group report. However, the students were also aware of unsuitable aspects of the programme and made some suggestions of their own. These are presented in the following theme.

8.4. Theme 3: "Problems and Suggestions"

The final theme, illustrated below in *Figure 8.3*, represents problems with the Walking Away programme as perceived by the students, who in addition offer some solutions to these problems which reflect on their wider learning experiences in a further education setting. These are regarding the way in which the programme was delivered, including the structure, setting and methods of delivery. Problems and suggestions are also represented regarding the Walking Away materials and resources as well as with wearing and recording the pedometers.

Figure 8.3: Theme 3) Problems and suggestions



8.4.1. "Delivery Suggestions"

An issue for the students in Group Two was the room size. These students were usually divided into classes of around 10 people. However, for logistical reasons, the units had to be delivered to all of the participants at once, which meant a group of 25 were situated in one room:

> Elspeth: "Can you think of anything to do differently?"
>
> Anita: "Maybe to have a big room."
>
> Catriona: "Oh yeah a big room."
>
> Nick: "A big room Anita: Maybe to have extra seats."

Although the students referred to the room size as the problem, it is more likely that the number of people in the room was the issue, as the room was large and could have accommodated more people. The number of people may have led to difficulties in supporting individuals, as the Walking Away programme was designed to be delivered to groups of 10. This was later affirmed by the teaching staff. Alongside this, some students appeared to feel that they did not have space to move around, which meant that they did not have an active learning experience. Elspeth was aware that this was something the students were used to receiving, and asked the students about their preferences:

> Elspeth: "Anything else that would've helped you when we had the key in the door – would it've helped if we'd had – do you think it's good to sit down all the time or do you think we should get up?"
>
> Anita: "Get up and walk around."

> Nick: "Aye get up."
>
> Catriona: "Walk around."
>
> Researcher: "Right. Cos there was lots of questions in that way that that was delivered but maybe a little bit more active – do you think?
>
> Catriona: "Yeah a bit more active."

Although there were activities in the programme which encouraged participants to be out of their seats, such as arranging activity cards, the number of people in the room limited the scope of this, and the students may have had more of a passive experience than the programme was designed to offer.

The students also seemed to be aware that there were teaching methods they usually received which could have facilitated their learning. This was in relation to learning new vocabulary, as highlighted in "Barriers to Learning":

> Catriona: "To spell it? Just spell it."
>
> Nick: "Spell it... to connect."
>
> Catriona: "It helps to spell."
>
> Elspeth: "It helps as well sometimes to do a bit of phonics."

In this extract, Catriona and Nick suggested that spelling new words could aid with learning them. Elspeth followed this up by commenting that this sometimes takes place in lessons, and the rest of the teaching staff later discussed this in their focus groups. The vocabulary in the "Blood Glucose" appeared to be a learning barrier for some of the students. However, there were time constraints in the delivery of the present study and this may have been a time-consuming activity.

This content may also have been conceptually complex, and the usefulness of spelling words could therefore have been limited.

A final suggestion to do with delivery concerned with whether teaching staff, rather than diabetes educators, would be better suited for this role. Steven in Group One seemed at first to be unsure about this possibility, but considered that it could be possible:

> Steven: "Well, they've got their own job here, do you know what I mean? It could be a bit hard for them …it would be [Ali agreeing] good if they could"

Steven appeared concerned that training teaching staff to deliver the Walking Away programme would place extra demands on their role, acknowledged its value if integrated into their training. There was varied opinion from some of the students in Group Two when asked if it would be better to have a familiar educator:

> Catriona: "Someone we didn't know do it"
> Anita: "We need to have someone we know."
> Nick: "Aye, definitely."
> Catriona: "Cause. Um they can also help the people that we know how to do it."

Catriona seemed to feel differently from the others, who thought that it would better if someone they knew delivered the course. However, at the end she seemed to suggest that an outside educator could work together in collaboration with the teachers, which was supported by others in the group. Catriona may have felt that a combination of knowledge from a specialist combined with someone who knew the students well would work best. This had been the arrangement in the present study. However, the teaching staff felt differently about this, as is discussed in their focus group report.

8.4.2. "Materials Suggestions"

In this sub-theme, the students' thoughts on the Walking Away materials are represented. In both focus groups the size of some of the materials was discussed. Many of the pictorial materials were hand-sized magnets, designed to be used within a small group activity or presented on the magnetic board. The consensus seemed to be that the materials were too small to be viewed properly.

Anita, Elspeth and Catriona all had difficulties seeing the materials. During the units, Catriona had been seated close to the front of the group, and the distance should not have affected her ability to see the magnets. For the others, the number of people in the room may have meant that they were less able to see. However, the second group suggested the materials may have been easier to see if they were presented on a Smartboard:

> Kerry: "Stuff up on the board."
>
> Kerry: "Well probably it's about the size but I did it at school, that's what I did sums and that on and using it's better for us"

As Kerry pointed out, regardless of the size of the materials, the students were used to seeing things presented on the Smartboard as this was the format they had received since school. If the Walking Away materials had been presented in this way, they could potentially be resized and enlarged onscreen, enabling the students to see them better. The teaching staff also later reported that the students were students used to accessing and using internet-based resources, which was a suggestion by Anita following the Smartboard suggestion:

> Anita: "Maybe seeing some pictures on the internet."
>
> Anita: "It's tell you whether you've got diabetes."

Although Anita struggled to explain why she thought using internet-based resources could have been helpful for the Walking Away programme, she may have been reflecting that as part of her wider college modules, students learn to research information of interest to them on the internet. This was later described by the teaching staff. This could potentially offer an active way of learning components of the Walking Away course, although could be challenging within the time constraints of the original course structure.

The final area in which the students made suggestions towards the programme was in the use of pedometers. As with the original study upon which the Walking Away programme was based (Yates et al., 2009), the pedometer issued to the participants was the Yamax Digiwalker SW 200. This model features an accelerometer, an LED display of number of steps, a steps to calories conversion chart and a reset button. There were mixed reports from the students about these pedometers, with some experiencing little or no difficulty and other problems. One issues for some the students in Group Two was wearing and attaching the pedometers:

> Catriona: "It was hard."
>
> Elspeth: "Sean? Did you clip on your pedometer to your belt?"
>
> Sean: "I can't do it really."

It was later pointed out by the teaching staff that additional support was needed for several students to attach their pedometers. This may have impacted on the students' likelihood to wear them out of college where this support may not have been available. However, two students in the other focus group reported appeared to have not experienced this to the same extent:

> David: "It wasnae that much of a hassle."
>
> Steven: "It's cos I'm not wearing it every day. If I was wearing it every day I'd get used to it."

David appeared to have experienced little difficulty, although his use of the word "hassle" may suggest his preference would be to not wear a pedometer. Steven's comments suggest that although he did not like wearing the pedometer, his discomfort was due to wearing something unusual and that this may have eased as he got used to it. Catriona however, found hers physically uncomfortable to wear attached to her belt:

> Catriona: "I didn't like it when it digged in to my skin though."

This discomfort may have made Catriona less likely to wear the pedometer over time. However, it is possible that she could have been supported to attach it to her clothing more comfortably. A second problem with the pedometers for some students was the opening and closing mechanism. The lid of the SW 200 pedometers clips onto the back, which has to then be pushed open with the thumb. Two students commented on their difficulties with this:

> Emily: "Quite tricky."
>
> Steven: "I found that a bit tricky."

The teaching staff later reported that they had observed several students experiencing this difficulty and found it difficult themselves. An easy open-close mechanism may have increased the likelihood of the participants wearing and recording the pedometer. However, the pedometers were new when issued to the participants, and the clip may have eased with use over time.

Finally, the display seemed unsuitable for some of the participants, with numbers approximately equivalent to a 14-point font on unlit black and white:

> Kerry: "I couldn't read it."
>
> Steven: "They were too small for me."
>
> Steven: "Too dark."

The comments in this extract suggest that the participants may have struggled to record pedometer readings without additional support. The students may also have been smartphone users and potentially used to larger, more colourful displays, as well as a range of portable devices. This may have influenced their suggestions for alternatives to the pedometers:

> Anita: "A watch?"
>
> Catriona: "My DS cause my DS records."

Lucy: "A Fitbit"

Catriona: "Aye 'cause it won't stick to me and I can stick it in my bag"

Anita and Catriona seemed aware that there are step recording devices which do not need to be worn at waist level and may therefore be more comfortable and convenient. It is possible that such items may be seen as accessories and subsequently as fashionable items to young students in a college setting. These may also be less conspicuous than pedometers, and therefore carry less stigma than pedometers.

8.4.3. “Problems and suggestions” conclusion

This theme has represented the students’ perceived problems with the Walking Away programme and their suggestions for improvements, in the areas of the delivery and materials, as well as the pedometers. It can be concluded that the students were used to educational approaches, such as through active learning and using electronic resources, and that their preference would be for a continuation of this teaching style. The suggestions provide practical feedback and guidance for adaptations to the Walking Away programme which could potentially increase its impact for young adults and adolescents with ID through familiarity. Some of these suggestions concurred with those of the teaching staff, which are presented in the staff focus group reports.

8.5. Conclusions

The two focus group discussions provided a rich set of data concerning the student experiences and perceptions of the Walking Away programme. The representations were positive, and it is possible to conclude that the students' found the programme acceptable, and that there was an immediate impact on some students, who appear to have understood a wide part of the programme's content and key messages.

To reach the majority of the group and ensure that all of the content was understood, adaptations would have needed to be made to the programme. The suggestions made by the participants may have further improved the acceptability and accessibility of the programme by making it more familiar. However, these may not have been sufficient to address the difficulties highlighted, such as the literal interpretations and limited vocabulary of some of the participants. This raises the following questions for further implementations of the Walking Away programme for people with ID in college settings:

1. Whether the programme should be simplified to reduce problematic content
2. Whether the programme should be enhanced to make problematic content easier for all of the students
3. Whether a tighter recruitment selection is made so that only students who would not struggle with the highlighted areas would be invited to attend the programme

These questions were also concluded by the teaching staff in their evaluation of the Walking Away programme, which is represented in the following focus group reports.

As the suggestions made by the students in this chapter are either supported or enhanced by the teaching staff, a set of recommendations which encompass all of the focus groups is presented at the end of the following chapter.

Chapter Nine: Teaching staffs' focus group report

9.1. Introduction

This chapter presents the analysis of the lecturer and support staff focus groups. This was an important part of the process evaluation as it described the mechanisms of impact from the perspective of the lecturers and support staff, who were in an expert position to evaluate how the Walking Away programme was received by the students in comparison to their ongoing curriculum. Furthermore, it can be said to describe the fidelity of the study, in other words the extent to which the core philosophies and values of the Walking Away programmeme were upheld. The questions focused on planning and consultation, recruitment and retention, and the acceptability and accessibility of the materials to the students. Each focus group was approximately one hour long and was audio recorded. The two focus groups, Focus Group Three and Focus Group Four took place at Edinburgh and Glasgow Further Education Colleges. The participants in these groups are listed as pseudonyms in *Table 9.1,* below:

Table 9.1: Staff focus group participants

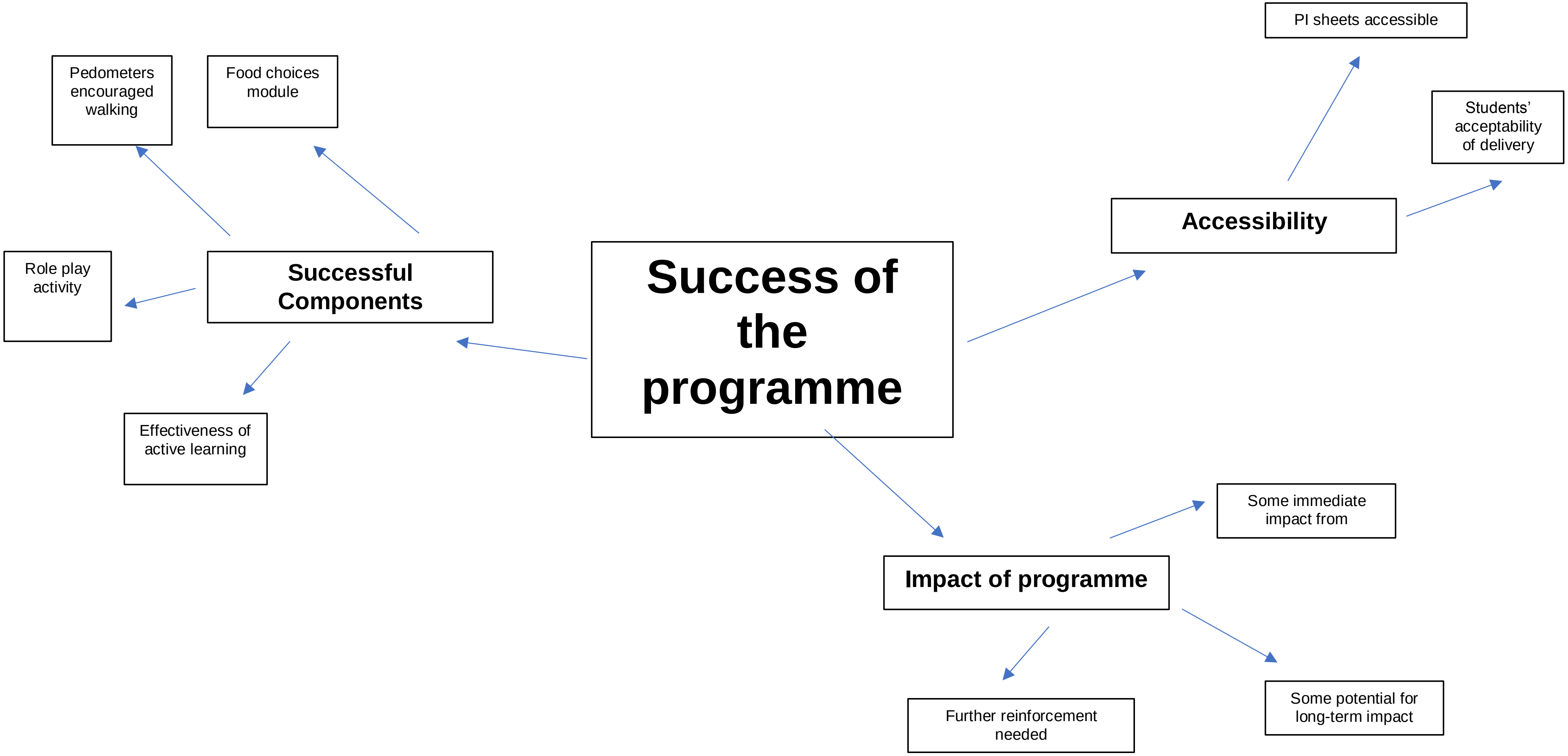
Edinburgh College	**Glasgow College**
Focus Group 3	Focus Group 4
Scott Margaret Kate Angela Lorna	Elspeth Susan Joseph Irene

Three themes were extracted from the data: “Success of the programme”; “Problems and limitations”; and “Suggestions and recommendations”. These contain representations of what the lecturers and support staff consider as strengths and weaknesses of the Walking Away programme in its current format, and suggestions on how it could be adapted to render it more suitable for people with ID. A diagrammatic overview is presented at the start of each section of the subordinate and superordinate themes. As there was considerable overlap in dialogue in these focus groups compared to the student groups, moments where one participant talked concurrently with another are represented in square brackets, e.g. [Susan: “…And certainly initially a lot of the participants were thinking in terms of their wider health where they were taking the stairs instead of the lift, [Elspeth: "Yeah there was some-"] and there were some with what they were eating [Elspeth: "Yeah there was"] I noticed an energy change].

9.2. Theme 1: “Success of the programme”

This theme, illustrated below in *Figure 9.1*, represents the lecturer and support staffs’ perceptions of the areas of the Walking Away programme which the students found acceptable and accessible. This encompasses aspects of the programme or wider study which they saw the students responding to with positivity. Areas of the course which were considered by the lecturers and support staff as appropriate for the students are also represented. Finally, examples are provided of areas where the lecturers and support staff suggested the programme had an impact upon the students’ beliefs towards their own lifestyles.

Figure 9.1: Theme 1) Success of the programme



9.2.1. "Successful components"

Participants highlighted specific examples of the Walking Away programme which the students were observed as enjoying, or elements that worked well. As highlighted in the student participant groups, activities which involved role play were described as popular with the students. This was reflected by Elizabeth, a participant in Group Four who had attended each of the educational sessions as well as the student participant focus group earlier that day:

> Elspeth: "Yep, really good role play. I think anything's that got a bit of humour, a bit of fun. Yep that definitely sort of sticks in their mind."

Elspeth attributed fun and humour to the popularity of the role play activity, which had involved balancing an increasing number of bottles on a tray to demonstrate increased risk through multiple risk-factors. The humour of the activity had also been described by the students in their focus group. Whilst it was unclear from the students' comments the extent to which the activity was understood, Elspeth indicated that the humour may have facilitated retention of information. However, the content may have been taken too literally by some students, as some of the student comments suggested. This was highlighted by the lecturers and support staff, as will be discussed further below in "Problems and Limitations".

Active learning was also considered as being well received by students. Here, students were actively engaged in learning exercises such as arranging activity cards into order and identifying food packaging labels. Scott and Margaret, participants in Group Three who had also attended all the Walking Away units, described examples of these:

> Scott: “I liked it when we had the different activities lined up and things” [Margaret: "and ordering them and things- an interaction"] … And I think looking at the different foods as well cause they all just recognise these things and think "oh great". So it's getting them to look at things.”

In the extract above, Scott described an activity where cards depicting different examples of physical activity were placed in a line along a table and ordered according to the perceived intensity. Margaret described this as an “interaction”, suggesting that the educator and students were responding to each other, and Scott praised the fact that the students were standing up and walking around as a way of encouraging them to look at the materials. The educational sessions that Scott and Margaret attended were at Edinburgh College, where students from Focus Group One were present. At this site, it was possible for the participants to remain in their classes, which were sized 8-10, rather than join together. This number was closer to the size recommended for the Walking Away delivery and enabled more movement and therefore participation in the room. The student participants in Group Two had expressed that they had felt the room was too small, indicating that there was not enough space to move around. However, lecturers and support staff from both sites appeared to feel that there could have been more active learning, as described in “Suggestions and Recommendations” below.

In the latter part of the extract above, Scott commented on the food choices activity, in which students were encouraged to look at the labels of food packaging and identify different food types. In addition to appearing to see this as successful because of it being an active-learning activity, Scott suggested that it was good that the students “recognised things”, suggesting that using examples from everyday life may have made the activity more meaningful for the students. Elspeth suggested that the students in her focus group and educational sessions had understood this activity particularly well:

> Elspeth: “I think they understood that probably the most out of them all…I think it's kind of, 'cause that was the most recent one, they seemed to remember that one best.”

Elspeth was in the unique position of being able to evaluate the students’ receptivity and comprehension of the programme due to her being in the focus group as well as the sessions and commented on how successfully the students were able to recall this session’s content. Elspeth also commented that they may have remembered this session better than the others as it was the most recent one, and not because it was an active-learning activity per se. However, this may nonetheless reflect a need for interactive activities and use of everyday resources. Although the students in Elspeth’s group looked at every day examples of food packaging as with the other group, they were less able to walk around and compare materials with each other, which may have reduced the impact of the activity.

The final part of the “Successful Components” subtheme concerned the pedometers. Susan, a member of the lecturers and support staff in Group Four, had not been able to attend any of the educational sessions, but had been involved with supporting a class to wear and record pedometers and reflected on the enthusiasm of some of the students towards this:

> Susan: “And they wouldn't let me off with sort of "we've to record out pedometers today" sort of thing.”

In the weeks leading up to the educational sessions, the students recorded their steps from the previous day as part of their morning classroom routine. In the extract above, Susan described the extent of enthusiasm towards using the pedometers for some of the students, who wouldn't "let" Susan neglect this daily activity. There were several problems with using the pedometers, as highlighted in the previous chapter and in further below in "Problems and Suggestions". However, the fact that some students were keen to record their pedometer counts prior to commencement of the programme suggests that there may have been some potential for impact on the students' attitudes and beliefs towards their lifestyles. This is discussed further in the following subtheme.

9.2.2. "Impact of Programme"

Following Susan's example at the end of the previous subtheme, the present subtheme begins with the use of pedometers an as example of impact. Kate and Margaret discussed Beth, who had changed her route to college, as described by Beth in the previous chapter:

> Margaret: "Some of them like Beth, who's more able, probably did take it on board [Kate: "Yeah"]. And actually she started to do a whole load of walking."
> Kate: "I think she was impressed at the number of steps... She was interested in seeing the number of steps she took in walking."

Kate and Margaret reflected that the step measurement had provided Beth with feedback on how much activity she engaged in, and how easily she was able to achieve her daily targets which in turn motivated her to continue. This may have served as “Mastery of Experience” for Beth, thus enhancing Self-efficacy (Bandura, 1977). However, as described by Margaret, Beth was more “able” than some of the other students and the issues with the pedometers described further below may therefore have been less problematic for her.

Susan, whose duties involved supporting the students at break times, observed some immediate impact from the programme on the students’ food choices:

> Susan: “… a lot of the participants were thinking in terms of their wider health where they were taking the stairs instead of the lift, [Elspeth: "Yeah there was some-"] and there were some with what they were eating [Elspeth: "Yeah there was"] I noticed an energy change, it maybe raised awareness in a way, although it wasn't maybe about specifically about overall health.

In this extract, Susan described the apparent influence of some of the Walking Away programme's key-messages, such as finding everyday ways to be more physically active and conscious of dietary choices. The suggestion that the "raised awareness" may not have been "specifically about overall health", suggests that there were possibly limits to how far the students would generalize these messages beyond the context of their break times at college. However, Susan's description highlights the potential for Walking Away to enthuse young people with ID's interest in their own health. Elspeth followed on from this by describing a need for further reinforcement to sustain this enthusiasm.

> Elspeth: "I think it would need to be reinforced but they have some of them changed their behaviour as Susan was saying, and some of them were talking about changing their behaviour but haven't quite got there yet. But when you asked did they want a refresher they all said yes. And they were all quite keen to have a refresher."

Elspeth echoed that there had been some immediate impact on the behaviour of some of the students, but that this would need to be further reinforced. The students' enthusiasm for a "refresher" follow-up session suggests that continuity of the programme would be well received, and opportunities for further reinforcement would be welcomed. This raises the question of how far the impact of the Walking Away programme could be sustained over time without reinforcement. In Focus Group Three, Kate and Margaret felt that that this might be difficult, although they were optimistic that Beth may continue with her efforts to be physically active:

> Margaret: "Beth's doing a lot of walking I would hope she keeps that up. She's not going to walking to college anymore though cause that's her left [Kate: "Yeah"] You'd like to think that she'll keep up the walking 'cause she has lost weight, hasn't she, and she seems a lot fitter I would think."

Margaret suggested that it was likely that Beth would keep up her walking, despite her not coming to college the following year. However, in asking if anybody's understanding is sustained over time, Kate may have been suggesting that information is forgotten, regardless of whether or not an intellectual disability is present. This question may also have implied that if people without an ID are likely to forget learning over time, then it is even less likely that people with ID whose memory may be impaired, would be able to retain what they had learned in the Walking Away units. The suitability of the length of the Walking Away programme is further discussed in "Suggestions and Recommendations" below.

9.2.3. "Accessibility"

The final subtheme in "Success of the Programme" concerns representations of the lecturers and support staff's statements about the accessibility of the wider study for the students. As these relate to the broader theme of success, the accounts are positive perceptions. However, some of these conflict with later statements which are represented further below in the second theme, "Problems and Limitations".

Elspeth, who had attended all of the Walking Away sessions and Group Two, had an overview of how well the student participants had received the programme and noted the positivity of their responses in the focus group:

> Elspeth: "They were all very positive and seemed to remember quite a bit... You asked do you think I was trained well enough and you got a resounding yes [Group: laughter]. Just looking at some of the things that I've noted – um – were you able to ask questions they all said yes, very much, things like that."

Elspeth's comments reflect her observations of the students as being able to engage with the programme and to ask questions about areas they had misunderstood. As described in the previous chapter, the researcher had met with the students several times before the educations sessions commenced, and there had been opportunities to build a rapport with the students, and for the students to ask questions about the study. Elspeth agreed that the students had demonstrated their understanding of the recruitment and consent process. Susan followed on from this, commenting on the accessibility of the student participant information sheets:

> Susan: "They were really user friendly because you used pictures and it was done in a way that was accessible to our students."

It is apparent from these comments that the staff and students from Glasgow College found the materials of the study to be accessible and appropriate overall. As will be discussed further below in "Problems and Limitations", there were procedural problems highlighted by the lecturers and support staff in from Edinburgh College, which led to a lack of clarity for some of the students represented in Group One. However, the positivity of the comments above suggest that the recruitment materials used in the present study, such as the participant information sheets and consent forms, were adequate for the students to understand the purpose of the study and their rights as potential participants and could therefore be used for recruitment in further trials of the Walking Away programme for this population.

9.2.4. "Success of the programme" conclusion

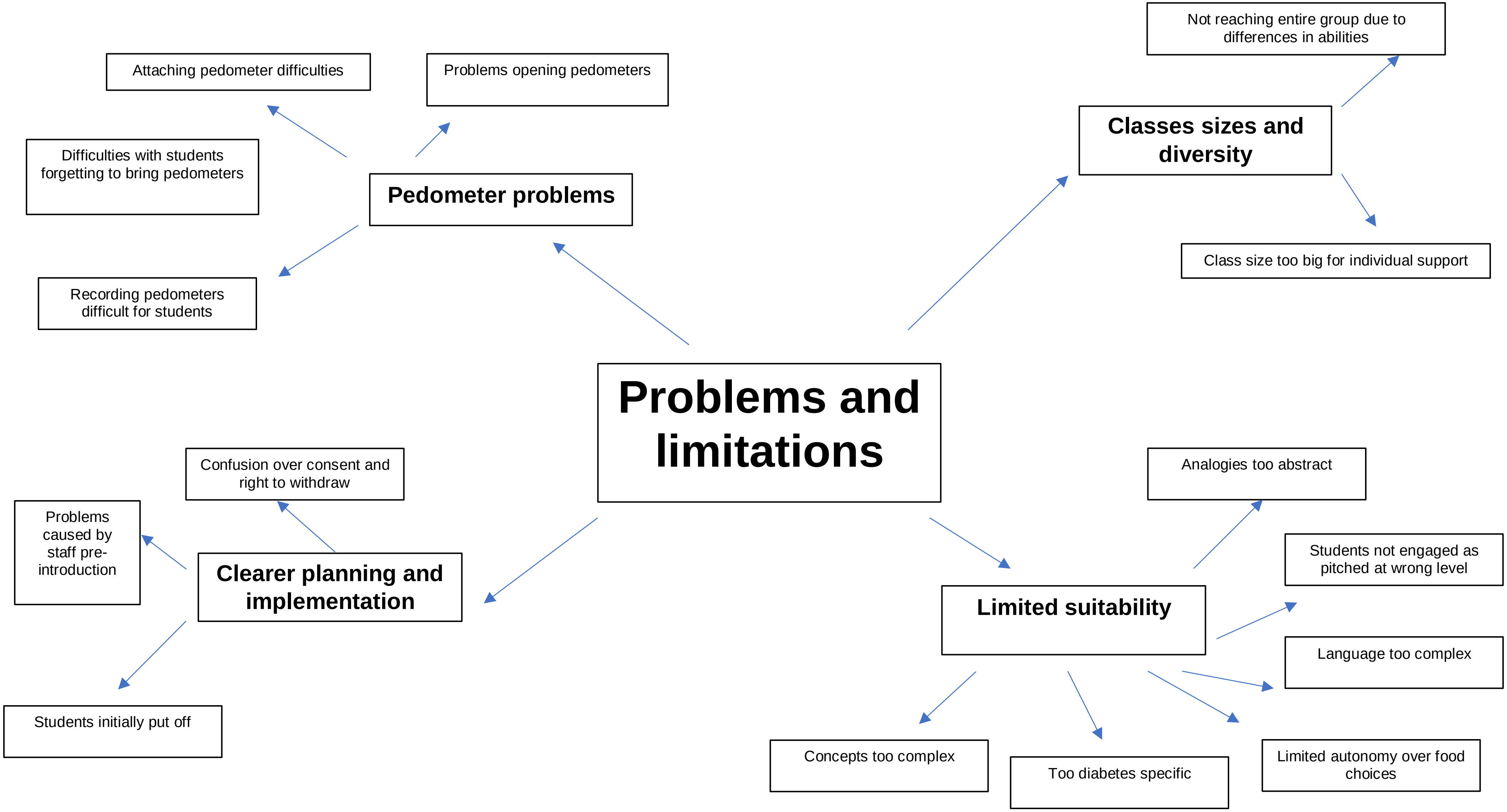
This theme closely mirrors the first theme of the student participants' focus group: "Acceptability and Impact", where there was an overall sense of positivity about the students' response to attending the Walking Away units and the wider study.

Support has been provided by the teaching staff for the conclusion in "Acceptability and Impact" that role play was the most popular and successful aspect of the educational units, and this was also linked to humour. However, whilst in the student participant focus groups it was unclear whether learning went beyond remembering humour, in the present theme it was suggested that such approaches are likely to aid learning of the subject. This, and the examples of active learning, were elements which increased the likelihood of the students learning and retention of the materials. However, not all insights into the students' engagement and interests were positive, as the following theme, "Problems and Suggestions" describes.

9.3. Theme 2: "Problems and Limitations"

This theme represents the lecturers and support staff's perceived problems and limitations of the Walking Away programme and wider study. Four subthemes were extracted from the data in the areas of: programme implementation, appropriateness, recruitment selection and the pedometers. These were highlighted in both sites, though there were differences the issues. *Figure 9.2* below presents the subordinate and superordinate themes herein.

Figure 9.2: Theme 2) Problems and limitations



9.3.1. “Clearer planning and implementation”

Planning and implementation initially followed the same procedure in both Edinburgh and Glasgow Colleges. However, there were differences in how the introductory information was received and acted upon. Both sites were initially visited by the researcher, who discussed the study and its aims with a teaching staff member. Joseph in, Glasgow College, agreed that this had been an acceptable approach when asked by the researcher:

> Joseph: "…I understood roughly what you were looking for and wanted to work with. So, yes."

Upon agreement over institutional participation and recruitment taking place, participant information sheets were sent out to staff and students. Following this, a further meeting was held at Edinburgh College, and due to distance, further correspondence was carried out by email with Glasgow College, until the researcher visited again to introduce the study to prospective participants at both sites. An issue arose at Edinburgh College at this point; prior to the researcher arriving, the lecturers and support staff gave their own introduction to the study, which caused some confusion for the students:

> Margaret: "...we had this urge to fill the gap, and start, just start trying to describe what it was about. Which [Kate: "Which was a mistake"] didn't go well."

> Scott: "Yeah it's a tricky thing to describe to be honest … how it's going to work, what's it going to be, then adding in the steps thing and stuff like that I think."

In this extract, Margaret, Kate, and Scott expressed the difficulties they encountered in trying to describe the different elements of the study. Margaret and Kate mentioned difficulties with the description of diabetes, whereas Scott mentioned difficulties with describing the study procedure. The information sheets which had been received in advance, did not appear to have helped to clarify these descriptions:

> Margaret: "They did have the information sheets. But I'm not really sure how much they understood of the information sheets."
> Kate: "… I just remember diving in with both feet. Describing, trying to describe what diabetes was. It was such a mistake. And then they got the sheets again that day. But nobody wanted to look at them because it was about diabetes."

Scott was able to confirm that the student participants had received the information sheets, however Margaret appeared doubtful as to how well the sheets had been understood by the participants. Kate suggested that the students were at that point not receptive to the idea of diabetes, which had followed the staff introduction. These issues contrasted with the comments of Susan in the previous subtheme, which praised the accessibility of the recruitment materials. The comments of the students also seemed to suggest that they had understood the purpose and procedure of the study, although the right to withdraw appeared not to have been fully understood in Edinburgh College. However, Scott seemed to feel that there was also some ambiguity around consent to participate:

> Scott: "And then things like that, trying to say that you've got a choice to be a part of this or not, you know when usually a lot of the things we try and encourage people to always take part anyway and things..."

In this extract, Scott highlighted that the notion of the study being optional for the students may have been confusing for them in that they were usually encouraged to take part in activities. The lecturers and support staff may therefore have felt that it was difficult to encourage participation without coercing the students. The difficulty reported by the staff in introducing this may have led to the issue of the student participant's right to withdraw not being fully understood.

