



## Strathprints Institutional Repository

MacMillan, Freya and Kirk, Alison and Mutrie, Nanette and Moola, Fiona and Robertson, Kenneth (2015) Building physical activity and sedentary behavior support into care for youth with type 1 diabetes: patient, parent and diabetes professional perceptions. Pediatric Diabetes. ISSN 1399-543X, http://dx.doi.org/10.1111/pedi.12247

This version is available at http://strathprints.strath.ac.uk/53755/

**Strathprints** is designed to allow users to access the research output of the University of Strathclyde. Unless otherwise explicitly stated on the manuscript, Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Please check the manuscript for details of any other licences that may have been applied. You may not engage in further distribution of the material for any profitmaking activities or any commercial gain. You may freely distribute both the url (<a href="http://strathprints.strath.ac.uk/">http://strathprints.strath.ac.uk/</a>) and the content of this paper for research or private study, educational, or not-for-profit purposes without prior permission or charge.

Any correspondence concerning this service should be sent to Strathprints administrator: <a href="mailto:strathprints@strath.ac.uk">strathprints@strath.ac.uk</a>

## **Abstract**

Objective: To explore stakeholder's perceptions of physical activity (PA) and sedentary behavior support in youth with Type 1 Diabetes (T1D), to aid intervention development.

Methods: Primary data were collected between February-September 2012. Patients (N=16), parents (N=16) and professionals (N=9) were recruited from a diabetes clinic into a qualitative study. Semi-structured interviews (*N*=33) and focus groups (*N*=2), using broad open-ended questions, were conducted in patient/parent's homes, and at the diabetes clinic. Data were analysed thematically.

Results: Based on participants' experiences and interpretations, parent and peer support were perceived as essential. Professionals identified they could do more to encourage PA. Technology and information on local opportunities, in addition to inperson support, and a combination of group and one-to-one support were perceived as useful. Important perceived components of support were: diabetes preparation, management and support; enjoyment; education; and incorporation of behavior change techniques. The time of diagnosis was described as an appropriate point to initiate interventions.

Conclusions: The findings will help the development of future PA and sedentary behavior interventions for youth with T1D.

#### Introduction

Physical activity has important health benefits for youth with Type 1 diabetes (T1D)(1, 2) and guidance exists for PA participation(3). However patients often do not meet the recommended daily amount of PA(4, 5) (60 minutes moderate to vigorous PA(6)), and can be less active than their peers without diabetes(7). Sedentary behavior (sitting or lying whilst awake) may also negatively impact on health(8). A review identified that almost all PA intervention studies in youth with T1D have incorporated supervised interventions, which are less likely to be sustained long-term, and none of the interventions targeted sedentary behavior(1). There is a need for unsupervised, theory-driven and pragmatic interventions to increase and maintain PA and minimise sedentary behavior in this target population(1).

At early stages of health intervention development, the perceptions of central stakeholders should be sought to ensure that such interventions are feasible, acceptable, and useable(9). Previously only one study has explored perceptions of PA in youth with T1D and their parents(10). However it is not clear if patients with a range of PA levels were recruited and the views of health providers were not explored(10). The aim of this paper was to explore what patients, parents and diabetes professionals perceive important to include in diabetes care to support youth with T1D to lead active lifestyles. An adjunct paper explores perceptions (including teachers' perceptions) on providing support specifically in school(11).

#### Methods

A qualitative research design was employed to explore insights into PA and sedentary behavior and suggestions for intervention in youth with T1D. Semi-structured, one-to-

one interviews and focus groups were conducted using broad open-ended questions. The following topics were explored in all discussions: knowledge, attitudes and experiences of PA, sedentary behavior and T1D; the affect of influential figures on behavior and behaviour change; and current support characteristics and ideas for future support. Previous research published in this area informed the selection of topics. A diabetes physician and three youth of similar age to participants, but without diabetes, reviewed the topic guide for vocabulary appropriateness. Interviews and focus groups were selected based on convenience (e.g. geographic location of participants). Ethical approvals were granted.

#### **Participants**

Patients and parents were recruited from a diabetes clinic in a Scottish city into a concurrent study measuring PA and sedentary behavior in children aged 7-9 years (primary 3-6 (UK); elementary grade 1-4 (US)) and adolescents aged 12-14 years (secondary 1<sup>st</sup>-4<sup>th</sup> year (UK); middle or high grade 6-9 (US)) with T1D(4). The first eight patients and their parents recruited into the above study were invited and participated in this study. Eight children (3 boys, 5 girls), eight adolescents (4 boys, 4 girls) and 16 parents aged 42±6 years (2 men, 14 women) participated. Three patients used insulin pump therapy. The remaining patients used injection therapy. Diabetes duration ranged from 2.3-13.4 years.

Diabetes professionals were invited via letter. Nine professionals (3 men, 6 women; mean age  $44.2 \pm 8.1$  years; 4 nurses, 3 dietitians, 2 physicians with 2-30 years of experience) participated. A one-to-one interview and two focus groups (with four participants each) were conducted with professionals.

#### Data collection

Interviews and focus groups lasted 30-45 minutes. Data were collected by a researcher with experience in conducting qualitative research and with extensive knowledge on PA, sedentary behavior, and T1D. Discussions were audio recorded and transcribed verbatim. Notes were taken on non-verbal cues during discussions to aid analyses. Age, gender and diabetes duration (if applicable) were recorded. To describe PA and sedentary behavior, participants wore accelerometers (Actigraph Model GT3X+; Manufacturing Technology Inc., Pensacola, FL, USA) for seven days (15sec epochs). Time in moderate to vigorous PA(12) and sedentary behavior(13) were calculated using validated cut-points developed for youth. A minimum wear requirement of 10 hours/day and three days of data were considered valid for inclusion(14).

#### Analysis

A constructivist thematic analysis approach was adopted and used to organise and explain the experiences of youth living with T1D in relation to PA, sedentary behavior and support needs. Patient, parent, and professionals data were analysed separately using constant comparison(15) before similarities and differences in perceptions across the different participants were explored. Data were systematically arranged into meaningful groups(16). Initial coding was conducted by reading and rereading the data, followed by sorting of codes into themes. Excerpts from transcripts were segregated under theme names to highlight the meaning of themes 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

multiple-coding checks. Two researchers from outwith the team independently coded 10% of the total data. Also, two additional researchers from the team checked the coding framework and excerpts of data coded under each theme (32 interviews with patients and parents and 2/3 professional discussions), and read the full report.

Meetings were held between researchers to find consensus in coding and language used to describe themes. Results are presented as the major themes relating to the development of interventions with example excerpts provided in tables. Excerpt numbers link table excerpts to the related section of the results. The type of respondent (child=C, parent=P or diabetes professional=D) and ID number (the same ID number is used for patients and parents from the same family), are provided with excerpts.

#### Results

Patients with a range of PA and sedentary behavior levels (moderate-to-vigorous PA range of 22.0-123.3 minutes and 7.0-12.3 hours of sedentary behavior) participated.

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

#### 1) Intervention target groups (Table 1)

Based on participants' experiences, parents and friends were recognised by patients, parents and professionals as the most significant figures that influenced PA participation. Parental influence was mentioned to change with increasing age as experienced by some parents (excerpt 1.1). Although patients and parents mentioned professionals as being influential due to their authoritative voice (excerpt 1.2a-c), professionals did not perceive themselves as being influential (excerpt 1.3). Teachers, sport coaches, sporting role models (from within the clinic or nationally/internationally renowned), siblings, and extended family were also recalled as being influential. The role of school staff in helping support PA in youth with T1D was identified and is reported on in another paper(11).

Participants saw it important to target parents and families rather than patients alone to change PA and sedentary behavior. Inclusion of peer support was also perceived as important (excerpt 1.4a-c). Some parents spoke against the idea of only including youth with diabetes, as they did not want their child to feel singled out (excerpt 1.5a). Patients also mentioned the importance of not being viewed as different because of their diabetes (excerpt 1.5b). Other parents and some patients and professionals identified socialising with others who have diabetes as a positive experience (excerpt 1.6a-c). 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 1.6d). Several patients and parents perceived parents as important communicators and translators, particularly between younger patients and professionals. Finding a balance between providing parental support and giving patients responsibility was perceived necessary. Most participants mentioned communication between influential figures and working together to provide support

for patients with T1D as important. Local community councils, Diabetes UK (the main UK diabetes charity), and the government were also recalled as potential targets to help improve support for youth with T1D, and youth in general, to be active.

## 2) Intervention delivery settings (Table 1)

Participants mentioned that multiple delivery settings are important for targeting PA and sedentary behavior. Almost all patients, parents and professionals spoke of limited PA encouragement provided in current care (excerpt 2.0a-d). Professionals described how they tend to encourage PA in specific patients including those that: were regularly active; had weight issues; or specifically asked for guidance. Professionals suggested that they could: incorporate PA as a third parameter (alongside diet and insulin) in discussions in all patients' regular check-ups and in the patient's management diary; educate patient's on the guidelines for PA; include PA in newly diagnosed patient group education sessions; and develop specific PA plans with newly diagnosed patients. Introducing a physical activity advisor to the clinic was also suggested. Patients, parents and professionals also mentioned schools, local communities, and the family home 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 T1D by introducing community/family based interventions such as walking buses.

## 3) Intervention delivery methods (Table 2)

Participants generally spoke positively about the inclusion of technology to support PA and sedentary behavior change. Advantages of technology based on participants' interpretations of their experiences (excerpt 3.0a-d) included: appeal for youth; for

monitoring and feedback; provision of support networks; and to reduce the number of intervention contacts. Parents highlighted the importance of policing social support to avoid negative messages being communicated to patients (excerpt 3.1a-b). Some patients and parents and all professionals described technology alone as not being enough to change behavior (excerpt 3.2a-b) and that in-person contact is a necessity. Information on local opportunities to be active in leaflet, poster, or website format was perceived as useful by some patients, parents and professionals. However, other strategies were perceived as necessary alongside providing information to encourage behavior change. Perceptions towards preference for group or one-to-one support were variable. Parents mentioned the importance of age. Given the importance of autonomy in adolescence, some participants suggested that one-to-one support would perhaps be preferred in adolescence. In contrast, it was perceived that children could potentially benefit more from group settings (excerpt 3.3a). In line with parents' perceptions, a few adolescents mentioned they would not like group support (excerpt 3.3b). In contrast, other patients and parents spoke positively regarding group support.

