Physical activity and sedentary behaviour intervention for youth with Type 1 diabetes: Determining the best approach

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Declaration of authenticity and author's rights

This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

Signed

Date: 26/07/2013

ABSTRACT

The purpose of this thesis was to aid the development of a physical activity and sedentary behaviour intervention for children and adolescents (youth) with Type 1 diabetes. Chapter 1 introduces the research area, target population and design of the thesis. Published guidance on the early development phase of complex health interventions was followed (Campbell et al., 2000; Craig et al., 2008), with three studies being undertaken as part of the thesis. The first study determined physical activity and sedentary behaviour levels and patterns using accelerometers, as well as quality of life using questionnaires, in a sample of Scottish youth with Type 1 diabetes. The second study systematically reviewed the evidence on study characteristics, intervention design and efficacy of phyiscal activity and sedentary behaviour RCT intervention studies in youth with Type 1 diabetes. The third study, developed as two manuscripts, explored perceptions of physical activity and sedentary behaviour and support needs in youth with Type 1 diabetes in patients, their parents, diabetes professionals and schoolteachers using interviews and focus groups. The novel findings of the studies in this thesis in relation to youth with Type 1 diabetes are: the need to target this population group due to low physical activity and high sedentary behaviour participation (study 1); the need for unsupervised, theory based interventions targeting sedentary behaviour in addition to physical activity and high quality evidence to support the efficacy of physical activity on health (study 2); and the requirement of parental and peer support in interventions, the necessity for diabetes professionals to encourage physical activity and the need for better support and training for schoolteachers to accommodate physical activity in schools (study 3). The final chapter of this thesis discusses how the findings of the studies can be used in future research and practice.

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Firstly I would like to thank my first supervisor, Alison Kirk, and second supervisor, Nanette Mutrie, for believing in me and providing me with the opportunity to start my research career. Your guidance has been fantastic, your support invaluable and your friendship has made the journey a very pleasant one.

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Thank you all so very much.

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SUMMARY OF PUBLICATIONS, SUBMITTED MANUSCRIPTS AND PRESENTATIONS

Publications and manuscripts from this thesis

Study 1 (paper 1)	**MacMillan**, **F.,** Kirk, A., Mutrie, N., Matthews, L., Robertson, K., Saunders, D., (In preparation). Physical activity, sedentary behaviour and quality of life in Scottish youth with Type 1 diabetes.
Study 2 (paper 2)	**MacMillan**, **F.,** Kirk, A., Mutrie, N., Matthews, L., Robertson, K., Saunders, D., (In press). A systematic review of physical activity and sedentary behaviour intervention studies in youth with Type 1 diabetes: Study characteristics, intervention design and efficacy. *Pediatric Diabetes.*
Study 3 (paper 3)	**MacMillan**, **F.,** Kirk, A., Mutrie, N., Moola, F., Robertson, K., (In preparation). Patient, parent and diabetes professional views on building physical activity and sedentary behaviour support into care for youth with Type 1 diabetes.
Study 3 (paper 4)	**MacMillan**, **F.,** Kirk, A., Mutrie, N., Moola, F., Robertson, K., (In preparation). Supporting physical activity participation in schools: Views of teachers, patients, parents and diabetes professionals.

Conference publications from this thesis

MacMillan, F., Kirk, A., Mutrie, N., (2011). Physical activity behaviour of paediatric patients with Type 1 diabetes. *International Journal of Exercise Science: Conference Abstract Submissions,* 5 (2), Article 45.

Publications not related to the PhD thesis

Matthews, L., Kirk, A., **MacMillan, F**., Mutrie, N (Submitted). How to implement a physical activity service for Type 2 diabetes: a systematic review. *Translational Behavioral Medicine*

Kirk, A.F., **MacMillan, F** (Submitted). How to get more people with diabetes cycling. *Practical Diabetes*

Yardley, J.E., Mollard, R.C., MacIntosh, A.C., **MacMillan, F.C.,** Wicklow, B.A., Berard, L., Hurd, C., Marks, S., McGavock, J.M (Submitted). Vigorous intensity exercise for glycemic control in patients with type 1 diabetes. *Canadian Journal of Diabetes*

Kirk A., **MacMillan, F.,** Rice, M., Carmichael, A., (2013). An exploratory study examining the appropriateness and potential benefit of the Nintendo Wii as a physical activity tool in adults aged ≥ 55 years. *Interacting with Computers,* doi: 10.1093/iwc/iws004

Blamey, A.M., **MacMillan, F.,** Fitzsimons, C.F., Shaw, R., Mutrie, N., (2013). Using programme theory to strengthen research protocol and intervention design within an RCT of a walking intervention. *Evaluation,* 19, pp 5

Mutrie, N., Doolin, O., Fitzsimons, C. F., Grant, P. M., Granat, M., Grealy, M., Macdonald.H., **MacMillan, F.,** McConnachie, A., Rowe, D. A., Shaw, R., & Skelton, D. A., (2012). Increasing older adults' walking through primary care: Results of a pilot RCT. *Family Practice,* 29 (6), pp 633-642

MacMillan, F., Fitzsimons, C., Black, K., Granat, M., Grant, P., Grealy, M., Macdonald, H., McConnachie, A., Rowe, D., Shaw, R., Skelton, D., & Mutrie, N., (2011). West End Walkers 65+ A randomised controlled trial of a primary care-based walking intervention for older adults: Study rationale and design. *BMC Public Health,* 11 (1), pp 120.

MacMillan, F., Kirk, A., (2010). Patterns of physical activity and the effect of accelerometer wear on physical activity participation in people with Type 2 diabetes. *CARE: A scholary journal for nursing midwifery & allied & community health*, 3 (1), pp 6-22

Kirk, A., **MacMillan, F.,** Webster, N (2010)., Application of the Transtheoretical model to physical activity in older adults with Type 2 diabetes and/or cardiovascular disease. *Psychology of Sport & Exercise*, 11 (4), pp 320-324

Conference publications not from this thesis

Carmichael, A., Rice, M., **MacMillan, F.,** Kirk, A., (2010). Investigating a DTV-based physical activity application to facilitate wellbeing in older adults. *Proceedings of the 24th BCS Interaction Specialist Group Conference*, 278-288.

Conference presentations from this thesis

2013

MacMillan, F., Kirk A., Mutrie, N., Robertson, K (2013, May). Physical activity and sedentary behaviour in Scottish youth with Type 1 diabetes. *Poster presented at the American College of Sports Medicine's 60th Annual meeting, Indianapolis, USA*

MacMillan, F., Robertson, K., Matthews, L., Mutrie, N., Kirk, A., (2013, March). Designing a physical activity intervention study for youth with Type 1 diabetes: lessons learned from a systematic review. *Poster presented at the Diabetes UK Annual Professional Conference, Manchester, UK*

2012

MacMillan, F., Kirk A., Mutrie, N. (2012, December) Physical activity and sedentary behaviour in children and adolescent with Type 1 diabetes. *Oral* *presentation presented at the 3rd Scottish Physical Activity Research Conference for PhD Students, Edinburgh, UK*

Kirk, A., Robertson, K., **MacMillan, F.,** Gold, A., (2012, July) Physical activity in diabetes management: The Science, education and medical contributions. *Symposium presented at the International Convention on Science, Education and Medicine in Sport, Glasgow, UK*

2011

MacMillan, F., Kirk, A., Mutrie, N (2011, September) Physical activity for health in children and adolescents with Type 1 diabetes. *Poster presentation at the 2nd Scottish Physical Activity Research Conference for PhD Students, Glasgow, UK. Winner of the best presentation of research*

MacMillan, F., Kirk, A., Mutrie, N., (2011, October). Physical activity behaviour of paediatric patients with Type 1 diabetes. *Oral presentation presented at the 2nd International e-conference on Kinesiology and Integrated Physiology, online*

MacMillan, F., Kirk, A., Mutrie, N (2011, June) Physical activity for health in children and adolescents with Type 1 diabetes. *Poster presentation at the University of Strathclyde research day, Glasgow, UK. Winner of the best Humanities and Social Sciences faculty student poster prize*

Conference presentations not from this thesis

2013

Matthews, L., **MacMillan, F**., Kirk, A., Mutrie, N., (2013, March) The importance of external networks in the implementation of physical activity interventions for Type 2 diabetes. *Poster presented at the Diabetes UK Professional Conference, Manchester, UK*

2012

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MacMillan, F., Shaw, R., Mutrie, N., (2011, September) West End Walkers 65+: Participants' evaluation of a walking intervention for older adults. *Oral presentation at the British Association of Sport and Exercise Science Annual Conference, Exeter, UK*

2011

MacMillan, F., Rowe, D., Grant, M., Granat, M. & Mutrie, N., (2011, May) What happens when people aren't wearing their pedometer? Comparison to 24-hour monitoring of walking behavior in older adults. *Poster presented at the 2nd International Conference on Ambulatory Monitoring and Physical Activity Movement, Glasgow UK. Shortlisted for best student poster presentation*

2010

MacMillan, F., Fitzsimons, C., Rowe, D., Black, K., Grealy, M., Evans, A., Macdonald, H., Grant, M., Granat, M., Skelton, D., Shaw, R., McConnachie, A., Mutrie, N., (2010, November) West End Walkers 65+: A randomised controlled trial of a primary care-based walking intervention study for older adults. *Poster presented at the British Heart Foundation National Centre Annual Conference, East Midlands, UK*

MacMillan, F., Fitzsimons, C., Black, K., Evans, A., Granat, M., Grant, PM., Grealy, M., Macdonald, H., McConnachie, A., Rowe, D., Shaw, R., Skelton, D., Mutrie, N. (2010, June). West End Walkers 65+ Recruiting older adults from a GP practice into a walking study. *Poster presented at the University of Strathclyde research day, Glasgow, UK*

MacMillan, F., Kirk, A., Peacock, L., Carmichael, A., Rice, M., (2010, May) Exergaming: Using the Nintendo Wii as a physical activity tool in adults aged 55 ≥years. *Poster presented at the 3rd International Congress on Physical Activity and Public Health, Toronto, Canada*

MacMillan, F., Kirk, A., Peacock, L., Carmichael, A., Rice, M., (2010, May) Exer-gaming in adults aged 55 years and above. *Poster presented at the 3rd International Congress on Physical Activity and Public Health, Toronto, Canada*

Declaration of the students contribution

This thesis aimed to answer a series of questions in the area of development of physical activity and sedentary behaviour interventions for youth with Type 1 diabetes. A further aim was to produce reports of the work that were suitable for peer-reviewed publication. As a result of this a number of co-authors were involved in manuscript preparation and reviewing. F MacMillan however led the study design, development, approval, analysis and manuscript development for all manuscripts. Specifically, F MacMillan led the writing of the University and National Health Service (NHS), ethics applications required for conduction of the research in studies 1 and 3 of this thesis, and was the chief investigator of the NHS application. F MacMillan ran the systematic review search for study 2 and collected all data for study 1 and 3 in relation to papers 1 and 3. A post-doctoral researcher conducted one of the focus groups in relation to study 3, paper 4, with school teachers, as two focus groups ran parallel to each other. All remaining data for study 3, paper 4, were collected by F MacMillan. F MacMillan transcribed 40/43 transcripts (undergraduate students transcribed three transcripts), and entered and analysed all quantitative and qualitative data. The drafting, editing, and submission of the four manuscripts included in this thesis were led by F MacMillan. Additional authors on the manuscripts provided feedback and suggestions to improve drafts of the manuscripts. All conference presentations, with F MacMillan listed as first author, were prepared, edited (after consultation with other authors) and presented by F MacMillan.

Contents

Chapter 1: Introduction

1.0 Preface

The aim of this chapter is to introduce the thesis by briefly reviewing related literature, concisely describing the original contributions that the thesis brings to the area of research explored and to explain the layout of the thesis. A systematic review of the most relevant literature follows in chapter 3. The areas of literature reviewed in this chapter are titled: 1) introduction to diabetes, (which includes sections on definitions and diagnosis of diabetes, characteristics, causes and complications); 2) definition of youth and focus of the thesis: youth with Type 1 diabetes; 3) youth with Type 1 diabetes, (including sections on the rising prevalence of Type 1 diabetes, definitions of health and health outcomes, and the health of youth with Type 1 diabetes); 4) definitions of physical activity, metabolic equivalents (METs), and sedentary behaviour; 5) the physical inactivity pandemic; 6) physical activity and sedentary behaviour recommendations and guidance; 7) physical activity and sedentary behaviour participation in youth with Type 1 diabetes; 8) the acute physiological responses to physical activity and sedentary behaviour; 9) adverse events during physical activity and barriers to physical activity participation; and 10) developing a complex health intervention: design of the thesis, (which includes sections on the use of mixed method studies in health intervention development and the ontological and epistemological underpinnings of the thesis research). A summary of the structure of the thesis and purpose of the research follows the literature review. Finally the thesis research questions and a summary of the chapters are detailed.

1.1 Introduction to diabetes

1.1.0 Definition, diagnosis, characteristics and causes

Diabetes Mellitus is a metabolic disorder resulting in chronic high blood glucose levels (hyperglycaemia). The condition is caused by a deficiency in production and/or sensitivity of the hormone insulin, which normally acts to lower blood glucose levels by stimulating glucose uptake into cells. Symptoms of the condition include frequent urination, excessive thirst, hunger or tiredness, weight loss, blurred vision and in some cases impaired growth or increased risk of specific infections (American Diabetes Association, 2012). Abnormal glucose levels in the blood are used to clinically diagnose diabetes by measuring fasting plasma glucose response to a glucose load, using an oral glucose tolerance test (OGTT) and/or average blood glucose over the preceding 8-12 weeks using a haemoglobin A1c (HbA1c) test (an indicator of glycaemic control over the long term). HbA1c is reported as percentage glycosylation of haemoglobin. The normal range for HbA1c in someone without diabetes is 4-5.6% and the range 5.7-6.4% would indicate someone at increased risk of developing diabetes (American Diabetes Association, 2012). Published criteria for defining diabetes using blood tests are as follows: fasting plasma glucose values ≥7.8 mmol/l (≥140 mg/dl); plasma glucose levels two hours after an OGTT and from a sample before two hours post-OGTT of ≥11.1 mmol/l (≥200 mg/dl); and HbA1c values ≥6.5% (The International Expert Committee, 2009). For the HbA1c measure, diabetes is confirmed in adults by two test results ≥6.5% or one positive test alongside a plasma glucose level ≥11.1 mmol/l and symptoms of diabetes. In youth an HbA1c value ≥6.5% confirms diabetes even with a plasma glucose value <11.1mmol/l or in the absence of symptoms (The International Expert Committee, 2009). It is estimated that 366 million people worldwide were living with diabetes in 2011 and by 2030 the prevalence will rise to 552 million people (Diabetes UK, 2012). Approximately £23.7 billion is spent on diabetes in the UK and by 2035/6 this cost is estimated to rise to £39.8 billion (Hex, Bartlett, Wright, Taylor, & Varley, 2012).

There are two main types of diabetes: Type 1 and Type 2. Type 2 diabetes is the most common, occurring in around 85% of all diabetes cases in the UK (Diabetes UK, 2012). Type 2 diabetes was previously termed non-insulin dependent diabetes. This was because the condition is progressive and in many instances can be effectively managed by diet and physical activity (lifestyle) changes or oral pharmacological treatment, as there is still a degree of insulin release and action. The condition can progress however to require insulin therapy. Prevalence of Type 2 diabetes is increasing rapidly worldwide and is linked to the rise in obesity caused by poorer diets and lower participation in physical activity (Herman & Zimmet, 2012). Type 2 diabetes was also in the past referred to as late-onset diabetes as it was most commonly diagnosed in adults aged >40 years (Herman & Zimmet, 2012). However in recent years with the rising incidence of obesity as a result of poor lifestyle behaviours, adolescents and children are now developing Type 2 diabetes (D'Adamo, 2011).

Type 1 diabetes, previously known as insulin dependent diabetes, is an autoimmune disorder which targets the beta cells (insulin producing cells) of the pancreas resulting in absolute deficiency of insulin. Symptoms of Type 1 diabetes develop rapidly and external insulin administration via multiple daily injection or continuous subcutaneous insulin infusion (insulin pump therapy) is essential for blood glucose control and survival. Around 15% of the UK diabetes population have Type 1 diabetes (Diabetes UK, 2012). Type 1 diabetes is sometimes referred to as juvenile-onset diabetes, as the condition more commonly develops in youth, with the average age of onset being 14 years in the UK (Feltbower, McKinney, Parslow, Stephenson, & Bodansky, 2003). As with Type 2 diabetes, the global incidence of Type 1 diabetes is also rising (Soltesz, Patterson, & Dahlquist, 2007). There is an established genetic link with Type 1 diabetes. However with a relatively stable gene pool, the rising prevalence of the condition cannot be attributed solely to changes in genetics. Environmental influences must therefore play a role. The environmental trigger resulting in an autoimmune attack, which causes Type 1 diabetes, is unclear and may be the result of a combination of factors.

Several hypotheses exist that attempt to explain the rising prevalence, which are listed now and discussed in turn: 1) the vitamin D hypothesis; 2) the persistent organic pollutants (POPs) hypothesis; 3) the accelerator hypothesis; 4) the hygiene hypothesis; and 5) the complex foreign protein, baby formula or cow’s milk hypothesis (Hurley, 2011). Vitamin D is important to ensure junctures between epithelial cells (including epithelial cells in the pancreas) remain tight, acting as a barrier to the passage of enzymes that can cause harm and viruses. In addition Vitamin D up-regulates tolerogenic lymphocytes (a type of white blood cell), which are important for protection against autoimmune attacks. A lack of sufficient vitamin

D intake results in cell junctures becoming leaky and can result in the passage of viral cells. Alongside a reduced white blood cell count, this leads to a reduced defence system to viral attack, putting the individual at an increased risk of an autoimmune attack. Exposure to man-made toxins (POPs) is also believed to result in a disturbance in the immune system that could lead to an autoimmune attack. Although epidemiological studies have linked POP exposure with some long-term conditions, little is known about the mechanisms involved and, limited evidence exists connecting Type 1 diabetes to POPs exposure as of yet. POPs exposure has been shown to result in an increase in an oxidative stress marker, called gamma-glutamyltransferase. The risk of Type 2 diabetes and other conditions including rheumatoid arthritis, which like Type 1 diabetes is also an autoimmune condition, is increased with higher concentrations of this marker. The accelerator hypothesis was originally developed to explain the effect of a period of weight gain during youth, resulting in increased stress on the pancreatic beta cells. Increased stress on the beta cells of the pancreas causes the cells to die quicker and this in turn leads to immune system up-regulation. In recent years the accelerator hypothesis has further developed to explain the accelerated loss of pancreatic beta cells and consequent auto-immune attack on beta cells from any or a combination of environmental factors (accelerators). The hygiene hypothesis suggests that due to changes in cleanliness over the years, there is less exposure to bacteria and infections. A consequence is that regulatory elements of the immune system do not correctly develop and individuals are at an increased risk of an autoimmune attack. Some of the strongest evidence for this theory comes from studies showing the protective effects of intestinal worms on regulating the immune system of patient's with conditions such as Crohn's disease – the worms down-regulate the immune system so that an auto-immune attack does not occur, protecting the worms from elimination. Finally, the cow's milk hypothesis explains that young babies with immune and intestinal systems that are not fully developed are not capable of effectively digesting formula milk, which has large complex proteins. Breast milk from mother's milk does not contain these complex foreign proteins and is easily digest-able. The correct name for this hypothesis is the foreign protein theory, as any complex protein can potentially distress the immune system and trigger an autoimmune attack on the body's cells. If the individual is already at an increased risk of developing diabetes then intake of the foreign protein can initiate an autoimmune attack (Hurley, 2011).

1.1.1 Complications of diabetes

Chronic hyperglycaemia results in tissue damage and can lead to the development of diabetic complications. Microvascular (small vessel) complications include retinopathy, neuropathy and nephropathy. Retinopathy affects the blood vessels of the eyes and can lead to visual impairment or loss. Neuropathy targets the nervous system. Peripheral neuropathy affects the lower limbs and can lead to loss of sensation in the feet, an increased risk of foot ulcers and lower limb amputation. Autonomic neuropathy can result in problems such as genitourinary and gastrointestinal complications. Nephropathy affects the kidneys and can result in renal failure. Macrovascular complications include cardiovascular and cerebrovascular disease (American Diabetes Association, 2012). Compared to persons without diabetes, individuals with diabetes are at an increased risk of developing cardiovascular disease (Diabetes UK, 2012). Cardiovascular disease is one of the main causes of morbidity and mortality in those with diabetes, with 44% of total deaths in those with Type 1 diabetes and 52% of those with Type 2 diabetes caused by cardiovascular disease (Diabetes UK, 2012). Tight glycaemic control reduces the risk of developing microvascular (The Diabetes Control and Complications Trial Research Group, 1993) and macrovascular (Nathan et al., 2005) complications in those with Type 1 and Type 2 diabetes (King, Peacock, & Donnelly, 1999). Micro and macrovascular disease develops over time and as patients with Type 1 diabetes tend to be diagnosed in youth, they potentially have many years of life ahead of them when complications can establish. The long-term HbA1c goal for youth is <7.5%, or as close to this target as possible, without frequent hypoglycaemia (low blood glucose readings). As for HbA1c, short-term blood glucose level targets should be set on an individual basis, with the following ranges intended as guidelines for youth: between 5-8 mmol/litre prior to eating; 5-10 mmol/litre after eating; 6.7-10 mmol/litre at bedtime; and 4.5-9 mmol/litre overnight (International Diabetes Federation, 2011). Youth with HbA1c and blood glucose levels outside of the recommendations above may require extra support from diabetes professionals due to the increased risk of complications.

2.0 Definition of youth and focus of the thesis: Youth with Type 1 diabetes

Type 2 diabetes has been the focus population of the majority of physical activity and sedentary behaviour intervention studies in the past. Youth with Type 1 diabetes are the target population of this thesis. Youth are defined in this thesis as children (5-11 years) and adolescents (12-17 years), in line with the definition of children and young people in the UK physical activity guidelines (UK Department of Health, 2011). The next section provides a summary of the problem as a means of justification for selecting youth with Type 1 diabetes as the focus of this thesis.

3.0 Youth with Type 1 diabetes

3.0.0 Rising prevalence of Type 1 diabetes in youth

Type 1 diabetes is one of the most common chronic conditions in youth (Torpy, Lynm, & Glass, 2007). A global total of approximately 480,000 youth (aged <15 years) have Type 1 diabetes, with roughly 76,000 newly diagnosed youth annually (Soltesz, Patterson, & Dahlquist, 2009). Prevalence of Type 1 diabetes in youth is rising. The annual global increase in prevalence is estimated to be 3% but varies considerably across countries (Patterson, Dahlquist, Gyürüs, Green, & Soltész, 2009; The DIAMOND project group, 2006). The UK rates number four in the list of greatest incidence of Type 1 diabetes in youth with an annual prevalence rate of roughly 25 cases per 100,000 youth (Soltesz, et al., 2009). A UK study examining the general practice research database found that Type 1 diabetes prevalence increased annually significantly more from 1991-2008 in youth aged <15 years (4.1%, 95% CI 3.0-5.2%) than in people aged 15-34 years (2.8%, 95% CI 1.6-3.9%) (Imkampe & Gulliford, 2011). It is estimated that there are 29,000 youth with diabetes in the UK, of which 26,500 have Type 1 diabetes, 500 have Type 2 diabetes and 2000 have an unclear diagnosis (Diabetes UK, 2012). Therefore youth with Type 1 diabetes are an important target population, as the prevalence is rising rapidly worldwide and most notably in younger people.

3.0.1 Definition of health and heath outcomes

'Health' as defined by the World Health Organisation is "a state of complete physical, mental and social well being and not merely the absence of disease or infirmity" (para. 1.), (International Health Conference, 1948). Blood triglyceride levels (referred to as triglycerides throughout the thesis) provide a measure of the amount of lipid in the blood. Values of triglycerides in the blood >150 mg/dL are associated with an increased risk of coronary heart disease in youth (American Diabetes Association, 2003). High-density lipoprotein (HDL) cholesterol refers to the concentration of cholesterol contained in HDL particles. HDL transports cholesterol from arteries to the liver. A greater HDL value is associated with a lower risk of cardiovascular disease. In youth with diabetes, HDL values <35 mg/dl indicate an increased risk of coronary heart disease (American Diabetes Association, 2003). Greater low-density lipoprotein (LDL) cholesterol levels, on the other hand increase the risk of coronary heart disease, by helping transport cholesterol into artery walls. In youth, LDL levels should ideally be <100 mg/dl (American Diabetes Association, 2003). Microalbuminuria is a measure of the amount of protein (albumin) excreted in the urine showing the 'leakiness' of the kidneys and therefore indicating kidney disease. 'Quality of life' is "a multidimensional construct incorporating an individual's subjective perception of physical and social well being, including both a cognitive component (satisfaction) and an emotional component (happiness)," (p.21), (Rubin, 2000). 'Health-related quality of life' specifically relates to how health and disease can impact on quality of life and can be split into 'overall' and 'diabetes specific health-related quality of life' (Polonsky, 2000). 'Overall health-related quality of life' is a measure of "the patient's sense of his own health and well-being in the broad areas of physical, psychological, and social functioning," (p.37), (Polonsky, 2000) and is useful for comparisons between different illnesses or populations. 'Diabetes specific health-related quality of life' refers to a patient's perceptions of how diabetes affects their well being in relation to physical, psychological, and social functioning (Polonsky, 2000). Hereafter the term 'quality of life' will be used in relation to overall health-related quality of life and diabetes specific health-related quality of life is referred to as 'diabetes specific quality of life.'

3.0.2 Health of youth with Type 1 diabetes

The effects of having Type 1 diabetes on health are briefly summarised here. Previous research has found that youth with Type 1 diabetes can have poorer health in relation to their peers without diabetes, particularly if glycaemic control is not optimal. 'Diabetic ketoacidosis' is the presence of hyperglycaemia (blood glucose >11 mmol/L), acidosis (blood pH <7.3 or bicarbonate <15 mmol/L), ketonaemia (ketones in the blood) and ketonuria (ketones in urine) (Wolfsdorf et al., 2009), and is a condition that can lead to diabetic coma if left untreated. Youth with diabetes have the greatest incidence of very poor blood glucose control and risk of diabetic ketoacidosis compared to other age groups (Diabetes UK, 2012). Poor blood glucose control makes youth more prone to poorer health outcomes than patients with better control. Patients with Type 1 diabetes are at an increased risk of death compared to people without diabetes (Laing et al., 2003) and specifically in youth mortality rates have been shown to be three-fold greater than in youth without diabetes (O'Grady, Timothy, Jones, & Davis, 2013). As mentioned earlier, in people with Type 1 diabetes (of all ages), cardiovascular disease is the main cause of mortality (Diabetes UK, 2012). Specifically in patients with Type 1 diabetes that have died during youth, the leading cause of death is from diabetic ketoacidosis (O'Grady, et al., 2013). Cardiovascular disease risk factors, such as hyperglycemia, dyslipidaemia and insulin resistance, have been reported in young patients with Type 1 diabetes (Snell-Bergeon & Nadeau, 2012) and the early stages of microvascular complications can be evident at 2-5 years post diagnosis (Cho et al., 2011). A population-based study including data from 1,658 children and adolescents with Type 1 diabetes from 25 out of a total of 26 paediatric clinics in Norway, explored the prevalence of cardiovascular disease risk factors. A total of 86% of all participants had at least one cardiovascular risk factor, 45% had two or more and 15% had at least three or more. The age range of participants was from 1.1-23.2 years, (mean age of 13.1 years) and diabetes duration ranged from 0.6-18.5 years (mean duration of 5.7 years) (Margeirsdottir, Larsen, Brunborg, Øverby, & Dahl-Jørgensen, 2007). Almost all patients with Type 1 diabetes will develop signs of retinopathy during the first 20 years of diagnosis (Scanlon, 2008).

Systematic review level evidence has established that youth with Type 1 diabetes: are at greater risk of depression (Grey, Whittemore, & Tamborlane, 2002) compared to their peers without diabetes and that those with greater depression also have poorer HbA1c levels (Johnson, Eiser, Young, Brierley, & Heller, 2013); can have lower cognitive performance compared to those without diabetes (Gaudieri, Chen, Greer, & Holmes, 2008; Naguib, Kulinskaya, Lomax, & Garralda, 2009); and that disease-specific issues can negatively impact on areas of quality of life in patients (Nieuwesteeg et al., 2012).

A literature review suggested the following health outcomes are worse in people with Type 1 diabetes (youth and adults) compared to people without diabetes: cardiorespiratory fitness; blood pressure; triglycerides, LDL and HDL cholesterol levels; vascular disease risk and endothelial function (particularly in patients with microalbuminuria); cardiovascular disease and mortality risk; insulin resistance; depression; and bone mineral density and risk of osteoporosis and/or bone fracture (Chimen et al., 2012). A review of observational studies also found cardiorespiratory fitness appears to be in the low range specifically in youth with diabetes (Liese, Ma, Maahs, & Trilk, 2012).

Individual studies comparing health of youth with Type 1 diabetes to healthy peers without diabetes have reported: poorer physiological outcomes, such as low cardiovascular fitness (Lukács et al., 2012; Williams, Guelfi, Jones, & Davis, 2011) and reduced bone turnover (A.B. Maggio et al., 2010); lower educational attainment (Wennick, Hallström, Lindgren, & Bolin, 2011); and impaired psychosocial health outcomes (Grey, Cameron, Lipman, & Thurber, 1995; Moussa et al., 2005). Disturbed eating behaviours, particularly in adolescent girls have also been reported in youth with Type 1 diabetes (Colton, Olmsted, Daneman, & Rodin, 2013).

In summary, published research highlights that youth with Type 1 diabetes are an important target group not only because of the increasing prevalence of the condition but also because of the negative impacts the condition can have on many areas of health. Often health is poorer in youth with Type 1 diabetes in relation to peers without diabetes and the patient can be at an increased risk of developing diabetic complications. Interventions improving health are thus important in this target group.

4.0 Definition of Physical activity, METs and sedentary behaviour

Physical activity is any body movement that results in an increase in energy expenditure above resting values. ‘Metabolic equivalents’ (METs) are a ratio of metabolic rate during physical activity to resting metabolic rate and relate to oxygen consumption and thus energy expenditure of physical activity (Ainsworth et al., 2011). Resting metabolic rate (RMR) refers to the amount of energy consumed under resting conditions and is equal to 1 MET. As the intensity of physical activity increases, oxygen consumption and energy expenditure also increase and the MET value in multiples of RMR rises too. Moderate intensity physical activity equates to approximately 3-6 METs (3-6 times greater energy expenditure than when at rest) and vigorous intensity physical activity is >6 METs (Ainsworth, et al., 2011). ‘Sedentary behaviour’ is used throughout this thesis to describe “any waking behaviour characterised by an energy expenditure ≤1.5 METs while in a sitting or reclining posture” (p.540), (Sedentary Behaviour Research Network., 2012).

5.0 The physical inactivity pandemic

“In view of the prevalence, global reach, and health effect of physical inactivity, the issue should be appropriately described as pandemic, with far-reaching health, economic, environmental, and social consequences,” (p.67) (Kohl. et al., 2012). Physical inactivity is the fourth leading cause of mortality in the world (World Health Organization., 2009), resulting in 6-10% of the four main non-communicable diseases (coronary heart disease, Type 2 diabetes, breast and colon cancer) and 9% of premature deaths (over 5.3 million deaths in 2008) (Lee et al., 2012). Global estimates suggest that 80.3% of adolescents aged 13-15 years are not sufficiently active for health benefits and that 66% of boys and 68% of girls watch TV for at least two hours/day (Hallal et al., 2012). Specifically in Scotland, the latest Scottish Health Survey (2012) reported that 24% of boys and 30% of girls are not sufficiently physically active to accrue health benefits (The Scottish Government, 2012b). The Scottish Health Survey estimates rely on self-report measures and are likely an overestimation of the true activity levels of youth. The bias of self-report has been confirmed from comparisons with objective measures of physical activity in the measurement of national activity levels in the US (Troiano et al., 2008) and in the

UK in a sub-sample of individuals completing the Health Survey for England (Basterfield et al., 2008). Despite the limitations in measurement, national surveys provide benchmark measures of physical activity levels. Scotland has a physical activity strategy in place ('Let's Make Scotland More Active'), with a goal for the year 2022 that 80% of children aged ≤16 years achieve sufficient physical activity levels for health benefits (Physical Activity Task Force, 2003). There is therefore a need to promote physical activity in youth in Scotland, particularly in girls, if the physical activity strategy target is to be met. Specifically in schools in Scotland, there is an aim to include two hours of physical education in the weekly schedules of primary aged pupils and two periods in high school aged pupils, by the year 2014 (Scottish Executive, 2007). A recent survey suggests that 84% of primary schools and 92% of secondary schools are achieving the two hour and two period targets, respectively (The Scottish Government, 2012a). Thus there is also room for improvement in increasing physical activity levels in youth via physical education in schools, and in particular in primary schools.

The Toronto Charter for physical activity was launched in 2010 (Global Advocacy Council for Physical Activity & International Society for Physical Activity and Health, 2010) and was followed by a publication focusing on non-communicable disease prevention (Global Advocacy for Physical activity (GAPA) the advocacy council of the International Society for Physical Activity and Health (ISPAH), 2011). Both highlight the need for physical activity promotion in patients at risk of, or living with, non-communicable disease as priority groups. In addition the International Play Association declaration of the child's right to play in 1977 and Article 31 of the United Nations convention on the rights of the child state that every child has a right to leisure and play (International Play Association, 1977).

6.0 Physical activity and sedentary behaviour recommendations and guidance

The physical activity recommendations for youth with Type 1 diabetes are the same as for youth without diabetes; to undertake a minimum of 60 minutes of moderate to vigorous physical activity (MVPA) per day for youth aged 5-18 years (UK Department of Health, 2011). The 60 minutes can be accumulated in bouts of 10 minutes or more and includes activities such as play and activities of daily living (e.g. walking to school, carrying shopping, climbing stairs). In addition youth should perform weight-bearing activity on a minimum of three days of the week. Weight-bearing activities include activities that youth often engage in during play such as running, jumping and skipping as well as more structured weight or resistance band training. The UK guidance also recommends that children and young people minimise the amount of time they spend in sedentary behaviour (UK Department of Health, 2011).

Physical activity is recognised as one of the cornerstones of diabetes management (Diabetes UK, 2005; Pihoker, Forsander, Wolfsdorf, & Klingensmith, 2009; Sigal, Kenny, Wasserman, Castaneda-Sceppa, & White, 2006). Guidance has been published specifically for individuals with Type 1 diabetes on how to manage diabetes effectively during physical activity (American Diabetes Association, 2002; National Institute for Clinical Excellence, 2004; Robertson, Adolfsson, Riddell, Scheiner, & Hanas, 2008). The ultimate goal in relation to physical activity in patients with Type 1 diabetes is to allow the patient to have the same opportunities and benefits as individuals without diabetes (American Diabetes Association, 2002). Specific health benefits of physical activity for youth with Type 1 diabetes are covered in a systematic review conducted as part of this thesis (chapter 3, paper 2).

Recommendations in relation to physical activity for youth with Type 1 diabetes include the following: regular physical activity should be encouraged in all patients; all types and levels of activity should be accessible with sufficient preparation in patients that are complication free and detailed advice from diabetes professionals and/or outside clinic support should be available to youth planning to participate in activities restricted for those with diabetes (e.g. scuba diving); diabetes professionals should equip patients and their parents with knowledge on the metabolic and hormonal effects of physical activity and strategies for controlling blood glucose prior to, during and after physical activity; blood glucose monitoring prior to, during and after activity should be promoted to understand changes in levels as a result of undertaking activities, to consider exercise induced and post-exercise hypoglycaemia and to improve performance; patients should be given tailored advice about the correct amount of carbohydrate to consume, how to adjust insulin adequately prior to participation for different activities and to have carbohydrate available whilst active and after activity; and patients should be taught to avoid physical activity if they have diabetic ketoacidosis (International Diabetes Federation, 2011; National Institute for Clinical Excellence, 2004; Robertson, et al., 2008). Specifically if blood glucose is particularly high (>14 mmol/l) and ketones are in the urine or blood then those with Type 1 diabetes should not be physically active until resolved. If there are no ketones in the blood or urine, the patient has no symptoms of illness, and blood glucose is <14 mmol/l, then hyperglycaemia does not require avoidance of physical activity (American Diabetes Association, 2011). Restrictions on activity may be required in people with long-term complications, such as avoidance of activities that can greatly raise blood pressure in patients with retinopathy or nephropathy (Robertson, et al., 2008). Blood glucose levels can be more erratic in youth (due to hormone changes in adolescents and intermittent patterns of physical activity in younger patients) than older patients with Type 1 diabetes during physical activity. Support for youth is therefore recommended from parents, teachers and coaches to attempt to control blood glucose levels as best as possible (American Diabetes Association, 2002). Participation in sports at school is particularly recommended for newly diagnosed patients for social inclusion benefits (American Diabetes Association, 2005).

7.0 Physical activity and sedentary behaviour participation in youth with Type 1 diabetes

Despite the recommendations and guidance available for safe participation in physical activity in youth with Type 1 diabetes, research has found conflicting results relating to whether patients meet the guidelines or if they are as active as their counterparts without diabetes. Physical activity and sedentary behaviour measurement studies are discussed in more detail in chapter 2. To briefly summarise here, limitations of previously published literature in this area are that the majority of studies did not report their recruitment phase fully and thus it is not clear if samples were representative of the population. Also studies have not always employed strong evidence based methodologies.

Sedentary behaviour is increasingly being studied. Research has found in adults that mortality from all causes and development of cardiovascular disease is increased in a dose-response manner with increasing length of sedentary behaviour independent of, if an individual is meeting the physical activity recommendations (Katzmarzyk, Church, Craig, & Bouchard, 2009). The literature on sedentary behaviour in relation to health in youth is less clear and more studies are required to explore this relationship further. A systematic review of sedentary behaviour studies in school aged youth found that more than two hours of television watching per day was associated with poorer physiological and psychosocial health outcomes, in a dose-response manner and independent of physical activity. A meta-analysis conducted as part of this review identified an overall significant improvement in body mass index (BMI), in sedentary behaviour RCT intervention studies (Tremblay et al., 2011). Although the review was comprehensive, a limitation was that studies measuring sedentary behaviour subjectively were included, which may have resulted in biased results. In contrast to the review, a recent study measuring sedentary behaviour objectively in 1,608 youth did not find an association between sedentary behaviour and BMI, waist circumference, blood pressure or non-HDL cholesterol (Colley et al., 2013). Poorer glycaemic control has been linked with self-reported sedentary behaviour (sitting whilst watching television) in youth with Type 1 diabetes (Margeirsdottir, Larsen, Brunborg, Sandvik, & Dahl-Joergensen, 2007). Discouraging sedentary behaviour in this population may therefore be important due to the potential health implications that can arise. Limited research has explored sedentary behaviour in youth with Type 1 diabetes and in particular using objective measurements.

To summarise, there is evidence in adults and youth without diabetes, that physical activity and sedentary behaviour can both independently impact on health, and public health recommendations relating to these behaviour's exist. However, specifically in youth with Type 1 diabetes, there is a paucity of evidence to support the promotion of physical activity and minimisation of sedentary behaviour, and little is known in regards to the dose response to these behaviours on health. It is therefore important to measure physical activity and sedentary behaviour levels accurately in this target group and to determine the effects of physical activity and sedentary behaviour on health outcomes, in particular on the key health objectives for youth of improving HbA1c and reducing insulin dose requirements. Due to limitations in methodologies and/or recruitment reporting it is not clear if youth with Type 1 diabetes adhere to physical activity guidelines or if they are achieving similar levels and patterns to youth without diabetes. In addition, physical activity and sedentary behaviour levels and patterns have not been measured specifically in Scottish youth with Type 1 diabetes.

8.0 Acute physiological responses to physical activity and sedentary behaviour

In individuals without diabetes autonomic and hormonal regulation maintain blood glucose levels during physical activity. In patients with Type 1 diabetes hormonal regulation does not occur and too little or too much exogenous insulin can lead to hyper or hypoglycaemia. During moderate intensity physical activity in someone without diabetes, there is an increase in blood flow to skeletal muscles and an increase in glucose uptake from the blood via non-insulin mediated glucose transport into cells resulting in a lowering of the concentration of blood glucose. Reduced blood glucose levels lead to a decrease in insulin secretion and an increase in counter-regulatory hormone (glucagon, catecholamines, growth hormone and cortisol) secretion, which stimulate the production of liver glucose to match the amount of glucose being utilised by the working muscles. Therefore blood glucose levels remain stable (normoglycaemia). Throughout activity, glucose production will increase as exercise intensity increases by hepatic glycogenolysis (the breakdown of glycogen stored in the liver to glucose).

In an individual with Type 1 diabetes, insulin levels are not regulated during activity and counter-regulation can be insufficient. Impaired insulin and counter hormone regulation result in no change or too much insulin secretion during physical activity, ultimately resulting in hypoglycaemia. At rest and during physical activity in a patient with reasonably well-controlled Type 1 diabetes, rates of glucose production are raised. This is due to gluconeogenesis (the production of glucose from non-carbohydrate substrates). Responses to physical activity are individualised and can be affected by several factors resulting in hypoglycaemia, hyperglycaemia or normoglycaemia. If a patient participates in the same activity on two different days, whilst adhering to the same insulin and meal regimen, then the effects of the activity will be reasonably similar. Factors that can lead to an increased risk of hypoglycaemia during physical activity include: hyperinsulinaemia (too much insulin), a consequence of injecting insulin too close to the active muscles, from injecting at the peak of the insulin action period, or from too large a dose; participation in a new activity that the individual is not trained in and therefore energy expenditure is raised; prolonged activity lasting over 30-60 minutes and/or no additional carbohydrate supplementation; and moderate intensity aerobic activity. Normoglycaemia occurs if insulin administration is adequately adjusted for the activity and/or if an adequate amount of carbohydrate is eaten. Hyperglycaemia can be caused by the following factors: hypoinsulinaemia (too little insulin) in advance of or during the activity; too much carbohydrate intake prior to the activity; an adrenal reaction from the emotions of participating in a competitive activity or from short, dispersed bouts of high intensity activity; or if the production of glucose is greater than required glucose following activity. Thus glucose levels during and after activity will depend on: the type, duration, intensity and timing of the activity as well as the amount of muscle groups/mass involved; the type of insulin administered or food consumed, how much and when in relation to activity; metabolic control of the patient; blood glucose level; the absorption rate of insulin; the training status of the individual; and the level of competition or stress as a result of engaging in the activity (Robertson, et al., 2008).

Insulin sensitivity (Short, Pratt, Teague, Dalla Man, & Cobelli, 2013) and activation of GLUT-4 glucose transporters (Kennedy et al., 1999) are increased in muscles during and after physical activity. In adolescents with Type 1 diabetes insulin sensitivity has been shown to be elevated for up to 11 hours post activity in a supervised, controlled lab setting (McMahon et al., 2007). Real life activity outside of the lab can result in raised insulin sensitivity for a minimum of 24 hours, increasing the risk of hypoglycaemia during this period (McMahon, et al., 2007). Therefore in youth that are not active on a regular basis and only at random, managing insulin levels can be challenging. In these individuals techniques for adjusting insulin to cope with random activity are required. A benefit of regular daily rather than random activity is that it is easier to prepare for and manage, especially if blood glucose and dietary intake diaries are kept (Robertson, et al., 2008). To aid replenishment of glycogen stores and reduce the risk of hypoglycaemia, a high carbohydrate content meal should be eaten after activity when insulin sensitivity is high and insulin dose reduced accordingly. Late or delayed hypoglycaemia is more likely to result after prolonged activity of moderate or greater intensity due to increased insulin sensitivity coupled with the time taken to replenish glycogen stores in muscle and liver. Nocturnal hypoglycaemia is difficult to predict based on bedtime readings but if blood glucose is <7.0 mmol/L then action should be taken (Robertson, et al., 2008).

The physiological mechanisms as to why sedentary behaviour is detrimental to health, is currently an emerging field of research (Owen, Healy, Matthew, & Dunstan, 2010; Tremblay, Colley, Saunders, Healy, & Owen, 2010). Studies of individuals exhibiting increased sedentary behaviour, such as in patients subject to bed rest, have provided illuminating sedentary physiology findings. Metabolic effects associated with sedentary behaviour include reduced lipoprotein lipase activity and thus decreased free fatty acid uptake, as well as decreased GLUT protein concentration, and therefore reduced glucose uptake. Poorer bone health has also been shown to be associated with sedentary behaviour, with increased bone resorption (indicated by markers of resorption such as urinary calcium), in the absence of changes in bone formation. In addition poor vascular health has been shown to be associated with high levels of sedentary behaviour as a result of reductions in peripheral vascular function (Tremblay, et al., 2010).

9.0 Adverse events during physical activity and barriers to physical activity participation

A review on the risks of physical activity in Type 1 diabetes (including adults) concluded that hypoglycaemia was the most common risk (whilst being active or following activity), but in most instances was not severe. No studies reported deaths from physical activity (Riddell & Burr, 2011). The ADA reported between 10-20% of hypoglycaemic episodes are the result of physical activity participation in youth with Type 1 diabetes (American Diabetes Association, 2005). In a sample of 91 youth with Type 1 diabetes, 38% reported having episodes of hypoglycaemia during or after physical activity and 18% experienced hyperglycaemia. Only 12% of hypoglycaemic episodes were symptomatic and the number of episodes was similar in those participating in sports as to those participating in non-competitive physical activity. Symptomatic nocturnal hypoglycaemia was reported by 10% of patients and nobody reported ketoacidosis (Bernardini et al., 2004). Delayed hypoglycaemia is common in youth with Type 1 diabetes. On a night following physical activity for 60 minutes delayed hypoglycaemia occurred in 48% of 50 youth with Type 1 diabetes. When the same children did not participate in physical activity, only 28% experienced hypoglycaemia that night (The Diabetes Research in Children Network (DirectNet) Study Group, 2005). The main perceived barrier to physical activity participation in adults with Type 1 diabetes was found to be fear of hypoglycaemia, as measured by questionnaire, with more barriers to physical activity being correlated with poorer blood glucose control ($r = 0.203$) and well-being ($r = -0.45$) (Brazeau, Rabasa-Lhoret, Strychar, & Mircescu, 2008).

10.0 Developing a complex health intervention: Design of the thesis

The structure of this thesis has been designed based on the framework for developing and evaluating complex health interventions published by the UK's Medical Research Council (MRC) in 2000 (Campbell, et al., 2000) and since updated in 2008 (Craig, et al., 2008). Complex interventions have many components that work independently and inter-dependently (Campbell, et al., 2000). Intervention components normally include the following: behaviours (such as physical activity or sedentary behaviour); parameters of behaviours (e.g. for physical activity this could include the frequency, intensity, time and type of activity); and methods to organise and deliver the behaviour (e.g. the interventionist and recruitment and delivery settings). In the updated guidance suggested additional features that make an intervention complex were identified (such as many or a variety of outcomes and focusing on several or difficult lifestyle behaviours) (Craig, et al., 2008). Initially the framework was developed as a sequential process with five distinct phases (Figure 1.1), with each subsequent phase increasing in the level of evidence: 1) Pre-clinical or theoretical; 2) Phase I or modelling; 3) Phase II or exploratory trial; 4) Phase III or definitive RCT; 5) Phase IV or long term implementation (Campbell, et al., 2000). The framework has been adapted to no longer follow a linear or sequential flow (Craig, et al., 2008). Figure 1.2 illustrates the newest framework consisting of development, feasibility and pilot testing, evaluation and implementation phases. The pre-clinical/theoretical and development phase from the original and updated framework respectively are discussed here as this thesis involves research falling under these stages. Chapter 6 discusses the remaining stages of the framework in relation to future research and practice.