The issue of introducing the topic of diabetes was recognised by the lecturers and support staff as having an impact on some of the students' reservations about taking part and following the staff introduction the students had been adverse to hearing more about diabetes, as Kate's comments about how the participant information sheets were received highlighted. As discussed in the student focus groups, Kerry and Steven had been particularly reluctant to participate following this introduction:

> Margaret: "…they were worried that they were gonna get it [Kate: "Mmm."]. Either about getting diabetes, or, they knew people who might be at risk, like Steven thought his mum and his aunt – was it his mum and his aunt? Or something? And he had them in mind, and I don't know whether if you

> described that somebody was maybe overweight or [Kate: "Had a test for their blood or something."] and he picked up on a couple of those symptoms and he thought oh my god!"

As described in the previous chapter, Kerry and Steven had overcome these reservations through discussions with the lecturers and support staff and the researcher. From the extract above and the comments of Kerry and Steven, it seems likely that these reservations would have been present, regardless of how the introduction about diabetes was made. However, better communication and consultation with the lecturers and support staff was required, so that their roles and expectations were made clear prior to commencement of the study.

At Glasgow College, the same issues were not reported, and the students appeared to have a clearer sense of the study procedure. This was despite much of planning taking place through email correspondence. However, Elspeth appeared to also feel that planning and consultation could have been better:

> Elspeth: "So I think, you know, maybe in the planning stage you would need to say who was really sort of interested in it and motivated, and maybe get some advice from lecturers about who we think would – it can surprise you but usually we kind of know who could really take part in that and be motivated."

In this extract, Elspeth highlighted recruitment selection as an issue related to planning and consultation, suggesting that advice could have been sought on who to approach for recruitment based on likelihood of engaging with the programme. It had been agreed with senior staff and as part of the study's ethical approval that there would be no inclusion criteria beyond being a member of a supported learning class at college, which was to avoid potential perceived stigma about diabetes risks. Further face-to-face meetings with all staff involved may have helped to clarify the reason behind the breadth of this selection. The issue of further selection at the recruitment stage is further discussed in the third theme, "Suggestions and Recommendations". This topic also leads on to the following subtheme, in which recruitment numbers are discussed.

9.3.2. “Class sizes and diversity”

This theme follows on from the issue of recruitment selection highlighted by Elspeth in the previous sub-theme. A wide inclusion-criteria approach had been taken by the researcher, which meant that entire classes attended the Walking Away units. In addition to this, the classes at Glasgow College needed to be joined for logistical reasons, which meant that the sizes were larger than both students and staff were used to. The first perceived problem with this was that the class size was too large for individual support. This was also highlighted by the student participants, and Elspeth recalled this and described the benefits of a smaller group:

> Elspeth: "Well it's more attention, they're getting more one-to-one, so I think maybe some of the ones that maybe weren't following it as well got a wee bit lost at times."

As illustrated above, Elspeth provided support for the analysis in the previous chapter which concluded that the students who said that the room was too small had meant that there were too many people. Although the students made this comment in relation to engaging in active learning whereas Elspeth mentioned one-to-one support, there was consensus that a smaller group would have worked better. Elspeth discussed this later regarding the pedometers:

> Elspeth: "… the ones that were interested, and I can think of a few I think, were very diligent with recording it, you know wanting me to help them with recording it. But again, that was just a few in that group."

Elspeth raised the issue of recruitment selection alongside group size in this extract, suggesting that the study would have more potential for success by focusing on the participants who were likely to engage in using the pedometers. This is also discussed further below in "Suggestions and Recommendations", and pedometers are discussed in the following subtheme.

9.3.3. "Pedometer problems"

The problems with the pedometers highlighted by the student participants were closely mirrored by the lecturers and support staff, who had observed the students experiencing difficulties. This was partly in regard to attaching and wearing them, as Kate and Margaret found in Edinburgh College:

> Margaret: "It's being busy though isn't it. And remembering to do it, in amongst all the other things we've got to do as well."] I should've done more.

> Kate: … and sometimes it was a little bit of a hoo-hah getting one or two of them to even put it on, and I don't know what the big issue was."

Alongside Kate's comments regarding the "hoo-hah" of attaching the pedometers, Margaret appeared to imply that supporting the students to remember to use and record the pedometers a challenge to fit into their activities. Lorna additionally suggested that numeracy difficulties were also a barrier in recording the pedometers:

> Lorna: "Well it's just numbers I think, I don't think they knew how many steps they were taking or how much it was or trying to get the number on the piece of paper-"

The students had seemed less aware of there being a problem regarding remembering to wear and record the pedometers. However, these problems were experienced in both sites:

> Joseph: "...you know, "did you bring the pedometer back", "the what?" [Group laughs] and I'd just think Ohh. So that, that was difficult… unless it's just a case of like just measuring somebody's steps while they're in college then give them back at the end of the day or something but then that’s probably not that useful, you know. Cause you're not really getting that much of a picture".

Joseph highlighted the difficulties he had experienced in encouraging and reminding the participants to wear pedometers outside of college. He seemed aware that this was a problem, as to provide a sense of the feasibility of the students wearing the pedometers over a lengthy period, a minimum requirement of 3 days a week needed to be recorded. This would require additional recording time at home. Alternatives to pedometers which may overcome these problems are further discussed in "Suggestions and Recommendations".

9.3.4. "Limited Suitability"

The final subtheme in "Problems and Limitations" represents the lecturers and support staff's perceived limitations of the Walking Away programme, in terms of its suitability for use with people with ID in a further education setting. The analysis confirms and augments the findings in the "Understanding Course Content and Procedure" theme in the previous chapter, which highlighted barriers to the students' understanding of the programme, including vocabulary and metaphors. The students had commented on the difficulty and unfamiliarity of some of the terms and concepts, and this was echoed by the staff in both sites:

> Irene: "I mean some of it was appropriate like the door thing, you could see the students understand [Elspeth: "Mhmm"]. But I think some of the language like Joseph said was a bit, a bit too advanced. I felt that the students weren't engaged at all. Mostly because of the big group thing and the level it was pitched at wasn't, I felt, the right level for the students."

Irene attended the first of the Walking Away units, which focused on the metabolism of Blood Glucose, and commented on the size of the group as well as the level the material was aimed at, which she felt led to the students not being engaged. At Edinburgh College, it was suggested that rather than the language being too complex, there should have been a broader focus on health and wellbeing, rather than diabetes specifically:

> Margaret: "I don't think they need to understand the level of detail about how diabetes works [Lorna: "They never understood it anyway." Kate: "It's too complicated"]. So, you know, I don't think it's, I think it's giving them too much information. It just needs to be a part of being healthy that walking's good for you."

Kate, Lorna, and Amanda appeared to agree with Margaret that a general healthy lifestyle and walking message would have been better for the students attending their college as the information on diabetes was too complex. This suggestion could potentially lead to a more inclusive approach, whereby fewer participants would be unable to understand content, and contrasts with the earlier comments on recruiting a smaller and more able sample. Another limitation perceived by the teachers which echoed the student participant analysis was over the use of analogies to describe concepts. As described in the previous chapter, a rusty key was used as an analogy for insulin resistance, and an overloaded tray as an analogy for multiple risk factors. These were discussed by Joseph:

> Joseph: "I mean with some people, anything abstract or any sort of like analogy like that it'd be hard for them to kind of generalise from that to the thing you're talking about … anybody who's more towards the autistic side

> probably won't get it – it's like this is this thing and that's that thing. And it's different."

Joseph felt that students with Autistic Spectrum Disorder or Asperger's Syndrome were unlikely to understand that one thing could represent another, and therefore that these analogies were not appropriate for everyone. However, as with Elspeth's earlier comments, Joseph seemed to feel that some things would work for some students and not for others due to the diversity of the group. The lecturers and support staff in Edinburgh College also commented on the analogies:

> Scott: "Yeah I mean [Margaret: "I think for a lot of the students."]. I think the metaphor was a good way of describing it but [Margaret: “For them. Uhuh."] it's just.. You know, I liked the bit where they were talking about the risk, you know the tray and things like that [Margaret: "Uhuh. That was good."]. I liked that and I think that got them thinking a bit. But I still think, linking that directly to diabetes you know, what are the risks, you know."

In this extract Robbie and Margaret appeared to see the value of using analogies but felt that they were not suitable for the students attending their college, implying at the end that a more explicit link was required for the students to understand what was being conveyed. Margaret later expanded on this, which is represented in "Suggestions and Recommendations".

The final area of the Walking Away programme which some of the lecturers and support staff highlighted as unsuitable for students with ID was the Food Choices unit. Although this appeared to have been well remembered by the students, which was commented on by Elspeth in Glasgow College, the staff from

Edinburgh College felt that the messages in this unit were not appropriate for the students:

> Kate: "I mean just one wee question is that our students – their parents cook their meals anyway – how much of a say do they get in what they eat, so.. I mean I suppose they could say to their parents they want to eat less sugar and stuff so.. Or is that being a bit negative? I don't know."
> Margaret: "I mean I think they are very dependent on other people. Or they're very set in their ways and they'll only eat certain things."
> Scott: "Yeah"
> Lorna: "If you're somebody who'd maybe given that information eh what, will they still continue to go and buy a bottle of coke as soon as [Group clamour]."

In this extract, Kate suggested that the students have limited opportunities for autonomous food choices, and that this unit may therefore have been unsuitable. This was also highlighted by Kerry who remarked that her father did most of the shopping, which was represented in the "Impact of the Course" subtheme in the previous chapter and reflected that this aspect of the unit may have been less relevant than other parts. By questioning her own negativity, Kate may have been alluding to a perceived rhetoric of empowerment regarding independence in people with ID. Margaret, Scott, and Lorna appeared to feel that the students were either dependent on others or resistant to change. However, Susan's comments in "Impact of the Programme" about the students at break times suggested that there was potential for healthy food choices in a college setting.

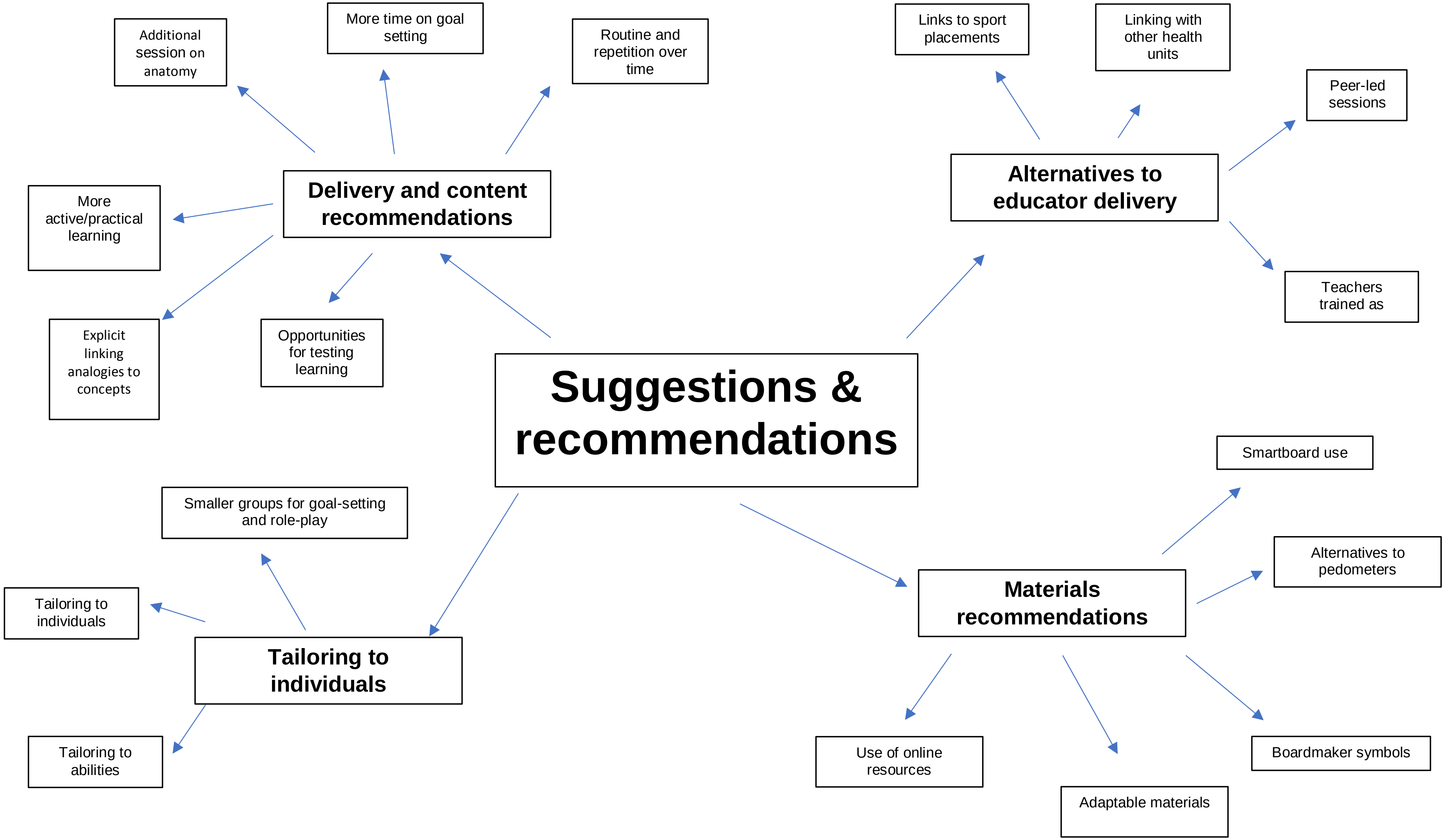
9.3.5. "Problems and Limitations" conclusion

The four subthemes, "Clearer planning and implementation", "Class sizes and diversity", "Pedometer problems", and "Limited Suitability" have highlighted the importance of involving lecturers and support staff with preparations for delivering the Walking Away programme. A question has been raised regarding whether recruitment should focus on a small, select group of participants identified by staff who are more likely to understand and engage with the full content of the programme, or if the programme should be modified to be as broadly inclusive as possible, thus reduced in complexity of content and materials. This would also call into question the purpose of delivering the Walking Away programme to people with ID in a further education setting: to provide preventative diabetes education, or to improve general physical health through diet and physical activity messages. The final theme, "Suggestions and Recommendations", which are based on the staff's perceptions and experiences, offers some potential solutions to this dilemma by suggesting how aspects of the programme could be more inclusive and effective, overcoming some of the barriers highlighted above.

9.4. Theme 3: "Suggestions and Recommendations"

The final theme of the staff focus group analysis represents suggestions and recommendations in terms of how the programme could be made more accessible to people with ID in a college setting. These were focused on the delivery, setting and materials of the programme. Several of these suggestions expand upon the perceived problems highlighted above and offer potential solutions. The subordinate and superordinate themes are illustrated below in *Figure 9.3.*

Figure 9.3: Theme 3) Suggestions and recommendations



9.4.1 “Tailoring to Individuals”

This subtheme echoes the comments of the student participants in Glasgow College, who appeared to feel that the room was too small to move around and be active, and Elspeth's comments which suggested that a smaller room would have worked better. Staff from both sites stated clearly that a more narrowly selected group would work better than a broadly inclusive group:

> Elspeth: "So, it's looking at the students, OK you've got to include everyone maybe at the beginning but there may be some who will take on board and do it."

In this extract Elspeth suggested that recruitment should involve a broadly inclusive approach at the start, before selecting those who are more likely to engage and continuing with this group. However, in the same group, Joseph seemed to suggest that although there would always be differences in classes, tailoring to individuals could lead to wider engagement:

> Joseph: "…cause the problem is there's always gonna be some people in this group who aren't gonna, you know, but on the other hand too if you kind of as you get to know people individualise things a bit – cause you'll find that within the group there are a few who are quite keen and can grasp it all … if it's a bit more pictorial, and then some people who if like it could be a web thing?

Joseph's comments suggest that techniques such as pictorial aids and computer-based resources could help individuals who otherwise struggled to engage. Additional learning exercises could be added to the Walking Away curriculum to provide further learning opportunities, potentially leading to a wider engagement. Joseph suggested that tailoring to individuals in this way was a necessary approach in the classes he taught:

> Joseph: "I kind of have to think well these 4 people over here can do this way, and this guy's gonna do it this way, so, yeah. It is really hard to try and do just like, to try and come up with one thing that's gonna work. For everyone [Susan: "Yeah."].

It was apparent that Joseph and his colleague Susan felt that they had to adapt within classes to include everyone and not exclude those who required tailored support. This brings into question the timescale of Walking Away programme used with people with ID, as it is unlikely that 3 hours would be sufficient were such focused support and additional exercises to be incorporated.

As this focus group took place first, the dilemma of tailored support versus selective recruitment was posed by the researcher in the later group. Margaret appeared to feel that a narrow recruitment selection should be made:

> Margaret: "I mean even when you talk about learning disabilities though, the range is so huge that it's hard to produce something that's gonna suit everybody."
> Researcher: "Well that's another question that came up over at Edinburgh College actually - should it be delivered to everyone and, you know, tailored or do you just select a few people you think are really gonna benefit from it?"
> Margaret: "I think you maybe select the people that are gonna benefit."

In this extract, Margaret appeared to feel that people who would not benefit from the study should not participate. However, she later discussed the need for a tailored approach to educating:

> Margaret: "I think it very much depends on the group and that's like when you teach the classes, you might have the same subjects every year but your approach has got to be different depending on what's put in front of you [Scott and Kate: "Yeah."]. You can't – it’s not like being a lecturer where you have your notes and you come in and you deliver your programme every year. The group that you've got and how they are socially and academically and then, work out what your approach is gonna be."

Margaret's comments were supported in this extract by Kate and Scott. There was therefore a consensus between and within the focus groups on the need for flexibility, which was related to tailoring to the needs of the group. Future adaptations of the Walking Away material therefore require additional flexibility in terms of time and resources.

9.4.2 “Materials recommendations”

This subtheme presents the staff participants' suggestions for practical adaptations to the materials of the Walking Away programme. As highlighted in the previous chapter, the student participants’ suggestions for materials included larger size, use of the Smartboard and internet-based resources. These were echoed by the lecturers and support staff, with some additional suggestions.

Larger materials and the use of a Smartboard was suggested by Margaret, in Edinburgh College:

> Margaret: " ...I thought that like the materials – you definitely needed something that could've gone up on the smart board. That was big and visual. And some of the materials looked really quite nice but they were quite small. And some of them I never really understood what they meant – I would ask for what was that, what does that one mean? Umm. I quite liked the wee people. But the symbols weren't always clear, what they meant."

Margaret appeared to feel that in addition to the size of the images which were used for the activity cards, they it was occasionally unclear what they were meant to represent. Margaret mentioned Boardmaker, a software tool for creating images to support communication, was a format that students with ID were familiar with since school:

> Margaret: "I don't understand why if they're going to work with people with learning disabilities they don't use Boardmaker … which is like what most folks symbols would be wouldn't they, they would be Boardmaker symbols. And I'm sure that there must've been Boardmaker symbols that you could get for most of what was there."

Margaret’s comments in the extract above suggests that there may have been some lack of clarity in the introductory meetings and information sheets as to the origins of the Walking Away programme and aims of the present study, as she seemed to believe that the materials had already been adapted for people with ID. However, future adaptations could involve supporting materials, such as Boardmaker, instead of or in addition to the Walking Away images. The benefit of this is that the students' learning could be facilitated through a familiar format.

The students' suggestion of internet-based materials was also echoed by the lecturers and support staff in Edinburgh College. Anita, a student in Glasgow College had mentioned internet resources, but had not been able to expand on why these may be useful. However, Scott discussed the recording of pedometer steps in relation to the internet:

> Scott: "Even if they could record their steps online or something like that, you know, or something that they could sign into and they could record things like, you know, how much they walked or how they got on with their targets, what did they think?"

In Glasgow College, Susan discussed the use of the internet as a way of engaging individuals by catering to their interests:

> Susan: In Joseph's class you might have some people doing a bit of research online. So some'll tidy up their tools, and the other ones are actually- so you're kind of playing to their skills but they're still learning what the overall things is but you know some of them might be bored or other ones absolutely freaked out by- you know it's trying to play to strengths almost [Joseph: yeah] cause they'll be getting the broad bit of learning with the 4 different activities going on at once.

Susan's comments in this extract provide support for Joseph's earlier in "Smaller groups and select inclusion" on the need for individual tailoring. As accessing and using the internet may be a popular interest for some young students with ID, incorporating this as an activity may be a way of making the Walking Away materials more accessible.

The final recommendations the lecturers and support staff made was in regard to the pedometers. As highlighted by the students in the previous chapter, and by staff in "Problems and Limitations", the students had experienced difficulties with attaching, wearing, and recording the pedometers, which had led to the suggestion that the model issued for the study was not suitable. The students had suggested alternatives such as Fitbits and other portable devices, and these suggestions were echoed by the staff at Edinburgh College:

> Margaret: "And a lot of them have got things like iPhones though or Fitbits and stuff like that. And really, if they were going out to try and to that kind of thing, you'd be trying to make sure that they had that all set up, so that it would record."
> Scott: "… you'd probably find that just about half the group would have a phone that would do, you know you'd just say right you keep that in your pocket and, it's maybe not quite as accurate or anything but still."

Margaret and Scott appeared to feel that alternatives such as Fitbits or Smartphones may be easier for the students to use and that many of the students would already have these, although they would need to ensure that they were set up correctly. As Scott pointed out however, some devices may be more accurate than others and it may be difficult to obtain a standardized and reliable measure. At Glasgow College, Susan offered a solution to the issue of students forgetting to bring their pedometers to college with them:

> Susan: “Sometimes when you ask students to bring, maybe a pound, and ask them maybe to put it in as a deposit? Saying that if you take care of this pedometer, you know, you'll receive that back, it might encourage them to …be responsible.”

In this extract, Susan was advocating the use of a deposit system for the pedometers, to encourage the students to return them. Whilst this may be a practice in educational settings, there may be ethical implications in research, for example an accrued cost for pedometers forgotten on more than one occasion.

9.4.3 “Delivery and content recommendations”

The third subtheme in "Suggestions and Recommendations" represents more practical suggestions. This follows on from the "Smaller Groups and Select Inclusion subtheme", where the need for individual tailoring was highlighted, and also provides further solutions to issues identified in "Problems and Limitations". Margaret addressed the issue of analogies not being understood by suggesting explicit links to the content:

> Margaret: "So you could've then had cards that stood up and went on the tray, that said.. Family History [Scott: "Yeah – Not Being Active"] not being

> active. Um. Eating Ten McDonalds a week. Um, you know, risk factors that were like that. And then OK, how can we reduce the risk, well if we can't change that, that's got to stay. That's got to stay because we can't change it. But we could take that away 'cause we could stop eating all those crisps or whatever. We could stop eating this. We could get more active…So something like a, you know a wee card or something that said, your family history. All those risks that you came up with. You know? So, you could put them all on the tray, and then you could take away the ones that you could change."

Margaret's suggestions in the extract above involve practical solutions for linking the analogy of the drinks balanced on a tray to multiple diabetes risk factors, with cards illustrating the risk factors placed next to the tray items. This, Margaret appeared to feel, would help the student participants to understand that the times represented risks. The current Walking Away materials could be used for this modification, as the magnetic activity cards depicting risks could be placed on the tray. This may provide a useful modification to the risk story analogy. However, it appeared that to Margaret, the rusty key and insulin analogy was too complicated altogether and should be left out:

> Margaret: "And I would've played more on that one, about, so right the risks being things like, things that you might eat, things in your lifestyle, so I would've spent longer on that, than on locks and keys and chemicals and trying to explain that bit of it. Cause I think that's actually quite hard for a lot of folk to understand. And it's whether to achieve your end you really need to do that with this kind of group. I'm not sure."

These comments suggest that for Margaret at least, there were limits to the amount of Walking Away content that could be adapted for students with ID, and that identifying diabetes or general health risks may be more important than explaining the process of insulin resistance. It is important to consider that the participants in the present study were not identified as being at risk of diabetes, and therefore they may have been less motivated to learn the diabetes-specific content, as it was perhaps less meaningful to them than generally improving their health. Scott made a similar comment in relation to this unit and the Food Choices unit:

> Scott: "Yeah, you know who's heard of the different types of fats and things, who's heard of saturated fats and things like that, what can you tell us people have heard from adverts in particular, and things like that and.. I think understanding those kind of complex words and just being aware of what roughly they are is maybe not, when you go into the particular effect they have in your body. Well, not so much the effect, but you know the chemistry and biology was maybe a bit too much."

Scott appeared to feel that the terminology for the different types of fats, such as poly and monounsaturated, were too complicated, as was the "chemistry and biology" being "too much", by which he meant the Blood Glucose unit was too complex. However, some of the lecturers and support staff in Glasgow College felt that more time could have been spent on the Blood Glucose unit:

> Elspeth: "I think maybe at the beginning some of the anatomy, which was new to quite a lot of them. So, even for them to work out what the pancreas was or what – maybe we could've spent a bit more time on that I think."

Elspeth's comments suggest that the students' difficulties with learning the content in the Blood Glucose unit may have been due to its unfamiliarity rather than the difficulty of the language or concepts, and that additional time spent on the unit could enable the students to successfully learn it. Additional time was suggested for other components of the programme, particularly in the Physical Activity unit where course attenders are encouraged to use the Walking Away resources to make written plans for increased walking, an activity which may have required one-to-one support for many of the students:

> Margaret: "I don't think we spent long enough with the workbooks [Scott: "Yeah I don't think it was long enough."] I think you'd have to spend longer with them and going through them with people and looking at them and reading bits of them with people..."

It was not possible in either of the sites to enable individuals to make plans and set goals for walking due to time constraints. Instead, examples were provided by the researcher of participants' earlier recordings of step counts. These demonstrated an average number of steps per week, and incremental additional target numbers were demonstrated. As reflected in the previous chapter, many of the student participants had not described this aspect of the unit with clarity, which suggests that the activity did not have a lasting impact. One-to-one support may have enabled individual goal planning and led to the students being more engaged in this unit, which contained the core messages of the programme on increasing physical activity.

The idea of delivering the Walking Away programme over a longer period was suggested by the lecturers and support staff in different ways. Scott highlighted the importance of repetition and routine for the students' learning:

> Scott: "...when you can build something into it, a lesson every week you know, then I think our students benefit quite a lot. It takes a while to get it but once they know that, right first thing we do when we come into class on a Wednesday is, we log on to the computers, get your pedometer out you know, put how many steps you've done or, or think about what different exercise have you done, log all the exercises you've done, and once you get into doing that every week, by the second semester, you know it becomes a bit more natural."

Scott discussed routine and repetition in relation to recording the pedometers and suggested that doing this regularly over time could help the students to learn to do this independently. There was a suggestion in both sites that rather than a three-hour educational programme, Walking Away could be incorporated into existing wider health modules. There was consensus for this in Glasgow College:

> Patricia: "It could be brought into some of the modules we do like self-awareness or into work – it could incorporate into that [Susan: Yeah]"
> Elspeth: "There's lots of units it could incorporate into isn't there?"
> Patricia: "The personal development ones maybe [Elspeth: Mmm]"
> Elspeth: "...maybe if it was incorporated into a unit it would be quite good cause then maybe you could maybe do some healthy cooking or some going

> out activity um and then that way it wouldn't just be the listening to it, it would then be practice as well. So that would work better I think."

In this extract the lecturers in Glasgow College reflected on the existing modules being taught at their college which they thought the Walking Away programme could be incorporated into. As Elspeth pointed out, this would provide opportunities for further practical activities such as cooking and outings, which could enhance the students' learning. These suggestions are further represented in the "Alternatives to Educator Delivery" further below.

Other practical suggestions were based around further active learning regarding assisted recall of prior lessons. Elspeth and Susan in Glasgow College suggested this as a solution to the perceived lengthy time spent sitting down mentioned earlier:

> Elspeth: "I think it was just, I think it was because it was a big group and there was a lot of sitting down, whereas I think maybe an activity session at the end of it even, you know or may a [Susan: "A rotation of activities."] Yeah, something like that might have helped with the classes a bit more."

Susan followed this up with the suggestion to record the sessions and use video recaps at the start of each unit to remind the students of the previous one:

> Susan: "And another thing is videoing it, and just going over the key points and if it was the following week that we're in a class, we could start off with those key points…"

As Susan had not attended all of the sessions she was perhaps unaware that each session had begun with a recap, asking the student participants questions about the previous unit. However, using video recaps may have been a familiar and useful technique for the supporting the students to remember previously taught content. In Edinburgh College, Scott made the suggestion of giving practical activities to test learning:

> Scott: "I think by doing a more practically bit, or letting some of them do some of it, you know certainly in this situation that gives you the time to go around and.. One of the things was there was no real chance to kind of test their understanding of it [Margaret: "No."] other than a few questions. Whereas I think if you do a sheet where they have to cut out and match the words [Margaret: "Match the words to words and pictures."] you can see there, right who's getting this and who's maybe understanding it better and who needs a bit of help."

Scott's suggestion, which was supported by Margaret, seemed to reflect on a practice that was currently used in their classes. In Glasgow College, Susan and Elspeth also suggested learning booklets as a way of indicating for the students their own learning progress:

> Susan: "And they could've maybe produce a booklet themselves about it about what they've learned. Cause they [Elspeth: "Yeah"], you know for other people to use. So, they're collating the information and researching it. Because I think when you're doing something and – you know you're using the two skills, it seems to go in easier. Doesn't it [Elspeth: "Mhmm"] when you're active ."

This may be an effective way of ensuring that a wider set of students are engaged by enabling those delivering the programme to identify and offer additional support. Providing opportunities for the participants to reflect on successful learning experiences may also lead to a greater sense of self-efficacy through "Mastery of Experiences" (Bandura, 1977), as identified in the first phase of this study. However, this additional exercise may also be a challenge due to time constraints. The question of how future adaptations of the Walking Away programme could be delivered is therefore raised again. The following subtheme discusses potential alternatives to the original delivery structure.

9.4.4. “Alternatives to Educator Delivery”

A practical implication of the suggestions in the preceding subtheme, which described a need for additional and tailored support, is that the Walking Away programme is potentially delivered over a longer period than three hours. In the present subtheme, this is expanded upon in terms of how a long-term delivery of the programme could be carried out, and by whom. Through suggesting that the programme be delivered as part of existing modules, it was implied that the lecturers could deliver the programme. This was confirmed when the researcher asked further about this possibility:

> Margaret: Given the right information and the time to prepare, yes ["Scott: Mmm."]

Margaret and Scott appeared to feel that it would be possible for them to be trained as diabetes educators and to deliver the Walking Away programme, but that they would need sufficient time to prepare. As suggested by the staff at Glasgow College, highlighted in the preceding subtheme, this could involve incorporating the programme into existing units. The student participants represented in the previous chapter had seemed receptive to the idea of lecturers being trained as educators, though some seemed to advocate the idea of outside educators working in collaboration with lecturers and support staff. The staff represented presently did not propose this, which may suggest that they did not feel it was necessary to have an outside educator to deliver the Walking Away programme.

A second alternative to outside educator delivery was suggested by Susan, in Glasgow College:

> Susan: "I don't know if it's something that people could actually use - peer educators and be peer educators at the same time. My experience is that young people always identify with other young people [Elspeth: "Yeah."]

In the extract above, Susan discussed the possibility of peer educators delivering the Walking Away programme. A clear distinction was not made between age peers and disability peers. However, Susan went on to describe a programme called CK Active (Common Knowledge UK), an inclusion and advocacy service for people with ID. Susan discussed the benefits of peer delivery, highlighting the potential for high receptivity due to age-relatedness, which Elspeth supported. Following this suggestion in the focus group at Glasgow College, the researcher raised the topic with the lecturers and support staff at Edinburgh College to explore their thoughts on its potential. There was limited receptivity to the idea amongst the group:

> Kate: "I don't think it would help them to understand better. They might listen more."
> Scott: "Yeah I wondered if you know if James's up talking about something would Ali, and maybe Steven [pseudonyms] maybe listen a bit more if he's talking about what he does at the gym … would that then rub off on Ali and Steven who are his good friends [Margaret: "His buddies."] this year more, you know a lot of them it might not, but I wonder if that might work in that [Kate: "I don't know – laughs."]. I mean Ali doesn't really strike me as someone that would go "OK, yep so James said eating an apple's good for my break [Group laughs]."

Kate, Scott and Margaret appeared to take peer-led to mean delivery by their own students rather than others and seemed to feel that although some students may listen more to their peers, this may be limited and may not facilitate understanding. Scott seemed to see this as being dependent on the level of support needed within classes, with some higher ability classes more likely to be successful.

> Scott: "And I think if maybe in Entry to Learning, Prep for Employment there's maybe more of an opportunity for that cause it's a slightly higher level that [Margaret: "But, yeah if you went to that next stage where it's Entry to Learning, Prep for Employment"] I mean I suppose it depends a bit on the, again cause the groups are so different…

The Entry to Learning and Preparation for Employment modules mentioned by Scott are aimed at students with mild disabilities who are likely to go on to employment after college. Scott and Margaret seemed to feel that students attending this module would be more likely than those in the Life Skills modules to engage in a peer-led version of the Walking Away programme. Scott described one student whose interest in health and safety and healthy eating could potentially predispose him to leading a session. Margaret and Scott agreed that any student would need a lot of support and to be able to do this. As with the other site, it was not clear whether the staff participants saw this happening for the entire Walking Away programme or components of it. However, in both sites there seemed to be a suggestion that a peer-led element to the programme, and there may be potential for integrating this into future adaptations of the programme. Shared examples of peer success may lead to greater self-efficacy, as highlighted by the second phase of the research project.