## 4) Intervention components/content (Table 2)

The most common diabetes related influencers on PA mentioned by patients, parents and professionals were: blood glucose levels and diabetes preparation and management; and diabetes support (excerpt 4.0a-c). Communication and trust in adults leading PA sessions were described as being important. Other important influencers mentioned by patients, parents and professionals included: levels of fear/anxiety related to illness (particularly early post diagnosis) in patients or those providing support to the patient, and the occurrence of hypoglycaemia during or after PA (excerpt 4.0d-f); and having diabetes, which could act as a barrier or facilitator of

PA for some people. Professionals highlighted that the negative impacts of PA on diabetes are often misunderstood (excerpt 4.1). The main influencer of PA unrelated to diabetes mentioned by all types of participant was enjoyment. Having "ownership" to select activities that were perceived to be "cool", was also perceived important. Other highlighted influencers included: weather; availability of others to be active with; child, family and community attitudes towards PA; safety; facilities and/or opportunities; and appeal of sedentary pursuits. Insulin pump therapy was described as being a facilitator to PA by patients and parents (excerpt 4.2a-c). However, concerns of users and parents related to the pump were recalled: movement of the pump during activity; fear of line detachment; and patients being conscious of others knowing that they have a pump.

Although patient and parent knowledge on the benefits of PA was generally good, knowledge on the recommendations was limited. Sedentary behavior was acknowledged as an important behavior for youth with T1D by patients, parents and professionals (excerpt 4.3a-c). Participants mentioned potential positive and negative effects of sedentary behavior on health, such as having less fluctuation in blood glucose and an increased risk of hyperglycaemia, respectively. Professionals identified educating families on the definition of PA is important, in particular emphasising the benefits of activities of daily living and not just planned, structured exercise. Parents and professionals mentioned that education on the definition of sedentary behavior was also important (excerpt 4.3d). Despite their generally high levels of knowledge, patients and parents perceived education on the benefits and risks of PA and sedentary behavior was important.

Behavior change techniques perceived as useful to include in support mentioned by patients, parents and professionals were: self and external monitoring and feedback to build awareness and increase motivation; including achievable individualised goals and providing rewards/incentives (excerpt 4.4a-b); linking behavior change to efficacy on health (excerpt 4.5a-b); competition; and providing encouragement and motivation.

## 5) Intervention timing and duration (Table 2)

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

## *Individualised approach (Table 2)*

The provision of individualised support suited to the individual's needs and preferences, was discussed in relation to all themes (excerpt 6.0).

#### Discussion

This study adds to the literature in youth with T1D by qualitatively exploring PA and sedentary behavior support needs from the experiences of central stakeholders. This study found that overall, parents and peers were perceived as the most influential figures on a patient with T1D and should be targeted, alongside patients, in interventions to support behavior change. Multiple delivery settings were identified as necessary to change behavior. Care in this Scottish clinic currently lacks consistent

encouragement in all patients, as described from participant's interpretations of their experiences; strategies to ensure consistent PA and sedentary behavior support were suggested. The inclusion of technology in interventions and information on local PA 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 behavior change (group or one-to-one and with peers with or without diabetes depending on the individual's preferences). Support for the incorporation of technology into interventions provides qualitative confirmation to support the conclusions of a previous review(17). Future researchers should explore the incorporation of technology alongside other delivery methods. Important influencers recalled by participants to address and include in an intervention included appropriate diabetes preparation, management and support, and enjoyment. Education on PA and sedentary behavior definitions and recommendations were perceived as important, as well as the incorporation of behavior change techniques. From participants' experiences, near the time of diagnosis was identified 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. A common perspective across participants was that intervention characteristics must be tailored to individuals.

Parent and peer support(10, 18), and enjoyment(19) have previously been reported as facilitators of PA in youth with T1D and other medical conditions. In adolescents with T1D, a family-based intervention found positive effects on PA and perceptions of family support for PA(20). Group-based workshops for adolescents with Type 1

diabetes have been found to improve diabetes management during PA(21), which was in contrast to this study where some adolescents mentioned they would not want group support. Peer-mentoring (relationships with non-parental adults) is an effective method for youth(22); lifestyle programmes incorporating PA have found promising effects on health(23, 24). A study exploring children's ideas for minimising sedentary behavior highlighted the need for peer and parental support to aid behavior change(25). The perspectives and experiences mentioned in the present study support the development of larger studies including peer and parental support in youth with T1D.

There is a current common perception of limited PA promotion in T1D care in this Scottish clinic. This may be due to limited PA encouragement from diabetes professionals or patients/parents not paying attention to, ignoring, or not remembering PA encouragement and advice. Although from their experiences parents and patients perceive professionals as central stakeholders to influence behavior, 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 might be an important strategy to increase their confidence in delivering PA messages. Specifically in this clinic setting, diabetes professionals identified that they should consider encouraging PA and discouraging sedentary behavior during regular clinic by: discussing and monitoring every patient's participation; and educating and/or reinforcing all patients on the guidelines. Diabetes professionals perceived that particularly for newly diagnosed patients, group education sessions and the provision of individualised plans should be considered. The feasibility of introducing an exercise advisor to diabetes clinics or training

existing diabetes professionals to deliver PA/sedentary behavior support requires investigation. Research exploring the effectiveness of incorporating an exercise toolkit for diabetes educators into care for adults with Type 2 diabetes is currently being explored(26). The development of similar toolkits for youth with diabetes requires exploration. Another important setting for intervention consideration is school: a large proportion of youth's PA can be gained during physical education, sports and recess. An adjunct paper provides guidance in this area(11).

Patients, from their experiences, did not recall many disease specific barriers to PA, and rather discussed general barriers such as lack of enjoyment. Furthermore parents' interpretations of their experiences focused on fostering normality and they described the importance of balance between the amount of parental vigilance and patient independence to avoid the sense of anxiety during activity. These points concur with previous research(12). Similar to research in youth with congenital heart disease(18), some parents viewed patient-interaction with other youth with diabetes negatively. For other parents, and for all patients, interaction with those with diabetes was perceived important. Fear of illness during or after PA in patients and people surrounding patients can act as a barrier to participation and has been reported elsewhere(10). Although patients did not speak of fear of illness in relation to PA, several parents mentioned hypoglycaemia fear and their children experiencing delayed hypoglycaemia. Hypoglycaemia fear in relation to PA, particularly in parents, is therefore important to combat. Insulin pump therapy was mentioned as a facilitator to participation in PA. Although not mentioned in this study, continuous glucose monitoring can also facilitate PA, and alone/in combination with pump therapy,

should be considered in interventions, to improve glycaemic control and prevent hypoglycaemia.

Theory-based PA interventions targeting specific behavioral processes are important for successful behavior change (27). A coding framework for behavior change techniques has been developed(28). From participants experiences several of these techniques were mentioned as useful including (the descriptions in brackets are how the techniques were described in the results section of the current study): prompt selfmonitoring of behavior (self-monitoring); provide feedback on performance (external monitoring and internal/external feedback); goal setting in terms of the behavior or outcome (individualised goals); set graded tasks (achievable goals); prompt rewards contingent on successful behavior (rewards); facilitate social comparison (competition); and motivational interviewing (encouragement and motivation). Technology has been used to self-monitor and provide feedback on behavior previously in those with T1D, such as pedometers to encourage PA participation(29), and a Smartphone Application to aid blood glucose management (30). A one-to-one physician delivered PA consultation incorporating goal setting and achievable graded tasks, had beneficial effects on PA in adults with T1D(31), whilst a personalised exercise prescription including realistic goals, performance feedback, reinforcement strategies (incorporating family support) and access to community resources, improved adherence to exercise and perceived health in adolescents(32). Combining technology with support delivered by professionals may be a way of targeting the behavior change techniques found in this study to be of importance to PA and sedentary behavior change, and should be explored in future.

Diagnosis has been identified as a teachable moment (when individuals have high motivation to learn about their condition(33)), which was in agreement with the perceived 'best' time to intervene in this study based on participants' own experiences.

Trustworthiness was ensured in this study by the conduction of discussions from multiple perspectives. Rigor was further ensured through multiple coding and checking of coding. A limitation of this study was the lack of inclusion of peers and siblings as participants. However the role of peers and siblings in PA and sedentary behavior were discussed. The target number of patients and parents to recruit was set a priori and was met. Saturation was reached for discussions with patients and parents - no new major themes arose nearing the end of data collection. Only two focus groups and one interview was conducted with diabetes professionals due to limited numbers of professionals working within the clinic. Although the same themes arose from the three discussions with diabetes professionals, it is difficult with such a small number of discussions to know if true saturation was met. Participants were only recruited from one city clinic in Scotland and perspectives may have differed had participants been recruited from other locations/countries, where differences in care are evident (including number of clinic appointments and availability of insulin pump technology). Different clinic schedules may allow for more frequent PA discussion.

To conclude, diabetes professionals should consider developing and delivering structured PA and sedentary behavior support consistently in all of their patients with T1D, regardless of their fitness or health status. Professionals and researchers should use the findings of this paper to help guide the development of such support.

Professionals should focus on promoting PA at a level on par with insulin and diet advice in every individual, to help patients realise the importance that PA can have in diabetes therapy.