Figure 1.1 The original MRC framework by Campbell et al., 2000

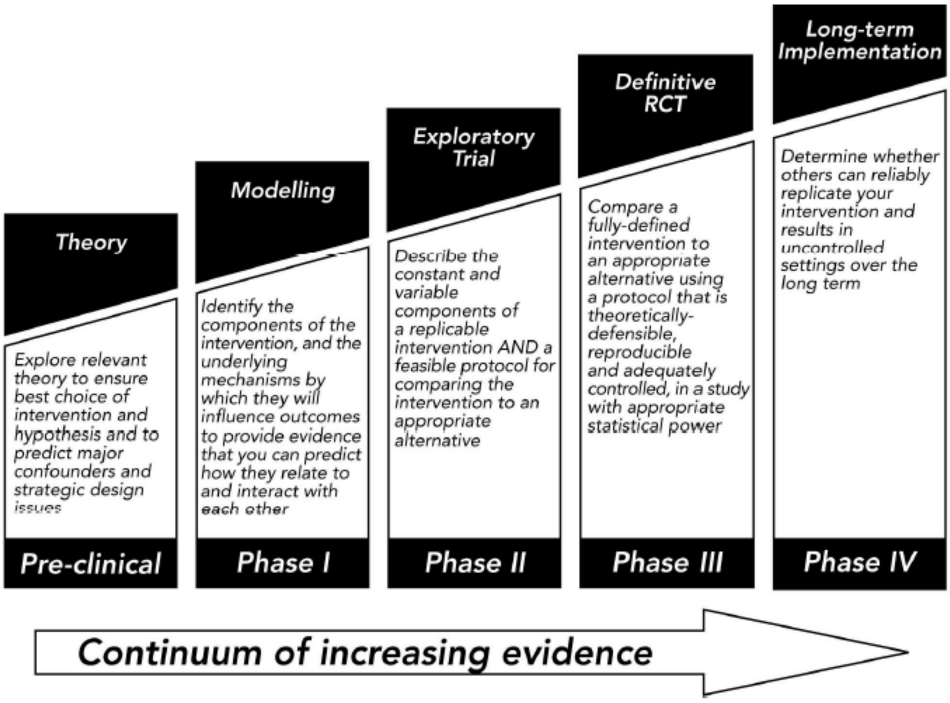
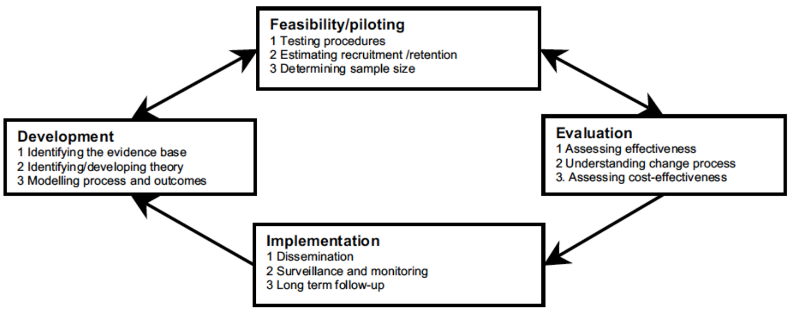


Figure 1.2 The updated MRC framework by Craig et al., 2008



During the pre-clinical phase (Figure 1.1), potential ‘active’ ingredients, (specific ingredients that make an intervention work), should be identified by exploring previous research and theories to base the intervention on. The worth of combining quantitative and qualitative research is highlighted as being important for evaluation during study design, conduction and implementation of the intervention into care (Campbell, et al., 2000).

The updated framework (Figure 1.2) recommends that researchers start the development phase by conducting a systematic review (if one has not already been published), of similar interventions and consulting theory. New primary research should be conducted early on in the development phase, if required, to build the argument for the intervention and identify expected changes and how changes may come about.

This PhD thesis follows the MRC guidance on how to develop a complex health intervention. Physical activity and sedentary behaviour in Scottish youth with Type 1 diabetes was explored quantitatively in paper 1 and qualitatively in papers 3-4, as these behaviours had not previously been explored in a Scottish sample. No systematic reviews had been published prior to this thesis exploring physical activity and sedentary behaviour interventions specifically tested in RCTs in youth with Type 1 diabetes. Therefore a systematic review in this area was conducted as part of this thesis (paper 2) focusing on study characteristics, intervention design and efficacy on health. Papers 1, 3 and 4 therefore bring new evidence whilst paper 2 pools evidence from previously published research, to aid the design of a physical activity and sedentary behaviour intervention. It is anticipated that the findings from papers 1-4, alongside previously published work in the topic area and on the development of theory based interventions, will be used to develop a complex health behaviour change intervention in the future.

10.0.1 Mixed method studies in health intervention development

Mixing methods, the use of a combination of qualitative and quantitative research methodology (also known as multi-strategy research), can “compensate for the perceived shortcomings of stand-alone methods,” to provide a “more complete picture or enhance coverage," (p.151) (Barbour, 2007) and fill in the gaps (Bryman, 2012). Physical activity and sedentary behaviour are difficult behaviours to measure. Bryman refers to mixed methods research as a way of combining 'static' and 'processual' components of social life (Bryman, 2012). For example accelerometers provide a static measure of physical activity and sedentary behaviour but interviews can build on these findings to determine factors such as why physical activity or sedentary behaviour is undertaken. Objective measurement tools and some subjective measurement tools provide quantitative data on levels and patterns of physical activity and sedentary behaviour – the 'what' participants are doing. Qualitative methods can provide in-depth contextual and social insights into physical activity and sedentary behaviour – the 'why' and 'how' individuals behave in a certain way. Qualitative and quantitative methodology can be employed in tandem to provide parallel but different types of data as is the case in this PhD. The goal of using different methods ('triangulation,' which is discussed in more depth in chapter 4) is to build "a fuller picture of phenomena, not necessarily a more certain one" (p.44) (Ritchie, 2003). In relation to this PhD, accelerometers were used to quantify how much physical activity and sedentary behaviour patients were doing and when. Questionnaires were used to determine the type of physical activity and sedentary behaviour undertaken as well as to assess quality of life. Interviews and focus groups were used to explore: what behaviours patients were participating in and why; who influences behaviours and how; the settings of these behaviours; and perceptions on what may or may not help individual's to become more physically active and less sedentary.

10.0.2 Ontological and epistemological underpinnings of the research

'Ontology', in relation to social research refers, to "the nature of the social world and what can be known of it" (p.22) and has three main positions, each with their own variant positions (Snape & Spencer, 2003). 'Realism' affirms "that there is an external reality which exists independently of people's beliefs or understandings about it" (p.11), (Snape & Spencer, 2003). So despite the perception and interpretation of the world by an individual, there are differences to what the world is actually like. 'Idealism' suggests that "reality is only knowable through the human mind and through socially constructed meanings" (p.11) (Snape & Spencer, 2003). 'Materialism' claims "there is a real world but that only material features, such as economic relations, or physical features of that world hold reality" (p.11) (Snape & Spencer, 2003).

'Epistemology' relates to "the ways of knowing and learning about the social world" (p. 13) (Snape & Spencer, 2003). 'Positivism' and 'interpretivism' are the main epistemological paradigms. 'Positivism' follows that "methods of the natural sciences are appropriate for social enquiry because human behaviour is governed by law-like regularities; and that it is possible to carry out independent, objective and value free social research" (p.23) (Snape & Spencer, 2003). 'Quantitative research' mostly falls into the positivist tradition, although not always, and tends to explore "hypothesis testing, causal explanations, generalisation and predication" (p.14) (Snape & Spencer, 2003). 'Interpretivism' on the other hand suggests that "natural science methods are not appropriate for social investigation because the social world is not governed by regularities that hold law-like properties" (p.23) (Snape & Spencer, 2003). Thus, in the interpretivist approach the researcher gains knowledge on the social world via participant's perceptions.

A third epistemological approach, which best describes the research undertaken in this thesis, is pragmatism. This approach suggests that quantitative and qualitative methods can be used to complement one another rather than being in competition or contradiction to each other, thus providing a better understanding and in-depth picture than using only one method. Rather than planning and conducting research based on philosophical stance, pragmatists select the most suitable methods to answer the research questions (Seale, 1999).

The ontological position that best describes the qualitative research in this thesis is 'subtle realism,' which accepts "the social world does exist independently of individual subjective understanding, but that it is only accessible…via the respondents' interpretations" (p. 19) (Snape & Spencer, 2003). Subtle realism accepts that individual differences in interpretations will be evident (either interpretations provided from the participants or from the researcher in relation to the participants interpretation). Reflexivity (awareness of the researcher's contribution to the interpretation of research) is thus important and is reported in the write up of the qualitative research in this thesis (papers 3 and 4). The epistemological approach adopted for the research in this thesis is largely based on pragmatism and draws on concepts from positivism and interpretivism. Attempts have been made to collect objective, neutral data. For example non-leading questions were used in interview and focus group discussions in an attempt to reduce the researcher influence on the data. Reliability and validity are also important and steps were taken to ensure rigour, which are detailed in the papers. Interpretivism was incorporated into the research as in-depth insights into participant's perceptions were gained. The steps taken to translate the participant's interpretations into the researcher's report are stated in papers 3 and 4. Finally pragmatism was evident in the research as the methods selected were based on the best way to answer the research questions rather than limiting the methods that could be employed by following only a positivist or interpretivist approach.

11.0 Structure of the thesis and purpose of the research

Chapters 2-5 of this thesis are presented in the format of manuscripts, prepared for peer-reviewed journals. Manuscripts have been prepared in terms of structure and word count to meet the requirements of the journals that they have been or will be submitted to. However exact formatting for target journals has not been used in this thesis but instead consistent formatting to allow for easier reading (such as page numbers being located at the bottom right hand corner of pages and the same indentation used in all manuscripts, as well as table numbers adjusted as to where they fit in the overall thesis). Each of these chapters (2-5) has a short preface introducing the manuscript/paper and summary section to link manuscripts/papers together. Given the space restrictions imposed by journals, following or prior to the publications/manuscripts in each chapter there is extra information on the methodology, additional analysis, and/or further comparisons with other research where necessary. The overall purpose of this thesis was to explore physical activity and sedentary behaviour in youth with Type 1 diabetes. The findings of this thesis will aid the development of future physical activity and/or sedentary behaviour interventions to support patients to increase and/or maintain physical activity participation and minimise sedentary behaviour. The thesis adds to existing literature by addressing several research gaps.

Chapter 2 (paper 1) provides the findings of a cross-sectional study measuring physical activity, sedentary behaviour and quality of life in a sample of Scottish youth and is currently in preparation for submission. Paper 1 addresses the lack of consistent findings in the measurement of physical activity and sedentary behaviour and adds to the limited quality of life research published in youth with Type 1 diabetes. The purpose of the second study (paper 2, chapter 3) was to address the gap in high quality evidence covering the literature on physical activity and sedentary behaviour interventions in youth with Type 1 diabetes. Paper 2 has been published in its current format in Pediatric Diabetes. To address the gap in qualitative research exploring physical activity and sedentary behaviour in youth with Type 1 diabetes and influential figures, studies exploring the perceptions of patients, their parents and diabetes professionals (chapter 4, paper 3) as well as schoolteachers (chapter 5, paper 4) were undertaken. Papers 3 and 4 are currently under review.

The final chapter of this thesis, (chapter 6): collates the findings of papers 1-4 (chapters 2-5) and provides an overall summary of the key findings; summarises the implications for future research and practice; and highlights the limitations of the thesis.

12.0 Overall thesis research questions

In chapters 2-5 the specific aims of each study are provided. This thesis addresses the following research questions:

1) What are physical activity, sedentary behaviour and quality of life levels and patterns in a sample of Scottish youth with Type 1 diabetes? How can patterns and levels inform future interventions? (chapter 2)

2) What are the study characteristics, intervention design features and intervention efficacy on health of previously published randomised controlled trial (RCT), physical activity and sedentary behaviour intervention studies of youth with Type 1

diabetes? How can summarising these studies help design future interventions and studies? (chapter 3)

3) What do patients, parents and diabetes professionals think can be done in diabetes care (clinic, home and community settings), to help those with Type 1 diabetes to be more physically active and less sedentary? (chapter 4)

4) What do patients, parents, diabetes professionals and school teachers think can be done to help youth with Type 1 diabetes to be more physically active in schools? (chapter 5)

13.0 Summary of chapter 1

To summarise, the aim of this thesis is to aid the development of physical activity and sedentary behaviour interventions for youth with Type 1 diabetes. The thesis structure was designed following early developmental phase guidance on designing complex health improvement interventions. Consultation of current literature identified youth with Type 1 diabetes as an important target group due to impaired health compared to peers without diabetes. Regular physical activity and minimal sedentary behaviour were identified as potential lifestyle behaviours that could positively impact on the health of youth with Type 1 diabetes. Literature searching also highlighted inconsistencies in the findings of physical activity and sedentary behaviour measurement studies in youth with Type 1 diabetes, which could be due to differences in data handling and processing decisions and unrepresentative samples of the population. Additionally the need for studies measuring quality of life in youth with Type 1 diabetes was noted. Primary research to address these research gaps by means of conducting a physical activity, sedentary behaviour and quality of life measurement study was undertaken using evidence based measures and full reporting of the recruitment phase was ensured to conclude on representativeness (paper 1). High quality evidence for the efficacy of physical activity and sedentary behaviour interventions on health, as well as a summary of previous study characteristics and intervention designs to help future research, does not exist in this target population. A systematic review of RCT intervention studies was thus carried out to fill this research gap (paper 2). Limited qualitative research on physical activity and sedentary behaviour participation in youth with Type 1 diabetes with patients and influential figures in their life was also identified during literature searching. Key potential stakeholders for the intervention were therefore included in qualitative studies exploring perceptions of physical activity and sedentary behaviour in youth with Type 1 diabetes and intervention needs (papers 3 and 4). Combined findings from papers 1-4 will inform the development and design of interventions targeting physical activity and sedentary behaviour in youth with Type 1 diabetes.

Chapter 2: Physical activity, sedentary behaviour and quality of life in Scottish youth with Type 1 diabetes

1.0 Preface

This chapter begins by summarising briefly physical activity and sedentary behaviour measurement studies in youth with Type 1 diabetes to introduce the reader to the need for study 1. A summary of physical activity and sedentary behaviour data processing issues is then provided. Paper 1 then follows, which investigates physical activity, sedentary behaviour and quality of life in a sample of Scottish youth with Type 1 diabetes. The paper addresses the need for measurement studies in this target population employing evidence-based data collection and reporting fully on recruitment to determine representativeness. NHS and University ethics approval were required for studies 1 and 3 (papers 1, 3 and 4). The NHS ethics approval letter and parent/carer information sheet relating to studies 1 and 3 can be found in appendix A and B, respectively.

2.0 Physical activity and sedentary behaviour measurement studies in youth with Type 1 diabetes

Several studies have measured physical activity and sedentary behaviour levels of youth with Type 1 diabetes either objectively or subjectively. Findings from these studies are conflicting in terms of whether youth with Type 1 diabetes meet the physical activity recommendations (≥ 60 minutes of MVPA/day (UK Department of Health, 2011)) and if they are as active as their peers without diabetes. Three main factors could explain conflicting results. Firstly subjective measures of the amount of physical activity or sedentary behaviour may be subject to recall bias particularly in youth who may find it difficult to contextualise these behaviours due to their cognitive and linguistic level (Sallis, 1991). As trustworthiness of subjective findings is questionable this literature review focused on objective or combined objective and subjective measurement studies. Secondly representativeness of the sample is important and is primarily determined by recruitment strategies. Limited reporting of recruitment across studies makes it difficult to comment on sample representativeness. Thirdly the validity and reliability of the measurement tool as well as data processing decisions can impact on the output and conclusions (the impact these decisions can have on data are summarised briefly in the next section of this chapter). Paper 1 compares findings with previously published studies of youth with (Cuenca-Garcia, Jago, Shield, & Burren, 2012; A. B. Maggio et al., 2010; Sundberg, Forsander, Fasth, & Ekelund, 2012; Trigona et al., 2010) and without diabetes (Basterfield et al., 2011; Riddoch et al., 2009). Here the findings of a recent review summarising observational measurement studies of physical activity, fitness and sedentary behaviour in youth with Type 1 and Type 2 diabetes are reported (Liese, et al., 2012). Following this a short summary of the findings from papers included in paper two as well as from other studies incorporating objective measures of behaviour is provided. Table 2.1 provides further details of each measurement study.

Objective methods to measure physical activity, physical fitness or sedentary behaviour identified in a review of measurement studies in youth with diabetes were: heart rate monitoring (*n*=4), fitness testing (*n*=4), pedometry (*n*=1), accelerometry (*n*=3) and hybrid technology (combining measures - in this case several physiological measures and accelerometry) (*n*=1) (Liese, et al., 2012). Time in MVPA ranged from 46-70 minutes across the studies. Boys tended to do more physical activity than girls. A large proportion of youth with Type 1 diabetes were not reaching the physical activity guidelines. From sedentary behaviour questionnaires it was identified that large amounts of time were spent watching television, with some studies finding television and electronic media use was greater on weekends than weekdays. Limitations of the studies included: small samples; no data on type of physical activities; and limited data on physical activity and sedentary behaviour patterns (Liese, et al., 2012). Although the review was conducted in a systematic fashion, only observational studies were included from the searching of one database and bias was not assessed in a standardised way.

A discussion of studies that have measured physical activity and sedentary behaviour objectively in youth with Type 1 diabetes follows. Fifteen studies including patients aged 3-19 years were identified, with the first having been published in 2005

(Särnblad, Ekelund, & Åman, 2005). Conflicting results have been reported in these studies (Table 2.1).

Table 2.1: Objective physical activity and sedentary behaviour measurement studies in youth with Type 1 diabetes

Author & publication year, country, study aim, participants	Outcome measures	Results	Data collection & analysis decisions
(Cuenca-Garcia, et al., 2012) England Aim: To assess PA and fitness levels of young people with T1D compared with non-diabetic siblings and to investigate the association between physical activity, fitness and HbA1c for those with T1D controlling for confounding factors Participants: 60 youth with T1D aged 8-16yrs and 37 siblings without diabetes. HbA1c was 8.4 ±1.1% and diabetes duration was 5 ±3.7yrs (HbA1c of	PA (Actigraph accelerometer GT1M; 7 consecutive days) Physical fitness (PWC_{170}) Blood pressure BMI Z-score Waist circumference Parental education Insulin dose and regimen Confounders explored for MVPA and HbA1c analyses: gender, age, pubertal status, BMI Z-	PA: T1D patients were doing 27.6 ±21.4 mins/day. Siblings were doing 20.1 ±11.4 mins/day (no difference between patients and siblings) Inverse relationship between HbA1c and total and light PA (but not after adjusting for confounders). MVPA predicted 30-37% of the variance for HbA1c. Inverse association between total PA and HbA1c when adjusted for physical fitness. 28% recruitment of eligible sample (recruitment via three clinics)	Minimum wear criteria: 3 days (any), 500 mins/day Non-wear periods; spurious counts: periods of zeros for more than 20 mins; >20,000 counts/min (excluded) Epoch: 10-sec Cut points – MVPA (Puyau et al, 2002) Full data sets for 54 youth with T1D and 33

non-participants was 8.1%)	score, waist-to-hip ratio, insulin dose or regimen		siblings
(Sundberg, et al., 2012) Sweden Aim: To examine if PA and sedentary time in children aged <7yrs with T1D differed from peers without diabetes Participants: 24 children with T1D & 26 non-diabetic peers aged <7yrs	PA and sedentary behaviour (Actiheart but only accelerometer data used; 7 consecutive days during two different periods within 1yr to account for seasons) BMI Z-score HbA1c	PA: Total PA and MVPA were greater in spring than autumn. Children with T1D did less PA than peers in spring and autumn (~15% less). After adjusting for season, age and gender, children with T1D were doing 11mins/day less MVPA and nearly 32mins/day more sedentary behaviour than peers. When adjusted for BMI Z-score, no difference in sedentary behaviour between those with T1D and peers. Boys spent more time in total PA and MPVA than girls. Total PA and MVPA were greater and sedentary behaviour less in older children than younger children (MVPA increased by 7.5mins/day with each additional year of age) Non-participating patients did not differ in age, diabetes duration, BMI Z-score or HbA1c from participants. A greater proportion of participants had insulin pumps than non-participants. Patients were recruited from one hospital. 45.3% (24/53) eligible patients recruited	Minimum wear criteria: NS Non-wear periods; spurious counts: periods of zeros ≥100 mins (excluded); Epoch: 60-sec Cut points – sedentary behaviour (<100cpm); MVPA (>2000cpm)

(Michaliszyn & Faulkner, 2010) Arizona Aim: To determine the associations between physical activity and fitness, body composition, lipids and HbA1c during an intervention Participants: 16 adolescents with T1D (12-17 yrs)	PA (seven day physical activity recall and Actigraph accelerometer GT1M; 16 weeks) BMI Z-score VO2peak Total cholesterol LDL-cholesterol HDL-cholesterol Triglycerides A1c Body fat Fat free mass	PA: Patients spent 10 hours in sedentary time (83.5% of the day), 1.3 hours in light PA, 39 mins (5.2%) in moderate activity and 2.7 mins (0.4%) in vigorous activity. Greater sedentary time was associated with poorer fitness and fat free mass and with greater total cholesterol, LDL cholesterol and triglycerides. Greater MVPA was associated with greater fitness, fat free mass and lower total cholesterol, LDL cholesterol, triglycerides and HbA1c Patients recruited from one clinic	Minimum wear criteria: 10 hours Epoch: 60-sec epoch Cut points – age specific MVPA equation (developed by Freedson et al., for youth)
(Särnblad, et al., 2005) Sweden Aim: To compare objectively measured PA & energy intake in girls with T1D compared to age-matched	PA (Actigraph accelerometer CSA 6471; 7 days) BMI Z-score Pubertal stage Food intake (7-day	PA: Patients were doing 56±20mins MVPA & 443±60mins in sedentary time. Patients with T1D spent more time in sedentary behaviour than the group without diabetes. Decreased PA was related to increasing age in both groups. 67% of eligible girls (26/39) participated from one	Minimum wear criteria: 5 days, 10 hours, 30mins each hour Epoch: 60-sec Cut-points: Sedentary

girls without diabetes Participants: 26 girls with T1D & 49 control girls (12-19yrs)	diary)	hospital. Non-participants did not differ in age, BMI Z-score, insulin dosage or HbA1c compared to participants	behaviour (<100 cpm), light (100-1952 cpm), MVPA (>1952 cpm) (Freedson et al., cut-points)
(Trigona, et al., 2010) ~ Switzerland Cross-sectional Aim: To determine which volume & intensity of physical activity is beneficial to cardiovascular health and to examine the association between fitness and artherosclerosis markers Participants: 26 youth with T1D & 35 youth without diabetes (6-17yrs)	PA (Actigraph accelerometer 6471; NS how many days of data collection) Physical fitness (VO_2max) BMI Z-score Pubertal stage Blood pressure Arterial geometry & function Artery dilatation	PA: Patients were doing 53.3mins/day (32.9-73.7 (95% CI)) in MVPA & 618.6 mins/day (548.9-688.2) in sedentary and light combined activity. 35% of patients were achieving over 60mins/day MVPA. Patients had lower VO_2max, total PA counts & MVPA compared to those without diabetes. Patients spent more time in sedentary and light activity than those without diabetes. Flow mediated dilatation was lower in participants doing <60 mins MVPA compared to those doing ≥60 mins regardless of having diabetes or not. Flow mediated dilatation was lower in patients meeting the recommendation than in participants without diabetes that were meeting the recommendation. T1D, PA count, MVPA, sedentary to low PA & pubertal stage were independently associated with flow mediated	Minimum wear criteria: 4 days (including at least 2 weekdays & 1 weekend day) Non-wear periods; spurious counts: periods of ≥20 minutes consecutive zeros (excluded) Epoch: 60 sec Cut-points: Sedentary & light combined (<1999), MVPA (>2000)

		dilatation Patients were recruited via two hospitals	(Ekelund et al.,) Full data sets for 26 youth with T1D & 35 youth without diabetes
(A. B. Maggio, et al., 2010) ~ Switzerland Aim: To compare PA levels and fitness in children & adolescents with different chronic conditions (obesity, T1D, juvenile idiopathic arthritis) with peers without chronic conditions Participants: 48 with T1D, 76 with other conditions, 85 without a chronic condition (4-17yrs)	PA (Actigraph accelerometer MT 6471; 7 days) VO_2 peak BMI	PA: 38.5% of those with T1D met the MVPA recommendations. 77% of time was spent in sedentary behaviour & 54.0± 6.5 mins in MVPA in youth with T1D. Total PA and age was inversely related in all groups. Total PA was lower in patients compared to those without a chronic condition when adjusted for age. No correlation was found between disease duration & PA. Time spent in sedentary behaviour was different between all groups (& greater in those with T1D compared to those without). Total amount of PA was 18.1% lower in chronic disease combined group compared to the group without a chronic disease (MVPA was not any different between those with and without diabetes). Maximal heart rate was similar in all groups. Fitness was 9% less in the combined chronic disease group compared to the control group. Fitness	Minimum wear criteria: 4 days (at least 2 weekdays & 1 weekend day), 10 hours Non-wear periods; spurious counts: periods of ≥20 minutes consecutive zeros (excluded) Epoch: NS Cut-points: Sedentary (<500cpm) & MVPA (>2000cpm) (Ekelund et

		was not related to disease duration. Male gender and high MVPA per day were associated with greater VO_2 peak. No correlation between sedentary time & VO_2peak was found in those with chronic conditions. An inverse relation between VO_2 peak & sedentary to light PA was found in analysis of all participants. Of all participants, those meeting the PA recommendations had greater VO_2 peak but there were no differences when separate groups were analysed. Patients were recruited via two hospitals	al.) Full data sets for 13 youth with T1D, 53 with other conditions & 54 without a chronic condition
(Heilman, Zilmer, Zilmer, & Tillmann, 2009) Estonia Aim: To explore bone mineral density and it's relationship between physical activity, glycaemia control and markers of systemic oxidative stress and inflammation in children with	PA (questionnaire and Actigraph accelerometer; 3 days) Bone mineral density Calcium intake	Youth with diabetes were achieving 18, 151 ±7962 counts/hour and scored 81.0±42.7 in the activity questionnaire. Boys with T1D were achieving less counts/hour than boys without diabetes. No correlations between bone outcomes and PA were found. Recruitment was via one clinic	Minimum wear criteria: 3 days (1 weekend and 2 weekdays) Non-wear periods: NS Epoch: NS Cut-points: NS

T1D Participants: 30 youth with Type 1 diabetes (4.7-18.6 yrs) and 30 peers age, sex and BMI matched			Full data sets for all 30 youth with and without T1D
(Newton, Wiltshire, & Elley, 2009) New Zealand Aim: To examine if pedometers and text messaging increase PA in adolescents with T1D in a RCT intervention study Participants: 78 adolescents with T1D (11-18yrs)	PA (pedometer, model NS; 4 days) PA (questionnaire) $A1_c$ Blood pressure BMI Z-score Quality of life Insulin dosage	PA: The control group were doing 10,900 (8,324-13,240) & the intervention group were doing 11,242 (8,380-13,537) steps/day at baseline. Boys (12,420± 4,919 steps/day) were doing more steps than girls (10,461 ±3,071 steps/day). The questionnaire showed the control group were doing 645 mins/week (298-895 mins) & intervention group were doing 712 mins/week (420-1,000 mins) in MVPA at baseline & that boys were more active than girls. Patients were recruited from four clinics	NA
(Massin, Lebrethon, Rocour, Gerard, & Bourguignon, 2005) Belgium Aim: To determine if PA patterns	PA (continuous HR monitoring; 1 day using MR45 Oxford recorder) HbA1c	PA: Pre-school children did 192.7 ±78.1, 39.1 ±24.3 & 21.3 ± 9.4 mins/day of light, moderate and vigorous physical activity, respectively. School children achieved 168.9 ± 76.7, 37.9 ±15.9 & 19.0 ±14.8 mins/day in light, moderate and vigorous physical activity, respectively. Adolescents did 166.3 ±67.5, 45.6 ±26.9 & 25.2 ±15.3	Minimum wear criteria: Normal weekday over one 24 hour period HR averaged every minute

differed between children and adolescents with diabetes and youth without diabetes & to explore if metabolic control is affected by PA volume Participants: 127 children & adolescents with T1D aged 3-6yrs, 7-12yrs, & 13-16yrs, & 200 peers without diabetes The clinic provided an educational programme to patients and thus maybe already providing enough PA support to patients to meet the PA recommendations		mins/day in light, moderate and vigorous physical activity, respectively. No differences in PA between genders were found. 67% of pre-school children, 60% of school children & 65% of adolescents achieved >30 min/day moderate PA/day & 50% of pre-school children, 29% of school children & 65% of adolescents achieved >20 mins/day vigorous PA/day. Patients with diabetes were doing more MVPA than those without diabetes. School children with diabetes did more moderate PA than those without diabetes & adolescents with diabetes did more MVPA than those peers without diabetes. HbA1c & time spent in light PA in school children were negatively correlated. Mean HbA1c for one year & light & moderate PA were negatively correlated in schoolchildren	Intensity categories: 20-40% HRR (light PA); 40-50% HRR (moderate PA); >50% HRR (vigorous PA)
(Edmunds, Roche, Stratton, Wallymahmed, & Glenn, 2007) England	PA (heart rate monitoring over 4 days; 2 week, 2 weekend) Diabetes quality of life	PA: Patients achieved 57.5±32.0 minutes in MVPA. 47% of patients met the MVPA guidelines. Boys did more MVPA than girls. No associations between MVPA and self-esteem, quality of life or HbA1c were found. Self-efficacy for diabetes	Minimum wear criteria: ≥8 hours data in each file to be included Intensity categories:

Aim: To examine associations between physical activity and psychological well-being and HbA1c in youth with T1D Participants: 36 youth aged 9-15 years with T1D*	for youths questionnaire Self efficacy for diabetes scale Physical self-perception Profile for Children (PSPP-C)	was greater in girls than boys. Boys scored higher for PSPP-C than girls. Patients were recruited from two hospitals. 46/83 (55.4%) patients that were invited consented to participation (10 of these individuals dropped out). Anecdotal reasons for non-participation were: distance to the data collection site and not wanting to wear the monitor for several days including school days. Patients were recruited from two hospitals	≥50%HRR (MVPA), ≥75%HRR (vigorous PA) Full data sets for 47% of patients, 28% had 3 complete files, 21% had 2 complete files & 3% had 1 complete file.
(Edmunds, Roche, & Stratton, 2010) England Aim: To explore patterns and levels of physical activity in youth with Type 1 diabetes & to determine if meeting the PA recommendations is associated with better physiological health Participants: 37 youth aged 12.8yrs	Heart rate monitoring over 4 days. PA recall questionnaire Body composition Peak VO_2 HbA1c	PA: Patients achieved 53.6 ±31.4mins MVPA/day. 41% of patients met the MVPA guidelines. Boys did more vigorous PA compared to girls (12.6 ±12.0 mins/day compared to 3.4±3.5 mins/day, respectively). Compared to those not meeting the guidelines, patients meeting the guidelines were younger. No differences in psychological well-being outcomes between those achieving and not achieving PA recommendations. PA was mostly performed in bouts of 5 minutes or less. No associations between PA and well-being or HbA1c	Intensity categories: ≥50%HRR (MVPA), ≥75%HRR (vigorous PA)

with T1D*		Patients were recruited from two hospitals	
(Roche, Edmunds, Cable, Didi, & Stratton, 2008) England Aim: To explore the relationships between aerobic fitness and physical activity with skin microvascular reactivity in youth with Type 1 diabetes Participants: 29 youth aged 12.5±2.0yrs*	Heart rate monitoring over 4 days (2 week days, 2 weekend days and 1 weekend night). Body composition Skin microvascular reactivity Peak VO_2	PA: 46.6±24.5mins/day in MVPA. Greater MVPA in boys (57.1 ±24.6mins/day) than girls (35.2±19.4 mins/day). Total vigorous PA for the entire group was 5.6±6.0 mins/day. 31% of participants achieved the 60 mins/day of MVPA guideline. No difference in weekend versus weekday activity. Patients were recruited from two diabetes clinics	Minimum wear criteria: ≥8 hours data in each file to be included Epoch: 60 sec Intensity categories: ≥50%HRR (MVPA), ≥75%HRR (vigorous PA) Full data sets from 52% of patients, 24% had 3 complete files, 17% had 2 complete files, 7% had 1 complete file. 100% had at least 1 week day & 86% had a weekend day and overnight recoding in addition.

(O'Neill et al., 2012) USA Aim: To examine the association between physical activity and physical abilities, physical appearance and general self-concept (self-concept constructs) Participants: 304 youth aged 10-20yrs	PA over 7 days (pedometers) Self concept constructs (physical abilities, physical appearance, general self-concept)	PA: 7413 ±3415 steps/day. Steps/day and physical abilities measured by questionnaire were correlated. Physical activity participation and perception of physical abilities were positively related (r = 0.29).	NA
(Maahs et al., 2012) Colorado, US Aim: To examine the effects of food, physical activity and insulin dosage on glucose excursions in a real-life setting Participants: 30 adolescents aged	PA over 5 days (questionnaire and Actical accelerometer) Glucose excursions Diet	PA: 15-20 mins/day (~2% of the day) in MVPA, ~4.5 hours/day (28-31% of the day) in light activity and >10 hours/day (67-70% of the day) in sedentary behaviour.	Minimum wear criteria: data over 2 days (30 and 27 data sets available on each day, respectively) Epoch: 15-s Cut-points: ≤50 cpm (sedentary); 51-2000cpm (light); 2001-

15.0±2.0yrs (20 insulin pump users and 10 patients administering insulin via multiple daily intjections)			2900 (moderate); >2900 (vigorous) Non-wear periods: periods of 0's >60 mins and activity <10 cpm excluded. Sleeping time: >2 hours without activity, <10 minutes with activity, or >1 hour of no activity prior to midnight
(Fintini et al., 2012) Italy Aim: To determine PA and fitness capacity Participants: 35 children with Type 1 diabetes & 31 youth without diabetes	PA and sedentary behaviour energy expenditure over 5-7 days (questionnaire and SenseWear Pro2 armband) Cardiovascular fitness BMI Z-score	PA: Those with T1D achieved less PA (1.8 ±0.8hrs/day) than those without diabetes (2.6 ±1.4hrs/day). Sedentary behaviour similar in those with T1D and those without (16.5 ±3.2hrs/day and 15.2 ±2.2hrs/day, respectively). Patients were recruited from one hospital	Minimum wear criteria: 2 week days and 2 weekend days

aged 9-11 yrs (10.2±0.8 yrs) matched for age, gender & BMI	HbA1c		

NS = not stated; PA = physical activity; T1D = Type 1 diabetes; NA = not applicable; BMI = body mass index; MVPA = moderate to vigorous physical activity; EE = energy expenditure; *, ˜ = data from the same sample of participants

From the table, it can be seen that several studies have found youth with Type 1 diabetes fall short of meeting the physical activity recommendations, achieving on average between 15-47 minutes daily MVPA (Cuenca-Garcia, et al., 2012; Maahs, et al., 2012; Michaliszyn & Faulkner, 2010; Roche, et al., 2008; Sundberg, et al., 2012). Other studies have found that patients almost met the guidelines and were achieving an average of ≥50 minutes of daily MVPA (Edmunds, et al., 2010; Edmunds, et al., 2007; A. B. Maggio, et al., 2010; Massin, et al., 2005; Särnblad, et al., 2005; Trigona, et al., 2010), or met the recommendations, achieving 1.8 ±0.8hrs/day (Fintini, et al., 2012).

Some studies have reported that those with Type 1 diabetes are as physically active as their peers (A. B. Maggio, et al., 2010; Särnblad, et al., 2005) or siblings (Cuenca-Garcia, et al., 2012). Edmunds et al., 2007, Edmunds et al., 2010 and Roche et al., 2008, did not include a comparison group without diabetes in their study (Edmunds, et al., 2010; Edmunds, et al., 2007; Roche, et al., 2008). However they concluded that physical activity levels in their study compared similarly to another study of youth without diabetes also conducted in the UK. Other studies have reported that those with Type 1 diabetes are less physically active than their peers without diabetes by ~15% (Sundberg, et al., 2012) to 31% (Fintini, et al., 2012; Trigona, et al., 2010) less MVPA mins/day, and achieving less accelerometer counts/hour (Heilman, et al., 2009). One study reported that youth aged 7-12 years of age with Type 1 diabetes performed more moderate intensity activity and that teenagers with Type 1 diabetes achieved more moderate and vigorous physical activity than peers without diabetes (Massin, et al., 2005). Pre-school aged children (3-6 years) with Type 1 diabetes performed similar levels of physical activity to peers without diabetes in this study (Massin, et al., 2005).

Adolescents aged 11-18 years with Type 1 diabetes were achieving more than 10,000 pedometer steps/day at baseline in an intervention study (Newton, et al., 2009), whilst O'Neill et al., found that patients were achieving 7413 ±3415 steps/day (O'Neill, et al., 2012). These step count levels fall short of current recommendations for youth to achieve 12,000 steps per day, which equates to approximately 60 minutes of MVPA (Colley, Janssen, & Tremblay, 2012).

Sedentary behaviour was reported in seven studies as: extra time spent sedentary per day compared to youth without diabetes (Sundberg, et al., 2012); total waking hours (Fintini, et al., 2012; Michaliszyn & Faulkner, 2010; Särnblad, et al., 2005; Trigona, et al., 2010), and/or percentage of the waking day (Maahs, et al., 2012; A. B. Maggio, et al., 2010; Michaliszyn & Faulkner, 2010), spent sedentary; and hours spent in sedentary and light behaviour combined (Trigona, et al., 2010). Five of these studies included a comparison group without diabetes, with four studies reporting youth with Type 1 diabetes were doing more sedentary behaviour than those without diabetes (A. B. Maggio, et al., 2010; Särnblad, et al., 2005; Sundberg, et al., 2012; Trigona, et al., 2010) and one reporting similar levels in those with and without diabetes (Fintini, et al., 2012).

2.0.0 Age and gender differences in youth with Type 1 diabetes

In adolescent girls, it was found that as age increased physical activity decreased (Särnblad, et al., 2005). Sundberg et al., (2012) found that older children with Type 1 diabetes were achieving more MVPA and less sedentary behaviour than younger children youth aged under 7 years (MVPA was 7.5mins/day greater for each additional year of age) (Sundberg, et al., 2012). This study (Sundberg, et al., 2012) and another (Edmunds, et al., 2007; Roche, et al., 2008), reported more MVPA in boys than girls. Massin and colleagues did not find a difference in activity achieved based on gender (Massin, et al., 2005).

2.0.1 Patterns of behaviour

A Swedish study found that all participants (those with and without diabetes) performed more MVPA in spring compared to autumn, whereas sedentary behaviour was similar at each time point (Sundberg, et al., 2012). Särnblad compared patterns of accelerometer counts during school time, after school and weekends in adolescent girls with and without Type 1 diabetes and found no differences (Särnblad, et al., 2005).

2.0.2 Potential explanations for conflicting findings

As mentioned at the beginning of this section, there are three main factors that could explain why there are conflicting results across physical activity and sedentary behaviour studies. Table 2.1 summarises the methods of measurement, any reported study recruitment details and data processing decisions. The reasons why different methods of measurement may affect findings relate to the validity and reliability of the method of data collection. The effects of using different data processing decisions on findings are explained in the next section of this chapter. Of particular importance is that not all of the studies managed to recruit large sample sizes (with 10 of the 15 studies having a Type 1 diabetes sample size of less than 40). In addition, sample size calculations were not always used or sufficient sample size to detect differences in physical activity/sedentary behaviour between youth with and without diabetes was not always reached, such as for the study by Särnblad and colleagues (Särnblad, et al., 2005). This highlights the challenges of recruiting youth with Type 1 diabetes in to this type of study and the caution that should be taken when interpreting results due to the potential lack of power in detecting differences between groups. Full reporting of recruitment is necessary to determine the representativeness of the sample. Other possible factors relating to the representativeness of study samples are: the care already delivered in the diabetes clinic (e.g. is there more physical activity support in some clinics than in others, which may explain differences in levels achieved) and the geographical location of where the study was undertaken (e.g. environmental setting and seasonal impacts on physical activity and sedentary behaviour).

3.0 Measuring physical activity and sedentary behaviour: Measurement issues and data decisions

Paper 1 includes a brief description of the decisions made to measure and analyse physical activity and sedentary behaviour. This section provides further discussion of the issues and decisions that are required to be made in physical activity and sedentary behaviour measurement research in youth, with a focus on recent reviews and relevant single studies where review level evidence is limited or non-existent. There are a number of important decisions to be made when considering the measurement of physical activity and sedentary behaviour including the following: the measurement tool to use and characteristics of behaviours to be captured; the number of days and hours of data which constitute a valid data set; and any data processing required to produce the final outcome measure/s of interest.

Several reviews have summarised physical activity and/or sedentary behaviour measurement and the issues concerned with measuring, processing and interpreting these behaviours specifically in youth (Cain, Sallis, Conway, Van Dyck, & Calhoon, 2013; Corder, Ekelund, Steele, Wareham, & Brage, 2008; Lubans et al., 2011; Ojiambo et al., 2011; Rachele, McPhail, Washington, & Chuddihy, 2012; Reilly et al., 2008; Rowlands & Eston, 2007; Trost, McIver, & Pate, 2005). Despite the abundance of research attempting to guide physical activity and sedentary behaviour measurement, there is no consensus on the best tools or methods of analysis to be used. As a result this section of the thesis presents as clearly as possible an evidence-based justification towards the tools and methods employed.

3.0.0 Measurement tool

Tools to measure physical activity can be categorised based on sources of error, with increasing sources of error moving from criterion (the most accurate tools available to measure the outcome) to objective to subjective methods (Sirard & Pate, 2001). Choice of physical activity measurement tool will not only depend on the desired behaviour/outcome of interest and target population, but also on availability of resources, participant burden and the validity and reliability of the tool (Rachele, et al., 2012). Reliability (or reproducibility), refers to whether a method consistently provides the same result over multiple assessments (Warren et al., 2010). Validity refers to whether a method measures what it is supposed to measure (Warren, et al., 2010). The relationship between a method and the criterion method is known as criterion validity. Exploring the relationship between two methods of unknown validity is referred to as concurrent validity (where neither method is the criterion method). Content validity indicates the amount that a method sufficiently indicates the aspects of the outcome being measured. Calibration studies involve the comparison of the measurement of one method with the measurement from another method. When critiquing the validity of physical activity tools it is important to consider: the setting (e.g. controlled setting or free-living conditions); the outcome measure being compared (e.g. energy expenditure, total activity, MVPA, activity or expenditure during a specific activity); and if the outcome is an activity then what type of activity is being performed (e.g. treadmill walking, over-ground walking, playing).

Moderate to high correlations between accelerometer counts and energy expenditure for several types of activity and fair to excellent accuracy in categorising activity as MVPA have been found in a review (Rowlands & Eston, 2007). Another review concluded that Actigraph accelerometers showed acceptable reliability and validity, having been validated against many other methods including direct observation, indirect calorimetry, whole room calorimetry, doubly labelled water and heart rate monitoring (Trost, 2007). A recent review also concluded that the Actigraph has been highly validated and applied in physical activity research (Plasqui, Bonomi, & Westerterp, 2013). Little guidance exists on sedentary behaviour measurement. A review concluded that accelerometers are valid and reliable at measuring total sedentary behaviour in youth (Lubans, et al., 2011). Only five of 26 studies included in the review had used accelerometers to measure sedentary behaviour. Actigraph accelerometers were used in study two of this thesis, as they were the most accurate tool for physical activity and sedentary behaviour measurement available to the researcher. Following the advice from reviews (Lubans, et al., 2011; Welk, Corbin, & Dale, 2000), a questionnaire was included alongside the objective assessments to explore the types of physical activity and sedentary behaviours undertaken and can be found in Appendix C. Findings on the types of physical activities and sedentary behaviours that patients in study 1 were participating in are summarised following paper 1 in a post-script section.

The remaining issues discussed below relate specifically to accelerometer data collection, processing and analysis. Accelerometer methodology as described by Cain and colleagues is ‘chaotic’ (Cain, et al., 2013); there is a lack of consensus on how best to process accelerometer determined data. To aid decisions on accelerometer data in this thesis, initial analyses of physical activity and sedentary behaviour data comparing different data decisions were conducted (Appendix D) and are referred to in the following sections.

3.0.1 Number of days and hours of accelerometer wear constituting valid data sets and days

Some studies suggest that the characteristics of the target population (including age) may affect the number of days and hours of accelerometer data required to reliably estimate physical activity as accelerometer cpm (Mattocks et al., 2008; Penpraze et al., 2006; Trost, Pate, Freedson, Sallis, & Taylor, 2000) or MVPA (Basterfield, Adamson, Pearce, & Reilly, 2011; Nader, Bradley, Houts, McRitchie, & O'Brien, 2008). Most Actigraph accelerometer studies have used a minimum wear criteria of 3 (52% of 273 included studies) or 4 days (49% of studies) in youth (Cain, et al., 2013). Corder and colleagues (2008), in their review suggest using four full days of wear including one weekend day in youth (Corder, et al., 2008). Trost et al., 2000, and Ojiambo et al., (2011) also recommend including a weekend day as they found differences in week and weekend levels of activity in youth (Ojiambo, et al., 2011; Trost, et al., 2000). In contrast other studies have found no difference in MVPA or sedentary behaviour reliability in 6-8 year olds (Basterfield, Adamson, Pearce, et al., 2011) and a slight decrease in physical activity reliability in pre-school aged children, when weekend days were included in analysis (Penpraze, et al., 2006).

The majority of Actigraph accelerometer studies used 10 hours as the minimum amount of data required for a day to be included in analysis (Cain, et al., 2013). The analysis in Appendix C explored the effect of changing the inclusion number of hours/day on calculated MVPA and sedentary behaviour. Increasing the minimum number of wear hours from 6 to 8 hours resulted in a significant difference in calculated MVPA, but not in the percentage of participants meeting the MVPA recommendations, when all other data decisions were kept consistent. Therefore although the absolute MVPA value changed slightly the overall message of whether participants met the guidelines or not did not change. Using 10 hours of data ensured the full sample (N =40) of participants would be included in analysis. Increasing to 12 hours meant that five participants would not be included in analysis. The effect of season has also been highlighted as an important consideration and where feasible longitudinal studies should be employed (Cain, et al., 2013). Due to time constraints it was not possible to conduct a longitudinal design in this thesis study.

3.0.2 Epoch

Accelerometer activity counts are summed over a given time sampling period known as an epoch. The smallest epoch length possible for data collection has been recommended because of the intermittent patterns and often short bursts of physical activity in youth, particularly in younger children (Corder, et al., 2008). Differences in MVPA, sedentary behaviour and percentage of participants meeting the physical activity recommendations using different epochs (15s versus 30s versus 60s) and MVPA cut-points (cut-points are discussed in the section below) in youth have previously been found (Ojiambo, et al., 2011). Conversely a review concluded that there is a lack of evidence to support the use of small epochs to determine sedentary behaviour and MVPA in youth, with differences in MVPA using 15, 30, 45 and 60 second epochs being insignificant in secondary analyses of the authors' data (Reilly, et al., 2008).

Initial analysis using different epochs for the data in paper 1 identified a significant impact on calculated MVPA data when using a 15 second epoch compared to a 60 second epoch when other data decisions remained constant (Appendix D). Although the absolute MVPA value changed significantly using different epochs, the percentage of participants meeting the recommendations did not change, therefore the overall message of the proportion of people meeting the guidelines remained the same. It has previously been highlighted that it is important to not make comparisons of MVPA and sedentary behaviour between studies using shorter and longer epochs due to the potential differences that may exist (Ojiambo, et al., 2011). A 15 second epoch was selected in study 1 as previously conducted UK studies, including youth with diabetes (Cuenca-Garcia, et al., 2012) and youth without diabetes (Basterfield, Adamson, Frary, et al., 2011) of the same age as participants in study 1, used a 15 second epoch and therefore could be used for comparison with the findings of study 1.

3.0.3 MVPA and sedentary behaviour cut-points

Accelerometer counts can be processed to estimate intensity of physical activity using prediction equations and development of intensity cut-points expressed in counts per minute (cpm). Validity of equations and consideration of how cut-points have been developed, namely the activities and participants used in validation studies is important when deciding on a cut-point to use. The selection of accelerometer cut-points has been described as a 'cut-point conundrum' (Trost, 2007), due to the many existing published cut-points but lack of equation validity evidence for them. Accelerometer cut-point choice has the biggest impact on calculated MVPA compared to other data processing decisions (Cain, et al., 2013).

Based on consistent findings from several well-designed calibration studies in youth, an Actigraph MVPA cut-point in the region of 3000-3600cpm has been recommended (Reilly, et al., 2008). In a review of sedentary behaviour measurement in youth, four of five included accelerometer-based validity studies compared accelerometer cut-points to criterion methods, and of these, three found excellent validity using cut points to define sedentary behaviour ranging from <100 cpm to <1592 cpm in youth aged from 3-14 years (Lubans, et al., 2011).

MVPA cut points developed and calibrated using whole body calorimetry by Puyau et al., (referred to hereafter as Puyau cut-points) in youth aged 6-14 years participating in free-play were used in study 2 of this thesis to estimate MVPA (≥3200cpm) (Puyau, Adolph, Vohra, & Butte, 2002). In a review of accelerometer studies in youth, the Puyau cut-points were the second most popular, having been used in 23/178 studies measuring physical activity (Cain, et al., 2013). A study of youth aged 5-15 years recommended using lower cut-points developed by Evenson et al., (Evenson, Catellier, Karminder, Ondrak, & McMurray, 2008) (referred to hereafter as Evenson cut-points), due to their greater accuracy when compared to indirect calorimetry over four other cut-points, including the Puyau cut-points (Trost, Loprinzi, Moore, & Pfeiffer, 2011). However, it was decided that Puyau cut-points would be applied in this thesis for the reasons now described. In an adjunct analysis to study 1 in this thesis, MVPA data was compared using the Evenson and Puyau cut-points on data not corrected for the amount of wear time or with reported non-wear periods removed (see Appendix D for results). Concluding messages on the percentage of participants meeting the physical activity recommendations using the Evenson or Puyau cut-points would have been remarkably different. For example, when using a 15 second epoch, applying an 8 hour minimum wear criterion, and the Evenson cut point, participants achieve an average of 56.9 ±21.1 minutes in MVPA/day, the MVPA guidelines are met by participants on 40% of total days of accelerometer wear (115/286), and one participant meets the MVPA guideline on every day of accelerometer wear. Using the same epoch and wear criteria with the Puyau cut point results in 32.4 ±15.4 minutes in MVPA/day, participants meet the MVPA recommendations on 12% of total days of accelerometer wear (35/286), and no participants meet the MVPA recommendations on every day of monitor wear. As a comparison group without diabetes was not included in study 1, it was important to apply similar data processing methods as previously published studies, to allow the data in study 1 to be compared with already available data. Therefore the higher more conservative Puyau cut-points were chosen: 1) to avoid over exaggeration of physical activity participation; and 2) for comparison with previous research in similar aged youth from the UK without diabetes, which also used Puyau cut-points (Basterfield, Adamson, Frary, et al., 2011) and a similar cut point of ≥3600, respectively (Riddoch, et al., 2009).