Susan followed her suggestion on peers with another regarding sports students:

> Susan: "It'd be good to have some kind of collation of health-related modules because, we used to have something with the sports students and they used to come up and do a list of activities, and you could actually even involve them in this. When sports students at a certain time of the year look for a placement [Elspeth: "and they plan it all out."] they could do planned activities as well as – it could be one week of doing the sports activity then one week of doing this."

Susan had reflected that in the past, sports students at her college had been given placements which involved providing physical activity for students with ID who attended supported learning modules. Elspeth agreed that there was potential for these students delivering the programme, though it was not clear whether this would encompass the whole programme or just the physical activity components. Susan attributed this potential success to what she saw as the motivational skills associated with sport, and to the youth or the students. Sports students seeking activity placements may be a potential teaching resource for the Walking Away programme and, as with the college at Glasgow College, are likely to be study in close proximity to supported education classes.

9.4.5. "Suggestions and Recommendations" Conclusion

This final theme has identified how future adaptations of the Walking Away programme should be delivered, as well to whom, and what materials should be used. The dilemma raised in "Problems and Limitations" has been raised again: whether entire classes of students should be selected to invite for participation, or whether selection be made based on students' abilities. These abilities include vocabulary, being able to generalise from concrete to abstract, and being able to act upon and sustain healthy behaviours. Practical solutions such as explicit links for analogies, familiar formatting, individual tailoring and relatable delivery were offered, but would be dependent on additional time and resources. These solutions could potentially have a wider impact which would lessen a need for selective recruitment. It can therefore be concluded that in order for future adaptations of the Walking

Away programme to be widely successful, delivery over a long period with flexible, interactive resources would be required.

9.5. "Teaching staff focus groups conclusion"

The findings of the lecturer and support staff focus group analysis considerably augments that of the student participants. Much of what the students expressed has been confirmed, but the expertise of the staff has enabled further clarification and a broader view of what would be required in future adaptations of the Walking Away programme.

Whilst the students advocated familiarity, the statements of the lecturers and support staff highlighted that familiarity is subjective, and a that range of flexible techniques and resources are required in order to reach individuals. It can also be concluded from both analyses that familiarity requires relationship-building, and that a three-hour session to groups of over the size of 10 is not appropriate for people with ID in a college setting.

The range of supportive techniques advocated by the lecturers and support staff suggests that it would be possible to take a widely inclusive rather than selective approach, although group sizes would need to be kept small. The practical implication of this is that lecturers and support staff, whose position and expertise could enable strong relationships and individual tailoring over a long period, would be more effective as deliverers of the Walking Away programme in colleges than diabetes educators. A further advantage of this is that the programme could be integrated into existing healthy lifestyle modules, where the key messages of

Walking Away could be reinforced over an entire academic term. During this, the components of the Walking Away programme which have been found in these analyses to be successful, together with the further practical suggestions of the student teaching and teaching staff participants, could be applied to whomever required individual support. The recommendations for future adaptations of the Walking Away programme are therefore as follows:

1. Students with ID are selected inclusively, rather than on the select basis of ability level
2. The programme should be delivered to groups of ten or less
3. Lecturers and support staff are trained as diabetes educators so that the Walking Away programme can be delivered within existing health modules over the course of an academic term
4. Elements of the Walking Away delivery should be peer-led, such as shared examples of participant success, which may enhance self-efficacy
5. The programme involves as much active content as possible, including role play, and practical exercises such as cooking and physical activity
6. Opportunities to test self-learning and identify successes as well as the need for further support should be provided throughout the course, which may also enhance self-efficacy
7. Materials are supplemented where possible by additional aids which are accessible and familiar to the students, such as electronic and pictorial formats
8. A more accessible alternative to pedometers is used, which could be an everyday item already used by participants such as a Smartphone

9. Where the programme uses analogies to explain concepts, additional materials are used to link concrete to abstract examples

Chapter Ten - Discussion

10.1. Introduction

This chapter will discuss the results of the three phases of the thesis: the two reviews in Phase One; the exploratory study in Phase Two; and the process evaluation and focus groups in Phase Three.

10.2. Phase One

10.2.1. Review One: Background literature on people with ID self-managing T2D

The primary aim of this review was to provide an overview of studies which qualitatively represent the experiences of people with ID and their caregivers living with and self-managing T2D. The first theme “Frustration over lifestyle adjustments”, described findings which highlighted challenges and barriers for people with ID. These provided support for the findings of McVilly et al. (2014) and MacRae et al. (2015). Regarding sense of loss, this review offered a further insight by looking at this theme alongside the participants' duration since diagnosis. This highlighted that adjustment difficulties can be long term for people with ID and that continued support may be necessary. The social setting of the participants was also highlighted as impacting upon mental wellbeing, as positive and negative social comparisons were made. As highlighted in the demographics, many of the participants lived together in residential settings, where they were likely to live alongside each other because of having a learning disability, rather than having diabetes. It has been reported that people with ID sometimes make downward social comparisons with each other as a self-esteem protecting mechanism (Paterson, McKenzie and Lindsay, 2012). This may further impact on frustrations regarding social comparisons to peers who do not have diabetes, and supporters should be aware of the potential for this. The suggestion in Hale et al. (2011) of a “buddy-system” for exercise, although positive, may also be subject to the complexities of social comparisons and social stigma.

The second theme, “Limited understanding and inadequate educational resources” highlighted gaps in people with ID’s diabetes knowledge. In terms of people with ID's lack of education, the fact that those with a long history of diabetes continue to struggle to understand the nature and implications of the disease suggests that there is a need for ongoing education, as well as at diagnosis or even prior to development. Preventative approaches aimed at younger adults and adolescents with ID (such as Yates et al., 2017) could provide an early foundation which establishes good health behaviours and reduces the risk of developing diabetes. Given the lower health status of people with ID compared to the general population it is likely that, regardless of glycaemic levels, they may have multiple risk factors for diabetes, such as obesity, sedentary lifestyles and poor diets, regardless of glycaemic levels. Therefore, it was identified in this initial review that it would be appropriate for this group to receive structured education aimed at reducing diabetes risk factors (such as Biddle et al., 2015 and Yates et al., 2009), though such programmes may need to be appropriately tailored. This provided rationale for the second review, discussed further below in section 10.2.2.

Quality and consistency of caregiver support was described in “Limited training and knowledge in staff”. As many of the participants in the studies highlighted in this review were in residential care, the level of support was high. People with ID who do not live in supported settings are less likely to access staff with general medical training such as nurses, however they may require a high level of training due to diabetes-related medication administration needs. It is therefore possible that the current literature does not fully represent the lack of training in the care of people with ID with diabetes, and further research is required on how to support people with ID who have diabetes in other settings. It was highlighted that further training and resources are required for caregivers, and this should be incorporated into structured educational programmes. A study by O’Leary, Taggart and Cousins, (2017) evaluating organisational barriers to health promotion in people with ID found that there was a lack of cultural ethos within residential settings. This finding may account for the inconsistency of approaches highlighted within the review, and creative approaches which foster autonomy may unfortunately be limited to individuals, rather than being present at an organisational level. It is therefore appropriate to suggest that diabetes self-management education is extended to managers and senior staff, so that such approaches are more widely implemented and embedded at a policy level across care organisations.

The final theme, "Potential for effective DSM with appropriate support" highlighted the strengths of people with ID and their caregivers in DSM, thus providing potential facilitators. Areas in which people with ID felt confident were identified, and it was suggested that self-efficacy (Bandura, 1977) may be an applicable theoretical construct. As with the findings above, these facilitators may be limited to people with a mild ID in a residential setting. However, the fostering of creative and flexible approaches may potentially enable caregivers to support autonomy in people with higher support needs across a range of settings. It is therefore important that structured education provides training for caregivers which steers away from prohibitive approaches.

The secondary aim of this review was to provide a qualitative appraisal of the selected studies. The overall quality was not high, as indicated by the Elliot et al. (1999) criteria who emphasise the importance of acknowledging the researcher position. This was not commonly adopted across the studies and may reflect a general lack of adherence to reflexivity in methodological approaches such Interpretative Phenomenological Analysis and Grounded Theory. However, the relationship of the researcher to the participants is a commonly applied criterion in appraisal tools, (for example CASP, 2017), and is important to include so that assumptive positions are clear. Findings were rigorous in terms of the provision of extracts and validity checks. This is reflected in the number of findings included in the present review’s analysis. However, there was an absence of description of analytical procedures. The Elliot et al. (1999) tool acknowledges that qualitative research is necessarily pragmatic, presenting a need for flexibility, and it is therefore acceptable for methods to be unique and innovative. However, this leads to a greater need for transparency, so that techniques can be evaluated and repeated. It is appropriate to suggest that diabetes self-management education is extended to managers and senior staff, so that such approaches are more widely implemented.

The final theme, "Potential for effective diabetes self-management with appropriate support" highlighted the strengths of people with ID and their caregivers in self-management, thus providing potential facilitators. Areas in which people with ID felt confident were identified, and it was suggested that self-efficacy (Bandura,

1977) may be an applicable theoretical construct. As with the findings above, these facilitators may be limited to people with a mild ID in a residential setting. However, the fostering of creative and flexible approaches may potentially enable caregivers to support autonomy in people with higher support needs across a range of settings. It is therefore important that structured education provides training for caregivers which steers away from prohibitive approaches and enables autonomous support.

10.2.2. Review Two: Systematic review of mainstream T2D diabetes intervention and prevention programs

The primary aim of the second literature review was to ascertain the characteristics of theory-based T2D intervention programmes and evaluate these in relation to the needs of people with ID. The findings demonstrated that the mean age in the studies extracted for this review (mean 57.1 years in T2D self-management studies and 47.4 years in preventative) was higher than that of the participants with ID in the studies highlighted in McRae et al. (2015), which was 40.06 years. This may indicate that the onset of T2D develops at an earlier age for people with ID, perhaps due to their lifestyle and subsequent lower health status. The studies in Macrae et al., (2015) and McVilly et al. (2014) highlighted that people with ID experienced frustration in adjusting to self-management behaviours, therefore there is a rationale for introducing preventative diabetes education at an earlier age to reduce the need for difficult adjustment later in life.

Dabelea et al., (2014) reported that the number of youth diagnosed with T2D increased by more than 30% from 2000 to 2009 and TD2 developed during childhood is more likely to result in higher morbidity and mortality rates than in adulthood. This highlights the importance of early intervention and preventative measures for people with and at risk of diabetes. Furthermore, a review of pharmacological and lifestyle interventions to prevent or delay T2D found that 80-90% of all cases of T2D could be prevented by targeting lifestyle factors using structured education programmes (Gillies et al., 2007). There were nine (39.1%) preventative studies identified in this second review (Biddle et al., 2015; Contento et al., 2010; Faro et al., 2005; Heideman et al., 2015; McCurley et al., 2017; Laatikainen et al., 2007; Saksvig et al., 2005; Yates et al., 2009; Yates et al., 2016). The characteristics of these studies were of particular relevance for the development of interventions aimed at people with ID. The potential to reduce diabetes related costs through lifestyle interventions is estimated at 40-60% (Gillies et al., 2007). However, given that the additional support requirements of T2D self-management for people with ID are likely to be higher than that of the general population, preventative approaches through risk factor reduction may be more cost-effective.

As illustrated by the logic model in *Figure 3.2*, the significant proximal, intermediate, and distal outcomes align to the needs of people with ID, as identified in the first review. The meta-aggregation identified that people with ID's understanding of T2D was limited. It was highlighted in Cardol et al. (2012a) for example, that whilst some people with ID worried about the consequences of T2D, others did not "feel ill", and only perceived diabetes as serious when injections of insulin were involved. In terms of improving this understanding, programmes which utilized Self-regulation theory (SRT) may be suitable, as these encouraged participants to reflect on and re-evaluate their current understanding within educational sessions. Additional techniques such as elicited learning, role play and storytelling, may also have aided learning and could potentially be adopted for people with ID. Studies which employed the DESMOND curriculum (Biddle et al., 2015; Davies et al., 2008; Taggart et al., 2017; Yates et al., 2009; Yates et al., 2016) utilised this model and intervention techniques, and this may have contributed to the success of Taggart et al.'s (2017) adaptation of DESMOND for people with ID. Participants in the process evaluation focus groups of this study described being able to understand the content, which therefore suggests that the programme sufficiently addressed this need. In addition to SRT, the Dual process theory (DPT) may aid people with ID's understanding through elicited, non-didactic learning, which was also successfully employed by Taggart et al. (2017).

It has been highlighted that existing T2D resources for people with ID are not appropriate, for example caregivers in Hale et al. (2011) reported that any available resources were not in an accessible format. Detailed information on the format of resources in the studies identified in the present review was not included in the research papers. However, it is likely that further modifications may be required, such as pictorial support and accessible language. The DESMOND-ID adaptation by Taggart et al. (2017) used modified resources, and furthermore delivery was provided with support from ID nurses, who may have been able to tailor materials and contents accordingly.

Another need identified by in the previous chapter was in emotional support regarding lifestyle adjustments. Participants with ID reported experiencing frustration around dietary and medication routines, and struggled with adherence (Dysch et al., 2012, Hale et al., 2011; Rey-Conde et al., 2005). Hartmann et al. (2012), and Miller et al. (2014) targeted diabetes related distress using mindfulness-based meditation. A systematic review by Chapman et al. (2013) found evidence for the efficacy of mindfulness for people with ID, in the areas of aggression and sexual arousal, though the evidence base was limited due to methodological inconsistencies. However, mindfulness may be a supportive tool for people with ID self-managing T2D.

A common approach across the studies identified in the present review was improving participants' beliefs in their ability to self-manage or reduce risks of developing T2D. The theoretical basis for this was SCT, utilising self-efficacy enhancing techniques such as goal setting, positive feedback, self-assessment/reflection, resiliency promotion, and social support. Regarding people with ID, these techniques may lead to a reduction in struggling to adhere to healthy lifestyle changes and coping with barriers such as living with others who do not have dietary restrictions. The self-efficacy enhancing mechanism, "Vicarious experiences" (Bandura, 1977), advocates learning from the successful experiences of peers. The majority of the programmes were delivered in a group setting (18/23, 78.3%), offering opportunities for social modelling. Additionally, the environment may have played a role in enhancing self-efficacy. Saksvig et al. (2005) and Faro et al. (2005) delivered programmes in a school setting over an academic term, and additionally involved parents and carers of students through correspondence. This may have contributed to a significant improvement in dietary habits and dietary self-efficacy through environmental and social opportunities for reinforcement of key-messages. An environment which provides this support may therefore be of paramount importance.

Pedometers were used to measure ambulatory in three studies (Bradshaw et al., 2007; Biddle et al., 2015, Yates et al., 2009). As well-being useful as a measure, wearing pedometers may have led to increases in physical activity; indeed Yates et al. (2009) yielded significant changes in ambulatory activity in the pedometer group only, which was attributed to the pedometers providing ongoing feedback and achieving goals, thus enhancing self-efficacy. Pedometers have been used successfully to measure ambulatory activity in people with ID (Temple and Stanish, 2009; Melville et al., 2015), and this may therefore be an important component in programmes for people with ID which aim to increase physical activity and reduce sedentary behaviour.

Limited training and knowledge in staff was identified as a theme in the previous chapter, further highlighting the need for the inclusion of social support components in potential interventions and prevention programmes. Whilst social support was a common approach across the studies in the present review, the support network of participants was not always clearly delineated. By having a cognitive impairment, people with ID who are approached to participate in research are more likely to have access to support, which could potentially be incorporated into intervention or prevention programmes. Taggart et al. (2017) invited carers/family members to attend alongside people with ID, and to an additional three-hour session on their own, which was met by a 94% attendance rate. The trial protocol of a second T2D self-management programme (Walwyn et al., 2015), also invited caregivers/family members to attend sessions. The development report of a third programme, STOP Diabetes, also involved carers in the pilot stages. A programme of one carer session followed by seven 2.5-h sessions over 7 weeks was reported as acceptable to participants. These studies therefore address some of the social support needs identified in the literature. As described above, the delivery environment may also be an important factor, and an educational setting, as utilised by Saksvig et al. (2005) and Faro et al. (2005), may provide a support and reinforcement so that key messages can be sustained over time. Recruitment of people with ID in further educational colleges or special schools for people with ID is worth further exploration. The discussion now turns to the application of theoretical models utilized in the studies selected in this review.

A key aim of this review was to evaluate the theoretical models used in mainstream T2D interventions in terms of clarity of application. As with the EPHPP evaluation, quality was not consistently high, and whilst this could also arguably be due to the suitability of criteria such as the advocacy of single models, the application of model constructs to intervention techniques remains unclear.

SCT was found to be the most clearly evidenced model, and the SCT construct, self-efficacy (Bandura, 1977), was associated with diabetes knowledge, physical activity, and dietary behaviours and thus provided several significant outcomes, as described above. SCT is based on the learning relationship between the individual and their social context (Bandura 1977), emphasising the importance of the learning environment. Behavioural change can come about through reciprocal determinism, a process in which the individual and environment influence each other. Social norms, the behaviour of peers (termed “vicarious experiences”) and the persuasive influence of others (termed “verbal persuasion”) shape the cognition of an individual (Nutbeam and Harris, 2010). For people with ID, whose learning environment is often restricted to home, day and residential care settings, socially-produced behavioural change may be a greater challenge than for the general population. In terms of “verbal persuasion”, the values, attitudes and care approaches of family members and support workers often determine the level of autonomy people with ID have in self-managing their T2D and thus determine their level of opportunity for learning (Trip et al., 2016 and Whitehead et al., 2016).

“Vicarious” learning experiences may be similarly restricted as PWID often live together in shared care settings on the basis of their disability rather than their diabetes status. Hale et al. (2011) reported a sense of ‘unfairness’ by those with T2D who compare themselves to the non-disabled with T2D regarding issues such as dietary restrictions and medication regimes. SCT-based interventions aimed at people with ID self-managing T2D should therefore take into account the complexities of peer comparisons and social support in relation to the learning environment.

The second component of SCT is outcome expectations, which focuses on the perceived consequences of behaviours, such as reducing the risk of cardiovascular complications because of poor diet and lack of physical activity (Nutbeam and Harris, 2010). Short term outcomes can be more straight-forward to understand when intellectually disabled than long term, necessitating small, manageable goals and steps. Hale et al. (2011) and Dysch et al. (2012) highlighted that people with ID can struggle to understand the long-term consequences of poor diabetes control such as blindness, renal failure and amputation. Goal setting which emphasises short–term health benefits may be of key importance to sustaining self-management behaviours over time, thereby reducing the possibility of long term and avoidable complications.

The final component of SCT is self-efficacy, the belief in the ability to successfully perform a behaviour (Bandura, 1977). This component of the model reflects the level of effort put into a task to effect change and is viewed as the most important SCT component (Nutbeam and Harris, 2010). Bandura proposed four sources of efficacy enhancing experiences; “Mastery of Experiences”, which describes the importance of successful past experiences, “Vicarious Experiences and Verbal Persuasion” (discussed above) and “Physical/Emotional Arousal”, which describes the importance of physiological feedback. The model was clearly delineated and successfully used in the study by Wu et al., (2011), who alongside Miller et al. (2014) received the highest TCS ratings in the present review. The Four Sources model has not been applied to people with ID self-managing T2D, and therefore there was further exploration of its appropriateness, which led to the second phase of the thesis.

Overall the two reviews supported the extant literature on the educational support needs of people with ID at risk of or diagnosed with T2D, and the pressing need for a preventative agenda aimed at younger adults. Four potential programs were identified, and the theoretical construct self-efficacy was demonstrated to be the most consistently and effectively applied model across mainstream studies, leading to the evaluation of its relevance for people with ID in Phase Two.

10.3. Phase Two

The aims of this phase of the thesis were to explore the experiences of people with ID self-managing T2D using Bandura’s (1977) Four Sources of Efficacy Information as a mode of enquiry and to assess the meaning and importance of the model’s constructs for people with ID. The model provided a useful framework for the nine identified sub-themes, which in turn provided support for its use with people with ID. These findings are summarized in relation to each of the Four Sources below.

The descriptions of task mastery in *“Mastery of Experiences”* highlight the areas in which people with ID may potentially enhance their confidence in diabetes self-management, and interventions such as Taggart et al. (2017) which encourage participants to reflect on areas in which they have been successful may therefore be appropriate for this population. However, several challenges were also apparent, such as engaging in regular exercise and medication management. There was also a sense of confusion over what constitutes a healthy diet for some participants. It is possible that assertions of competence may not be a true reflection of these self-reported diabetes management skills, some of which may have been over-estimated. This would be consistent with the findings of Salaun, Reynes, and Berthouze-Aranda (2014), who found that Positive Illusory Bias (PIB) was an important factor in the self-perceptions of adolescents with ID undergoing a physical activity programme. In a discursive analysis of people with ID self-managing T2D, Rouse and Finlay (2016) reported conflicting constructions of competence, where empowered positions were taken despite dependence on caregivers. Future studies may benefit from the use of proxies, such as carers or family members, who could corroborate statements, or additional observational work. However, the perceptions of the participants in the present study may yet have contributed to the participants' sense of Self-Efficacy, regardless of the accuracy.

"Vicarious Experiences" was found to be important to some participant's self-management confidence. Social modelling opportunities are not always possible for people with ID self-managing their diabetes, since shared living situations do not always provide examples of others with diabetes. However, some participants' experiences suggest that where there is opportunity, people with ID may potentially enhance their efficacy in self-management through learning from others. Group-based interventions which facilitate positive peer comparisons may therefore be of benefit. However, the extent to which people with ID see themselves as the same as

or different from people without ID when making social comparisons should be considered. Examples of social modelling may also be provided by caregivers, which may be of higher value to people with ID than their peers (Paterson et al., 2012).

The participants made statements about themselves which may give an insight into their *“Verbal Persuasion”*. This feedback was both positive and negative and could reflect varying levels of self-confidence in self-management skills, as well as intentions to change. As with *“Mastery of Experience”*, some additional support from proxies may have helped to confirm or contest these statements. The importance of feedback from caregivers and health professionals was also highlighted, though this may also be subject to the participants' sense of autonomy, which was highlighted in *"Mastery through Autonomy"*. Cardol et al. (2012b) reported that attitudes of caregivers reflected a dilemma between enabling a sense of autonomy and ensuring competence in T2D self-management. It is therefore important to consider that autonomy may be negotiated across situations, as highlighted by Whitehead et al. (2016). Despite this, the overall impression given by the participants was that *Verbal persuasion*, from themselves and others, may be a source of Self-efficacy enhancement.

Regarding the final of component in Bandura’s efficacy enhancing model, “*Physical/emotional arousal”,* the adjustment experiences of the participants were not wholly positive and reflected the need for support in coping with lifestyle changes. This is consistent with the findings of Hale et al. (2011) and Cardol et al. (2012a), who reported people with ID’s frustrations at loss of autonomy due to adherence to dietary and exercise regimes. This may have led to a low sense of self-efficacy, although some participants had made the adjustment and were therefore more at ease with their situation, potentially offering them a sense of *“Mastery of experiences”*.

Symptom recognition and acting accordingly was a clear indicator of participant’s response to physiological arousal, and as such was a source of Self-efficacy enhancement. This aspect of the Four Sources model can be extended, as some participants drew confidence from recognising symptoms in others, rather than just in themselves. Therefore, there is potential for facilitating the process of symptom recognition for people with ID to enhance confidence in diabetes self-management. Future interventions may benefit from supporting people with ID to develop this recognition following diagnosis, for example by using reflective diaries or through discussion with peers, as with the buddy system suggestion in Hale et al. (2011).

As to the overall usefulness of the model in supporting people with ID to self-manage T2D, it may be that some components are more valuable than others. Bandura (1977) proposed that *"Mastery of Experience"* is the most efficacious component of Self-Efficacy, and has accordingly been given importance in the development of mainstream interventions (such as Davies et al., 2008). However, given the additional social-support needs of people with ID, strong emphasis should be given to *"Vicarious Experiences"* and "*Verbal Persuasion"* when considering the development of efficacy-enhancing resources for this population. With regard to the latter, it is important to continue to ensure that the autonomy of people with ID is upheld as far as possible, and that persuasion does not become acquiescence.
This phase of the research project has taken a rigorous approach to exploring the T2D self-management experiences of people with ID. There was strong theoretical basis, and a robust, clearly delineated methodology. It is important to note

limitations. Firstly, recruitment was restricted by the willingness and resources of gatekeepers to highlight and approach people with ID to take part, which meant that neutrality of approach could not be fully ensured; it is possible that biases from gatekeepers about the value of the study could influence the decision to take part. An easy read information sheet was sent out to Gatekeepers so that they could in turn send to participants, or assist with reading, which may have helped to reduce any recruitment biases through consistency of approach.

A sample size of 10 is acceptable for a qualitative study of this scale; studies with people with ID self-managing T2D range from N=4 (Dysch et al., 2012) to N=14 (Hale et al., 2011). A larger sample may have compensated for communication difficulties in some participants. However, as transcripts were analysed concurrently, it was possible to achieve data saturation as no new themes were identified from later interviews.

10.4. Phase Three

The third part of the discussion is first focussed on the implementation of the programme, including the recruitment and retention of participants and baseline measures. Next, the results of the four focus groups, (described in the preceding chapters), are discussed in relation to the wider literature. The application and relevance of Social Cognitive Theory (Bandura, 1977) and other models including the Transtheoretical model (Prochaska and DiClemente, 1983), and the Theory of Planned Behaviour (Ajzen, 1991) are also discussed in relation to these themes. The implications of the findings are then presented and evaluated alongside the extant literature. Finally, recommendations are highlighted for future research, policy and practice.

10.4.1. Demographics

The literature reviews in Chapters Two and Three provided a rationale for taking a preventative approach to T2D and targeting a young age group of people with ID. At this age, participants would be mature enough to make independent lifestyle decisions and are less likely to have developed habitual risk behaviours well-established (e.g. poor diet, low physical activity) for T2D. The reviews also highlighted that people with ID develop T2D around ten years earlier than the general population, adding to the necessity of early intervention. Subsequent to the conducting of this study, a feasibility study was published by Mitchell et al. (2018), in which the lifestyle behaviours of people with ID transitioning from school to adulthood was examined. Data indicated that this was a high risk period for weight gain. Educational interventions implemented during this period are therefore extremely timely. The mean participant age in the current study was 20.9 years, which was substantially lower than the mean age of participants in the mainstream preventative studies (54.5 years). Therefore, the strategy of recruiting participants in a further education setting was an appropriate and successful approach in terms of targeting a younger demographic.

The physiological data suggested that measures of waist circumference and BMI were risk factors for many participants. According to NHS guidelines, a waist circumference of 94cm and above for men and 80cm and above for women is indicative of a higher risk of cardiovascular disease and type 2 diabetes. 102cm for men and 88cm for women is considered very high risk. According to the mean participants' waist circumferences, males were at high risk (96.9cm) and females at very high risk (96.8). Although participants were not recruited on the basis of individual diabetes risk factors, these findings support the extant literature on the health of people with ID, and further highlight the need for the evaluation, adaptation and application of such programmes as the ‘Walking Away programme’.

10.4.2. Baseline questionnaires

The baseline questionnaires were conducted to provide data on the current physical activity habits of the participants using the International Physical Activity Questionnaire (IPAQ), which was adapted and validated for people with ID by McKeon et al. (2013), and also the participants’ physical activity Self-efficacy beliefs using the Self-efficacy for Leisure Physical Activity (SELPA), validated for people with ID by Peterson et al., (2009). Both tools proved difficult to use with people with ID in a further education setting as the questions did not account for lifestyles which were predominantly college-based. However, the IPAQ questionnaire highlighted that for a young age group who might be expected to be more physically active, the participants did not engage in activity which could be described as “vigorous”, and in small amounts of “moderate” activity. Participants also engaged in low levels of ambulatory activity, either as a mode of transport or recreationally. This is consistent with the findings of McKeon et al. (2013), who used the IPAQ alongside a physical activity monitor armband and found there to be no sustainable high physical activity intensity levels amongst men with ID in younger age groups (19-39 years), or older

(40-59 years). It has therefore been important to evaluate the potential for an intervention which aims at increasing physical activity in this population.

The SELPA questionnaire can be discussed in relation to the findings of the first phase of the present thesis, which qualitatively explored the application of the Self-efficacy construct to people with ID self-managing T2D. The majority (64%) of the participants who undertook the SELPA questionnaire appeared to have a high self-efficacy regarding their being able to engage in physical activity and did not see external factors like transport or finances as barriers. The participants in the qualitative study also described a high level of self-efficacy, although this was in regard to general diabetes self-management rather than specifically physical activity. However, the findings of the Phase One study suggested that some of the participants may have been overestimating their competence in T2D self-management. This has been reported elsewhere in the literature by Salaun et al. (2014), who suggested that Positive Illusory Bias may exist in people with ID as a self-esteem protecting mechanism. The participants who undertook the SELPA questionnaire may also have applied this bias regarding their physical activity Self-efficacy. However, it should be noted that in both phases, the participants may have had a higher sense of self-efficacy regardless of the accuracy of their beliefs, and this confidence may have led to higher competence or engagement in healthy behaviours.

The participants' responses in the “Social support from family” section indicated that they had a high level of support, with 74% saying that their family ‘sometimes’ reminded them to engage in physical activities, and 18% saying this happened ‘a lot’. “Social support from staff” was slightly less strong with 64% of students saying they sometimes were sometimes reminded by lecturers to engage in physical activity, however the students were not enrolled in physical activity-based modules other than gardening and were therefore unlikely to have been supported in this way by lecturers. The fact that there was still a high level of encouragement from staff for students engaging in physical activity (despite this not being part of curriculum) suggests that there is strong potential for social support in a college setting. Social support was highlighted in the Phase One study as intrinsically linked to “Verbal Persuasion”, which was identified as a Self-efficacy enhancing mechanism arguably more important to people with ID than “Mastery of Experiences”, as had been suggested by Bandura (1977). The level of social support received by the students in Phase Two, whether from home or within college, confirms the rationale of implementing an intervention in this setting where healthy behaviours can be reinforced over time.

10.4.3. Focus groups

10.4.3.1. Introduction

This section discusses the feedback from the students and lecturers on the Walking Away programme, as indicated by the focus groups. The themes and subthemes which emerged from these groups are organised below into three subsections: i) Positive outcomes, which discusses elements of the programme which were well received; ii) Potential limitations and barriers, which discusses drawbacks which may have impacted upon the success and reception of the programme; iii) Potential solutions: those offered by the lecturers and students discussed in relation to the literature. Following this, the focus group findings are discussed in relation to the theoretical models introduced in Chapter One.

10.4.3.2. Positive outcomes

There was an overall positive response from the students and this appeared to be linked to relationship-building, as highlighted in “Acceptability and impact” and “Success of the programme”. The researcher had made several visits prior to delivering the Walking Away programme and this seemed to help create a sense of familiarity. Guidelines provided by Kaehne and O’Connell’s (2010), recommend a minimum of four visits prior to conducting research with people with ID. The implications of this may be that the programme is more acceptable to students with ID when delivered by a familiar person, rather than an outside diabetes educator, as is the model of delivery in the original ‘Walking Away’ design. The importance of the self-efficacy construct, “verbal persuasion” is raised here, where positive feedback from others can enhance self-efficacy (Bandura, 1977). It is therefore important to acknowledge that future participants may have a higher belief in their own ability to engage in the ‘Walking Away’ curriculum depending on their familiarity with the deliverer.

Conversely, there was also a suggestion of positive response due to change of routine, with students enjoying the novelty of the programme as a break from their current studies. As a brief, 3-hour intervention, the ‘Walking Away programme’ may be suited to students whose engagement in learning is sustained by variety, a teaching approach endorsed in higher education (Biggs and Tang, 2011). However, there were suggestions which are discussed further below recommending delivery of the programme over a longer period. In this scenario, students may potentially lose this arguably superficial interest over time, and it would therefore be important to include varied teaching activities within an extended curriculum of the ‘Walking Away’ programme.

The overall positive student response was validated by the teaching staff. A deeper evaluation of why the programme was acceptable to the students was provided, and it was suggested that activities where humour and role play were integrated had been most enjoyed. This perhaps also highlighted the importance of relationships as these activities enabled personal interaction between the participants, researcher, and the lecturers who supported the activities. As indicated by the second phase of the thesis, relationships and social support are important to the Self-efficacy enhancing mechanism, “Verbal persuasion”. This sense of familiarity may therefore have led to a higher sense of Self-efficacy in the participants. This was also found in the pilot feasibility studies conducted by Taggart et al. (2017), Walwyn et al. (2015), and Dunkley et al. (2017), where the importance of rapport building with service users and their parents and caregivers was highlighted.