#### References

- 1. MacMillan F, Kirk A, Mutrie N, Matthews L, Robertson K, Saunders DH. A systematic review of physical activity and sedentary behavior intervention studies in youth with type 1 diabetes: study characteristics, intervention design, and efficacy. Pediatr Diabetes. 2014; 15:175-89.
- 2. Short KR, Pratt LV, April MT, Dalla Man C, Cobelli C. Postprandial improvement in insulin sensitivity after a single exercise session in adolescents with low aerobic fitness and physical activity. Pediatr Diabetes. 2013; 14:129-37.
- 3. Robertson K, Riddell MC, Guinhouya CB, Adolfsson P, Hanas R. Exercise in children and adolescents with diabetes. Pediatr Diabetes. 2014; 15:203-23.
- 4. MacMillan F, Kirk A, Mutrie N, Robertson K. Physical activity and sedentary behaviour in Scottish youth with Type 1 diabetes. Pract Diab. 2014; 31:228-33c.
- 5. Nguyen T, Obeid J, Walker RG, Krause MP, Hawke TJ, McAssey K, et al. Fitness and physical activity in youth with type 1 diabetes mellitus in good or poor glycemic control. Pediatr Diabetes. 2014. doi: 10.1111/pedi.12117.
- 6. UK Department of Health. Start active, stay active: A report on physical activity from the four home countries' Chief Medical Officers. 2011.

  http://www.gov.uk/government/publications/start-active-stay-active-a-report-on-physical-activity-from-the-four-home-countries-chief-medical-officers.
- 7. Sundberg F, Forsander G, Fasth A, Ekelund U. Children younger than 7 years with type 1 diabetes are less physically active than healthy controls. Acta Paediatr. 2012; 101:1164-69.
- 8. Margeirsdottir HD, Larsen JR, Brunborg C, Sandvik L, Dahl-Joergensen K. Strong association between time watching television and blood glucose control in children and adolescents with Type 1 diabetes. 2007; 30:1567-70.

- 9. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: The new Medical Research Council guidance. BMJ. 2008; 337.
- 10. Fereday J, MacDougall C, Spizzo M, Darbyshire P, Schiller W. "There's nothing I can't do I just put my mind to anything and I can do it": A qualitative analysis of how children with chronic disease and their parents account for and manage physical activity. BMC Pediatr. 2009; 1:1.
- 11. MacMillan F, Kirk, A., Mutrie, N., Moola, F., Robertson, K. Supporting participation in physical education at school in youth with type 1 diabetes: Perceptions of teachers, youth with type 1 diabetes, parents and diabetes professionals. Eur Phys Educ Rev. 2014. doi: 10.1177/1356336X14534367.
- 12. Puyau MR, Adolph AL, Vohra FA, Butte NF. Validation and calibration of physical activity monitors in children. Obes Res. 2002; 10:150-7.
- 13. Evenson KR, Catellier DJ, Karminder G, Ondrak KS, McMurray RG. Calibration of two objective measures of physical activity for children. J Sports Sci. 2008; 24:1557-65.
- 14. Cain KL, Sallis JF, Conway TL, Van Dyck D, Calhoon L. Using accelerometers in youth physical activity studies: A review of methods. J Phys Act Health. 2013; 10:437-50.
- 15. Glaser BG. The constant comparative method of qualitative analysis. Social Problems. 1965; 12:436-45.
- 16. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol.2006; 3:77-101.

- 17. Lau PWC, Lau EY, Wong DP, Ransdell L. A systematic review of information and communication technology-based interventions for promoting physical activity behavior change in children and adolescents. J Med Internet Res. 2011; 13:e48.
- 18. Moola F, Faulkner GEJ, Kirsh JA. Physical activity and sport participation in youth with congenital heart disease: Perceptions of children and parents. Adapt Phys Act Quart. 2007; 25:49-70.
- 19. Williams B, Hoskins G, Pow J, Neville R, Mukhopadhyay S, Coyle J. Low exercise among children with asthma: A culture of over protection? A qualitative study of experiences and beliefs. Br J Gen Pract. 2010; 60:e319-26.
- 20. Faulkner MS, Michaliszyn SF, Hepworth JT. A personalized approach to exercise promotion in adolescents with type 1 diabetes. Pediatr Diabetes. 2009; 11:166-74.
- 21. Akhter K, Zeffertt A, Evans M, Abdullah N, Pesterfield C. Development and evaluation of a pilot one-stop workshop for young adult people with type 1 diabetes. Arch Dis Child. 2012; 97.
- 22. DuBois DL, Portillo N, Rhodes JE, Silverthorn N, Valentine JC. How effective are mentoring programs for youth? A systematic assessment of the evidence. Psych Sci Pub Int. 2011; 12:57-91.
- 23. Stock S, Miranda C, Evans S, Plessls S, Ridley J, Yeh S, et al. Healthy Buddies: A novel, peer-led health promotion program for the prevention of obesity and eating disorders in children in elementary school. Pediatrics. 2007; 120:e1059-68.
- 24. Cawley JC, Cisek-Gillman L, Roberts R, Cocotas C, Smith-Cool T, Bouchard M, et al. Effect of HealthCorps, a high school peer mentoring program, on youth diet and physical activity. Child Obes. 2011; 7:364-71.

- 25. Sebire SJ, Jago R, Gorely T, Cillero IH, Biddle SJH. 'If it wasn't for technology then I would probably be out everyday": A qualitative study of children's strategies to reduce their screen viewing. Prev Med. 2011; 53:303-8.
- 26. Shields CA, Dillman C, Fowles JR, Murphy R, Dunbar P, Perry A, et al. Diabetes educators' exercise-related perceptions and practices 12 months after receiving the physical activity and exercise toolkit. Ann Beh Med. 2010; 39:S83.
- 27. Hillsdon M, Foster C, Cavill N, Crombie H, Naidoo B. The effectiveness of public health interventions for increasing physical activity among adults: A review of reviews: Evidence briefing. National Health Service, UK, 2005.
- 28. Michie S, Ashford S, Sniehotta FF, Dombrowski SU, Bishop A, French DP. A refined taxonomy of behavior change techniques to help people change their physical activity and healthy eating behaviors: The CALO-RE taxonomy. Psychol Health. 2011; 26:1479-98.
- 29. Newton KH, Wiltshire EJ, Elley CR. Pedometers and text messaging to increase physical activity: Randomized controlled trial of adolescents with type 1 diabetes. Diabetes Care. 2009; 32:813-15.
- 30. Kirwan M, Vandelanotte C, Fenning A, Duncan MJ. Diabetes self-management smartphone application for adults with type 1 diabetes: Randomized controlled trial. J Med Internet Res. 2013; 15:e235.
- 31. Hasler TD, Fisher BM, MacIntyre PD, Mutrie N. Execise consultation and physical activity in patients with type 1 diabetes. Pract Diab Int. 2000; 17:44-8.
- 32. Faulkner MS, Michaliszyn SF, Hepworth JT, Wheeler MD. Personalized exercise for adolescents with diabetes or obesity. Biol Res Nurs. 2014; 16:46-54.
- 33. Valentine V. Educational strategies at diagnosis and beyond, or diabetes, Type 2, and what to do! Diabetes Spectr. 2000; 13:197-200.



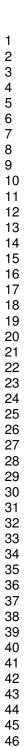




Table 1 Themes: Support/intervention target group and support/intervention delivery setting

<b>Sub-themes</b>	Example excerpt	<b>Considerations for</b>	Excerpt
		interventions	number
			in text
Target groups			
Parental influence changes with increasing age	'I think we [parents] try to be influentialunfortunately at this age [adolescence] you're just seen more as a hinderance than a helpsometimes we can be our own worst enemy because [we] can keep pushing at something and uhm that gives the opposite effectI 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" but you need to know what battles to pick and which ones to avoid and when to step back.' – mother of an adolescent girl (103P)	Incorporate parent support. The level of parental support may depend on the patient's age.	1.1
Parents and patients perceive professionals as influential	'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 (101P)  If you're like doing more exercise then it'll keep [blood glucose levels] down	Health professionals are influential due to their authoritative voice and should play a key role.	1.2a
	which means you'll get a better reading at the hospital andyour mum and dad and the doctors [are] a bit happier.' – adolescent girl (103C)		1.2b
	If the nurse at the diabetic hospital told him [son] something I had, [he's] more		

	likely to listen to them [nurses] thanto me [laughs] – mother of a young boy (124P)		1.2c
Professionals do not perceive themselves as influential	'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 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 (109D)	Develop health professional self-efficacy to deliver physical activity and sedentary behavior messages.	1.3
Inclusion of peers	'I think if they [peer role-models from clinic] went to say the parents groups or spoke at schoolsI think that would have much more impact than any adult talkingI 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 "wowIf he can do itmy child could.' – physician (109D)	Incorporate peer-support.	1.4a
	'Sometimes you want to include your friends cause they're young when I see all my friends joining in I sort of want toIf you're just by yourself and people you don't know it doesn't really make it fun.' – young girl (105C)		1.4b
	'The other thing is you know that their friends are so important to themBringing in friends andfacilitating something where there is a group of them to do something.' – mother of an adolescent boy (119P)		1.4c
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 childrenand for that reason we've never really kind of gotinvolved [with diabetes support groups].' – father of a young boy (111P)	Be careful not to single out patients with diabetes.	1.5a

'I think the main thing for me is ... "right I want to show everyone that I'm not any different from everyone else just because I'm diabetic." I want to do all the sports and I want to go to the clubs with my friends and ...take part in everything.' – adolescent girl (101C)

1.5b

1.6a

Socialising with others with diabetes and one-to-one contact plus parental and peer support 'There was a girl in my school in primary and she had [diabetes] like when she was like really young, like 5 or something...she was just saying "oh it's nothing,"... and [she] obviously does [blood glucose monitoring]...I like [didn't do] my sugars every day and she was saying "oh it's important." – adolescent boy (119C)

Incorporate peers with diabetes if the patient and family are happy to do so. Balance one-to-one and 'parent plus patient' contact.

1.6b

'I definitely think it would benefit them [socialising with others who have diabetes], definitely. Because, although uhm X's [daughter] got a brother who's diabetic, but if she never I think she would maybe find things a wee [little] bit strange. But having said that there is...other kids in the school that are diabetic so she's not just out there on her own. I think if she was, then I would make a point of going to [social diabetes] things. – mother of a young girl (123P)

1.6c

'We'd went to the Xmas party once and she'd met a wee [little] girl...Uhm just a, a year younger than her. And they got on quite well and they'd started kind of emailing, but I think they were maybe just a wee [little] 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... cause there's nobody in our family or anything.' – mother of a young girl (118P)

1.6d

'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 (103C)

## **Delivery setting**

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 (106D)

ringing in Incorporate physical activity in a systematic way into clinic care.