During the conception phase of study 1 of this PhD, the student was heavily focused on the measurement of physical activity and thus concentrated on this outcome as the primary measure when designing the study. However over the course of the PhD the student's focus shifted to recognise the equal, or possibly even greater, importance of accurately measuring sedentary behaviour as they became more aware of the importance of this behaviour on health. Initially analyses for study 1 used the Puyau sedentary behaviour cut point (<800cpm). Since undertaking the initial analysis, although a consensus has still not been met, the student became aware that researchers are tending to use, and more evidence is being published, to support a sedentary behaviour cut-point of <100cpm in youth (Fischer, Yildirim, Salmon, & Chinapaw, 2012; Ridgers et al., 2012; Trost, et al., 2011). Therefore study 1 data was re-analysed incorporating a sedentary behaviour cut-point of <100cpm. Appendix C includes an exploration of the impact of using the Evenson sedentary behaviour cut-point of <100cpm (7.8 ±1.4 hours) compared to the Puyau cut-point of <800cpm (10.2 ±1.2 hours) on average daily sedentary behaviour when the same epoch (15 seconds) and minimum wear criteria (8 hours) are applied on data not corrected for the amount of accelerometer wear or with non-wear removed based on wear diaries.

3.0.4 Rationale for data handling and cleaning decisions

Missing data is defined here as any physical activity or sedentary behaviour done during a measurement period when the accelerometer has been removed (non-wear activity). Efforts to identify and deal with accelerometer non-wear time should be made (Ottevaere et al., 2011). Again, there is a lack of consensus on how best to identify and deal with non-wear periods. Parallel measures of physical activity and sedentary behaviour alongside accelerometer data collection are recommended to help determine missing data (Reilly, et al., 2008). Strings of continuous 0's in accelerometer data could indicate periods of sedentary behaviour or accelerometer non-wear. A review including 181 studies measuring physical activity and sedentary behaviour in youth, found that a large proportion (48 studies), did not report if strings of continuous 0's during waking hours were treated as sedentary behaviour or non-wear. A further 22 studies treated strings of 0's longer than 20 minutes in duration as non-wear, whilst 17 studies treated strings of 0's lasting over 10 minutes as non-wear. As there is no current consensus in the literature, in study 1 strings of 0's in accelerometer data were assumed to be sedentary behaviour, unless the participant reported not wearing the accelerometer and performing activity during this time in their accelerometer wear diary (in which case the strings of 0's were removed from analysis during that period). Appendix C provides a summary of initial analyses conducted exploring the impact of using different criteria for defining non-wear based on strings of 0's and the resultant effect on sedentary behaviour levels. During an initial analysis using the <800cpm cut-point to define sedentary behaviour, addition of MVPA time was made when the accelerometer had been removed and activity undertaken. When sufficient information (e.g. indicators of duration and intensity of activity), were provided in wear diaries, regarding physical activity performed when the accelerometer was removed, minutes in MVPA were added to that individual's data. A total of 743 minutes of activity was reported in diaries to have been undertaken whilst the accelerometer was not worn (a combined total of 328 minutes of light and 415 minutes of MVPA were added to total daily light and MVPA data for six participants reporting activity whilst not wearing the accelerometer). Of the six participants one removed the accelerometer during football, five during water-based activity (swimming (*n* =4); playing in a pool (*n* =1)), and one that removed the accelerometer during swimming also removed the monitor playing rugby. During this initial analyses, replacement of missing data with estimated MVPA did not significantly affect overall mean MVPA of participants (33.3 ±3 minutes/day prior to adjustment versus 34.7±18.1 minutes/day after adjustment) or the percentage of participants meeting the physical activity recommendations (remained at 0%), but did result in six more days of data meeting the MVPA guidelines. As MVPA data was not significantly affected in this initial analysis, the final analysis included in paper 1 does not include the addition of MVPA for activities undertaken during accelerometer non-wear.

4.0 Paper 1: Physical activity, sedentary behaviour and quality of life in Scottish youth with Type 1 diabetes

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The following paper is currently in preparation for submission to a journal.

Abstract

Aims: Study aims were to measure physical activity, sedentary behaviour, and quality of life (QoL) in youth with type 1 diabetes.

Methods: Forty patients aged 7-9yrs (*n*=20) or 12-14yrs (*n*=20) wore accelerometers for seven days. They and their parents completed the Pediatric QoL Inventory (Peds-QoL). Validated cut-points categorised sedentary behaviour and moderate to vigorous physical activity (MVPA). Differences in behaviour and QoL based on age, gender, and treatment therapy and patterns in behaviour were explored.

Results: Average sedentary time was 10.2 ±1.7 hours/day and MVPA was 43.2 ±23.8 minutes/day. Two participants achieved 60 minutes MVPA on each day of accelerometer wear and 19/40 did not achieve 60 minutes of MVPA on any day. Adolescents (11.5 ±1.2 hours) were more sedentary than younger children (8.9 ±1.0 hours) (d = 2.36, $p<0.001$). MVPA (d = 0.32) and sedentary behaviour (d = 0.00) were similar for insulin injection and pump users. MVPA was lower on Saturdays (32.3 ±27.7 mins, d =0.56) and Sundays (34.5 ±33.7 mins, d =0.40) than weekdays (44.1 ±14.2 mins), $p<0.05$. Adolescent boys had poorer school functioning scores (63.2 ±14.7) than adolescent girls (82.2 ±17.0, d =1.07) and younger girls (72.8±15.8, d =0.63) in the Peds-QoL proxy reports. Also in the proxy report, treatment barrier scores were lower in adolescent boys (55.1 ±18.3) versus younger boys (79.2 ±14.7, d =1.46) and younger girls (77.8±5.7, d =1.89), ($p<0.05$).

Conclusions*:* Physical activity was below the recommendations for health in youth and sedentary behaviour was high, confirming the need for intervention. MVPA at weekends appear an important target.

Introduction

Physical activity is recommended as part of diabetes management [1] and guidance on safe participation in physical activity has been published specifically for youth with type 1 diabetes [2]. For any child or adolescent, regular physical activity can result in significant health benefit. The potential benefits [3-5] are especially pertinent for those with type 1 diabetes who can have poorer health [6-8], and are at an increased risk of developing cardiovascular disease [9] compared to their peers without diabetes. The physical activity recommendations for youth with type 1 diabetes are the same as for those without diabetes: to achieve a minimum of 60 minutes of moderate-to-vigorous physical activity (MVPA) per day [10]. Despite these recommendations, previous studies have found conflicting results in whether youth with type 1 diabetes meet the guidelines and if they are less active than peers without diabetes [11-15]. Differences in findings could be due to differences in recruitment (e.g. biased samples may have been recruited that were not representative of the total population), and/or data collection and analysis (e.g. measurement tools vary in their validity, and specifically in the case of using accelerometers, the cut-points used to measure physical activity and sedentary behaviour may not be comparable).

Recent research has highlighted the importance of minimising sedentary behaviour (sitting time), for health [16]. A review found that sedentary behaviour negatively impacts on health in youth, and that interventions targeting sedentary behaviour can improve BMI [17]. A recent large longitudinal study, however, did not find an association between objectively measured sedentary behaviour and cardiovascular disease risk in youth [18]. Studies measuring sedentary behaviour are important in youth to investigate inconsistencies in the literature. Research on sedentary behaviour specifically in youth with type 1 diabetes is limited.

Some studies have found quality of life (QoL) in youth with type 1 diabetes to be poorer than in youth without diabetes [8, 19]. Improving QoL is a primary public health goal [20]. There is some evidence in youth for a positive relationship between physical activity and QoL (better QoL with greater physical activity), and a negative association between sedentary behaviour and QoL (lower QoL with higher sedentary behaviour) [21, 22]. Specifically in youth with type 1 diabetes, QoL is an under-researched area and studies reporting on QoL are required to develop the measurement of this outcome by helping define population norms for this group, and to explore the relationships between lifestyle behaviours and quality of life [8].

The study aimed to:

1) determine daily physical activity and sedentary time in Scottish youth with Type 1 diabetes

2) explore variation across school days, school holidays and weekend days and between weekdays and weekend days (e.g. identifying when patients are most and least active and sedentary), and population subgroups (based on age and gender), to target for physical activity and sedentary behaviour interventions

3) add QoL data to the current literature to aid the definition of norms, and report data alongside physical activity and sedentary behaviour patterns.

Analysis of associations between physical activity and sedentary behaviour with quality of life was beyond the scope of this paper, but will be the focus of another paper currently in development. Previously published physical activity and sedentary behaviour measurement studies in youth with Type 1 diabetes have not fully reported on recruitment (e.g. recruitment methods and details of the sample recruited versus the total eligible population). Thus it is not clear how to most effectively recruit patients into this type of study, or if representative samples have been recruited into studies. This paper advances the area of physical activity and sedentary behaviour measurement as thorough reporting of the recruitment process is provided (Supplemental Figure 1), and purposive methodology was employed to ensure a representative sample.

Methods

The West of Scotland Research Ethics Service and the University of Strathclyde ethics committees granted ethical approval to conduct this cross-sectional study. A comparison group of youth without diabetes was not included in data collection as adequate published information using similar methodology [23, 24] was available. Written informed consent (or assent from those aged <12 years) was obtained from participants and their parents.

Participants

Inclusion criteria were: diagnosed type 1 diabetes for >12months; and aged 7-9 or 12-14 years. Exclusion criteria were: unable to understand study requirements or contraindicated medical reason. Children (7-9 years) and adolescents (12-14 years) were recruited to allow comparisons between primary (elementary) and secondary age groups.

Procedures

Two visits, at least eight days apart, were made either to the participant's home, clinic or another suitable location. At visit 1, informed consent/assent and demographic questionnaires were completed and participants were given instruction on accelerometer wear and accelerometer wear diary completion. Participants were asked to continue with normal physical activity participation. At visit 2, the researcher collected the accelerometer and wear diary. Physical activity/sedentary behaviour and QoL questionnaires were completed.

Outcome measures

Descriptive characteristics

Socioeconomic status was determined using the Scottish Index of Multiple Deprivation (SIMD) categorised from home postcode data for each participant. BMI z-score (age and gender specific), blood pressure, HbA1c (%) and diabetes duration data were also collected from the clinic database. BMI z-score and HbA1c are measured every three months and blood pressure yearly at the clinic. Measurements were taken at the clinic nearest to the participant joining the study. Demographic questionnaires captured information on diabetes therapy mode (insulin pump versus insulin injection).

Accelerometry

Participants were given an accelerometer (Actigraph Model GT3X+; Actigraph, LLC. Pensacola, FL, USA). Accelerometers were worn around the waist using elastic belts during waking hours for 7 days excluding water-based activities. An accelerometer wear diary was given to record accelerometer attachment and removal. Accelerometer data were downloaded to Actilife software (version 6.4.3). A 15-s epoch was selected to compare to previously published studies and to capture as accurate a picture of behaviour as possible. In line with previous studies of youth [25], a minimum wear time for a valid day was defined as 10 hours per day. This criterion allowed all participants to be included in analysis. Three days of data were required to be included in analysis, based on previous research with youth [25, 26]. The primary outcome measure of daily time spent in MVPA and sedentary behaviour was determined using cut-points calibrated and validated in pediatric studies: sedentary (<100 cpm) [27] and MVPA (≥3200 cpm) [28]. These cut-points have been used in several previously published studies providing a comparison. Wear diaries were used to identify wear time and to remove any non-wear periods as previously described [29], using the filter option in the Actilife software. Although patients were instructed to remove accelerometers at bedtime, several participants wore accelerometers overnight. To ensure that sleep data was not included in analysis, only data recorded between 06:00-12.00am and corresponding to reported wear time reported in diaries was included in analyses. Periods of consecutive zeros, other than that recorded in wear diaries as sleep time or non-wear, were kept in the data, as assumptions were not made to define periods as non-wear or sedentary behaviour. Additional days were included in analysis if participants wore the accelerometer for more than seven full days. As wear time differed between types of day and across participants (see Table 2.1) for wear time in participants), adjustments were made to time in sedentary behaviour and MVPA. The absolute maximum wear time across all participants and all days of wear (1004.25 minutes/day or 16.7 hours/day) was used as a standardized wear value to adjust sedentary behaviour and MVPA time, as has been used previously [30]. If, for example, a participant achieved 30 minutes of MVPA on a given day and had worn the monitor for 840 minutes, then MVPA was adjusted as follows: (30*1004.25)/840 = 35.9 minutes in MVPA.

Type of physical activity and sedentary behaviour

Participants, with the help of their parent/s where necessary, completed a physical activity and sedentary behaviour questionnaire developed based on the findings of a previously conducted survey study [31]. The questionnaire explored the type and frequency of behaviours the individual had participated in over the previous week.

QoL

The PedsQoL 4.0 Generic Core Scale was used to measure general QoL [32]. It is a 23-item questionnaire with the following subscales: Physical Functioning; Emotional Functioning; Social Functioning; and School Functioning. A Psychosocial Health summary score is calculated from the average of the Emotional, Social and School Functioning subscales, a Physical Health summary score (from the Physical Functioning subscale) and a total overall score from the average of all subscales. The PedsQoL 3.0 type 1 Diabetes Module is a 28-item questionnaire measuring diabetes specific QoL consisting of five subscales: Diabetes Symptoms; Treatment Barriers; Treatment Adherence; Worry; and Communication (29). Patients (self-report) and their parents (proxy-report of the child’s QoL) completed questionnaires by rating items on how much each was a problem in the previous month using a five-point likert scale (‘0’= never a problem; ‘4’= almost always a problem). When >50% of data from a subscale was missing, the average of the remaining subscale scores for that participant was imputed (1% of subscale scores were missing). Answers were reverse scored on a 0-100 scale where 0=100, 1=75, 2=50, 3=25 and 4=0. A higher score indicates a better QoL.

Statistical analysis

Data were analysed using SPSS version 21.0.0 (IBM Corp., Armonk, NY). Normality of all data was initially assessed using Kolmogorov-Smirnov tests. Normally distributed data ($p>0.05$) and non-normally distributed data ($p<0.05$) with skew and kurtosis values <2, were analysed using parametric tests. Non-normally distributed data with skew and kurtosis values >2 were successfully transformed using the square root or cosine transformations before analysis using parametric tests. Parametric test results are reported in this paper. Non-parametric tests were conducted to compare with parametric results for analyses including transformed variables (full results available from the corresponding author).

Differences in sedentary behaviour, MVPA and QoL, when data were grouped by age (adolescent or younger patient) or gender (boy or girl), were explored using independent t-tests. Data was also explored when grouped by age-gender (1 = adolescent boy; 2 = adolescent girl; 3 = younger boy; 4 = younger girl) using one-way ANOVA (with age-gender group as a factor), followed with Fisher’s LSD post hoc tests. In order to create similar groups for comparisons between participants administering insulin injection therapy (n =9) or using insulin pump therapy (n =9), patients of the same age and gender were selected. Differences in sedentary and MVPA time between these participants were determined using independent t-tests.

School holidays were defined as weekdays when not at school (e.g. public holidays or school vacation). Table 2.1 details the number of days of data for different types of day and the number of participants with data for those types of day. Patterns in average daily sedentary and MVPA time were examined using repeated measures ANOVA followed with Fisher’s LSD post hoc tests (school versus holiday versus weekend days and weekday versus Saturday versus Sundays), for participants with data for these types of day. If two or more of the same weekend/weekdays were collected for the same participant, then the average of the days was used in analysis. When only a Saturday or Sunday was collected, that day was used as weekend data. Significance was set at $p<0.05$. Effect size was calculated using Partial Eta Squared (η_p^2; where 0.01 = a small effect; 0.06 = a medium effect and 0.14 = a large effect) and Cohen's *D* (referred to hereafter as '*d*'; where 0.2 = a small effect, 0.5 = a medium effect and 0.8 = a large effect) [33]. Mean ±SD data are presented in tables.

Results

Supplemental Figure 1 details recruitment and participant flow through the study.

Accelerometer data

All participants (*N*= 40) had at least 10 hours of data over three days and were included in analysis. Mean duration of accelerometer wear was 6.1 ±1.2 days (range = 4-9 days) and 12.9 ±1.0 hours/day (range =10.7-15.0 hours/day). Table 2.2 includes accelerometer wear time for the total sample and for age-gender groups. Adolescents (13.6 ±0.8 hours/day) had greater wear time than younger patients (12.2 ±0.7 hours/day) $t(38)=6.02$, $p<0.001$, $d=1.87$. Wear time was not significantly different between boys and girls, $d = 0.20$. An overall effect of age-gender group was found for wear time $F(3,36)=12.97$, $p<0.001$, $\eta_p^2 = 0.519$. Adolescent boys had greater wear time than younger boys ($d=0.03$) and younger girls ($d=0.08$), ($p<0.005$). Adolescent girls also had greater wear time than younger boys ($d=1.64$) and younger girls ($d=0.82$), ($p<0.005$). Wear time did not differ significantly between adolescent boys and adolescent girls ($d=1.05$), or between younger boys and younger girls ($d=0.07$).

MVPA and sedentary behaviour

Table 2.2 shows time in MVPA and sedentary behaviour as well as descriptive characteristics for the total sample and for age-gender groups. For the full sample, average daily MVPA time was 43.2 ±23.8 minutes/day (range: 7.6-123.3 minutes/day) and sedentary time was 10.2 ±1.7 hours/day (range: 7.0-14.6 hours/day, (78.9 ±10.4% of wear time). Two participants (5%), achieved ≥60 minutes MVPA every day that they wore the accelerometer and 19/40 (47.5%), participants did not meet the guidelines on any wear day.

Gender, age and therapy comparisons

Adolescents (11.5 ±1.2 hours) spent more time sedentary than younger patients (8.9 ±1.0 hours), $t(38)=7.36$, $p<0.001$, $d=2.36$. There was no significant difference in sedentary time between boys and girls, $d=0.12$. An overall effect of age-gender group was found for sedentary time, $F(3,36)=19.11$, $p<0.001$, $\eta_p^2=0.614$. Sedentary time was greater in adolescent boys compared to younger boys, $d = 2.94$, and younger girls, $d = 2.00$, ($p<0.001$ for both comparisons). Likewise adolescent girls were more sedentary than younger boys, $d = 2.95$, and younger girls, $d = 2.16$, ($p<0.001$ for both comparisons). Sedentary time did not differ between adolescent boys and adolescent girls, $d = 0.51$, or between younger boys and younger girls, $d = 0.43$. No significant differences between adolescents and younger patients, $d = 0.34$, or between boys and girls, $d = 0.45$, and no overall significant effect of age-gender group, $\eta_p^2 = 0.177$, was found for MVPA time. Daily MVPA time and sedentary behaviour did not differ between participants that administered insulin pump therapy (MVPA=36.2 ±16.3 mins; sedentary time=10.0 ±1.2hours) compared to participants administering injection therapy (MVPA=43.8 ±31.4 mins; sedentary time=10.0 ±1.9 hours), ($d = 0.32$ for MVPA and $d = 0.00$ for sedentary behaviour, $p>0.05$ for both).

Patterns across days

The number of participants with data included in comparisons for different types of day was as follows: school days versus school holidays versus weekend days ($n = 6$); and weekdays versus Saturdays and Sundays ($n = 25$). No significant differences for sedentary behaviour between school days, school holidays and weekend days, $\eta_p^2 = 0.049$, and between weekdays, Saturdays and Sundays, $\eta_p^2 = 0.002$, were found. No overall significant effect for MVPA between school days, school holidays and weekend days was evident, $\eta_p^2 = 0.017$. MVPA time differed between weekdays, Saturdays and Sundays, $F(2,48)=3.80$, $p<0.05$, $\eta_p^2 = 0.137$. MVPA time was significantly greater on weekdays (44.1 ±14.2 mins) than Saturdays (32.3 ±27.7mins, $d = 0.56$) and Sundays (34.5 ±33.7mins, $d = 0.40$), ($p<0.05$ for both comparisons). MVPA time did not differ significantly between Saturdays and Sundays ($d = 0.07$).

Type of physical activity and sedentary behaviour

Playground games and active transport were the most performed activity: $n = 12/40$ and $n = 11/40$ participants reporting taking part in these activities ≥7 times in the previous week, respectively. Television/DVD watching followed by talking/texting on the phone then computer/internet use and reading (not for school) were the most reported sedentary activities, with $n = 13/40$, $n = 8/40$, $n = 6/40$ and $n = 6/40$ participants respectively taking part in these behaviours ≥7 times in the past week.

QoL data

Communication subscale scores for the Diabetes Module self-report were lower in girls (69.2 ±21.9) than boys (83.8 ±16.3), $t(38)=2.38$, $p<0.05$, $d=0.76$ and School Functioning subscale scores for the Generic Core Scale parent-report were lower in boys (65.3 ±14.1) than girls (80.3 ±13.9), $t(38)=-3.38$, $p<0.005$, $d=1.07$. Treatment Barrier subscale scores were lower for adolescents (56.6 ±23.3) than children (78.4 ±16.7) for the parent Diabetes Module parent-report, $t(38)=-3.41$, $p<0.005$, $d=1.09$. No other significant differences were found for age or gender comparisons (Table 2.3 provides effect sizes, which ranged from small to large effects for age and gender comparisons). PedsQL scores for the total sample and overall ANOVA significance and effect sizes for age-gender comparisons are provided in Table 2.4. A significant overall effect of age-gender group for School Functioning subscale scores from the parent proxy Generic Scale was found, $F(3,36)=3.80$, $p<0.05$, $\eta_p^2=0.249$, with adolescent boys scoring significantly less (63.2 ±14.7) than adolescent girls (82.2 ±17.0), $d=1.20$ and younger girls, (72.8 ±15.8), $d=0.63$, ($p<0.05$ for both comparisons). School Functioning subscale scores from the parent proxy Generic Scale were not significantly different between: adolescent boys and younger boys, $d=0.32$; adolescent girls and younger girls $d=0.26$; adolescent girls and younger boys, $d=0.93$; or younger boys and younger girls, $d=0.87$. Treatment Barrier subscale scores also differed significantly across age-gender groups for the proxy Diabetes Module, $F(3, 36)=3.90$, $p<0.05$, $\eta_p^2=0.227$ with adolescent boys scoring lower (55.1 ±18.3) than younger boys (79.2 ±14.7), $p<0.01$, $d=1.46$ and younger girls (77.8 ±5.7), $p<0.05$, $d=1.89$. Treatment Barrier subscale scores did not differ significantly between: adolescent boys and adolescent girls, $d=0.14$; adolescent girls and younger boys, $d=0.95$; adolescent girls and younger girls $d=0.83$; and younger boys and younger girls $d=0.08$ .No other overall significant differences in Generic Scale or Diabetes Module self or proxy-report subscale scores were found, with effect sizes ranging from trivial to large.

Discussion

MVPA and sedentary behaviour levels

The findings of this study confirm the need for physical activity and sedentary behaviour intervention in youth with type 1 diabetes as: 1) only two participants met the minimum guideline for physical activity on every day of monitor wear and just under half (47.5%) of participants did not meet the recommendation on any day; and 2) a large proportion of the day (average of 78%) was spent in sedentary behaviour. Sedentary behaviour was highlighted as a priority target for interventions in adolescence as older patient participated in significantly more sedentary behaviour compared to younger patients. Type of diabetes therapy (pump versus injection) did not appear to be associated with MVPA or sedentary behaviour levels.

Participants achieved a median of 40.2 minutes of MVPA/day, which is not any less active than youth without diabetes of similar ages from previously published UK studies using similar data collection and handling techniques [23, 24]. Riddoch et al. used an MVPA cut-point (≥3600 cpm) slightly greater than in the current study (≥3200 cpm) and found that 12 and 14 year olds were achieving medians of 20 and 21 minutes of MVPA/day respectively [24]. Basterfield et al. used the same MVPA cut-point as in the current study and found seven and nine year olds achieved 26 and 24 minutes of MVPA/day respectively [23]. In addition Basterfield et al. reported a median of 78% and 81% of time being spent in sedentary behaviour at age seven and nine years respectively [23], similar to the amount of sedentary behaviour found in this study (*Mdn*= 79.1%). However, the previous study used a sedentary behaviour cut point <800cpm, which is greater than in the current study. Average daily sedentary behaviour in the current study (10.2 ±1.7 hours/day or 78% of waking time), was greater than in previous studies also using a cut point of <100cpm in adolescent girls with Type 1 diabetes (7.4 ±1 hours/day) [13] and in youth of similar ages without diabetes (8.3 ±7.9 hours/day [34] and 50.8% of waking time [35]).

MVPA levels (43.2 ±23.8 mins/day) were slightly greater than a study by Cuenca-Garcia and colleagues of 8-16 year olds with type 1 diabetes [11] that found patients were achieving 27.6 ±21.4mins of MVPA/day and that those with diabetes were as active as their siblings without diabetes. In contrast Sundberg at al. found that children aged < 7 years with type 1 diabetes were achieving less physical activity and spending more time in sedentary behaviour than age and gender-matched youth without diabetes [14]. Other studies have found youth with type 1 diabetes to be less physically active than peers without diabetes [12, 15]. MVPA levels in these studies were closer to the recommended guidelines (Mean=53.3mins [15] and 54.0mins [12] per day). Although the same accelerometer was used in the studies by Maggio et al. and Trigona et al. [12, 15] as in this study, differences in MVPA may be due to different data collection and processing decisions, such as the larger epoch (60-s), greater sedentary behaviour cut-point (<500cpm), and lower MVPA cut-point (≥2000cpm) applied. The study by Cuenca-Garcia et al. [11], also conducted in the UK, used very similar procedures to the current study (10-s epoch and the same MVPA cut-point). In the present study, although not statistically significant, adolescent girls were achieving the lowest amounts of MVPA.

Previous studies have found in youth with [14] and without type 1 diabetes [23, 24] decreases in MVPA with increasing age to the adolescent years and lower MVPA levels in girls compared to boys.

MVPA and sedentary behaviour patterns

Patterns of physical activity in this study suggest that for youth with type 1 diabetes physical activity at weekends may be particularly important to target, as physical activity was significantly lower on Saturdays and Sundays compared to weekdays. Playground games and active travel appear to be popular physical activities for this group and should be encouraged. Television/DVD watching was the most common sedentary pursuit for this population. Prolonged participation in these activities should be discouraged by interventions.

A Canadian study exploring pedometer count patterns in 10-11 year old youth without diabetes, found participants were more active on school days compared to weekends [36]. In the current study no differences in MVPA or sedentary behaviour were identified in comparisons of school days, holidays and weekends. However, only six participants had data spanning all three types of day to be included in this analysis and therefore it is likely that power was lacking. The corresponding small-medium overall effect size (η_p^2 =0.017) for the ANOVA comparing holidays, school days and weekend days confirms this. Unlike the MVPA findings in the current study, Steele et al. did not find differences in vigorous activity between weekdays and weekend days and they found sedentary behaviour was greater during weekends than weekdays [37].

QoL

QoL was on the whole similar in adolescents and younger patients. Differences between age-gender groups were only found for proxy measures from the School Functioning subscale of the Generic Core scale and the Treatment Barriers subscale from the Diabetes Module.

Varni et al. assessed QoL in 300 US youth aged 5-18 years with type 1 or type 2 diabetes and found similar scores to this study for each of the subscales from the Generic Core scale and Diabetes Module [32]. In the current study scores were slightly higher (a better score) than the previous study [32] apart from scores for the ‘Diabetes Symptoms’ and ‘Worry’ subscales of the parent Diabetes Module in which scores were slightly lower in this study. Sand et al. used the same questionnaires as in this study in 108 Swedish youth with type 1 diabetes aged 5-18 years [38]. They found girls had lower Psychological Functioning and Treatment

Adherence compared to boys and that older children (13-18 years) had lower Diabetes Module scores compared with younger children [38]. The only age-gender differences found in this study were for adolescent boys who scored lower in the proxy report for two of the subscales (one from the Generic Core Scale and one from the Diabetes Module). Interestingly a UK study comparing Generic Core Scale scores in youth with chronic conditions and healthy children found those with diabetes were the only participants with chronic conditions that did not score lower than healthy children [39]. Similar to this study, parent scores were lower than patient scores for each subscale [39]. Differences in parent and patient scores could be due to parents of youth with type 1 diabetes perceiving their child's QoL to be poorer than patient's perceptions of their QoL or due to differences of interpretation of the QoL questions in adults and children. Scores from the patient and parent Diabetes Module subscales in this study are also slightly higher than in a study conducted in England of youth aged 4-15 years with type 1 diabetes [40].

Study strengths, limitations and future directions for research

A strength of the study was the use of an objective measure of MVPA and sedentary behaviour. However inclusion of a subjective activity diary may have helped to more clearly define behaviour during non-wear periods. Of those that participated in the study, 100% provided accelerometer data, confirming viability of this measure in youth with type 1 diabetes. No consensus currently exists as to the most accurate accelerometer MVPA and sedentary behaviour cut-points to apply in research with youth and this is a matter of current debate in the literature [41]. The present study used an MVPA cut-point of ≥3200cpm [28] and <100cpm to identify sedentary behaviour [27], as they have been extensively used in youth research and therefore allow comparisons with previous research. Other accelerometer cut-points may have produced different findings. For example, the MVPA cut-point used here is greater than another commonly used age related cut-point developed for youth [42], and application of the latter cut-point in the current study would have resulted in greater MVPA than was found using the Puyau cut-point. QoL sub-scale scores were consistent across age and gender groups (apart from two subscales; one from the General Core Scale and the other from the Diabetes module proxy reports). Statistical associations between QoL and MVPA or sedentary behaviour will be explored in a subsequent paper. Future studies should examine associations between QoL and MVPA or sedentary behaviour to better understand the relationship between them. A primary and secondary school aged sample of youth with type 1 diabetes were recruited to allow a comparison of different age and gender groups. An age and gender-matched comparison group without diabetes were not recruited as there was already sufficient published data using almost the same methodology as the present study, to allow close comparison with the data on youth with type 1 diabetes. It appears that there was a lack of power to detect differences in several of the comparisons in this study. Effect sizes ranged from small to medium to large. Thus readers should be cautious of their interpretation of non-significant results of medium or smaller effect size in this study, as there may be low statistical power. Despite small participant numbers and the conservative statistical methods used, significant differences with large effect sizes (such as for the gender-age sedentary time comparisons) were identified for some comparisons, providing confidence that important differences existed. Parametric tests were used for consistency in analysis across the study, with transformations used to normalise distribution where necessary. Using a parametric test, MVPA was not found to differ between age-gender groups. Interestingly from observation of mean MVPA data across age-gender groups and comparison with non-parametric findings (available from the author), it appears that adolescent girls with Type 1 diabetes are the least active. More research is required to explore differences in MVPA between age-gender groups further.

In conclusion, this study confirmed the need for physical activity and sedentary behaviour interventions in Scottish youth with type 1 diabetes because average MVPA time was lower than recommended for health benefits and sedentary time was high. Adolescent boys and girls were more sedentary than their younger counterparts. Although MVPA and sedentary behaviour levels appear to be similar between youth with diabetes and youth without diabetes from previous studies, with effective support and guidance, youth with type 1 diabetes have the potential to gain greater health benefits than those without diabetes due to initial poorer health. There is therefore a need for interventions in all children regardless of whether they have Type 1 diabetes or not, but with the potential extra health benefits, youth with type 1 diabetes should be highlighted as an important target group for physical activity and sedentary behaviour intervention. Comparisons across days of data collection (weekday, Saturday and Sunday), identified patients were least active at weekends, providing useful information for intervention development. Groups involved in the care of children and adolescents with Type 1 diabetes need to consider how to emphasise physical activity and minimise sedentary behaviour as part of the on-going management of type 1diabetes.

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Table 2.2 Summary of the amount of total accelerometer data collected and when split by type of day (school day, holiday, weekend day)

	All days	Schools days	Holidays	Weekend days	Weekdays	Saturdays	Sundays
Days of data (*n*) / total days of data (*N*)	242/242	139/242	41/242	62/242	180/242	34/242	28/242
Patients with data (*n*) / total patients (*N*)	40/40	33/40	13/40	36/40	40/40	33/40	28/40
Patients with data (*n*) for X days	• 9 days, n=1 • 8 days, n=0 • 7 days, n=16 • 6 days, n=13 • 5 days, n=3 • 4 days, n=7	• 6 days, n=1 • 5 days, n=16 • 4 days, n=9 • 3 days, n=4 • 2 days, n=2 • 1 day, n=1 • 0 days, n=7	• 5 days, n=4 • 4 days, n=1 • 3 days, n=4 • 2 days, n=1 • 1 day, n=3 • 0 days, n=27	• 3 days, n=1 • 2 days, n=24 • 1 day, n=11 • 0 days, n=4	• 6 days, n=2 • 5 days, n=25 • 4 days, n=6 • 3 days, n=5 • 2 days, n=2	• 2 days, n=1 • 1 day, n=32 • 0 days, n=7	• 2 days, n=28 • 0 days, n=12

Table 2.3 Descriptive characteristics of the full sample (*N*=40) and data when analysed by age and gender group (mean ± SD (range))

	Full sample (N=40)	Adolescent boys (*n*= 11)	Adolescent girls (*n*=9)	Younger boys (*n*=9)	Younger girls (*n*=11)
Age (range), y	11.1±2.7(7.0-14.9)	13.8±0.8 (12.2-14.9)	13.4±0.7 (12.6-14.4)	8.5±1.0 (7.0-9.7)	8.6±0.9 (7.3-9.5)
BMI z-score	0.07±1.07(-2.3-2.1)	0.38 ±0.83 (-1.05-1.41)	0.78±1.18 (-1.29-2.07)	-0.29±0.94 (-1.35-1.30)	-0.53±0.93 (-2.30-0.47)
Diabetes duration (yrs)	5.5±2.8 (2.1-13.4)	7.7±3.6 (2.4-13.4)	4.8±2.7 (2.1-10.0)	4.8±1.7 (2.1-7.7)	4.5±1.7 (2.4-6.8)
HbA1c (%)	8.2±0.9 (6.8-11.1)	8.5±1.2 (7.1-11.1)	8.4±0.9 (7.3-9.7)	7.8±0.5 (7.2-8.7)	7.9±0.8 (6.8-9.1)
Diastolic blood pressure (mmHg)	63.9 ±6.8 (49-79)	65.8±8.3 (49-77)	65.8± (59-79)	63.2±6.0 (54-72)	61.1±6.2 (51-72)
Systolic blood pressure (mmHg)	113.2 ±9.4 (89-140)	116.3±11.1 (98-140)	118.2±8.2 (109-135)	108.8±6.5 (99-120)	109.5±8.1 (89-117)
Average daily MVPA time (minutes)	43.2±3.8 (7.6-123.3)	48.8±26.0 (13.2-117.5)	27.5±13.5 (7.6-52.0)	48.2±11.7 (25.6-65.5)	46.6±31.5 (23.2-123.3)
Average daily sedentary time (hours)	10.2±0.3 (7.0-14.6)	11.2 ±1.0 (9.7-12.9)[* †]	11.8±1.4 (10.1-14.6)[‡ §]	8.7±0.7 (7.6-9.5)[* ‡]	9.1±1.1 (7.0-10.6)[†§]
Average daily wear time (hours)	12.9 ±1.0 (10.7-15.0)	13.5 ±0.6 (12.4-14.5)[* †]	13.8 ±1.1 (11.6-15.0)[‡ §]	12.4±0.6 (11.8-13.5)[* ‡]	12.0±0.7 (10.7-13.1)[†§]
% meeting the MVPA recs on all days	2/40 (5%)	1/40 (2.5%)	0	0	1/40 (2.5%)
% not meeting the MVPA recs on any day	47.5% (19/40)	36.4% (4/11)	77.8% (7/9)	22.2% (2/9)	54.5% (6/11)

[* †, ‡, §,] = significant difference between age-gender groups.
Comparisons made across age and gender groups for: HbA1c, blood pressure, MVPA, sedentary behaviour and wear time

Table 2.4 PedsQL 4.0 Generic Core scales and PedsQL 3.0 Type 1 Diabetes Module patient self-report and parent proxy report Cohen's *D* effect size values for age and gender comparisons

	Effect size for age comparison		Effect size for gender comparison	
Scale	Patient questionnaire	Parent questionnaire	Patient questionnaire	Parent questionnaire
Generic Core Scales				
Total score	0.02	0.21	0.02	0.55
Physical Functioning (and Physical Heath summary score)	0.07	0.26	0.17	0.07
Psychosocial Health	0.06	0.15	0.10	0.64
Emotional Functioning	0.30	0.48	0.06	0.17
Social Functioning	0.15	0.01	0.15	0.36
School Functioning	0.32	0.13	0.19	1.07**
Diabetes Module				
Total score	0.19	0.49	0.03	0.24
Diabetes Symptoms	0.29	0.11	0.22	0.37
Treatment Barriers	0.00	1.09˜	0.11	0.14
Treatment Adherence	0.11	0.14	0.01	0.07
Worry	0.00	0.25	0.08	0.09
Communication	0.06	0.45	0.76*	0.03

* Scores were significantly lower in girls than boys; ^ Scores were significantly lower in boys than girls;

˜ Scores were significantly lower in adolescents than children

Table 2.5 PedsQL 4.0 Generic Core scales and PedsQL 3.0 Type 1 Diabetes Module patient self-report and parent proxy report mean scores, overall age-gender ANOVA p-value and overall age-gender ANOVA effect size (η_p^2)

		Patient questionnaire			Parent questionnaire		
Scale	Items (n=)	Mean ±SD	Overall ANOVA p-value	Overall ANOVA effect size	Mean ±SD	Overall ANOVA p-value	Overall ANOVA effect size
Generic Core Scales							
Total score	23	84.5±10.6	0.93	0.012	82.3±9.6	0.26	0.104
Physical Functioning (and Physical Heath summary score)	8	86.6±10.2	0.91	0.015	90.5±8.1	0.81	0.026
Psychosocial Health	15	83.4±12.4	0.90	0.015	78.0±12.4	0.20	0.119
Emotional Functioning	5	81.0±16.7	0.44	0.071	75.9±16.4	0.36	0.084
Social Functioning	5	90.4±12.1	0.86	0.020	85.3±14.1	0.75	0.033
School Functioning	5	78.9±14.9	0.66	0.043	72.8±15.8	0.02	0.249
Diabetes Module							
Total score		76.3±13.0	0.93	0.012	69.9±12.9	0.39	0.080
Diabetes Symptoms	11	68.6±18	0.63	0.047	62.6±14.6	0.66	0.043
Treatment Barriers	4	80.0±16.6	0.97	0.008	67.5±22.9	0.02	0.227
Treatment Adherence	7	87.3±12.7	0.64	0.045	80.3±15.8	0.98	0.006
Worry	3	73.3±21.0	0.82	0.025	68.1±21.9	0.81	0.026
Communication	3	76.5±20.5	0.15	0.136	77.1±25.0	0.35	0.086

Figure 2.1: (Supplemental material) Recruitment and participant flow through the study (February – August 2012)

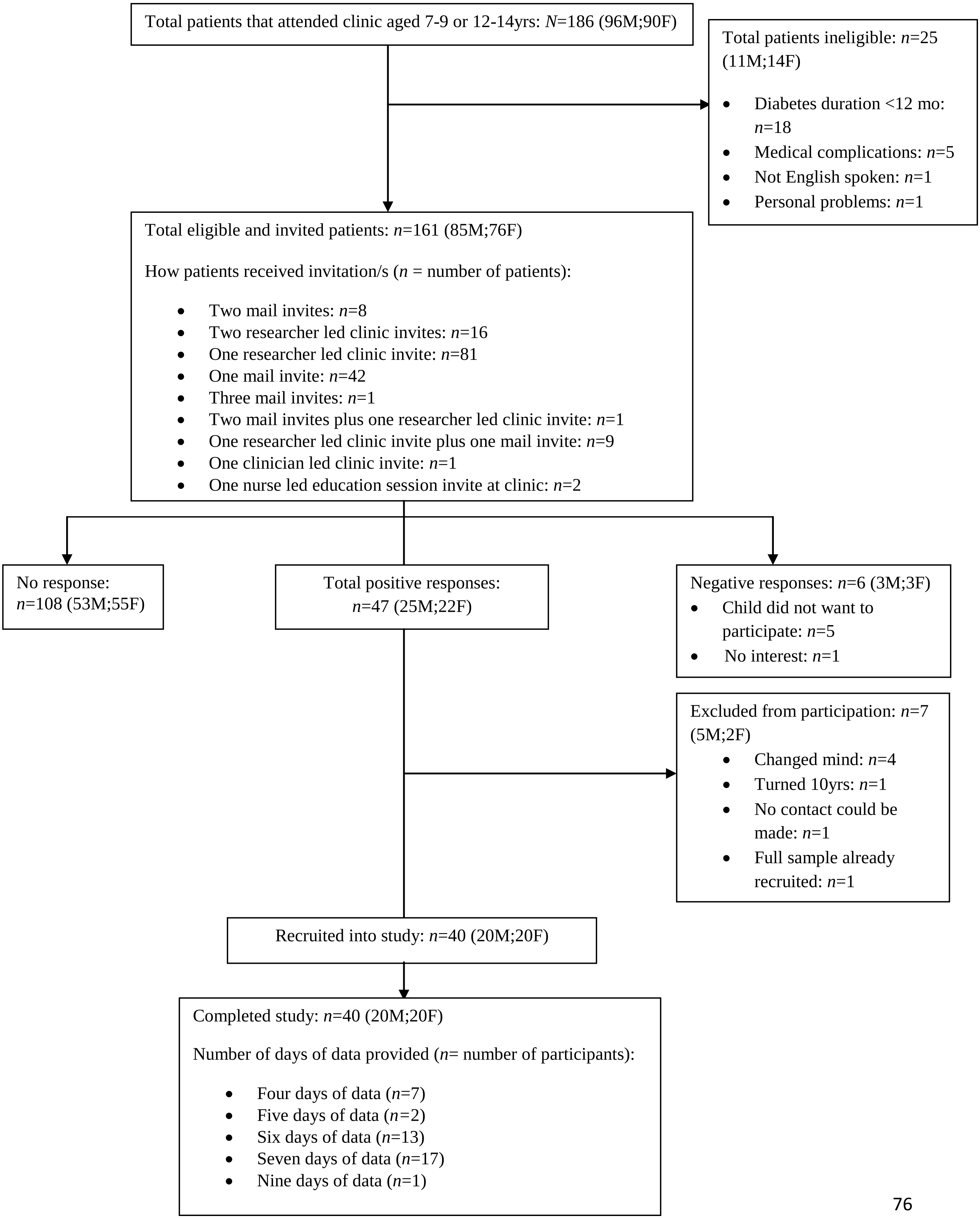

Figure 1 footnote

Patient medical records were screened at clinic by a diabetes healthcare team member. Recruitment strategies were: face-to-face researcher, nurse or doctor invitation at clinic; mail invitation sent by the lead clinician to patients; and invitation at a clinic education session. All participants described themselves or were described by their parents as being white Scottish.

Gender, age and Scottish Index of Multiple Deprivation (SIMD) data for the total potential sample of participants was collected. SIMD data was missing for one individual (excluded from SIMD analysis). There were no significant differences in age or gender between those responding to study invitation (responders) and patients that did not respond to invitation (non-responders) ($p>0.05$), suggesting a representative sample in terms of gender and age. There was a significant association between SIMD and those that responded or did not respond to study invitation $\chi^2(4) = 2.65$, $p=0.015$, with the biggest difference between responders and non-responders being those in the most affluent SIMD category (28.3% of responders versus 18.5% of non-responders).

4.1 Additional data not included in the paper

4.1.0 Sample size

In the early stages of designing study 1, it was planned that a gender and age matched comparison group of peers without diabetes would be recruited to compare physical activity, sedentary behaviour and quality of life data to. However due to the constraints of the PhD, and the fact that comparison physical activity and sedentary behaviour data for youth without diabetes using the same data collection procedures already existed, it was decided that a comparison group was not essential. A target sample size of 40 patients was deemed appropriate within the timescale and restraints of the PhD. Although study 1 could be underpowered for some comparisons, differences were still evident and effect sizes are reported in the paper as an indicator of the strength of the differences found.

Large effect sizes were evident for the overall omnibus ANOVA for age-gender comparisons and for post-hoc differences in sedentary behaviour with 40 participants (11 adolescent boys, nine adolescent girls, nine younger boys and 11 younger girls). The overall omnibus ANOVA for MVPA time for the age-gender comparison was not significant ($F = 0.187$). The results of paper 1 were used to determine the sample size that would have been required to find a significant omnibus one-way ANOVA for MVPA between the four age-gender groups using a power analysis. To ensure a large effect size of 0.80 and with power at $p = 0.05$, a total sample size of 316 (n = 79 per group), would be required for MVPA time.

4.1.1 Summary of data transformations and differences using non-parametric tests

Table 2.6 on the next page details a summary of the data transformations used, effects on distribution of the data and differences in results found using non-parametric tests from paper 1.

Table 2.6: Summary of data transformations and differences when using non-parametric tests

Variable, comparison groups	Skew pre transformation	Kurtosis pre transformation	Trans-formation used	Skew post transformation	Kurtosis post trans-formation	Kolmogorov-Smirnov post	Non-parametric findings (if different from parametric)
boys	1.89	6.83	SQRT	0.61	3.88	>0.05	Significantly lower MVPA
girls	2.25	5.65		1.40	2.89	>0.05	in girls than boys (p<0.05)
adol boy,	1.89	5.39	SQRT	0.81	3.30	>0.05	Significant overall
adol girls,	0.63	0.03		-0.13	0.33	>0.05	difference (p<0.05). Adol
young	-0.48	0.91		-0.88	1.70	>0.05	girls less active than adol
boys,	1.91	3.07		1.61	1.89	>0.05	boys and young girls (both
young girls							p<0.05) and also less
							active than young boys
							(p<0.01). No other
							significant differences
school,	1.74	2.82	COS	0.60	-1.35	>0.05	
weekends,	1.47	2.10		0.40	-1.0	>0.05	
holidays	1.72	3.19		-0.00	-2.06	>0.05	
weekdays,	0.09	-0.69	SQRT	-0.27	-0.39	>0.05	Overall significant
Saturdays,	1.14	0.48		0.39	-0.50	>0.05	difference between

Sundays,	2.56	8.65		0.98	2.04	>0.05	weekdays, Saturdays and Sundays (p<0.05). Less MVPA on Saturdays than weekdays (p<0.05). No other significant differences
adol boy,	-0.51	0.04	COS	-0.20	-0.74	>0.05	
adol girls,	-0.20	-1.68		-0.42	-1.26	>0.05	
young	-0.23	-1.04		-0.16	-1.06	>0.05	
boys,	-1.77	3.11		1.29	1.07	<0.05	
young girls							
adol boy,	-0.28	-0.19	SQRT	-0.59	0.41	>0.05	
adol girls,	-0.62	-1.19		-0.71	-1.03	>0.05	
young	-1.08	0.91		-1.29	1.50	>0.05	
boys,	-0.39	-1.10		-0.48	-1.05	<0.05	
young girls							

SQRT = square root transformation; Cos = Cosine transformation; adol = adolescent

4.1.2 Physical activity and sedentary behaviour questionnaire results

The questionnaire used to capture the types of physical activities and sedentary behaviours that patients participated in during the week they wore the accelerometer is provided in Appendix C. Tables 2.7 and 2.8 on the following pages, summarise the findings of the questionnaire by detailing the number of patients reporting participation in various physical activities and sedentary behaviours.

Table 2.7 Reported physical activities for all patients (*N*=40) during the week the accelerometer was worn

	Number of patients (*n*=) performing the activity in each of the frequency per week (x/wk) categories				
	0 x/wk (*n*=)	**1-2 x/wk (*n*=)**	**3-4 x/wk (*n*=)**	**5-6 x/wk (*n*=)**	**≥7 x/wk (*n*=)**
Type of activity					
Team games	11	13	14	1	1
Racquet sports	30	8	2	0	0
Individual sports	6	13	14	3	4
Outdoor recreation	24	9	3	2	2
Water -based	29	10	0	0	1
Dance	26	8	3	1	2
Fitness	20	14	6	0	0
Active video games	27	10	2	0	1
Martial arts	36	4	0	0	0
Winter sports	37	2	1	0	0
Active transport	9	7	4	9	11
Playground games	17	3	2	6	12
*Other**	32	5	1	1	1

* Activities not captured by the questionnaire were: soft play, playing in a paddling pool, playing outside with friends (but not playground games), roller-skating (not for active travel), work (paper round), playing in a ball pit, fruit picking

Table 2.8 Reported sedentary behaviours for all participants (*N* =40) during the week the accelerometer was worn

	Number of patients (*N*=) performing the activity in each of the frequency per week (x/wk) categories				
	0 x/wk (*n*=)	**1-2 x/wk (*n*=)**	**3-4 x/wk (*n*=)**	**5-6 x/wk (*n*=)**	**≥7 x/wk (*n*=)**
Sedentary behaviour					
Computer/internet[$]	7	9	6	7	10
Sitting playing video games	12	13	8	2	5
*Homework, studying**	9	7	11	9	4
Reading (not for school)	12	10	6	5	7
*Sitting during school breaks**	19	7	2	2	3
Sitting talking with friends (not on phone)[$]	10	7	6	9	7
Listening to music	15	8	8	4	5
Talking or texting on the phone	17	5	4	2	12
Television or DVD watching	2	2	11	7	18
*Other^*	31	2	2	0	5

* Reasons for *N*≠40 included: no school days during the measurement period and/or homework not being assigned. [$]Missing data for *N*=1. ^ Behaviours not captured by the questionnaire were: playing a board game, sewing, watching a film in the cinema, drawing, playing with lego, crafts, writing (not for school)

5.0 Summary of chapter 2

Study 1 confirmed the need for physical activity and sedentary behaviour intervention in youth with Type 1 diabetes due to only 5% (2/40) of the participants meeting the MVPA guidelines and a large percentage of the waking day being spent in sedentary behaviour. Physical activity and sedentary behaviour pattern findings and differences in these behaviours by age and gender will be useful for developing interventions in knowing when to target these behaviours and at whom. Detailed reporting on the recruitment phase of study 1 will help in the design of future studies recruiting youth with Type 1 diabetes from paediatric clinics and helps to conclude on the representativeness of the study sample. As shown in the supplement to paper 1, multiple recruitment strategies (in-person and mail invitation), and for some people multiple contacts (up to three), were required to successfully recruit the target sample size. Patients that responded to the study invitation were representative of the total invited population in terms of age and gender. However it appeared that those responding to the study invitation tended to be of greater socioeconomic status than those that did not respond to the invitation, suggesting that less affluent patients were not reached as successfully by the recruitment procedures.