It was suggested by the lecturers that despite the issues with the suitability of the pedometers, using them encouraged the participants to walk, and furthermore increased their overall enthusiasm for the participating in the programme. Yates et al. (2009) reported that there were significant increases in the group using pedometers as well as diabetes education over 12 months, but not in the education only group, concluding that being able to observe and record changes was key to motivation in increased ambulatory activity. Beth was highlighted by the teaching staff as making behavioural changes as a result of wearing a pedometer and being motivated by being able to achieve her daily targets easily. This may have provided her with a sense of “Mastery of Experience”, thus enhancing her Self-efficacy. Other students may have also experienced this if they had been provided with pedometers appropriate to their needs. It would therefore be essential to research and provide a suitable alternative to the SW 200 provided in the present study.

Regarding the wider study materials, the lecturers from Site B appeared to feel that participant information sheets, consent, and debrief sheets were appropriate for people with ID in a college setting, describing them as accessible and picture-based. These had been previously used in an unpublished study conducted by Edinburgh Napier University and the format, picture and language was approved by professionals in ID practice. Based on this and the feedback from Site B, these materials would therefore be appropriate for use in further trials of the Walking Away programme for people with ID or in related studies. Site A feedback was less positive about the materials, though this was linked to procedural difficulties which are highlighted in the following section.

10.4.3.3. Potential limitations and barriers

A limitation of the student feedback was that the students did not expand greatly beyond confirmation of the researcher questions, which could be interpreted as participant leading, given the absence of qualifying content. However, the views of the students were supported in the lecturer focus groups, which therefore improves the validity of the findings.

It is possible that some of the participants did not see themselves as ‘at risk’ of developing diabetes, despite the waist circumference and BMI levels reported in the demographics section above. Understanding risk was an important aspect of the programme, and one of the sections was specifically devoted to identifying risk factors. This section was guided by Leventhal’s Common Sense theory (Leventhal et al., 1980), which was explicitly acknowledged in the ‘Walking Away’ educator delivery training. During this section, participants were invited to reflect on their own personal risk factors, and it was apparent that some of the participants had multiple risk factors. However, it was difficult to conclude that this led to a motivation to change in the participants.

A key difference between the original ‘Walking Away’ programme and the present study was that in the original programme, participants had been clinically diagnosed as ‘at risk’ using a risk score calculator. This diagnosis may have primed the participants to consider the potential consequences of developing diabetes and taking preventative action. In the present study, participants were not recruited based on being ‘at risk’, and the perceived consequences of risks may therefore have been less acute. The potential for Positive Illusory Bias in people with ID (Salaun et al., 2014) may also have reduced the participants’ perceived risks and consequences as their healthy behaviours may have been overestimated.

The participants’ understanding of the dietary choices unit also appeared limited. The unit emphasised awareness of saturated fats, particularly in regard to cooking oils. A demographic limitation of this study is that data was not collected on the living status of the participants since the focus was on the college setting. However, it was apparent from the participant responses that autonomy was limited in terms of grocery shopping and cooking, as this was done by families at home or in residential care. The dietary choices unit was therefore not fully suited to participants in this setting, though could potentially be modified by incorporating discussion of lunchtime choices. A concern later raised by the lecturers and teaching support staff was the attraction of vending machine food to the students. These machines were easy to use and subsequently highly accessible to the students, and were described as commonly used. A section devoted to content of vending machine snacks would potentially benefit those attempting to engage in healthy behaviours. These concerns have implications for wider policy and practice regarding the prominence and accessibility of machines selling snacks with high sugar and saturated fat content. A recent study on the prevalence of obesity in healthcare professionals by Kyle et al. (2017) has led to the banning of vending machines selling sugary snacks and drinks by an NHS trust in England (Telegraph, 2018). A similar approach was undertaken by a T2D prevention programme in a school setting (Saksvig et al., 2005), which led to significant improvements in dietary habits and knowledge. Such a measure may therefore be effective in a further education setting, although this raises this issue of choice and autonomy. Students from a special education setting are unlikely to have been able to readily access vending machines prior to college, and their availability for students vulnerable to their attraction of their ease of use should be reviewed.

Learning approaches, including activities, resources and technology were important to participants and there was a wide suggestion that diabetes education should encompass familiar approaches. Some of these approaches were already a part of the ‘Walking Away’ curriculum, but pragmatic adaptations were necessary to implement and deliver the programme within the constraints of the study. For example, classes were larger and there were fewer opportunities for active learning, and these issues were noted by the students. The ‘Walking Away’ programme recommended group size is 8-10, which was typical of the class sizes, although the Glasgow groups were merged into a group of 25. This reduced the possibility for a fully inclusive approach or individual support.

A major limitation of the programme from the teaching staffs’ perspective was the suitability of the content and materials, in terms of the students' capacity to understand and recall it. This was attributed to the complexity of the language and the use of abstract analogies, and it was suggested that these were not likely to have been understood by people with ASD or Asperger's Syndrome. People with ASD tend to make literal interpretations of analogies and metaphors (Tager-Flusberg, 1999), and this may have been a barrier to understanding. These analogies were pivotal to the explanation of risk factors and insulin resistance, which were core concepts of the programme. It is therefore important that additional adaptations are made in order to explicitly link these analogies to the concepts they represent.

As there was no formal assessment of the students' understanding of the materials or the overall programme, it is difficult to evaluate how accurate this perception was. However, the statements in the students' focus group did not indicate a strong understanding and the areas which the lecturers highlighted as problematic mirror those where the students struggled to recall or accurately describe content.

One of the other main issues identified in the teaching staff focus groups was planning and implementation. There were differences between sites in how successfully this was perceived. Site B reflected that although some additional consultation would have been helpful, implementation was a success, and Site A experienced problems that led to initial recruitment difficulties. In the latter case, the lecturers had carried out their own introduction of the programme to the students and disseminated the participant information sheets at this point, rather than waiting for the researcher. This had led to some confusion on the part of the students over what was to be expected of them, and the lecturers reported that they had found describing the study and its purpose to be more complex than they had anticipated. Both sites had received the same information from the researcher, yet it is possible that this information was interpreted differently due to ambiguity. Were a larger trial to take place, the potential for this to happen should be taken into account, and the roles and responsibilities of teaching staff should be clearly appointed.

In addition to differences in interpretation, it is possible that teaching staffs' attitudes and beliefs towards the students' capacity to understand the purpose and content of the study may have impacted on how they introduced the study and presented the materials. These views are reflective of differences in teaching styles, where dispositional limitations of the students are affect learning outcomes, rather than what the teacher does (Biggs and Tang, 2011). The TPB (Ajzen, 1991) would be applicable; in the present study, the lecturers in both sites demonstrated a strong interest in healthy lifestyles for people with ID, yet in Site A there were indications that either the material was too complex, or that the students lacked the capacity to understand. In the latter case, these attitudes may have led to preconceptions about how the study would be received, which in turn could have impacted on how it was presented, potentially leading to negative responses from the students.

Other barriers were regarding the materials. Although these were picture-based, the students struggled with the size of the images unless handed out individually. This was possible with smaller groups, but some activities, such as the magnetic figure and timeline, were designed to be delivered by the educator to the whole group. Alternatives were discussed by students and teaching staff, and these are presented in the following section.

The students' level of engagement in wearing and recording pedometers, as indicated by their self-report and focus group comments, was sparse and brief. Discomfort wearing the pedometers, forgetting to bring them to college and re-setting the daily step count meant that using pedometers would be problematic for a trial recording ambulatory activity in this setting. There are several reasons why these problems may have occurred. Firstly, the students were given pedometers to trial their use and report back the experience of wearing them and recording their steps in focus groups. The students and lecturers were aware of this and may have perceived any data collection as informal, whereas in a repeated measure design this information may have been more important, both to students and lecturers.

Secondly, the Yamax Digiwalker SW200 appeared to have been not fit for purpose for people with ID. The model had been recommended for use in research by Leicester Diabetes Centre and one of the aims of the present study was to replicate the materials of the original ‘Walking Away’ programme as closely as possible. However, the participants reported difficulties with opening and closing the pedometers, discomfort wearing them on their waistbands and difficulties reading the screen.

10.4.3.4. Potential solutions

One practical suggestion from the students was the use of phonics for learning new vocabulary. As confirmed by the teaching staff, this was a technique they were used to, and may have helped them to learn unfamiliar vocabulary such as medical terminology. With less time constraints, students could have been given the opportunity to rehearse the spelling of important words like "insulin", which they struggled to recall despite repetition and cues, which were designed to facilitate heuristic processing (Chaiken, 1987). The "Blood Glucose" unit formed a substantial part of the overall course as the concepts, most importantly insulin resistance provided the basis for the later units. Understanding at this stage was therefore important, though it is possible that the students may have understood the concepts without learning the vocabulary. This raises the question of how important it would be to use medical vocabulary in this setting, and whether simpler alternatives which were conceptually similar would be viable. For participants to struggle at this early stage of the programme may arguably reduce their task-mastery and overall Self-efficacy for subsequent learning in the programme (Bandura, 1977).

Suggestions were made for the materials to be presented via the Smartboard, which again was a format that the students were used to. Vygotsky (1978) proposed that learning occurs through appropriation of cultural tools, including language and technology, and this principle is recognised as quality practice in higher education (HEA, 2012). It is therefore important to embed learning within a cultural and technological context, and incorporating the tools used by the students would help to achieve this end. Internet-based resources were also suggested, which the lecturers later acknowledged was an approach used to enable independent learning, where students could actively search information on a given topic. This technique could potentially be used to learn about diabetes resources. Accessible information on diabetes is available at the Diabetes UK website (Diabetes UK, 2014). There would be advantages and disadvantages in this approach, as students in higher education settings from diverse backgrounds may have differing levels of digital literacy (Selwyn, 2010).

Alternative ambulatory recording devices were suggested, such as Fitbits, and a Nintendo DS. There has been a recent growth of studies exploring the use of technology assistance in improving fitness. Mobile phone apps have been evaluated, based on the now common prevalence of Smartphones. A recent review by Direito et al. (2014) found that there are a range of paid and unpaid apps available which target physical activity and diet. However, evidence for their efficacy is limited, and the apps lacked many important behavioural change components such as overcoming relapses and setting goals. Similar findings were reported in a review by Wang et al. (2016) of Android and iPhone fitness apps, in that whilst many of the Apps did fulfil some functions recommended by medical guidelines, exercise risk factors and professional instructions were often not included. The validity of these apps for people with ID to use would need to be evaluated prior to incorporated use in programmes such as Walking Away. Furthermore, whilst there was an assumption that young people are likely to have digital literacy and access to technology (Selwyn, 2010), this may not be the case for people with ID who are more likely to subject to social-economic inequalities (Emerson and Baines, 2010). In the lecturer focus groups, it was estimated that many students do not have Smartphones, and it was suggested that in addition to financial restrictions, the college and parents would have concerns about access to adult content, which may further reduce the likelihood of students accessing Smartphones apps as an alternative to pedometers.

Both students and lecturers suggested The Fitbit as a viable alternative to pedometers as these could be worn on the wrist and were less likely to be forgotten.

It is possible that students who perceive stigma in relation to wearing the pedometers may feel more comfortable wearing these, although this was not reflected this concern in the focus groups. The Fitbit also comes with a range of features beyond pedometer readings, such as activity prompts and heartrate monitoring. Furthermore, data can be imported directly to other devices, resolving the issue of forgetting to record data, although this may reduce autonomy, and people with ID should be supported to independently record where possible. The cost, approximately £20 for the basic model based on a 2018 Google Shopping search, is currently comparable to the Yamax Digiwalker SW200 (£10-15), therefore this may be a financially viable alternative.

In the mainstream population, The Fitbit has been validated when assessed alongside previously validated accelerometers (Brewer, Swanson, and Ortiz, 2017), although it was found that The Fitbit was a valid indicator for a seven-day period, but not for a single day. Using the last seven days is a standardized measure (McKeon et al., 2013; Yate et al., 2016) The Fitbit would be an appropriate tool. However, it should be noted that due to the difficulties highlighted above in encouraging people with ID, a recording over seven days may be difficult to obtain. With similar difficulties in consideration, Temple and Stanish (2009) recommended a measure of three out of the last seven days as a valid indicator of accelerometer measurement in people with ID. It is unclear whether three days would be sufficient for The Fitbit validity, as Brewer et al. (2017) only reported validity for seven days. However, the higher usability of The Fitbit could make a seven-day measure more feasible. The Fitbit may therefore potentially be a viable alternative to the Yamax SW-200, though further validity assessment for people with ID may need to be conducted.

Some short-term impact was discussed by the teaching staff, though this was described as a change of mood rather than a behavioural change, and it was suggested that further reinforcement would be required for a long-term impact. This raised the question of whether the Walking Away programme should be delivered as a brief, 3-hour session or instead delivered over a longer period, which was a point the lecturers returned to throughout the focus groups. A key difference between the original ‘Walking Away’ programme and the present study was the setting; whereas ‘Walking Away’ was designed to meet the needs of a primary care setting with high time and resource demands, the higher education was les bound by these restrictions. Participants were already in attendance at the colleges where they were studying a related subject, therefore time off work or other life schedules and transport costs were not applicable concerns. There were also no additional costs for using the classroom spaces, which could potentially be a cost factor in a primary care setting, particularly if a venue was sought for a longer period than three hours. One significant potential cost would be the educator. As this role is typically embedded within the duties of dieticians or diabetes nurses, long term delivery could reflect an associated professional salary. The suitability of a diabetes educator to deliver the programme in a college setting was also raised as an issue at this point. Aside from the cost implications, it was highlighted by the lecturers that a long-term delivery of the ‘Walking Away’ programme would enable greater opportunities for additional support and subsequently higher participation, as well as continued reinforcement of key messages.

It was also suggested by the teaching staff that intentions to change and understanding of the course may not be sustained over time, and that this was would be applicable to anyone regardless of having or not having an ID. As highlighted in the literature review of mainstream T2D programmes in Chapter Two, there was a dearth of evidence for interventions which provided sustained impact beyond 12 months. As was concluded from this review, the traditional primary care setting of intervention and prevention programmes (such as Davies et al., 2008, and Yates et al., 2016) may have been a factor in the lack of impact over a longer period. Part of the rationale for the present study was to assess the feasibility of delivery in an educational institutional setting, where opportunities for social support and reinforcement may be higher, which may in turn lead to sustained motivation and engagement in positive behavioural change. One issue with this is that many students attend single academic year modules and then no longer attend college, therefore obtaining measures beyond 12 months could be difficult as participants may be less accessible once no longer enrolled in college. Follow-up measures beyond this point would potentially require home visits or data-collection events, in which participants may require reimbursement or incentive for time and travel. It is also unknown whether a programme enhanced by social support over a year would continue to have impact once the support network ended. However, this level of support would still be substantially higher than a single session in a primary care setting, and the implications of this, such as higher Self-efficacy and Intention to Change, have strong theoretically support towards have a long-term impact.

Another potential issue with a long-term implementation of the ‘Walking Away’ programme embedded with a higher education setting would be in evaluating the efficacy of the programme as distinct from other learning activities which were focussed on health promotion. During the delivery of the programme and within the focus groups there were references from the students and lecturers towards such activities, including healthy eating and recreational activity choices, and it was likely that there may have been some overlap between these and the ‘Walking Away’ curriculum. One option for future trials would be to have a control group which participated in the healthy behaviours only, and another which participated in this together with’ Walking Away’. Differences between colleges in terms of course curriculum may present further difficulties with this and would need to be balanced where possible.

The teaching staff highlighted similar issues to the students of the usability of the pedometers. However, from the educators’ perspective, remembering to bring the pedometers into college and to record them at home were more significant problems. As discussed, above alternatives to the SW 200 such as The Fitbit could provide participants with a tool which would remove the necessity of remembering to record results. In terms of taking measures beyond an academic year, this may be a useful method of collecting data as participants could present several weeks or months of data at once. Where necessary, an elected supporter may be able to upload results, removing the necessity for researcher visits or further participant data collection events where transport and time off schedules would need to be considered. A scenario where caregivers are trained to support people with ID to upload the data themselves would ensure that autonomy and meaningful participation is not lost. It has been reported that people with ID construct themselves as autonomous in T2D self-management (Rouse and Finlay, 2016), and that self-management autonomy can be a process of negotiation with caregivers (Whitehead et al., 2016). It is therefore important that opportunities for negotiated autonomy are provided as far as possible. It would also be important to ensure that participants continue to frequently monitor their step counts so that they are able to assess their progress and task mastery.

One of the most important suggestions was tailoring the programme to the specific needs of individuals. In practical terms, this meant providing one-to-one support where required as well as creating person-centred opportunities where students' individual strengths were played to, such as technological skills or recreational interests. However, whilst most of the teaching staff advocated such a flexible approach, there were conflicting suggestions of narrower participant selection, where only those who were likely to be able to engage with the materials and make behavioural changes would selected. This reflects a dilemma highlighted where the successful outcome of the programme is seen as either due to the materials, or to the disposition and capacity of the students. A limitation of a narrower recruitment selection would be the lack of inclusivity, where students are excluded who may have been able to participate given the right level of support. It is possible that students who struggle to understand and engage with the programme are more likely to have a lower health literacy, and subsequently be in greater need of diabetes education. However, it should also be noted that some of the students were categorised as being of a healthy weight and engaged in regular recreational physical activity prior to implementation of the ‘Walking Away’ programme. These students may therefore have been at lower risk of developing diabetes and potentially less motivated to participate in the programme. Exclusion of these students may not be inappropriate, which raises the question of whether or not to conduct baseline diabetes risk assessment tests in further trials of the ‘Walking Away’ programme. In the mainstream ‘Walking Away’ RCT (Yates et al., 2016), recruitment selection was based on individuals above the 90th percentile of the Leicester Practice Risk Score (Gray et al., 2012), where age, ethnicity, gender, family history of diabetes, antihypertensive therapy, and BMI were used as factors to calculate risk. Future trials of ‘Walking Away’ aimed at people with ID could consider recruitment based on this tool. Part of the rationale for wide inclusivity in the present study was that people with ID are likely to experience greater health inequalities than the mainstream population (Emerson and Baines, 2010), and on the basis of this are more likely to carry diabetes risk factors. Therefore, it was deemed ethically appropriate to provide diabetes education for the whole group.

Another potential benefit of wider inclusion is that people with ID who are more physically active could act as role models with the programme, and could "buddy-up" with less active peers. A buddy system for T2D self-management was a suggestion from people with ID in Hale et al. (2011). In these matters, social stigma and social comparisons should are important to acknowledge. Any exclusion of participants, or alternatively narrow recruitment of a select few, could lead to stigma and subsequently low self-esteem. People with ID have demonstrated downward social comparisons with each other (Paterson, McKenzie, and Lindsay, 2012) and lateral comparisons to those they see as more able than them as self-esteem protecting mechanisms (Paterson, McKenzie, and Lindsay, 2012). Wide inclusion may help to reduce this stigma and provide opportunities for positive social comparisons, thus enhancing self-efficacy through "vicarious experiences" (Bandura, 1977).

Following from this, a further suggestion from the teaching staff for adaptations to the ‘Walking Away’ programme was for there to be opportunities for peer educators. This was discussed in relation to peers with ID within classes, and peers of without ID of a similar age group. In ether sense, this could provide an opportunity for "vicarious experiences". Regarding peers with ID, some of the lecturers appeared concerned about the competence of these students to deliver the programme and suggested that additional support and planning would be required. There were also doubts over the willingness of students to make behavioural changes following positive examples of their peers. Once again, this may reflect attitudes of perceived limited capacity and disposition, which could affect the success of these adaptations (Ajzen, 1991). However, the lecturers were in the position to have a strong sense of the abilities of the students who had participated in the ‘Walking Away’ programme, and it is also possible that these concerns were realistic and pragmatic. There was not a clear definition of what was meant by peer-led education in the focus groups, and it is possible that the lecturers were considering a level of involvement which was beyond the capacity of students, rather than a level suited to abilities and tailored to strengths.

One of the practical suggestions for tailoring to individuals was using the internet. It was pointed out that accessing and researching interests online was a skill for many students, and that a potential learning approach could be to encourage seeking out T2D information online. Another potential option be a web page containing access to Walking Away learning resources, subject to licencing and sharing agreements. A further advantage of this would be that students could continue to access resources beyond the timeframe of the programme, enabling continued support and reinforcement. Web-based interventions such as Wu et al. (2011) and Jennings et al. (2014) led to significant improvements in diabetes self-management in the mainstream population, demonstrating the reach of such approaches. The ‘Walking Away’ programme was selected for people with ID partly based on its being a group-based educational programme offering more opportunities for social support than internet approaches which have an individual approach. However, supplementing a group programme with internet-based activities may extend scope and inclusivity.

Perhaps the most significant suggestion was to incorporate the ‘Walking Away’ programme into existing further education modules, and subsequently be delivered by lecturers, rather than a visiting diabetes educator. It was mentioned at both sites that there were several modules that the programme could be aligned to. There would be several advantages to this delivery approach. Firstly, this would enable a long-term delivery of the programme rather than a single 3-hour approach. As described above the duration of the programme was too limited in terms of being able to provide close support and individual tailoring, and a longer approach would make this possible. Secondly, the importance of relationships has been highlighted, and lecturers would be in a better position to build rapport with the students than a diabetes educator. Lecturers would also be aware of the individual needs and interests of students, further facilitating individual tailoring. Thirdly, this would enable lecturers to take ownership of the programme and adapt it as required, supplementing its curriculum with additional activities which could enhance knowledge and reinforce messages. Alongside this, lecturers would have a far greater insight into the philosophical approaches of the ‘Walking Away’ programme and may see this as aligned to their existing curriculum. Finally, from a pragmatic perspective, lecturers would already be on site, which means there would not be additional resource demands other than training costs. Given the potential reach of recruitment in higher educational organisations, in the long term this training is likely to be cost-effective, as the number of people with ID at risk of or diagnosed with diabetes may be significantly reduced.

10.5. Further theoretical discussion

The ‘Walking Away’ programme is an associated module of the DESMOND programme (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed). The curriculum of DESMOND is based upon recommended learning theories, such as deep learning (Marton and Saljo, 1976), socially constructed learning (Vygotsky, 1978) and Dual Process Theory (Chaiken, 1987). These approaches inform national guidelines for education such as the UK Quality Code for Education and Quality Enhancement Scotland, and as such are likely to inform higher education college courses, including those aimed at people with ID. However, for DESMOND values to be integrated into a college setting, the needs of people with ID need to be considered. This means sufficient time and resources for supported, tailored learning, repetition, and reinforcement.

There were differences, both between and within the teaching staff focus groups, regarding well the materials and content were understood. As many of the staff were not able to attend all of the programmes and hence did not have an overview of the programme, it is possible that where unsuitability was perceived, this may have reflected attitudes towards the students' capacity to learn and understand, rather than towards the course content and materials. This perceived limitation of the students rather than the programme was also apparent when the teaching staff discussed the "Healthy Eating module", where it was suggested that some students would be too "set in their ways" to change. Attitudes towards behavioural change have been studied in relation to the Theory of Planned Behaviour (Ajzen, 1991). The Theory of Planned Behaviour (TPB) suggests that beliefs and attitudes can impact upon the behaviour of self and others. It has been applied, for example, to physical activity studies (Davies, Mummery, and Steele, 2010) and self-management of T2D (Jennings, Vandelanotte, Caperchione, and Mummery, 2014). Should a larger trial assessing the Walking Away programme for people with ID to take place, there would be a greater number of teaching staff and subsequently a wider range of teacher's attitudes, which may impact upon the behaviour of the students. It would therefore be important to use the lens of the TPB as an analytical tool, so that the impact of lecturer attitudes on student participation, engagement, and retention could be evaluated.

The risk awareness section was informed by Leventhal's Illness Perceptions (1980) theory, with the rationale that an understanding of these processes could lead to behavioural change. However, the Precontemplation stage in Prochaska and DiClemente's (1983) TTM suggests that the appropriateness of learning materials can impact upon progression from this stage to the next, and it is therefore essential that information guiding change is tailored to the needs of participants. O'Leary, Taggart, and Cousins (2017) reported that within residential care services, there was not an ethos which supported healthy lifestyle for people with ID. Thus, in terms of the TTM, the organisations had not moved from "Pre-contemplation" to "Contemplation", and lacked the interest to support behavioural changes. The lecturers and students from Site A could therefore be described as being in the "Contemplation" Stage, where the benefits of making change were understood but the perceived barriers prevented action being taken in the near future (Prochaska and DiClemente, 1983). This would also have implications for Self-efficacy enhancement (Bandura, 1978), whereby "verbal persuasion" may have been less impactful due to feedback being framed negatively.

There were examples of enthusiasm from some of the students towards wearing the pedometers. This, together with the description above of novelty as a way of engaging some of the students raises the relevance of the Transtheoretical model (TTM) proposed by Prochaska and DiClemente (1983), which was described in Chapter One. The TTM model presents a five-stage descriptive model of readiness to change, which includes “Pre-contemplation”, “Contemplation”, “Preparation”, “Action”, and “Maintenance”. The extent to which the students were interested in engaging in the Walking Away programme, or drawn by more superficial reasons, may reflect their stage of readiness to change. The Pre-contemplation stage could describe the students prior to receiving information about the study, where they were unlikely to have been thinking about making lifestyle changes which could reduce the risk of diabetes. The Contemplation stage could potentially describe the point where the students had received some preliminary information about the benefits of exercise and healthy diet, but had yet to gain an understanding of manageable ways of integrating increased ambulatory activity into their daily routines. As described by the lecturers, some students were initially put off participation in the ‘Walking Away programme’ by the idea of having to do extra walking, and may therefore have been in this stage. It was difficult to conclude from the participants’ responses in the focus groups whether any had reached the Preparation stage. Whilst there was positivity and enthusiasm, responses did not indicate that they had made use of the ‘Walking Away’ goal-setting booklets to make plans for increased walking, and it appeared that the current version of the programme had not been sufficient to promote progression to this stage by the time the focus groups were conducted. For participants to be at the action stage, repeated measures at six months would need to indicate significant increases in ambulatory activity, as was achieved in the mainstream Walking Away RCT (Yates et al., 2016). As with SCT, the self-efficacy construct is applied to the Maintenance stage, in that people have a sense of task accomplishment which leads to confidence in overcoming barriers and subsequently fewer relapses. This stage may be applicable to an extended implementation of the ‘Walking Away’ programme. Participants in the Yate et al. (2016) study may have struggled with this stage as changes in ambulatory activity were not significant beyond 12 months. As described in Phase Two, additional social support may be required for people with ID to enhance Self-efficacy; this may in turn increase the duration of the Maintenance stage. The application of the TTM is discussed further below in relation to other themes and its use elsewhere in the literature. However, there may be potential for the model’s useful usability as a lens for evaluating the “Acceptability and Impact” theme.

An additional model of relevance is Leventhal’s Common Sense Model (Leventhal et al. 1980), which was used by Cardol et al. (2012a) to evaluate the findings of a qualitative study exploring people with ID’s experience of self-managing T2D. The findings provided some support for the model’s proposition that understanding of illness determines action for change, however this was limited to people who lived alone, and diabetes was only perceived as serious when insulin was required. This may reflect that for some people with ID, the consequences of chronic illnesses like diabetes may be difficult to comprehend, which could impact on their motivation to make behavioural changes. The implication of this for the TTM is that progression beyond Precontemplation may be difficult if consequences of illness are not understood. For the participants in the present study, the level of understanding of the consequences of diabetes may have influenced the impact of the programme.

The students who were reluctant to take part due to anxieties about discovering their own diabetes risk factors were an exception to the appropriateness of the TTM, and Illness Perception Theory. Their understanding may have been advanced to the extent that they could understand consequences very well, and as such were reluctant to find out more in case this enhanced their anxiety. Participants with high functioning autism and Asperger's syndrome may have higher levels of anxiety, and it is important to consider this when applying behavioural change models based on motivation and consequences. One participant's reservations were linked to her awareness of the effects of epileptic seizures, which had appeared to influence her overall illness perceptions. Prior illnesses and conditions may therefore play a role on the impact of learning new information about the potential consequences of healthy behaviours, and these should be considered when considering readiness to change.

Anxiety over participation raises the issue for recruitment of people with ID who have communication impairments. People with ASD and Asperger's Syndrome are likely to have difficulties in understanding the intentions of others (Tager-Flusberg, 1999). This may impact upon their perception of the study purpose, leading to further anxieties. It is possible that the students who had reservations about participating, who were described by the lecturers as having ASD, may have misunderstood the purpose of the study and were cautious about agreeing to participate. Information sheets were designed to be easy read and pictorially however additional support aids such as Social Stories may have facilitated understanding and reduced anxiety for some participants.

The TTM was also mirrored in one of the activities in the Physical Activity session, where a diagram was presented to depict stages of motivation, including facing and overcoming relapses. Although there was an enthusiastic recall from participants, understanding was superficial. Further work may need to be undertaken to evaluate the stages of change model for people with ID, in order to ascertain its appropriateness. Facing and overcoming relapses also mirrors Self-efficacy, as this describes the confidence to overcome barriers. As suggested by Phase One of the thesis, additional social support may be required to facilitate Self-efficacy enhancement, and the diagrammatic model used in Walking Away could potentially incorporate a section suggesting support from peers and caregivers to overcome barriers to engaging in physical activity.

Whitehead et al. (2016) proposed a model of negotiated autonomy, where choices and boundaries around dietary restrictions could be fluid and situational in order to reduce frustration. Whilst many of the participants were in the overweight or obese category, none had been diagnosed with diabetes and were therefore unlikely to have imposed dietary restrictions to the degree described in the studies by Cardol et al. (2012a&b), Dysch et al. (2012) and Whitehead et al. (2016). Autonomy was limited in the sense of not independently shopping for food, rather than having restricted diets. Therefore, Whiteheads et al.'s (2016) model of negotiated autonomy is less appropriate for the participants in the present study. However, were a long term, socially supported version of the Walking Away programme to be implemented, the model may usefully highlight the need for flexibility in dietary management.

10.6. Conclusion

This chapter has discussed and integrated the three phases of the thesis. The support needs of people with ID with or at risk of T2D have been highlighted. A potential solutions to some of the challenges faced by this population was identified, and the feasibility of implementing some of these solutions was assessed. It can be concluded that the main misgivings of the lecturers were directed at the present, unadapted version of the ‘Walking Away’ programme, and that they believed a version incorporating their suggestions could be viable. Whilst a version of the programme in which lecturers can take ownership has been suggested, support and guidance may be required to ensure successful planning and implementation. This raises the question of whether lecturers should undertake the ‘Walking Away’ educator training programme in its present format and then make subsequent adaptations of their own, or whether an adapted version of the training programme should be developed which incorporates the suggestions of the lecturers in the present study. Whilst it has been highlighted that ownership of the programme and opportunities for flexibility and creativity are important to the lecturers, an adapted version of the training programme could be piloted with groups of lecturers to validate its suitability before a larger implementation. This pilot could be assessed by an expert panel and delivered to staff from multiple higher education organisations so that a range of teaching approaches and wider curriculums are represented. This lead to the final chapter, in which the overall conclusions are presented, in more detail together with implications for policy and practice.

Chapter Eleven – Conclusions

11.1. Introduction

This chapter draws together and presents the conclusions of the research project. A reflexivity section is first presented, in which the author provides a self-appraisal of their role in relation to the research project. The concept of reflectivity is first explored, followed by a quality evaluation. Following this, implications for policy and practice are presented. Finally, the thesis is completed with a conclusive statement.

11.2. Original contribution to knowledge

This extensive piece of research is the first of its kind to identify an urgent need to enable behavioural change in young adults with ID, which could lead to the prevention of developing T2D. A systematic and rigorous evaluation of existing mainstream programmes and theoretical models has led to the delivery of a selected mainstream prevention programme in a further education setting. This has highlighted a substantial potential for successfully recruiting a subpopulation which has in the past been consistently demonstrated as difficult to access. Furthermore, this setting has the potential to yield high programme attendance and retention rates, which have also been traditionally highlighted as problematic in both ID and mainstream studies. Although there were limitations with some of the content and materials of the Walking Away programme, the receptivity of the students together with the high level of engagement and support from the teaching staff demonstrates that a structured educational programme could be delivered in this setting with great success. The implications of this are outlined in the following section.