2.0a

'When I've been to hospital, exercising has never been mentioned at all as being a big part of what she should be doing. You know yourself...it's important but it's never been sort of stressed.' – mother of a young girl (105P)

2.0b

'Mmm, not necessarily they [doctors] only like, if my, if my blood sugars have been bad and they ask me what I've been doing [then] – young boy (111C)

2.0c

I don't think we've ever specifically spoken about...no we don't spend a lot of time talking about exercise...more time talking about diet. Which I guess that's because, although I think exercise is important, I think diet is the most important factor in controlling uhm blood glucose – mother of a young girl (115P)

2.0d



**Table 2** Themes: Support/intervention method of delivery, support/intervention components to include and address, support/intervention timing and duration, and individualised approach

Example excerpt	Considerations for interventions	Excerpt number in text
'I think if you're looking at young people then using social networking, Facebook is absolutely the way to go causewhether we like it or notthat's how they communicate with each otherand if you do it on their wavelength I think it's going to make a big difference.' – mother of an adolescent girl (101P)	Technology can be useful for monitoring and feedback, and for the provision of	3.0a
'We've looked at a few things onuhm YoutubeBecause obviously teenagers they, they feel awkward asking questions and stuff like that or, or by the time they leave the clinic they could forget and stuff like that. So it's like, "let's just have a look on Youtube" cause there's everything on Youtube.'—mother of an adolescent boy (116P)	support networks.	3.0b
'It's like social networks and like thousands of young people go into it so it could helpThey could help you like with advice and thatthey have like Twitter pages like sports and everything I followUhmDavid Beckham You could try and like copy him so that's like quite good.' – adolescent girl (108C)		3.0c
'I think it'd be more Twitter, Facebook, these sort of big companies And the apps would be good, because there's lots and lots of children with apps. – young		3.0d
	is absolutely the way to go causewhether we like it or notthat's how they communicate with each otherand if you do it on their wavelength I think it's going to make a big difference.' – mother of an adolescent girl (101P)  'We've looked at a few things onuhm YoutubeBecause obviously teenagers they, they feel awkward asking questions and stuff like that or, or by the time they leave the clinicthey could forget and stuff like that. So it's like, "let's just have a look on Youtube" cause there's everything on Youtube.' – mother of an adolescent boy (116P)  'It's like social networks and like thousands of young people go into it so it could helpThey could help you like with advice and thatthey have like Twitter pages like sports and everything I followUhmDavid Beckham You could try and like copy him so that's like quite good.' – adolescent girl (108C)  'I think it'd be more Twitter, Facebook, these sort of big companies And the	"I think if you're looking at young people then using social networking, Facebook is absolutely the way to go causewhether we like it or notthat's how they useful for monitoring and feedback, and for going to make a big difference.' – mother of an adolescent girl (101P)  "We've looked at a few things onuhm YoutubeBecause obviously teenagers they, they feel awkward asking questions and stuff like that or, or by the time they leave the clinicthey could forget and stuff like that. So it's like, "let's just have a look on Youtube" cause there's everything on Youtube.' – mother of an adolescent boy (116P)  "It's like social networks and like thousands of young people go into it so it could helpThey could help you like with advice and thatthey have like Twitter pages like sports and everything I followUhmDavid Beckham You could try and like copy him so that's like quite good.' – adolescent girl (108C)  "I think it'd be more Twitter, Facebook, these sort of big companies And the

## boy (110C)

# Policing social support

'One of my concerns has always been meeting with other kids with diabetes you've, how do you police that?...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 (103P)

Ensure that support from others with diabetes is policed to avoid inappropriate messages being communicated.

3.1b

3.1a

'I don't know if X [son] would [use social networks] or not because they're doing the internet thing just now at school - "...don't use Facebook, it's very dangerous."... Yeah for the older one's it'll be alright... I mean I would be quite happy to...say to him, without telling him it's Facebook that I was on... "oh look there's somebody here that's doing what you're doing and this is what they're saying." ...but he doesn't necessarily need to know that it's Facebook.' – mother of a young boy (124P)

Technology alone is not enough to change behavior '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 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 (109D)

Other support delivery 3.2a methods should be used alongside technology.

'Everything's getting done on the social networking and everything elsebut obviously having these like get-togethers every now and then would also help
because it, [she] should be in touch with other kids with diabetes that she doesn't
know and things like thatandparents can share their stories and
experiences.' – mother of a young girl (123P)

3.2b

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 (117P)

Offer group and or one-to-one support.

3.3a

'...[I'd prefer to] get on with it myself.' – adolescent boy (116C)

3.3b

'If it's like just by the person [patient] then, like they can take responsibility over it.' – adolescent boy (117C)

## Components/content

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.' –

Co-ordinate diabetes 4.0a support with the patient, their family and others working

dietitian (102D)	with the patient	
'Making sure that they've had enough to eat, that they've always got Lucozade or whatever there to [take on]check a wee [little] bit more regular their blood sugars.' – mother of a young boy (124P)		4.0b
'She [daughter] has to feel confident thatsomeone that understands is thereif it's not at school it, it's either her dad or I. She wants us there on the side-lines so she can give us a sign.' – mother of a young girl (115P)		4.0c
'She's [daughter] been in a dancing class, uhm oh for quite a few years nowand I think X [daughter] just herself was petrified to go back after being diagnosed andI probably pushed her into going to do it because I knew it would be good for her.' – mother of a young girl (105P)		4.0d
'A lot of parents will betoo frightened to put their kids to certain activities for fear of them having a hypo. So a lot of it's due to confidence of the parents as well.' – father of a young boy (111P)		4.0e
'I think it's uhm quite unpredictable, often what happens when they do exercise uhm. We went on a bouncy castle the other dayAnd we were on it for about half an hour and X [daughter] was, I think we were just hypo when we came of it. Butit continued - we couldn't bring her up. So it's, it's the effect that it has, and swimming can have that affect as well, later it seems to affect if it's at the end of the day [risk of delayed hypo is] particularly [increased] yeah.' – mother of a young girl (115P)		4.0f

Negative impacts of physical activity often misunderstood	'In many years of diabetes camps, I've seen one child 'slump' with a hypoI've never seen anyone have a convulsionI've never had to for example give glucagon or had to give them a dripAnd yet the sporting activity we've done has beenvery intense,and also has been totally out of the normal activity pattern of the childSo uhm I think the dangers are over-stated.' – physician (109D)	Educate patients, family, and those working with patients, to build their confidence in the patient to participate in physical activity.	4.1
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 therapythe pumps phenomenal dealing with our distress [laughs], fear of letting her exercise.' – mother of an adolescent girl (103C)	Consider providing insulin pump therapy if available and appropriate.	4.2a
	'Uhm like before I had the pump and the injections it was a nightmare to take part cause I couldn't go swimming and 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 [the court] or that. And now I've got the pump I can do whateverit's a whole lot easier to go and do stuff than it was.' – adolescent girl (103C)		4.2b
	'He's [son] more in control cause he can just take it [the pump] off and [unclear], put it back on [for swimming]. Uhm you know obviously it's good for, you know there's more flexibility than[X number of] injections a dayBut not everybody's on the pump and it's so hard to get just now.' – mother of a young		4.2c

Education on what

boy (111P)

'Uhm I think sitting down for no reason can be a bad thing where you could be

Educate patients and

4.3a

sedentary behavior is	instead going out and doing exercise. But also like I think it's still important to tell people like if you're getting low not to go and run a marathon.' – adolescent girl (101C)	families on the definition and recommendations for	
	'We have seen it [there's] days eh I have been too busy so we haven't gone out very much and his [son's] sugar levels have been 12 [pause] most constantly you need to sit sometimesbut you have to have a balance.' mother of a young boy (110P)	sedentary behavior.	4.3b
	'I mean it's just you know abalancing life, I think. I mean I do know that ifshe sits in front of a DVD and is on normal insulinthen 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		4.3c
	more active, then it does, does have an affect You don't chase around with a big stick all day.' – mother of a young girl (115P)  'I suppose it's also trying to teach them about knowing sedentary behaviorrather than having to start tennis or whateverthings that they will do rather than putting them off.' – dietitian (107D)		4.3d
Goal setting and rewards	Getting people to set goals for themselvesso it's things that they can achieve would be good achievable goalsfor children that don't really do anything. You know big charts and things like thatand as they reach each goal they get somea reward.' – mother of an adolescent boy (117P)	Set realistic, achievable targets/goals and provide incentives/rewards.	4.4a
	$(C_{-}; A)_{n-1} = A$		

'So it's not just go outside and do something... A target, so each time you go to

4.4b

Linking behavior	'Some sort of way of introducing it [physical activity] that it's something that, in
change to health	addition to your HbA1c you need to be thinking about your exercise as well and

'Some sort of way of introducing it [physical activity] that it's something that, in addition to your HbAlc 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 doctor then they say....this is your target for this time.' – young boy (110C)

the HbA1c as well...So that they can see that everything they're putting in is worthwhile.' – mother of an adolescent girl (103P)

adolescent boy (117C)

'It's quite interesting [gaining feedback] ...like you find out how healthy or unhealthy you are and I wannae [want to] do more, like, because I'm quite unhealthy.' – adolescent girl (108C)

## Feedback to patients on the efficacy of changing their behavior/s on their health outcomes.

4.5a

4.5b

## **Timing**

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 (101P)

Intervene as near to diagnosis as possible depending on the severity and experiences of diagnosis.

5.0a

...............................

5.0b

"...I think the sooner they understand, the better." – mother of a young girl

'Well like getting used to like taking insulin and stuff and then you should

introduce [physical activity] ... so that they're like used to having all that.' -

5.0c

(112P)

"...I think right away. Yeah I mean there's obviously so much information that you get immediately but that's kind of easier and memorable one with all the kind of stuff that's going on, so yeah I mean any opportunity as soon as possible...I think probably parents feel very motivated at that point as well.'—mother of a young girl (115P)

5.0e

5.0d

"...When X [son] was diagnosed as much as it was a shock we recognised it and we thought that he was [diabetic] ....and [with] X's [husband being] diabetic as well. So as much as it was a shock, we also knew how to deal with it. And we could have probably spoke[n] about it [physical activity] reasonably quickly after diagnosis. But other people that maybe don't have anything, and they're trying to just take in what diabetes is about, it might be a wee [little] bit too, too quick to talk about it straight away...Maybe mentioning it to them, you know, "just because they now have diabetes doesna'e [doesn't] mean to say that they can't have their, their normal childhood," but maybe not make such a big issue about it until...they've accepted the diabetes kind of thing.' – mother of a young boy (124C)

t's

ment's Avoiding a

ild homogenous, "cookie
on the cutter approach."