Study 1 gave an objective measure of how much physical activity and sedentary behaviour a sample of youth with Type 1 diabetes were achieving, highlighting the need for intervention. The next chapter (study 2) explores what is already known from previous intervention studies in a systematic review of the literature.

Chapter 3: A systematic review of physical activity and sedentary behaviour intervention studies in youth with Type 1 diabetes: Study characteristics, intervention design, and efficacy

1.0 Preface

This chapter provides a systematic review of RCT physical activity and sedentary behaviour intervention studies in youth with Type 1 diabetes. The findings provide the rationale for the requirement of physical activity intervention for youth with Type 1 diabetes to improve health as well as providing guidance for designing studies and interventions for future research. Material supplementary to the published manuscript is provided to give further detail on: keywords used in the systematic search; the reasons for exclusion of studies; and the risk of bias in included studies. Methods advised by the Cochrane collaboration (Liberati et al., 2009), which are recognised internationally as the gold standard for reviewing the effectiveness of health interventions (The Cochrane Collaboration, 2013), were adopted in the review.

2.0 Paper 2: A systematic review of physical activity and sedentary behaviour intervention studies in youth with Type 1 diabetes: Study characteristics, intervention design, and efficacy

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The following paper has been accepted by Pediatric Diabetes and is currently in press.

Abstract

Objective: To systematically review physical activity and/or sedentary behaviour intervention studies for youth with Type 1 diabetes.

Methods: Several databases were searched for articles reporting on RCTs in youth (<18yrs) with Type 1 diabetes. Data was extracted and bias assessed to evaluate study characteristics, intervention design and efficacy of interventions on physical activity and health. Where sufficient data were available meta-analyses of health outcomes (for HbA1c) were performed. Weighted mean differences were calculated using fixed and random effects models.

Results: The literature search identified 2397 results, of which 12 full-text articles reporting on 11 studies met inclusion criteria. Two interventions were wholly unsupervised and only one was based on behaviour change theory with no studies exploring changes in behaviour processes. Nine interventions aimed to improve fitness or physical activity, two aimed to improve health and none aimed at changing sedentary behaviour. Eight interventions improved physical activity and/or fitness. At least one beneficial effect on health was found in each intervention group apart from two studies where no changes were found. Meta-analysis of ten studies showed the interventions have a significant beneficial reduction of HbA1c (%), indicating an improvement in glycaemic control (WMD, -0.85% (95% CI -1.45 to -0.25%). There were insufficient data to pool other health outcome data.

Conclusions: Few RCTs explored the efficacy of unsupervised theory-based physical activity and/or sedentary behaviour interventions in youth with Type 1 diabetes. Limited reporting made comparison of findings challenging. There was an overall significant beneficial effect of physical activity on HbA1c.

Introduction

Physical activity is any bodily movement resulting in an increase in energy expenditure from rest so includes exercise and sport. Physical fitness (referred to as 'fitness' hereafter) is the ability to perform body movement satisfactorily. Physical activity participation is one of the primary determinants of physical fitness (1). Regular physical activity is recommended for management of Type 1 diabetes (2) and guidance on safe physical activity participation has been developed for children and adolescents (youth) with Type 1 diabetes (3). Despite this, some studies (4-7) have found that youth with Type 1 diabetes do not meet the physical activity recommendation (at least 60 minutes of moderate to vigorous activity per day (8)) and that they are less active than their non-diabetic peers (5, 7). Guidance on how best to encourage physical activity participation in this population is lacking.

Studies have found that even if individuals are adequately physically active, if they spend large amounts of time in sedentary pursuits (sitting) then they are still at an increased risk of cardiovascular disease compared to individuals spending little time doing sedentary pursuits and in a dose-response manner (9). Interventions should be developed which minimise sedentary behaviour and promote physical activity. Interventions based on theoretical models and targeted at specific behavioural processes (10, 11) are more likely to result in sustained behavioural changes than those not based on theory. It is therefore important to examine theories explaining physical activity and sedentary behaviour for the development of successful interventions.

Systematic reviews exist demonstrating the efficacy of physical activity interventions on health of adults with Type 2 and Type 1 diabetes (12-14). Although literature has been reviewed examining the efficacy of physical activity interventions on health in youth with Type 1 diabetes (15), systematic review evidence in this group has not been published. Systematic reviews provide a way of summarising research evidence using rigorous, peer reviewed protocols and can help to identify the true effect of a behaviour on health and the development of effective behaviour change interventions. It is important to examine the efficacy of interventions in youth separately from adults. Important design features for interventions include appeal to different age groups as well as acceptability and usability. Also anatomical, physiological and psychological differences exist between age groups, which may affect responses to physical activity.

The objectives of this research were to systematically review RCT studies published on physical activity and/or sedentary behaviour interventions for youth with Type 1 diabetes to explore: 1) study characteristics and intervention design, including intervention behaviour change theory and analysis of study quality/risk of bias; and 2) the efficacy of interventions on physical activity and/or sedentary behaviour and health.

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance was followed during the planning, conduction and writing of this review (16).

Methods

Study eligibility

Full review protocol details are available from the author. Study eligibility criteria are as per the PICOS principles for systematic reviews (17):

- *Population:* youth aged ≤18 years with Type 1 diabetes
- *Intervention:* physical activity (or an outcome/parameter of physical activity (e.g. exercise or fitness, respectively)) or sedentary behaviour intervention where the intervention was more than a one-off acute activity session
- *Comparisons:* usual physical activity or sedentary behaviour (i.e. sitting time)
- *Outcomes:* measure of physical activity (or an outcome/parameter of physical activity), sedentary behaviour, any physical or psychological health outcomes or behaviour change processes
- *Study designs:* randomised-controlled trials (RCTs). RCTs provide the greatest internal validity and best evidence of the efficacy of interventions (18).

Only peer-reviewed, published articles in English were included with no limitation on the year of publication or length of follow-up.

Search strategy

The following databases were searched: Embase (OVID); MEDLINE (OVID); the Cochrane library; Physical education index (Cambridge Scientific Abstracts). The search strategy was reviewed by the research team and an experienced subject librarian. Supplement 1 (Table 3.3) details the search strategy for the Embase database. Similar keywords were used to search other databases and Mesh headings were used where available. Searches were conducted in

October 2011, with search alerts set-up to capture additional relevant publications up to November 2012. A follow-up search was conducted in November 2012 of the Cochrane library, which lacked the search alert facility. Reference lists of key articles were searched for eligible studies.

Data extraction and appraisal

Study titles and abstracts were screened independently by two researchers following the review protocol. Discrepancies were discussed. Full articles were reviewed independently by two researchers and disagreements resolved by discussion.

Data extraction was performed by one reviewer and reviewed for agreement by one of four additional reviewers. Methodological risk of bias (systematic error) of included studies was assessed and reported following guidance from the Cochrane Handbook (18) and data extracted using the Cochrane Consumers and Communication Review Group template (19). The following elements for RCTs were assessed for each study: random sequence generation; allocation sequence concealment; blinding (outcome assessment); completeness of outcome data; selective outcome reporting. The research team identified bias related to the appropriateness of statistical analyses, and in relation to sample size and adherence to the intervention, to be additional potential sources of bias. Blinding of participants and personnel was not assessed, as this is impossible in physical activity/sedentary behaviour research. Unless articles stated that there were dropouts it was assumed that outcome data was complete. Studies with multiple pairwise comparisons that did not adjust the significance value were rated as high risk for statistical analysis appropriateness due to the increased risk of making a Type I error: the risk of finding a change in an outcome when actually there is not a change. Studies not reporting on attendance/programme adherence and not measuring physical activity level or intensity were rated high risk for adherence.

Authors were contacted for clarification of the study methods and to recommend other relevant articles for inclusion. Four authors (20-23) responded with additional study details. Results of the risk of bias assessment were tabulated and systematic narrative description and commentary for each study element were used to determine an overall assessment of the risk of bias and to comment on overall internal validity of the review's results.

If possible meta-analyses of continuous variables were performed using Review Manager software (RevMan 5.2, Cochrane Collaboration, Oxford, UK). Weighted mean differences

(WMD) and 95% confidence intervals (95% CI) were calculated from either end of intervention mean and SD or change from baseline mean and SD data. Heterogeneity between studies was determined using χ^2 and I^2 tests; random-effects analysis was performed when significant heterogeneity was present, and a fixed effects analysis when it was not present. For studies with more than two intervention groups, the comparison control mean±SD data were entered twice and the control group sample size halved for each comparison. Funnel plots were conducted to check for publication bias. Sub-group analysis was also performed to examine the influence of intervention duration (≤ 3 months or > 3 months), frequency of activity (< 3 days/week or ≥ 3 days/week), activity duration (< 60 minutes or ≥ 60 minutes) and type of activity (aerobic based, combined aerobic and resistance training or Pilates).

Results

Objective 1: Study characteristics and intervention design

Figure 3.1 shows the flow of studies through the review process. Supplement 1 (Table 3.4) summarises reasons for exclusion at the final screening stage. Twelve articles (20-31) reporting on 11 RCT studies met inclusion criteria. Two papers reported on the same trial (27, 28). The remainder of the results section reports on findings from the 11 included studies. None of the studies focused on sedentary behaviour. Table 3.1 reports study aim, setting and duration, population characteristics, the intervention design, physical activity or fitness and health outcome measures, changes in outcomes and attendance for each study. The majority of studies included one intervention and one control group (20-23, 26-30). Two studies had two intervention groups with intervention groups differing in the number of sessions that participant's took part in weekly (24, 25). Three RCTs were conducted in Europe (20, 23, 30), three in North America (26-29), two in Africa (24, 25), two in Asia (22, 31) and one in New Zealand (21). Four articles were published in the 1980's (26-30). The remaining seven were published after the year 2000 (20-25, 31).

Participants

Across included studies the total sample size was 471 (214 males and 257 females) and in individual studies ranged from eight (29) to 196 participants (24), with five studies having less than 20 participants (20, 23, 26-29). Two studies included power calculations to determine sample size (21, 23). The target sample size (n=84 (21) and n=40 (23)) was not achieved in either study (n=78 (21) and n=16 (23) participants were recruited). Across all studies mean age was 13.6 years (age range 5-19 years). Six studies (20, 22, 24, 25, 27-29) recruited only adolescents (aged ≥12years) whilst five also included children aged <12 years (21, 23, 26, 30, 31). Duration of diabetes was reported in all but one study (21). Five studies collected ethnicity data (20, 21, 23, 26, 29).

Recruitment and intervention setting

All studies recruited participants via diabetes clinics set in hospitals with the exception of one study in which recruitment setting was not reported (25). No study reported on recruitment methods. After correspondence with four authors it was determined that recruitment was undertaken face-to-face in the clinic (22), by mail invitation (23), via telephone (20) and by a combination of face to face and mail invitation (21). Recruitment was performed by doctors (22, 23) or researchers (20, 21). Eight studies consisted of interventions delivered in supervised conditions (22-30). One intervention was delivered in a hospital (29), one solely in a gym (22) and one in a gym and outdoors (25). The remaining studies including only supervised interventions did not report location. One study reported encouraging unsupervised activity in addition to supervised sessions (30). Two studies consisted of solely unsupervised interventions: pedometer-based (21) and video-based programmes (31). Another study combined supervised sessions delivered in a training facility with an unsupervised programme to be completed at home (20).

Intervention design

One RCT (21) based the intervention development and delivery on the Trans-theoretical model of behaviour change (32). Changes in behavioural processes were not assessed in any studies. Intervention duration ranged from 8 (29) to 24 weeks (20, 24, 25), with most studies (n=5) having an intervention period of 12 weeks (21, 22, 26-28, 31). Seven interventions were aerobic based (21, 25-31); three were combined aerobic and resistance programmes (20, 23, 24); and one was a Pilates programme (22). Five studies used trained professionals (e.g. physiotherapist, certified activity instructor) to deliver the intervention (22-26), four used researchers or students (20, 21, 27, 28, 30) and two did not provide details of the interventionist (29, 31).

Fidelity and adherence

Fidelity of the intervention, in terms of the delivery of the content, was not reported in any study and no articles reported user involvement in the development of interventions. Only two studies reported on adherence to physical intensity targets during sessions (20, 26) whilst five reported on attendance (20, 23, 26, 30, 31). Table 3.1 summarises how adherence and attendance was reported in these studies.

Risk of bias (within and across studies)

Supplement 1 (Tables 3.5 and 3.6) summarise risk of bias within the included studies. No articles reported details of random sequence generation or allocation concealment. After correspondence with four authors, it was determined that three studies had a low risk of bias for both outcomes (20, 21, 23) and one had a high risk of bias regarding the generation of a random sequence but took appropriate measures to conceal group allocation (22). Researchers collecting fitness (20, 22) and quality of life (20) data were aware of group allocation in two studies. Insufficient details were provided in five studies to conclude if blinding of outcome assessment occurred (26-31). All studies provided complete outcome data for participants. One study rated high risk for 'selective outcome reporting' as changes in the control group were not reported (25). Another study did not report HbA1c values but this information was gained by correspondence with the lead author (20). Five studies rated high risk as inappropriate statistical analyses were used or p-values were not altered to take in to consideration multiple comparisons (20, 22-24, 26). Only one study replaced missing data and in this study intention to treat analysis was applied (21). Four studies reported attendance and measured intensity of activity sessions and rated low risk for programme adherence (20, 23, 26, 30), with the remaining seven studies (21-22, 24, 25, 27-29, 31) rating high risk.

Objective 2: Effect on physical activity and/or sedentary behaviour, health and quality of life

A wide range of health measures were used to assess efficacy. Outcome measures were assessed at baseline and at the end of the intervention period in all studies. Eight interventions successfully improved physical activity and/or an area of fitness (20, 22, 23, 26, 28-30). At least one significant beneficial change in health was found for the intervention group in each study apart from two studies, which did not find any changes in outcomes for those in the intervention group (21, 31). Changes in intervention groups are now discussed followed by changes in control groups and then pooled effects analyses. Table 3.1 documents all outcome measures assessed and changes found in each study.

Physical activity and fitness

Changes in physical activity were measured in two studies using pedometers (21) and questionnaires (20). One study found no change in pedometer counts (21) whilst the other found an increase in reported activity (20). Eight studies measured changes in parameters of fitness with seven of these studies reporting an improvement in some area of fitness (20, 22, 23, 26, 28-30) and one finding no change (31). Two studies did not include a measure of physical activity or fitness (24, 25).

Diet and insulin

Only two studies reported on changes in diet over the intervention period (26-28). Seven measured changes in insulin dosage (21-24, 26-29) and one study reported on the frequency of participants to have a change in insulin dosage (25). The only studies to find a significant change in insulin dosage were by Salem et al., and D'Hooge et al., which both found a reduction in dosage in intervention groups (23, 24).

Blood chemistry

HbA1c was measured in all studies. Three reported a decrease in HbA1c (24-26). Aouadi et al., only found a decrease in HbA1c in the intervention group that were exercising four times weekly and not the group exercising twice weekly (25). An increase in HbA1c was found in the intervention group of one study (30). The remaining studies did not find a change in HbA1c in the intervention group (20-23, 27-29, 31).

Improvements in other blood glucose control indicators were found in studies measuring mean blood glucose (29), glucose utilisation (27, 28) and fasting blood glucose (26). Six studies measured blood lipids (20, 22, 24, 25, 27-29), three of which found positive changes in the intervention group/s (24, 25, 27, 28) and three which reported no changes (20, 22, 29). Other beneficial effects on blood chemistry found in intervention groups were on apolipoprotein (20) and glycosylated serum albumin levels (29).

BMI and body composition

Two studies did not report on changes in BMI or body composition (30, 31). Of the nine studies that did measure BMI and body composition, six did not find any changes (21-23, 25, 27-29). Campaigne et al, reported an increase in weight in the intervention group (26). Fat free mass and weight increased in the intervention group of another study (20). Salem et al., found a decrease in BMI in the group performing activity thrice weekly (intensity detailed in Table 3.1) and in both intervention groups a decrease in waist circumference but no change in weight (24).

Blood pressure

Blood pressure was measured in two studies (21, 24), with one finding a positive change in the intervention group (24) and the other no change (21).

Hypoglycaemic episodes

Six studies reported on hypoglycaemic episodes during programmes (20, 23-28). Only one reported on changes in total hypoglycaemic frequency (not just episodes during supervised sessions) and did not find a change pre to post intervention (24).

Quality of life

Three studies included a measure of quality of life (20, 21, 23) with one reporting a positive effect on quality of life in the intervention group (20).

Control group changes

Changes in outcomes for the control group were only found and reported in five studies (20, 22-24, 31). One study reported an increase in HbA1c in the control group undertaking self-directed activity (31) whilst another reported an increase in insulin dose in the control group (23). Salem et al., and Heyman et al., found an increase in weight (20, 24) in the control groups. A beneficial increase in HDL cholesterol was found in the control group of one study (22).

Meta-analyses

Ten studies reporting HbA1c could be pooled in a meta-analysis (Figure 3.2). This analysis shows an overall significant improvement in HbA1c (WMD, -0.85% (CI-1.45 to -0.25%). There was significant heterogeneity between studies ($p < 0.0001$, $I^2 = 73\%$). Subgroup analyses of potentially influential intervention characteristics were used to explore the sources of heterogeneity (Table 3.2); these show greater beneficial effects focussed in interventions, which were longer in total and session duration, had greater frequency per week and involved combined exercise. There were too few studies to pool other health outcome data reliably.

Discussion

Following the structure of the objectives, this section focuses firstly on discussing included study characteristics and intervention design and secondly on the efficacy of interventions on physical activity and/or fitness and health. Recommendations are provided in a recommendations box at the end of the discussion for improving future research in the area of physical activity and sedentary behaviour change in youth with Type 1 diabetes.

Objective 1: Study characteristics and intervention design

Only two interventions in this review were unsupervised, based in home and community settings (21, 31). Supervised physical activity interventions are useful to examine the efficacy of interventions on health. For public health interventions to be cost-effective and sustained long-term, it is recommended that they do not require attendance at a facility (10, 11). Only one study included in this review was based on theory (21) and none measured changes in behavioural processes. It is important to measure these to develop interventions that target the key processes involved in physical activity and sedentary behaviour change. In general, lifestyle interventions based on behaviour change theory are more effective when compared with interventions not based on theory (10, 11). For example RCT studies using physical activity consultation in adults with Type 1 (33) and Type 2 diabetes (34) have proved successful. In these examples consultations were based on the Trans-theoretical model of exercise behaviour change (35), allowing tailoring of the interventions by use of different strategies depending on the individual's motivation to change. None of the included studies in the current review targeted sedentary behaviour.

All but a few included studies (20, 21, 24, 25, 30) had a goal of improving fitness and included a measure to assess an area of fitness. Three studies described in their aims that their interventions were physical activity programmes (20, 21, 30). However one of these studies did not assess changes in physical activity and instead reported changes in fitness (30). Two studies described their interventions as programmes aiming to improve health (24, 25). Although both studies included measures of health, they did not actually measure changes in physical activity/fitness. If no significant increase in activity or fitness actually occurred then changes in health would not be expected. If significant changes in health were found, without measuring changes in activity or fitness, it cannot be concluded that the intervention led to changes in health.

All included studies apart from one (21) had a weekly activity goal totalling less than is recommended for health benefits (a minimum of 60 minutes of moderate to vigorous physical activity a day (8)) and may not have provided a stimulus great enough for health changes. The intervention by Newton et al., (21) had a goal to be active daily. However participants were already achieving the universal intervention goal of 10,000 steps per day at baseline (21). None of the included studies reported measurement of intervention fidelity.

Study quality/risk of bias

The risk of a Type II error (missing a change in an outcome when actually there could have been a change if there had been greater power) is increased with a small sample size. Sample size across included studies was small thus studies may be underpowered (36). Appropriate statistical analyses were not always applied to consider small participant numbers increasing the risk of making a Type I error, especially if the significance value was not adjusted to counteract multiple pairwise comparisons. The two studies that used power calculations (21, 23) did not manage to recruit the target sample size suggesting recruitment may be particularly challenging in this population. Recruitment methods and recruiter details were not reported in any articles and were only determined for studies (20-23) in which correspondence with the author was achieved. Intention to treat analysis is recommended when there have been dropouts (18). Only one study reported using this analysis (21).

A small number of included studies reported attendance at supervised sessions (20, 23, 26, 30, 31). Although a number of studies reported measuring the intensity that participants were reaching during sessions (20, 23, 25-28, 30, 31), only two studies actually reported adherence to achieving intensity targets (20, 26). To conclude intervention affects on health, it is essential to know whether individuals performed as intended and adhered to the planned programme. Conclusions may be made that an intervention is ineffective when in fact adherence is the issue.

Control participants were asked to continue with their normal physical activity behaviour apart from in one included study where participants participated in non-physical activities under supervised conditions (30) and another study where participants were given an exercise programme and encouraged to participate in more activity than usual (29). Of importance for this review is the included study by Wong et al., which was originally designed as a RCT with a physical activity intervention group and a control group that continued with their normal physical activity level. Study design was modified to include a third group who increased their physical activity level without the intervention (self-directed group) (31). Therefore the true control group (who continued with their normal physical activity participation) was reduced in size.

Across included studies, reporting of study details was limited, with correspondence being required with all authors. Guidance is now available to aid reporting of RCTs (37).

Objective 2: Effect on physical activity and health

To capture the full effect of interventions, data on any physical activity/fitness or health outcome were extracted and included in this review (Table 3.1 details all outcomes). Included studies measured an array of outcomes making assessment of efficacy difficult. However, the majority of interventions successfully improved physical activity and/or an area of fitness (20, 22, 23, 26, 28-30) and all studies, apart from two which reported no changes (21, 31), found at least one positive effect on health. A previously published literature review also reported benefits of physical activity on health in youth with Type 1 diabetes but mentioned inconsistencies across studies (15). Inconsistencies may be due to many reasons including insufficient reporting, as is now discussed may be the case for HbA1c findings in this review.

Meta-analysis of HbA1c data in this review suggests physical activity can positively affect HbA1c. Interpretation of this finding must be considered with caution. Firstly, bias was present in almost all included studies. It is appropriate however to ‘take stock’ of currently available data even with bias issues to guide future research. Secondly, there was a lack of measurement and/or reporting of changes in insulin dosage and diet in included studies, which can affect HbA1c. Limited insulin dosage and diet data meant meta-analysis of these outcomes was not possible in this review. The impact of physical activity on HbA1c is complex and individualised, leading to difficulties for researchers to find and/or explain changes during intervention periods and on reporting the efficacy of programmes. Without full reporting of insulin dosage, diet, physical activity and hypo/hyperglycaemic episodes, drawing conclusions on the efficacy of physical activity on HbA1c is confounded. Improving HbA1c is a priority for youth with type 1 diabetes as complications can develop as early as 2-5 years post-diagnosis (38) and HbA1c is an important marker for risk of developing such complications. Type 1 diabetes is diagnosed most commonly at age 14 years (39) thus patients have potentially many years to live with the condition. Lowering insulin dose is favourable to reduce patient burden. Only one study in this review (24) recorded hypoglycaemic episodes during the full intervention period (e.g. during supervised exercise sessions plus remaining hours in the day).

Significant heterogeneity in meta-analysis of HbA1c data was explored in this review using subgroup analyses to examine whether the dose and type of interventions could be influential. Benefits to HbA1c were associated with longer programmes (>12 weeks), more frequent activity (≥ 3 days/week), longer duration activity (≥60 minutes; the recommended volume guideline for youth) and combined aerobic and resistance training. It was not possible to examine the effects of different intervention intensities on HbA1c due to variations in how intensity was measured and inconsistencies across studies on target intensities.

Due to the potential confounding by diet and insulin dosage changes and the small number of studies consistently measuring the same health construct, it was not appropriate to perform pooled effects analysis on other physiological health outcomes in this review. Only three included studies (20, 21, 23) measured changes in quality of life. Previous research highlights the importance of this outcome in youth with Type 1 diabetes as quality of life can often be poorer than in comparison to peers without diabetes (40).

An intervention may not result in an improvement in physical activity or health but it may prevent or postpone deteriorations in these outcomes, which is still a beneficial effect and should be considered when reporting results.

Limitations

This review only included RCTs as the aim was to gather the best available evidence. It is acknowledged that important information may have been missed regarding intervention design from studies of other designs (41). Publication bias may have affected the findings in this review as the funnel plot for HbA1c (Supplement 1 (Figure 3.3)) did not follow the symmetric inverted funnel shape indicative of no publication bias.

Conclusions

The present review of studies in youth with Type 1 diabetes highlights: 1) the lack of unsupervised physical activity interventions and interventions targeting sedentary behaviour; 2) the lack of physical activity and/or sedentary behaviour interventions based on theory and lack of exploration of the important processes involved in behaviour change; and 3) that physical activity interventions can beneficially affect physical activity/fitness and health.

Pooled effects of interventions on HbA1c suggest a beneficial effect but future research must fully report on insulin dosage and diet changes to confirm this. Findings suggest that longer interventions (programme duration >12 weeks), more frequent activity ($\geq$ 3 sessions/week), longer activity duration ($\geq$ 60 minutes/session) and inclusion of resistance exercise alongside aerobic activity may be most effective at improving HbA1c. Although the evidence for proving the benefit of physical activity in youth for Type 1 diabetes is still incomplete (the 'what' we should be encouraging) the findings of this review suggest positive effects. Future research should now explore the development of interventions to promote physical activity and minimise sedentary behaviour (the 'how' we should encourage these behaviours). A number of ways to improve future research in the field of physical activity and/or sedentary behaviour intervention in youth with Type 1 diabetes have been highlighted in the recommendations box.

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Recommendations for future physical activity and sedentary behaviour intervention research in youth with Type 1 diabetes

1. Research is required to develop and test interventions that:-
    - Are unsupervised and community and/or home based;
    - Are based on theory and target specific behaviour processes;
    - Target sedentary behaviour either simultaneously or separately with physical activity behaviour.
2. Studies should clearly state their intervention and overall study goals. Appropriate outcome measure/s should be included to measure changes in the targeted parameter and hypothesised outcome/s.
3. A suitable measure/s of physical activity and sedentary behaviour should be used. Including both an objective and subjective measure of physical activity will provide a comprehensive overview of physical activity behaviour.
4. Baseline characteristics of participants should be considered to determine the likelihood of ceiling or floor effects. Individualised physical activity goals building on baseline activity may be more appropriate and accomplishable than universal goals. Intervention fidelity is important and should be assessed, especially when multiple interventionists are employed.
5. The following details should be reported to inform the most effective recruitment strategies for youth with Type 1 diabetes:-
    - Methods of recruitment
    - Who performed recruitment
    - Number of eligible patients (potential sample)
    - Percentage of the eligible sample recruited into the study (recruitment rate).

    Appropriate sample size, data replacement and statistical analyses should be employed to ensure sufficient power in findings.
6. Adherence needs to be measured, fully reported and considered in analysis prior to making conclusions.
7. Report exactly what physical activity education or support is provided in standard care. Include a control group also with Type 1 diabetes whom continue with their normal physical activity behaviour and report on changes in their health outcomes.
8. Utilise the Consolidated Standards of Reporting Trials (CONSORT) guidelines (37) to plan, conduct and report research to a high standard.
9. HbA1c and other early signs of diabetes complications should be measured in intervention research. To understand and fully review changes in HbA1c researchers

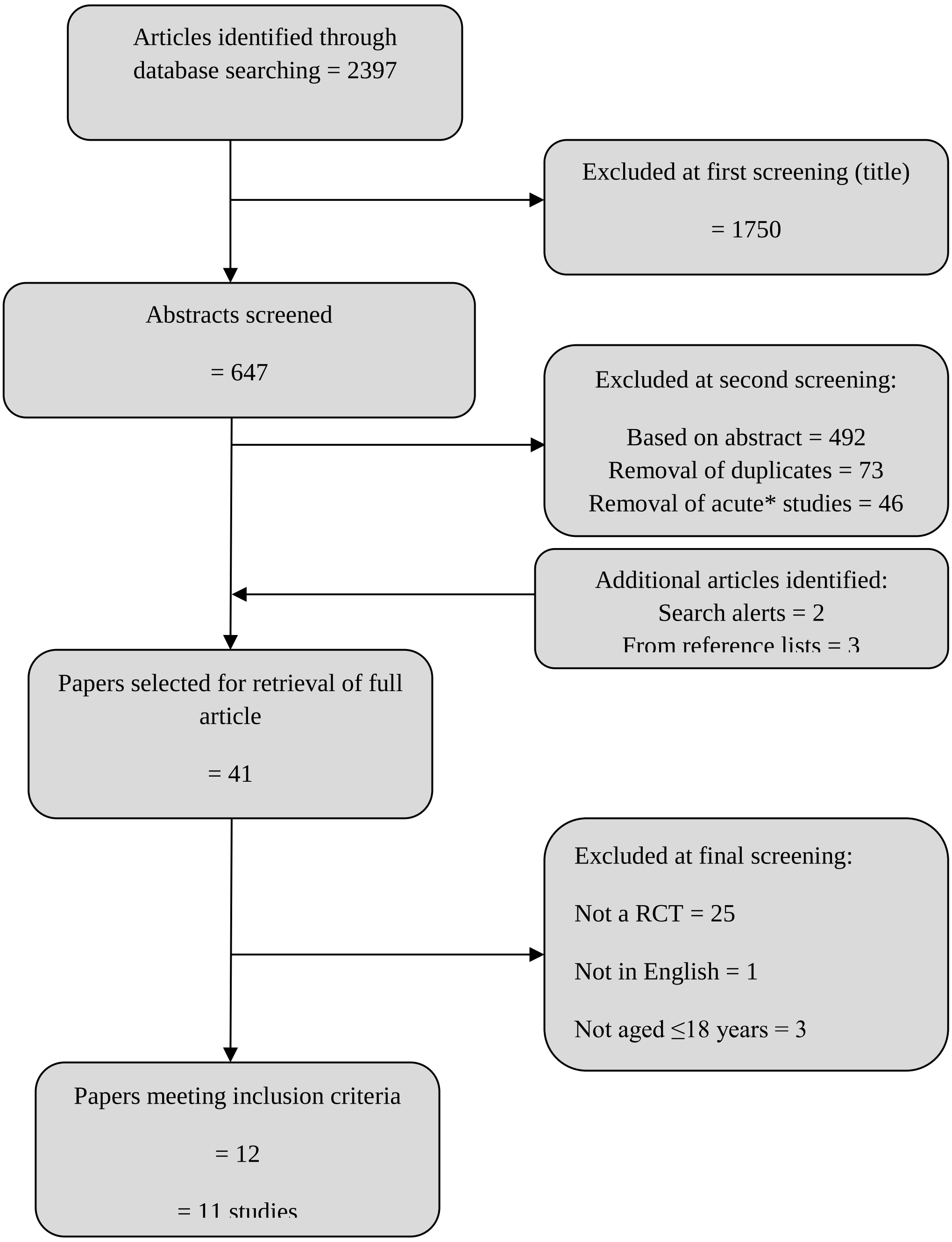
must measure as accurately as possible and completely report changes in:-

- Insulin dosage
- Diet
- Physical activity
- Hypo/hyperglycaemic episodes

Baseline HbA1c also needs considered. Hypoglycaemic episodes should be measured during and after physical activity sessions as delayed hypoglycaemic episodes can occur.

10. The impact of physical activity should not just focus on physiological health outcomes but also on other important outcomes such as quality of life.

Figure 3.1 Flow diagram of study selection



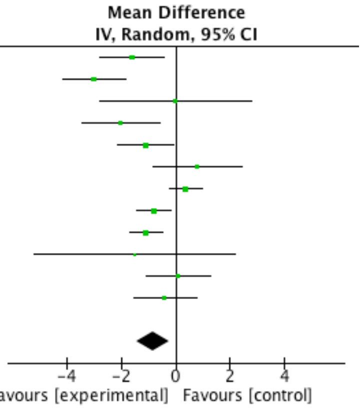
* Acute study = A one-off physical activity session

Figure 3.2 Forest plot showing overall estimates of the size of changes in HbA1c (%) due to physical activity interventions (CI = confidence intervals)

	Physical activity			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Aouadi et al., 2011 (a)	8.2	1.3	11	9.8	1.1	6	8.8%	−1.60 [−2.77, −0.43]
Aouadi et al., 2011 (b)	6.8	1.1	11	9.8	1.1	5	8.9%	−3.00 [−4.16, −1.84]
Campaigne & Landt., 1985	12	3	9	12	2.5	6	3.4%	0.00 [−2.80, 2.80]
Campaigne et al., 1984	11.3	1.5	9	13.3	1.7	10	7.5%	−2.00 [−3.44, −0.56]
Heyman et al., 2007	7.1	0.8	9	8.2	1.2	7	9.5%	−1.10 [−2.13, −0.07]
Huttunen et al., 1989	10.5	2.5	16	9.7	2.2	16	6.7%	0.80 [−0.83, 2.43]
Newton et al., 2009	0.35	1.5	38	−0.02	1.1	40	11.8%	0.37 [−0.22, 0.96]
Salem et al., 2010 (a)	8.1	1.1	75	8.9	1.4	24	11.7%	−0.80 [−1.41, −0.19]
Salem et al., 2010 (b)	7.8	1	73	8.9	1.4	24	11.7%	−1.10 [−1.71, −0.49]
Stratton et al., 1987	9.9	2.4	4	11.4	2.9	4	2.2%	−1.50 [−5.19, 2.19]
Tunar et al., 2012	8.8	1.5	17	8.7	1.8	14	8.8%	0.10 [−1.08, 1.28]
Wong et al., 2010	7.8	1.17	12	8.2	1.6	11	8.9%	−0.40 [−1.55, 0.75]
Total (95% CI)			**284**			**167**	**100.0%**	**−0.85 [−1.45, −0.25]**

Heterogeneity: $Tau^2 = 0.70$; $Chi^2 = 41.27$, df = 11 ($P < 0.0001$); $I^2 = 73\%$

Test for overall effect: Z = 2.78 (P = 0.006)



* Two studies had more than one intervention group (24, 25). Details of the interventions can be found in Table 3.1 Aouadi et al., 2011 (a) = the intervention group performing physical activity twice weekly; Aouadi et al., 2011 (b) = the intervention group performing physical activity four times weekly; Salem et al., 2010 (a) = the intervention group performing physical activity once weekly; Salem et al., 2010 (b) = the intervention group performing physical activity thrice weekly.

Table 3.1 Summary of RCT study characteristics, intervention design and efficacy

Author, Year, ref	**Aim, setting and duration**	**Study population**	**Intervention**	**PA/fitness, and health measures**	**Efficacy on PA, health and reported adverse events and adherence**
*Tunar et al., 2012 Turkey (22)	Aim: To explore the efficacy of Pilates training on anthropometric measurements, metabolic control and exercise capacity Setting: Recruited via hospital. Delivered in a gym centre Intervention length: 12 weeks Follow-up: 12 weeks (12 month data not published yet)	Age: Intervention: 14.2±2.2yrs; Control: 14.3±1.8yrs, (range:12-17yrs) N=31 (15M, 16F) Diabetes duration: Intervention: 5.3 ±4.1yrs; Control: 6.0 ±4.2yrs PA level: no participants participating in MVPA. Average weekly walking time was 51.6±22mins HbA1c: Intervention: 8.9 ±1.6%; Control: 9.2 ±2.1%	Thirty-six 40 minute, three times weekly supervised Pilates sessions. Intensity NS Staff: Certified Pilates instructor and paediatric endocrinologist for medical intervention if necessary Control: Continued with normal physical activity behaviour	IPAQ (baseline only) Flexibility Mean power Peak power Vertical jump BMI HbA1c Insulin dosage Blood lipids	HDL cholesterol increased in the control group. Peak power, mean power, flexibility and vertical jump increased in the intervention group.

*D'hooge et al., 2011 Belgium (23)	Aim: To explore the efficacy of combined aerobic and resistance training on glycaemic control, fitness and QOL Setting: Recruited and delivered in a hospital Intervention duration: 20 weeks Follow-up: 20 weeks	Age: intervention 14.1yrs (range:10.1-16.8yrs); control 13.2yrs (10.1-15.3yrs) N=16 (7M:9F) Diabetes duration: intervention 5.4yrs (range:3.4-7.3yrs); control 5.3yrs (range:2.9-5.9yrs) PA/fitness level: intervention 1748 ml/min; control 1725 ml/min (peak VO_2) HbA1c: Intervention: 7.9% (range:6.6-10.1%); Control: 8.8% (range:6.9-9.7%)	Thirty-eight 70 min, twice weekly supervised combined aerobic and resistance sessions. Intensity: graduated, starting at 60% of HRR (measured by monitors). Strength exercises graduated Staff: Physiotherapists Control: Continued with normal physical activity behaviour	Peak VO_2 6 min walk test 1 rep max Functional sit to stand test Hand grip strength Muscle fatigue resistance Insulin dose BMI Body composition HbA1c Pre & post exercise blood glucose concentration QOL (SF-36)	Insulin dose decreased in the intervention group and increased in the control group. Muscle fatigue score, number of sit to stand, 6 minute walk distance, upper and lower limb strength increased in the intervention group and greater post intervention than in the control group. Ratio of peak VO_2 to peak power decreased in the intervention group. Adverse events: Post training, the median number of hypoglycaemic levels was 3 with a minimum of 1 and a maximum of 6 for 7 out of the 8 children in the intervention group. One child had 15 low blood glucose levels in 31 training sessions. The median decrease of glycaemia after the training was 85mg/dL with a minimum of 20 and a maximum of 130 mg/dL Adherence: Attendance: Median sessions attended = 24 (minimum 20 and maximum 32).

Aouadi et al., 2011 Tunisia (25)	Aim: To examine the effect of exercise frequency on glycaemic control and lipid profile Setting: NS where participants were recruited. Intervention delivered in a gymnasium or outdoors Intervention length: 24 weeks Follow-up: Baseline, 12 and 24 weeks	Age: 12.4±1.5yrs, (range:12-14yrs) N=33 (all M) Diabetes duration: 3.7 ±0.5yrs PA/fitness level: Not participating in organised sports or exercise training (validated questionnaire) HbA1c: Intervention group 1: NS; Intervention group 2: 8.2 ±1.5%; Control: NS	Forty-eight twice weekly (group 1) or 96 four times weekly (group 2) aerobic sessions lasting 60 minutes each. Intensity: 50-55% maxHR at weeks 1-2, 55-60% maxHR at weeks 3-4 and 60-65% maxHR at weeks 5-24 (measured by monitors) Staff: Physical trainer Control: Continue with normal physical activity behaviour	BMI HbA1c Blood lipids Hypoglycaemic episodes Insulin dose (frequency that increased, decreased, remained the same – not statistical analysis)	HbA1c decreased in group 2 at 6 months and was lower than in group 1. Triglyceride levels decreased in group 1 and group 2 at 3 and 6 months and more in group 2 than group 1 at 3 and 6 months. HDL cholesterol increased in group 1 at 6 months and in group 2 at 3 and 6 months. LDL cholesterol decreased at 6 months in group 2 and was lower than group 1 at 6 months. Frequency of hypoglycaemic episodes during and immediately after sessions was collected but not reported. Insulin dose decreased in four participants in group 1 by 12.5±5% and in nine participants in group 2 by 17.1±4.9%. The number of insulin injections decreased in eight group 2 participants and in three group 1 participants.
Wong et al., 2010	Aim: To examine the efficacy of an individualised home-based aerobic programme on HbA1c and	Age: 12.4 ±2.1yrs, (range:9.5-16.4yrs)	At least 3 times weekly aerobic home-based exercise delivered via VCR plus phone calls from a researcher to aid	Peak VO_2	HbA1c was greater in control group 2 than in the intervention and control group 1 at 9 months post-intervention.

Northern Taiwan (31)	VO_2 Setting: Recruited via hospital. Delivered at home Intervention length: 12 weeks Follow-up: 12 months post-intervention	N=28 (8M, 20F) Diabetes duration: 4.0 ±2.8yrs PA/fitness level: mean daily energy expenditure through physical activity = 1502.0 ±530.5 Kcal HbA1c: Intervention: 8.1 ±1.1; Control group 1: 8.3 ±1.7; Control group 2: 8.5 ±1.0	compliance and a handbook to provide guidance and log exercise. Session duration increased from 10-20mins at week one to 20-30mins at weeks 3-12. Intensity: 10-30% HRR during warm-up and cool down and 40-60% HRR during aerobic exercises (measured by perceived exertion and heart rate monitor) Staff: NS Control group 1: Continued with normal physical activity behaviour (n=11) Control group 2: Self-directed exercise (n=5)	HbA1c	Adherence: Attendance: Subjects were considered adherent if they reported in telephone interviews to have exercised at least twice weekly (at least 67% of the goal per week) and adhered to the intervention for at least two months (at least 67% of the total intervention duration).
Salem et al., 2010	Aim: To examine the efficacy of an exercise programme on glycaemic control, plasma lipids, blood	Age: 14.8 ±2.3yrs	Twenty-four once weekly (group 1) or 72 three times weekly (group 2) supervised combined aerobic and strength	HbA1c	Weight decreased in group 1 and group 2 and increased in the control group from baseline to 6 months. In group 1 and 2 HbA1c, insulin dose, BMI and

Egypt (24)	pressure, frequency of hypoglycaemia, anthropometric measures and insulin requirements Setting: recruited via hospital, NS where intervention delivered Intervention duration: 24 weeks Follow-up: 24 weeks	N=196 (M75 F121) Diabetes duration: 4.6 ±1.9yrs, (range: 3-10yrs) PA/fitness level: measured but NS HbA1c: Intervention group 1: 8.9 ±1.4%; Intervention group 2: 8.9 ±1.6%; Control group: 8.3 ±2.1%	training sessions (plus flexibility, neuromuscular and balance components). Sessions lasted ~100minutes each. Intensity: Increased gradually. Aerobic section 65-85%maxHR (NS how measured) Staff: Physiatrist Control: Continued with normal physical activity behaviour	Blood lipids BP Hypoglycaemic episodes BMI Waist circumference Weight Insulin dose	waist circumference decreased. In groups 1 and 2 LDL cholesterol triglycerides and total cholesterol decreased whilst HDL cholesterol increased. Pre-exercise diastolic blood pressure reduced in group 2. Greater HbA1c level was associated with greater levels of cholesterol, LDL cholesterol and triglycerides before and after the programme. Frequency of hypoglycaemic episodes per month similar in groups at baseline and at 6 months.
*Newton et al., 2009	Aim: To assess whether pedometers and text messaging increase PA Setting: Recruited via hospital. Delivered in	Age: 14.4 ±2.4yrs, (range:11-18 yrs), N=78 (36M; 42F)	Pedometer with at least 10,000 steps/day goal plus weekly motivational text messaging Staff: Researcher	Pedometer counts NZPAQ MOH-Short SPARC-Long	Adverse events: Seventeen participants (45%) lost their pedometers and fourteen (37%) stopped wearing pedometers before follow up (11 agreed to wear pedometers for follow up)

New Zealand (21)	home/community Intervention duration: 12 weeks Follow-up: 12 weeks	Diabetes duration: NS PA/fitness level: Achieving >10,000 steps/day at baseline HbA1c: Intervention: 8.0% (range:7.3-9.1%); Control: 8.5% (range:7.6-9.3%)	Control: Continued with normal physical activity behaviour	A1c BP BMI-Z score Insulin dose QOL	
*Heyman et al., 2007 France (20)	Aim: To examine, in post-menarcheal girls, the efficacy of PA training on QOL, fitness, body composition, lipid and apolipoprotein profiles, and adiponectin and leptin levels Setting: Recruited via hospital. Supervised (at a training facility) and unsupervised (at home) components	Age: Intervention 15.9±1.5yrs; control 16.3±1.2yrs, (range:13.0-18.5yrs). N=16 (16F) Diabetes duration: Intervention 6.3±4.4yrs; Control 8.4 ±4.5yrs	Forty-eight, twice weekly combined aerobic and strength sessions (one 2-hour session (supervised) and one 1-hour session (unsupervised). Intensity: 80-90% of HRR (measured by monitors) Staff: Trained sports instructor Control: Continue with normal physical activity behaviour	Validated PA questionnaire PWC_{170} Body composition Height Weight HbA1c Blood lipids Serum	Total PA increased in the intervention group and was greater in the intervention group compared to the control at 6 months. FFM and PWC_{170} increased and apolipoproteinB:apolipoproteinA-1 ratio decreased in the intervention group. Height and weight increased in both groups. Improved scores in the 'satisfaction with diabetes' subscale in the intervention group. Adverse events: 17 mild (capillary

	Intervention duration: 24 weeks Follow-up: 24 weeks	PA/fitness level: Intervention 4.3 ±2.2 total hrs of PA/wk; Control 3.9±1.7 total hrs of PA/wk HbA1c: Intervention 7.3 ±0.9%; Control 8.5 ±1.3%		Apolipoproteins Lipoprotein (a) Leptin Adiponectin QOL (DQOL)	glycaemia <3.64mM) hypoglycaemic episodes (11.4 ±2.5% of the sessions versus the total number of sessions) during sessions. No severe episodes reported Adherence: Participation rate was calculated as the number of sessions (supervised and unsupervised) during which participants effectively performed the duration of the aerobic activity requested (at ±5bpm of target HR) versus the total number of sessions proposed. Participation was ~83% (minimum of 63%, maximum of 100%) for supervised sessions and ~73% (minimum 52%, maximum 89%) for unsupervised sessions
Huttunen et al., 1989 Finland	Aim: To examine the efficacy of a PA programme on fitness and metabolic control Setting: Recruited via	Age: 11.9yrs (range: 8.2-16.9yrs) N=32 (18M;14F)	Thirteen 60 min weekly supervised sessions, consisting of aerobic activities. Intensity: heart rate at 150 bpm for 45 mins (measured by a monitor). Encouraged to participate in PA outside sessions	Peak VO_2 Pedalling time HbA1c Blood glucose	Increase in VO_2, pedalling time and HbA1c in the intervention group. Adherence: Attendance: The intervention group participated in 5-13 sessions (median of 11.5). Three participants in both groups attended all sessions. Two control participants did

(30)	hospital, NS where intervention delivered Intervention duration: 12 weeks Follow-up: 13 weeks	Diabetes duration: 0.6-13.1yr PA/fitness level: Peak VO_2 = 40 ml/min/kg HbA1c: Intervention: 9.8 ±2.3%; Control: 9.4 ±2.1%	Staff: Physiotherapy students Control: supervised non-physical activities (age and sex matched group)	Urinary glucose	not attend any sessions. Nineteen participants (11 in the intervention and eight in the control group) took part in more than 11 sessions (frequent exercisers). Thirteen participants (5 in the intervention and 8 in the control group) participated in less than 11 sessions (infrequent exercisers)
Stratton et al., 1987 Oklahoma (29)	Aim: To examine the efficacy of a fitness programme on glycaemic control Setting: Recruited and delivered in hospital Intervention length: 8 weeks Follow-up: 8 weeks	Age: Intervention: 15.1±1.2yrs; Control: 15.5 ±0.9yrs N=8 (4M, 4F) Diabetes duration: Intervention: 3.7±2.1yrs; Control 5.5±3.3yrs PA/fitness level: Bruce treadmill time (min) =	Twenty-four 30-45 mins, 3 times weekly supervised sessions (mostly aerobic) plus diet advice once weekly. Intensity = NS Staff: NS Control: Encouraged to exercise unsupervised and given an outline exercise program	Bruce treadmill time Submax HR Body composition Height Weight HbA1c Glycosylated serum albumin Blood glucose	Bruce treadmill time increased in the intervention group. . Submax HR decreased in the intervention group. Glycosylated serum albumin decreased in the intervention group.. Decline in mean blood glucose in the final 3 weeks of the program for the intervention group compared to the first 3 weeks. Overall change in insulin dosage was significant with a trend to decline in the intervention group. Daily insulin dose decreased in five intervention participants and remained constant in the remaining three

		Intervention: 12.1 ±1.5; Control: 12.4 ±2.0. Submax HR (bpm) = Intervention: 175.0 ±11.8; Control: 168.1 ±12.9. 'From sedentary to athlete...' HbA1c: Intervention: 10.1 ±2.2%; Control: 11.7 ±2.9%		Blood lipids Insulin dosage	participants.
Campaigne et al., 1985. Landt et al., 1985. Cincinnati (28, 27)	Aim: To determine the efficacy of exercise training on fitness, blood lipid and lipoprotein profiles, insulin sensitivity and metabolic control Setting: Recruited via hospital. NS where intervention delivered Duration length: 12 weeks	Age: 12-19yrs. Intervention: 16.0±(SEM)1yr; Control: 15.0±(SEM)0.4yr N=14 (M6; F8) Diabetes duration: 2-10yrs. Intervention: 6.6±(SEM)1.1yrs; Control 6.2±(SEM)1.1yrs	Thirty-six 45 min three times weekly supervised aerobic sessions. Intensity = HR >160bpm (measured by palpation) Staff: researcher Control: Continued with normal physical activity behaviour	VO_{2max} Blood lipids Lipoprotein profile HbA1 Body composition Weight Diet Glucose utilisation Insulin sensitivity	Decrease in LDL cholesterol, increased VO_{2max} and increased glucose utilisation in the intervention group. Polyunsaturated fat intake and the polyunsaturated/saturated ratio decreased in the intervention group. Positive univariate correlation between the change in LDL cholesterol and change in the polyunsaturated/saturated fat ratio in the intervention group. Adverse events: No increase in hypoglycaemic reactions recorded

	Follow-up: 12 weeks	PA/fitness level: Not participating in team sports or a training programme. VO_2 = Intervention: 36.3±(SEM)3.1ml/kg/min; Control: 39.2±(SEM)4.0ml/kg/min HbA1c: Intervention: 12.0±(SEM)1%; Control: 12.0±(SEM)1%		(euglycaemic clamp) Insulin dosage	during the study
Campaigne et al., 1984 Michigan (26)	RCT Aim: To determine the efficacy of a PA programme on metabolic control and fitness Setting: Recruited via hospital. NS where delivered	Age: 5-11yrs. Intervention: 9.0±(SEM)0.5yrs; Control 8.5±(SEM)0.6yrs N=19 (12M, 7F) Diabetes duration: Intervention: 5.1±(SEM)1.0yrs; Control 3.9±(SEM)0.7	Thirty-six 30 minute, 3 times weekly supervised aerobic sessions. Intensity: 80% maxHR (measured by monitors or pulse in random participants) Staff: Activity instructor trained in the implementation of the programme	VO_2 Weight HbA1 Fasting blood glucose Diet Insulin dosage	HbA1c and fasting blood glucose decreased in the intervention group and were less in the intervention group than the control group at 12 weeks. Peak VO_2 and peak VE and weight increased in the intervention group. Adverse events: One hypoglycaemic episode reported during a session. No other adverse events reported

	Intervention length: 12 weeks Follow-up: 12 weeks	PA/fitness level: VO2 peak = Intervention: 47.1±(SEM)1.9 ml/kg/min; Control: 45.9±(SEM)2.5 ml/kg/min HbA1c: Intervention: 12.5±(SEM)0.7%; Control: 13.9 ±(SEM)0.6%	Control: Continued with normal physical activity behaviour		Adherence: Attendance: Intervention participants needed to attend a minimum of 75% of the supervised sessions (27 sessions) to be included in analysis. Intensity: Mean exercise heart rates during the initial 25 minutes of the sessions was above the target heart rate

Only significant changes and/or differences are reported in the final column. NS = not stated; * = Email correspondence was made with authors to collect additional details than was reported in articles; (SEM) = standard error of the mean (all other figures in brackets are standard deviation); PA = physical activity; ~ = approximately; HR = heart rate; bpm = beats per minute; maxHR = maximum heart rate; VO2 = maximal oxygen uptake; VE = ventilation rate; IPAQ = International Physical Activity Questionnaire; QOL = quality of life; HRR = heart rate reserve; SF-36 = Short form health survey (36 item); VCR = video cassette recording; NZPAQ = the New Zealand physical activity questionnaire; MOH-Short = Ministry of Health short physical activity questionnaire; SPARC-Long = Sport and Recreation New Zealand long physical activity questionnaire; FFF = Fat free mass; DQOL; Diabetes Quality of Life questionnaire; PWC-170 = Physical work capacity at a heart rate of 170 beats per min; MVPA = moderate to vigorous physical activity.