11.3. Implications for further research

Following the analysis of the staff and lecturer focus groups and the discussion of these findings in relation to the literature and relevant theoretical models, the following recommendations for further research can be made:

1. An adapted version of the ‘Walking Away’ training programme which aims to maximise inclusivity should be developed in consultation with its original developers, Leicester Diabetes Centre, and a multi-disciplinary expert panel which includes people with ID and their carers
2. The training programme is piloted with a nationally representative selection of lecturers who deliver supported education to adults with ID
3. This programme should incorporate opportunities for peer-led learning, which are realistic and achievable
4. The programme should incorporate materials and technology familiar to students with ID in a higher education setting
5. A viable alternative to the SW 200, such as The Fitbit or a similar device, is researched and piloted with of group of people with ID in a higher education setting

6. Further demographics on the health status of young adults with ID as indicated by diabetes risk factors should be researched to build a national and international picture of the need for diabetes prevention

11.4. Implications for policy and practice

The results of this phase of the thesis has a range of implications for educating and supporting people with ID.

1. Diabetes risk-factors may be high in young adults with ID and measures should be taken to reduce these risks. Investment with and engagement in education about risk prevention is of paramount importance.
2. Staff in residential and educational settings must carry a strong awareness of these risks and be adequately equipped with knowledge and training to do so. Within this, an awareness of role-models and social modelling should also be strongly present, as the behaviours and attitudes of staff impact greatly on those they support and educate.
3. People with ID should be supported to reflect upon and share their experiences of risk-reducing and self-managing T2D. Opportunities should be provided for peer support, including buddy-systems and peer-educators.
4. Relationships are key to building confidence and sustaining behaviours which reduce the risk of and effectively self-manage T2D. Where possible, these relationships should be fostered and maintained through rapport building opportunities and staff consistency.

5. Technology is an important part of the lives of young adults with ID, and for some this is a mode of communication and accessing information. Such technology should be accessible to people with ID in home, residential, and educational settings.
6. Continuity of format is also important, and multi-disciplinary and multi-agency working should strive towards shared-knowledge of histories so that people with ID are provided with familiar materials and resources, or appropriately supported through changes.

11.5. Reflexivity

The second and third phases of the present research project involve qualitative research. As discussed in Chapters five and six, a qualitative approach is appropriate for exploring the complexities of illness experiences. Accompanying the rising prominence of this approach has been a call for transparency and rigour in order to support the credibility of data collection and analysis (Darawsheh, 2014). As described by Elliot et al. (1999), an important criterion to ensure this rigour is the process of reflexivity.

Reflexivity refers to a continuous process of self-reflection carried out by the researcher which enables an awareness and critical appraisal of one's own thought processes and actions in research (Anderson, 2008). Despite this, there has been a lack of consensus regarding the meaning and application of reflexivity (Darawsheh, 2014). For example, the term reflexivity has been used to describe a peer-debriefing process in contrast to an individualised approach which values personal introspection (Finlay, 1998). Darawsheh (2014) and Finlay (2002) have developed guidelines for ensuring consistency in utilising and reporting reflexivity. These guidelines are considered within the present reflexivity section. However, many of the criteria, such as “situating the reader” and “transparency”, converge with those of the Elliot et al. (1999) guidelines. As the latter were used to evaluate qualitative literature in Chapter Two, it would be appropriate to use this tool to structure and inform the subsequent sections. This also provides a quality appraisal of the research project which can subsequently be compared to the studies in the literature identified in Chapter Two, and this part of the thesis may therefore also be described as a strengths and limitations section.

The following subsection presents the seven criteria of Elliot et al. (1999). As recommended by this and by the guidelines described above, the language is presented in the first person, so that reflexivity is evocative in the writing style (Smith, 2006).

11.5.1. “Owning perspective”

This criterion advocates the importance of acknowledging the background and position of the researcher, and is described by Darawsheh (2014) as “situating the reader”. In Chapter One, section 4, I presented an overview of my professional background in social care, in which I discussed my experience of the health status of people with ID. To provide a succinct summary, my experiences led to a belief that health literacy and levels of physical activity are limited in people with ID, which leads to reduced quantity and quality of life, but also that there exists a potential for behavioural change given appropriate support. This belief closely aligns to what I report throughout the thesis, including the synthesis of the literature review in

Chapter Two, the analysis of the qualitative study in Chapter Five, and the focus groups in Chapters Eight and Nine. It may be argued that these beliefs led to a confirmation bias, in which my beliefs influenced my analysis. Reflecting again on my beliefs and assumptions, I have witnessed the difference between structured activity engagement and its absence, and I subsequently place high value on any form of health intervention compared to receiving nothing at all. This could have led to an overly favourable appraisal of the Walking Away programme's impact. However, other than in the present section, I have taken several steps to ensure rigour so that my findings are not subject to bias. These are presented in the subsequent sections. In addition, the descriptive statistical data presented in Chapter Seven provides an objective account of the baseline health status and physical activity levels of the participants, which further validates the qualitative analysis.

In addition, I noted that I felt very comfortable delivering the Walking Away programme to people with ID in a college setting, as doing so reminded me of my experiences as a day service work shop leader. I believe this strengthened the delivery of the programme and enabled me to establish a rapport with the students, and which subsequently led to their engagement in the sessions and focus groups. This was a rewarding experience for me, and it is possible that this could have led to a positive bias in my facilitation and analysis of the student focus groups. There were moments during these groups where I experienced it as challenging to build a conversation without leading the students' answers. People with ID are vulnerable to suggestibility and acquiescence (NES, 2014), and there is a danger of this occurring in research, where the assumptions and beliefs of the researcher can influence the views and subsequent statements of participants with ID. However, the teaching staff focus groups provided an objective appraisal of the students' experiences. My social care background was in an organisation where values were held in accordance with protective legislation such as the Adults with Incapacity (Scotland) Act (2000). This provided me a strong awareness of the potential for leading when presenting topics to people with ID, and I believe I have cultivated a communicative approach, where this is avoided as far as possible.

11.5.2. “Situating the sample”

This purpose of this criterion is to evaluate the extent to which sufficient detail has been provided about the participants, such as the location and nature of the sample and demographics. A limitation of the demographic sections presented in chapters five and seven is the level of background information about the participants. Physiological data and ethnicity was not obtained from the participants in Phase Two, and ethnicity, living situation and severity of ID were not obtained in Phase Three. This limits the comparability of these demographics to those reported in other studies. However, in terms of the research aims of these phases, the recorded details were appropriate, and these additional details were surplus to requirement.

Data on the level of ID and type of developmental disorder were not collected from the colleges. This is a limitation in terms of understanding differences in health status and receptivity to the Walking Away programme between sub-groups. However, there are several reasons why I did not carry this out. Firstly, participants were recruited for a predominantly qualitative study. To observe statistical differences between levels of ID would have required a larger, powered sample. Secondly, the process of recruiting for and implementing the Walking Away programme was assessed, rather than its effects. Therefore, these comparisons would have been appropriate. Finally, the supported learning classes were not divided based on these characteristics, therefore it would not have been to divide the findings. Each of these arguments in defence of the study design also point to the fact that in a larger trial which measures the effect of a programme, collecting this additional data would be valuable, and provide direction for future research.

11.5.3. “Grounding in example”

This refers to the inclusion and depth of examples from raw data provided in the studies. Within this thesis I have included substantial transcript examples to illustrate each theme and subtheme and this is a strength of the overall project. Carrying out a meta-aggregation in Chapter Two was a useful process in terms of considering my how well I evidenced my own analysis during the second and third studies phases. In addition, the appendices contain further examples of raw data which the reader can refer to throughout so that it is possible to evaluate my decision making.

11.5.4. “Credibility checks”

In addition to providing examples, I have supported my findings by asking my supervisors to undertake independent assessments throughout several stages of the research project. These include the qualitative analyses of phase one and two, and quality assessments, data synthesis and logic model in the literature reviews in phase one. An additional step would have been to obtain an independent literature search and selection, which would have furthered the validity and reliability of the reviews. However, this would have been a time-consuming process, given that two reviews were carried out. The search terms, selection criteria and databases were discussed in supervision meetings and through draft feedback. In addition, these chapters were peer reviewed, where the search strategies and selection were appraised and approved.

11.5.5. “Coherence”

Coherence refers to the comprehensibility of the studies, including the presentation and structure. In writing a thesis for the first time, providing a consistently coherent flow has been a challenging learning process and I have had to work on the skill of creating a flow between chapters and subsections. Creating concise versions of chapters for publication has helped me to write with clarity, which I have been able to apply when editing later thesis drafts. I have also honed an ability to illustrate concepts and structures using diagrams. The purpose of these are to aid the reader, although I have also found them useful for organising my own thought processes. I believe this skill stems from developing pictorial aids for service users in social care, as well as in my research materials.

11.5.6. “Accomplishing general versus specific research tasks”

Acknowledgement of generalizability and limitations, for example sample size, homogeneity, and setting, has been important in the present research project. It was necessary to emphasise throughout the thesis that the research focussed upon feasibility of a larger trial, and that the processes, rather than impact, were evaluated. At times, I experienced a temptation to report the success of the Walking Away programme as the delivery process had been so positive, which I acknowledge above in "owning perspective". It was important to include the perception of impact by the students and lecturers, as this could be linked to which aspects of the programme were more acceptable and accessible than others. Overall, claims about the efficacy of the programme would not be appropriate, however, a similar programme may be acceptable to a similarly represented sample in another location, and in this sense, there is a claim for generalisability.

11.5.7. “Resonating with the reader”

The final criterion invites the reader to reflect upon their overall impression of the study report, in this case the thesis, summarising the extent to which the previous points have been addressed. My experience of carrying out this reflexivity section is that it has been very useful as an iterative quality checklist, and is one to revisit for subsequent appraisals.

11.6. Limitations

There are several important limitations of the overall thesis, as these highlight areas for potential further research and also enable the reader to evaluate the strength of the claims made through the findings. Firstly the fidelity of the Walking Away intervention program was not measured. Fidelity is the extent to which the core values and philosophies of an intervention are adhered to during implementation (Moore et al. 2014). In the DESMOND-ID study (Taggart et al. 2017), interviews and focus groups were conducted with the deliverers of the program, during which fidelity was assessed. As the program was delivered by the researcher, this was not possible as there may have been potential for bias despite the reflexivity described above. An alternative could have been to structure the interview schedule for the teaching staff focus groups so that the fidelity of the walking away program was discussed. However, there was not a consistent attendance from teaching staff throughout the program, so it may have been challenging to obtain an overall appraisal of fidelity. It is also important to point out that the values and philosophies of Walking Away are drawn from the DESMOND program, and this appraisal has already been conducted by Taggart et al. (2017). The focus in the present study was instead on acceptability and accessibility of the materials to people with ID in further education colleges, which has provided an original contribution to knowledge.

A second substantial limitation is that the effects of the Walking Away study were not evaluated using repeated measures. These could potentially have included measuring changes in ambulatory activity and in HbA1c levels, assessed at intervals over 12 months. A challenge in this approach would have been in obtaining an adequate sample size to demonstrate a significant change in these levels. The mainstream Walking Away study (Yates et al., 2016), recruited a powered calculation sample of 808 participants; this would not have been possible in the present study due to pragmatic constraints. As discussed in Chapter Six, evaluating the feasibility of conducting a study is an important step prior to conducting a large trial with the resources to overcome these pragmatic challenges, and such a step has been a key focus of the present thesis.

Finally, although recruitment can be described as successful in that 92% of participants who were invited to participate agreed to take part in the study, only two of six invited colleges agreed. This may be indicative of the recruitment challenges in the educational sector. However, as the first two colleges that were approached provided a sufficient sample size for the study design, it was not necessary to pursue recruitment vigorously in additional colleges, and multiple follow-ups were not made.

11.7. Final conclusion

This thesis has described a robust piece of work which has followed best practice guidelines for developing a complex intervention from an early stage, with a strong and scoping theoretical basis. The work carried out in this research project is unlikely to substantially change the lives of the people with ID who participated in the short term. Some of the adults with ID who discussed their self-management experiences in Phase Two, may have superficially raised awareness of their own Self-efficacy through being asked to reflect on areas in which they were successful. Some of the students in Phase Three may have begun to consider how finding ways of integrating increased physical activity and healthy eating into their daily lives could reduce the risk of developing T2D and other diseases in later life. However, in both cases, the tools to support and sustain these possibilities have yet to be developed and refined. The same may be said of the wider impact of the study results. The impact, costings, reach, and efficacy of the Walking Away programme have yet to be assessed. For these changes to grow, nurturing is required. Early steps however, are as developmentally important as later ones, and this research project has provided a strong basis for further development. The importance of early intervention and prevention for T2D has been robustly evidenced, through synthesising and building upon the literature. This has led to the identification of adolescents and young adults as a sample in pressing need of educational support. In tandem with this, further educational colleges have been identified as potentially high yielding recruitment centres which are representative of this population. Finally, receptivity to a health intervention programme in this setting in potentially very high. Taking these findings together, there is the blueprint for a truly innovative approach to T2D prevention, which may extend to other chronic illnesses, and break the mould of primary care setting interventions with limited longitudinal impact.

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Reducing the risk of Type 2 diabetes in people with intellectual disabilities: A three phase study

Volume II of II

Andrew Maine

BSc (Hons) in Psychology
BA History and English
SVQ4 Health and Social Care

School of Health and Social Care

EDINBURGH NAPIER UNIVERSITY

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University, for the award of Doctor of Philosophy
August 2018

Table of Contents

Appendix 1: Phase Two - Participants with ID information booklet

Information about the study

Hello my name is Andrew.

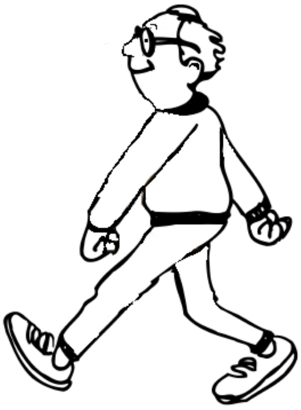
I am a research student at Edinburgh Napier University and I work with people like you.

We are doing a study.
A study is a way of finding things out.

Do you want to be in the study?
This information sheet tells you about the study.

It helps you to decide if you want to be in the study or not.

This is what we want to find out:
Having Type 2 Diabetes requires extra care to keep your feet, eyes, heart, circulation and kidneys healthy.



But the good news is that if you pay more attention to the kind of food you eat, do more exercise and stop smoking, you can keep control of your diabetes and enjoy life the way you want to.

We are trying to find out how you feel about having Type 2 diabetes, how it affects your life and how it is managed. We are also interested in finding out about what helps give you the confidence to do these things which keep control of your diabetes.

Why do we want to find out?
Listening to your views will help us understand better what it is like for you to have Type 2 diabetes.

This will help us let other people like you, health professionals and carers know the best ways to support you with managing your diabetes.

Then we can tell others about it.

What will you have to do?
We would like you to take part in an interview.
An interview is where someone asks you questions to try and find out about your experiences

Andrew will ask you questions about your health, life and how you feel about having Type 2 diabetes.

Andrew will find out a good time to visit your home or workplace to do this interview. This may take up to 1 hour to complete.

We will ask you to be in our study.
You can say:

"Yes" or "No"

You don't have to decide yet.

If you say "yes, maybe I want to be in the study", Andrew will arrange to visit your home or workplace and complete the interview.

You can decide if you want to say "Yes".

If you want to be in the study, you must sign your name on the consent form at the end of this information sheet.

If you find it difficult to write, someone else can help you.

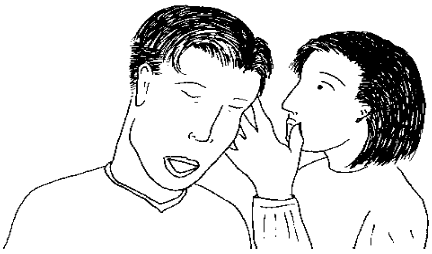
What happens if I say "no"?

If you don't want to be in the study, that's OK.

You will still get the same support from others to help you manage your diabetes.

Andrew will NOT contact you again.

What will Andrew do after the event?



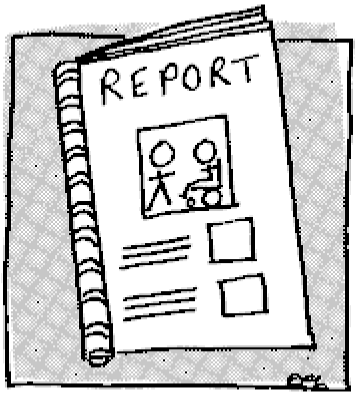
Everything you tell Andrew is private.
Andrew will not let anyone know who talked to him for this study.

Andrew will put your answers to the questions you were asked onto a computer.

Andrew will not put your name onto the computer so no one will know that the answers are about you.

The only people who will be able to see your answers are Andrew's supervisors

If you tell us that someone is hurting you or you are hurting somebody we will have to pass this information on. But we will tell you if we are going to do this.
When we have finished, we will tell others what we have found out and we will make a report.



We will write down what we have found out.
If you would like, we will give you the paper so you can read what we found out.

We might write what you say in a magazine or a report.

No one will know that it was you who said it.
We won't tell anyone your name.
We will use a pretend name instead.

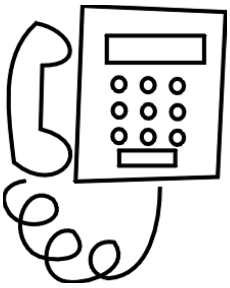
Can the study upset you?

Most people will not be upset by the study. But thinking about your diabetes and how it affects your life might be sad and if you feel upset you can leave the interview at any time.

You may have someone (a carer, family member or friend) who you can talk to about this. You can also talk to Andrew and others after the meeting if you want to.

Contacting Andrew

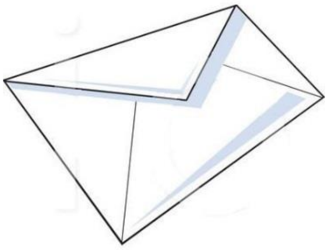
You or your carer can contact Andrew if you want to know more about the study.



Andrew’s phone number is: [redacted]
or his mobile number is: [redacted]

Or you can write to Andrew.

His address is:



[redacted]
School of Nursing, Midwifery & Social Care
Edinburgh Napier University,
Sighthill Campus,
Sighthill Court.
Edinburgh
EH11 4BN

If you find it difficult to write, someone else can help you.

Or you can send Andrew an email.
His email address is:

[redacted]

Appendix 2: Phase Two – Professionals information booklet

Professional Information letter

Principle Investigator:

Andrew Maine (School of Nursing, Midwifery & Social Care)
Mres Supervisors:
Professor Michael Brown, Professor Thanos Karatzias, Dr. Adele Dickson (School of Nursing, Midwifery & Social Care)

Professional Information Letter

Experiences of People with Intellectual Disabilities who self-manage their Type 2 Diabetes:
Mres Research Study

Title of study: Self-efficacy Experiences of People with Intellectual Disabilities (ID) Self-managing Type 2 Diabetes (T2D)

I would like to inform you about my study in order for you to assist with recruitment of potential participants. It is important that the purpose of the research and what it will entail is made clear to you before you speak about the project to others. Please take time to read the following information carefully.

What is the aim of this study?

Self-efficacy is defined by Bandura (1977) as the confidence a person has in his or her ability to perform a behaviour, including confidence in overcoming barriers to perform the behaviour. The aim of this study is to explore the meaning of self-efficacy for people with ID who have T2D. The study will look at specific aspects of self-efficacy theory to explore the meaning for people with ID, of psychosocial factors which have been demonstrated elsewhere to enhance self-efficacy and thereby improve health outcomes.

Why have you been approached?

You have been approached because your work involves meeting the health care needs of people with ID and T2D.

Do you have to take part?

No, it is up to you whether or not you wish to participate. If you do, you are still free to withdraw at any time.

What is involved for you?

You are being asked to distribute participant information sheets, consent forms and invitations to take part in a one-off, 1-1 interview, to adults with mild to moderate ID who have T2D. The information sheet informs the person what the purpose and nature of the study is in an easy read format. However, you or your staff may still need to assist the person with ID to read this.

What are the possible disadvantages and risks of taking part?
It is hoped that by careful attention to the discussion process, HCPs will feel supported to contribute to the study without any ill effect.

What happens to the information?
A code will be used instead of participant names when transcribing and analysing data. At no point will their names be identifiable on the analysis or in the final report. All data will be stored securely and subsequently destroyed after six years in accordance with the Napier University's policy.

A report summarizing the findings will be disseminated to each person with ID and their carer and we will be willing to discuss the findings at future meetings you may consider appropriate. We will also inform participants should the study be published in the future.

How can you make a complaint?
Participant and professional organisation wellbeing is of great importance to us and we hope that through careful planning, participating in the individual interviews and the subsequent analysis and publication of the data gathered through the interviews will not cause you distress. Complaints can be discussed in the first instance with me and I will try to resolve them to your satisfaction. If I fail to resolve your concern or complaint, you can direct it to Edinburgh Napier University. Your complaint will be addressed in accordance with either university's Complaints Process.

What should you do now?
Please forward the participation information sheets and consent forms to any adults with a mild to moderate ID and T2D within your organisation. Everyone who returns a consent form will be contacted; either to outline the next steps or to thank them for their interest in the study.
Thank you for reading this letter. Please contact me on the details below should you have any queries.

Yours Sincerely

Andrew Maine [redacted]

Tel: [redacted]

e-mail: [redacted]

Appendix 3: Phase Two - Participants with ID consent form

Consent form

I say it is OK for Andrew from Edinburgh Napier University to spend time with me for this study.

I have seen the information sheet about the study.

I understand what it says.

I had a chance to ask questions about it.

I agree to be in the study.

YES ☐

NO ☐

I say it is OK for Andrew to keep my name and contact details for further research studies in diabetes education.

YES ☐

NO ☐

If I do not want to be in the study anymore, I do not have to.

I can tell Andrew if I do not want to be in the study anytime. I will still get good care from my doctors, nurses and carers.

Andrew will not let anyone know who is in this study. He may write what I say and what I do but no one will know it was me.

I can phone Andrew if I want to know more about the study.
Andrew’s phone number is [redacted]

My signature Date

____ __________

Andrew’s signature

Date

My address is: ____

____

____

My phone number is: _______________________________________

My date of birth is: ______/________/________

Appendix 4: Phase Two – Professionals information booklet

Debrief Sheet

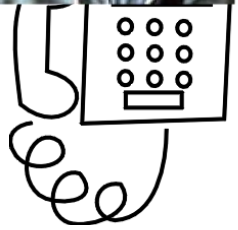
This study was about the experiences of people like you who manage their diabetes.
Studies by other people have shown that being confident about doing something can make you better at doing it. So, if you are more confident at looking after your diabetes, you will be better at doing it.
I wanted to see if your experiences showed that being confident at looking after your diabetes made you better at doing it.
I also wanted to look at what kind of things helped you to be more confident at doing it. Because of studies by other people, I thought that maybe you felt more confident by:

- remembering that you managed to look after your diabetes before
- seeing other people manage their diabetes well
- being told by people like doctors and nurses that you've been managing your diabetes well
- listening to what your body is telling you (like being hungry or tired)

That's why I asked you some questions – to see if those things help people like you to feel more confident about managing their diabetes.
If you have any more questions about it, you can contact me (Andrew)

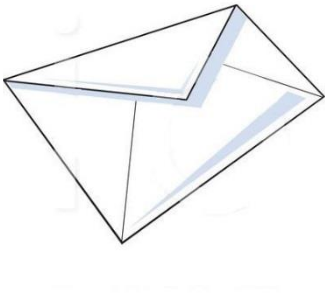
Contacting Andrew

Andrew's phone number is: [redacted]
or his mobile number is: [redacted]



Or you can write to Andrew.

His address is:



[redacted]
School of Nursing, Midwifery & Social Care
Edinburgh Napier University,
Sighthill Campus,
Sighthill Court.
Edinburgh
EH11 4BN

If you find it difficult to write, someone else can help you.

Or you can send Andrew an email.
His email address is:

[redacted]

Appendix 5: Phase Two ethical approval

Hello Andrew,

Many thanks for your prompt response and amendments to your professional information sheet. I have reviewed these again and confirm that you have now addressed all of the requirements of your ethics application feedback. On this basis I am now able to grant you approval to proceed with your study on behalf of the FHLSS ethics approvals group.

Best wishes with your study.

Regards,

Barbara

Appendix 6: Phase Two – Interview schedule

Interview schedule

NB: Questions serve as introductions to topic and the researcher may use follow ups to encourage participants to speak broadly.

Part 1: General self-management experiences of managing diabetes

1) People like you, who have diabetes, often have to make changes about what they eat and drink. How does it feel to make these changes?

2) Another thing that people with diabetes have to do is to change the way they live, like doing more exercise. Are you doing more exercise than before? How does it feel, to have to do more exercise?

3) Do you know about keeping an eye on your blood sugar levels? How does it feel to have to do this?

4) Having diabetes can also mean going for lots of visits to the doctor or nurse for check-ups. How does it feel to have to do this?

Part 2: Efficacy experiences

1) You've been looking after your diabetes like this for a while now [chat about how long]. Do you feel like you're getting better at it the more you do it? [Previous experiences]

2) Let's have a look at this story [read vignette with participant]. Do you think Douglas is doing well with managing his diabetes? Do you know any other people who are managing their diabetes, apart from yourself? Do you think Douglas' story, or other people who are doing well with managing their diabetes, encourages you to manage your own diabetes better? [Vicarious experiences].

3) Looking after diabetes can be tough work. Does it help when people, like doctors and nurses, tell you that you're doing well? [Verbal persuasion experiences]

4) Sometimes people who have diabetes have feelings in their bodies, like hunger, thirstiness, tiredness and aches and pains. What is it like to have these feelings? Are they different when you look after you diabetes?

Is there anything else that you would like to tell me about your diabetes and how you take care of it?

Thank you for taking the time to participate in this study. I will let you know what we find out once the study is finished.

Appendix 7: Phase two analysis, stages four and five

Mastery of Experiences	Vicarious Experiences	Verbal Persuasion	Emotional/physical arousal
• Confidence about diet (S,D,A) • Confidence about medication (F,D,G,I) • Independence and autonomy (F,S,D,A) • Trial and error (F,S) • Confidence about exercise (R,F,D,A) • Diabetes awareness and knowledge (S,A,N,F,I) •	• Shared poor dietary habits (D) • Dietary difficulties – social comparisons/isolation (I) • Dietary knowledge- social support (A) • Weight awareness & self-image (A,M) • Hospital setting and diet (M) • Past low motivation • for exercise due to self-image (A)	• Dietary education gives confidence (F) • Dietary knowledge or following rules? (Ga) • Lack of diabetes education (D) • Recognizing need for help with diabetes related health problems (D) • Avoiding expert support – not understanding consequences? (D) • Avoiding expert support – worried about side effects of medication after change? (D) • Autonomy through approachable support and accessible equipment (D) • Values expert support for serious	• Symptom awareness – shaking (D) • Recognizing physical symptoms (I,S,F) • Struggle to reflect on physiological experiences • Struggle to reflect on physiological experiences (A) • Reliance on symptom awareness (S) • Recognizing others' symptoms (S,F,M)

		consequences (I) • Self-management confidence from diabetes education (A) • Learning confidence from diabetes education (A) • Sense of wellbeing from positive feedback (A) • Mistrusts government – & authority (S) • Confusion – lack of diabetes education? (S) • Autonomy in health changes (S, Ga) • Autonomous self-management (S, Ga) • Mistrusts Doctors (S) • Values positive feedback (S) • Reliance on caregiver support for all aspects of SM (G) • Autonomous learning over being taught (F) • Good relationship with health professionals (F)	

		• Respect for health professionals (F) • Aware of consequences from doctor and family illnesses (Da) • Health professional appraisal is important • Medication control dependent on staff (I, J) • Support needed for medication control (A,D) • Support to keep to appointments (Da) • Exercise – motivated by challenge • Exercise limited by social support (Ga) • Exercise enhanced by relationships (Ga)	

Appendix 8: Phase Three - Participants with ID information booklet

Edinburgh Napier
UNIVERSITY

Walking Away Adaptation study

Information about the study

Hello my name is Andrew.

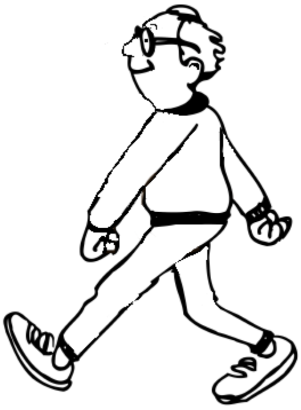
I am a research student at Edinburgh Napier University.

I am doing a study.
A study is a way of finding things out.

Do you want to be in the study?

This information sheet tells you about the study.
It helps you to decide if you want to be in the study or not. You are eligible to take part in this study because been involved in this first part, where you answered th and recorded your pedometer readings.

What is Type 2 Diabetes?



- Type 2 Diabetes happens when your body does not make enough insulin, or cannot use insulin properly.
- Insulin helps you to use blood sugar and to be active.
- People with diabetes get too much sugar in their blood and this makes it difficult for them to be active.
- Having Type 2 Diabetes requires extra care to keep your feet, eyes, heart, circulation and kidneys healthy.
- Although you may not have Type 2 Diabetes, it is very important to prevent it from developing.
- Anyone can get diabetes and there is no cure yet, though treatment is available.

But the good news is that if you pay more attention to the kind of food you eat, do more exercise and don’t smoke, you can reduce the risk of developing diabetes.

A program has been made to help people learn about how to be aware of diabetes risks and how to reduce them. The program is called **Walking Away from Diabetes.**

It is called **Walking Away** because as well as helping people to avoid diabetes, it helps people plan to do more walking, and teaches other ways to be healthy.

What do we want to find out?

We already know that the Walking Away program works well for some people. We don’t know if it works for everyone yet. We don’t know if it works for people who are doing life skills classes at college, and we want to find out.

What would you have to do?
We would like you to come to some classes where Andrew will run the Walking Away program. Andrew has been trained to do this. After the classes, you would try to do a bit more walking than you normally do, every day. You will be given a **pedometer** to wear.

A **pedometer** is a device that tells you have many steps you have done.

Andrew would ask you a few questions at the start and take some measurements, like how many steps you think you do a day normally, what you like to eat and drink and your height and weight.

Focus Groups

You would also be invited to take part in a **focus group**.

A focus group interview is where a group of people meet together to chat about some questions. Focus groups are very important because they give people a chance to share their views alongside each other. This can help to show that some people feel the same about something (like taking part in a diabetes program), whereas some people feel differently. Some other students, teachers and support workers will also be part of the group.

Andrew will lead the focus group and ask you questions about your experiences of taking part in the Walking Away Program, how you got on with the pedometers, and what you thought of the study.

Andrew will talk to your teachers about when would be a good time to have a focus group in the college. This may take up to 1 and a half hours to complete.

The focus group will be audio recorded. After the focus group has finished, Andrew will copy this onto a computer and it will be password protected so that only he can hear it. Andrew will then write down everything he hears in the recording. Your name will be kept anonymous.

So do I want to take part?

We will ask you to be in our study. It is up to you if you want to take part.

You can either say:

"Yes" or "No"

You don't have to decide yet.

If you want to be in the study, you must sign your name on the consent form at the end of this information sheet.

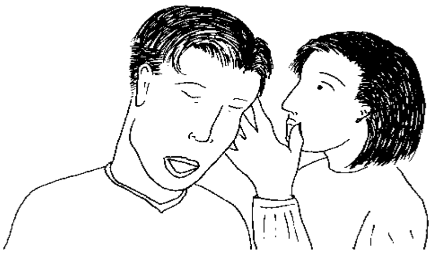
If you find it difficult to write, someone else can help you.

What happens if I say "no"?
If you don't want to be in the study, that's OK.

You will still get the same support from others to help you manage your diabetes.

Andrew will NOT contact you again.

What will Andrew do after the event?



Everything you tell Andrew is private.

Andrew will not let anyone know who talked to him for this study.

Andrew will put your measurements and questionnaire answers onto a computer.

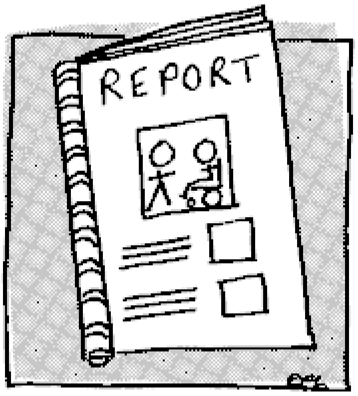
Andrew will not put your name onto the computer so no one will know that the answers are about you.

The only people who will be able to see your answers are Andrew's supervisors

If you tell us that someone is hurting you or you are hurting somebody we will have to pass this information on. But we will tell you if we are going to do this.

After the study is finished

When we have finished, we will tell others what we have found out and we will make a report.



We will write down what we have found out.
If you would like, we will give you the paper so you can read what we found out.

We might write what you say in a magazine or a report.

No one will know that it was you who said it.
We won't tell anyone your name.
We will use a pretend name instead.

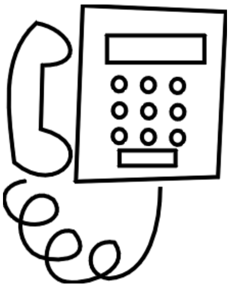
Can the study upset you?
Most people will not be upset by the study. But thinking about the possibility of getting diabetes might make some people sad. **You may find out that some things in your life, like the food you eat, make you more likely to have diabetes in the future**.