6.0

Individualised approach

'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 (119P)

#### Abstract

Objective: To explore stakeholder's perceptions of physical activity (PA) and sedentary behavior support in youth with Type 1 Diabetes (T1D), to aid intervention development.

Methods: Primary data were collected between February-September 2012. Patients (N=16), parents (N=16) and professionals (N=9) were recruited from a diabetes clinic into a qualitative study. Semi-structured interviews (N=33) and focus groups (N=2), using broad open-ended questions, were conducted in patient/parent's homes, and at the diabetes clinic. Data were analysed thematically.

Results: Based on participants' experiences and interpretations, parent and peer support were perceived as essential. Professionals identified they could do more to encourage PA. Technology and information on local opportunities, in addition to inperson support, and a combination of group and one-to-one support were perceived as useful. Important perceived components of support were: diabetes preparation, management and support; enjoyment; education; and incorporation of behavior change techniques. The time of diagnosis was described as an appropriate point to initiate interventions

Conclusions: The findings will help the development of future  $\underline{PA}$  and sedentary behavior interventions for youth with  $\underline{T1D}$ .

Physical activity has important health benefits for youth with Type 1 diabetes (T1D)(1, 2) and guidance exists for PA participation(3). However patients often do not meet the recommended daily amount of PA(4, 5) 60 minutes moderate to vigorous  $\underline{PA}(6)$ ), and can be less active than their peers without diabetes(7). Sedentary behavior (sitting or lying whilst awake) may also negatively impact on health(8). A review identified that almost all PA intervention studies in youth with T1D have incorporated supervised interventions, which are less likely to be sustained long-term, and none of the interventions targeted sedentary behavior(1). There is a need for unsupervised, theory-driven and pragmatic interventions to increase and  $maintain \ \underline{PA} \ and \ minimise \ sedentary \ behavior \ in \ this \ target \ population (1).$ 

At early stages of health intervention development, the perceptions of central stakeholders should be sought to ensure that such interventions are feasible, acceptable, and useable(9). Previously only one study <a href="https://example.com/has-explored-perceptions">has-explored-perceptions</a> of <a href="https://example.com/PA">PA</a> in youth with TID and their parents(10). However it is not clear if patients with a range of PA levels were recruited and the views of health providers were not explored(10). The aim of this paper was to explore what patients, parents and diabetes professionals perceive important to include in diabetes care to support youth with T1D to lead active lifestyles. An adjunct paper explores perceptions (including teachers' perceptions) on providing support specifically in school(11).

A qualitative research design was employed to explore insights into PA and sedentary behavior and suggestions for intervention in youth with  $\underline{\text{T1D}}.$  Semi-structured, one-to-

Detects:
Type 1 Districts Mellius (Type 1 DMT1D) is one of the most common chronic health conditions in youth and the worldwide incidence is rising (1) The UK currently ranks fifth inn the world for greatest prevalence of Type 1 DMT1D (2). Youth with Type 1 DMT1D may experience poor health compared to their peers without diabetes (3, 4). In addition youth with Type 1 DM are at an increased risk of developing complications of diabetes compared to those without T1D (5)

Comment [fm2]: Added reference by Short et al.

Comment [fm3]: Added reference by Robertson et al.

Comment [fm4]: Added reference by Nguyen et al.

The following topics were explored in all discussions: knowledge, attitudes and experiences of PA, sedentary behavior and T1D; the affect of influential figures on behavior and behaviour change; and current support characteristics and ideas for future support. Previous research published in this area informed the selection of topics. A diabetes physician and three youth of similar age to participants, but without diabetes, reviewed the topic guide for vocabulary appropriateness. Interviews and focus groups were selected based on convenience (e.g. geographic location of  $\underline{\text{participants}}).\ \underline{E}\text{thical approval}\underline{s}\ w\underline{\text{ere}}\ g\text{ranted}.$ 

Patients and parents were recruited from a diabetes clinic in a Scottish city into a concurrent study measuring PA and sedentary behavior in children aged 7-9 years (primary 3-6 (UK); elementary grade 1-4 (US)) and adolescents aged 12-14 years (secondary  $1^{st}$ - $4^{th}$  year (UK); middle or high grade 6-9 (US)) with  $\underline{\text{T1D}}(4)$ . The first eight patients and their parents recruited into the above study were invited and participated in this study. Eight children (3 boys, 5 girls), eight adolescents (4 boys, 4 girls) and 16 parents aged 42±6 years (2 men, 14 women) participated. Three patients  $\underline{{\sf used}}$  insulin pump therapy. The remaining patients used injection therapy. Diabetes duration ranged from 2.3-13.4 years.

Diabetes professionals were invited via letter. Nine professionals (3 men. 6 women: mean age 44.2 ±8.1 years; 4 nurses, 3 dietitians, 2 physicians with 2-30 years of experience) participated. A one-to-one interview and two focus groups (with four participants each) were conducted with professionals.

Comment [ImS]:
Deleted:
1 a roview of relevant literature; the findings of a systematic review of PA intervention RCTs in youth with T1D conducted by the research team; and the expertise of the researchers involved in the study

Comment [fm6]: Deleted: Interviews and foc

Comment [fm7]: Deleted:

Deleted:
patients and parent's homes was widespread, thus one-to-one interviews with patients and parents could be conducted in the participants' home; group discu

Comment [fm8]:
Deleted:
from the researcher. The letters were distributed at clinic team meetings by the lead physician

#### Data collectio

Interviews and focus groups lasted 30-45 minutes. Data were collected by a researcher with experience in conducting qualitative research and with extensive knowledge on <u>PA</u>, sedentary behavior, and <u>TID</u>. Discussions were audio recorded and transcribed verbatim. Notes were taken on non-verbal cues during discussions to aid analyses. Age, gender and diabetes duration (if applicable) were recorded. To describe <u>PA</u> and sedentary behavior, participants wore accelerometers (Actigraph Model GT3X+; Manufacturing Technology Inc., Pensacola, FL, USA) for seven days (15sec epochs). Time in moderate to vigorous <u>PA</u>(12) and sedentary behavior(13) were calculated using validated cut-points developed for youth A minimum wear requirement of 10 hours/day and three days of data were considered valid for inclusion(14).

#### <u>Analysis</u>

A constructivist thematic analysis approach was adopted and used to organise and explain the experiences of youth living with TID in relation to PA, sedentary behavior and support needs. Patient, parent, and professionals data were analysed separately using constant comparison(15) before similarities and differences in perceptions across the different participants were explored. Data were systematically arranged into meaningful groups(16). Initial coding was conducted by reading and rereading the data, followed by sorting of codes into themes. Excerpts from transcripts were segregated under theme names to highlight the meaning of themes 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

#### Comment [fm9]: Deleted:

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 mological and epistemiological viewpoints. It is 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 etween the research and participant.

thematic coding framework and report of the findings, rigour was ensured by multiple-coding checks. Two researchers from outwith the team independently coded 10% of the total data. Also, two additional researchers from the team checked the coding framework and excerpts of data coded under each theme (32 interviews with patients and parents and 2/3 professional discussions), and read the full report. Meetings were held between researchers to find consensus in coding and language used to describe themes. Results are presented as the major themes relating to the development of interventions with example excerpts provided in tables. Excerpt numbers link table excerpts to the related section of the results. The type of respondent (child=C, parent=P or diabetes professional=D) and ID number (the same ID number is used for patients and parents from the same family), are provided with excerpts.

#### Results

Patients with a range of <u>PA</u> and sedentary behavior levels (moderate-to-vigorous <u>PA</u> range of 22.0-123.3 minutes and 7.0-12.3 hours of sedentary behavior) participated.

Five central themes in relation to important intervention characteristics arose from the data: 1) intervention target groups; 2) intervention delivery settings; 3) intervention delivery methods; 4) intervention components/content; 5) intervention timing and duration.  $\underline{A}$ n overarching theme relating to all support characteristics was also identified (individualised approach). Tables 1 and 2 document example excerpts in relation to  $\underline{k}\underline{v}$  identified sub themes.

1) Intervention target groups (Table 1)

Based on participants' experiences, parents and friends were recognised by patients, parents and professionals as the most significant figures that influenced PA participation. Parental influence was mentioned to change with increasing age as experienced by some parents (excerpt 1.1). Although patients and parents mentioned professionals as being influential due to their authoritative voice (excerpt 1.2a-c), professionals did not perceive themselves as being influential (excerpt 1.3). Teachers, sport coaches, sporting role models (from within the clinic or nationally/internationally renowned), siblings, and extended family were also recalled as being influential. The role of school staff in helping support PA in youth with T1D was identified and is reported on in another paper(11).

Participants saw it important to target parents and families rather than patients alone to change PA and sedentary behavior. Inclusion of peer support was also perceived as important (excerpt 1.4a-c). Some parents spoke against the idea of only including youth with diabetes, as they did not want their child to feel singled out (excerpt 1.5a). Patients also mentioned the importance of not being viewed as different because of their diabetes (excerpt 1.5b). Other parents and some patients and professionals identified socialising with others who have diabetes as a positive experience (excerpt 1.6a-c). 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 1.6d). Several patients and parents perceived parents as important communicators and translators, particularly between younger patients and professionals. Finding a balance between providing parental support and giving patients responsibility was perceived necessary. Most participants mentioned communication between influential figures and working together to provide support

for patients with <u>TID</u> as important. Local community councils, Diabetes UK (the main UK diabetes charity), and the government were also recalled as potential targets to help improve support for youth with <u>TID</u> and youth in general, to be active.