Table 3.2 Meta-analytic HbA1c (%) results for specific intervention and study design characteristics (intervention duration, frequency of activity, duration of activity and type of activity)

Intervention characteristic	Subgroup	Number of comparisons*	Number of intervention participants	Effect size	95% CI lower limit	95% CI upper limit	Significance
Programme Length	≤ 3 months	7	105	0.01	-0.42	0.44	NS
	> 3 months	5	179	-1.41	-2.06	-0.76	P < 0.0001
Frequency	< 3 x/week	3	102	-0.69	-1.73	0.36	NS
	≥ 3 x/week	9	182	-0.93	-1.71	-0.14	P = 0.02
Duration	< 60 mins	5	51	-0.61	-1.29	0.08	NS
	≥ 60 mins	7	233	-0.93	-1.71	-0.14	P = 0.02
Type	Aerobic	8	110	-0.92	-1.99	0.16	NS
	Combined	3	157	-0.97	-1.37	-0.58	P < 0.00001
	Pilates	1	17	0.10	-1.08	1.28	NS

* Two studies had two intervention groups. This column provides the number of intervention groups rather than the number of studies.

Table 3.3: (Supplemental material) Keywords used for the Embase database search

Embase database search keywords
1. Insulin dependent diabetes.mp. or insulin dependent diabetes mellitus/
2. child/
3. adolescent/
4. adolescence.mp. or adolescence/
5. juvenile diabetes mellitus.mp. or juvenile diabetes mellitus/
6. juvenile/ or juvenile.mp.
7. exercise.mp. or isometric exercise/ or leg exercise/ or anaerobic exercise/ or static exercise/ or stretching exercise/ or isokinetic exercise/ or aquatic exercise/ or dynamic exercise/ or arm exercise/ or aerobic exercise/ or muscle exercise/ or treadmill exercise/ or isotonic exercise/ or exercise/
8. physical activity.mp. or physical performance/ or physical activity/
9. (1 or 5) and (2 or 3 or 4 or 6) and (7 or 8)

Table 3.4: (Supplemental material) Reasons for exclusion of articles at the final

Author (Year)	**Journal**	**Title**	**Reason for Exclusion**
Ramalho et al., (2011)	Diabetes research and clinical practice; 72(3): 271-276	The effect of resistance versus aerobic training on metabolic control in patients with type-1 diabetes mellitus	No control group (performing usual activity)
Dahl-Jorgensen et al., (1980)	Acta paediatrica; 283: 53-56	The effect of exercise on diabetic control and hemoglobin A1 (HbA1) in children	Not randomised
Niewiadomska et al., (2010)	Pediatric endocrinology and diabetes metabolism; 16: 89-93	Agility in treatment of children with type 1 diabetes - pilot study	Not in English
Jung (1982)	Journal of sports medicine and physical fitness; 22(1): 23-31	Physical exercise therapy in juvenile diabetes mellitus	Not a RCT
Wallberg et al., (1981)	Clinical physiology; 1(6): 611	Effects of muscle adaptation, insulin sensitivity and blood glucose control	Not a RCT
Rychlewski et al., (1996)	Polskie archiwum medycyny wewnetrznej; 95:	Fructosamine in blood serum, binding and degradation of 125J-	Not a RCT

	212-217	insulin by erythrocyte receptors in young persons with type I diabetes - effect of physical exercise	
Rigla et al., (2001)	Diabetologia; 44: 693-699	Physical training decreases plasma thrombomodulin in type I and type II diabetic patients	Mostly adults (age inclusion was ≥17years
Rigla et al., (2000)	Metabolism: 49: 640-647	Effect of physical exercise on lipoprotein(a) and low-density lipoprotein modifications in type 1 and type 2 diabetic patients	Mostly adults (age inclusion was ≥17years
Luzi et al., (2004)	Sport sciences for health:1: 41-46	Insulin sensitivity of protein and glucose metabolism in overweight female adolescents with type 1 diabetes mellitus: positive modulation by physical exercise	Not a RCT
Haider et al., (2006)	Journal of clinical endocrinology and metabolism: 91: 4702-4704	Exercise Training Lowers Plasma Visfatin Concentrations in Patients with Type 1 Diabetes. Journal of Clinical Endocrinology and Metabolism	Not paediatric patients only adults
Johansen (1978)	Journal of	Physical training and	Review article

	endocrinological investigation: 1: 367-371	diabetes mellitus	
Koivisto et al., (1993)	Diabetes care: 16(7): 990-995	Seven years of remission in a type I diabetic patient: Influence of cyclosporin and regular exercise	Case study
Faulkner et al., (2009)	Pediatric diabetes: 11: 166-74	A personalized approach to exercise promotion in adolescents with type 1 diabetes	Not a RCT
Michaliszyn et al., (2010)	Research in nursing and health: 33(5): 441-449	Physical activity and sedentary behavior in adolescents with type 1 diabetes	Not a RCT
Huber et al., (2010)	Pediatric diabetes: 11(6): 383-385	The influence of physical activity on ghrelin and IGF-1/IGFBP-3 levels in children and adolescents with type 1 diabetes mellitus	Not a RCT
Ruzic et al., (2008)	Journal of pediatrics and child health	High volume-low intensity exercise camp and glycemic control in diabetic children	Not a RCT
Woo et al., (1999)	Acta paediatrica: 99: 1263-1268	Antioxidant enzyme activities and DNA damage in children with type 1 diabetes mellitus	Control group did not have diabetes

		after 12 weeks of exercise	
Roberts et al., (2002)	Journal of pediatric endocrinology & metabolism: 15(5): 621-627	Exercise training and glycemic control in adolescents with poorly controlled type 1 diabetes mellitus	No control group (performing usual activity)
Rowland et al., (1985)	American journal of diseases of children: 139(3): 307-310	Glycemic control with physical training in insulin-dependent diabetes mellitus	No control group during same time as intervention
Marrero et al., (1988)	Pediatrics: 81: 519-525	Improving compliance with exercise in adolescents with insulin-dependent diabetes mellitus: results of a self-motivated home exercise program	Not a RCT
Larsson et al., (1964)	Journal of applied physiology: 19: 629-635	Functional adaptation to rigorous training and exercise in diabetic and nondiabetic adolescents	Not a RCT
Larsson et al., (1962)	Diabetes: 11: 109-117	Physical fitness and the influence of training in diabetic adolescent girls	Not a RCT
Mosher et al., (1998)	Archives of physical medicine and rehabilitation: 79(6): 652-657	Aerobic circuit exercise training: effect on adolescents with well-controlled insulin-dependent diabetes mellitus	Control group did not have diabetes

Sideraviciute et al., (2006)a	Medicina: 42(8): 661-666	The effect of long-term swimming program on body composition, aerobic capacity and blood lipids in 14-19-year aged healthy girls and girls with type 1 diabetes mellitus	Control group did not have diabetes
Sideravicitue et al., (2006)b	Medicine: 42(6): 513-518	The effect of long-term swimming program on glycemia control in 14-19-year aged healthy girls and girls with type 1 diabetes mellitus	Control group did not have diabetes
Seeger et al., (2011)	Diabetes, obesity & metabolism: 13: 382-384	Exercise training improves physical fitness and vascular function in children with type 1 diabetes	Control group did not have diabetes
Larsson et al., (1964)b	Lancet: 1: 350-355	Effect of exercise on blood lipids in juvenile diabetes	Not a RCT
Baevre et al., (1985)	Scandinavian journal of clinical & laboratory investigation:45: 109-114	Metabolic responses to physical training in young insulin-dependent diabetics	Not a RCT
Peterson et al., (1980)	Diabetes care: 3: 586-589	Changes in basement membrane thickening and pulse volume concomitant with improved glucose control and exercise in patients with insulin-	Not a RCT

		dependent diabetes mellitus	

Table 3.5: (Supplemental material) Risk of bias summary for included

	Random sequence generation	Allocation concealment	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Sample size and statistical analysis	Adherence
Heyman at al., 2007	-	-	+	-	-	+	-
Salem et al., 2010	?	?	-	-	-	+	+
Campaigne et al.,1985 and Landt et al., 1985	?	?	?	-	-	-	+
Stratton et al., 1987	?	?	?	-	-	-	+
Campaigne et al., 1984	?	?	?	-	-	+	-
D'Hooge et al., 2011	-	-	-	-	-	+	-
Newton et al., 2009	-	-	-	-	-	-	+
Huttunen et al., 1989	?	?	?	-	-	-	-
Aouadi et al., 2011	?	?	-	-	+	-	+
Tunar et al., 2012	+	-	+	-	-	+	+
Wong et al., 2010	?	?	?	-	-	-	+

'-' = low risk of bias; '?' = risk of bias unclear; '+' = high risk of bias

Table 3.6: (Supplemental material) Summary of why studies scored ‘high risk’ or ‘unclear’ on the risk of bias tool outcomes

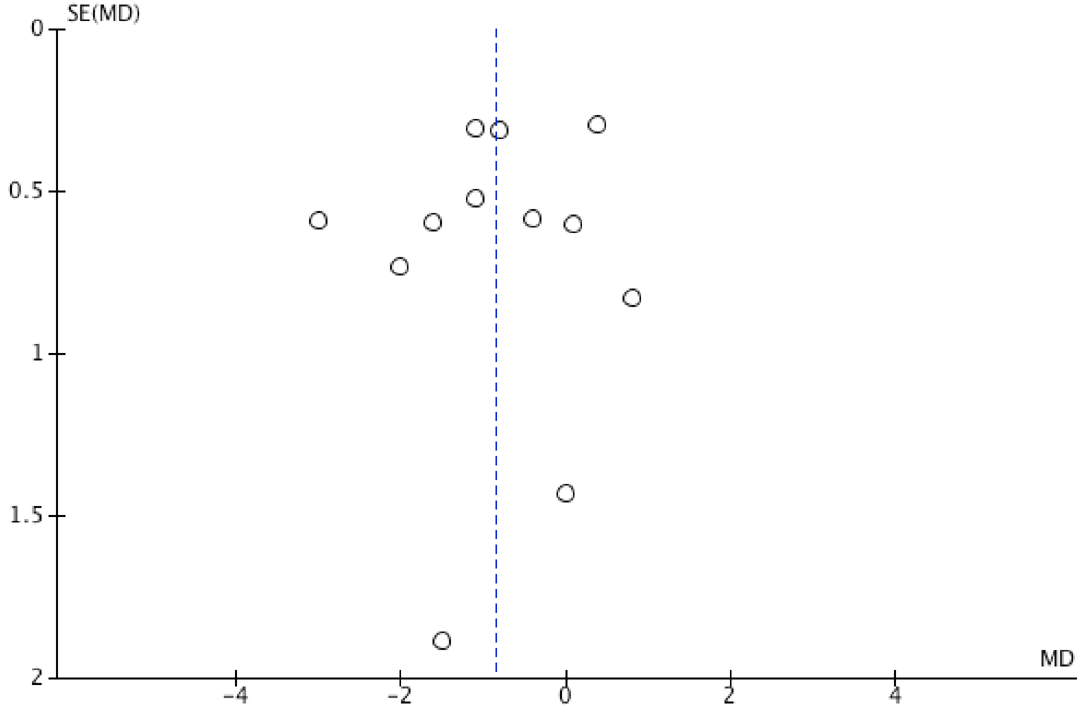
	Random sequence generation	**Allocation concealment**	**Blinding on outcome assessment**	**Incomplete outcome data**	**Selective reporting**	**Sample size and statistical analysis**	**Adherence**
Heyman et al, 2007	-	-	Researcher aware of grouping for QOL and fitness measures	-	-	No p-value adjustment for t-test and Wilcoxin Signed Rank test	-
Salem et al, 2010	NS	NS	-	-	-	One way ANOVA used instead of 2X3 way ANOVA	Attendance NS
Campaigne et al., 1985 and Landt et al., 1985	NS	NS	NS if fitness outcome assessor knew group allocation	-	-	-	Attendance NS. Intensity by self-assessment
Stratton et al., 1987	NS	NS	NS if fitness assessor knew group allocation	-	-	-	Attendance NS. Intensity not measured
Campaigne et al., 1984	NS	NS	NS if fitness outcome assessor knew group allocation	-	-	No p-value adjustement for t-test	-
Huttunen	NS	NS	NS if fitness	-	-	-	-

et al., 1989			outcome assessor knew group allocation				
Aouadi et al., 2011	NS	NS	-	-	Changes in the control group NS	-	Attendance not measured
Tunar et al., 2012	Based on distance participants lived from the gym centre	-	Researcher collecting VO_2 data knew group allocation	-	-	Differences between groups not analysed. Wilcoxin Signed Rank test used but p-value not stated	Attendance not reported. Intensity not measured
Wong et al., 2010	NS	NS	Not stated if fitness outcome assessor knew group allocation	-	-	-	Attendance not reported
D'Hooge et al, 2011	-	-	-	-	-	No p-value adjustment for Wilcoxin and Mann-Whitney U-test	-
Newton et al., 2009	-	-	-	-	-	-	Pedometer wear adherence measured. Programme adherence

							NS

‘-’ = scored ‘low’ for this outcome and met criteria for appropriate measures taken; QOL = quality of life; VO_2 = maximal oxygen uptake; NS = not stated

Figure 3.3. (Supplemental material) Funnel plot (effect estimates plotted against the standard error of the intervention effect estimate) for HbA1c



3.0 An unsupervised theory based intervention for youth with Type 1 diabetes

Few unsupervised and/or theory-based physical activity interventions (and none focusing on sedentary behaviour), have been developed for youth with Type 1 diabetes and tested in RCTs as identified in paper 2. A key study not included in paper 2 because of its design (it was not a RCT) is now described. The study is of importance as it included an unsupervised, theory-based intervention, incorporating parental support, which proved successful at increasing physical activity participation in adolescents with Type 1 diabetes.

Faulkner et al., (Faulkner, Michaliszyn, & Hepworth, 2009) explored the use of an individualised, community/home based physical activity intervention for adolescents, which incorporated family support and was based on social cognitive (Bandura, 2001) and family systems theories (Broderick, 1993). Measurement of behaviour change processes in this study will help identify the key processes necessary for physical activity behaviour change and when they are most important to be targeted. Results for the first 12 participants recruited into the study indicate that individuals achieving more days with bouts of 60 minutes MVPA/day had significant increases in cardiovascular fitness pre to post intervention (Faulkner, et al., 2009). It took 16 months to recruit 12 out of 35 eligible patients highlighting the challenge of speed of recruitment. As this was a longitudinal study without a control group, it was excluded from inclusion in paper 2. However the study provides an example of the only well designed, theory based, unsupervised physical activity intervention specifically for youth with Type 1 diabetes. A paper including results of the full study is currently under review for publication. If proved efficacious on improving health further testing in a RCT to explore overall effectiveness will be necessary. The findings of this previous study therefore suggest that an unsupervised intervention based on behaviour change theory for youth with Type 1 diabetes can be successful when targeted to the individual’s needs and preferences when teamed with parental support.

4.0 Summary of chapter 3

The findings of study 2 support the rationale for the use of physical activity to improve the health of youth with Type 1 diabetes and identified the need for more research on physical activity and sedentary behaviour interventions in this target group. Studies 1 and 2 provided useful quantifiable information regarding physical activity and sedentary behaviour participation and intervention but did not provide detailed information on what patients were doing and why. Qualitative methods are required to answer these questions. Chapters 4 and 5 will address these questions along with perceived physical activity and sedentary behaviour support needs.

Chapter 4: Patient, parent, and diabetes professional views on building physical activity and sedentary behaviour support into care for youth with Type 1 diabetes

1.0 Preface

Studies 1 and 2 determined the need for the development of theory based, unsupervised, physical activity and sedentary behaviour interventions for youth with Type 1 diabetes. To understand physical activity and sedentary behaviour participation in youth with Type 1 diabetes and to aid the development of a useable, feasible and acceptable intervention, perceptions of potential major stakeholders of interventions were explored. Qualitative studies were undertaken with patients, parents, diabetes professionals and schoolteachers. In this chapter, paper 3 focuses on stakeholder's perceptions in relation to diabetes care. Paper 4 (in chapter 5) then focuses on stakeholder's perceptions on accommodating physical activity in schools. Youth spend a considerable amount of their day at home with their parents. In addition, youth with Type 1 diabetes also attend diabetes clinics regularly (usually every three months), where they are in contact with health professionals whom they may view as having an authoritative voice. Hence, to explore the needs of youth with Type 1 diabetes in care, perceptions of patients, parents and diabetes professionals were included in paper 3.

A summary of qualitative research is provided at the start of this chapter, which introduces qualitative research to the reader, details how to ensure rigour and summarises thematic analysis. A section supporting the inclusion of youth and influential figures in qualitative research is also provided. Appendix A provides the NHS ethics approval letter for studies 3 and 4 and appendix B includes the information sheets for parents/carers and diabetes professionals.

The interview schedule used with parents/carers and the focus group topic guide for diabetes professionals is provided in appendix E. Social cognitive theory was used to help guide the questions that were included in the semi-structured interviews (Bandura, 2001). Social cognitive theory incorporates a triad of factors, which can influence each other and in turn physical activity and sedentary behaviour: behavioural skills; personal/cognitive factors within a person; and environmental factors. The theory thus recognises that personal experiences, behavioural skills, and context and setting will affect an individual's physical activity or sedentary behaviour participation. Constructs which are used to explain and change behaviour fall into the three factor categories. For example, cognitive/personal constructs include an individual's perceived self-efficacy, perceived outcomes (benefits and barriers), and coping mechanisms. Behavioural constructs incorporate self-control (which includes setting goals, monitoring and adjusting plans and self-reinforcement), and behavioural capability. Environmental constructs consist of the social environment, which includes social norms, role models and social support, and the physical environment, such as access to facilities (Bandura, 2001).

Interview questions were asked relating to the three factors from the social cognitive theory. For example, knowledge, and beliefs of physical and sedentary behaviour were explored, which relate to personal/cognitive and social environment constructs. Another example of how the construct of social environmental was explored, was the examination of influential figures. During patient interviews, individuals were asked about their current physical activity participation and several participants spoke of their behavioural capability. Questions were also asked in relation to perceived support needs for youth with Type 1 diabetes, which incorporated constructs from all three factors from the social cognitive theory.

2.0 Qualitative methodology

2.0.0 Introducing qualitative research and ensuring rigour

Snape and Spencer offer the following definition of 'qualitative research': "research …generally directed at providing an in-depth and interpreted understanding of the social world, by learning about people's social and material circumstances, their experiences, perspectives and histories" (p.22) (Snape & Spencer, 2003). Qualitative research tends to focus on developing understanding, deep descriptions and building theories and does not attempt to generalise findings or identify causal relationships as in quantitative research. Quantitative criteria for rigour such as including a control group and controlling for confounders are therefore not suited to qualitative research. The relationship between rigour checklists and qualitative research is often the wrong way round: the tail (checklists) wagging the dog (qualitative research) (Barbour, 2001). Researchers feel pressure to conduct and report research following a prescribed checklist that they perceive necessary rather than allowing the research to guide systematic and thorough rigour checks suited to the research (Barbour, 2001). A systematic and thorough approach to ensure rigour in the qualitative elements of this thesis was undertaken as reported in papers 3 and 4 and expanded on here.

Triangulation, in relation to the use of multiple methods of data collection to address a research question, can be used to ensure rigour if one method is viewed as superior to another or others. As this thesis follows a realist perspective where several views have the same value, the quantitative and qualitative findings were triangulated not to ensure rigour, but rather to give a more complete and deeper understanding, and insight into the explored behaviours (Tobin & Begley, 2004). Triangulation was achieved firstly by the combination of quantitative and qualitative data collection of physical activity and sedentary behaviour data, providing a comprehensive picture of these behaviours. Secondly triangulation occurred by use of two different methods to collect qualitative data (one-to-one interviews and focus groups), allowing the research questions to be explored from different angles. Finally another layer of triangulation was present as interviews were either conducted with patients or parents alone or in the presence of each other. Respondent validation was not employed in these studies for reasons of participant burden and because other rigour checks as described above and in paper 3 and 4 (such as multiple researcher coding strategies) were in place.

2.0.1 Thematic analysis

Thematic analysis is described by Braun and Clarke as a six-stage process consisting of the following phases: 1) familiarisation with the data; 2) initial coding; 3) development of themes; 4) re-visiting and adjustment of themes; 5) describing and naming themes; and 6) producing a report of the analysis (Braun & Clarke, 2006). A code is “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998) and coding therefore systematically arranges your data into meaningful groups (Braun & Clarke, 2006). Themes are repeated patterns of response or meaning. Themes had internal homogeneity (the extracts 'said the same thing' and were grouped together in a way that made sense) and external heterogeneity (the extracts for different themes had clearly different meanings) (Braun & Clarke, 2006). The guidance by Braun and Clarke was followed during the analysis of the qualitative data in this thesis. Appendix F provides an example of the coding framework, coding map, data laid out under a theme with excerpts of participants coded data, and an excerpt from the full report providing the write up for a sub-theme, for the patient and parent interviews in study 3.

3.0 Research with youth and influential figures

Article 12 of the UN convention on children and young people's rights states that it is a young person's right 'to say what they think about matters that affect them and to have those views taken seriously' (United Nations Children's Fund). It is therefore important to *include* youth in research *about* youth. A systematic review of qualitative studies exploring Type 1 diabetes in adolescence recognised the importance of social relationships between patients and parents, peers, diabetes professionals and teachers on diabetes management (Spencer, Cooper, & Milton, 2010). Youth with Type 1 diabetes, their parents, teachers and diabetes professionals were therefore included in the studies in this thesis for the aforementioned reasons and because the researcher had access to these individuals. Peers and siblings were not included due to the feasibility of reaching these target groups. The role of peers and significance in the shaping of a patient's physical activity behaviour was discussed with participants involved in the research.

4.0 Paper 3: Patient, parent, and diabetes professional views on building physical activity and sedentary behaviour support into care for youth with Type 1 diabetes

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The following paper is in preparation for submission to a journal.

Abstract

Purpose: The purpose of this study was to explore patient, parent, and diabetes health care professional's perceptions of physical activity and sedentary behaviour in youth with Type 1 diabetes (T1DM) to aid the development of feasible, acceptable and useable interventions.

Methods: Patients (N=16), parents (N=16) and professionals (N=9) were recruited from a clinic in Scotland. Qualitative interviews (*N*=33) and focus groups (*N*=2) were conducted. Data were analysed thematically.

Results: Five main themes relating to intervention development were identified: 1) target groups; 2) delivery settings; 3) delivery methods; 4) components/content; and 5) timing and duration. The importance of tailoring support based on the individual's needs and preferences spanned across themes. Parent and peer support were viewed as essential. Professionals felt they could do more to encourage physical activity at the clinic. Technology, information on local opportunities, and a combination of group and one-to-one support were perceived as useful delivery methods in addition to in-person support. The most important perceived components of support were: diabetes preparation, management and support; enjoyment; education; and incorporation of behaviour change techniques. The time of diagnosis was perceived as an appropriate point to initiate interventions.

Conclusions: The findings provide vital novel information for future research developing physical activity and sedentary behaviour interventions for youth with T1DM.

Introduction

Type 1 diabetes (T1DM) is one of the most common chronic health conditions in youth[1] and the worldwide incidence is rising.[2] The UK currently ranks fourth in the world for greatest prevalence of Type 1 diabetes.[3] Youth with T1DM may experience poor health compared to their peers without diabetes.[4-6] Although regular physical activity can improve the health of youth with T1DM,[7] research suggests that patients do not always meet the recommended daily amount of physical activity participation for health benefits (60 minutes moderate to vigorous physical activity[8]). The research has also demonstrated that patients with T1DM can be less active than their peers without diabetes.[9, 10] Sedentary behaviour (sitting or lying whilst awake) also negatively impacts on health, independently of physical activity.[11] In addition to the limited research, there is a lack of knowledge on how best to intervene in this target population to increase and maintain physical activity and minimise sedentary behaviour.[12]

In the early states of complex intervention development, it is suggested that the views and opinions of central stakeholders be sought to ensure that such interventions are feasible, acceptable, and useable.[13] Previously only one study explicitly set out to explore perceptions of physical activity in youth with T1DM[14]. As participation was not measured objectively, it is not clear from this study if patients with a range of physical activity levels were recruited.[14] In addition, the views and perceptions of health providers have not been explored in relation to youth with T1DM. The present study was part of a larger investigation exploring key stakeholder perceptions of physical activity and sedentary behaviour in youth with T1DM to aid the development of interventions targeting these behaviours. This paper focuses on data collected from patients, parents, and professionals relating to physical activity and sedentary behaviour support outside of school. An adjunct paper explores perceptions (including teachers' perceptions) on providing support for physical activity in youth with T1DM specifically in school.

Research design and methodology

A qualitative research design was employed to explore insights into physical activity and sedentary behaviour and suggestions for intervention in youth with T1DM. Semi-structured, one-to-one interviews and focus groups were conducted using broad open-ended questions. The following topics were explored: knowledge, attitudes and experiences of physical activity, sedentary behaviour and T1DM individually and as combined experiences (i.e.

physical activity and Type 1 diabetes); influential figures for behaviour and behaviour change; current support and future intervention characteristics. In addition professionals were asked about patients' school performance and current clinic care for TIDM youth. A diabetes physician and three youth of similar age to participants without diabetes, reviewed the topic guide for vocabulary appropriateness. Interviews and focus groups served as a way in which to describe, understand, and explain the particular area/topic.[15] University and local NHS ethical approvals were granted.

Participants

Patients and parents were recruited in conjunction with another study measuring physical activity and sedentary behaviour in 20 children aged 7-9 years (primary 3-6 (UK); elementary grade 1-4 (US);) and 20 adolescents aged 12-14 years (secondary 1^{st}-4^{th} year (UK); middle or high grade 6-9 (US)) with T1DM. The first eight patients and their parents recruited into the above study were invited and accepted the invitation to participate in this qualitative study. Eight children (3M, 5F), eight adolescents (4M, 4F) and 16 parents (mean age 42 ±6 years; 2M, 14F) participated. Three patients administered insulin via pump therapy. The remaining patients used injection therapy.

Professionals were invited via letter from the researcher. These letters were distributed at clinic team meetings by the lead physician in a city clinic in Scotland. Eighteen letters were provided to the clinic. Nine professionals (3M; 6F) consisting of four nurses, three dietitians and two physicians, replied positively and participated in the study. Professionals had a range of two-30 years of specialist experience. A one-to-one interview and two focus groups (with four participants each) were conducted with professionals.

All participants provided written assent (<12 years) or consent (>12 years).

Data collection

Interviews and focus groups lasted approximately 30-45 minutes. The data was collected by a researcher with experience in conducting qualitative research and with extensive knowledge on physical activity, sedentary behaviour, and T1DM. Notes were taken on non-verbal cues during discussions, as video recording equipment was not available to the student at the time of this study and ethical approval was not granted to video record discussions. Discussions were audio recorded and transcribed verbatim. Demographic questionnaires captured age, gender and diabetes duration (if applicable). Physical activity and sedentary behaviour data of patients were collected using a valid and reliable measure of these behaviours in youth[16] (Actigraph Model GT3X+; Manufacturing Technology Inc., Pensacola, FL, USA). Time in moderate to vigorous physical activity[16] and sedentary behaviour[17] were calculated using validated cut-points.

Analysis

Thematic analysis was the qualitative research approach used to inform this study.[18, 19] Thematic analysis is an approach adopted by numerous fields, such as psychology and sociology. It seeks to systematically identify, analyse, and report patterns in the data, and can be understood as a tool to assist with data organization, description, and analysis. While the epistemic foundations of thematic analysis are poorly articulated in comparison to more popular research traditions—such as grounded theory or phenomenology—it is compatible with both realist-positivist and interpretive-constructivist ontological and epistemological viewpoints. It is thus compatible with researchers who believe that there are real experiences and true facts to be reported, as well as those who consider knowledge to be a socially and historically situated production between the research and participant. In this study, a constructivist thematic analysis approach was adopted and used to organise and explain the physical activity, sedentary behaviour and health experiences of children living with T1DM.

Patient, parent, and professionals data were analysed separately using constant comparison [20, 21], before similarities and differences in perceptions across the different participants were explored. Data were systematically arranged into meaningful groups.[19] Initial coding was conducted by reading and re-reading of the data, followed by the sorting of codes into themes (patterns within the data). Excerpts from transcripts were segregated under theme names to highlight the meaning of the theme and to provide an indication of frequency. Themes were refined by comparison over the full data set. Once the lead researcher had grouped the data under themes and developed a thematic coding framework and report of the findings, rigour was ensured by the following multiple-coding checks. Two researchers from outwith the team independently coded 10% of the transcripts and discussions. Also, two additional researchers from the team checked the coding framework and excerpts of data coded under each theme (100% of patient and parent data and 67% of professionals data.. They also read the full report. Meetings were held between researchers to find consensus in coding and language used to describe themes. Necessary adjustments to the coding, coding frameworks, and full report were made. Results are presented as the major themes relating to the development of interventions with example excerpts provided in tables to illustrate themes. Excerpt numbers link table excerpts to the related section of the results. The type of respondent (patient, parent or professional) and ID number are provided with the excerpts.

Results

Patients with a range of physical activity and sedentary behaviour levels (daily health enhancing physical activity range of 22.0-123.3 minutes and 7.0-12.3 hours of sedentary behaviour) and diabetes duration (2.3-13.4 years) participated.

Five central themes in relation to important intervention characteristics arose from the data. Themes were: 1) intervention target groups; 2) intervention delivery settings; 3) intervention delivery methods; 4) intervention components/content; 5) intervention timing and duration. In addition, an overarching theme relating to all support characteristics was identified (individualised approach). Tables 4.1-4.4 document example excerpts in relation to identified sub themes.

1) Intervention target groups (Table 4.1)

Parents and friends were recognised as the most significant figures that influenced patient's physical activity participation. Parental influence changed with increasing age (excerpt 1.1). Although patients and parents also mentioned professionals as being influential due to their authoritative voice (excerpt 1.2), professionals did not perceive themselves as being influential (excerpt 1.3). Teachers, sport coaches, sporting role models (from within the clinic or national/international renowned), siblings, and extended family were also mentioned as influential. The role of the school staff in helping support physical activity in youth with T1DM was identified (excerpt 1.4), and is explored in detail in a further paper.

Participants on the whole felt it was important to target parents and families rather than patients alone to change physical activity and sedentary behaviour. Inclusion of peer support was also viewed as important (excerpt 1.5a and 1.5b). Some parents were against the idea of only including youth with diabetes, as they did not want their child to feel singled out (excerpt 1.6). Others spoke positively about socialising with others who have diabetes (excerpt 1.7). Patients and parents highlighted that some contact with the patient on a one-to-one basis might be beneficial in addition to family and peer support, to foster independence (excerpt 1.8). However parents were also viewed as important communicators and translators (excerpt 1.9), particularly between younger patients and professionals. Thus, finding a balance between providing parental support and giving patients responsibility is necessary. Communication between influential figures and working together to provide support for patients with T1DM was perceived as important. Local community councils, Diabetes UK (the main UK diabetes charity), and the government were also mentioned as potential targets to help improve support for youth with T1DM and youth in general to be physically active.

2) Intervention delivery settings (Table 4.2)

Participants mentioned that multiple delivery settings are important for targeting physical activity and sedentary behaviour. Almost all participants talked of limited physical activity encouragement provided in current care (excerpt 2.0). Professionals spoke of tending to encourage physical activity participation in specific patients: those that were regularly physically active prior to diagnosis; those that had weight issues (excerpt 2.1); and patients that specifically asked for physical activity guidance. Professionals suggested that they could: incorporate physical activity as a third parameter (alongside diet and insulin advice) in discussions at the patient's regular check-up and in the patient's management diary (excerpt 2.2); educate patient's on the guidelines for physical activity (excerpt 2.3); include physical activity in newly diagnosed patient group education sessions (excerpt 2.4); and develop specific physical activity plans with newly diagnosed patients (excerpt 2.5). Introduction of a sport therapist/exercise leader to the clinic was also suggested (excerpt 2.6). Schools, local communities, and the family home were also suggested as potentially useful settings to target support to be more active and less sedentary. Professionals spoke of the importance of targeting society rather than only youth with T1DM by introducing community/family based interventions such as walking buses (excerpt 2.7a) and park guards (excerpt 2.7b).

3) Intervention delivery methods (Table 4.3)

Participants generally spoke positively about the inclusion of technology to support physical activity and sedentary behaviour change. Advantages of technology included: appeal for youth (excerpt 3.0); for monitoring and feedback (excerpt 3.1); provision of support networks for those lacking support at home or in school (excerpt 3.2); and to reduce the number of in-person visits in an intervention (excerpt 3.3). Parents cautioned against the importance of policing social support to avoid negative messages regarding diabetes care being communicated to patients (excerpt 3.4). Some patients and parents and all professionals felt that technology alone would not be enough to change behaviour (excerpt 3.5) and that in-person contact is a necessity. Information on local opportunities to be active in leaflet, poster, or website format (excerpt 3.6) was perceived as useful. However, other strategies were perceived as necessary alongside providing information to encourage behaviour change (excerpt 3.7). Preference for group or one-to-one support was variable. Parents mentioned the importance of age. Given the importance of autonomy in adolescence, participants suggested that one-to-one support would perhaps be preferred in adolescence. In contrast, children could potentially benefit more from group settings (excerpt 3.8a). This was confirmed by a few adolescents who mentioned that they would not like group support (excerpt 3.9b). In contrast, others spoke positively regarding group support (excerpt 3.9c).

4) Intervention components/content (Table 4.4)

The most common diabetes related influencers on physical activity mentioned by participants were: blood glucose levels and diabetes preparation and management (excerpt 4.0); and diabetes support (excerpt 4.1). Communication and trust in adults leading physical activity sessions was believed to be important. Other important influencers included: levels of fear/anxiety related to illness (particularly early post diagnosis) in patients or those providing support to the patient; and having diabetes, which could act as a barrier or facilitator of physical activity for some people. Professionals highlighted that the negative impacts of physical activity on diabetes are often misunderstood (excerpt 4.2). The main influencer of physical activity unrelated to diabetes mentioned by participants was enjoyment (excerpt 4.3) Having “ownership” to select activities that were perceived to be “cool”, was also important. Other highlighted influencers included: weather; availability of others to be active with; child, family and community attitudes towards physical activity; safety; facilities and/or opportunities; and appeal of sedentary pursuits. Insulin pump therapy was viewed as a facilitator to physical activity (excerpt 4.4). However, the concerns of users and parents related to the pump were: movement of the pump during activity; fear of line detachment; and patients being conscious of others knowing that they have an insulin pump.

Although patient and parent knowledge on the benefits of physical activity was generally good, knowledge on the recommendations was limited. Sedentary behaviour was acknowledged as an important behaviour for youth with T1D. Participants mentioned potential positive (excerpt 4.5) and negative (excerpt 4.6) effects of sedentary behaviour on health. Professionals felt that educating families on the definition of physical activity (excerpt

4.7) is important, in particular emphasising the benefits of activities of daily living and not just planned, structured exercise and sports. Parents and professionals felt that education on the definition of sedentary behaviour (excerpt 4.8) was also important. Despite their generally high levels of knowledge, patients and parents felt education on the benefits and risks of physical activity and sedentary behaviour was important (excerpt 4.9.0).

Behaviour change techniques perceived as useful to include in support were: self and external monitoring and feedback to build awareness and increase motivation (excerpt 4.9.1); including achievable individualised goals and providing rewards/incentives (excerpt 4.9.2); linking behaviour change to efficacy on health (excerpt 4.9.3); competition (excerpt 4.9.4); and providing encouragement and motivation (excerpt 4.9.5).

5) Intervention timing and duration (Table 4.5)

Nearly all participants felt that it was important to provide support as close to the time of diagnosis as possible, (excerpt 5.0), depending on the extremity and experiences at diagnosis (excerpt 5.1). Several patients and parents felt regular check ups, every six months or so, at the clinic would be sufficient support (excerpt 5.2) with additional visits for patients struggling to change their behaviour (excerpt 5.3).

Individualised approach

Provision of individualised support suited to the individual's needs and preferences spanned across all themes, and was the overarching context in which participants negotiated their relationship to physical activity. The importance of avoiding a homogenous, "cookie cutter approach," is exemplified in the following quote.

'Every child's different and their attitudes are different and their environment's different. It's, it's very hard to say, you know what motivates one child and… completely different to another…it's all very subjective. It depends on the child…it's all very dependent on who…you're dealing with.' – mother of an adolescent boy (119)

Discussion

The novel findings of this study add to the qualitative research literature base in youth with T1DM by specifically exploring physical activity: a cornerstone of diabetes management. In summary this study found that overall, parents and peers were perceived as the most influential figures on a patient with T1DM and should be targeted, alongside patients, by interventions to support behaviour change. Multiple delivery settings were viewed as necessary to change behaviour. Clinic care currently lacks encouragement; strategies to ensure consistent physical activity and sedentary behaviour support is provided in current care were suggested. The inclusion of technology in interventions and information on local physical activity opportunities were perceived as useful components of support. These delivery methods were perceived as not being sufficient as stand alone intervention delivery methods and would be required alongside face-to-face support for behaviour change (group or one-to-one and with peers with or without diabetes depending on the individual's preferences). In regards to the incorporation of technology into interventions, the findings of this study are novel as they provide qualitative confirmation to support the conclusions of a previous review which found interventions using technology efficacious in children.[22] Future researchers should explore the incorporation of technology alongside other intervention delivery methods. Important influencers to address and include in an intervention included appropriate diabetes preparation, management and support, and enjoyment. Education on physical activity and sedentary behaviour definitions and recommendations were highlighted, as well as the incorporation of behaviour change techniques. Near the time of diagnosis was viewed as the best point of intervention. Check-ups at clinic every six months were perceived to be sufficient support, with the option of social networking or additional visits if required. Intervention characteristics need to be adjusted to suit the individual.

Parent and peer support [14, 23] and enjoyment[24] have previously been reported as important facilitators of physical activity in previous studies including youth with T1DM and other medical conditions. In adolescents with T1DM, a family-based intervention found positive effects on physical activity and perceptions of family support for physical activity.[25] Group-based workshops for adolescents with Type 1 diabetes have been found to improve diabetes management during physical activity,[26] which was in contrast to the novel finding in this study that some adolescents did not want group support. Peer-mentoring (relationships with non-parental adults) is an effective method for youth[27] ; lifestyle programmes incorporating physical activity have found promising effects on health.[28, 29] A study exploring children's ideas for minimising sedentary behaviour also highlighted the need for peer and parental support to aid behaviour change.[30] The findings of the present study support the development of larger studies including peer and parental support in youth with T1DM.

There is a current perception of limited physical activity promotion in Type 1 diabetes care. This may be due to: limited physical activity encouragement from diabetes professionals; or patients/parents not paying attention to, ignoring, or not remembering physical activity encouragement and advice. Although parents and patients perceive professionals as central stakeholders to influence behaviour, the professionals themselves do not think they are influential people. This mismatch needs to be addressed for a successful intervention. Methods to enhance health professional self-efficacy for patient education, for example, might be an important strategy to increase their confidence in delivering physical activity messages. Specifically in the clinic setting, diabetes professionals should consider encouraging physical activity and discouraging sedentary behaviour during regular clinic by: discussing and monitoring the patient's participation; and educating and/or reinforcing patients on the guidelines. Particularly in newly diagnosed patients group education sessions and the provision of individualised plans should be considered. The feasibility of introducing sports therapists/exercise leaders to diabetes clinics or training existing diabetes professionals to deliver physical activity/sedentary behaviour support requires investigation. Research exploring the effectiveness of incorporating an exercise toolkit for diabetes educators into current care for adults with Type 2 diabetes is currently being explored.[31] The development of similar toolkits for youth with diabetes requires exploration.

As in previous research in youth with T1DM,[14] patients did not report many disease specific barriers to physical activity, and rather discussed general barriers such as lack of enjoyment. Parents focused on fostering normality (patients being the same as any other youth) as in previous research in youth with T1DM.[14] Interestingly and similar to previous research in youth with congenital heart disease,[23] some participants viewed patient interaction with other youth with diabetes negatively. For others, interaction with those with diabetes was important. This contradictory finding may be related to perceptions of normalcy and how interacting with others who are perceived to be "ill" impacts on youth with diabetes. Fear of illness during physical activity in patients and people surrounding patients can act as a barrier to participation and has been reported elsewhere.[14] Similar to this study, parents reported a balance between the amount of parental vigilance and patient independence as important to avoiding the sense of anxiety during activity that can develop in patients with diabetes[14]. Subtle background strategies (e.g. communicating with other adults) to aid diabetes management were used by parents without the patient always being aware.[14]

Theory based physical activity interventions targeting specific behavioural processes are more successful at changing behaviour than interventions not based on theory or targeting behavioural processes.[32, 33] A coding framework for behaviour change techniques has been developed.[34] Participants mentioned several of these techniques including (the descriptions in brackets are how the techniques were described in the results section of the current study): prompt self monitoring of behaviour; provide feedback on performance (external monitoring and internal/external feedback); goal setting in terms of the behaviour or outcome (individualised goals); set graded tasks (achievable goals); prompt rewards contingent on successful behaviour (rewards); facilitate social comparison (competition); and motivational interviewing (encouragement and motivation). Important behaviour change techniques and combinations of techniques for youth with T1DM need to be investigated to determine if targeting interventions at specific behaviour processes at certain time points improves the effectiveness of interventions by helping adherence.

Diagnosis has been identified as a teachable moment (when individuals have high motivation to learn about their condition), which was in agreement with the perceived 'best' time to intervene in this study.[35]

Implications and recommendations for diabetes professionals

Diabetes professionals should consider developing and delivering structured physical activity and sedentary behaviour support in their patients with T1DM. Professionals should focus on promoting physical activity at a level on par with insulin and diet advice to help patients realise the importance that physical activity can have in diabetes therapy.