If you are worried about this Andrew and your class leader can help you with this, and they can give you more advice about who to talk to, such as your doctor.

Contacting Andrew

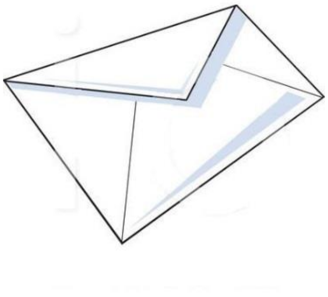
You or your carer can contact Andrew if you want to know more about the study.

Andrew’s phone number is: 0131 455 5679



Or you can write to Andrew.

His address is:



[redacted]
School of Nursing, Midwifery & Social Care
Edinburgh Napier University,
Sighthill Campus,
Sighthill Court.
Edinburgh
EH11 4BN

If you find it difficult to write, someone else can help you.

Or you can send Andrew an email.
His email address is:

[redacted]

You could also contact Andrew's director of studies, Professor Michael Brown. Michael's email address is

[redacted]

What happens if I want to complain or if I would like to speak to someone who is not a researcher on the study but knows about the study method?

You can contact Andrew's Independent Adviser. Her name is:

Barbara Neades

Her email address is:[redacted]

Appendix 9: Phase Three – Teaching/support staff information booklet

Walking Away Adaptation study

Background

People with learning disabilities are at higher risk of developing type 2 diabetes (T2D) than the general population. This is because they tend to have more risk factors, including obesity, difficulties with understanding and making choices about diet and lower levels of physical activity.

There is growing recognition that T2D does not just affect older adults, but also adolescents and young adults. Structured educational programs have successful been employed to reduce T2D risk factors in these age groups, however there are presently no programs developed for people with learning disabilities. This study therefore pilots the use of an existing mainstream T2D program, *Walking Away*, for adolescents with learning disabilities who are at risk of T2D, and will assess the feasibility of a larger trial through recruitment, participation in the program and drop-out rates.

Methods

Participants will be recruited from local higher education colleges and will attend education sessions totalling 3 hours, delivered by the researcher. During this, participants will identify their own risk factors through a *Walking Away* risk score identification tool and set personalized goals for increased daily walking and healthy dietary choices.

Participants will then try to increase their daily walking, using pedometers and keeping a record of this at certain points.

Carer support

As some participants will have higher support needs than others, additional support may be required to participate. It is anticipated that college attenders who bring a support worker may need additional support to participate.

Additional support would involve things like:

- **Help to understand the materials (these will already be adapted for people with learning disabilities but extra support may be required)**
- **Help to participate in the educational sessions (this may involve helping people to articulate and express themselves)**
- **Encouragement and reminders to do extra walking**
- **Help to record levels of walking**

Focus groups

We would also like to invite you to participate in two focus groups, in which the processes of taking part in the Walking Away program will be discussed. The first of these will comprise mainly of students and will be an opportunity for them to describe their experiences of being recruited, attending and participating in the program, and the use of pedometers. Your role in this group would be to support the students to reflect on their experiences and voice their opinions, where needed. The second focus group will comprise of teaching and support staff only. This will be your own opportunity to describe your experience of supporting the students to engage in all areas of the study, and also your opinions on the appropriateness of the program and its materials for students with additional support needs. Each focus group will take up to one and a half hours to complete. The focus group will be audio recorded. After the focus group has finished, the recording will be copied onto a computer and password protected. This will then be transcribed and analysed, and the findings may be published. Your name will be anonymised. A separate consent form will be given to you if you would like to take part in these focus groups.

The participants will be given a consent form to sign, which would show that they agree to participate in this study.

All data will be anonymised as much as possible and pseudonyms will be used so that, and it will not be possible for the participants to be identified in any reporting of the data gathered. All data collected will be kept in a secure place (specify e.g. locked cabinet in locked room/stored on a pc that is password protected) to which only the researcher (Andrew) has access. These will be kept till the end of the examination process, following which all data that could identify the participants will be destroyed.

If you have any questions or concerns about the study, Andrew (the researcher) can be contacted by phone:

[redacted]

In writing:

[redacted]
School of Nursing, Midwifery & Social Care
Edinburgh Napier University,
Sighthill Campus,
Sighthill Court.
Edinburgh
EH11 4BN

Or by email: [redacted]

You could also contact Andrew's director of studies, Professor Michael Brown for further information. Michael's email address is

[redacted]

What happens if I want to complain or if I would like to speak to someone who has impartial knowledge of the project?

You can contact Andrew's Independent Adviser. Her name is:

Barbara Neades

Her email address is: [redacted]

Appendix 10: Phase Three – People with ID consent form

Walking Away Adaptation Study

Consent form

I agree to be in the study:

YES ☐

NO☐

I have seen the information sheet about the study:

YES ☐ **NO☐**

I understand what it says:

YES ☐ **NO☐**

I had a chance to ask questions about it:

YES ☐ **NO☐**

I understand that if I do not want to take part in the study I do not have to:

YES ☐ **NO☐**

I understand that if I change my mind about wanting to be in the study I can stop whenever I want:

YES ☐ **NO☐**

I understand that the study will be audio recorded

YES ☐ **NO☐**

I understand that Andrew (the researcher) will not let anyone know who is in this study. He may write what I say and what I do and this might be read but other people, but no one will know it was me:

YES ☐ **NO☐**

I understand the information will be used in publications and I give my permission for this:

YES ☐ **NO☐**

I understand that my contact details and the information about what I say and do in this study will be stored safely, so that nobody else can see it and will be destroyed once this study is complete:

YES ☐ **NO☐**

I can phone Andrew if I want to know more about the study.
Andrew’s phone number is [redacted]

My signature Date

____ _________

Andrew’s signature

Date

My date of birth is: ______/________/________

You could also contact Andrew’s director of studies, Professor Michael Brown for more information. Michael’s email address is

[redacted]

What happens if I want to complain or if I would like to speak to someone who is not a researcher on the study but knows about the study method?

You can contact Andrew's Independent Adviser. Her name is:

Barbara Neades

Her email address is: [redacted]

Appendix 11: Phase Three – teaching/support staff consent form

Walking Away Adaptation Study

Consent form

I agree to be in the study:

YES ☐ **NO☐**

I have seen the information sheet about the study:

YES ☐ **NO☐**

I understand what it says:

YES ☐ **NO☐**

I had a chance to ask questions about it:

YES ☐ **NO☐**

I understand that if I do not want to take part in the study I do not have to:

YES ☐ **NO☐**

I understand that I can withdraw from the study at any point:

YES ☐ **NO☐**

I understand that the study will be audio recorded

YES ☐ **NO☐**

I understand that my name will be anonymised:

YES ☐ **NO☐**

I understand the information will be used in publications and I give my permission for this:

YES ☐ **NO☐**

I understand that my contact details and the information about what I say and do in this study will be stored safely, so that nobody else can see it and will be destroyed once this study is complete:

YES ☐ **NO☐**

I can phone Andrew if I want to know more about the study.
Andrew's phone number is [redacted]

My signature Date

_______________________________________ _________

Andrew's signature

Date

My address is: ______________________________________

____

____

My phone number is: ____________________________________

My date of birth is: ______/________/________

You could also contact Andrew's director of studies, Professor Michael Brown for more information. Michael's email address is

[redacted]

What happens if I want to complain or if I would like to speak to someone who is not a researcher on the study but knows about the study method?

You can contact Andrew's Independent Adviser. Her name is:

Barbara Neades

Her email address is:[redacted]

Appendix 12: Phase Three – All parties debrief sheet

Walking Away Study: Students' Debrief Sheet

What was this study all about?

Thank you for taking part in our study. The study was about using the **Walking Away from Diabetes Program** in college.
We wanted to find out what taking part in the program was like for you. This meant finding out how **easy or difficult** it was for you to take part, the things that you **liked about it**, and the things you **didn't like about it**.

We used the **focus groups** to help find out what you thought about it. We also looked at how you got on with using the pedometers, and what your health was like at the start.

The things you have told us will be very helpful because we can use them to work out **what changes need to be made** and **what could be better**, if more people would take part in the future.

Although it could take a long time, your answers will help people with diabetes in the future. Thank you again for taking part.

What if I'm worried about the risk of diabetes?

What happens if I am worried about diabetes, now that I have finished the study?

If you are worried about this Andrew and your class leader can help you with this, and they can give you more advice about who to talk to, such as your doctor.

What if I want to know more?

I can phone Andrew if I want to know more about the study.
Andrew's email is [redacted]

You could also contact Andrew's director of studies, Professor Michael Brown for further information. Michael's email address is

[redacted]

What happens if I want to complain or if I would like to speak to someone who has impartial knowledge of the project?

You can contact Andrew’s Independent Adviser. Her name is:

Barbara Neades

Her email address is: [redacted]

Appendix 13: Ethical approval letter

26th April 2016

Dear Andrew

Project Title: Adaption of the Walking Away Type 2 Diabetes Prevention Program for People with Intellectual Disabilites: a two stage Feasibility and Acceptability Study
Project start dateSeptember 2016
Project reference: *FHLSS/1647* ***Version no***. *1*

Further to your application for Ethical approval to undertake a research study at Edinburgh Napier University, I am pleased to inform you that the committee have approved your application and we wish you all the best with your study.

May I remind you of the need to apply to the Research Integrity Committee prior to making any amendments to this study or of any changes to the duration of the project and provide notification of study completion. All documents related to the research should be maintained throughout the life of the project, and kept up to date at all times.

Please bear in mind that your study could be audited for adherence to research governance and research ethics.

Yours sincerely,

[redacted]

Dr. Barbara Neades
Chair

3 May 2017

Dear Andrew

Project Title: Adaption of the Walking Away Type 2 Diabetes Prevention Program for People with Intellectual Disabilities: a two stage Feasibility and Acceptability Study. Stage 2: Amendment to previously approved study (FHLSS/1647, approved on 26/4/16)
Project start date: *September 2016*
Project reference: *FHLSS/1783* **Version no**. *3*

Further to your application for Ethical approval to undertake a research study at Edinburgh Napier University, I am pleased to inform you that the committee have approved your application and we wish you all the best with your study.

May I remind you of the need to apply to the Research Integrity Committee prior to making any amendments to this study or of any changes to the duration of the project and provide notification of study completion. All documents related to the research should be maintained throughout the life of the project, and kept up to date at all times.

Please bear in mind that your study could be audited for adherence to research governance and research ethics.

Yours sincerely,

[redacted]

Dr. Barbara Neades
Chair

Appendix 14: INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the last 7 days. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the vigorous and moderate activities that you did in the last 7 days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal.

PART 1: JOB-RELATED PHYSICAL ACTIVITY

The first section is about your work. This includes paid jobs, farming, volunteer work, course work, and any other unpaid work that you did outside your home. Do not include unpaid work you might do around your home, like housework, yard work, general maintenance, and caring for your family. These are asked in Part 3.

1. Do you currently have a job or do any unpaid work outside your home?

Yes

No Skip to PART 2: TRANSPORTATION

The next questions are about all the physical activity you did in the last 7 days as part of your paid or unpaid work. This does not include traveling to and from work.

2. During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, heavy construction, or climbing up stairs as part of your work? Think about only those physical activities that you did for at least 10 minutes at a time.

_____ days per week

No vigorous job-related physical activity Skip to question 4

3. How much time did you usually spend on one of those days doing vigorous physical

activities as part of your work?

_____ hours per day

_____ minutes per day

4. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do moderate physical activities like carrying light loads as part of your work? Please do not include walking.

_____ days per week

No moderate job-related physical activity Skip to question 6

5. How much time did you usually spend on one of those days doing moderate physical activities as part of your work?

_____ hours per day

_____ minutes per day

6. During the last 7 days, on how many days did you walk for at least 10 minutes at a time as part of your work? Please do not count any walking you did to travel to or from work.

_____ days per week

No job-related walking Skip to PART 2: TRANSPORTATION

7. How much time did you usually spend on one of those days walking as part of your work?

_____ hours per day

_____ minutes per day

PART 2: TRANSPORTATION PHYSICAL ACTIVITY

These questions are about how you traveled from place to place, including to places like work, stores, movies, and so on.

8. During the last 7 days, on how many days did you travel in a motor vehicle like a train, bus, car, or tram?

_____ days per week

No traveling in a motor vehicle Skip to question 10

9. How much time did you usually spend on one of those days traveling in a train, bus, car, tram, or other kind of motor vehicle?

_____ hours per day

_____ minutes per day

Now think only about the bicycling and walking you might have done to travel to and from work, to do errands, or to go from place to place.

10. During the last 7 days, on how many days did you bicycle for at least 10 minutes at a time to go from place to place?

_____ days per week

No bicycling from place to place Skip to question 12

11. How much time did you usually spend on one of those days to bicycle from place to place?

_____ hours per day

_____ minutes per day

12. During the last 7 days, on how many days did you walk for at least 10 minutes at a time to go from place to place?

_____ days per week

No walking from place to place Skip to PART 3: HOUSEWORK,

HOUSE MAINTENANCE, AND CARING FOR FAMILY

13. How much time did you usually spend on one of those days walking from place to place?

_____ hours per day

_____ minutes per day

PART 3: HOUSEWORK, HOUSE MAINTENANCE, AND CARING FOR FAMILY

This section is about some of the physical activities you might have done in the last 7 days in and around your home, like housework, gardening, yard work, general maintenance work, and caring for your family.

14. Think about only those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, chopping wood, shoveling snow, or digging in the garden or yard?

_____ days per week

No vigorous activity in garden or yard Skip to question 16

15. How much time did you usually spend on one of those days doing vigorous physical activities in the garden or yard?

_____ hours per day

_____ minutes per day

16. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do moderate activities like carrying light loads, sweeping, washing windows, and raking in the garden or yard?

_____ days per week

No moderate activity in garden or yard Skip to question 18

17. How much time did you usually spend on one of those days doing moderate physical activities in the garden or yard?

_____ hours per day

_____ minutes per day

18. Once again, think about only those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do moderate activities like carrying light loads, washing windows, scrubbing floors and sweeping inside your home?

_____ days per week

No moderate activity inside home Skip to PART 4: RECREATION,

SPORT AND LEISURE-TIME

PHYSICAL ACTIVITY

19. How much time did you usually spend on one of those days doing moderate physical activities inside your home?

_____ hours per day

_____ minutes per day

PART 4: RECREATION, SPORT, AND LEISURE-TIME PHYSICAL ACTIVITY

This section is about all the physical activities that you did in the last 7 days solely for recreation, sport, exercise or leisure. Please do not include any activities you have already mentioned.

20. Not counting any walking you have already mentioned, during the last 7 days, on how many days did you walk for at least 10 minutes at a time in your leisure time?

_____ days per week

No walking in leisure time Skip to question 22

21. How much time did you usually spend on one of those days walking in your leisure time?

_____ hours per day

_____ minutes per day

22. Think about only those physical activities that you did for at least 10 minutes at a time.

During the last 7 days, on how many days did you do vigorous physical activities like aerobics, running, fast bicycling, or fast swimming in your leisure time?

_____ days per week

No vigorous activity in leisure time Skip to question 24

LONG LAST 7 DAYS SELF-ADMINISTERED version of the IPAQ. Revised October 2002.

23. How much time did you usually spend on one of those days doing vigorous physical activities in your leisure time?

_____ hours per day

_____ minutes per day

24. Again, think about only those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do moderate physical activities like bicycling at a regular pace, swimming at a regular pace, and doubles tennis in your leisure time?

_____ days per week

No moderate activity in leisure time Skip to PART 5: TIME SPENT

SITTING

25. How much time did you usually spend on one of those days doing moderate physical activities in your leisure time?

_____ hours per day

_____ minutes per day

PART 5: TIME SPENT SITTING

The last questions are about the time you spend sitting while at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading or sitting or lying down to watch television. Do not include any time spent sitting in a motor vehicle that you have already told me about.

26. During the last 7 days, how much time did you usually spend sitting on a weekday?

_____ hours per day

_____ minutes per day

27. During the last 7 days, how much time did you usually spend sitting on a weekend

day?

_____ hours per day

_____ minutes per day

This is the end of the questionnaire, thank you for participating

Appendix 15: Self-efficacy for leisure physical activity questionnaire

Paterson et al. (2009) for PWID

Appendix 1: Total Item Pool

Table A1 Self-efficacy for leisure physical activity

1. Do you think that you can make time for physical activities almost everyday?
2. Do you think that you can do physical activities even when someone important in your life wants you to spend more time with them?
3. Do you think that you can do physical activities even when you are very busy?
4. Do you think that you can do physical activities even when you are feeling sad or depressed?
5. Do you think that you can do physical activities even after a long, hard day at work?
6. Do you think that you can do physical activities on days when you are tired or don’t have much energy?
7. Do you think you can do physical activities when you feel lazy?
8. Do you think you can do physical activities by yourself when you can’t find other people to do them with?
9. Do you think you can find a place to do physical activities if you don’t have a ride when you need one?

Table A2 Social support from family for leisure physical activity

1. Does anyone in your family remind you to do physical activities?

2. Does anyone in your family do physical activities with you?

3. Does anyone in your family plan physical activities when you spend time with them?

4. Does anyone in your family show you how to do physical activities?

5. Does anyone in your family tell you that you are good at physical activities?

6. Does anyone in your family pay for you to do physical activities somewhere or buy you things that you need to do physical activities?

7. Does anyone in your family drive you somewhere to do physical activities when you need them to?

8. Does anyone in your family tell you not to do physical activities?

9. Does anyone in your family tell you that physical activities will hurt you?

10. Does anyone in your family tell you that you are bothering them when you do physical activities?

11. Does anyone in your family ever tease or make fun of you when you do physical activities?

Table A3 Social support from staff for leisure physical activity

1. Does your staff remind you to do physical activities?

2. Does your staff do physical activities with you?

3. Does your staff plan physical activities for you, or help you to plan physical activities?

4. Does your staff show you how to do physical activities?

5. Does your staff tell you that you are good at physical activities?

6. Does your staff pay for you to do physical activities somewhere or buy you things that you need to do physical activities?

7. Does your staff drive you somewhere to do physical activities when you need them to?

8. Does your staff tell you not to do physical activities?

9. Does your staff tell you that physical activities will hurt you?

10. Does your staff tell you that you are bothering them when you do physical activities?

11. Does your staff ever tease or make fun of you when you do physical activities?

Table A4 Social support from roommates for leisure physical activity

1. Do any of your roommates remind you to do physical activities?

2. Do any of your roommates do physical activities with you?

3. Do any of your roommates ask you to do physical activities with them, or is it ever their idea?

4. Do any of your roommates show you how to do physical activities?

5. Do any of your roommates tell you that you are good at physical activities?

6. Do any of your roommates pay for you to do physical activities somewhere or buy you things that you need to do physical activities?

7. Do any of your roommates drive you somewhere to do physical activities when you need them to?

Appendix 16: Phase Three – People with ID focus group guide

Walking Away from Diabetes Feasibility study: LD Student and Teacher/support Staff Focus Group Guide

Section 1: Questions about the study process

Q: What did you think about the process of being asked to take part?

Prompts:

- Do you remember the forms I gave you to sign at the beginning of the study? Were they easy to understand or did you need some extra help?
- Did you feel like it was up to you whether or not you part? Was there anything that made you feel like you had to take part?
- Do you feel like you could stop taking part in the study if you wanted to? Did anyone want to stop taking part?
- Do you remember when I talked about keeping your names a secret? Did everyone feel ok about talking about themselves in the study? Was anyone worried about what people would think of their answers?
- Did you find it helpful when I visited to tell you about the study?

Section 2: Questions about the education sessions

Q1: What did you think of the overall delivery of the Walking Away program?

Prompts:

- Did you enjoy the sessions?
- Was the length of the sessions OK? Do you think they have been longer or shorter?
- Were they easy or difficult to understand? Why?
- Do you think you will remember them?
- Were you able to ask questions throughout the sessions? Did you have your questions answered?
- What did you think of the educator? Were they knowledgeable?

Q2: What did you think about the content of each of the sessions?

Prompts

- What did you like best?
- Was there anything you did not like?
- Do you have any suggestions on how it could be improved?
- Do you remember learning about blood glucose?
- How did you find it to learn about this?
- Was it easy or difficult to understand?
- What do you think of the magnetic man? (*magnetic board and parts so show anatomy and 'rusty key' analogy for describing insulin resistance*).
- What did the rusty key tell you about diabetes?
- How did you find it to think about your own health risks? Were the magnets helpful? In what way?
- Do you remember the balancing story? (*Activity using overloaded tray to demonstrate risk factors*). What did this tell you about risks?
- Do you remember learning about ways to increase physical activity? Was it helpful to talk about making your own plans for walking? Can anyone give any examples of plans that worked really well? Did anything get in the way? Did you find a way to deal with this?
- Do you remember learning about food choices? Can you remember the types of fats we talked about? Has anyone been looking at labels on food when they go shopping or making

Section 3: Questions about the study materials

Q1: Did you enjoy using the pedometers?

Prompts

- What did you like best about wearing the pedometers?
- Was there anything you didn't like about the pedometers? Did you have any difficulties with them?
- Could you open and close them?
- Could you read the display?

Q2: How did you find answering the questionnaires?

Prompts

- Were they difficult or easy to understand? Why?
- Were there any questions you didn't like?
- Was there anything you didn't think should have been included?

Are there any other comments that you would like to make about any of the areas we have talked about today?

Appendix 17: Phase Three – Teaching/support staff focus group guide

Walking Away from Diabetes Feasibility study: Teacher/support Staff Only

Focus Group Guide

Section 1: Questions about the study process

Q: What did you think about the recruitment process?

Prompts:

- Were the information sheets clear? Was there anything you would have changed?
- Did the students seem to understand that participation was optional? Did they feel they could stop participating at any point?
- Did the students seem to understand confidentiality?

Section 2: Questions about the education sessions

Q1: What did you think of the overall content of the Walking Away program?

Prompts:

- Do you think the students enjoyed the sessions?
- Was the language and supporting visuals appropriate for the students' level of understanding and age?
- Do you think the students' knowledge of diabetes, physical activity and reducing saturated fats has improved overall?
- Do you think the students will remember what they have learned?
- Is there anything that you feel should have been included that wasn't?

Q2: What did you think about each of the sessions?

Prompts

- Do you think that overall the students understood what they were told about blood glucose?
- Were the analogies, such as the rusty key and balancing tray, appropriate for the student's level of understanding and age?

- Was the individual goal setting helpful? Were the students able to do this independently, or was additional support required?
- Do you think the students intend to modify their lifestyles in terms of diet and exercise following this program?
- If so do you think they will sustain this motivation? What sort of barriers are they likely to face?

Section 3: Questions about the study materials

Q1: How did you experience supporting the students to wear and use the pedometers?

Prompts

- Did the students have any difficulties with them, beyond those discussed in the previous focus group?
- Is there something which would work better for them?
- Do you think the experience of being given a pedometer to use helped the students to engage with the study?

Q2: How did you find supporting the students to answer the questionnaires?

Prompts

- Were they difficult or easy to understand? Why?
- Were there any questions you didn't like?
- Was there anything you didn't think should have been included?

Appendix 18: Participant demographics raw data

Participant number	Age	Gender	Height (CM)	Weight (KG)	BMI	Waist (CM)
1	21	Male	172	93	31.4 Obese	112
2	19	Male	178	102	32.1 Obese	116
3	19	Female	158	101	40.4 Obese	119
4	19	Female	148	68	31 Obese	100
5	19	Male	180	115	35.4 Obese	143
6	22	Male	162	60.7	23.1 Healthy weight	100
7	19	Male	158	74.4	29.8 Overweight	101
8	19	Male	178	77	24.3 Health weight	101
9	22	Male	178	95	29.9 Overweight	110
10	18	Female	156	53	21.7 Healthy weight	80
11	18	Male	171	53.4	18.2 Underweight	76
12	22	Male	173	108	36 Obese	108
13	21	Male	184	142	41.9 Obese	132
14	18	Female	174	100	33 Obese	103
15	23	Female	153	105	44.8 Obese	130
16	19	Female	150	90	40 Obese	102
17	25	Female	169	104	36.4 Obese	103
18	26	Male	180	64	19.7 Health weight	100
19	22	Female	174	74	24.4 Healthy weight	63
20	18	Male	177	74	23.6 Healthy weight	104

21	21	Female	145	69	32.8 Obese	96
22	21	male	168	82	29 Overweight	104
23	20	Male	191	120	33.8 Obese	111
24	18	Female	164	120	44.6 Obese	120
25	18	Male	175	55	17.9 Underweight	72
26	19	Female	146	55	25.8 Overweight	85
27	18	Male	167	75	26.8 Overweight	91
28	19	Male	182	120	36.2 Obese	124
29	19	Male	180	85	26.2 Overweight	85
30	18	Male	176	60	19.3 Healthy weight	90
31	18	Female	162	52	19.8 Healthy weight	71
32	18	Male	165	70	25.7 Overweight	92
33	19	Male	176	72.5	23.4 Healthy weight	72
34	19	Male	171	82	28 Overweight	95
35	20	Male	173	65	21.7 Healthy weight	79
36	19	Female	168	75	26.5 Overweight	161
37	21	Male	176	74	23.8 Healthy weight	96
38	19	Male	167	45	16.1 Underweight	79
39	16	Male	185	88	25.7 Overweight	54
40	18	Female	160	50	19.5 Healthy weight	18
41	21	Male	179	70	21.8 Healthy weight	86
42	44	Female	155	85	35.5 Obese	106
43	19	Male	183	124	37 Obese	122
44	29	Female	67	101	224.9 Obese	120
45	27	Male	184	71	20.9 Healthy Weight	90
46	20	Female	172	61	20.6 Healthy Weight	77
47	39	Female	148.5	64	29 Overweight	89
48	19	Male	165	75	27.5 Overweight	62

Appendix 19: International physical activity questionnaire raw data (single site)

											Total MET	
Particpant	Question			MET			MET			MET	Total MET PW	SCORE
	1	2: Vig days	3: Vig mins		4: mod days	5: mod min		6: Walk days	7: Walk mins			
1	Yes	3	30	720	3	20	240	3	30	297	1257	MODERATE
2	Yes	3	20	480	4	30	480	3	10	99	1059	MODERATE
3	Yes	3.5	30	840	3	9	108	1	10	33	981	MODERATE
4	Yes	3	15	360	3	20	240	1	20	66	666	MODERATE
5	Yes	3	40	960	3	30	360	1	30	33	1353	MODERATE
6	Yes	3	20	480	3	20	240	3	30	99	819	MODERATE
7	Yes	3	20	480	3	10	43	3	10	99	1582	MODERATE
8	Yes	3	15	360	3	30	360	1	20	66	786	MODERATE
9	Yes	3.5	10	280	3	30	360	3	30	297	937	MODERATE
10												
11	Yes	0	0		4	40	640	1	30	99	739	MODERATE
12	Yes	0	0		4	50	800	2.5	10	82.5	882.5	MODERATE
13	Yes	0	0		4	30	480	4	40	528	1008	MODERATE
14	Yes	0	0		4	30	480	4	60	792	1272	MODERATE
15	Yes	0	0		4	40	640	1	50	165	805	MODERATE
16	Yes	0	0		3	20	240	3	20	198	438	LOW
17	Yes	0	0		3	20	240	3	40	396	636	MODERATE
18	Yes	0	0		3	30	360	0	0	0	360	LOW
19	Yes	0	0		3	10	120	0	0	0	120	LOW
20	Yes	0	0		3	30	360	1	20	67	427	LOW
21	Yes	0	0		3	20	240	3	45	445.5	685.5	MODERATE
22	Yes	0	0		3	15	180	3	20	198	378	LOW
23	Yes	0	0		1	30	120	3	30	297	417	LOW
24	Yes	0	0		1	30	120	4	30	396	516	LOW
25	Yes	0	0		4	30	480	3	15	148.5	628.5	MODERATE
26	Yes	0	0		3	20	240	3	15	148.5	388.5	LOW

Appendix 20: Ambulatory activity raw data

Table 4: Ambulatory activity

Site A (*N*=12)	24/10/16		7/11/16		21/11/16		5/12/16		9/1/17	
	Days recorded	Mean Steps	Days recorded	Mean Steps	Days recorded	Mean Steps	Days recorded	Mean Steps	Days recorded	Mean Steps
Participant 1	3	4228.5	3	1714	2	5948	2	4397	0	0
Participant 2	3	6307	3	3693.5	2	4656	2	5063	0	0
Participant 3	1	1553	3	1675	1	5919	0	0	3	2890
Participant 4	3	9212	2	3284	2	7949	0	0	1	9464
Participant 5	0	0	2	11839	0	0	0	0	0	0
Participant 6	1	485	3	8820	0	0	2	5455.2	2	3540.5
Participant 7	3	9088.75	2	5313.5	2	8920	3	8405	2	7738
Participant 8	0	0	3	11074	0	0	0	0	0	0
Participant 9	1	5354	3	2785	0	0	2	7214	2	5060

Participant 10	3	5771	3	8277.5	2	7556	3	5967	3	4888
Participant 11	2	766	3	5024	2	7023	3	2135	3	2981
Participant 12	2	5444	3	5038	2	6701	3	6023	3	6743
Mean (SD)	1.83 (1.19)	4017.4 (3388.3)	2.75 (0.45)	5711.5 (3495.9)	1.25 (0.96)	4556 (3530.1)	1.7 (1.3)	3721.6 (3128.3)	1.58 (1.58)	3608.7 (3273.9)

Site B (*N*=10)	24/10/16	
	Days recorded	Mean Steps
Participant 1	3	5067
Participant 2	3	4055
Participant 3	3	8999
Participant 4	3	4340
Participant 5	2	3099
Participant 6	3	6612
Participant 7	3	3096
Participant 8	3	4675
Participant 9	3	9002
Participant 10	2	5670
Mean (SD)	2.8 (0.42)	5461.5 (2150)

Appendix 21: Student focus group thematic analysis stage one and two

Focus Group 1: Edinburgh College Students

Facilitator: Andrew Maine

Participants (psuedeonyms): Ali, Emily, Arran, Beth, Neil, Kerry, Steven, David, Carer (non-participatory)

AM: There were lots of different parts of the study really, and we're gonna go through each of those. But first of all we're gonna try and have a little exercise, just to get people talking. And this is going to be about celebrities. What we're gonna do is, over here we're gonna put some pictures of some famous people. [Lays out selection of celebrity photos on table] OK? And then I want everyone to come around and choose one. And.. what I want you to do afterwards – we're gonna have a chat and you can hopefully tell me something that you don't like about the person that you've chosen. And if that's too difficult you can just say something that you do like. If you can do both, even better [Participants select photos]

AM: Did everyone get one?

Several Participants: Yes.. yes.

AM: So who have we got – who do you have Kerry, you're smiling?

Kerry: I think I've got Ronaldo

15) **AM:** Ronaldo

16) **Kerry:** Yes

17) **AM:** You've got a big grin about Ronaldo

18) **Kerry:** Oh aye

19) You're a big fan of Ronaldo?

20) **Kerry:** Yes. I've got a picture of him cos I went to Portugal, um for 2 weeks. And I just came back from my holidays and I'm a big fan of him

21) **AM:** Excellent

22) **Kerry:** And there's a picture of him there cos it's his shop, cos he is famous, so I've just got a picture of him, I've got it in my home

23) **AM:** does.. is there anything you don't like about Ronaldo?

24) **Kerry:** There's not a lot I don't think! [laughs]

25) **AM:** Does anyone not like Ronaldo?

26) **Ali:** I like him – I like Ronaldo [general assent from group]

27) **AM:** He's a hard man not to like. What about someone else?

28) **Ali:** May I please go next?

29) **AM:** sure

30) **Ali:** I've got a singer..

31) **AM:** Aha. And what's his name?

32) **Ali:** His name's Drake and he's a rapper and he's from Toronto, Ontario in Canada

33) **AM:** Aha so you know lots about him. What do you like about Drake?

34) **Ali:** He's got almost the same skin colour as me. And he's done a lot of songs and he's been in the charts. And I went to see him in Glasgow one day

34) **AM:** Oh did you? Excellent. So is there anything you don't like?

35) **Ali:** No he’s alright I would say. He’s better than Eminem.

36) **AM:** Better than Eminem? I think lots of people would agree with you there. What about you Emily?

37) **Emily:** I’ve got Simon Cowell.

38) **AM:** Simon Cowell.

39) **Emily:** He’s got a sense of humour

40) **Ali:** And he says, “it’s a no from me” [group laughs]

41) **AM:** Good impression Ali! Does everyone like Simon Cowell?

42) **Ali:** Nah. Cos he’s like..

43) **Emily:** He’s OK..

44) **Kerry:** He’s OK..

45) **Arran:** Some people don’t like him.