#### 2) Intervention delivery settings (Table 1)

Participants mentioned that multiple delivery settings are important for targeting PA and sedentary behavior. Almost all patients, parents and professionals spoke of limited PA encouragement provided in current care (excerpt 2.0a-d). Professionals described how they tend to encourage PA in specific patients including those that: were regularly active; had weight issues; or specifically asked for guidance. Professionals suggested that they could: incorporate PA as a third parameter (alongside diet and insulin) in discussions in all patients' regular check-ups and in the patient's management diary, educate patient's on the guidelines for PA include PA in newly diagnosed patient group education sessions; and develop specific PA plans with newly diagnosed patients. Introducing a physical activity advisor to the clinic was also suggested. Patients, parents and professionals also mentioned schools, local communities, and the family home 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 TID by introducing community/family based interventions such as walking buses.

### 3) Intervention delivery methods (Table 2)

Participants generally spoke positively about the inclusion of technology to support

PA and sedentary behavior change. Advantages of technology based on participants'
interpretations of their experiences (excerpt 3.0a-d) included: appeal for youth; for

monitoring and feedback; provision of support networks; and to reduce the number of intervention contacts. Parents highlighted the importance of policing social support to avoid negative messages being communicated to patients (excerpt 3.1a-b). Some patients and parents and all professionals described technology alone as not being enough to change behavior (excerpt 3.2a-b) and that in-person contact is a necessity. Information on local opportunities to be active in leaflet, poster, or website format was perceived as useful by some patients, parents and professionals. However, other strategies were perceived as necessary alongside providing information to encourage behavior change. Perceptions towards preference for group or one-to-one support were variable. Parents mentioned the importance of age. Given the importance of autonomy in adolescence, some participants suggested that one-to-one support would perhaps be preferred in adolescence. In contrast, it was perceived that children could potentially benefit more from group settings (excerpt 3.3a). In line with parents' perceptions, a few adolescents mentioned they would not like group support (excerpt 3.3b). In contrast, other patients and parents spoke positively regarding group support (excerpt 3.3c).

### 4) Intervention components/content (Table 2)

The most common diabetes related influencers on <u>PA</u> mentioned by patients, parents and professionals were: blood glucose levels and diabetes preparation and management; and diabetes support (excerpt 4.0a-c). Communication and trust in adults leading <u>PA</u> sessions were described as being important. Other important influencers mentioned by patients, parents and professionals included: levels of fear/anxiety related to illness (particularly early post diagnosis) in patients or those providing support to the patient, and the occurrence of hypoglycaemia during or after

PA (excerpt 4.0d-f); and having diabetes, which could act as a barrier or facilitator of PA for some people. Professionals highlighted that the negative impacts of PA on diabetes are often misunderstood (excerpt 4.1). The main influencer of PA unrelated to diabetes mentioned by all types of participant was enjoyment. Having "ownership" to select activities that were perceived to be "cool", was also perceived important. Other highlighted influencers included: weather; availability of others to be active with; child, family and community attitudes towards PA; safety; facilities and/or opportunities; and appeal of sedentary pursuits. Insulin pump therapy was described as being a facilitator to PA by patients and parents (excerpt 4.2a-c). However, concerns of users and parents related to the pump were recalled: movement of the pump during activity; fear of line detachment; and patients being conscious of others knowing that they have a pump.

Although patient and parent knowledge on the benefits of PA was generally good, knowledge on the recommendations was limited. Sedentary behavior was acknowledged as an important behavior for youth with TID by patients, parents and professionals (excerpt 4.3a-c). Participants mentioned potential positive and negative effects of sedentary behavior on health, such as having less fluctuation in blood glucose and an increased risk of hyperglycaemia, respectively. Professionals identified educating families on the definition of PA is important, in particular emphasising the benefits of activities of daily living and not just planned, structured exercise. Parents and professionals mentioned that education on the definition of sedentary behavior was also important (excerpt 4.3d). Despite their generally high levels of knowledge, patients and parents perceived education on the benefits and risks of PA and sedentary behavior was important.

Behavior change techniques perceived as useful to include in support mentioned by patients, parents and professionals were: self and external monitoring and feedback to build awareness and increase motivation; including achievable individualised goals and providing rewards/incentives (excerpt 4.4a-b); linking behavior change to efficacy on health (excerpt 4.5a-b); competition; and providing encouragement and

### 5) Intervention timing and duration (Table 2)

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

### Individualised approach (Table 2)

The provision of individualised support suited to the individual's needs and preferences, was discussed in relation to all themes (excerpt 6.0).

This study adds to the literature in youth with  $\underline{\text{T1D}}$  by  $\underline{\text{qualitatively}}$  exploring  $\underline{PA}$  and sedentary behavior support needs from the experiences of central stakeholders. This study found that overall, parents and peers were perceived as the most influential figures on a patient with  $\underline{\text{T1D}}$  and should be targeted, alongside patients,  $\underline{\text{in}}$ 

interventions to support behavior change. Multiple delivery settings were identified as necessary to change behavior. Care in this Scottish clinic currently lacks consistent encouragement in all patients, as described from participant's interpretations of their experiences; strategies to ensure consistent PA and sedentary behavior support were suggested. The inclusion of technology in interventions and information on local  $\underline{PA}$ 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 behavior change (group or one-to-one and with peers with or without diabetes depending on the individual's preferences).  $\underline{\text{Support for}}$  the incorporation of technology into interventions\_provides qualitative confirmation to support the conclusions of a previous review(17). Future researchers should explore the incorporation of technology alongside other delivery methods. Important influencers recalled by participants to address and include in an intervention included appropriate diabetes preparation, management and support, and enjoyment. Education on  $\underline{\text{PA}}$  and sedentary behavior definitions and recommendations were perceived as important, as well as the incorporation of behavior change techniques. From participants' experiences, near the time of diagnosis was identified 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. A common perspective across participants was that intervention characteristics <u>must</u> be <u>tailored</u> to individual<u>s</u>.

Parent and peer support(10, 18), and enjoyment(19) have previously been reported as facilitators of  $\underline{PA}$  in youth with  $\underline{T1D}$  and other medical conditions. In adolescents

with  $\underline{\text{TID}}$ , a family-based intervention found positive effects on  $\underline{PA}$  and perceptions of family support for  $\underline{PA}(20)$ . Group-based workshops for adolescents with Type 1 diabetes have been found to improve diabetes management during  $\underline{PA}(21)$ , which was in contrast to this study where some adolescents mentioned they would not want group support. Peer-mentoring (relationships with non-parental adults) is an effective method for youth(22); lifestyle programmes incorporating  $\underline{PA}$  have found promising effects on health(23, 24). A study exploring children's ideas for minimising sedentary behavior highlighted the need for peer and parental support to aid behavior change(25). The perspectives and experiences mentioned in the present study support the development of larger studies including peer and parental support in youth with  $\underline{\text{TID}}$ .

There is a current common perception of limited  $\underline{P}\underline{A}$  promotion in  $\underline{T}\underline{I}\underline{D}$  care in this Scottish clinic. This may be due to limited  $\underline{P}\underline{A}$  encouragement from diabetes professionals or patients/parents not paying attention to, ignoring, or not remembering  $\underline{P}\underline{A}$  encouragement and advice. Although from their experiences parents and patients perceive professionals as central stakeholders to influence behavior, 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 might be an important strategy to increase their confidence in delivering  $\underline{P}\underline{A}$  messages. Specifically in this clinic setting, diabetes professionals identified that they should consider encouraging  $\underline{P}\underline{A}$  and discouraging sedentary behavior during regular clinic by: discussing and monitoring every patient's participation; and educating and/or reinforcing all patients on the guidelines. Diabetes professionals perceived that particularly for newly diagnosed patients, group

education sessions and the provision of individualised plans should be considered. The feasibility of introducing an exercise advisor to diabetes clinics or training existing diabetes professionals to deliver PA/sedentary behavior support requires investigation. Research exploring the effectiveness of incorporating an exercise toolkit for diabetes educators into care for adults with Type 2 diabetes is currently being explored(26). The development of similar toolkits for youth with diabetes requires exploration. Another important setting for intervention consideration is school: a large proportion of youth's PA can be gained during physical education, sports and recess. An adjunct paper provides guidance in this area(11).

Patients, from their experiences, did not recall many disease specific barriers to PA, and rather discussed general barriers such as lack of enjoyment. Furthermore parents' interpretations of their experiences focused on fostering normality and they described the importance of balance between the amount of parental vigilance and patient previous research(12). Similar to research in youth with congenital heart disease(18), some parents viewed patient-interaction with other youth with diabetes negatively. For other parents, and for all patients, interaction with those with diabetes was perceived important. Fear of illness during or after PA in patients and people surrounding patients can act as a barrier to participation and has been reported elsewhere(10). Although patients did not speak of fear of illness in relation to PA, several parents mentioned hypoglycaemia fear and their children experiencing delayed hypoglycaemia. Hypoglycaemia fear in relation to PA, particularly in parents, is therefore important to combat. Insulin pump therapy was mentioned as a facilitator

to participation in  $\underline{\text{PA.}}$  Although not mentioned in this study, continuous glucose

Comment [Im11]:
Deleted:
for helping schools to encourage regular participation in PA for young people with Type 1 DM from the perspectives of central stakeholders

monitoring can <u>also</u> facilitate <u>PA</u>, <u>and alone/in combination with</u> pump therapy, should be considered in interventions, to improve glycaemic control and prevent hypoglycaemia.

Theory-based PA interventions targeting specific behavioral processes are important for successful behavior change (27). A coding framework for behavior change techniques has been developed(28). From participants experiences several of these techniques were mentioned as useful including (the descriptions in brackets are how the techniques were described in the results section of the current study): prompt self-monitoring of behavior (self-monitoring); provide feedback on performance (external monitoring and internal/external feedback); goal setting in terms of the behavior or outcome (individualised goals); set graded tasks (achievable goals); prompt rewards contingent on successful behavior (rewards); facilitate social comparison (competition); and motivational interviewing (encouragement and motivation).

previously in those with TID, such as pedometers to encourage PA participation(29), and a Smartphone Application to aid blood glucose management(30). A one-to-one physician delivered PA consultation incorporating goal setting and achievable graded tasks, had beneficial effects on PA in adults with TID(31), whilst a personalised exercise prescription including realistic goals, performance feedback, reinforcement strategies (incorporating family support) and access to community resources, improved adherence to exercise and perceived health in adolescents(32). Combining technology with support delivered by professionals may be a way of targeting the behavior change techniques found in this study to be of importance to PA and sedentary behavior change, and should be explored in future.