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Table 4.1 Theme: Support/intervention target group

Sub-themes	**Example excerpt**	**Excerpt number in text**
Parental influence changes with increasing age	*'I think we [parents] try to be influential, I think unfortunately at this age [adolescence] you're just seen more as a hinderance than a help...sometimes we can be our own worst enemy because [we] can keep pushing at something and uhm that gives the opposite effect…I think you still remain influential because you come back to the kind of core principles that "would my mum want me to do that, would my dad want me to do that." So I think you still have a degree of influence but you need to know what battles to pick and which ones to avoid and when to step back.' – mother of an adolescent girl (103)*	1.1
Parents and patients perceive professionals as influential	*'Even if it's not been right out and said to you, "you need to do X amount of exercise," just the fact that they [professionals] talk about it and how good that balance is...somebody from, in authority saying it to you is much more important than mum telling you!...They're the professionals, they're going to know best and they'll [patients] listen.' – mother of an adolescent girl (101)*	1.2
Professionals do not perceive themselves as	*'The motto is that we can provide education but we can't provide motivation …there's so many other pressures that whatever we recommend is…lost in the…noise of everything else*	1.3

influential	*going on. So can we influence [physical activity]? I'd like to think so but realistically I don't think so. But we can support them…I don't think us saying you need to do more exercise is going to work.' – physician (109)*	
Teachers and schools are influential	*'They're attending school with these same teachers for more than half their life really I mean so they're there structured, disciplined, having to go - so that's [school] the place to get it [support].' – dietitian (104)*	1.4
Inclusion of peers	*'Sometimes you want to include your friends cause they're young. They're young and they can do more things.' – young girl (105)*	1.5a
	'I think if they [peer role-models from clinic] went to say the parents groups or spoke at schools…I think that would have much more impact than any adult talking…If a fifteen year old tri-athlete went and spoke to the diabetes UK family group…I think two things would happen. The young people might be inspired but I think the other things is, more importantly perhaps, is the parents would be less fearful. They'd say "wow…If he can do it…my child could."' – physician (109)	1.5b
Wanting patients to be treated the same as others	*'We really just didn't want to get into the whole kind of thing that he was just hanging about with other diabetic children...and for that reason we've never really kind of got...involved [with diabetes support groups].' – father of a young boy (111)*	1.6

Socialising with others with diabetes	*'We'd went to the Christmas party once and she'd met a wee girl [with diabetes]...and they'd started kind of emailing but I think they were maybe just a wee bit young so it kind of teemed off. But I think it was good because she was the only one in her school. So I think it was good for her to see that there actually was other kids with the same thing.' – father of a young girl (118)*	1.7
One-to-one contact plus parental and peer support	*'It's quite good...when you meet other boys and girls that are doing the same thing as you. And then if you've got like any personal questions then you might want to just talk to your doctor about it or whatever and then if your mum and dad had questions then they might just come in with you and just say uhm what they think.' - adolescent girl (103)*	1.8
Parents are communicators and translators	*'I would usually ask mum and then mum would ask them [doctors]…They [doctors] do try and help me but cause I'm a bit young I don't really understand sometimes...the hospital use like words that I don't know but my mum and dad can explain it to me better.' – young girl (105)*	1.9

Table 4.2 Theme: Support/intervention delivery setting

Sub-themes	Example excerpt	Excerpt number in text
Limited physical activity discussion at clinic	*' The food and the insulin dominate and until people understand those - bringing in a third variable…is challenging… we're talking…about exercise to people* ***who do*** *exercise…. we're not really talking about exercise to those* ***who don't do*** *any… I can't think of anything we've ever done here or anywhere else I've worked that's been focused on encouraging activity.' - physician (106)*	2.0
Focus on promoting physical activity in those with weight issues	*'Unless…they have a weight problem, I don't do it [encourage physical activity]. And that's not right, I probably should… I could ask about…do you ride your bicycle and…are you, do you walk to school? And sometimes I do ask that, I must admit, but uhm it's usually prompted by the fact that they're overweight. If they're not overweight then I suppose I'm assuming that they're already doing some activity, but maybe that's wrong?' – physician (109)*	2.1
Add physical activity to discussions during check-ups	*'So one of the things that we do in a much more systematic way now is we give people plans and we actually write in their books what we want them to do between now and next time…but we could introduce that [physical activity] as a, a third point.' – physician (106)*	2.2

Educate patients on the physical activity guidelines	*'We should tell them what's recommended cause we tell them what's recommended for food like their five a day and all that so we should.' – nurse specialist (108)*	2.3
Newly diagnosed group education sessions	*'We do have eh [pause] sort of a newly diagnosed…teaching session for patients and families…But that might be a good opportunity you know… I think there is in general terms [discussion in session on physical activity]…But I don't know how specific it deals with activity. But it might be an opportunity there to you know introduce the idea that now we're working to stabilise things…I actually think these sorts of sessions [group education] are, if people attend are actually good. The problem is that the people that attend such sessions are not, you're sort of preaching to the converted. The people [who] would benefit most from such physical activity are probably those that don't come… but that's always going to be the case, that doesn't mean you shouldn't try it.' – physician (109)*	2.4
Individualized physical activity plans for newly diagnosed patients	*'It would be quite fun to try and develop some guidelines….that we then said that you know you have to take this much insulin a day and this much carbohydrate and do this much exercise a week…it would be fun to do that…to see if we get any kind of compliance at all… but people are, they really will do what you tell them and if we believe what we say which is if they get into good habits with their eating and with their blood sugar testing and so on and its easier to*	2.5

	manage those things then the same should be true for their exercise.' – physician (106)	
Addition of sport therapist/exercise leaders to clinic	*'If you could have the equivalent of a more grown up play therapist but they were a sports therapist.... at clinic that would be brilliant… I, I would do it. I would do the course to take it you know.' – dietitian (104)*	2.6
Community and family interventions	'*We're targeting one poor individual and he's part of a peer group and its their friends that don't do those things…so you know, its all very well for us to encourage people to do stuff but it's the societal problem…and you know…there are innovative ideas…you hear about walking buses and things… and folk organising neighbourhood walks to school and I mean I think that's the kind of thing that will probably, will make a difference rather than us [diabetes professionals] just saying do this, do that.' – physician (106)*	2.7a
	'If you go to a swimming pool there's a lifeguard. If people are concerned about children being out in a football pitch why could we not have the concept of you know properly regulated sports pitch guards or whatever you want to call it so that the children can play safely and be monitored?' – physician (109)	2.7b

Table 4.3 Theme: Support/intervention method of delivery

Sub-themes	Example excerpt	Excerpt number in text
Technology is appealing to youth	*'I think if you're looking at young people then using social networking, Facebook is absolutely the way to go cause...whether we like it or not...that's how they communicate with each other...and if you do it on their wavelength I think it's going to make a big difference…Facebook and Twitter...she uses the Wii as well and does all these kind of dance along to music and, and all these things are exercise without them sometimes even realising they're exercising.' – mother of an adolescent girl (101)*	3.0
Technology for monitoring and feedback	*'If you're worried that you're not doing too much [physical activity] and then you can be like say "okay oh right I've done that and I've done this and, or I need to do bit more." – adolescent girl (103)*	3.1
Technology for support	*'It's about community and if your local peer community aren't really that into doing anything… then you know, there is a worldwide community that you might get support from… that's not going to be for everyone but it might be for some people.' – nurse specialist (105)*	3.2

Technology substituting in-person contact	*‘Oh I think it’s [technology’s] a good idea cause then you don’t need to keep going up and down, up and down [to the clinic].' – mother of an adolescent boy (116)*	3.3
Policing social support	*'One of my concerns has always been meeting with other kids with diabetes you’ve, how do you police that? How do you watch what they’re saying to each other? Because X [daughter] has had that said to her “if you don’t take your insulin you’ll burn some more calories” and you’re like “hold on a minute,” she came straight home and said “oh somebody said this” and I’m like “Oh no that’s rubbish, that doesn’t work like that.”… I would be apprehensive if it was just a group of kids...all right their privacy has got to be protected, but safety comes first at the end of the day.' – mother of an adolescent girl (103)*	3.4
Technology alone is not enough to change behaviour	*‘I think that having an app on your iPhone that measures how far you run - that is not going to work. It will help the person…**if** they’re motivated… But I think technology helps you do what you already want to do... will it encourage, no…I might be wrong but I, I just don’t see it… I think peer group and role models…young people going and talking…I think that is far, **far** more important than any technology… I couldn’t say that strongly enough…* *I think it needs to be personal... I think it needs to be like we’re having now, we’re having a chat.’ – physician (109)*	3.5

Information on local opportunities	*'Whether that’s something that they could introduce into like say the clinic even as an information leaflets...get all the health partnerships in [X – city name] or where-ever...get [X – city name] to start with and build it up… I think leaflets would be great... Cause then it might even give people from other areas, I, I don’t know what happens in the north of [X – city name], there might be activities going on there that we don’t find out about or you find out after they’ve had it.' – father of a young girl (118)*	3.6
Information alone is not enough to change behaviour	*‘It’s also the same thing as the school because it’s mandatory and they have to do it, they’re, they’ve got to just do it. I mean you can give people leaflets but actually getting them to do it.’ – nurse specialist (101)*	3.7
Adolescents may prefer individual support and children may prefer group support	*‘X [son] definitely would hate that [group support], he would hate it! And I think you’d find probably most teenagers would. I don’t think they would open up enough in a group situation…It would depend on the child definitely. I think that [groups] would work for the younger ones if their parents were there… But not if they were on their own...that would be probably a good idea actually – one parent and the child. Uhm because the parents would then encourage the child, the children to talk and discuss things amongst themselves.' – mother of an adolescent boy (117)*	3.8

Some adolescents did not want group support	*'[I would want to] get on with it myself.' – adolescent boy (116)*	3.9a
Some adolescents would want group support	*'I think having it in a group cause you can see people that like have done a lot of exercise and people that didn't do a lot and then they can share their ideas of different ways that they do exercise and things that motivate them.' – adolescent girl (101)*	3.9b

Table 4.4 Theme: Support/intervention components to include and address

Sub-themes	Example excerpt	Excerpt number in text
Addressing influencers		
Appropriate diabetes preparation and management	*‘Making sure that they’ve had enough to eat, that they’ve always got lucozade or whatever.’ – mother of a young boy (124)*	4.0
Diabetes support	*‘I think for the child themselves is knowing that…their diabetes is properly supported that they feel safe when they’re doing it, that there are proper systems in place that if they have a hypo or whatever then it’ll be managed properly.’ – dietitian (102)*	4.1
Negative impacts of physical activity often misunderstood	*‘In many years of diabetes camps, I’ve seen one child ‘slump’ with a hypo...I’ve never seen anyone have a convulsion. I’ve never seen anyone seriously unwell from a hypo…I’ve never had to for example give glucagon or had to give them a drip. That has never happened…And yet the sporting activity we’ve done has been...very intense…,and also has been totally out of the normal activity pattern of the child…So uhm I think the dangers are over-stated.’ – physician (109)*	4.2

Enjoyment	*'If it sounds good and it makes fun and, and if it's something that they're, they're peer group think it's a good thing to do.' – mother of an adolescent girl (101)*	4.3
Insulin pump therapy facilitates physical activity participation	*'X [daughter] has been able to join clubs, do exercise, go out on her own now which she just couldn't do when she was on the injection therapy…the pumps phenomenal… dealing with our distress [laughs], fear of letting her exercise.' – mother of an adolescent girl (103)*	4.4
Education		
Positive effects of sedentary behaviour on diabetes	*'They might get less fluctuations in blood glucose if they do it [sedentary behaviour] all the time I suppose… It could be that they're easier to control if they just don't do anything extreme.' – dietitian (104)*	4.5
Negative effects of sedentary behaviour on diabetes	*'If she sits in front of a DVD and is on normal insulin…then she will go high and likewise if she sits in a car a long journey she's having normal insulin she will go high. So…if she's not physically active, because of her norm is much more active, then it does, does have an affect.' – father of a young girl (112)*	4.6
Education on what physical activity is	*'I think maybe having a leaflet or something that we could give at diagnosis entitled something like "what do we mean by exercise" might be helpful because it changes the perimeters. We're not just talking about two hours of football on a Saturday… and tie that in*	4.7

	you know if you had pictures up there and said "right what would this group of people have to think about in relation to their blood sugars? As opposed to that lot of people? What are the differences between these two groups of people, how they would look after their diabetes?"' – physician (106)	
Education on what sedentary behaviour is	*'I suppose its also trying to teach them about knowing sedentary behaviour…rather than having to start tennis or whatever….things that they will do rather than putting them off.' – dietitian (107)* '*Just by not allowing himself [scientist on television show] to sit still for an hour he used an extra 500 calories a week. I thought that was an amazing fact. And that's the kinda thing that telling teenage girls would be perhaps useful… I think it's about trying to give people something that catches their imagination.' - physician (106)*	4.8
Education of the risks and benefits of physical activity and sedentary behaviour	*'Getting them [patients] to know like how good it [physical activity] would be for them in the long term ...get them to really know how, how serious it is really and how, how important it is that they need to maintain their, their exercise and their diet balance.' – mother of a young girl (123)*	4.9.0

Behaviour change techniques		
Monitoring and feedback	*'Something to build awareness.' - Mother of a young girl (115*)	4.9.1
Goal setting and rewards	*'Getting people to... set goals for themselves...so it's things that they can achieve would be good... achievable goals...for children that don't really do anything. You know big charts and things like that...and as they reach each goal they get some-...a reward.' – mother of an adolescent boy (117)*	4.9.2
Linking behaviour change to health	*'Some sort of way of introducing it [physical activity] that it's something that, in addition to your HbA1c you need to be thinking about your exercise as well and actually you're able to then plot by coming along to this club [potential physical activity intervention] and being more mindful of exercise that you see drops in the HbA1c as well...So that they can see that everything they're putting in is worthwhile.' – mother of an adolescent girl (103)*	4.9.3
Competition	*'And does it need to be competitive? …I might be swimming against the tide…I say yes because I think… life is competitive and I think sport…I played lots of competitive sport….it made me realise that life is competitive and sometimes you win and sometimes you lose and you take joy in participating… I suppose not everyone needs competition but I think there's no harm in it.' – physician (109)*	4.9.4

Encouragement and motivation	*'You could encourage them for every day, if it's sunny,...run about in their back garden or if they don't have a back garden... go out to the park and have a good run...walking your dog and things…I think people should encourage people to...go out to the park and play and run about...and if you do have a back garden spend the whole day out there.' – young boy (124)*	4.9.5

Table 4.5 Theme: Support/intervention timing and duration

Sub-themes	Example excerpt	Excerpt number in text
Near diagnosis	*'The things that they tell you in that two weeks [post-diagnosis] you don't ever forget...there's a heightened awareness of everything you're getting told and I think if you build into that the need for exercise and how much exercise is going to benefit children as a whole, but certainly children with diabetes then…I think yes…the earlier you kind of tell them that then the better.' - mother of an adolescent girl (101)*	5.0
Timing may depend on the experience at diagnosis	*'I think it depends on how bad the diagnosis was. Personally Xs [daughters] wasn't great. She was right ill and uhm I think it would have been too overwhelming for us, too much information...if somebody was caught in time and they weren'ae that bad then I, I would be up for a meeting just as a kind of getting to know other parents and their experiences and things like that. But depends on what stage their diagnosed at.' – mother of a young girl (123)*	5.1
Regular check-ups	*'[Every] six months or something...Cause they go to clinic, what is it, every 4 months or something.' – mother of an adolescent girl (108)*	5.2

Additional contact when necessary	*'I think it would depend on like the person... cause like if you get someone who wants to make their life better and wants more exercise so, like if, like if you had your first meeting and then you had another session and you seen that it was all going well, then that would be fine like having it a one off but there's other people that turn up and haven't done anything else then they would need to be monitored.' – adolescent girl (101)*	5.3

6.0 Summary of chapter 4

The findings of study 3 provide novel findings by exploring perceptions of perceived physical activity and sedentary behaviour support needs in diabetes care and the perceptions of not just patients and parents but also diabetes professionals. The novel findings will be useful for consideration when developing interventions targeting patients in home and community settings, or in clinic. Youth also spend a large proportion of their time in schools. Paper 4 addresses support needs to encourage physical activity and PE participation in youth with Type 1 diabetes in school settings.

Chapter 5: Supporting physical activity participation in youth with Type 1 diabetes in schools: Views of teachers, patients, parents and diabetes professionals

1.0 Preface

School can have an important influence on youth's physical activity participation for the following reasons: 1) the large proportion of time spent in school and throughout the entire year; 2) the attendance of all youth at school (regardless of ethnic and socioeconomic background; 3) school is a place of education allowing physical activity to be incorporated into health education; and 4) school provides access to additional physical activity opportunities outside of the curriculum (Stratton, Fairclough, & Ridgers, 2008). Effective Type 1 diabetes management requires blood glucose monitoring and appropriate adjustment of dietary and insulin intake throughout the day. Therefore diabetes management support from schoolteachers can be important, particularly in newly diagnosed or younger patients or patients who are hypoglycaemic, as they may have difficulty calculating appropriate changes in diet and insulin intake. The perceptions of schoolteachers, patients, parents and diabetes professionals in managing and encouraging physical activity participation in youth with Type 1 diabetes have not previously been explored. Paper 4 addresses this gap in the literature.

Appendix A includes an email confirming University ethics approval for the inclusion of teachers in study 3. Qualified practicing teachers and University students undergoing teacher training were included. The qualified practicing teacher participant information sheet is provided in appendix G and the focus group topic guide used with teachers is included in appendix H.

2.0 Paper 4: Supporting physical activity participation in schools: Views of teachers, patients, parents and diabetes professionals

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Abstract

Background: Physical activity is an important component of diabetes management, as well as to generate health and development for youth with Type 1 diabetes. Encouragement of youth with Type 1 diabetes to participate in physical activity at school is important as youth spend large amounts of their time at school. The aim of this qualitative study was to explore physical education and physical activity participation at school in youth with Type 1 diabetes and to determine how schools can help support patients to be physically active.

Methods*:* Interviews and focus groups were conducted with patients aged 7-9 (*n*=8) and 12-14 (*n*=8) years with Type 1 diabetes, their parents (*N*=16), diabetes professionals (*N*=9) and schoolteachers (*N*=37). Data were thematically analysed.

Results: Four main themes were identified relating to support needs for the accommodation of youth with diabetes in physical activity in schools: 1) differences between primary and secondary schools; 2) areas requiring address in all schools; 3) what teachers can do to help accommodate patients; and 4) what schools can do to help accommodate patients. Diabetes support varied across schools. Primary schools in particular could improve communication between schools and primary specialist teachers regarding patients. Diabetes knowledge was limited among all teachers. Participants felt that diabetes could be used as an excuse to sit out of physical education and that teacher and coaches' fears could facilitate this. Improved and consistent diabetes management training and guidance on the responsibilities of teachers is necessary. Better communication between schools, teachers, parents, patients and diabetes professionals is also required.

Conclusions: The findings have helped produce guidance for practice and research on how to improve physical activity support in schools for youth with Type 1 diabetes.

Introduction

In Scotland, primary (elementary) schools educate children aged 4-11 years and secondary (high) schools include adolescents aged 12-17 years. Physical activity incorporates any activity done throughout the day in any location. Physical activity at school includes curricular and extra-curricular activity. Physical education (PE) consists of mandatory physical activity classes (plus optional additional classes after reaching secondary year three in Scotland), undertaken during curricular time as part of the school timetable. Extra-curricular physical activities are done at school or with teachers in an external location, outside of the school timetable. This paper focuses on any physical activity undertaken at school (e.g. PE and extra-curricular activity). Secondary schools in Scotland have PE teachers based within single schools. Primary schools have either primary specialist PE teachers who teach at several schools, or teachers that are based within single primary schools that lead PE sessions.

There is a target for all schools in Scotland to deliver a minimum of two hours (primary) or two periods (secondary) of mandatory PE per week (Scottish Executive 2007). All youth should be treated equally in schools, regardless of any disability they may have, including the medical condition Type 1 diabetes (Gooding 1994, United Nations 2002). A lack of translation of anti-discrimination legislation to implementation of diabetes support in schools, is evident in most countries worldwide, with confusion over the roles and responsibilities of school staff (Lange *et al.* 2009). Limited research has explored if this lack of translation affects participation in PE and physical activity at school in youth with Type 1 diabetes.

Type 1 diabetes is one of the most common long-term conditions in youth (Torpy *et al.* 2007). The condition occurs when the pancreas does not produce insulin (a glucose lowering hormone) and therefore blood glucose levels remain chronically raised. The condition requires appropriate management for safe participation in physical activity (Robertson *et al.* 2008, American Diabetes Association 2004). Effective management requires the balancing of external insulin intake (via injection or insulin infusion pump therapy), carbohydrate intake and physical activity, with the aid of regular blood glucose monitoring. Under or over estimation of insulin or carbohydrate in relation to the amount of physical activity undertaken can result in higher (hyperglycaemia) or lower (hypoglycaemia) than the normal range of blood glucose levels for patients with diabetes. Acute hypoglycaemia and hyperglycaemia can negatively affect cognitive functioning and mood (Sommerfield *et al.* 2004, Gonder-Frederick *et al.* 2009), and untreated hyperglycaemia and hypoglycaemia is life threatening. Over the long-term, poor blood glucose control can lead to the development of complications such as kidney disease, blindness, and cardiovascular disease. As the process of managing diabetes is complex for youth with Type 1 diabetes, it is recommended that parent, teacher and coach support be available to aid management for physical activity to ensure good blood glucose control (Robertson *et al.* 2008, American Diabetes Association 2004). Without support, blood glucose management may be inadequate putting the patient at an immediate risk of negative effects and at a long-term increased risk of developing complications. In a study including 499 parents, 51% reported that their children had experienced hypoglycaemia during PE (Amillategui *et al.* 2007). No studies have explored specifically issues related to diabetes management and support for physical activity participation in schools.

This research is part of a larger qualitative study examining physical activity and sedentary behaviour (sitting time) and perceived support needs for youth with Type 1 diabetes in patients, parents, diabetes professionals and schoolteachers. The aim of this paper is to provide guidance for schools on how to help support physical activity participation in youth with Type 1 diabetes and to guide future intervention research.

Methods

Participants and recruitment

Purposeful samples of patients and teachers were recruited to explore differences between primary and secondary schools. Patients and parents were recruited from a paediatric diabetes clinic in a city in Scotland into a concurrent study measuring physical activity and sedentary behaviour in 40 youth with Type 1 diabetes. The UK currently has the fourth greatest prevalence of Type 1 diabetes in the world (Soltesz *et al.* 2009). The first eight patients and their parents recruited into the measurement study were invited and agreed to participate in the current study. Physical activity and sedentary behaviour of patients were measured using accelerometers (Actigraph Model GT3X+; Manufacturing Technology Inc., Pensacola, FL, USA), with time in health enhancing physical activity (Puyau *et al.* 2002) and sedentary behaviour

(Fischer *et al.* 2012), determined using validated cut-points. Eight children (5F; 3M) aged 7.0-9.7 years (elementary grade 1-4 (US); primary year 3-6 (UK)) and eight adolescents (4F; 4M) aged 12.2-14.9 years (middle or high grade 6-9 (US); secondary 1^{st}-4^{th} year (UK)) and their parents (2M, 14F; aged 31.7-51.8 years) participated in interviews (individually or in the presence of each other or with both parents/carers present). Patients varied in diabetes duration (2.3-13.4 years), physical activity level (22.0-123.3 minutes of health enhancing physical activity/day) and sedentary behaviour (7.0-12.3 hours).

Teachers varied in terms of experience (student or fully qualified practicing teachers), age and gender. Five secondary schools were invited via telephone/email to the head teacher or head of the PE department. Three schools responded positively and two schools participated in focus groups held in the schools (one school changed their mind due to time commitments). The lead primary specialist teacher for the county area was approached via email to invite teachers from the area to participate in focus groups held in a primary school where the teachers meet regularly. Student teachers were recruited from two Universities via email from course leaders from the following three courses: general primary teaching (undergraduate Bachelor of Education level); primary specialist PE teaching (Professional Graduate diploma level); and secondary PE teaching (Professional Graduate diploma level). Student teachers participated in four focus groups consisting of 4-5 students (BEd primary (n=4), PGDE primary specialist (n=4), secondary PGDE PE students (n=9)). Practicing teachers participated in four focus groups consisting of 2-8 teachers (primary specialist PE (n=13) and secondary PE teachers (n=7)).

Diabetes professionals were invited from the same clinic as patients via a letter from the researcher distributed at team meetings by the lead physician. Eighteen letters were provided and nine professionals replied positively and participated. Two physicians, three dietitians and four specialist nurses participated in two focus groups (n=4 in each) and an individual interview (n=1).

Adults and adolescents provided written consent. Children <12 years provided assent. University (teachers) and NHS (patients, parents, professionals) ethical approval were obtained. Local authority approval was received to approach schools to recruit practicing teachers.

Data collection

Focus groups and interviews lasting approximately 30-45 minutes were conducted using broad topic guides and interview questions. Focus groups and interviews can be utilised to describe, understand and explain areas/topics of interest (Barbour 2000). The following topics were explored with patients, parents and professionals: knowledge, attitudes and experiences of physical activity, sedentary behaviour and Type 1 diabetes individually and as combined experiences (e.g. physical activity and Type 1 diabetes); influential figures for behaviour and behaviour change; current support and future support ideas and characteristics. Professionals were also directly asked about school performance of patients with Type 1 diabetes and current clinic care for Type 1 diabetes. Teacher discussions covered the following areas: knowledge of Type 1 diabetes in general and in relation to physical activity; influencers and influential figures for PE and physical activity participation in Type 1 diabetes; teaching practice and ideas to accommodate youth with diabetes; and current diabetes support and training for teachers and perceived needs. Focus groups with teachers were conducted at Universities (student teachers) and schools (practicing teachers). Focus groups and an individual interview were conducted with professionals at the diabetes clinic. Individual interviews with patients and parents were conducted in patients' homes (*n*=31) or another convenient location (*n*=1). A researcher with extensive knowledge on physical activity, sedentary behaviour and diabetes and experience in conducting qualitative research collected data. Discussions were audio recorded and researcher/s took notes on non-verbal cues during discussion, as video equipment was not available to the student at the time of this study and ethical approval was not granted to video record discussions. Demographic data were captured by questionnaire. Recordings were transcribed verbatim.

Data analysis

Thematic analysis was the qualitative analytic approach used to inform this study (Boyatzis 1998, Braun and Clarke 2006). Thematic analysis is an approach that is adopted by numerous fields, such as psychology and sociology. It seeks to systematically identify, analyse, and report patterns in the data, and can thus be understood as a tool to assist with data organization, description, and analysis. While the epistemic foundations of thematic analysis are poorly articulated in comparison to more popular research traditions—such as grounded theory or phenomenology—it is compatible with both realist-positivist and interpretive-constructivist ontological and epistemological viewpoints. In this regard, it is compatible both with researchers who believe that there are real experiences and true facts to be reported, as well as those who consider knowledge to be a socially and historically situated production between the research and participant. Thus, in this study, a constructivist thematic analysis approach was adopted and used as a way in which to organize and explain the physical activity and health experiences of children living with Type 1 diabetes from multiple perspectives.

Coding was done initially by a single researcher. Themes are patterns within data. Tables collating all excerpts relating to major and sub-themes were created to highlight the meaning of themes and to provide an indication of frequency. Three separate reports of findings from patients/parents, teachers and professionals were produced before comparisons were made between participants. Rigour was ensured using the following multiple-coding checks. Two external members to the research team independently coded 10% (5% each) of the data to consolidate the original coding. Additionally, two researchers from the study read excerpts arranged under themes to check for agreement in coding of 100% of patient and parent excerpts, 12% of teacher excerpts and 67% of diabetes professional excerpts. Discussions with internal or external researchers and the main researcher were held to discuss discrepancies in coding and vocabulary used for coding until consensus was met. Results are presented in relation to the major themes with example excerpts provided in Tables 5.1-5.4 to illustrate themes. Excerpt numbers link table excerpts to the related section in the results. The type of respondent (patient, parent, professional, teacher (student or practicing primary or secondary teacher)), and study participant identification number are provided with excerpts. Tables 5.3 and 5.4 also include recommendations for teachers and schools to help accommodate patient participation in physical activity and PE.

Results

Four main themes arose relating to support needs for accommodating physical activity and PE in youth with Type 1 diabetes in schools: 1) differences between primary and secondary schools; 2) areas requiring address in all schools; 3) what teachers can do to help accommodate patients; and 4) what schools can do to help accommodate patients.

Differences between primary and secondary schools

Experiences and diabetes support varied considerably across schools. Parents generally spoke of there being better facilities and equipment, more variety and greater exposure to physical activity and better teacher diabetes knowledge and/or support (such as nurses) in secondary compared to primary schools (excerpt 1.0). From discussions with teachers, it appeared that primary specialist teachers were least aware of which pupils had medical conditions and had the least communication and support with schools regarding medical conditions (excerpt 1.1). Primary specialist teachers mentioned they teach at several schools making it challenging to learn about individual pupil's needs. Primary specialist teachers felt the responsibility of care for those with diabetes should be with full-time staff within schools (excerpt 1.2), which was in agreement with some secondary teachers who felt that it was their responsibility to learn about and deal with diabetes (excerpt 1.3). Some teachers felt that school visits from diabetes professionals may be viewed negatively by secondary school aged patients but useful for primary aged patients (excerpt 1.4). Classroom peers were mentioned by teachers as potentially useful for providing diabetes support but more so in secondary schools when patients are older than in primary schools (excerpt 1.5).

Areas requiring address in all schools

Diabetes knowledge and support

Teachers (student and practicing) had limited diabetes knowledge, with areas of confusion that could potentially result in very serious consequences (excerpt 2.0). Most teachers had acquired their diabetes knowledge from knowing/teaching someone with diabetes, with no teachers reporting training in dealing with diabetes during University training. The benefits of physical activity on health in general were well known by teachers. Only a couple of patients actually mentioned inadequate teacher knowledge or support. Teachers (excerpt 2.1a), professionals (excerpt 2.1b) and parents (excerpt 2.1c and 2.1d) however often highlighted the limited knowledge, training, and support teachers received regarding diabetes management in pupils.

The effects of having Type 1 diabetes on performance in school and PE

Patients and parents mostly said that diabetes did not affect patients in school. A few parents mentioned negative effects of diabetes when blood glucose control was poor, such as their child missing/disrupting classes and having difficulty concentrating (excerpt 2.2). Several teachers, parents and professionals perceived that some youth with Type 1 diabetes would use their diabetes as an excuse to sit out of PE (excerpt 2.3) and that there were no diabetes related barriers to PE but rather the individual’s attitude towards PE determined participation (excerpt 2.4). Participants spoke of teacher and coaches’ fears of diabetes related illness as being a potential barrier to encouraging and supporting physical activity as teachers may treat patients with excessive caution (excerpt 2.5). Professionals pointed out that the risks of physical activity in Type 1 diabetes are often over-stated (excerpt 2.6). Parents felt strongly that their children should not be singled out and treated any differently to youth without diabetes (excerpt 2.7). Professionals mentioned that diabetes discrimination in schools was less apparent now than in the past. However parents and professionals mentioned a few instances when patients had been singled out because of their diabetes or inappropriate action regarding diabetes control had been taken in school (excerpt 2.8).

What teachers can do to help accommodate physical activity and PE participation in youth with Type 1 diabetes

Appropriate planning and procedures in place, including advanced warning for patients (excerpt 3.0) so the child feels supported and comfortable (excerpt 3.1) to participate in PE and physical activity in school, was one of the most important diabetes related facilitators to participation. Communication between teachers/coaches and patients and parents was seen as essential for effective planning and management of diabetes during PE and physical activity (excerpt 3.2). Ensuring that patients’ are surrounded by peers who perceive diabetes as not being a ‘big deal’ was also viewed as important to avoid patients from feeling isolated. Educating pupils on diabetes was mentioned as a way of ensuring this (excerpt 3.3). Trust between the patient and teacher was perceived as important (excerpt 3.4). Teacher confidence to deal with diabetes (excerpt 3.5) and having a positive attitude towards diabetes (excerpt 3.6) were perceived as helpful for encouraging diabetes management and participation in physical activity through motivation and reassurance. The amount of encouragement for diabetes management required from teachers was seen as age and diabetes duration dependent (excerpt 3.7). Professionals felt that schools provide most support to highly active pupils (excerpt 3.8). Teachers, however, spoke of being guided by the patient and providing an individualized experience in physical activity based on the patient's needs, as for any pupil (excerpt 3.9). Teachers described their roles during physical activity as: watching for symptoms of illness, alerting the appropriate person in case of emergency and carrying diabetes support bags. Peer support and enjoyment were the main general facilitators for PE and physical activity in and outside of school for any youth, including those with diabetes. Some teachers suggested that peer buddies during PE might be useful to support patients (excerpt 3.9.1).

What schools can do to help support physical activity and PE participation in youth with Type 1 diabetes

Continuity, facilities and communication

Continuity in the school timetable to aid diabetes preparation was mentioned as important (excerpt 4.0). A couple of parents highlighted limited facilities in school for diabetes preparation/management (excerpt 4.1). Communication between schools and clinics and parents was perceived essential. Some parents and teachers mentioned that schools had declined visits from professionals, as they perceived they already had sufficient knowledge about diabetes. However, parents pointed out that each patient differs and therefore individualised advice for each patient should be welcomed by schools (excerpt 4.2). The majority of teachers felt that schools have a responsibility to ensure that procedures are in place so all teachers know which patients have medical conditions and what the teachers responsibilities are in the support of the patient with diabetes (excerpt 4.3). Knowledge exchange between schools was mentioned by teachers as potentially useful for gaining ideas on best practice for inclusion of youth patients in PE and physical activity (excerpt 4.4).

Training and support requirements

Patients, parents and professionals spoke of a lack of training and support for teachers on dealing with diabetes. The majority of participants felt practical hands on diabetes training in schools is needed (excerpt 4.5) as well as education to increase diabetes knowledge (excerpt 4.6). A couple of parents spoke of times when their child's school had provided extra support above and beyond their expectations to cater for their child with diabetes, such as extensive contact with parents or hiring of diabetes assistants during school trips (excerpt 4.8).

Discussion

The novel findings of this study highlight the need for improved support from schools and teachers to support patients with Type 1 diabetes to participate in physical activity and PE in school. Better and consistent training in diabetes management for teachers is required to help achieve improved support for patients in school. Procedures for communicating which pupils have medical conditions, how to manage diabetes and the responsibilities of teachers varied considerably across schools. Differences in primary and secondary schools were highlighted suggesting different intervention support may be required. In summary, primary schools could ensure greater variety and exposure to physical activity and better diabetes support including improved communication between schools and primary specialist teachers regarding patients. Previous research has also indicated poor communication in schools. For example a Spanish study reported that 22% of 499 parents perceived that their children's PE teachers did not know that their children aged 3-18 years had diabetes (Amillategui *et al.* 2007). Procedures could be in place in schools so that teachers know which pupils have medical conditions and teachers could be informed of their responsibilities and roles toward helping manage diabetes in patients. Diabetes knowledge in all teachers (primary and secondary) was limited. Several teachers did not mention and/or were not clear of what hypoglycaemia was, which in PE setting is the most likely diabetes problem to occur. The recognition and management of hypoglycaemia are highly specific and essential skills for anyone working with patients with diabetes. The present study identified teachers require better professional development in regards to dealing with diabetes (and medical conditions in general) in physical activity and PE settings and regular continuing professional development should be provided. Inclusion of primary specialists teachers who move between schools could be considered when delivering training. Previous research also acknowledged the need for general diabetes management training in teachers (Pinelli *et al.* 2011). Survey data of 1905 youth and 4099 parents, identified 58% of youth and 73% of parents perceived teachers should have better diabetes knowledge and 86% of 650 diabetes professionals felt that schools should have better diabetes knowledge and support (Lange *et al.* 2009).

Schools could consider continuity in timetabling and informing patients/parents of changes in timetabling to support the complexity of diabetes regimens, in alignment with published guidance for care of children with diabetes in schools (American Diabetes Association 2012). An appropriate location where the patient can perform blood glucose checks and administer insulin in privacy should be available (American Diabetes Association 2012). Guidance also advises school support be in place so parents are not required to attend to administer insulin (American Diabetes Association 2012). In the UK, a survey of 3000 primary schools identified that 70% of schools anticipated that parents would visit the school to administer insulin if patients were not able to manage diabetes independently (Diabetes UK 2009). Another study including 499 parents reported that 16% of their children's diabetes regimen had to be adjusted because schools were not providing sufficient support to continue with the patient's normal routine (Amillategui *et al.* 2007).

The present study identified inclusion of youth with Type 1 diabetes in PE as an important issue with several participants believing that patients would use their condition as an excuse to sit out of PE. Parents felt strongly that their children should be treated as normal and did not want their children using their condition as an excuse. Teachers, professionals and parents spoke of teachers' fears of diabetes illness during physical activity, which could encourage the patient sitting out of PE. Low teacher confidence to deal with Type 1 diabetes in general in school has also been reported elsewhere (Pinelli *et al.* 2011, Amillategui *et al.* 2007) and for dealing with asthma specifically in PE at school (Williams *et al.* 2010). Determining patients who were unmotivated from those who were not physically able to participate in PE was, as in the present study in relation to diabetes, found to be an issue for teachers with patients with asthma (Williams *et al.* 2010). To boost the teacher's confidence in encouraging participation in patients, communication with parents/carers was perceived in the present study as necessary and being aware of procedures and responsibilities for managing diabetes in the school was also important. Strategies teachers could use to ensure an inclusive, supportive and comfortable atmosphere for participation in physical activity and PE include: communicating with patients during activity; providing advanced warning of class content to aid diabetes management; educating all pupils on diabetes; building trust with patients; displaying teacher confidence to handle diabetes and awareness of the benefits of physical activity for diabetes; allowing the patient to help guide the teacher; and including peer 'buddies' to support the patient.

Training from diabetes professionals was perceived to be important in the current study to effectively prepare for individual patient differences in support needs. Schools could therefore be encouraged to accept training from diabetes professionals. Only 33.3% of Italian schools received training from diabetes professionals as reported by parents (Pinelli *et al.* 2011). Training from diabetes professionals was perceived as necessary for teachers by 60.8% of parents (Pinelli *et al.* 2011). Although 40.4% of teachers reported that they had completed diabetes management training, only 33.3% of teachers had received training from diabetes professionals, with most teachers gaining training from parents (Pinelli *et al.* 2011). The American Diabetes Association and the International Society for Paediatric and Adolescent Diabetes recognise the responsibility of parents to provide teachers and coaches with written and verbal information on hypoglycaemia risk, symptoms and treatment regarding the patient (American Diabetes Association 2005, Robertson *et al.* 2008).

Only a few parents and patients mentioned that nurse support in school was or had been available in the past. A previous study found that although a large portion of parents felt blood glucose control was at an acceptable level at school, 72% and 66% perceived the inclusion of a school nurse or trained teacher, respectively, would result in better control (Amillategui *et al.* 2007). Other studies have also reported low or no availability of nurse support in school (Pinelli *et al.* 2011).

Sixteen per cent of parents reported challenges (relating to the schools responsibilities) in including their children with Type 1 diabetes in one-day extra-curricular physical activity trips, in a previous study (Amillategui *et al.* 2007). In the current study, discrimination actually stopping participation in physical activity was rare. Some parents, however, spoke of inappropriate actions to treat diabetes.

Guidance for managing diabetes in schools recommends that schools, parents and diabetes professionals should develop individualised diabetes health care plans together clearly stating the responsibilities of patients, school staff and parents (American Diabetes Association 2012). The findings of the current study confirm that this guidance is not being followed universally across schools in Scottish city. There is currently no national approach for the care schools should provide for diabetes management in Scotland, as is the case for many countries (Lange *et al.* 2009). Despite Scotland's 'Additional Support for Learning (Scotland) Act 2009,' (Scottish Government 2010) which advocates that necessary extra support should be provided to youth that require it so that all youth can successfully learn, there is a gap between having and applying legislation (Lange *et al.* 2009). Although the UK rated adequate for availability of diabetes educational resources and training for school staff in a previous study, a limited rating for legislation allowing nurses or school staff to provide diabetes support and handle emergencies was evident (Lange *et al.* 2009). Examples of well functioning national approaches such as in Germany, Sweden and the USA (Lange *et al.* 2009) and local level approaches in the UK (Hill *et al.* 2007) should be aspired to. Diabetes UK have also suggested strategies to ensure consistent and appropriate care of youth with Type 1 diabetes across UK schools (Diabetes UK 2008). Teachers and schools, if applying new approaches for diabetes/medical condition training and support, could attempt to measure the impact of introducing training/support (for example on patient's participation in physical activity/PE and teacher's confidence) to determine effectiveness. Proving the worth of training and support will help gain backing from funders, local authorities and government to legislate for the implementation of better training and support on diabetes management for schools and teachers.

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Table 5.1 Theme: Differences between primary and secondary schools

Sub-themes	Example excerpts highlighting sub-theme meaning	Excerpt number relating to text
Secondary schools have better facilities, equipment, variety and exposure to physical activity and greater teacher diabetes knowledge and support	'I don’t think that uhm PE in primary is as good as it is in secondary schools...in secondary schools you’ve got specialists and in secondary schools it’s set up, the equipment is setup...very well. Plus you have really good facilities...secondary schools is set up to give you such a varied eh kind of selection.’ – mother of an adolescent boy (119)	1.0
Primary teachers less aware of pupils with medical conditions	‘I once had a child who was diabetic and had just been diagnosed and…her medication wasn’t settled and a few times she came to gym she took a hypo which is very scary and then she left the school so I don’t really know what happened but it made me kind of read up, well not read up, but find out a wee bit more about it because up until that point I hadn’t had anyone…We [primary specialists] are visiting people…The teachers and the classroom assistants took the responsibility, because I think in our situation where we don’t have the same class all day, they only come to us for a period and then they are away we might not even have them the whole year so we tend not to have the responsibility although…certainly in anytime I’ve diabetics, there tends to be a back up.’ – primary teacher 127 (F2)	1.1
Primary specialists alert teachers based in the school regarding	‘I think we are really just dependent on sending, you know if anything were to happen, just sending immediately for help… This is just what we have to depend on.’ – primary teacher 126 (F2)	1.2

diabetes issues		
Teachers based in one school felt it was their responsibility to learn about diabetes	‘We also know that when we went on teaching practice for the full year and then on, that our education doesn’t stop…the classes change all the time and situations change and so do pupils so…the onus is with us that we need to make sure that we’re providing somewhere safe for them to work and to make sure that you know that if we’re faced with a situation that uhm does require extra additional information that we’re actually gonnae spend a bit of time and doing something about it instead of too little too late…When we are going out as teachers it’s our responsibility to find out what their background is.’ – secondary PE student teacher 101 (F1)	1.3
Diabetes professional visits in primary compared to secondary school	‘With the primary school with the nurse coming in then that would work fine but I think when you go into secondary school that would be more of an “Oh no that’s so embarrassing.” … And if they told them outside the school, if they had like, spoke to the diabetes nurse whatever outside the school they’d be like quite, they would be ok and confident in themselves…But I think that coming in to secondary would be a no-go.’ – primary student teacher 138 (F2)	1.4
Peer support may be useful, particularly in secondary schools	‘Especially because like in high school uhm it’s probably, a lot of the kids will probably be like “that kids got diabetes” and they can tell the teacher as well. Whereas in primary you’ve got like 33 kids [laughs] and they’re all running riot in the gym hall [laughs] and you don’t know!’ – primary student teacher 138 (F2)	1.5

Table 5.2 Theme: Areas requiring address in all schools

*S*ub-themes	Example excerpts highlighting sub-theme meaning	Excerpt number relating to text
Diabetes knowledge and support		
Limited teacher diabetes knowledge could be serious	'I think that also it's being able to recognise the difference between a hypo and a hyper… I think that's important - I mean my understanding is you always give sugar? Is that correct?' – specialist primary teacher 118 (F1)	2.0
Limited diabetes knowledge, training and support for teachers	'Nobody sat me down at the beginning of the year when I inherited the class and explained about diabetes…and what it meant. All, all I was told was I was given a form that said make sure she eats at 10, she eats at 2…It was kind of like "this is what happ-, this is what you do with her" but there was no kind of explanation behind it or anything like that...' – primary teacher student 131 (F1)	2.1a
	'I have great sympathy actually for the schools. Although legally they are supposed to provide the same level of care that they would receive at home, teachers, they train to teach. And the sad fact is that uhm, is not just diabetes that…impinges on their time: asthma, epilepsy. And these also will have impacts on physical activity too. So I do have sympathy for teachers who are suddenly asked to give an injection, eh and monitor blood sugars…but things are moving in the right direction, it's just that I think uhm [pause], education needs more support. And that, whether that comes from the education	2.1b

	world or whether it's actually a health issue I'm not, entirely, sure but there used to be school nurses in school for example. There aren't now. There's one for every 5 schools. Now that's never going to solve this issue.' – physician (109)	
	'What would be really helpful actually...is...working with PE teachers...cause they haven't got a clue!...I feel as though they as, as a group of teachers of all that should be made aware of it... So I think from an activity point of view PE teachers could be made much, much more knowledgeable about managing the condition... X [daughter] was doing cross-country running and I said "who takes your monitor? Who takes your lucozade?" "Well no I get it when I come back." And I'm like "Oh my good lord!" So I spoke to the teacher and they went "should we have?" And I said "of course! This activity of all!"" – mother of an adolescent girl (103)	2.1c
	'I'll go to the school every lunch-time anyway to give them their insulin if they don't come home for lunch…There is no registered nurse going in to the school, otherwise she would probably not need to go in.' – mother of a young girl (123)	2.1d
Affects of having Type 1 diabetes on school and PE performance		
Missing class and difficulty concentrating	'I suspect it [diabetes] does [affect school] because…when she's low she spends quite a long time out of the classroom cause she doesn't go back in till they test her again and [if] she's high that can be up to half an hour sometimes…It's a good week when there's no hypos at school. Uhm but other weeks	2.2

	it’s five hypos at school… And also when she’s low and sometimes when she’s very high, she can be a bit kind of silly and a bit...I imagine it does have that affect on her concentration...in class.' – mother of a young girl (115)	
Using diabetes as an excuse to get out of PE	‘That has happened with X [my daughter] where she’s been told “just sit out the class.” And I’ve said, “no, absolutely [not]...” you don’t want them sitting out the class, you don’t want them thinking you know, “Oh I don’t feel well, right I won’t do the class.” Cause children will use that, manipulate that!...“I’m not doing it!”' – mother of an adolescent girl (103)	2.3
Mind set barrier not a diabetes related barrier to PE participation	‘There’s not really a…diabetic barrier. There’s…a mind-set barrier. But I’m not certain that that mind-set doesn’ae [doesn’t] always come from protecting themselves from diabetes. I think it’s the mind-set of eh “I don’t like physical education” or “I don’t like school” or some kind of combination of that. They’re the ones we have the barrier with and unfortunately nobody’s produced the thing that gets you over that hurdle… just having eh diabetes uhm is not a precursor for having to… limit participation, particularly in school PE where we rarely work to extremes… So the one’s who are interested in sport will overcome…their diabetes and get on wi[th] it… I don’t think it’s the illness. I think there’s a mind set... that indicates what they’ll do and how much they’ll do.’ – secondary PE teacher 116 (F2)	2.4
Teachers fear of diabetes related illness resulting in over caution during physical activity	‘Teachers… Might molly coddle them… So reacting the wrong way about someone who is independent or…if they buy…this person and “oh you just take a wee rest whenever you want” …or “just do what you can.” – specialist primary teacher 124 (F2)	2.5
Risks of physical activity in Type 1 diabetes are often	‘In many, 8 years, of diabetes camps, I’ve seen one child ‘slump’ with a hypo who needed a bit of glucagel or hypostop. I’ve never seen anyone have a convulsion. I’ve never seen anyone seriously	2.6

over-stated	unwell from a hypo. Uhm [pause] I've never had to for example give glucagon or had to give them a drip. That has never happened…And yet the sporting activity we've done has been... intense, very intense…,and also has been totally out of the [pause] normal activity pattern of the child…So uhm I think the dangers are over-stated.' – physician (109)	
Patients with diabetes should not be singled out or treated any differently to those without diabetes	'There was one instant when, it was when X [daughter] had not long been diagnosed with Type 1 diabetes and it was high, her blood sugar, and they took her out of the school classroom and made her run around the gym hall. Which I know might be a good thing to do if it's high but to do it in the middle of school and take her out! I, I was really annoyed…So I don't think they [school] handle things that well to be honest with you…I've always tried to say to them [teachers] that they shouldn't treat her any differently to, to any of the other kids cause I don't want her to be singled out' – mother of a young girl (105)	2.7
Inappropriate action regarding diabetes control (in this case teacher/patient preparation)	'X [daughter] was doing cross country running and I said "who takes your monitor? Who takes your lucozade?" "Well no I get it when I come back." And I'm like "Oh my good lord!" So I spoke to the teacher and they went "should we have?" And I said "of course! This activity of all!" – mother of an adolescent girl (103)	2.8

Table 5.3 Theme: What teachers can do to accommodate physical activity and PE participation in patients

Sub-themes	**Example excerpts highlighting sub-theme meaning**	**Recommendation for teachers**	**Excerpt number relating to the text**
Appropriate planning and procedures	'I would plan the week before and say to them next week we're going to be doing a higher level of exercise… so that they could… adjust their sugars… But the thing is you need to know that a diabetic needs to know that. And I wouldn't know that had it not been for my circumstances… I wouldn't know that just by being a teacher… I have learned a lot through the circumstances.' – primary specialist teacher 119 (F1)	Provide advanced warning of the content of the next PE class to patients and be aware of procedures for diabetes management or in case of emergency	3.0
Provide a supportive and comfortable environment	'It's a case of you making them feel comfortable in the environment and not feel isolated.' – secondary PE teacher 112 (F1)	Ensure the patient feels supported, comfortable and included in the class	3.1
Communication between teachers/coaches and parents and patients	'Maybe just kind of half way through the lesson just kind of as they're all busy doing activity you can just kind of go off and just go "everything ok?" Usually…the kid just doesn't want to be spoken to or kind of singled out so if you do it when everyone's busy, everyone's not really watching and you can just kind of walk past and just go "everything alright" and you'd just get a wee thumbs up… just engaging the child and just speaking to them to make the child and yourself aware that I know that you may need some extra help or that you may need to leave…I like that…link idea. If	Subtly communicate with the patient during physical activity. Communicate with parents if necessary to aid the patient's participation in physical activity	3.2

	everyone's kind of got this…shared goal and the point of…achievement is just to kind of get them involved…kind of give them as best experience as they can possibly achieve through the teaching that they receive and as their parents backing it up at home kind of thing...If you're maybe kind of struggling with the people in school you can maybe talk to parents. The message can be reinforced at home. And it's kind of very much a two way street in a sense, you can actually share a lot of information, "has he changed at home" or... "are things ok in school" that's very much, parents can then really get involved.' – secondary PE teacher student 106 (F1)		
Educate all pupils on diabetes	'The girl in my class actually her mum came and spoke to the whole class, which was quite good cause I think we were all a bit like "why is he going out to eat toffee crisps? I'd be like, "why is she getting that and nobody else?" You know we didn't understand it cause we were so young so her mum actually came in and spoke to us about it…so that was quite good to have an insight why X…needs to go cause she's not feeling well or whatever…I think having a shared understanding then X wasn't singled out having to leave the class the whole time, you knew why.' – primary teacher student 135 (F2)	Ensure all pupils are educated on diabetes to avoid the patient being viewed as different/socially excluded	3.3
Develop trust between the patient and teacher	'I think trust's probably an important word. They need to trust that you know they can go down there and participate in the way they want to and they're never going to feel embarrassed or even if there is a situation the teacher's going to deal with it.' – secondary PE teacher 111 (F1)	Build trust with the patient	3.4
Show teacher	'Maybe the teachers attitude as well. You could probably think that they'd [teachers]	Ensure you show confidence to deal	3.5

confidence to deal with diabetes	sort of molly coddle them in a way as well because of, well obviously we've all said that we're not confident and that we wouldn't know what to do so the teacher might be kind of like "right you don't need to do this part." And if it's a child that isn't confident or isn't that interested they would just be like "oh right, fine, not bothered."' – primary teacher student 138 (F2)	with diabetes so that the patient does not use their condition as an excuse to sit out of physical activity	
Have a positive teacher approach to diabetes	'I think having a positive approach…that's probably the most important thing…if they think that you actually…care about…what you're doing for them and, "it is to your benefit," and it's trying to get that across to these…young people because it's not easy.' – secondary PE teacher 112 (F1)	Show patients that you care and highlight the benefits of being physically active for the patient	3.6
Adjust encouragement for diabetes management based on age and diabetes duration	'And also if you had a really young child with diabetes you wouldn't expect them to…it takes them a long time before they can understand the feelings.' – primary specialist teacher 123 (F2) 'Yes and I think initially it takes a wee while to get the, well to understand the levels and when they need to have or take or do anything about it. I think its harder initially.' – primary specialist teacher 130 (F2)	Provide more or less support depending on the age and diabetes duration of the patient	3.7
Target everyone, not just the most physically active pupils	'Schools important but again schools view of exercise is gym, football, hockey, rugby-it's not keeping moving, its not generally…I'm quite certain that although they have an obligation to make everybody do these things, they put all their efforts into the people that are good at them, because they get a reward out of that as well - the team wins a football cup or whatever. That's, that's good for them so they're not really going to bother about the folk that don't care…They're not going to go beyond their statutory	Provide equal support to patients of all physical activity levels	3.9

	obligation.' – physician (106)		
Allow the patient to provide some guidance	'I would let them help guide me… so once if I've set the class up and say "ok if you get to the stage where you're not feeling [well] then you have to tell me straight away."' – primary specialist teacher 121 (F1) 'But are you not doing that with all children anyway?...So you wouldn't necessarily only do it for a diabetic.' – primary specialist teacher 119 (F1)	Allow the patient to help guide you but not to use their condition as an excuse	3.8
Peer buddies	'I don't know if I'm right with this…not to give any responsibility to any other pupils but maybe just have a, a buddy next to them or someone that, that knows them quite well that they feel safe with… Because if they go in to that emergency situation yes as a teacher you're there but it's eh [pause], you know it's, it's nice having somebody next to you that maybe knows how it works as well...' – secondary PE teacher student 109 (F1)	Consider pairing up patients with a 'buddy' (another pupil) to help watch for diabetes symptoms	3.9.1

Table 5.4 Theme: What schools can do to accommodate physical activity and PE participation in patients

Sub-themes	**Example excerpt highlighting sub-theme meaning**	**Recommendation for schools**	**Excerpt relating to text**
Continuity, facilities and communication			
Continuity	‘In school the timing of their lessons doesn’t necessarily fit with their injection and eating regime.’ – primary specialist teacher 119 (F1)	Provide continuity to avoid minimal disruption to diabetes regimens	4.0
Facilities	'When he was in primary school he had to go in the disabled toilet to do his injections. So I just felt the standards then, so I brought it to their attention... I think eventually I think by the time he was just leaving school, primary 7, they let them go into... the office thing to do his injection. So I just don’t feel there’s somewhere there for them to do injections aha. And I feel to let them go in to a toilet and do it, I think that’s appalling.’ – mother of an adolescent boy (116)	Provide a private space that can be patients if they do not wish to test their blood glucose or administer insulin around others	4.1
Communication between schools and clinics	‘”Oh we’ve, we’ve, we’ve had hundreds of diabetics through the school,” is what they’ll say to you and you’ll go, “ yeah but that implies every diabetic’s the same,” but they are not...***They*** as, as a group of teachers of all that should be made aware of it that...I think from an activity point of view PE teachers could be made much, much more knowledgeable about managing the condition...Whereas I don’t think they [PE	Utilise diabetes professional visits and communication to gain individual information about patients	4.2

	teachers] really know how to do that and the difficulty is what will make X high [will] make another child hypo...this umbrella term ‘diabetes’ is just that...Very poorly understood.' – mother of an adolescent girl (103)		
Schools have a responsibility to inform teachers of youth with medical conditions and the teachers role in helping support youth with diabetes in PE and physical activity	‘You’ve got like so many other children in the class and they pure like “oh freaking out,” you know yourself you’d be freaking out as well if they were having a hypo. So it’s just like making sure like everyone, all the teachers in the school are aware of the child’s, uhm diagnosis so they can all help out…I think like more information we need as well on like responsibility cause we were talking about “oh do you send them to the office and stuff” at schools and then in other schools it might be a case of you know that’s your…the teachers responsibility or it’s all on the child and I, I think obviously it would differ between cases but you just wouldn’t even know [laughs]… like responsibilities, who’s role.’ – primary teacher student 138 (F2)	Schools should have procedures in place so that teachers are aware of patients with medical conditions. Schools should clearly state the roles of teachers in the support of youth with diabetes	4.3
Knowledge exchange between schools	‘What we don’t know is what else is there…that we don’t know... so it might be quite good once your findings are.. sharing practice yep… pass them back to us.’ – secondary PE teacher 112 (F1)	Knowledge exchange between schools on the care of patients could be useful	4.4
Training and support requirements			
Practical hands on diabetes training	‘What’s needed [for teachers] is one to one or maybe one to three.... practical [pause] guidance on this is how you put a pen together, this is how you add the needle, this is	Universities during teacher training and/or schools should provide	4.5

	how you [pause] prepare a pen, this is how you give the injection uhm. This cannot be done in a, in a broad sense with a lecture you know or with 30 or 40 or 100 people… I would think you could do general discussion. But I think a lot of it now is coming down to very [pause] precise, hands on, information. How do you do a blood glucose? What had, what do you do with the lancet once you've finished with it? What do you do with the pen, needle? Uhm these practical things are very, very important uhm with risks of needle stick injury and all the rest of it. Plus the fact that you're giving something that potentially is lethal. So you know there, understandable concerns.' – physician 109	practical training for student and practicing teachers on dealing with diabetes	
Education on diabetes at school	'I think that in their in-service days...every year as a teacher I have to go through training on...child protection. Why can't they have something on medical conditions?... I think it should be part of their training. and it should be every year. So that they get bored silly with it...because it's been reinforced. They know what routine, what if he has a hypo in class.' – mother of an adolescent boy (119)	Schools should provide regular education on medical conditions for teachers (such as yearly in-service training days)	4.6
Extra support above parental expectations	'I organised a meeting with the head teacher, the depute head, a nurse, a nutritionist and the class teacher and me [before a school trip]...we uhm got the menus for two weeks, we did all the calculations on it...I've written out all the protocols… they [teachers] were excellent cause they would phone me and they sent me pictures of him having a good time...it was all about... speaking to the people that were taking care of him… We couldn't have been any more prepared. And then it was just for me, I had to wave him goodbye.' – mother of an adolescent boy (119)	Schools should consider additional support that they can provide for patients, such as contact with parents or hiring nurse assistants during school trips	4.8

3.0 Summary of chapter 5

Novel findings were reported in paper 4 on supporting PE and physical activity participation in youth with Type 1 diabetes in schools. Guidance to address the needs of teachers and schools were detailed in the paper and will be useful for the development of interventions targeting schools.