46) **AM:** Why do you think that is?

47) **Arran**: There must be a reason

48) **AM:** Did you have a reason Emily?

49) **Emily:** He can be a bit mean

50) **AM:** He can be a bit mean [several agree]

51) **Ali:** And he can kick people off the stage

52) **AM:** Anyone else find him a bit mean?

53) **David:** I do. He’s quite opinionated isn’t he?

54) **AM:** Do you think that makes him good at his job?

55) **David:** I think it’s good and bad for him

56) **AM:** Mm. I guess you’d have to have some strong opinions to-

57) **David**: - Be a judge, yeah.

58) **AM**. And who did you have Beth?

59) **Beth:** Is that from Coronation street?

60) **Ali:** Let's see. I think – EastEnders I think.

61) **Kerry:** No that's Coronation street

62) **AM**: I think she's from Coronation street. I wasn't sure who she was but I picked her in case anyone was a soap fan

63) **Beth:** Yeah. Cos I like all the soaps me. Can't think of her name though

64) **AM:** Can't think of her name. But can you think of the character? [nods] Is she a good character?

65) **Beth:** She was, aye. But she's not in it anymore.

66) **AM:** She's not in it anymore?

67) **Beth**: I think she died. Did she die, Kerry?

68) **Kerry:** Aye I think she did, aye she died.

69) **AM:** What about you Arran, who did you have?

70) **Arran:** Uh it's the man, Will Smith

71) **AM:** The man, Will Smith, yeah. So what do you like about him?

72) **Arran**. He's been in a lot of good movies.. He's funny

73) **AM:** He's funny and does he rap?

74) **Arran:** yeah

75) **AM**: So who's a better rapper? Him or Drake?

76) **Ali:** I would suggest Drake's more better. But Will Smith doesn't really rap anymore now. He's just doing comedy films

77) **Kerry**: Aye he does.

78) **Arran:** I think he does still rap

79) **AM:** I saw him rapping on the Graham Norton show

80) **Kerry**: Aye

81) **AM:** He’s pretty old-school though isn’t he

82) **Kerry:** Aye [laughs]

83) **AM:** Who else?

84) **Ali:** Neil?

85) **AM:** Neil? [Neil hold up card]

86) **Ali:** Mr. Styles

87) **Neil**: Harry Styles

88) **Kerry:** That’s.. He’s my.. I’ve got a lot of him [several voices at once]

89) **AM:** So do you prefer him as a celebrity to Ronaldo?

90) **Kerry:** Yeah obviously I like Ronaldo, and Harry. But it’s hard to pick

91) **AM**: So they’ve got different qualities

92) **Kerry:** I’d probably just stick with Ronaldo [laughs]

93) **AM:** And.. Steven, who did you have?

94) **Steven:** David Beckham.

95) **AM:** Are you a fan?

96) **Ali:** He’s too old to be a footballer, he’s retired

97) **Steven:** I liked him when he used to play football do you know what I mean, but now he doesne do anything. He doesnae really bother me, like I say I used to like him when he used to play football and that do you know what I mean?

98) **AM:** Yeah. Does everyone feel the same about David Beckham now, is he-

99) **Ali:** How old is he?

100) **Steven:** He’s 42. 43, 42, something like that.

101**) AM:** So he’s getting on a bit? Not quite in his prime maybe?

102) **Steven**: No.

103) **AM:** And. David?

104) **David:** Yeah I've got David Craig.

105) **AM:** Daniel Craig? You're a big fan?

106) **Ali**: Is he the guy that played James Bond?

107) **AM:** Does anyone else think that there's a bit of a passing resemblance between David and Daniel Craig there?

108) **David:** [laughs] Do you think?

109) **AM:** Yeah you should get the tuxedo!

110) **Ali**: Can I ask a question is a James Bond a person or is Daniel Craig James Bond?

112) **AM**: Daniel Craig is his real name, James Bond is the character.

113) **Ali**: That should've been his real name.

114) **AM**: OK so we'll have to wrap up this part of the conversation so we can move on to the other bit, cos we're bit pushed for time. But, did you find it easier to talk about thinks that you liked or that you didn't like?

115) [general agreement]

116) **Steven**: Things you liked

117) **Ali**: Yeah, cos everyone's different to be honest. Cos Neil, you like One Direction, Steven, you're into Football, Kerry, you're into Taylor Swift and Justin Timberlake

118) **AM**: Good, so you've summed it up really well Ali, so we all like different things. And sometimes it's harder to find things that we don't like than things that we do. So for the rest of what we're going to talk about, I want you to try and remember the sessions and talk about the things you liked and didn't like as well. And as Ali was saying, there'll maybe be things that some people like and other things that people don't like cos we're all different

119) **Ali**: Can I go to the toilet please?

120) Yeah sure Ali, We'll carry on OK but you can come back and join in. OK, so the first bit is about the overall study process. And that's been about the recruitment. So, even just today you've had me come in and ask you if you wanted to be a part of the focus group. And I've come in and I've.. disrupted your day a bit really [group laugh] haven't I, cos you would've been doing something else.. How's that been – would you rather have been having your lesson?

121) **Steven**: No.

122) **AM:** Why's that?

123) **Steven**: Borin'

124) **AM:** so has it been good to have something different going on?

125) **Steven**, Kerry and Emily: Yea, uh huh

126) **AM**: Does anyone mind being asked to do this stuff of find it a bit of a pain? And I don't mind, I've got a thick skin.. [no response] Did anyone feel like they had to take part or that they felt pressured to take part.

127) **Arran**: No, I knew that I didn't have to take part, if I didn't want to take part.

128) **AM:** OK. Did everyone else feel the same, that they felt they didn't have to take part like Arran? Did you feel the same

129) **David**: Yeah.

130 **AM:** What about you Beth?

131) **Beth**: Yeah.

132) **AM**: OK. And did you know. Because the study's been going on since September, did everyone realise that they could stop taking part at anytime?

133) **David**: No I didn't realise that.

134) **AM:** Did anyone else feel like that?

135) **Ali**: I didn’t know you could stop taking part

136) **AM**: OK. So that’s maybe something that needs to be a bit clearer then. Cos I think we had that on the original consent forms at the beginning of the year, but do you think there should have been more reminders?

137) **David**: Yeah

138) **AM:** OK. Well that’s good to know. Did everyone understand about your names being kept secret? Did everyone understand that-

139) **Ali**: What names?

140) **AM**: So when you gave your name to take part in the study, as we were talking about before with the forms that you signed, we’ll change your name so that the people who see the study won’t know it was you

141) **Ali**: Is it because it’s got some private information in it?

142) **AM**: well it might do – there might be some information that you don’t want other people to know came from you. So that’s why we make stuff anonymous. Do people know what I mean by anonymous?

143) **David**: Means no one knows like who you are or that.

144) **AM**: So did that make sense before taking part in the study?

145) **Ali**: It’s a bit of a tricky question

146) **AM**: Would you say that’s easy or difficult to understand then?

147) **David**: Probably easy

148) **AM**: Easy for you David

149) **Steven**: I find it a bit difficult

150) **AM**: Wee bit difficult for you Steven, OK. And then the last one about the recruitment stuff, so I came along, particularly before today, and I’ve got to know some of you a bit. Do you think that’s been helpful?

151) **Steven**: Yeah

152) **AM**: Not just for talking today, but for all of the sessions I'd got to know some of you a bit. Because we did the questionnaires. Was it helpful that I came along and met you first? [general agreement]

153) **AM**: Any ideas about why that might be?

154) **Ali**: Just to give us some ideas

155) **AM:** Just to give you some ideas?

156) **Steven**: Of what you're like and that

157) **Ali**: And what your diagnosis was and if you're a diabetic or something like that

158) **AM**: Ok. So when you were learning about it – do you mean you found it easier to understand because you knew me a bit?

159) **Ali**: Yeah.

160) **AM:** OK. Well, thinking about that for a minute, so I've come along and done this as someone who's not a teacher. Would it be easier then – the course that we did – would it have been easier if it was taught by your own teachers cos they've known you a longer time?

161) **Steven**: No.

162) **AM**: No from Steven – why's that then do you think?

163) **Steven**: Cos you've got a better understanding of it than Fran and Sasha and the other teachers

164) **AM**: OK well, do you think that's something they could go away and learn though?

165) **Steven**: Well, they've got their own job here, do you know what I mean? It could be a bit hard for them

166) **AM**: Sure. What about if it became part of their job to learn some of this stuff – would that be a good thing?

167) **Steven**: Definitely yeah it would be [Ali agreeing] good if they could

168) **AM**: Would everyone else agree with that? Because to be fair I think some of the stuff, in fact most of the stuff they knew quite a lot about already, like the diet choices, the physical activity, do you think you've learned some of that in your other classes?

169) **Ali**: In the other classes – is it learning about the past and that?

170) **AM**: Learning about history do you mean?

171) **Ali**: Yeah

172) **AM:** Well I was just thinking about the other classes you've been to where you've learned about health living and diet choices, and physical activity. Do think you've – does everyone remember learning about that stuff before? …Are we not too sure?

173) **David**: I do

174) **AM**: You do David. OK. So, that was really about the recruitment process and everything, so we'll move on to the actual sessions that we had. So we had 4 sessions, does everyone remember those?

175) **Ali**: Yeah

176) **AM**: Did you enjoy them?

177) **Ali**: Mm they were OK

178) **AM**: OK? Again, you can be as honest as you like. If you found them at all boring, I don't mind, because it's not about me, it's about how they were designed, if you like. So you thought they were OK Ali?

179) **Ali**: They were OK, when you practiced it made perfect

180) **AM**: When you practiced it? Tell me more about that – what do you mean by practiced it?

181) **Ali**: By practicing using the pedometers and then they were perfect

182) **AM**: OK. So the more you wore those

183) **Ali**: **-** The more steps you did

184) **AM**: OK. And what about the actual lessons when I was standing up there..

185) **Ali**: They were quite brilliant, cos you learned all about your body, and hoping not to die, and how you can keep on doing regular exercise and stuff

186) **AM**: OK. Anyone else? Was there anything you weren't too sure about? Anything you found difficult to follow or a bit boring maybe? No? Was there anything anyone was worried about before the started?

187) **Steven**: In case I got it

188) **Kerry**: I'm the same – I'm the same as Steven

189) **AM**: OK So you were both a bit worried that you'd get diabetes if you did the course?

190) **Kerry**: So for me the difficulty was going to be like, hearing it and then like, hearing that I was the same

191) **AM:** OK. So was it that you were worried about finding out more?

192) **Kerry**: Aye

193) **Steven**: Aye. In case you found out something that you had

194) **AM**: Did anyone else feel worried like that? No? How about you Beth? [Shakes head]

195) **AM:** So with that in mind, cos one part of it was doing the risk factors – and that was when we looked at people's different risk factors – so the things about

themselves which might be a diabetes risk later on? Cos I'm not sure but I think for you [Kerry] you found that you didn't have that many factors. So did that –

196) **Kerry**: Well for me I was worried cos I've got epilepsy. That's why I was worried. Cos I've got epilepsy. I take seizures. Cos I had one on Saturday. I've been taking quite a lot of them – had one last week. So that was why I felt a bit uncomfortable doing it

197) **AM**: Mm. Did it make sense that you seizures and the symptoms you had weren't the-

198) **Kerry**: -it's cos I had seizures, two different kinds. It's been a whole different world – it's just hard.

199) **AM**: Yeah. What kind of seizures do you have?

200) **Kerry**: Sometimes it's like the weather, or like I'm not sleeping very well or not drinking enough. And that's why I'm taking medications and I'm wearing a bandage cos it's really sore

201) **AM**: That sounds really tough. And so were you worried about more things going wrong on top of that

202) **Kerry**: uhuh, yeah, that's what I was starting to feel like.

203) **AM**: OK. That's understandable. And you, Steven, you were a bit worried about..

204) **Steven**: In case I got it – that's why I didn't want to do it at first

205) **AM**: So when you say in case you got it do you mean, in case you found out that you might have it?

206) **Steven**: Mm in case I found out more about it

207) **AM**: So it's more like there might be a diagnosis for it. And you said "at first" – was there something that changed along the way that made it feel a bit easier for you?

208) **Steven**: Just like, talking about it and things like that, know what I mean?

209) **AM**: Just talking about it. And any of the stuff you learned – do you think that helped you to understand it better? Did understanding it make it easier to not worry about it?

210) **Steven**: Yeah

211) **AM**: And no worries with you David?

212) **Steven**: No

213) **AM**: OK. So on the whole, do you think the sessions were easy enough to understand or were some bits difficult?

214) **Ali**: I think that there were some bits which were very very ultra hard

215) **AM**: Ok, which bits would you say were really ultra hard?

216) **Ali**: Mmm.. I can't remember to be honest with you

217) **AM:** Ok. Well we'll go through some of the materials in a bit and maybe you can tell me if there were any bits that you found hard. Is anyone else remembering stuff feeling a bit too difficult? [No answer] No? Cos it seemed at the time like everyone was understanding quite well, cos everyone was joining in, and lots of good questions and answers along the way… Do you think you'll remember the stuff that we talked about? [General assent] Yeah? So there's not going to be a test, don't worry, but if I did come back, you know, in a year's time or something, and asked you questions do you think you'd still be able to answer them then?

218) **David**: Yeah

219) **AM**: Same for everyone?

220) **Ali** (and others) yeah

221) **AM**: That’s great. And you’ve said you felt like I’d had enough training for it. Does everyone feel like I had enough knowledge about it?

222) **Ali**: Yeah. You’ve done very well.

223) **AM**: Cos I had some tricky questions from one or two people-

223) **Ali**: What's it like – there was a film called Elf, you know the Elf film, you know in the film Elf, the guy that’s played by Will Ferral, he went to the doctors and he had diabetes – remember he had to go and get his finger done

224) **AM**: I don't remember that bit

225) **Ali:** That was the funniest bit about it, where he went "finger prick? Ahhh let's go!" [laughs]

226) **AM**: I haven't seen all of Elf buy yeah, I'll have to check that bit out

227) **Ali**: He asks him so many questions lie why does that bit go like that?

228) **AM**: So everyone felt that there was enough – that I knew enough about it to answer your questions yeah? I think David, you asked me some tricky questions, I think about type 1 diabetes?

229) **David**: Yeah

230) **AM**: What was that, do you remember?

231) **David**: Yeah I think it was, what was the difference between Type 1 and Type 2, and which was worse and that

232) **AM**: And it was something to do with your family

233) **David**: Yeah it was my sister's boyfriend, has Type 1 I think - and he was diagnosed quite late

234) **AM**: So you corrected me cos I'd said that it was usually from birth that people get diagnosed -

235) **David**: - Yeah -

236) **AM**: But you were right to say that with some people it is quite late that they get it picked up – yeah. So did you think at that moment there was a bit of a gap or some holes in -?

237) **David**: - Yeah

238) **AM**: Ok, good to know. Ok. Let's see – so out of the overall sessions what did people like best? Do you remember we had 4 sessions so we had the "What's going on inside your body" as you said Ali, and then we had the risks and the risk factors, then we had the physically activity, then we had, finally the food choices. So, which of those do people think was best? What about you [addressing Neil] what did you like best? [No answer] Putting you on the spot. That's ok, I'll show you some stuff cos it's a bit tricky to remember it all without. So we had this bit to start with (shows magnetic board)-

239) **Ali**: Oh yeah! The stomach, the muscles, the pancreas and all that

240) **AM**: So you remember all those bits Ali. So we had this one. And we had – do you remember when I was holding the tray?

241) **Kerry**: Mhm

242) **AM**: And there was the cat and I knocked everything over?

243) **Steven**: Yeah it helps when it’s fun

244) **AM**: So was that your favourite bit? [general assent] with some of them I did it, and Janice did it, and Robbie helped out a bit too -

245) **Steven**:

246) **AM**: And then we had the physical activity bit [shows board with cycle of change?

247) **Kerry:** (and other voices including Ali and Steven) Yeah I remember that bit

248) **AM**: So that was the cycle of.. Doing planning and where some people might relapse

249) **Kerry** and **Steven**: Yeah, yeah I liked that one. ~It gave us a wee laugh

250) **AM**: What was it you liked about that one, Kerry and Steven? Cos you both said you liked that and I remember you liking it Steven in the sessions?

251) **Steven**: Cos it's um, it's a bit like motivating yourself, um -

252) **Kerry**: I also felt the same

253) **Steven**: Not being glued to the TV and that, you know what I mean like. Get yourself out of bed in the morning and go out for a walk you know what I mean?

254) **AM**: Mhm. What do you think about that one [to David]

255) **David**: Um, it was pretty good

256) **AM**: Because I think a few people said that they were at that stage

257) **Ali**: What annoying, er avoiding?

258) **AM**: But you're not too sure about that?

259) **Ali**: I'm not sure. But I liked it

260) **AM**: OK.

261) **Ali**: But then, getting up, getting' out the door, walkin' and then inside the door.

262) **AM**: So everyone seemed to like that one – that made sense yeah? Was there anything that didn't make sense?

263) **Ali**: He got an idea straight in his head

264) **AM**: Did that make sense to you Beth? [Beth shrugs] Do you remember doing that bit?

265) **Beth**: No I don't remember that it. I remember the other bit more

266) **AM**: OK. Cos you had something – you've been doing a lot of pedometer wearing?

267) **Beth**: Yeah

268) **AM**: But you don't remember doing the cycle and coming up against different stages?

269) **Beth**: No

270) **AM**: OK, OK, So maybe you weren't here for that one. OK, so what about the physical activity bit where we all made the big line of physical activities to show you that we could do different ones – did that make sense?

271) **Steven**: What one was that again?

272) **AM**: So that was the one - remember where we each did different sports and things, where people had a different card?

273) **Kerry**: Oh right

274) **AM**: Do you remember that Emily [nods] What about you Beth?

275) **Beth**: no I never did that

276) **AM**: Oh I think you must've maybe not been there for that – OK that's a shame. But did that one seem OK Emily?

277) **Emily**: Yeah it was good

278) **AM:** And then we also learned it that one about the recommended time for doing physical activity each day. Do you remember doing that? Not so sure about doing that? Do you think we could've spent a bit more time on that one?

279) **David** and **Ali**: Yeah, aye.

280) **AM**: Because part of that is planning – and everyone would make their own plan, in the packs that we had. And really what we just did is to show people, to show what you could do, if you were planning. Does anyone feel like we could've spent more time on that?

281) **Ali**: Yeah if you like

282) **AM**: Do you think it would've been helpful?

283) **Ali**: Yeah

284) **AM:** why do you think it would've been helpful

285) **Ali**: By kenning more about diabetes in your blood system

286) **AM**: OK. But in terms of planning it why do you think it would've been helpful to make your own plan?

287) **Ali**: Maybe just to make up what you want to do and all that?

289) **AM**: To make up what you want to do?

290) **Ali**: Aye.

291) **AM**: And why do you think it would be good to make up your own plans do you think?

292) **Ali**: In case you've got smart or clever ideas

293) **AM**: So remember when we were doing these cards you said we were all a bit different?

294) **Ali**: Mhmm

295) **AM**: OK. So again, was there anything that you didn't like? And I'm not going to be offended. What about you, David?

296) **David**: Not really

297) **AM**: No, nothing you didn't like? OK. And any suggestions on anything you would change? Nothing at all? OK. So do you remember learning about the blood glucose stuff here? [Shows magnetic board] This one do you remember learning about that?

298) **David**: Yeah I remember that one

299) **AM**: OK. Did you find that easy to follow?

300) **Steven**: Not so much, no.

301) **AM**: That was.. That was a bit trickier to follow? Did you find it OK Emily?

302) **Emily**: Yeah

303) **AM**: Did you find that OK Neil? Were there any new words for people to learn that you don't hear very often?

304) **Ali**: Well swearin' some people swear?

305) **AM**: Not so much swear words but words that we were talking about in here – were there any unusual words that you hadn't heard before?

306) **Kerry**: I hadn't heard a lot of Glucose

307) **AM:** And then, what was the "in" word we were talking about a lot before? Insu..

308) **David**: Insulation?

309) **AM:** Not insulation but insul.. The chemical we were talking about using to get in [pointing to cell picture]. Maybe there needed to be a bit more help with that one? Do you think – because we did this over 4 sessions – and it was over a month and it was quite a long time. Would it have been easier if we did it closer together do you think? If we did it all at once?

310) **Ali**: Something like that

311) **AM**: Why do you think that would be?

312) **Steven**: Because you'd get a better understanding of it

313) **AM**: OK. So do you think you would have a better understanding of it if you were doing it all in one go? All at once in 3 hours or having a break in between?

314) **Steven**: Probably having a break in between

315) **AM**: Ok, a break in between, ok. But, it seems like, was it better to have a break in between like we did? DO you think it was too long or too short? Cos it seems like some of this stuff was a bit difficult to remember after each week? Anyone feel like the breaks should've been longer or shorter?

316) **Ali**: Longer

317) **Emily**: Shorter

318) **Ali**: I didn't think our class had a break

319) **AM**: I think all of you had breaks – I think it was all over 4 weeks, about one a week in the end. Cos the original way that it's delivered is, everything at once in 3 hours. But do you think that would've seemed like a long time, to sit through 3 hours of stuff?

320) **Steven**: Yeah

321) **AM**: How long are your lessons normally?

323) **Emily**: About 2 hours

324) **AM**: About 2 hours. OK. So they can still be quite long. So maybe they could've been more in the time that we had? Does anyone feel that we could've filled out the lessons a bit more cos they were quite short? Do you think that Beth

325) **Beth**: Yes

326) **AM**: Why?

327) **Beth**: To give yourself time for what you've got to do?

328) **AM**: Time for what you've got to do? Yeah? OK, Ok, Let's see, if there's some other stuff to cover. So one of the main things was about this rusty key thing. That was one of the main things. Does everyone remember that?

329) **Ali**: No

330) **Steven**: Not a clue

331) **Ali:** Don't have a scoobie

332) **AM**: No? You don't have a clue? You don't remember this key with the cells? Emily you said you remember?

333) **Emily**: Yeah

334) **AM:** Anyone else? I'm not going to test you on it? Do you remember-

335) **Ali**: Can I go back to class now I'm getting a bit bored

336) **AM**: Sure, yeah, if you want to finish that's fine. No problem. Is everyone else sort of wanting to finish up? [Ali leaves group]

337) **David**: No I'm fine

338) **Steven**: Can I go to the toilet though?

339) **AM**: Sure, we've just got a bit more to go. So, did everyone remember the balancing story, with the tray? [General assent]. Do you remember that one, Beth, with the tray?

340) **Beth**: yeah

341) **AM**: Did that make sense? Do you remember what it was trying to tell you about?

342) **Emily**: Um.. It's difficult to explain

343) **AM:** Ok. But everyone seemed to like that part? What was it you liked about it? [No answer] Difficult to say? Because we had this stuff on the board here. Do you think we could've done more kind of role play with me clowning around a bit and stuff – would that've been more helpful? More interesting? [No answer] Not sure? OK And lastly the food choices then. [Neil laughs and mimics eating food]. Is it making you hungry? Do we all remember the last one that we did about the food choices? And we did the labels – Beth?

344) **Beth**: I think I'm not sure about that. I remember the other bit more

355) **AM**: Not sure about that one. So remember we talked about different kinds of fats?

356) **Kerry**: Mhmm. Yeah.

357) **AM**: Was that one ok?

358) **Kerry**: Was that with the different kinds of oils?

359) **AM**: Yes Was there anything that you would've changed about that one? [No answer] Were the labels easy to read do you think, on the packaging that I brought? Was it easy to read about that fats?

360) **David**: I think so

361) **AM**: You think so – yeah? Cos everyone found out about different kinds of fats when they read them on there? [nods] OK. And just again, looking at the reading stuff, so when you think about the packs that you had, could you read everything on those? Was it a bit small? Anyone have problems reading those? [No answer] Do you remember reading them or not sure what was in them? No? OK. See when you have stuff in here, do you normally have stuff up on this board? On the electronic board?

362) **Kerry**: Yeah normally yeah

363) **AM**: Do you think that would've been better, if the course stuff had been presented up on the screen? Or small stuff you can see in your hands? Which would be better?

364) **Kerry**: Stuff up on the board

365) **AM**: OK. Um, Why do you think.. Do you think it's because it's what you're used to or is it something about the size in particular?

366) **Kerry**: Well probably it's about the size but I did it at school, that's what I did sums and that on and using it's better for us

367) **AM**: Ok, so maybe there's a way of scanning some of this stuff and putting it up there

368) **Kerry**: Uhuh I agree

369) **AM**: Yeah? Would everyone else agree that? Arran and Beth? If it was up on the board would it be better [both nod] Yep. OK that's good to know. Back to the food stuff again, has anyone been looking at the food labels?

370) **Kerry**: Well, I don't buy the stuff from the shops, I do sometimes, to get the stuff that I like. My Dad goes to Tesco's to get food for dinner and things

371) **AM**: OK. Is that the same for everyone, does anyone do their own shopping? What about you Beth, do you do your own?

372) **Beth**: Aye

373) **AM**: Yeah, do you think you look at the labels since that bit of the course?

374) **Beth**: Aye a bit but [Group interrupted as staff member enters the room and talks to Beth and others in the class about timetable]

375) **AM**: OK, so the last bit we're going to talk about is the pedometers. Did everyone have a go at the pedometers in here? [General assent] OK. So it sounded like you used yours quite a bit Beth is that right?

376) **Beth**: Yeah cos I walk everyday. I walk into the college in the morning and I walk home. Now I walk round the shops to get here instead of the bus

377) **AM**: And have you changed your walking since you got the pedometer?

378) **Beth**: Yes I have

379) **AM**: Do you record the steps you were doing?

380) **Beth**: Yes

381) **AM**: And did you look at it at the end of the day and record it?

382) **Beth**: I haven't done it for ages

383) **AM**: OK, but when you changed your route at the beginning, was that when you were wearing the pedometer?

384) **Beth**: Yeah

385) **AM**: And were you looking at the number of steps you were doing?

386) **Beth**: yeah and I was writing it down

387) **AM**: Did that help you to plan it would you say? [nods] OK. Has anyone else done more walking since they got the pedometers?

388) **Kerry**: I wore it at my work. I look after children and I work in a nursery

389) **AM**: Ok great.

390) **Kerry:** My boss doesn't mind me wearing it. I love my job

391) **AM**: I bet you're running around a lot there

392) **Kerry**: Oh yes, And they always run up to me and they always remember my name and like it when they see me. But yeah, I love it.

393) **AM**: Oh that's great. Ok, so how about with wearing the pedometers, did everyone have a go at doing that – Steven did you do that? David do you wear them?

394) **David**: Yeah, a wee bit yeah.

395) **AM**: Did you find it easy to wear them?

396) **David**: It wasnae that much of a hassel

397) **Steven**: I didnae like it

398) **AM:** Ok WHat was it you didn't like about it?

399) **Steven**: It's cos I'm not wearing it everyday. If I was wearing it everyday I'd get used to it

400) **AM**: OK. So you think it would take some time to get used to?

401) **Steven**: Yeah

402) **AM**: Alright. So, do you think it would be better if it was on something that you were wearing all the time? Cos some people have phones, or watches – like a Fitbit – do you think those would work better than. Anyone else think that? You found it OK

to wear the pedometer Beth? [nods] Did anyone else think it would be better to wear a watch or a phone or a fitbit?

403) **Arran**: I found them OK

404) **AM**: OK. You used them when you were scooting about didn't you?

405) **Arran**: I wasnae really using them on the scooter but I'd walk around a lot

406) **AM**: You'd walk around a lot, ok. And you found it easy enough to wear. OK, Opening and closing them, was that ok for people or was a bit tricky?

407) **Emily**: Quite tricky

408) **Steven**: I found that a bit tricky

409) **AM**: Ok. A few people found that tricky. Right ok, And, the display, with the numbers? Could everyone read the numbers on there?

410) **Kerry** I couldn't read it

411) **Steven**: They were too small for me

412) **AM**: Ok so better if it was bigger. Was it bright enough or was it too dark?

413) **Steven**: Too dark.

414) **AM**: Ok that's good to know, thank you. Ok, so there's one more small bit and then we're done. So the last bit is about the questionnaires. That was quite a while ago – so we did those back in September? Does everyone remember doing the questionnaires? [general assent]

415) **Emily**: I can't remember that

416) **AM**: Ok. So some people did it in this room, others in the office over there. Ok So maybe that was too long ago to talk about for some people

417) **Kerry**: I can't mind that but yeah

418) **AM**: Ok. And you Steven do you remember doing that? [nods] How did you find doing them?

419) **Steven**: OK they were a bit difficult at a couple of points but once I got through a couple of pages I got used to it

420) **AM**: OK. So it took a bit of time to get into your stride?

421) **Steven**: a bit yeah definitely

422) **AM**: Were they a bit too long? Or was the length OK

423) **Kerry**: The length was OK

424) **Steven**: A bit long

425) **AM**: A bit long for Kerry, bit long – David?

426) **David**: I didn't think they were that bad

427) **AM**: Ok with some types of questionnaires they have pictures – dp you think that would've been helpful? If there were more pictures? [nods] And another way we could've done it would've been to have the big picture up on the board?

Group interrupted by another group needed resources – end of focus group at 51:40

Appendix 22: Student focus group thematic analysis stage three

1) People are different	2) Enjoyed change of lesson	3) Understanding consent	4) Not understanding right to withdraw	5) Limited understanding of confidentiality
Ali: Yeah, cos everyone's different to be honest. Cos Neil, you like One Direction, Steven, you're into Football, Kerry, you're into Taylor Swift and Justin Timberlake	**AM:** How's that been – would you rather have been having your lesson? **Steven**: No. **AM:** Why's that? **Steven**: Borin' **AM:** so has it been good to have something different going on? **Steven:**, Kerry and Emily: Yea, uh huh	**Arran**: No, I knew that **I** didn't have to take part, if **I** didn't want to take part. **AM:** OK. Did everyone else feel the same, that they felt they didn't have to take part like Arran? Did you feel the same **David**: Yeah. **AM:** What about you Beth? **Beth**: Yeah.	**AM:** …OK. And did you know. Because the study's been going on since September, did everyone realise that they could stop taking part at any time? **David**: No **I** didn't realise that. **AM:** Did anyone else feel like that? **Ali**: **I** didn't know you could stop taking part	**David**: Yeah **AM:** OK. Well that's good to know. Did everyone understand about your names being kept secret? Did everyone understand that- **Ali**: What names? **AM**: So when you gave your name to take part in the study, as we were talking about before with the forms that you signed, we'll change your name so that the people who see the study won't know it was you **Ali**: **I**s it because it's got some private information in it? **AM**: well it might do – there might be some information that you don't want other people to know came from you. So that's why we make stuff anonymous. Do people know what I mean by anonymous? **David**: Means no one knows like who you are or that. **AM**: So did that make sense before taking part in the study? **Ali**: **I**t's a bit of a tricky question **AM**: Would you say that's easy or difficult to understand then? **David**: Probably easy

				AM: Easy for you David **Steven**: I find it a bit difficult

6) Building relationships	7) Relationship with teachers	8) Improving through practice	9) Enjoyed leaning about body and health	10) Anxiety about participating – discovering symptoms

AM: Not just for talking today, but for all of the sessions I'd got to know some of you a bit. Because we did the questionnaires. Was it helpful that I came along and met you first? [general agreement] **AM**: Any ideas about why that might be? **Ali**: Just to give us some ideas **AM:** Just to give you some ideas? **Steven**: Of what you're like and that	**AM:** …would it have been easier if it was taught by your own teachers cos they've known you a longer time? **Steven**: No. **AM**: No from Steven – why's that then do you think? **Steven**: Cos you've got a better understanding of it than Fran and Sasha and the other teachers **AM**: OK well, do you think that's something they could go away and learn though? **Steven**: Well, they've got their own job here, do you know what I mean? It could be a bit hard for them **AM**: Sure. What about if it became part of their job to learn some of this stuff – would that be a good thing? **Steven**: Definitely yeah it would be [Ali agreeing] good if they could	**Ali**: They were OK, when you practiced it made perfect **AM**: When you practiced it? Tell me more about that – what do you mean by practiced it? **Ali**: By practicing using the pedometers and then they were perfect. **AM**: OK. So the more you wore those- **Ali**: - The more steps you did.	**AM**: OK. And what about the actual lessons when I was standing up there.. **Ali**: They were quite brilliant, cos you learned all about your body, and hoping not to die, and how you can keep on doing regular exercise and stuff	**AM:** Was there anything anyone was worried about before the started? **Steven**: In case I got it **AM**: OK So you were both a bit worried that you'd get diabetes if you did the course? **Steven**: Aye. In case you found out something that you had… In case I got it – that's why I didn't want to do it at first **AM**: So when you say in case you got it do you mean, in case you found out that you might have it? **Steven**: Mm in case I found out more about it

11) Anxiety about taking part – further health complications	12) Anxieties relieved during sessions	13) Perceived difficulties in understanding content	14) Perceived overall understanding of content	15) Acceptability of delivery

Kerry: So for me the difficulty was going to be like, hearing it and then like, hearing that I was the same **AM:** OK. So was it that you were worried about finding out more? **Kerry**: Aye **Kerry**: Well for me I was worried cos I've got epilepsy. That's why I was worried. Cos I've got epilepsy. I take seizures. Cos I had one on Saturday. I've been taking quite a lot of them – had one last week. So that was why I felt a bit uncomfortable doing it **AM**: Mm. Did it make sense that you seizures and the symptoms you had weren't the- **Kerry**: -it's cos I had seizures, two different kinds. It's been a whole different world – it's just hard.	**AM**: So it's more like there might be a diagnosis for it. And you said "at first" – was there something that changed along the way that made it feel a bit easier for you? **Steven**: Just like, talking about it and things like that, know what I mean? **AM**: Just talking about it. And any of the stuff you learned – do you think that helped you to understand it better? Did understanding it make it easier to not worry about it? **Steven**: Yeah	**AM**: OK. So on the whole, do you think the sessions were easy enough to understand or were some bits difficult? **Ali**: I think that there were some bits which were very, very ultra-hard **AM**: Ok, which bits would you say were really ultra-hard? **Ali**: Mmm.. I can't remember to be honest with you	**AM:** Yeah? So there's not going to be a test, don't worry, but if I did come back, you know, in a year's time or something, and asked you questions do you think you'd still be able to answer them then? **David**: Yeah **AM**: Same for everyone? **Ali** (and others) yeah	**AM**: That's great. And you've said you felt like I'd had enough training for it. Does everyone feel like I had enough knowledge about it? **Ali**: Yeah. You've done very well.