Comment [fm13]:

Deleted:
Similar to this study, parents described 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 in a previous study [12].

omment [fm14]:

Unercetur.
Important behavior change techniques and combinations of techniques for youth with T1D need to be investigated to determine if targeting interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improves the effectiveness of interventions at specific behavior processes at certain time points improve the effectiveness of interventions at specific behavior processes at certain time points improve the effectiveness of interventions at specific behavior processes at certain time points improve the effectiveness of interventions at specific behavior processes at certain time points improve the effectiveness of interventions at the effectiveness of the effectiveness at the effectiveness of the effectiveness of the effectiveness at the effectivenes

Diagnosis has been identified as a teachable moment (when individuals have high motivation to learn about their condition(33)), which was in agreement with the perceived 'best' time to intervene in this study based on participants' own experiences.

Trustworthiness was ensured in this study by the conduction of discussions from multiple perspectives. Rigor was further ensured through multiple coding and checking of coding. A limitation of this study was the lack of inclusion of peers and siblings as participants. However the role of peers and siblings in PA and sedentary behavior were discussed. The target number of patients and parents to recruit was set a priori and was met. Saturation was reached for discussions with patients and parents - no new major themes arose nearing the end of data collection. Only two focus groups and one interview was conducted with diabetes professionals due to limited numbers of professionals working within the clinic. Although the same themes arose from the three discussions with diabetes professionals, it is difficult with such a small number of discussions to know if true saturation was met. Participants were only recruited from one city clinic in Scotland and perspectives may have differed had participants been recruited from other locations/countries, where differences in care are evident (including number of clinic appointments and availability of insulin pump technology). Different clinic schedules may allow for more frequent PA discussion.

To conclude, diabetes professionals should consider developing and delivering structured  $\underline{PA}$  and sedentary behavior support consistently in all of their patients with  $\underline{T1D}$ , regardless of their fitness or health status. Professionals and researchers should

#### Comment [fm18 Deleted:

(including more or less regular clinic appointments and availability to insulin pump and continuous glucose monitoring technology for patients). The clinic in this study tends to arrange appointments with patients every three months, or mor frequently if glucose control is not at a target levels. Clinics in other countries may have different schedules, allowing for more frequent physical activityPA discussion. Despite the study being conducted at only one clinic, the findings provide a

use the findings of this paper to help guide the development of such support. Professionals should focus on promoting  $\underline{PA}$  at a level on par with insulin and diet advice in every individual, to help patients realise the importance that  $\underline{PA}$  can have in diabetes therapy.

#### Reference

- MacMillan F, Kirk A, Mutrie N, Matthews L, Robertson K, Saunders DH. A systematic review of physical activity and sedentary behavior intervention studies in youth with type 1 diabetes: study characteristics, intervention design, and efficacy.
   Pediatr Diabetes. 2014; 15:175-89.
- Short KR, Pratt LV, April MT, Dalla Man C, Cobelli C. Postprandial improvement in insulin sensitivity after a single exercise session in adolescents with low aerobic fitness and physical activity. Pediatr Diabetes. 2013; 14:129-37.
- Robertson K, Riddell MC, Guinhouya CB, Adolfsson P, Hanas R. Exercise in children and adolescents with diabetes. Pediatr Diabetes. 2014; 15:203-23.
- MacMillan F, Kirk A, Mutrie N, Robertson K. Physical activity and sedentary behaviour in Scottish youth with Type 1 diabetes. Pract Diab. 2014; 31:228-33c.
- Nguyen T, Obeid J, Walker RG, Krause MP, Hawke TJ, McAssey K, et al. Fitness
  and physical activity in youth with type 1 diabetes mellitus in good or poor glycemic
  control. Pediatr Diabetes. 2014. doi: 10.1111/pedi.12117.
- UK Department of Health. Start active, stay active: A report on physical activity
  from the four home countries' Chief Medical Officers. 2011.

 $\underline{\text{http://www.gov.uk/government/publications/start-active-stay-active-a-report-on-}} \\ \underline{\text{physical-activity-from-the-four-home-countries-chief-medical-officers.}}$ 

- Sundberg F, Forsander G, Fasth A, Ekelund U. Children younger than 7 years with type 1 diabetes are less physically active than healthy controls. Acta Paediatr. 2012; 101:1164-69.
- Margeirsdottir HD, Larsen JR, Brunborg C, Sandvik L, Dahl-Joergensen K. Strong association between time watching television and blood glucose control in children and adolescents with Type 1 diabetes. 2007; 30:1567-70.

 Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: The new Medical Research Council guidance. BMJ. 2008; 337.

10. Fereday J, MacDougall C, Spizzo M, Darbyshire P, Schiller W. "There's nothing I can't do - I just put my mind to anything and I can do it": A qualitative analysis of how children with chronic disease and their parents account for and manage physical activity. BMC Pediatr. 2009; 1:1.

11. MacMillan F, Kirk, A., Mutrie, N., Moola, F., Robertson, K. Supporting participation in physical education at school in youth with type 1 diabetes:

Perceptions of teachers, youth with type 1 diabetes, parents and diabetes

professionals. Eur Phys Educ Rev. 2014. doi: 10.1177/1356336X14534367.

12. Puyau MR, Adolph AL, Vohra FA, Butte NF. Validation and calibration of physical activity monitors in children. Obes Res. 2002; 10:150-7.

13. Evenson KR, Catellier DJ, Karminder G, Ondrak KS, McMurray RG. Calibration of two objective measures of physical activity for children. J Sports Sci. 2008;

 Cain K.L., Sallis JF, Conway TL, Van Dyck D, Calhoon L. Using accelerometers in youth physical activity studies: A review of methods. J Phys Act Health. 2013; 10:437-50

 Glaser BG. The constant comparative method of qualitative analysis. Social Problems. 1965: 12:436-45

 $16.\ Braun\ V, Clarke\ V.\ Using\ the matic\ analysis\ in\ psychology.\ Qual\ Res\ Psychol.$   $2006;\ 3:77-101.$ 

17. Lau PWC, Lau EY, Wong DP, Ransdell L. A systematic review of information and communication technology-based interventions for promoting physical activity behavior change in children and adolescents. J Med Internet Res. 2011; 13:e48.
18. Moola F, Faulkner GEJ, Kirsh JA. Physical activity and sport participation in youth with congenital heart disease: Perceptions of children and parents. Adapt Phys Act Quart. 2007; 25:49-70.

19. Williams B, Hoskins G, Pow J, Neville R, Mukhopadhyay S, Coyle J. Low exercise among children with asthma: A culture of over protection? A qualitative study of experiences and beliefs. Br J Gen Pract. 2010; 60:e319-26.

20. Faulkner MS, Michaliszyn SF, Hepworth JT. A personalized approach to exercise promotion in adolescents with type 1 diabetes. Pediatr Diabetes. 2009; 11:166-74.
21. Akhter K, Zeffertt A, Evans M, Abdullah N, Pesterfield C. Development and evaluation of a pilot one-stop workshop for young adult people with type 1 diabetes.
Arch Dis Child. 2012; 97.

22. DuBois DL, Portillo N, Rhodes JE, Silverthorn N, Valentine JC. How effective are mentoring programs for youth? A systematic assessment of the evidence. Psych Sci Pub Int. 2011; 12:57-91.

23. Stock S, Miranda C, Evans S, PlessIs S, Ridley J, Yeh S, et al. Healthy Buddies: A novel, peer-led health promotion program for the prevention of obesity and eating disorders in children in elementary school. Pediatrics. 2007; 120:e1059-68.

24. Cawley JC, Cisek-Gillman L, Roberts R, Cocotas C, Smith-Cool T, Bouchard M, et al. Effect of HealthCorps, a high school peer mentoring program, on youth diet and physical activity. Child Obes. 2011; 7:364-71.

25. Sebire SJ, Jago R, Gorely T, Cillero IH, Biddle SJH. 'If it wasn't for technology then I would probably be out everyday": A qualitative study of children's strategies to reduce their screen viewing. Prev Med. 2011; 53:303-8.

26. Shields CA, Dillman C, Fowles JR, Murphy R, Dunbar P, Perry A, et al. Diabetes educators' exercise-related perceptions and practices 12 months after receiving the physical activity and exercise toolkit. Ann Beh Med. 2010; 39:S83.

- 27. Hillsdon M, Foster C, Cavill N, Crombie H, Naidoo B. The effectiveness of public health interventions for increasing physical activity among adults: A review of reviews: Evidence briefing. National Health Service, UK, 2005.
- 28. Michie S, Ashford S, Sniehotta FF, Dombrowski SU, Bishop A, French DP. A refined taxonomy of behavior change techniques to help people change their physical activity and healthy eating behaviors: The CALO-RE taxonomy. Psychol Health. 2011; 26:1479-98.
- Newton KH, Wiltshire EJ, Elley CR. Pedometers and text messaging to increase
  physical activity: Randomized controlled trial of adolescents with type 1 diabetes.
  Diabetes Care. 2009; 32:813-15.
- 30. Kirwan M, Vandelanotte C, Fenning A, Duncan MJ. Diabetes self-management smartphone application for adults with type 1 diabetes: Randomized controlled trial. J Med Internet Res. 2013; 15:e235.
- 31. Hasler TD, Fisher BM, MacIntyre PD, Mutrie N. Execise consultation and physical activity in patients with type 1 diabetes. Pract Diab Int. 2000; 17:44-8.
- 32. Faulkner MS, Michaliszyn SF, Hepworth JT, Wheeler MD. Personalized exercise for adolescents with diabetes or obesity. Biol Res Nurs. 2014; 16:46-54.
- Valentine V. Educational strategies at diagnosis and beyond, or diabetes, Type 2, and what to do! Diabetes Spectr. 2000; 13:197-200.