Chapter 6: Collation of findings and recommendations for future research and practice

1.0 Chapter outline

The aim of this chapter is to collate the findings of the three studies conducted as part of this thesis and to provide recommendations for future research and practice. An overview of the findings from the thesis is provided first. Next a summary of considerations for developing interventions in general and based on the findings of this thesis in relation to the MRC complex health intervention framework are given, before a discussion of the next stages of development in the MRC framework and a summary of the strengths and limitations of the thesis studies. Final conclusions are then given.

2.0 Overview of the thesis

This thesis followed developmental phase guidance for the production of complex health interventions by: the conduction of primary research to determine the need for intervention; rigorously reviewing current literature; and exploring perceptions of potential intervention stakeholders. Paper 1 (chapter 2) identified that Scottish youth with Type 1 diabetes are a primary target for physical activity and sedentary behaviour intervention – patients were not meeting the physical activity recommendations and were spending high proportions of time in sedentary behaviour. Paper 2 (chapter 3) justified the use of physical activity intervention for youth with Type 1 diabetes by detailing the potential health effects of being physically active in this target group. Paper 2 also highlighted the need for well-designed future intervention research, with interventions that are based on theory, are unsupervised and that incorporate sedentary behaviour in addition to physical activity support. Papers 3 and 4 (chapters 4 and 5) considered the views of potential intervention users and deliverers and highlighted the need for interventions that: include peer and parental support; promote diabetes professionals to encourage physical activity in diabetes care; and educate and support teachers in the promotion of participation in physical activity and PE. Collectively the findings of the four papers incorporated in this thesis, alongside existing published knowledge of theories of behaviour change and intervention development in youth, provide the building blocks for the development of an intervention/s to aid physical activity and minimise sedentary behaviour in youth with Type 1 diabetes.

3.0 Designing an intervention: considerations

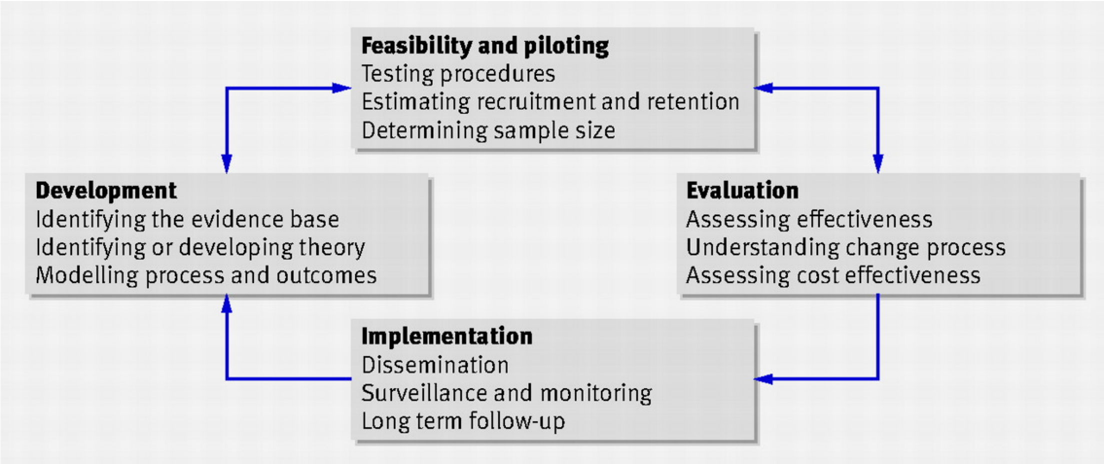
Guidance on developing physical activity and sedentary behaviour interventions for youth in community, school and home settings is available (National Institute for Health and Clinical Excellence, 2009; Timperio, Salmon, & Ball, 2004; Ward, Saunders, & Pate, 2007), as well as advice on making physical activity appealing to youth (Kelly, Matthews, & Foster, 2012). The importance of including theory in the design and implementation of health behaviour interventions has been highlighted (Glanz & Bishop, 2010). The construction of intervention maps to indicate what and how behaviour/s will be changed (Brug, Oenema, & Ferreira, 2005) and the use of a behaviour change wheel to characterise behaviour change interventions and policies (Michie, van Stralen, & West, 2011), may be useful for designing effective interventions. Previously published resources, such as those mentioned at the start of this paragraph, and studies incorporating theory-based interventions should be consulted alongside the findings of this thesis to aid the development of interventions for youth with Type 1 diabetes. Social cognitive theory has been widely used and is one of the most successful theories in physical activity intervention research in youth (Ward, et al., 2007), and should therefore be explored further in the development of interventions for youth with Type 1 diabetes.

The importance of developing a standardised way of defining behaviour change techniques in interventions has been identified (Abraham & Michie, 2008; Michie et al., 2011). Explicitly stating behaviour change techniques applied in an intervention can allow researchers to identify useful and unnecessary techniques in successful interventions. Theory linked behaviour change techniques are particularly important when reviewing the literature in the design phase of a new theory based intervention, in order to link the behaviour change techniques to the most suited theory. Clearly stating the behaviour change techniques used in an intervention and how they are used aids replication of an intervention as accurately and effectively as possible. As a result of the need for a standardised way to name behaviour change techniques, Michie and colleagues developed a taxonomy of 40 behaviour change techniques relating to increasing physical activity and healthy eating: the 'CALO-RE' taxonomy (Michie, Ashford, et al., 2011). The authors advise researchers to: report behaviour change techniques in journal articles using their taxonomy; report characteristics of interventions in articles; and to link detailed intervention manuals to articles that readers can consult for further information on the design and delivery of interventions (Abraham & Michie, 2008; Michie, Ashford, et al., 2011). The taxonomy was used in paper 3 (chapter 4), to identify the behaviour change techniques mentioned by participants as important components to include in interventions. Interventions incorporating these techniques should now be developed and/or tested.

4.0 Designing an intervention: conclusions so far and relating the findings of this thesis to the MRC framework

In regards to the updated MRC complex health intervention development and evaluation framework, the studies in this PhD have contributed mostly to the development stage as well as providing some indicative information around the feasibility and piloting stages (the stages are described in Figure 6.1 below).

Figure 6.1 The updated MRC framework by Craig et al., 2008



A discussion of the impact of each study within this thesis and how each study has contributed appropriate knowledge and evidence for future interventions now follows.

Relating to the stages of the MRC framework, study 1 had an impact firstly in regards to identifying the evidence base, by confirming the need for physical activity and sedentary behaviour intervention in Scottish youth with Type 1 diabetes for the following reasons: MVPA participation was below the recommendations for youth; and sedentary behaviour constituted a large percentage of the waking day. In addition, this study identified that time in MVPA was lower at weekends than weekdays and that sedentary behaviour was greater in adolescents compared to younger patients. Future behaviour change interventions therefore need to focus on encouraging time in MVPA, particularly at weekends, and minimising sedentary behaviour, especially in adolescence. Secondly, study 1 also provided some indicative information towards the feasibility and pilot phase of the MRC framework. Useful information on the recruitment of youth with Type 1 diabetes into a physical activity and sedentary behaviour study from a diabetes clinic was gathered. Using the recruitment methods employed in this study, the target sample size of 40 was successfully reached within a six-month period. Future researchers will be able to use the recruitment data from study 1 to estimate the required time and resources necessary to reach their desired sample size. Of 47 patients that responded positively to the study invitation, only four changed their mind and decided not to participate before they were enrolled in the study, and all 40 participants included in the study provided sufficient data to be included in the analysis. These figures show high study retention and compliance to the protocol in study 1 in this target population. Effect sizes were calculated and reported in study 1. These will help guide sample size calculations in future studies with the primary outcome of exploring differences in MVPA or sedentary behaviour between age and gender or age-gender groups in youth with Type 1 diabetes. In terms of testing/piloting procedures, using accelerometers over 7 days with this target group appeared feasible, as did the use of questionnaires, which were successfully completed by participants.

Study 2 also added to the identification of the evidence base (part of the development phase of the MRC framework as shown in Figure 6.1), by the undertaking of a systematic review to identify what was already known in regards to physical activity and sedentary behaviour interventions in youth with Type 1 diabetes. Study 2 identified that future interventions should: target sedentary behaviour in addition to physical activity; include unsupervised programmes; and be developed based on a theoretical behaviour change background. In addition, the study provided pooled evidence for the positive effect of physical activity on HbA1c, providing higher quality evidence than had been available prior to this study on the beneficial effects of physical activity in this target group. Other important data gathered from the intervention studies included in the systematic review, summarised in the recommendations box at the end of paper 2, will also help guide the design, conduction and reporting of future intervention studies (informing the pilot and feasibility stage of the MRC framework). For example, the review identified a lack of reporting on the recruitment stages of intervention studies and calls for more detailed reporting to guide recruitment strategies in future studies. Also there is an imperative need to measure and report on changes in physical activity and/or sedentary behaviour, diet, insulin and hypo/hyperglycaemic episodes, in order to conclude soundly on the efficacy of future interventions.

Study 3 also fed into the development stage of the MRC framework (Figure 6.1). Physical activity and sedentary behaviour support in diabetes clinics and at school had not previously been explored qualitatively in youth with Type 1 diabetes. In addition the views of not just patients but other central stakeholders of a potential intervention (such as teachers, patients and professionals) had not been explored in regards to this topic. The findings of papers 3 and 4 thus provide new, in-depth insight for this target population. This new insight provided new information to the evidence base as well as helping identify and develop theory (e.g. identifying factors and types of support that are important for physical activity and sedentary behaviour change in youth with Type 1 diabetes), as a basis for future interventions. An important finding from paper 3 was the need for support to be individualised, suiting the needs and preferences of the patient. Incorporating behaviour change theory into an intervention would help achieve the deliverance of individualised support, as theories help target important processes at the appropriate stage of the individual's behaviour change. In addition paper 3 identified: the need for parental and peer support in an intervention; the current lack of physical activity encouragement from professionals in clinic; that technology and information on local opportunities to be physically active may be useful additions to in-person support; that group and one-to-one support may be required; that support should include information on diabetes preparation, management and support and should have elements of education as well as being enjoyable; behaviour change techniques that participants felt could be useful to include in an intervention; and that targeting youth near the time of diagnosis was appropriate. It is now the challenge of future researchers to identify and test how these elements and characteristics of support can be effectively incorporated into interventions in care in further pilot and feasibility testing. In regards to paper 4, the findings helped identify the evidence base by highlighting the: variation in diabetes support existing across schools; need for better communication regarding pupils with Type 1 diabetes between schools and primary specialist physical education teachers; limited knowledge surrounding diabetes evident in primary and secondary school teachers; fact that it was perceived diabetes could be used as an excuse to sit out of physical education and fears of teachers and coaches could encourage this; need for training on diabetes management and guidance on the responsibilities of teachers; and need for improved communication between schools, teachers, parents, patients and diabetes professionals. Future interventions should target schools to ensure consistent training and support for teachers to help youth with Type 1 diabetes to participate in physical activity at school. The findings of study 3 in papers 3 and 4 also aid the 'modelling process and outcomes,' element of the development stage of the MRC framework (Figure 6.1), as participant's perceptions regarding the feasibility, acceptability and usability of support were explored. An example of how acceptability and usability of support was explored in discussions was by the use of picture prompts (including images of e.g. technology, group discussions, written material). The use of the prompt initiated talk of what participants felt they personally would like or dislike and why, and what they perceived youth with Type 1 diabetes in general would think. An example of an important finding from paper 3 in regards to the feasibility of delivering support in diabetes care was that both professionals and parents spoke of the limited time available in clinic for such support. Therefore interventions would need to be time efficient to be incorporated into current clinic. Similarly in paper 4, teachers spoke of the lack of time that they have for training, again highlighting the need for interventions, which are not time intensive.

Overall the findings of papers 1-4 allow for the comprehensive development of interventions. The epistemological viewpoint of the researcher was that quantitative and qualitative data had equal value: the findings of papers 1 and 2 are as important as that of papers 3 and 4. Studies 1 and 2 provide different but complimentary data to study 3, and combined the findings provide a fuller picture of physical activity and sedentary behaviour, and intervention needs, in youth with Type 1 diabetes. A consideration in health research when data on perceptions are gathered is that participants may tell the researcher in discussions or answer questions in a questionnaire in a way that the participant perceives the researcher (or others in the group if it is a discussion) wants. With the incorporation of quantitative and qualitative data into the overall mixed-methods design of this thesis, it was possible to link objective accelerometer data with the qualitative data from discussions (as patient interviews were gathered from a sub-group of participants that wore accelerometers). In relation to physical activity and sedentary behaviour, the quantitative and qualitative findings supported each other: objective findings showed that participants with a range of physical activity and sedentary behaviour levels were recruited and interview discussions also highlighted that the experiences and perceptions of youth achieving a range of physical activity and sedentary behaviour levels were captured (suggesting a bias sample in terms of physical activity and sedentary behaviour was not recruited). In regards to other participants in study 3 (parents, professionals and teachers), discussions were taken at face value. Including a quantitative questionnaire or survey with parents, professionals and teachers, may have been useful to support the qualitative findings. For example, a professional during a focus group discussion may have held back a view or gone along with the rest of the group if they felt they were challenging the views of other professionals of perceived higher authority than themselves. Participant burden is an important consideration in research however and completion of a questionnaire or survey would have increased the burden on these participants.

To summarise, the findings of study 1 allowed conclusions to be made on the quantifiable need of physical activity and sedentary behaviour interventions (e.g. for physical activity, daily MVPA time needs to be increased on average by about 20 minutes in order for youth to meet recommendations). The findings of study 2 also allowed quantifiable conclusions to be made (e.g. physical activity intervention for up to 6 months is likely to result in a mean decrease in HbA1c of between -1.45% and -0.25%). Study 3 provided a qualitative insight into how to achieve the results from study 1 and 2 – that is how to make an intervention acceptable and feasible, from the perspectives of potential intervention users and deliverers. Without the incorporation of studies 1 and 2, quantification of the gap in physical activity from the recommendations in youth and the likely health effects to be expected from intervention would not have been captured. Without the qualitative input from study 3, key intervention design issues, which could affect acceptability and usability, may have been missed.

5.0 The next stages of the MRC framework

The early developmental phase of the MRC framework for designing and evaluating complex interventions was discussed in the introduction section. Here the succeeding phases of intervention development are summarised. Phase I of the original MRC framework involves the identification of different components of the intervention and how components affect the desired behaviour (thus the findings of this thesis fall into the early stages of phase I). In phase II the findings from phase I are used to develop an intervention which is tested in an exploratory trial. The aims of the exploratory trial are to: 1) test the feasibility of delivering the intervention, which should include testing the fidelity of the intervention to identify ways of ensuring the intervention is delivered consistently; 2) test the acceptability of the intervention for those receiving and delivering the intervention (key stakeholders); 3) decide on an appropriate comparison group (control); 4) determine an appropriate sample size for the trial in the next phase (thus the exploratory trial needs to be randomised so effect size can be calculated); and 5) identify and pilot appropriate outcome measures for the trial in the next phase. Phase III normally consists of a definitive RCT where the intervention is tested against a control comparison with sufficient statistical power to find differences between groups. The final phase is to explore the long-term effectiveness of the intervention once incorporated into practice (Campbell, et al., 2000).

The updated MRC framework documents additional important points for the design of interventions. Modelling studies should be undertaken in the developmental stage to gather useful information on and to refine the intervention and evaluation design. During feasibility and piloting testing, the main areas of uncertainty should be explored as well as intervention acceptability, compliance and delivery. Recruitment and retention should also be examined. Outcome measures for RCTs need to be defined (primary and secondary) and any subgroup analysis decided upon. Long-term follow up should be considered to determine if short-term changes continue over time. Process evaluations can be conducted alongside efficacy assessments to determine overall intervention effectiveness. Fidelity checks may be challenging, particularly if an intervention is to be adapted to particular situations, in which case the degree of adaptation needs to be assessed. It is recommended that researchers provide a detailed description of the intervention, to a level that it could easily be replicated, and that outcome and process evaluations are reported in full (Craig, et al., 2008).

An example of the use of the MRC framework to guide the development of an intervention for youth with Type 1 diabetes is that by Eiser et al., which aimed to improve current diabetes care for adolescents (Eiser et al., 2013). Firstly authors scoped the evidence base to provide rationale for the development of an intervention. This phase involved: the conduction of two systematic reviews (exploring depression and eating patterns in adolescents); exploration of the findings from previous reviews (focusing on design characteristics and theories of behaviour change used in interventions for adolescents); and the undertaking of a study to examine anxiety, depression and diabetes distress in adolescents in their clinic (using an audit of medical records and survey). Secondly a theory was developed to improve care based on: findings from a qualitative study with staff, patients and parents exploring current care and perceived needs for future care; and previous theories relating to the target group and interventions. Thirdly the new care model was proposed which targeted: the clinic team by introducing a standard pro forma; individual patients with self-management training and goal setting within clinic; and families by parent group education aimed at increasing communication within families, decreasing conflict and increasing self-management. The service is currently being evaluated in terms of feasibility and acceptability, efficacy and cost-effectiveness. Once the early development phase is complete adjustments will be made to the service prior to roll out and formal evaluation across several clinics (Eiser, et al., 2013).

It is hoped that the findings from this thesis alongside previously published literature, can be used in a similar way to Eiser et al., (2013), to develop physical activity and sedentary behaviour interventions for youth with Type1 diabetes. The findings from paper 1 will aid future research and support by highlighting patients at most need of physical activity and sedentary behaviour support and by pinpointing specific days when levels are particularly low or high. Paper 2 will help the development of interventions in future by: highlighting the gaps in the literature so that researchers and professionals know important research areas that require further exploration and helping guide how interventions should be conducted and assessed (the recommendations box in paper 2 will be particularly useful for intervention development guidance). The paper also provides the evidence for the positive effects of physical activity on health through meta-analysis of HbA1c data and a narrative summary of changes in other health outcomes. This evidence will be useful in research for gaining grant funding and in practice by diabetes professionals to provide an evidence-based rationale for physical activity intervention. Paper 3 findings indicate important elements, which should be incorporated or targeted by interventions developed for research or practice purposes. The findings of paper 4 highlight the urgency of better guidance on handling diabetes in PE and physical activity in schools and future research should explore efficacy of interventions aiming to improve teacher support for youth with Type 1 diabetes.

6.0 Strengths and limitations

This thesis has several strengths. Published guidance for the development of health behaviour interventions was followed (Campbell, et al., 2000; Craig, et al., 2008), providing a strong overall thesis design. Study 1 fully reported on recruitment to allow determination of the representativeness of the sample and the target sample size was reached within the planned timescale. In addition study 1 used evidence-based protocols to collect, process and analyse physical activity and sedentary behaviour. Focusing on study 2, a systematic and thorough approach was taken to conduct a comprehensive review of the current literature. Study 3 included several major potential stakeholders of an intervention to determine multiple perspectives, applying a rigorous analysis.

The following limitations were evident in study 1: a relatively small sample size of only white Scottish youth (no other ethnicities were successfully recruited) and the disproportionate recruitment of patients of higher socioeconomic status; the lack of consensus in the literature on the best way to analyse accelerometer data, which may have significantly impacted on overall conclusions; the possibility that those who were recruited were already relatively active and most interested in physical activity compared to those that refused participation; the lack of a group without Type 1 diabetes to directly compare physical activity and sedentary behaviour to over the same time period due to resource and time constraints; the inability to explore the effects of seasonality on physical activity and sedentary behaviour, also due to time constraints; and the lack of a participant record of the type of day (school day or holiday), that the accelerometer was worn. Although the sample size was relatively small, significant differences were apparent, some with large effect sizes. Recruitment of minority ethnic groups, individuals from lower socioeconomic backgrounds, and those that are already likely to be physically active, are problems common in physical activity and sedentary behaviour research and are not specific issues related to this study). Differences in physical activity and sedentary behaviour across youth of different ethnicities and socioeconomic status have been reported previously in reviews (Eyre & Duncan, 2013; Van Der Horst, Paw, Twisk, & Van Mechelen., 2010), but have not specifically been explored in youth with Type 1 diabetes. The complete lack of recruitment of youth of ethnicity other than white Scottish and smaller proportion of patients from more deprived backgrounds in study 1, highlight challenges in recruitment. Recruitment strategies to target patients with Type 1 diabetes from a range of ethnic and socioeconomic backgrounds should be explored in future to identify if differences in physical activity and sedentary behaviour based on these characteristics exist in youth with Type 1 diabetes. Accelerometer analysis decisions, (as discussed in detail in chapter 2), such as choice of physical activity and sedentary behaviour cut-points, can significantly affect conclusions. For example, had lower sedentary behaviour and MVPA cut-points been employed than were used in study 1, this would have resulted in significantly less sedentary behaviour and more MVPA, possibly to a mean value exceeding the physical activity recommendations. Having a control group without Type 1 diabetes to directly compare physical activity and sedentary behaviour with was not viewed as essential in study 1, as data had already been collected including UK youth of similar age using similar data collection and analysis procedures, which could be compared to. However incorporation of a control group may have helped identify possible seasonal differences in physical activity and sedentary behaviour. For example if patients with Type 1 diabetes and a control group without diabetes were both found to be doing more or less MVPA than previously conducted studies, then potential reasons to explain differences could be differences in when data was collected (seasons) or in the physical environment (e.g. many physical activity opportunities available, built infrastructure suited to being physically active) and geographic location. Ideally, longitudinal studies should be conducted to explore changes in physical activity and sedentary behaviour across seasons. A recent review concluded that seasonal differences exist in physical activity participation of youth living in the UK, with lower participation during winter months (Rich, Griffiths, & Dezateux, 2012). The data collection period in this study was between February-August, with the majority of participants having a measurement period in April (n=10) or May (n=10). Based on the previous review, measured physical activity would have been less had data collection occurred during winter. Participants were not asked to record if the days they wore the accelerometer were school days, holidays or sick days. Rather school term dates were identified by the PhD researcher from local council websites post-data collection. Therefore it is possible that some days were wrongly captured as school days or holidays. In addition some patients may have had days off school due to illness or other reasons. However, this should have been captured in the physical activity and sedentary behaviour questionnaire. In future, studies should collect information on the types of day that accelerometers are worn to explore patterns in behaviour.

Study 2 had some limitations including: limited reporting by authors on potential confounders of HbA1c, resulting in caution over the interpretation of meta-analysis results; the use of various outcome measures making meta-analyses of outcomes other than HbA1c impossible; a lack of successful contact with some authors of included studies meaning that additional important information regarding studies could not be gained; and the presence of bias in many studies (particularly in terms of randomisation and group allocation concealment). These limitations may have impacted on overall conclusions. The impact of diet and insulin changes on HbA1c and other physiological outcomes in the majority of studies was not known. The efficacy of physical activity on health outcomes is therefore not conclusive. Almost all studies failed to qualify as having a low risk of bias for each of the bias components explored. It is not clear, due to a lack of success in contacting the majority of lead authors of included studies, if bias was indeed present in these studies and could have therefore impacted on findings or if measures were in place to avoid bias but were not reported in journal articles. An example of how bias could affect results in terms of group allocation concealment is, if sufficient measures are not in place to ensure that participants are not aware of grouping then a dilution effect could occur. That is, participants in a control group, if aware of participants in an intervention group, could seek advice/information on the intervention from intervention participants and therefore have indirect, part exposure to the intervention and change their behaviour.

Study 3 limitations included: the limited number of diabetes professionals who were available to the researcher from a single clinic; a lack of inclusion of peers and siblings perceptions; reliance on the researcher collecting notes on non-verbal cues during discussions; and the fact that perceptions were only gained from participants living within one area of Scotland. Due to the time constraints of the PhD it was not possible to include other sites across Scotland or to attempt to recruit peers or siblings. Schools and clinics in other areas of Scotland may have less or more support in place to encourage youth with Type 1 diabetes to do more physical activity and less sedentary behaviour, thus differing areas with different clinic and school set-ups may have resulted in different conclusions. The use of a national survey across Scotland or interviews and focus groups conducted in different regions of Scotland would be interesting in future research, to identify perceptions on feasible interventions and/or to identify already existing good practice. Although peers were identified as important influential figures, and discussed by other stakeholders in study 3, capturing the perceptions of peers themselves will also be important in future research to determine if peers themselves feel they can play an important role and how. Video recording equipment was not available at the time of study 3 and ethical approval was not recorded to video record discussions. Therefore important non-verbal cues may have been missed by the researchers. However notes on noticed non-verbal cues were taken by the researchers and these were noted in the full report of qualitative findings. Future studies should seek approval to capture non-verbal actions via video data collection.

7.0 Final conclusions

The three studies in this thesis successfully achieved what they set out to do: develop the building blocks of a physical activity and sedentary behaviour intervention for youth with Type 1 diabetes. Physical activity was confirmed as an important agent to improve health in youth with Type 1 diabetes and the requirement of interventions targeting physical activity and sedentary behaviour were highlighted. Perceptions of potential major stakeholders of interventions were identified to allow for the development of appropriate, feasible and useable support. Individualised feedback has been provided to patients that participated in study 1, by mailing summaries of step counts recorded by the accelerometer during the study wear period. In addition the student presented the findings of all three studies to the diabetes healthcare team that worked in collaboration with the student. Following submission of this thesis the student will develop a poster summarising the overall findings of the study to be displayed in the paediatric clinic and will also mail a summary of findings to teachers that participated in study 3. In collaboration with the clinic involved in study 1 and 3 of this thesis, it is hoped that a grant proposal will be submitted in the near future to continue this area of research. MRC guidance will be followed to use the findings from this thesis to build a behaviour change intervention for this ever-important target group.

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Williams, B. K., Guelfi, K. J., Jones, T. W., & Davis, E. A. (2011). Lower cardiorespiratory fitness in children with Type 1 diabetes. *Diabetic Medicine, 28*(8), 1005-1007.

Wolfsdorf, J., Craig, M. E., Daneman, D., Dunger, D., Edge, J., Lee, W., et al. (2009). Diabetic ketoacidosis in children and adolescents with diabetes. *Pediatric Diabetes, 10*(12), 118-133.

World Health Organization. (2009). *Global health risks: Mortality and burden of disease attributable to selected major risks*. Retrieved from http://www.who.int/healthinfo/global_burden_disease/GlobalHealthRisks_report_full.pdf.

LIST OF APPENDICES

Appendix A

NHS and University ethics approval for studies 1 and 3 (papers 1, 3-4)

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 4
Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT
www.nhsggc.org.uk

Miss Freya C MacMillan
PhD Student
University of Strathclyde
Sports and Arts Building
Jordanhill Campus
76 Southbrae Drive
Glasgow
G13 1PP

Date 23 December 2011
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail evelyn.jackson@ggc.scot.nhs.uk

Dear Miss MacMillan

Study title:	**Physical activity behaviour of Scottish paediatric patients with Type 1 diabetes (T1D) and knowledge, attitudes and experiences of physical activity in these patients, their carers and main healthcare professionals**
REC reference:	**11/WS/0021**

Thank you for your letter of 7 December 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered, in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

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

Conditions of the favourable opinion

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

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Delivering better health

www.nhsggc.org.uk

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	-	14 July 2011
Evidence of insurance or indemnity	-	10 August 2011
Interview Schedules/Topic Guides	1	14 July 2011
Investigator CV	-	06 July 2011
Letter from Sponsor	-	12 July 2011
Letter of invitation to participant	1	14 July 2011
Other: Alison Kirk's CV	-	05 July 2011
Other: Nanette Mutrie's CV	-	12 July 2011
Other: Activity monitor instructions	1	14 July 2011
Other: Letter of support from Consultant Paediatrician	-	16 June 2011
Other: E-mail from Clare Calder - approval from Caldicott Guardian	-	07 December 2011
Other: Letter from Dr K Robertson (Academic Supervisor) re. gatekeeper of information	-	29 September 2011
Other: E-mail from Dr Michael Barber, R&D, re. honorary contract	-	02 December 2011
Participant Consent Form: 12-14 years - physical activity monitoring study	2	07 December 2011
Participant Consent Form: 12-14 years - Physical activity monitoring and interview study	2	07 December 2011
Participant Consent Form: 7-9 years - Physical activity monitoring study	2	07 December 2011
Participant Consent Form: 7-9 years - Physical activity monitoring and interview study	2	07 December 2011
Participant Consent Form: Carer Consent Form - Physical activity monitoring and interview study	2	07 December 2011
Participant Consent Form: Carer Consent Form - Physical activity monitoring study	2	07 December 2011
Participant Information Sheet: Children Aged 7-9 years	1	14 July 2011
Participant Information Sheet: Carer (full study)	1	14 July 2011
Participant Information Sheet: Carer	1	14 July 2011
Participant Information Sheet: Diabetes Health Care Staff	1	14 July 2011

Participant Information Sheet: Diabetes healthcare staff	2	07 December 2011
Participant Information Sheet: 7-9 years - Physical activity measurement and interview study	2	07 December 2011
Participant Information Sheet: 12-14 years - Physical activity measurement study	2	07 December 2011
Participant Information Sheet: 12-14 years - Physical activity measurement and interview study	2	07 December 2011
Participant Information Sheet: Carer - Physical activity measurement study	2	07 December 2011
Participant Information Sheet: Carer - Physical activity measurement and interview study	2	07 December 2011
Participant Information Sheet: 7-9 years - Physical activity measurement study	2	07 December 2011
Protocol	1	14 July 2011
Protocol	2	07 December 2011
Questionnaire: PedsQL	4.0	
Questionnaire: A bit about you - patient	1	14 July 2011
Questionnaire: A bit about you - carer	1	14 July 2011
Questionnaire: A bit about you - diabetes staff	1	14 July 2011
Questionnaire: Physical Activity for Paediatric Patients	1	14 July 2011
Questionnaire: A bit about you	2	07 December 2011
REC application	-	13 July 2011
REC application	-	
Response to Request for Further Information	-	07 December 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

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

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

11/WS/0021	Please quote this number on all correspondence

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

Yours sincerely

Evelyn Jackson

for **Dr Brian Neilly**
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: Mrs Louise McKean, University of Strathclyde
Dr Michael Barber, R&D Office, Tennent Building, Western Infirmary

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor, 38 Church Street
Glasgow, G11 6NT

NHS
Greater Glasgow
and Clyde

Coordinator/Administrator: JMcG/LR
Direct Line: 0141 211 8548
E-mail: Joanne.McGarry@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

24th Jan 2012

Dr Kenneth Robertson
Lead Consultant Paediatrician
Diabetic Service, 7th Floor
Royal Hospital for Sick Children
Dalnair Street
Glasgow
G3 8SJ

NHS GG&C Board Approval

Dear Dr Robertson

R&D Reference: GN11KH266
REC Ref: 11/WS/0021
Study Title: Physical activity behaviour of Scottish paediatric patients with Type 1 diabetes (T1D) and knowledge, attitudes and experiences of physical activity in these patients, their carers and main healthcare professionals
Chief Investigator: Miss Freya MacMillan
GG&C HB site: R H S C
Sponsor: University of Strathclyde
Protocol no: V2 dated 07/12/11

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
   a. During the life span of the study GGHB requires the following information related solely to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

Please Note: Management approval applies to Dr Kenneth Robertson and Miss Freya Macmillan only. Research passports must be in place and Honorary Contracts issued before any other research members are in contact with participants.

2. **For all studies** the following information is required during their lifespan.

a. Recruitment Numbers on a quarterly basis
b. Any change of staff named on the original SSI form
c. Any amendments – Substantial or Non Substantial
d. Notification of Trial/study end including final recruitment figures
e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely

Joanne McGarry
Research Co-ordinator

Cc: Miss Freya MacMillan, Chief Investigator, Uni of Strathclyde.

Subject: FW: Ethics Application- MacMillan & Kirk ethics (school of psychological sciences and health) type 1
Date: Friday, 1 April 2011 11:16:05 British Summer Time
From: HaSS Research and Knowledge Exchange
To: Susan Rasmussen, Alison Kirk, Freya MacMillan

Good Morning Ladies

Vice Dean Joanna McPake has given full sponsorship approval for the project **"Exploring the knowledge, beliefs and experiences of trainee and qualified teachers involved in Physical Education (Primary & Secondary) towards physical activity in children and adolescents with Type 1 diabetes"**.

Kind regards

Jill Coleman
Research and Knowledge Exchange Team (RaKET)
Faculty of Humanities and Social Sciences
LT418, Livingstone Tower
University of Strathclyde
26 Richmond Street
Glasgow G1 1XH

Tel: 0141 548 3910
Fax: 0141 548 4757

From: Joanna McPake
Sent: 01 April 2011 10:32
To: HaSS Research and Knowledge Exchange
Cc: Susan Rasmussen
Subject: Re: Ethics Application- MacMillan & Kirk ethics (school of psychological sciences and health) type 1

Happy to sign this off.

Joanna

From: H&SS Ethics <hass-rke@strath.ac.uk>
Date: Thu, 24 Mar 2011 13:18:53 +0000
To: qrb09106 <joanna.mcpake@strath.ac.uk>
Cc: Susan Rasmussen <s.a.rasmussen@strath.ac.uk>
Subject: Ethics Application- MacMillan & Kirk ethics (school of psychological sciences and health) type 1

Good Afternoon Joanna

Please find attached the Type 1 Ethics application for **Alison Kirk – Freya MacMillan - Exploring the knowledge, beliefs and experiences of trainee and qualified teachers involved in Physical Education (Primary & Secondary) towards physical activity in children and adolescents with Type 1 diabetes** – for your consideration.

Kind regards

Jill Coleman
Research and Knowledge Exchange Team (RaKET)
Faculty of Humanities and Social Sciences
LT418, Livingstone Tower

University of Strathclyde
26 Richmond Street
Glasgow G1 1XH

Tel: 0141 548 3910
Fax: 0141 548 4757

From: Susan Rasmussen
Sent: 24 March 2011 11:36
To: Freya MacMillan; Alison Kirk
Cc: Diane Dixon; HaSS Research and Knowledge Exchange
Subject: MacMillan & Kirk ethics (school of psychological sciences and health) type 1

Dear Freya,

The ethics committee has now approved your study entitled "Exploring the knowledge, beliefs and experiences of trainee and qualified teachers involved in Physical Education (Primary & Secondary) towards physical activity in children and adolescents with Type 1 diabetes", and it has been forwarded to the faculty for sponsorship approval. Please bear in mind that you may not begin your study until you have received both ethical and sponsorship approval. You will receive a final email from the faculty when the vice dean has signed off sponsorship.

Good luck with your study

Susan

Dr Susan Rasmussen
CPsychol, Health Psychologist
Lecturer
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow G1 1QE

Email: s.a.rasmussen@strath.ac.uk
Phone: 0141 548 2575

http://www.strath.ac.uk/humanities/courses/psychology/staff/rasmussensusandr/

Appendix B

Parent/carer and diabetes professional information sheets

This appendix includes the participant information sheets for parents/carers and diabetes professionals. Patient information sheets contained the same information but were age appropriate, with an adolescent and younger child version. The parent/carer information sheet provided here was for those participating in the both studies 1 and 3 (full version). Shorter versions of the information sheets were used for parents/carers and patients only participating in study 1.

School of Psychological Sciences and Health
University of Strathclyde
Jordanhill Campus
76 Southbrae Drive
Glasgow
G13 1PP

Participant Information Sheet – Carer - physical activity measurement and interview study

<u>Study title: Physical activity in paediatric patients with type 1 diabetes</u>

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. If you decide not to take part this will not affect your child's medical care.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

Who is conducting the research?

The research is a joint project between the paediatric diabetes service at Yorkhill and the University of Strathclyde and is being conducted by researchers from the School of Psychological Sciences and Health, University of Strathclyde.

What is the purpose of the study?

About 35% of Scottish children are not regularly physically active. Children and young people with type 1 diabetes can be less physically active than similar aged children/young people that do not have diabetes. The Scottish physical activity strategy "let's make Scotland more active" has a target of

80% of children aged 16 years and under being physically active at the recommended level by 2022. As children and young people with type 1 diabetes can be less active than healthy children they are a key target if Scotland is to make the goal for children. Therefore it is important to find ways of encouraging and supporting children and young people with type 1 diabetes to lead a physically active lifestyle. The aim of this research is to explore what children and young people with type 1 diabetes and their main carers think about physical activity. The research is being carried out as part fulfilment of a PhD degree at the University of Strathclyde, Glasgow. The potential benefits of taking part in this research are that it may help in the development of a resource to aid physical activity promotion in children and young people with type 1 diabetes.

Why have I been invited?

You are being asked to take part in this study because your child is a registered patient at the paediatric diabetes clinic in the Royal Hospital for Sick Children – Yorkhill. We hope to recruit up to 40 patients and their carers to take part in this study.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving reason. This would not affect the standard of care you or your child receive or your future treatment.

What does taking part involve?

There are two main elements to this study: 1) an interview component; and 2) a physical activity measurement, questionnaire and survey component. Participation in the two elements of this study (1) interview component and 2) physical activity measurement, questionnaire and survey element) is completely voluntary and you are free to decide if you/your child want to take part in one or both. **One of the researchers for this project will go through the information sheet with you and answer any questions you have before you consent to participate.** This should take no more than 15 minutes.

Interview component

For the interview component we would like to interview you and your child separately to talk about physical activity.

- Interviews will last no more than 30 minutes each and will be conducted at the same time in parallel rooms with the PhD student and another researcher.
- We would like to voice record the interviews to help with the analysis process. This aspect of the study may derive direct quotations that are

of interest. If any of these quotations are published, your name will not be associated with them.

Physical activity measurement, questionnaire and survey component

In addition we would like to monitor your child's physical activity patterns for a week by asking them to wear a small device (similar in size to a small match box) called an actigraph accelerometer.

- The activity monitor is attached to a belt and is worn on the waist.
- The activity monitor will be fitted by the student at the clinic at least two weeks before the interviews are conducted.
- During the 7 day period where the monitor is worn we would ask that your child (with the help of you if necessary) keeps a diary of when they wore the activity monitor.
- ***It is really important that during the week when the activity monitor is worn that your child does not change their normal physical activity behaviour and that they carry on as usual. The point of wearing the monitor is not to try and increase how much activity your child is doing but to measure how much activity they currently do so that we can get a picture of how active children/adolescents with type 1 diabetes in Scotland are. This will help us to decide what type of support is required by patients.***
- We will also ask you and your child to complete three short questionnaires (one to tell us a bit about yourself, another looking at your child's physical activity and one looking at your child's quality of life).
- Thus in total the study will involve 3 visits (the first for your child to be fitted with the activity monitor and to complete a questionnaire, the second to collect the monitor and complete the other questionnaires and a third to conduct the interviews). Visits can take place at the diabetes clinic, in your own home or another relevant location.

- We would like for you and your child to be involved in developing the support package to aid physical activity participation in young people with diabetes. This would involve an online survey (that can be completed at home) where the package will be displayed and detailed and will ask for you and your child's feedback on it. If you feel you want to tell us more about the package you will have the option to come and speak to us again in another interview or a group discussion with other patients and carers.

The flow chart on the next page shows the typical flow through the study indicating: the visit number; expected duration of each visit; and what happens at each visit.

Visit 1 (30-40 minutes):

- Explanation of study and consent
- Child fitted with activity monitor
- Given activity monitor wear diary
- 'About you' questionnaire

Visit 2 (7 days later; ~35 minutes):

- Collect activity monitor & wear diary
- Complete study questionnaires

Visit 3 (at least 14 days after visit 2; 30-40 minutes):

- Interviews

Support package feedback:-

- Online survey

- Group discussion/interview

Expenses and payments

You will not receive any financial reward for taking part in the study. However travel expenses will be offered to you. In addition we would like to give child participants a £5 (Amazon) gift voucher as a thank you for their participation.

What are the possible disadvantages and risks of taking part?

It is possible that you or your child could experience some discomfort or become distressed if you are to recall a bad experience with physical activity. The findings from the interview part of this study will be essential in developing a support package to help children/adolescents with type 1 diabetes to lead physically active lifestyles. Therefore describing negative experiences of physical activity will be as important as discussing positive experiences in order to determine what does and does not work for the child/young person with type 1 diabetes. We wish to highlight that you/your child do not have to speak about anything that you do not feel comfortable with and at any point you can stop the discussion, take a break or change the topic.

We will ask that your child wears the physical activity monitor at all times over the 7 day period apart from when sleeping and washing. The monitor is small, light weight and can be worn around the waist without necessarily needing to be noticed (as it is worn under clothing). We will also provide a coloured pouch and/or belt if the child wishes to have one to keep the monitor in. The PhD student will provide ideas on how to remember to wear the monitor to you and your child. Your child may find it difficult to complete the monitor wear diary and thus might need assistance from you or another adult to record wear times. We are not asking your child to do any extra physical activity than normal. The activity monitor will tell us about the amount of physical activity your child does. It will not tell us any information on where your child is or what they are doing.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to hopefully improve the treatment of children and young people with type 1 diabetes by development of a support package to help aid physical activity participation. Your child may also appreciate the feedback we provide to them on physical activity. Participation in the interviews will provide you and your child with the chance to speak about your concerns and experiences of physical activity.

What happens when the research study stops?

Once a support package has been developed by the PhD student we wish to test the package in another study. We will ask if you and your child would be interested in being contacted in the future to take part in such a study.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What if relevant new information becomes available?

If new information becomes available about physical activity in people with diabetes, you will be informed and given the option as to whether to continue in the study. Physical activity is known to be good for health and thus it is unlikely that we would stop the study early.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any point. If you withdraw, we will destroy all your identifiable samples, but we will need to use the data collected up to your withdrawal.

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Freya MacMillan, 0141 950 3441). If you remain unhappy and wish to complain formally, you can do this through the University of Strathclyde Complaints Procedure. Details can be obtained from the University. Please have the study title (which is written at the top of the first page of this information booklet) to hand.

Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS processes. To do so you can submit a written complaint to the Patient Liaison Officer, Comments/Complaints Office, Royal Hospital for Sick Children, Dalnair Street, Yorkhill, Glasgow, G3 8SJ (Phone: 0141 201 9278). Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Greater Glasgow and Clyde but you may have to pay your legal costs.

Harm

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Strathclyde who are acting as the research sponsor. The University of Strathclyde has insurance policies that provide cover for any professional negligence of its staff and/or students. Details about this are available from the research team.

Will my taking part in this study be kept confidential?

Yes. Hard copies of your data will be stored securely in a locked cabinet at the University of Strathclyde by Freya MacMillan (the PhD researcher). Electronic copies of the data will be kept on a password protected University network drive and anonymous data will also be stored on a password protected laptop. We will not use your name or address when analysing the data but will allocate each person who takes part in the study a unique identification code which will then be used throughout the study. The PhD researcher will allocate each person an identification code when they join the study. The PhD researcher and their supervisors will be the only people with access to your name, contact details and ID number for the study once you provide consent to be contacted. All information which is collected about you during the study will be kept strictly confidential. Your personal data will be stored securely for 5 years to allow sufficient time for analysis/completion of the PhD and then destroyed appropriately. The study data will also be held for five years. You will be asked if you would like your name and address to be added to a database so we can contact you regarding future studies taking place within the University of Strathclyde. This is entirely voluntary and does not affect your participation in the current study. You may have your details removed from the list at any time. The database will be stored securely and will be strictly confidential.

Involvement of the diabetes health care team

If you agree your child's diabetes health care team will be informed that you are participating in the study by the PhD researcher. The researchers that are involved in this study will not be able to provide you with any health care advice. Please speak to your diabetes health care team if you have any specific questions.

What will happen to the results of the research study?

A summary of the results of the study will be mailed/emailed out to you on completion of the study if you wish to receive this. We intend to publish the results of this study in academic journals and to present findings at relevant conferences. You will not be identified in any presentation or publication.

Who is organising and funding the research?

This research is sponsored by the University of Strathclyde. Funding for the PhD studentship is being provided by the Scottish Funding Council. The diabetes health care team are not being paid for your inclusion in this research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the West of Scotland Research Ethics Committee 4 and University of Strathclyde Research Ethics Committee.