16) Uncertainty over perceived educator knowledge	17) Demonstrating understanding of content	18) Enjoying role play content	19) Enjoyed behaviour model content	20) Understanding content
AM: So you corrected me cos I'd said that it was usually from birth that people get diagnosed - **David**: - Yeah - **AM**: But you were right to say that with some people it is quite late that they get it picked up – yeah. So did you think at that moment there was a bit of a gap or some holes in -? **David**: - Yeah	AM: So we had this bit to start with (shows magnetic board) **Ali**: Oh yeah! The stomach, the muscles, the pancreas and all that	**AM**: And there was the cat and I knocked everything over? **Steven**: Yeah I liked that one **AM**: So was that your favourite bit? **Steven**: yeah.	**AM**: And then we had the physical activity bit [shows board with cycle of change? **Kerry:** (and other voices including Ali and Steven) Yeah I remember that bit **AM**: So that was the cycle of.. Doing planning and where some people might relapse **Kerry** and **Steven**: Yeah, yeah I liked that one **AM**: What was it you liked about that one, Kerry and Steven? Cos you both said you liked that and I remember you liking it Steven in the sessions? **Steven**: Cos it's um, it's a bit like motivating yourself.. **Kerry**: I also felt the same	**Steven**: Cos it's um, it's a bit like motivating yourself… Not being glued to the TV and that, you know what I mean like. Get yourself out of bed in the morning and go out for a walk you know what I mean?

21) Limited understanding of key-messages	22) Limited understating of content	23) Problematic delivery schedule	24) Uncertainty over structure	25) Limited or no understanding of key-content

AM: Because part of that is planning – and everyone would make their own plan, in the packs that we had. And really what we just did is to show people, to show what you could do, if you were planning. Does anyone feel like we could've spent more time on that? **Ali**: Yeah if you like **AM**: Do you think it would've been helpful? **Ali**: Yeah **AM:** why do you think it would've been helpful **Ali**: By kenning more about diabetes in your blood system **AM**: OK. But in terms of planning it why do you think it would've been helpful to make your own plan? **Ali**: Maybe just to make up what you want to do and all that? **AM**: To make up what you want to do? **Ali**: Aye. **AM**: And why do you think it would be good to make up your own plans do you think? **Ali**: In case you've got smart or clever ideas	**AM:** So do you remember learning about the blood glucose stuff here? [Shows magnetic board] This one do you remember learning about that? **David**: Yeah I remember that one **AM**: OK. Did you find that easy to follow? **Steven**: Not so much, no. **AM**: That was.. That was a bit trickier to follow? Did you find it OK Emily? **Emily**: Yeah **AM**: Did you find that OK Neil? Were there any new words for people to learn that you don't hear very often? **Ali**: Well swearin' some people swear? **AM**: Not so much swear words but words that we were talking about in here – were there any unusual words that you hadn't heard before? **Kerry**: I hadn't heard a lot of Glucose **AM:** And then, what was the "in" word we were talking about a lot before? Insu.. **David**: Insulation?	**AM:** Do you think – because we did this over 4 sessions – and it was over a month and it was quite a long time. Would it have been easier if we did it closer together do you think? If we did it all at once? **Ali**: Something like that **AM**: Why do you think that would be? **Steven**: Because you'd get a better understanding of it	**AM**: How long are your lessons normally? **Emily**: About 2 hours **AM**: About 2 hours. OK. So they can still be quite long. So maybe they could've been more in the time that we had? Does anyone feel that we could've filled out the lessons a bit more cos they were quite short? Do you think that Beth **Beth**: Yes **AM**: Why? **Beth**: To give yourself time for what you've got to do?	AM: So one of the main things was about this rusty key thing. That was one of the main things. Does everyone remember that? **Ali**: No **Steven**: Not a clue **Ali:** Don't have a scoobie **AM:** No? You don't have a clue? You don't remember this key with the cells? Emily you said you remember? **Emily**: Yeah **AM:** Anyone else? I'm not going to test you on it? Do you remember- **Ali**: Can I go back to class now I'm getting a bit bored

26) Limited understanding of content, despite enjoyment	27) Mixed understanding/remembering of content	28) Preference for board maker style of delivery	29) Increased walking after pedometers	30) Problems with pedometers
AM: …does everyone remember the balancing story, with the tray? [General assent]. Do you remember that one, Beth, with the tray? **Beth**: yeah **AM**: Did that make sense? Do you remember what it was trying to tell you about? **Emily**: Um.. It's difficult to explain	**AM:** Do we all remember the last one that we did about the food choices? And we did the labels – Beth? **Beth**: I think I'm not sure about that **AM**: Not sure about that one. So remember we talked about different kinds of fats? **Kerry**: Mhmm. Yeah. **AM**: Was that one ok? **Kerry**: Was that with the different kinds of oils?	**AM**: Do you think that would've been better, if the course stuff had been presented up on the screen? Or small stuff you can see in your hands? Which would be better? **Kerry**: Stuff up on the board **AM**: OK. Um, Why do you think.. Do you think it's because it's what you're used to or is it something about the size in particular? **Kerry**: Well probably it's about the size but I did it at school, that's what I did sums and that on and using it's better for us	**AM:** Did everyone have a go at the pedometers in here? [General assent] OK. So it sounded like you used yours quite a bit Beth is that right? **Beth**: Yeah cos I walk every day. I walk into the college in the morning and I walk home **AM**: And have you changed your walking since you got the pedometer? **Beth**: Yes I have **AM**: Do you record the steps you were doing? **Beth**: Yes **AM**: And did you look at it at the end of the day and record it? 382) **Beth**: I haven't done it for ages 383) **AM**: OK, but when you changed your route at the beginning, was that when you were wearing the pedometer? 384) **Beth**: Yeah 385) **AM**: And were you looking at the number of steps you were doing? 386) **Beth**: yeah and I was writing it down	**AM:** OK, Opening and closing them, was that ok for people or was a bit tricky? **Emily**: Quite tricky **Steven**: I found that a bit tricky **AM**: Ok. A few people found that tricky. Right ok, And, the display, with the numbers? Could everyone read the numbers on there? **Kerry** I couldn't read it **Steven**: They were too small for me **AM**: Ok so better if it was bigger. Was it bright enough or was it too dark? **Steven**: Too dark.

31) Remembering recruitment process	**32) Didn't enjoy completing forms, wanted to just get on with it**	**33) Some understanding of consent process**	**34) Information clear on forms**	**35) Understanding of consent**
[**Sean**: I remember] And lots of questionnaires and things as well – do you remember we all did those **Anita**: I remember that **Nick**: I remember that	**Catriona** : I didn't like doing the forms **AM**: OK so we'll start with that then – so you didn't like doing the forms Catriona **Catriona** : Yeah I would've liked to just take part **AM**: You would've liked to just take part **Catriona** : Yeah **AM**: Was that the questionnaires or the forms about taking part? Do you remember? **Catriona** : Yeah I didn't like doing them cause I would rather start doing it automatic- doing- writing down	**AM**: You understand Catriona , is anyone not sure about that? **Helen**: Did you understand why we filled in the forms? **Michael**: Taking part **Helen**: Taking part	**AM:** Now you don't need to read them all, it's just so you can maybe tell me. [hands out PI sheets] So it's maybe difficult to remember what you read about them cause it's maybe [**Catriona** : oh yeah] quite old but, was the information clear enough on there? **Anita**: Yes	**AM**: Did everyone understand that you didn't have to take part if you didn't want to? **Catriona** : Yeah **AM**: Did you feel like it was your choice **Several voices**: yes! **Sean**: Yeah we felt like it was our choice, definitely **AM**: OK. Did anyone feel like they had to do it? **Catriona** : No

Appendix 23: Student analysis stage four

Enjoyed change from normal lessons

AM: How's that been – would you rather have been having your lesson?
Steven: No.
AM: Why's that?
Steven: Borin'
AM: so has it been good to have something different going on?
Steven:, Kerry and Emily: Yea, uh huh

Enjoyed overcoming barriers model

AM: And then we had the physical activity bit [shows board with cycle of change?
Kerry: (and other voices including Ali and Steven) Yeah I remember that bit
AM: So that was the cycle of.. Doing planning and where some people might relapse
Kerry and **Steven**: Yeah, yeah I liked that one
AM: What was it you liked about that one, Kerry and Steven? Cos you both said you liked that and I remember you liking it Steven in the sessions?
Steven: Cos it's um, it's a bit like motivating yourself..
Kerry: I also felt the same

Enjoyed leaning about body and health

AM: OK. And what about the actual lessons when I was standing up there..
Ali: They were quite brilliant, cos you learned all about your body, and hoping not to die, and how you can keep on doing regular exercise and stuff

Pedometers easy to use

AM: Could you open and close them OK? [**Group**: Yes] No problems with opening and closing them?
Nick: Nope, no problems
AM: And what about reading the numbers on there? [**Anita**: yes]. Was that OK? [**Sally**: Yes]. Anyone have problems reading them? [**Group**: No]

1: Enjoyment/acceptability of study and course content

Understanding and enjoyment of broad aims

AM: OK. What did you like about them?
Catriona : Um, learning, learning how to not get diabetes
Anita: And how to be healthy, how to be very good and healthy all the months of the year
Nick: Well, I liked the taking part and being healthy

Enjoying role play content

AM: And there was the cat and I knocked everything over?
Steven: Yeah I liked that one
AM: So was that your favourite bit?
Steven: yeah.

Comfortable with length of sessions

Catriona : umm [AM: maybe an extra half hour?] no
Helen: Did you think they were just the right length Catriona ?
Catriona : Yeah. Maybe a wee bit longer [**AM**: repeats] not half an hour though!
AM: Would you like there to have been more in them then if they were a bit longer?
Catriona : Yeah
AM: Or do you think – we had four, so we could've had fewer sessions which were longer – would that have been better or was it good to have four?
Catriona : Good to have four.

Increased walking after pedometers

AM: Did everyone have a go at the pedometers in here? [General assent] OK. So it sounded like you used yours quite a bit Beth is that right?
Beth: Yeah cos I walk every day. I walk into the college in the morning and I walk home
AM: And have you changed your walking since you got the pedometer?
Beth: Yes I have
AM: Do you record the steps you were doing?
Beth: Yes
AM: And did you look at it at the end of the day and record it?
382) **Beth**: I haven't done it for ages
383) **AM**: OK, but when you changed your route at the beginning, was that when you were wearing the pedometer?
384) **Beth**: Yeah
385) **AM**: And were you looking at the number of steps you

Satisfied with educator knowledge and competence

AM: And then, one last question, it's a bit about me. And I'm very thick skinned so don't worry! But, do you think that I was trained well enough? To deliver the program? [**Group**: Yes]
Anita: Yes you have
Sean: You definitely have

AM: That's great. And you've said you felt like I'd had enough training for it. Does everyone feel like I had enough knowledge about it?
Ali: Yeah. You've done very well.

Understanding Consent

Arran: No, I knew that I didn’t have to take part, if I didn’t want to take part.
AM: OK. Did everyone else feel…like Arran? Did you feel the same
David: Yeah.
AM: What about you Beth?
Beth: Yeah.

Understanding Content

. **Steven**: Cos it's um, it's a bit like motivating yourself…
Not being glued to the TV and that, you know what I mean like. Get yourself out of bed in the morning and go out for a walk you know what I mean?

Understanding of consent

AM: Did everyone understand that you didn't have to take part if you didn't want to?
Catriona : Yeah
AM: Did you feel like it was your choice
Several voices: yes!
Sean: Yeah we felt like it was our choice, definitely

Understanding and varied understanding of content

AM: So what did we think of this session?
Nick: Good
Anita: Very good, fantastic, brilliant
AM: Right, does everyone remember about this bit here?
Sean: Key to the door
AM: [repeats]
Nick: To the door
Catriona : Yeah – to the cells
AM: Right and what was the chemical – In-
Anita: Food?
Sean: Glucose?
AM: Glucose, good, and what was the chemical called – In..?
Anita: Muscles
Helen: Do you remember the chemical that we said that's how we can open the door? [Sean: Yeah?] It's something that you produce and it's called Ins- [**Group**: Insulation] No it's shorter than that, insulin [**Sean**: insulin]

Information clear on forms

AM: …it's maybe difficult to remember what you read about them cause it's maybe [**Catriona** : oh yeah] quite old but, was the information clear enough on there?
Anita: Yes

Some understanding of consent process

AM: You understand Catriona , is anyone not sure about that?
Helen: Did you understand why we filled in the forms?
Michael: Taking part
Helen: Taking part

Understanding Content

. **Steven**: Cos it's um, it's a bit like motivating yourself…
Not being glued to the TV and that, you know what I mean like. Get yourself out of bed in the morning and go out for a walk you know what I mean?

2: Understanding of study and course content

Potential understanding of barriers concept

Helen: There was something you said earlier Michael about your football, that you'd stopped it but what were you thinking
Michael: I'm thinking of going back.. I got lots of injuries of that football and then I stopped it
Helen: Right. But you're thinking of going back are you?
Michael: Aye

Some understanding of key-messages

AM: OK. That's good to know. Good. Do you think you'll remember the stuff that I talked about?

Anita: Probably – some of the stuff is not good for you [AM: yeah] you need to change your diet every month of the year. The stuff, like the fat stuff is bad

Understanding confidentiality

AM: …does everyone know about confidentiality?
Catriona : Yes
AM: Catriona knows. Anyone else?
Catriona : It means, no-one knows. It's all secret and hush hush.
AM: OK. And, so about this study, what does that mean then, it being hush hush and secret?
Catriona : That only the people that are in it know
AM: Did everyone understand that
Most voices: Yes, aye

Demonstrating understanding of content

AM: So we had this bit to start with (shows magnetic board)
Ali: Oh yeah! The stomach, the muscles, the pancreas and all that

Some understanding of healthy eating content

AM: Ok. The last session then was about the types of fat, does everyone remember that? [**Group**: Yes] Alright, so what was happening in that session, does anyone remember?
Catriona : We were talking about Glucose [**Michael**: about diabetes]
Anita: We were talking about butter had fat in it [**Helen**: that's right] And sugar [**Nick**: About what's in it] Bad for your diet and health [**Nick**: Aye]

Understanding physical activity concept

AM: Alright. So we remember the risk factors. Then, the next one we talked about was physical activity [**Sean**: Yep]
Anita: What's good for your exercise
Catriona : Walking
AM: Yep
Anita: Yoga's good for your exercise
Michael: Swimming
Anita: Some people do exercise for their gardening [**Michael** I'm getting lazy now]

Some understanding of pedometer benefits

AM: why do you think, having the numbers there, why do you think knowing how many steps [**Anita**: To be healthy, fit]
AM: How do think it helps you to know that you're healthy and fit
Anita: It tells me how many steps you walk and places for going out

Mixed understanding/remembering of content

AM: Do we all remember the last one that we did about the food choices? And we did the labels – Beth?
Beth: I think I'm not sure about that
AM: Not sure about that one. So remember we talked about different kinds of fats?
Kerry: Mhmm. Yeah.
AM: Was that one ok?
Kerry: Was that with the different kinds of oils?

Perceived overall understanding of content

AM: Yeah? So there's not going to be a test, don't worry, but if I did come back, you know, in a year's time or something, and asked you questions do you think you'd still be able to answer them then?
David: Yeah
AM: Same for everyone?
Ali (and others) yeah

Understanding risk timeline

AM: What about this [shows magnetic timeline] does anyone remember that
[**Group**: Yeah]
Sean: No diabetes
Michael: No diabetes. If we hit that, good!
Nick: And then at risk
Helen: You're moving towards diabetes
Michael: And then at the red you've got it [Helen: that's it]

3: Limited understanding of study and course content

Not understanding right to withdraw

AM: …OK. And did you know. Because the study's been going on since September, did everyone realise that they could stop taking part at any time?
David: No I didn't realise that.
AM: Did anyone else feel like that?
Ali: I didn't know you could stop taking part

Limited understanding of confidentiality

David: Yeah
AM: OK. Well that's good to know. Did everyone understand about your names being kept secret? Did everyone understand that-
Ali: What names?
AM: So when you gave your name to take part in the study, as we were talking about before with the forms that you signed, we'll change your name so that the people who see the study won't know it was you
Ali: Is it because it's got some private information in it?
AM: well it might do – there might be some information that you don't want other people to know came from you. So that's why we make stuff anonymous. Do people know what I mean by anonymous?
David: Means no one knows like who you are or that.
AM: So did that make sense before taking part in the study?
Ali: It's a bit of a tricky question
AM: Would you say that's easy or difficult to understand then?
David: Probably easy
AM: Easy for you David
Steven: I find it a bit difficult

Limited understanding of key-messages

AM: Because part of that is planning – and everyone would make their own plan, in the packs that we had. And really what we just did is to show people, to show what you could do, if you were planning. Does anyone feel like we could've spent more time on that?
Ali: Yeah if you like
AM: Do you think it would've been helpful?
Ali: Yeah
AM: why do you think it would've been helpful
Ali: By kenning more about diabetes in your blood system
AM: OK. But in terms of planning it why do you think it would've been helpful to make your own plan?
Ali: Maybe just to make up what you want to do and all that?
AM: To make up what you want to do?
Ali: Aye.
AM: And why do you think it would be good to make up your own plans do you think?
Ali: In case you've got smart or clever ideas

Limited understanding of key-content

AM: So one of the main things was about this rusty key thing. That was one of the main things. Does everyone remember that?
Ali: No
Steven: Not a clue
Ali: Don't have a scoobie

Limited understating of content

AM: So do you remember learning about the blood glucose stuff here? [Shows magnetic board] This one do you remember learning about that?
David: Yeah I remember that one
AM: OK. Did you find that easy to follow?
Steven: Not so much, no.
AM: That was.. That was a bit trickier to follow? Did you find it OK Emily?
Emily: Yeah
AM: Did you find that OK Neil? Were there any new words for people to learn that you don't hear very often?
Ali: Well swearin' some people swear?
AM: Not so much swear words but words that we were talking about in here – were there any unusual words that you hadn't heard before?
Kerry: I hadn't heard a lot of Glucose
AM: And then, what was the "in" word we were talking about a lot before? Insu..
David: Insulation?

Difficulties communicating understanding

AM: Did that make sense? Do you remember what [tray risk factor] was trying to tell you about?
Emily: Um.. It's difficult to explain

Not remembering/understanding key-content

AM: Do we remember talking about risks?
Catriona : Yeah, eating more healthy stuff
Anita: No eating –cakes are not healthy
AM: And about risk factors? Does anyone remember that bit?
Group: Fats. No

Limited understanding, though metaphor understood

AM: Ok. And, what happened to that try in the end
Anita: You need to carry one things at a time
AM: Right Ok. It tipped over. And what was the message? Does anyone remember?
Catriona : Too much sugar or fat is bad for you [**AM** repeats]
Anita: Some of the stuff got bad calories [**Nick**: Bad calories]

Perceived difficulties in understanding content

AM: OK. So on the whole, do you think the sessions were easy enough to understand or were some bits difficult?
Ali: I think that there were some bits which were very, very ultra-hard
AM: Ok, which bits would you say were really ultra-hard?
Ali: Mmm.. I can’t remember to be honest with you

Struggling with vocabulary or concept?

AM: So, were there any words that were a bit difficult in that session?
Catriona : That word, whatever that word was
AM: Insulin?
Catriona : Yeah
AM: Was that one a bit harder to remember? [**Group**: yeah]
AM: Ok. A new word. So maybe we could've had some new ways to learn that new word?
Catriona : yeah
AM: What might've helped?
Catriona : To spell it? [**AM** repeats]
Anita: Just spell it [Nick: spell it] to connect
Catriona : It helps to spell

Struggling to understand concept of individualized goal planning

AM: Do you think it would've been helpful to plan things for yourself then, and make your own plans? [**Group**: yes]. Why would it be helpful to make your own plans?
Catriona : Um, to get more healthy?
Anita: Getting more fit
Nick: Getting more healthy
Anita: More walking for me to be independent college myself
Nick: More going to the gym for me
AM: Alright. If we made a plan and said what everyone's going to do, would that work better or would it work better if each of you sat down and made your own plan for yourselves

Struggling to remember key-content

Do we remember talking about risks?
Catriona : Yeah, eating more healthy stuff
Anita: No eating –cakes are not healthy
AM: And about risk factors? Does anyone remember that bit?
Group: Fats. No

Lack of understanding of consent form purpose

Catriona : I didn't like doing the forms
AM: OK so we'll start with that then – so you didn't like doing the forms Catriona
Catriona : Yeah I would've liked to just take part
AM: You would've liked to just take part
Catriona : Yeah
AM: Was that the questionnaires or the forms about taking part? Do you remember?
Catriona : Yeah I didn't like doing them cause I would rather start doing it automatic…

4: Importance of Relationships

Building relationships

AM: Not just for talking today, but for all of the sessions I'd got to know some of you a bit. Because we did the questionnaires. Was it helpful that I came along and met you first? [general agreement]
AM: Any ideas about why that might be?
Ali: Just to give us some ideas
AM: Just to give you some ideas?
Steven: Of what you're like and that

Relationship with teachers

AM: …would it have been easier if it was taught by your own teachers cos they've known you a longer time?
Steven: No.
AM: No from Steven – why's that then do you think?
Steven: Cos you've got a better understanding of it than Fran and Sasha and the other teachers
AM: OK well, do you think that's something they could go away and learn though?
Steven: Well, they've got their own job here, do you know what I mean? It could be a bit hard for them
AM: Sure. What about if it became part of their job to learn some of this stuff – would that be a good thing?
Steven: Definitely yeah it would be [Ali agreeing] good if they could

Acceptability of delivery

AM: That's great. And you've said you felt like I'd had enough training for it. Does everyone feel like I had enough knowledge about it?
Ali: Yeah. You've done very well.

Independent Planning

Anita: I like to plan my own to be independent college myself [**Catriona** : unclear]. I want to do activities myself to be independent mature.
Helen: OK Anita, so you'd prefer if we asked you what you'd like to do for exercise on your own?
Anita: I like to be independent
Helen: Is that to go walking?
Anita: I want to go to bus stop to travel college by myself [**Helen**: Oh right] I did get the bus here

Preference for educator partnership with teachers

AM: Ok. And when I'd come in I'd done the questionnaires and got to meet you a few times, and I'm come in to check up on how things were getting on, was it helpful that you knew me a bit better before the start?
Group: Yes
AM: It's also maybe something that the educational sessions that your teachers could go away and do as well – they could go away and have the same training. Do you think it would be better if your teachers did it or someone you didn't know
Catriona : Someone we didn't know do it
Anita: we need to have someone we know [**Nick**: Aye, definitely] [**Sally**: Yes]
AM: You think someone you don't know, **Catriona** , and someone you do know Anita?
Anita: Yes
AM: Why someone you don't know Catriona ?
Catriona : Cause. Um they can also help the people that we know how to do it
Helen: So you can work together is that what you mean?
Catriona : yeah
AM: Ok, so do you think it's important that they talk to each other then?
Catriona : Yes
AM: So me and the teachers for example the should talk to each other
Group: Yeah

Preference for group activities over individual

Helen: Ok, and do you think that some people would stick to it if it was pulled out of a hat? [**Group**: mixed yes and no]
AM: What is it you like Catriona about the idea of people doing it together?
Catriona : Um cause we're a team [**AM** repeats]
AM: Cause you like joining in with group activities?
Catriona : Yeah. I also like doing my own activities
Helen: But it's better in a group. OK
AM: Ok, that's really interesting, yeah.

5: Anxieties/reservations about taking part

Anxiety about participating – discovering symptoms

AM: Was there anything anyone was worried about before the started?
Steven: In case I got it
AM: OK So you were both a bit worried that you'd get diabetes if you did the course?
Steven: Aye. In case you found out something that you had… In case I got it – that's why I didn't want to do it at first
AM: So when you say in case you got it do you mean, in case you found out that you might have it?
Steven: Mm in case I found out more about it

Anxiety about taking part – additional health complications

Kerry: So for me the difficulty was going to be like, hearing it and then like, hearing that I was the same
AM: OK. So was it that you were worried about finding out more?
Kerry: Aye
Kerry: Well for me I was worried cos I've got epilepsy. That's why I was worried. Cos I've got epilepsy. I take seizures. Cos I had one on Saturday. I've been taking quite a lot of them – had one last week. So that was why I felt a bit uncomfortable doing it
AM: Mm. Did it make sense that you seizures and the symptoms you had weren't the-
Kerry: -it's cos I had seizures, two different kinds. It's been a whole different world – it's just hard.

Anxieties relieved during sessions

AM: So it's more like there might be a diagnosis for it. And you said "at first" – was there something that changed along the way that made it feel a bit easier for you?
Steven: Just like, talking about it and things like that, know what I mean?
AM: Just talking about it. And any of the stuff you learned – do you think that helped you to understand it better? Did understanding it make it easier to not worry about it?
Steven: Yeah

Uncertainty over perceived educator knowledge

AM: So you corrected me cos I'd said that it was usually from birth that people get diagnosed -
David: - Yeah -
AM: But you were right to say that with some people it is quite late that they get it picked up – yeah. So did you think at that moment there was a bit of a gap or some holes in -?
David: - Yeah

6: Problems or suggestions for improvement

Problematic delivery schedule

AM: Do you think – because we did this over 4 sessions – and it was over a month and it was quite a long time. Would it have been easier if we did it closer together do you think? If we did it all at once?
Ali: Something like that
AM: Why do you think that would be?
Steven: Because you'd get a better understanding of it

Uncertainty over structure

AM: How long are your lessons normally?
Emily: About 2 hours
AM: About 2 hours. OK. So they can still be quite long. So maybe they could've been more in the time that we had? Does anyone feel that we could've filled out the lessons a bit more cos they were quite short? Do you think that Beth
Beth: Yes
AM: Why?
Beth: To give yourself time for what you've got to do?

Improving through practice

Ali: They were OK, when you practiced it made perfect
AM: When you practiced it? Tell me more about that – what do you mean by practiced it?
Ali: By practicing using the pedometers and then they were perfect.
AM: OK. So the more you wore those-
Ali: - The more steps you did.

Preference for board maker style of delivery

AM: Do you think that would've been better, if the course stuff had been presented up on the screen? Or small stuff you can see in your hands? Which would be better?
Kerry: Stuff up on the board
AM: OK. Um, Why do you think.. Do you think it's because it's what you're used to or is it something about the size in particular?
Kerry: Well probably it's about the size but I did it at school, that's what I did sums and that on and using it's better for us

Suggestion for using internet based resources

Anita: Maybe seeing some pictures on the internet
Helen: Look for some pictures on the internet
AM: Why do you think the internet would be better do you think
Anita) It's tell you ever you've got diabetes
Helen: Do you think the internet because the pictures are on the screen, is that why?
Anita: You google on the internet – google it

Problems with pedometers

AM: OK, Opening and closing them, was that ok for people or was a bit tricky?
Emily: Quite tricky
Steven: I found that a bit tricky
AM: Ok. A few people found that tricky. Right ok, And, the display, with the numbers? Could everyone read the numbers on there?
Kerry I couldn't read it
Steven: They were too small for me
AM: Ok so better if it was bigger. Was it bright enough or was it too dark?
Steven: Too dark.
Lucy: I lost my one

Preference for using smartboard

AM: Yeah that's right cos we had some problems sticking up the pictures on the board [**Anita**: Blue tack]. What do you think, if they were all electronic, would that be better?
Helen: Would it be easier to see them on the Smart Board do you think?
Group: Yeah

Materials too small

AM: Can I ask you about these things, these magnets we were using for a minute ok? Do you remember these? What was the size of them like?
Anita: small [**Helen:** could you see them OK]
AM: You think small. Were they difficult to see? [**Catriona** and **Sally**: yeah] Some people think they were difficult to see. Cos we said before about the big classroom – do you think that had something to do with it, about them being difficult to see?

More active learning wanted

Helen: Anything else that would've helped you when we had the key in the door – would it've helped if we'd had – do you think it's good to sit down all the time or do you think we should get up
Anita: Get up and walk around
Nick: Aye get up
Catriona : Walk around
AM: Right. Cos there was lots of questions in that way that that was delivered but maybe a little bit more active – do you think?
422) **Catriona** : Yeah a bit more active

Better alternatives to pedometer

AM: Ok. Lastly then, oh actually just one more thing with the pedometers – does anyone think there is something better they could use to record their steps?
Anita: A watch?
Catriona : My DS cause my DS records [Some people use a walking watch]
AM: A DS or a watch [**Lucy:** a fitbit]
Helen: What was that Lucy?
Lucy: A Fitbit
AM: A fitbit – do people think those things would be better [**Sally**: Swimming]. Swimming's a good exercise [**Catriona** : Aye cause it won't stick to me and I can stick it in my bag]
AM: Ok [We need to make sure we wear the steps every year] so a few different options for wearing it then and do you think that's better? Um, **Catriona** you've said that's better cause you don't need to think about it and it can just go into your bag. What about Fitbits? Why might they be better?
Lucy: So you can put it round your wrist – and wear it

Extra support needed for 1-1 planning

AM: Is making plans something people extra need help with? [**Group**: Yeah] Or is it something you do yourselves? So you're saying yep, you need extra help to [**Group**: Yeah]
Anita: I like extra help for support [**AM**: Right] Social work
AM: Were these books, if you remember back, would they be helpful, in using them to make plans? [**Group**: Yes] Why do you think they would be helpful?
Anita: With places you walked
AM: You could write down the places you walked do you think?
Sally: You don't [Michael: It's rubbish] write them down
AM: Ok. And um, would it be helpful to do them in a classroom or at home, if you were [**Catriona** : Home] [**Anita**: Both] [**Catriona** : Both] sorry? [**Group**: Both] Ok. So you need a bit of help at home [**Group**: yes] and at college [**Group**: yes]

Felt crowded - limited space or too many people?

Helen: Can you think of anything to do differently?
Anita: Maybe to have a big room
AM: Maybe to have a big room
Catriona : Oh yeah a big room
Nick: A big room
AM: We needed to have a bigger room. Were the sessions – did we have more people in here than you normally have? [**Group**: Yeah, yes]
AM: OK. Did that feel like too many people? [**Group**: Yeah]
Anita: Maybe to have extra seats
AM: Extra seats
Catriona : And maybe go to a big conference room
AM: And having so many people in the room, did that make it less easy for you to understand what I was talking about?
341) **Catriona :** No
AM: OK. But, you're saying extra seats – was anyone uncomfortable?
Catriona : Yeah just [**Sally**: Yes] there was not a lot of room to move
Anita: We needed more space
Nick: Aye definitely more space

Issues with attaching pedometer

AM: And attaching them to your belt? Was it easy to [**Catriona** : It was hard] Right
Helen: Sean? Did you clip on your pedometer to your belt?
Sean: I can't do it really

Discomfort with pedometer

Anita: I didn't like when it digged into my skin [**AM** repeats] Yeah. Did anyone else find that?
Gordon: It was a bit sore [**AM** repeats]

Uncertainty over perceived educator knowledge

AM: So you corrected me cos I'd said that it was usually from birth that people get diagnosed -
David: - Yeah -
AM: But you were right to say that with some people it is quite late that they get it picked up – yeah. So did you think at that moment there was a bit of a gap or some holes in -?
David: - Yeah

[redacted]