You will be given a copy of this information sheet and a signed consent form to keep.

What next?

If you and your child have decided you would like to participate then please contact the PhD researcher (Freya MacMillan) either by telephone (0141 950 3441), email (freya.macmillan@strath.ac.uk) or using the reply slip at the end of this booklet and stamp addressed envelope provided to you.

Further information and contact details

1) General information about research

Dr Susan Rasmussen

School of Psychological Sciences and Health

University of Strathclyde

Graham Hills Building

40 George Street

Glasgow

G1 1QE

Telephone: 0141 548 2575

Email: s.a.rasmussen@strath.ac.uk

2) Specific information about this research project and who you should approach if you are unhappy with the study (please have the study title to hand)

Dr Alison Kirk

School of Psychological Sciences and Health

Sport and Arts Building

Jordanhill Campus, University of Strathclyde

76 Southbrae Drive

Glasgow ,G13 1PP

Telephone: 0141 950 3527

3) Advice as to whether you should participate

Dr Kenneth Robertson, Consultant Paediatrician

Royal Hospital for Sick Children, Yorkhill, Dalnair Street,

Glasgow, G3 8SJ

Telephone: 0141 201 0331

Physical activity in paediatric patients with Type 1 diabetes

Name:__________________________________

I provide my consent for the researcher to contact me regarding the above study.

Signed: ___________________________ Date: __________________

I would prefer for the researcher to contact me by (please tick and complete details):

Telephone ☐ Number: ____________________

Email ☐ Email : ____________________

Mail ☐ Address:_________________________________

____

Please return in the enclosed stamp addressed envelope to:

Freya MacMillan
Sports and Arts Building
University of Strathclyde, Jordanhill Campus
76 Southbrae Drive
Glasgow
G13 1PP

Physical activity in paediatric patients with Type 1 diabetes

Name:____________________________

Address:____

____

____

I decided not to take part in this study because:

____

____

____

____

____

____

____

Please return in the enclosed stamp addressed envelope to:

Freya MacMillan

Sports and Arts Building

University of Strathclyde, Jordanhill Campus

76 Southbrae Drive

Glasgow

G13 1PP

School of Psychological Sciences and Health
University of Strathclyde
Jordanhill Campus
76 Southbrae Drive
Glasgow
G13 1PP

Participant Information Sheet: Diabetes health care staff

Study title: Physical activity in paediatric patients with Type 1 diabetes

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. If you decide not to take part this will not affect your current employment.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

Current research indicates that around 35% of Scottish children are not regularly physically active. Children and young people with type 1 diabetes can be less physically active than similar aged children/young people that do not have diabetes. The Scottish physical activity strategy "let's make Scotland more active" has a target of 80% of children aged 16 years and under being physically active at the recommended level by 2022. As children and young people with type 1 diabetes can be less active than healthy children they are a key target if Scotland is to make the goal for children. Therefore it is important to find ways of encouraging and supporting children and young people with type 1 diabetes to lead physically active lifestyles. The aim of this research is to explore what children and young people with type 1 diabetes and their main carers and the diabetes health care team think about physical activity. The research is being carried out as part fulfilment of a PhD degree at the University of Strathclyde, Glasgow. The potential benefits of taking part in this research are that it may lead to the development of a resource to aid physical activity promotion in children and young people with type 1 diabetes.

Why have I been invited?

You are being asked to take part in this study because you are a member of staff in the Royal Hospital for Sick Children at Yorkhill. We hope to recruit up to 18 staff members to take part in this study.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect your current employment in any way.

What will happen to me if I take part?

We would like for you to take part in a group discussion with another 4-5 members of the paediatric diabetes team and complete a short questionnaire. The discussion will last between 35-45 minutes and will be conducted in a room at the clinic. If it is more convenient and preferred then you can participate in a one to one interview lasting no more than 30 minutes instead. A PhD student will be conducting all focus groups and interviews. We would like to voice record the interviews to help with the analysis process. This aspect of the study may derive direct quotations that are of interest. If any of these quotations are published, your name will not be associated with them.

Expenses and payments

You will not receive any financial reward for taking part in the study. You will be offered travel expenses as well as a pedometer as a thank you for your participation.

What will I have to do?

You will be asked to take part in a discussion relating to physical activity and to complete a questionnaire. The findings of this study will hopefully be used to develop a support package to help children and young people with type 1 diabetes to lead physically active lifestyles. You will be asked if you would like to help in the making of this package by providing feedback through an online survey and optional interview/discussion group once it has been developed by the PhD student.

What are the possible disadvantages and risks of taking part?

We wish to highlight that you do not have to speak about anything that you do not feel comfortable with and at any point you can stop the discussion, take a break or change the topic. The aim of the discussions are not to judge the knowledge or practicing skills of the diabetes team but to establish your needs in terms of promoting physical activity participation to your patients in the future.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to hopefully improve the treatment of children and young people with type 1 diabetes by development of a support package to aid physical activity participation. Participation in the discussions will provide you with the chance to speak about your concerns and experiences of physical activity as well as provide your opinion on what would be the best way to aid patients to lead a physically active lifestyle.

What happens when the research study stops?

Once a support package has been developed by the PhD student we wish to test the package in another study. We will ask if you would be interested in being contacted in the future to be involved in this study.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What if relevant new information becomes available?

If new information becomes available regarding physical activity in people with diabetes, you will be informed and given the option as to whether to continue in the study. Physical activity is known to be good for health and thus it is unlikely that we would stop the study early.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any point. If you withdraw, we will destroy all your identifiable samples, but we will need to use the data collected up to your withdrawal.

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Freya MacMillan, 0141 950 3441). If you remain unhappy and wish to complain formally, you can do this through the University of Strathclyde Complaints Procedure. Details can be obtained from the University.

Harm

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Strathclyde who are acting as the research sponsor. The University of Strathclyde has insurance policies that provide cover for any professional negligence of its staff and/or students. Details about this are available from the research team.

Will my taking part in this study be kept confidential?

Yes. Hard copies of your data will be stored securely in a locked cabinet at the University of Strathclyde by Freya MacMillan (the PhD researcher). Electronic copies of the data will be kept on a password protected University network drive and anonymous data on a password protected laptop. We will not use your name or address when analysing the data but will allocate each person who takes part in the study a unique identification code which will then be used throughout the study. The PhD researcher will allocate each person an identification code when they join the study. The PhD researcher and their supervisors will be the only people with access to your name, contact details and ID number for the study once you provide consent to be contacted. All information which is collected about you during the study will be kept strictly confidential. Your personal data will be stored securely for 5 years to allow sufficient time for analysis/completion of the PhD and will then be destroyed appropriately. The study data will also be held for five years. You will be asked if you would like your name and address to be added to a database so we can contact you regarding future studies taking place within the University of Strathclyde. This is entirely voluntary and does not affect your participation in the current study. You may have your details removed from the list at any time. The database will be stored securely and will be strictly confidential.

What will happen to the results of the research study?

A summary of the results of the study will be mailed out to you (if you wish to receive this) on completion of the study or presented in person (by the PhD student) at a clinic meeting. We intend to publish the results of this study in academic journals and to present findings at relevant conferences. You will not be identified in any presentation or publication.

Who is organising and funding the research?

This research is sponsored by the University of Strathclyde. Funding for the PhD studentship is being provided by the Scottish Funding Council.

Who has reviewed the study?

All research in the NHS is looked at by a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the West of Scotland Research Ethics Committee 4 and the University of Strathclyde Research Ethics Committee.

You will be given a copy of this information sheet and a signed consent form to keep.

Further information and contact details

*1**) General information about research***

Dr Susan Rasmussen
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow
G1 1QE
Telephone: 0141 548 2575

Email: s.a.rasmussen@strath.ac.uk

2) Specific information about this research project and who you should approach if you are unhappy with the study (please have the study title to hand)

Dr Alison Kirk
School of Psychological Sciences and Health
Sport and Arts Building
Jordanhill Campus, University of Strathclyde
76 Southbrae Drive
Glasgow
G13 1PP
Telephone: 0141 950 3527

3) Advice as to whether you should participate

Dr Kenneth Robertson
Consultant Paediatrician
Royal Hospital for Sick Children,
Yorkhill,
Dalnair Street,
Glasgow, G3 8SJ
Telephone: 0141 201 0331

Physical activity in paediatric patients with Type 1 diabetes

Name:__________________________________

I provide my consent for the researcher to contact me regarding the above study.

Signed: _____\`______________________ Date: __________________

I would prefer for the researcher to contact me by (please tick and complete details):

Telephone ☐ Number: _____________________

Email ☐ Email : _____________________

Mail ☐ Address:__________________________________

Physical activity in paediatric patients with Type 1 diabetes

Name:___________________________

Address:____

____

____

I decided not to take part in this study because:

____

____

____

____

____

____

____

Please return in the enclosed stamp addressed envelope to:

Freya MacMillan

Sports and Arts Building

University of Strathclyde, Jordanhill Campus

76 Southbrae Drive

Glasgow

G13 1PP

Appendix C

Accelerometer data: analysis to support data inclusion and handling decisions

Introduction

The aim of this analysis was to explore the impact of using different accelerometer data processing and handling decisions on calculated sedentary, light, and MVPA time, and percentage of participants meeting the physical activity recommendations. The data processing and handling decisions examined were choice of: sedentary, light and MVPA cut-points; epoch; the minimum number of wear hours per day; and the effect of using different durations of strings of 0's to define non-wear.

Methods – Statistical analysis

Actigraph data for all participants (*N*=40) was downloaded into Actlife software (version 6.4.3). Data between 6am-11pm for each participant was analysed without adjustment for wear duration. In all analyses, apart from the analysis of different durations of strings of 0's, non-accelerometer wear as recorded in wear diaries was not removed (Actilife software had been updated by the time the strings of 0's analysis was conducted so that wear diaries could be uploaded and saved easily). Combinations of varying epochs (15 seconds vs 60 seconds), minimum daily wear time hours (6 hours vs 8 hours), and sedentary and MVPA cut-points (Evenson cut-points (Evenson, et al., 2008) vs Puyau cut-points (Puyau, et al., 2002)), were used to determine total weekly sedentary, light and MVPA time when all other parameters were kept constant in the software. The Evenson cut-point for sedentary behaviour is <100cpm and for MVPA is >2296cpm. Puyau cut-points are <800cpm and >3200 for sedentary behaviour and MVPA, respectively. The percentage of total included days, which had an MVPA total of ≥60 minutes were determined. Analysis exploring effects of using different durations of strings of continuous 0's to define non-wear during waking hours (10 minutes vs 20 minutes vs 60 minutes vs 480 minutes), on sedentary behaviour was also undertaken.

The Kolmorgorov-Smirnov test was used to explore normality. Data were normally distributed ($p>0.05$) and analysed using repeated measures ANOVA followed by

Bonferroni’s post hoc-test. When the assumption of sphericity was violated ($p<0.05$), a Greenhouse-Geisser correction was used. For the analysis comparing the effect of using different 0 string durations, paired t-tests were applied (the number of participants with sufficient data for inclusion differed depending on the selected duration of strings of 0’s). Significance was set at $p<0.05$.

Results

Mean (SD), average daily time spent in sedentary behaviour, light and MVPA, the number of participants achieving ≥60 minutes MVPA based on average daily MVPA, and the number of days when participants achieved ≥60 minutes MVPA whilst using different data handling and processing decisions are provided in Table 1 on the following page.

Sedentary time

The minimum number of wear hours, epoch and cut points used had a significant overall effect on sedentary time $F(1.88, 73.26)=395.97$, $p<0.001$. Sedentary time was no different when using Puyau cut-points with 15 sec epochs and 6 hours minimum wear compared to Puyau cut-points with 60 sec epochs and 8 hours wear ($p>0.5$) or compared to Puyau cut-points with 60 sec epochs and 6 hours wear ($p>0.05$). Sedentary time was also no different when using Puyau cut-points with 15 sec epochs and 8 hours wear compared to Puyau cut-points with 60 sec epochs and 8 hours wear ($p>0.05$). All other comparisons resulted in significant differences in sedentary time ($p<0.05$).

Light physical activity

The minimum number of wear hours, epoch and cut points used had a significant overall effect on light physical activity $F(1.31, 50.89)=512.88$, $p<0.001$. Significant differences between all comparisons were found ($p<0.05$).

MVPA

The minimum number of wear hours, epoch and cut points used had a significant overall effect on MVPA $F(1.51, 58.86) = 242.57$, $p < 0.001$. There were significant differences between all comparisons ($p<0.05$).

Table 1: Time in sedentary behaviour, light and MVPA, and participants and days meeting the daily MVPA recommendations, using different combinations of data handling and processing criteria (*N*=40 for all comparisons). Data are means (SD)

Cut-point, epoch, wear time	**Sedentary time/day (hours)**	**Light PA* time/day (mins)**	**MVPA time/day (mins)**	**Days of MVPA time ≥60mins / total days data**
Puyau, 15sec, 8hrs	10.21 (1.19)	111.6 (32.2)	32.4 (15.4)	35/286 (12.2%)
Puyau 15sec, 6hrs	9.98 (1.13)	108.9 (32.3)	31.8 (15.4)	35/301 (11.6%)
Puyau, 60sec, 8hrs	10.18 (1.31)	128.9 (43.6)	23.6 (14.4)	22/289 (7.6%)
Puyau, 60sec, 6hrs	9.93 (1.31)	126.1 (43.8)	23.3 (14.3)	22/306 (7.2%)
Evenson, 15sec, 8hrs	7.78 (1.44)	233.2 (56.6)	56.9 (21.1)	115/286 (40.2%)
Evenson, 15sec, 6hrs	7.61 (1.36)	227.2 (56.8)	55.7 (21.3)	115/301 (38.2%)
Evenson, 60sec, 8hrs	6.52 (1.64)	326.7 (74.8)	45.7 (21.6)	86/289 (29.8%)
Evenson, 60sec, 6hrs	6.37 (1.59)	317.7 (75.8)	45.1 (21.6)	88/306 (28.6%)

* PA; physical activity

Achieving physical activity guidelines

The physical activity recommendations for youth are to achieve a minimum of 60 minutes of MVPA per day. When using a 15sec epoch, 6 hours or 8 hours minimum wear and the Evenson cut point to analyse data only one participant met the physical activity guideline (achieved 60 mins MVPA or more on 100% days the monitor was worn). Using all other combinations of cut points, epochs and minimum wear times resulted in no participants meeting the MVPA guideline on each day of wear.

Table 2 Average daily MVPA and steps using different combinations of cut-points, epoch and minimum wear hours

Cut-point, epoch, wear time	Average daily MVPA (mins)	Average daily steps
Puyau, 15sec, 8hrs	32.4	9843
Puyau 15sec, 6hrs	31.8	10031
Puyau, 60sec, 8hrs	23.6	9882
Puyau, 60sec, 6hrs	23.3	10127
Evenson, 15sec, 8hrs	56.9	9843
Evenson, 15sec, 6hrs	55.7	10031
Evenson, 60sec, 8hrs	45.7	9882
Evenson, 60sec, 6hrs	45.1	10127

*12,000 steps/day = ~60 mins MVPA in youth

Daily MVPA and steps

Based on published guidelines, 60 minutes of MVPA equates approximately to 12,000 steps (Colley, Janssen & Tremblay, 2012).

Number of days of data

Table 3 The effect of changing epoch or minimum wear time on total days of data and participants included in analysis

Epoch, wear time*	Days data	Participants
60sec, 6hrs	306	40
15sec, 6hrs	301	40
60sec, 8hrs	289	40
15sec, 8hrs	286	40
60 sec, 10hrs	262	40
15 sec, 10hrs	259	40
60sec, 12hrs	201	36
15sec, 12hrs	191	35

*Evenson cut-point were used for comparisons in Table 3

A minimum wear hour criteria of eight, nine or ten hours (Evenson cut points & 15 or 60 second epoch) still results in all participants being included in analysis (*N*=40) as they would all have at least three days of data. When 12 hours of minimum wear and a 15 second epoch are applied, five participants would be excluded (four children (3F;1M) and one adolescent (male)) from analysis. Of the 35 participants included in analysis, five of them would not have a weekend day. With 12 hours of minimum wear and a 60 second epoch, four participants would be excluded (three children (2F:1M) and one adolescent (male)) from analysis. Of the 36 participants that would be included in analysis six of them would not have a weekend day.

Differences between days in MVPA

Using a 15 sec epoch, 12 hour minimum wear criterion, and the Evenson MVPA cut-point, participants with seven days or more data (n=19/35) were included in an analysis to explore differences in MVPA time between days of wear (e.g. is day one greater than day two or day three etc). No significant differences in MVPA time across days of wear were found when using a repeated-measure ANOVA ($p>0.05$).

Effect of using different strings of 0's to define non-wear

Table 4 provides a summary of the effect of using different criteria to define non-wear during waking hours. For this analysis sedentary behaviour was identified as being <100cpm and MVPA was >3200 cpm.

Table 4 Effect of using different lengths of continuous strings of 0's to define non-wear during waking hours on sedentary behaviour

Duration of continuous strings of 0's	Number of participants included in analysis (n=)	Sedentary behaviour (mins/day)	Valid days of data (n=)	Number of strings in the data, including sleep (n=)	Wear time (% of total time)
10 minutes	15/40	287.3 (29.1)	65	699	7.5%
20 minutes	36/40	375.8 (46.8)	186	928	22.9%
60 minutes	40/40	459.0 (88.8)	242	401	33.6%
480 minutes*	40/40	476.4 (106.2)	242	287	39.7%

* Using a criterion of 480 minutes would mean that any strings of 0's during waking hours would be included as sedentary behaviour rather than excluded as non-wear, as 480 minutes is the maximum possible non-wear duration when a minimum wear criterion for inclusion of 600 minutes is applied (e.g. 18 hours between 6am-midnight, thus 18 hours – 10 hours minimum wear for inclusion in analysis = 8 hours of possible non-wear)

Significant differences in average daily sedentary behaviour existed between all comparisons of the different durations of continuous strings of 0's to define non-wear during waking time ($p<0.05$). Using a criterion of 60 minutes or 480 minutes of continuous strings of 0's to define non-wear resulted in all participants being included in analysis. Reducing the strings of continuous 0's criterion to 10 or 20 minutes resulted in 15 and 36 participants having sufficient data to be included in analysis, respectively.

Appendix D

Patient physical activity and sedentary behaviour questionnaire

Physical activity questionnaire for paediatric patients

Participant ID number: _______________

We are trying to find out about your level of physical activity from ***the last 7 days*** (in the last week). *Moderate* physical activity is any activity that makes your heart beat faster and makes you get out of breath some of the time. You may also sweat a little or your legs might feel tired.

Physical activity can be done in sports, school activities, playing with friends or walking to school. Some examples of physical activity are running, walking quickly, cycling, dancing, skateboarding, swimming, football and gymnastics.

Physical Education (PE or gym) happens *at school with your class teacher*.

Physical activity is activity done in your *spare time* and includes *before school*, at *break times*, *after school* or at the *weekends*.

Remember:
1. There are no right and wrong answers — this is not a test.
2. Please answer all the questions as honestly and accurately as you can — this is very important.

Question 1: Physical activity in your spare time and physical education at school: Have you done any of the following activities in the past 7 days (last week) during your spare time or in physical education? If yes, how many times, where and when? (Tick only one circle per row.)

Types of activities	Click the number of times you have done these activities in the past 7 days (last week)	Where do you usually do this activity? (Click all that apply)	When do you usually do this activity? (Click all that apply)
Team games - Examples: basketball, cricket, football, hockey, netball, rounders, rugby, volleyball	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Racquet sports - Examples: badminton, squash, tennis	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Individual sports - Examples: athletics, cheerleading, golf/pitch & putt, gymnastics, trampoline	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend

Outdoor recreation activities - Examples: canoeing, cycling, hiking, horse riding, mountaineering, orienteering, water-skiing, rowing, sailing	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Water-based activities - Examples: diving, swimming, water polo	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Dance activities - Examples: ballet, ballroom, jazz, Latin, line dancing, modern, Scottish, social/recreational, street/hip-hop, tap	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Fitness activities - Examples: aerobics, exercise machines (cycle, treadmill, weights), jogging, push-ups, sit-ups, weight training	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend

Active video games - Examples: dance mats, Wii Fit, Wii Sport	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Martial arts - Examples: judo, karate, Tae Kwon Do	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Winter sports - Examples: curling, skating, skiing (downhill or cross-country)	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Active transport - Examples: cycling, scooter, skateboarding, skating, walking	☐ none ☐ 1-2 ☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool ☐ Home	☐ Before school ☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend

Playground games - Examples: chasing, hopscotch, obstacle courses, skipping	☐ none ☐ 1-2☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool☐ Home	☐ Before school☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend
Other types of physical activities - please type the activity here:	☐ none ☐ 1-2☐ ☐ 3-4 ☐ 5-6 ☐ 7 times or more	☐ School ☐ Club ☐ Leisure centre ☐ The outdoors ☐ Swimming pool☐ Home	☐ Before school☐ After school ☐ Break time ☐ During PE ☐ Evening ☐ Weekend

Question 2: This question is about other types of things that you usually do during your spare time (not in class at school). Have you done any of the following activities in the past 7 days (last week) during your spare time? If yes, how many times?

Types of activities	Click the number of times you have done these activities in the past 7 days (last week)
Computer /Internet	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Sitting playing video games (Gaming, Xbox)	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more

Homework, studying	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Reading (not for school)	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Sitting during school breaks	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Sitting and talking with friends (not on phone)	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Listening to music whilst sitting/lying	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Talking or texting on the phone	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Television or DVD watching	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more
Other (specify):	☐ none ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 times or more

Question 3: In the last 7 days, during your *physical education (PE) classes*, how often were you very active (playing hard, running, jumping, throwing)? (Tick one only.)

How often I was very active in PE	Click one only
I don't do PE	☐
Hardly ever	☐
Sometimes	☐
Quite often	☐
Always	☐

Question 4: In the last 7 days, what did you do most of the time *at break times (*include activities besides eating at lunch break)? (Click one only.)

What I did during break times	Tick one only
Sat down (talking, reading, doing schoolwork)	☐
Stood around or walked around	☐
Ran or played a little bit	☐
Ran around and played quite a bit	☐
Ran and played hard most of the time	☐

11. Were you sick last week, or did anything prevent you from doing your normal physical activities? (tick one.)

Yes	☐
No	☐
If yes, what prevented you?	

Appendix E

Parent/carer interview schedule and diabetes professional focus group topic guide

The interview schedule used in studies 3 and 4 (chapters 4 and 5) with parents/carers is provided on the following pages. Patient interview schedules covered the same topics but used age appropriate language. Also provided here is the topic guide used during focus group discussions with diabetes professionals in studies 3 and 4.

Interview topic guide: Parent/Carer

(optional questions)

Icebreaker: Tell me about your child's hobbies?

Topic 1: Knowledge, beliefs & experiences of PA

Question

- **What do you think about diabetes and exercise/physical activity?**
  - **What do you think are the risks of physical activity on diabetes? (e.g. poorer glucose management)**
  - **What do you think are the benefits of physical activity on diabetes? (e.g. weight maintenance)**
  - **What do you think are the risks of having diabetes on physical activity? (e.g. hypos)**
  - **What do you think are the benefits of having diabetes on physical activity?**
- **How much physical activity do you think a young person with Type 1 diabetes should be achieving?**
- **What do you view as the main things that help children with diabetes/your child to take part in physical activity?**
- **What do you view as the main things that stop children with diabetes/your child taking part in physical activity?**

Looking to examine the knowledge & beliefs that parents/carers have in relation to physical activity recommendations & benefits/risks of physical activity in children/adolescents with Type 1 diabetes. Expecting a discussion on the risk of becoming ill during physical activity (e.g. hypos) and possible health benefits of becoming regularly active (e.g. weight control, decreased risk of complications). Also looking to explore the knowledge & beliefs that carers have in relation to motivators and barriers to participation in physical activity for children/youth with Type 1 diabetes.

Topic 2 – knowledge & experiences of Type 1 diabetes

Question

- **How would you describe diabetes to one of your friends who knows nothing about it?**
- **How, if at all, do you think diabetes affects your child's PE experience at school?**
  - **How, if at all, do you think that having diabetes affects your child's performance in other classes than PE at school?**

- **How, if at all, do you think diabetes affects your child's physical activity/sport experience outside of school?**

Looking to find what knowledge they have in regards to understanding what diabetes is is and to explore their experiences of having the condition on the activities their child does and their school performance.

<u>Topic 3: Knowledge and beliefs about sedentary behaviour</u>

Question

- **Do you know what sedentary behaviour is? If so how would you explain it to one of your friends who does not know what it is?**

Facilitator: Show sedentary behaviour images and give pre-amble on what sedentary behaviour is. Sedentary behaviour consists of sitting down time and includes activities such as driving the car, watching TV, surfing the internet, reading a book.

- **What, if any, do you think are the risks of sedentary behaviour on diabetes?**
- **What, if any, do you think are the benefits of sedentary behaviour on diabetes?**
- **Do you think that we should monitor the amount of time spent sitting down?**
    - **How much sitting down do you think a young person with Type 1 diabetes should be doing each day?**
- **What reasons can you think of that do help or would help your child cut down on the amount of sitting down activities that they do? (motivators)**
- **What reasons make it hard for your child to stop taking part in these activities? (barriers)**
- **How do you think diabetes affects how much time your child spends sitting down?**
    - **Do you think if they did not have diabetes that they would do any more/less/same amount of sitting down? Why?**

Looking to examine the knowledge & beliefs that parents/carers have in relation to sedentary behaviour, benefits/risks of sedentary behaviour and to explore what they perceive as the motivators and barriers to being sedentary in patients with Type 1 diabetes. Expecting a discussion on the possible acute (e.g. feeling tired and down) and long-term (e.g. overweight, poorer glucose control) negative health effects of being sedentary and possibly positive health effects (e.g. relaxation, stress control).

<u>Topic 4: Influential figures</u>

Question

- **How influential do you think parents or carers can be on their child with diabetes' physical activity level and sitting down participation?**
- **Who else do you think can influence the child with diabetes' participation in physical activities and sitting down activities and how?**

Looking to examine who the carer beliefs could influence the willingness of children/adolescents with Type 1 diabetes to engage in physical activity and to minimise sedentary time.

<u>Topic 5: Support to encourage physical activity/minimise sedentary participation in those with Type 1 diabetes</u>

Question

- **If anything what has helped or would you have liked/would have helped your child to take part in more physical activity or to sustain the amount that they do?**
    - **Who should be involved in providing this support (e.g. who should deliver it, who should be receiving it (e.g. parent/carer and patient versus patient only))?**
    - **What would this support look like:**
        - **How would it be delivered? (prompt: images)**
        - **What content would be included?**
        - **How would it be structured?**
        - **How often would it be given?**
- **If anything what has helped or would you have liked/would have helped your child to take part in less or to sustain the amount of sitting down that they do?**
    - **Who should be involved in providing this support (e.g. who should deliver it, who should be receiving it (e.g. parent/carer and patient versus patient only))?**
    - **What would this support look like:**
        - **How would it be delivered? (prompt: images)**
        - **What content would be included?**
        - **How would it be structured?**
        - **How often would it be given?**

Looking to determine what help and support carers perceive as being useful for encouraging participation in physical activity for those with Type 1 diabete/their child.

Group discussion topic guide: Diabetes health care staff

(Optional questions)

Icebreaker: Say your name and how long you've been practicing in this clinic?

Topic 1: Physical activity participation & school performance of the patient with Type 1 diabetes

- **How do you think having diabetes affects the amount of physical activity that an individual does?**
  - **How do you think that having diabetes affects a patient's participation in PE at school? How do you think this differs in children compared to adolescents?**
    - **How do you think diabetes affects performance in other classes at school?**
    -

Looking to explore how they think that having diabetes affects physical activity/sedentary behaviour participation in general, physical activity at school and other class performance.

Topic 2: Attitudes and beliefs of physical activity

Question

- **What do you think are the main things that help participation in physical activity for the patient with Type 1 diabetes?**
- **What do you think are the main things that stop participation in physical activity for the patient with Type 1 diabetes?**
- **What do you think are the risks of physical activity for the patient with Type 1 diabetes?**
- **What do you think are the benefits of physical activity for the patient with Type 1 diabetes?**
- **What do you think are the risks of having diabetes on physical activity for the patient with Type 1 diabetes?**
- **What do you think are the benefits of having diabetes on physical activity for the patient with Type 1 diabetes?**

Looking to examine what they think are the motivators barriers to physical activity participation, the risks/benefits of being active and risks/benefits of having diabetes on physical activity participation.

Topic 3: Attitudes and beliefs of sedentary behaviour

- **How would you describe what sedentary behaviour is to a friend who did not know what it is?**

Facilitator: Pre-amble to define sedentary behaviour

Question

- **What do you think are the risks of sitting down activities for the patient with Type 1 diabetes? (e.g. poor glucose control)**
- **What do you think are the benefits of sitting down activities for the patient with Type 1 diabetes? (e.g. relaxation)**
- **Do you think that we should monitor the amount of time spent sitting down?**
    - **How much sitting down should a young person with Type 1 diabetes be doing each day?**
- **How do you think having diabetes affects the amount of sitting time that the individual does?**
    - **Do you think if they did not have diabetes that they would do any more/less/same amount of sitting down? Why?**
- **What reasons can you think of that do help or would help a patient with diabetes from stopping taking part in sitting down activities? (motivators)**
- **What reasons make it hard for a child to stop taking part in sitting down activities? (barriers)**
-

Looking to examine what they think are the motivators barriers to sedentary behaviour, the risks/benefits of being sedentary and risks/benefits of having diabetes on sedentary participation.

Topic 4: The care you provide

Question

- **How do you encourage participation in physical activity with patients, if at all, and do you do this with all of your patients?**
    - **What are the physical activity recommendations for young people with Type 1 diabetes?**
    - **What do you know about the International Society for Pediatric and Adolescent Diabetes (ISPAD) exercise guidance? How do you use this guidance at your clinic (if you use it)?**
- **How do you give guidance on sitting down time to your patients, if at all, and do you do this with all of your patients?**

Looking to examine knowledge of physical activity/sedentary behaviour and to explore their current practicing methods.

Topic 5: Influential figures

Question

- **How influential do you think the diabetes health care team is on a paediatric patient with diabetes' physical activity and sitting down behaviour?**
- **Who else do you think can influence the child with diabetes' participation in physical activity and sitting down time**?

Looking to explore who could influence the willingness of children/adolescents with Type 1 diabetes to engage in physical activity and minimise sedentary time

<u>Topic 6 – Support to encourage physical activity & minimise sedentary behaviour in those with Type 1 diabetes</u>

Question

- **If anything what has helped your patients to become more physically active?**
- **If anything what ideas do you have for helping the child with diabetes to take part in more physical activity and to minimise sitting down time?**
    - **What would this support look like?**
    - **Who would receive the support (e.g. carer and child or just child)?**
    - **Who would deliver this support?**
    - **How often would the support be given?**
    - **How would this support be delivered? (Prompt: images)**
    - **What content and structure would this support have?**
- **If anything what ideas do you have for helping the paediatric patient with diabetes to minimise sitting down time?**
    - **What would this support look like?**
    - **Who would receive the support (e.g. carer and child or just child)?**
    - **Who would deliver this support?**
    - **How often would the support be given?**
    - **How would this support be delivered? (Prompt: images)**
    - **What content and structure would this support have?**

Looking to determine what help and support the health care team perceive as being useful for encouraging participation in physical activity and minimising sedentary behaviour for patients with Type 1 diabetes.

Appendix F

Qualitative analysis process: Example

Conceptual Framework for patient and parent interviews

1. Physical activity

1.1 Participation

1.2 Recommendations

1.3 Benefits of physical activity

1.4 Negative effects/risks/challenges of physical activity

2. Sedentary behaviour

2.1 Participation

2.2 Recommendations

2.3 Benefits of sedentary behaviour

2.4 Negative effects/risks of sedentary behaviour

3. School

3.1 Physical Education participation

3.2 Teacher diabetes knowledge

3.3 Contact, communication & support for diabetes

3.4 Effects of diabetes on school & PE participation & performance

4. Current clinic care

4.1 Communication

4.2 Physical activity discussion

4.3 Praise for clinic

4.4 Additional support

5. Intervention

5.1 Ideas

5.2 Important intervention components

5.3 Intervention characteristics (target, setting, duration, contact, timing)

6. Diabetes

6.1 “don’t want them…singled out”

6.2 Fear

6.3 Diabetes definition

6.4 Hypo awareness & detection

6.5 Treatment & control

6.6 Diagnosis & coping with diabetes

6.7 Other

7. Other

Figure 1: Conceptual map for the theme of 'physical activity'

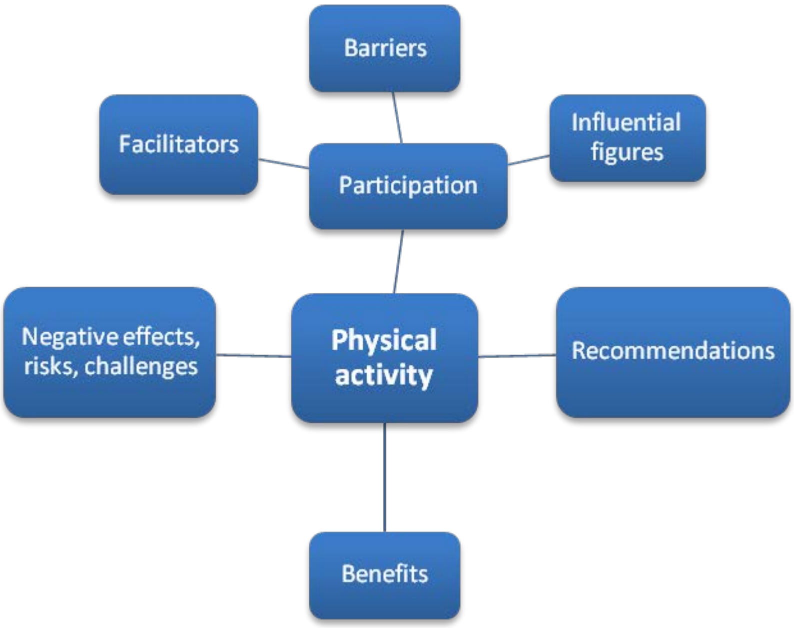

Table 1: Data for the theme 'physical activity participation' laid out for patient and parent participants

1.1 Physical activity - participation	Barriers	Facilitators	Influential figures	General
105C	*Safety*: dad doesn't let her help cut the grass. *Weather*: 'Depends if it's nice or not,' 'If it's sunny, no, you should be going out.' When asked is there is anything stopping them from PA participation replied not really. *No barriers*	Food: 'When I get a sweet so then I can burn it off.' Social: 'when I see all my friends joining in I sort of want to.' Fun: 'if you're just by yourself and people you don't know it doesn't really make it fun.'	Friends: 'When like my friends don't want to go out I sort of… R: Does it put you off? 105:…aha because I can't, I don't really want to do it on my own.' Parents. Grandparents. Teachers. Doctors (help but difficult to understand them as she's young). Lazy people: negative effect on participation	
105P	*Unwell* (NS if diabetes specific or in general). *No diabetes specific reason*: 'specific to diabetes just having diabetes I wouldn't say there's any other reason.' *Weather*: 'X's out constantly in the summer whereas in the winter she's probably in the house a lot more.'	Not sure of the things that help children with diabetes or her child in particular to be active: 'I don't really know specifically what I would say to that.' Encouragement/parent pushing: Spoke of child's fear to dance after diagnosis & how she pushed her to go back 'I think X just herself was petrified to go back after being diagnosed and I did, I probably pushed her into going to do it because I knew it would be good for her. R: So yeah encouragement 105: Well I suppose encouragement aha. And just to try and explain to them that it is good for them. Again that's important even if you weren't diabetic, i suppose you should try and encourage them.'	Parents: very influcencing. 'I'm really influencing her when it comes to that [PA] especially if her blood sugar is high because I'll tend to get her to go out….burn it off to bring it down.' School: doesn't think they get enough PA. Clinic. Extended family. Friends: mostly active. Best friend has diabetes 'her best friend [laughs] is the other wee girl that is Type 1 diabetic…even if they are playing in the room they tend to be jumping up and down.'	Thinks PA is important & helps those with diabetes
112C	*None*: When asked if anything stops them from taking part in PA they said no	Facilities: classes nearby	Parents. Friends sometimes play with them & like the activities she likes. Extended family (provoked my mother). Asked if anyone affects PA in a bad way & replied no.	
112P	*None*: when asked if there was anything stopping their child from being PA they said no, nothing. *Weather*: 'just the weather that keeps you in sometimes.'	Child's nature: 'she's always wanted try new things, be active. I've…got more difficult asking her to sit down.' Facilities/equipement: spoke of having a bike, trampoline, swing parks	Parents: very influencing 'Very say you've been active, they're active but if they see you sitting down you'll get an argument if you say "exercise" and say "well you've been sitting down for long.' School: 'the school's very good…A lot of after school activities.' Doctors.	Asked what they thought of PA & diabetes on the whole: 'It's about getting the balance.'

Example section from patient and parent full report on the sub-theme of 'barriers' from the theme 'physical activity participation'

Barriers

Participants talked about barriers in relation to what specifically stopped them (patients) or their children (parents) from taking part in physical activity and also what they felt potential barriers could exist in general for youth with and without diabetes. Several participants mentioned that there were no or should not be any reason in relation to diabetes why an individual could not participate in physical activity (101 mother). Others spoke of barriers connected to having diabetes. The most commonly mentioned diabetic barrier was inappropriate blood glucose level for participation. Participants mentioned that this could result in a delay in activity but would not necessarily completely stop them from being active (101 adolescent). Insulin injection therapy was noted as a barrier to physical activity due to the severe fluctuations in blood glucose level that some participants experienced (103 adolescent). Other diabetic barriers to physical activity were: the extra planning and organization required (115 mother); other parents fear of diabetes (111 child); parental fear of the child's participation in activity (103 mother), (124 child); the child's fear in getting ill during activity and lack of confidence which could be initiated by parent's fear (119 mother); being conscious of others knowing the patient has an insulin pump or is checking their blood glucose levels (103 mother); and a lack of teacher knowledge on diabetes resulting in the child missing out on PE (103 mother). The remaining barriers that were discussed were common to all youth and included: poor weather; a lack of facilities or opportunities; safety of the child; not enjoying activity; not having other people to be active with; the appeal of sedentary pursuits; activity not being perceived as 'cool;' the child not having ownership in the choice of activity; the child's nature; family background and residing community; injury; being overweight (which can affect confidence); and financial reasons. Example extracts now follow:-

101 mother: ‘'Absolutely nothing...The fact that they don’t want or can’t be bothered doing it is nothing to do with their diabetes.'

101 adolescent: 'I wouldn’t say stops me but like if I’m about to go to like the gym or something and check my sugars and I’m like low then maybe I’ll like text my friends and say can we maybe do it 10 minutes later.'

103 adolescent: 'I couldn’t really do a lot of kind of basketball in case it kind of like I had to like go too high or whatever and I’d have to come off.'

115 mother: ‘you could say that is a barrier, that extra layer of organisation that you need when you are taking your child to be active...that does get quite tiresome.'

111 child: ‘Sometimes people like mums and dads ask me when I’m going over to a sleep over “are you sure you’re allowed to do this” and I say “I’m fine, my mum allows me."'

103 mother: 'you can be a bit apprehensive about the exercise because X had, used to have an awful lot of very severe hypos...it would have been quite easy to slip into not exercise...she would ride a bike and she could have a seizure...she would miss out on going to things like brownies and stuff like this cause we said look even running about a hall, anything at all affected it...So I can completely understand where a parent would go “just sit there.”’

124 child: 'Mummy and daddy don’t let me really run about a lot because they want my blood to not go low.'

119 mother: ‘He still has a kind of fear of hypos...it’s, my only impression is that they’re worried that something will happen. That they’ll be out, lose control and something bad will happen to them…If you've got very protective parents who are so worried about what might happen that it inhibits everything that the child does and

then they start to think “Oh I can’t do that” and then they start to lose their confidence.'

103 mother: 'she often didn’t want to go to sports because people would see her pump… she would be checking her blood sugar...and people would be saying “why do you need to do that” and that kind of put her off.'

103 mother: ‘She’s been told “just sit out the class.” Children will use that, manipulate that!'

Appendix G

Qualified practicing teacher information sheet

The study information sheet given to qualified, practicing teachers is provided below. A similar information sheet was provided to student teachers, with appropriate adjustments made to the section on why the individual had been asked to participate in the study.

Participant Information Sheet

Name of department: School of Psychological Sciences and Health

Title of the study: Physical education and physical activity opportunities for children with long-term health conditions

Introduction

I am a PhD student from the University of Strathclyde and would like to invite you to take part in a research study. Before you decide if you would like to participate it is important for you to understand why the research is being done and what it will involve for you. Talk to others about the study if you wish. Please take time to read the following information carefully and if there is anything you are unsure about please contact me if you would like additional information. If you decide not to take part this will not affect your current employment.

About 35% of Scottish children are not physically active. Children with a long-term health condition (such as cystic fibrosis, type 1 diabetes or asthma) can be less physically active than healthy similar aged children. The Scottish physical activity strategy “let’s make Scotland more active” has a target of 80% of children aged 16 years and under being physically active at the recommended level by 2022. As children with long-term health conditions can be less active than healthy children they are a key target if Scotland is to make the goal for children. Therefore it is important to find ways of encouraging and supporting children with long-term health conditions to become more physically active.

What is the purpose of this investigation?

The aim of this research is to explore what primary and secondary Physical Education teachers think about working with children who have a long-term health condition in both physical education at school and extra-curricular physical activity. The research is being carried out as part fulfilment of a PhD degree at the University of Strathclyde, Glasgow. The potential benefits of taking part in this research are that it may help in the development of a resource for teachers to help them support children with a long-term health condition to become more physically active.

Do you have to take part?

It is up to you to decide. Your participation is entirely voluntary and you are free to withdraw at any time, without giving a reason. This would not affect your career in any way. If you do not wish to take part then no further action is required and the researcher would like to thank you for your interest and consideration.

What will you do in the project?

The researcher would like you to take part in a group discussion with other teachers and complete a questionnaire. You will not receive any financial reward for taking part in the study in the form of payment, expenses or gifts. However refreshments or pedometers (depending on the scheduled time of the discussion) will be provided as a thank-you for your participation. The discussion will last between 30-45 minutes and the questionnaire will take no longer than 15 minutes to complete. In total I am requesting 1 hour of your time (to allow for time to set up and conduct the discussion as well as complete the questionnaire). The discussion will, with your consent, be audio-taped to help the researcher with the analysis process. This aspect of the study may derive direct quotations that are of interest. If any of these quotations are published, your name and the name of the school that you work in will not be associated with them. If you are happy to take part in the research then please contact the student by telephone or email (contact details are at the end of this sheet). The student will then arrange a suitable date and time with you for the discussion. The discussion will take place either in the school where you work or in another suitable location. Dates and times for the discussion are flexible and the student will work with you to schedule an appropriate time.

Why have you been invited to take part?

You are being asked to take part in this research because you are a primary teacher or secondary Physical Education teacher working in Scotland. INSERT NAME suggested you may be interested in taking part in this research.

What are the potential risks to you in taking part?

Participants will be asked not to discuss the content of the discussions after the session in order to respect others confidentiality.

What happens to the information in the project?

Interviews or ‘focus groups’ or ‘discussion groups’ will be voice recorded (if participant’s consent is provided) and the content of the recordings will be typed to produce transcripts of the interviews. Voice recordings will be stored on the student’s private folder on the University’s secure network drive (only the student has access to this folder) and will be destroyed after 5 years of collection. Discussion transcripts and an analysis report will be anonymised and saved on a password protected laptop, on a secure University network drive, as well as paper copies being stored securely in a locked cabinet at the University. The transcripts and report will be kept for the duration of the student's career for potential future analysis. The PhD student's supervisors as well as another PhD student will have access to the transcripts and report in order to check the analysis and to formally assess the PhD. The findings will be written up for publication in research journals, presentations at conferences and submitted as part fulfilment of the PhD. Quotations used will remain anonymous and no information will be included that could in any way identify a participant or the school in which they work. Participants will be asked to complete a short questionnaire gathering information on the following: age, gender, previous employment/training and medical status. Questionnaires will be stored in a secure cabinet within the University and will be labelled with a participant identification number. Only the student and the chief investigator on the project will have access to a list matching identification numbers to participant names. Questionnaire data will be entered onto a database and stored on a password protected laptop and on a secure University network drive (again only including participant identification numbers). Data will be destroyed after 5 years of collection.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?

If you are happy to be involved in this project then you will be asked to contact the student via telephone or email to provide your consent that they may contact you to arrange a suitable date for the discussion. On the day of the discussion, you will be asked to confirm your consent by completing a consent form. Participants will be asked if they would like to receive a short summary of the findings which will be mailed out after the student has completed analysis and written up a report. The findings will be published in appropriate research journals, written into the student's PhD thesis and will be presented at relevant conferences. If you do not want to participate in this project then you do not have to take any further action and I would like to thank you for your attention and consideration.

This investigation was granted ethical approval by the School of Psychological Sciences and Health of the University of Strathclyde.

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

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Appendix H

Teacher focus group topic guide

The topic guide used during focus groups with qualified practicing and student teachers is provided in this appendix. Questions were modified during discussions depending on the experience of the participants in relation to Type 1 diabetes. For example those with less/no experience of working with pupils with Type 1 diabetes in PE settings were asked ‘how do you think you would modify your teaching plan if you had a pupil with Type 1 diabetes in your PE class,’ rather than ‘how have you modified your teaching plan…,’ for participants with more experience.

Secondary PE teacher – Focus Group schedule (30-45 minutes)

- ❖ **Icebreaker: How long have you been a teacher and where do you currently teach?**
- ❖ **Props; images of 1) a child injecting insulin & using a blood glucose monitor; 2) a child using an inhaler; 3) an obese child**

<u>Topic 1 – knowledge of Type 1 diabetes</u>

Prompts to stimulate discussion prior to question...

- **What do the images mean to you and in particular in a PE/PA setting?**
- **What is a long-term health condition? Examples of conditions in children/adolescents?**

Facilitator: I’m particularly interested in Type 1 diabetes and how this condition can impact on PE/PA participation in childhood and adolescence.

Question

- **If someone knew about diabetes how would they describe it briefly to someone who knew nothing about it?**
  (Often people can get confused over different types of diabetes – do they know any differences? Cover differences between Type 1 and Type 2 if time)
- **Where did you obtain your knowledge on diabetes? (e.g. you/family member/friend has diabetes)**

- **What information did you receive at/since University in relation to diabetes?**

Exploring knowledge teachers have gained in regards to physical activity in children/adolescents with Type 1 diabetes.

<u>Topic 2 – knowledge & beliefs in relation to physical activity in children/adolescents with Type 1 diabetes</u>

Question

- **What risks/benefits of physical activity might a person highlight in relation to Type 1 diabetes?**
    - **Short/long term effects**
- **What differences might there be in the benefits/risks of physical activity for a person with Type 1 diabetes compared to those without?**
- **What are the physical activity recommendations for children/adolescents with Type 1 diabetes?**

Looking to examine knowledge & beliefs in relation to physical activity recommendations & benefits/risks of physical activity in children/adolescents with Type 1 diabetes. Expecting a discussion on the risk of becoming ill during the session (e.g. hypos) and possible health benefits of becoming regularly active (e.g. weight control, decreased risk of complications)

<u>Topic 3 – Motivators & barriers for participation in PE/Physical activity in those with Type 1 diabetes</u>

Prompts to stimulate discussion prior to question...

- **Do you think having Type 1 diabete affects participation in physical activity/PE in children/adolescents? If so how?**

Question

- **What do you think are the motivators/barriers to taking part in PE at school and in physical activity outside of school in children/adolescents with T1D?**
- **How do you think motivators/barriers differ (if at all) between:**
    - **PE at school and physical activity outside of school?**

    - **Those with Type 1 diabetes and those without?**
    - **Primary & secondary aged pupils?**

Looking to explore the knowledge & beliefs in relation to motivators and barriers to participation in physical activity/PE for those with Type 1 diabetes.

<u>Topic 4 – The PE session</u>

Question

- **If there has been in the past, or there was a pupil with Type 1 diabetes in your class, how did you/would you modify the activity or your lesson plan to suit this pupil's needs (if indeed you would modify the session)? Why did you/would you make these changes?**
    - **What motivators/barriers of the pupil did you/would you consider?**

Looking to explore knowledge on working with Type 1 diabetes here but also to gain ideas from them

<u>Topic 5 – Influential figures</u>

Prompts to stimulate discussion prior to question...

- **Who might have a significant influence on a child/adolescent with Type 1 diabetes in relation to their participation in PE in school & in physical activity in general?**

Question

- **What reasons can you find that would suggest PE teachers are influential in relation to pupils' participation in PE at school? Physical activity outside of school?**
    - **What strategies have you used/could you use to encourage pupils with Type 1 diabetes to participate in PE at school? To participate in physical activity outside of school?**

Looking to examine how the teacher feels they could influence the willingness of children/adolescents with Type 1 diabetes to engage in physical activity in general & in PE

<u>Topic 6 – Support to encourage physical activity participation in those with Type 1 diabetes</u>

Question

- **If anything what would you have liked/would have helped you during your professional training and thereafter to include children/adolescents with Type 1 diabetes in PE sessions & physical activity in general?**

Looking to determine what help and support the teachers would perceive as being useful for encouraging participation in PE and physical activity outside of school for those with Type 1 diabetes.