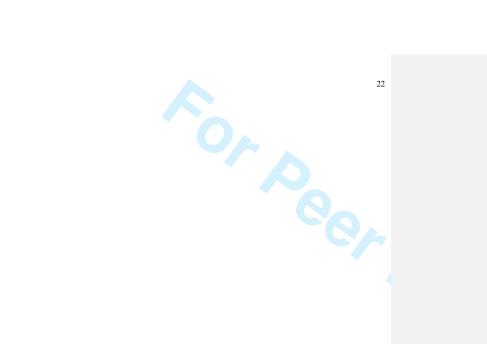


Table 1 Themes: Support/intervention target group and support/intervention delivery setting

Sub-themes	Example excerpt	<b>Considerations for</b>	Excerpt
		interventions	number
			in text
Target groups			
Parental influence changes with increasing age	'I think we [parents] try to be influentialunfortunately at this age [adolescence] you're just seen more as a hinderance than a helpsometimes we can be our own worst enemy because [we] can keep pushing at something and uhm that gives the opposite effectI 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" 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 (103P)	Incorporate parent support. The level of parental support may depend on the patient's age.	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 isSomebody 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 (101P)	Health professionals are influential due to their authoritative voice and should play a key role.	1.2a
	If you're like doing more exercise then it'll keep [blood glucose levels] down		1.2b

	which means you'll get a better reading at the hospital andyour mum and dad and the doctors [are] a bit happier.' – adolescent girl (103C)		1.2c
	If the nurse at the diabetic hospital told him [son] something I had, [he's] more likely to listen to them [nurses] thanto me [laughs] – mother of a young boy (124P)		1.20
Professionals do not perceive themselves as influential	'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 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 (109D)	Develop health professional self-efficacy to deliver physical activity and sedentary behavior messages.	1.3
Inclusion of peers	'I think if they [peer role-models from clinic] went to say the parents groups or spoke at schoolsI think that would have much more impact than any adult talkingIf a fifteen year old tri-athlete went and spoke to the diabetes UK family groupI 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 "wowIf he can do itmy child could.' – physician (109D)	Incorporate peer-support.	1.4a
	'Sometimes you want to include your friends cause they're young when I see all my friends joining in I sort of want toIf you're just by yourself and people you don't know it doesn't really make it fun.' – young girl (105C)		1.4b
	'The other thing is you know that their friends are so important to themBringing in friends and you know making, facilitating something where there is a group of them to do something.' – mother of an adolescent boy (119P)		1.4c

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 (111P)

Be careful not to single out patients with diabetes.

1.5a

'I think the main thing for me is ... I'm kind of like "right I want to show everyone" that I'm not any different from everyone else just because I'm diabetic." I want to do all the sports and I want to go to the clubs with my friends and ... everything, take part in everything. — adolescent girl (101C)

1.5b

Socialising with others with diabetes and one-to-one contact plus parental and peer support

'There was a girl in my school in primary and she had [diabetes] like when she was like really young, like 5 or something...she was just saying "oh it's nothing,"... and [she] obviously does [blood glucose monitoring] ... I like [didn't do] my sugars every day and she was saying "oh it's important." – adolescent boy (119C)

Incorporate peers with 1.6a diabetes if the patient and family are happy to do so. Balance one-to-one and 'parent plus patient' contact.

'I definitely think it would benefit them [socialising with others who have diabetes], definitely. Because, although uhm X's [daughter] got a brother who's diabetic, but if she never I think she would maybe find things a wee [little] bit strange. But having said that there is ... other kids in the school that are diabetic so she's not just out there on her own. I think if she was, then I would make a point of going to [social diabetes] things. – mother of a young girl (123P)

1.6b

'We'd went to the Xmas party once and she'd met a wee [little] girl...Uhm just a, a year younger than her. And they got on quite well and they'd started kind of emailing, but I think they were maybe just a wee [little] 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

1.6c

think it was good for her to see that there actually was other kids with the same
thing cause there's nobody in our family or anything.' – mother of a young girl
(118P)

'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 (103C)

## **Delivery setting**

Limited physical clinic

'The food and the insulin dominate and until people understand those - bringing in activity discussion at 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 (106D)

> 'When I've been to hospital, exercising has never been mentioned at all as being a big part of what she should be doing. You know yourself...it's important but it's never been sort of stressed.' – mother of a young girl (105P)

'Mmm, not necessarily they [doctors] only like, if my, if my blood sugars have been bad and they ask me what I've been doing [then] – young boy (111C)

I don't think we've ever specifically spoken about...no we don't spend a lot of time talking about exercise I don't think no, no ... more time talking about diet. Which I guess that's because, although I think exercise is important, I think diet is the most

Incorporate physical	2.0a
activity in a systematic	
way into clinic care.	

1.6d

2.0b

2.0c

2.0d

important factor in controlling uhm blood glucose – mother of a young girl (115P)



**Table 2** Themes: Support/intervention method of delivery, support/intervention components to include and address, support/intervention timing and duration and individualised approach

Sub-themes	Example excerpt	Considerations for interventions	Excerpt number in text
Delivery methods			
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 causewhether we like it or notthat's how they communicate with each otherand if you do it on their wavelength I think it's going to make a big difference.' – mother of an adolescent girl (101P)	Technology can be useful for monitoring and feedback, and for the provision of	3.0a
	'We've looked at a few things on FacebookNot on Facebook, on uhm YoutubeBecause obviously teenagers they, they feel awkward asking questions and stuff like that or, or by the time they leave the clinic, or by the time tomorrow comes, they could forget and stuff like that. So it's like, "let's just have a look on Youtube and stuff," cause there's everything on Youtube.' – mother of an adolescent boy (116P)	support networks.	3.0b
	'It's like social networks and like thousands of young people go into it so it could helpThey could help you like with advice and that In Twitter-they have like Twitter pages like sports and everything I followUhm McFly so uhm. Selena Gomez and David Beckham You could try and like copy him so that's like quite good.' – adolescent girl (108C)		3.0c
	'I think it'd be more Twitter, Facebook, these sort of big companies And the apps would be good, because there's lots and lots of children with apps. – young		3.0d

# boy (110C)

# Policing social support

'One of my concerns has always been meeting with other kids with diabetes you've, how do you police that?...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 (103P)

Ensure that support 3.1a from others with diabetes is policed to avoid inappropriate messages being communicated.

3.1b

'I don't know if X [son] would [use social networks] or not because they're doing the internet thing just now at school - "...shouldn't use Facebook, don't use Facebook, it's very dangerous."...Yeah for the older one's it'll be alright...I mean I would be quite happy to...say to him, without telling him it's Facebook that I was on..., I'd be quite happy to say to him "oh look there's somebody here that's doing what you're doing and this is what they're saying." ...And so that's on the computer but he doesn't necessarily need to know that it's Facebook.' – mother of a young boy (124P)

Technology alone is not enough to change behavior '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.' —

Other support delivery 3.23 methods should be used alongside technology.

# physician (109D)

'Everything's getting done on the social networking and everything else...but obviously having these like get-togethers every now and then would also help because it, [she] should be in touch with other kids with diabetes that she doesn't know and things like that...and...parents can share their stories and experiences.' – mother of a young girl (123P)

3.2b

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 (117P)

Offer group and or one-to-one support.

3.3a

'...[I'd prefer to] get on with it myself.' – adolescent boy (116C)

3.3b

'If it's like just by the person [patient] then, like they can take responsibility over it.' – adolescent boy (117C)

'I think it would just kind of depends on what the person wants.. .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

<del>3.3e</del>

# think.' - adolescent girl (103C)

# Components/content

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 (102D)

'Making sure that they've had enough to eat, that they've always got Lucozade or whatever there to [take on]...check a wee [little] bit more regular their blood sugars.' – mother of a young boy (124P)

'She [daughter] has to feel confident that...someone that understands is there...if it's not at school it, it's either her dad or I. She wants us there on the side-lines so she can give us a sign.' – mother of a young girl (115P)

'She's [daughter] been in a dancing class, uhm oh for quite a few years now...and I think X [daughter] just herself was petrified to go back after being diagnosed and...I probably pushed her into going to do it because I knew it would be good for her.' – mother of a young girl (105P)

'A lot of parents will be...too frightened to put their kids to certain activities for fear of them having a hypo. So a lot of it's due to confidence of the parents as well.' – father of a young boy (111P)

'I think it's uhm quite unpredictable, often what happens when they do exercise uhm. We went on a bouncy castle the other day...And we were on it for about

Co-ordinate diabetes support with the patient, their family and others working with the patient

4.0b

4.0c

4.0a

4.0d

4.0e

4.0f

half an hour and X [daughter] was, I think we were just hypo when we came of it. But...it continued - we couldn't bring her up. So it's, it's the effect that it has, and swimming can have that affect as well, **later** it seems to affect... if it's at the end of the day [risk of delayed hypo is] particularly [increased] yeah.' – mother of a young girl (115P)

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 (109D)

Educate patients, 4.1 family, and those working with patients, to build their confidence in the patient to participate in physical activity.

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 (103C)

Consider providing insulin pump therapy if available and appropriate.

'Uhm like before I had the pump and the injections it was a nightmare to take part cause I couldn't go swimming and 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 [the court] or that. And now I've got the pump I can do whatever...it's a whole lot easier to go and do stuff than it was.' – adolescent girl (103C)

4.2b

4.2a

'He's [son] more in control cause he can just take it [the pump] off and

Education on what

sedentary behavior

Goal setting and

	[unclear], put it back on [for swimming]. Uhm you know obviously it's good for, you know there's more flexibility than[X number of] injections a dayBut not everybody's on the pump and it's so hard to get just now.' – mother of a young boy (111P)		4.2c	
t r is	'Uhm I think sitting down for no reason can be a bad thing where you could be instead going out and doing exercise. But also like I think it's still important to tell people like if you're getting low not to go and run a marathon.' – adolescent girl (101C)	Educate patients and families on the definition and recommendations for	4.3a	
	'We have seen it [there's] days eh I have been too busy so we haven't gone out very much and his [son's] sugar levels have been 12 [pause] most constantly you need to sit sometimesbut you have to have a balance.' mother of a young boy (110P)	sedentary behavior.	4.3b	
	'I mean it's just you know abalancing life, I think. I mean I do know that if we, like, if she sits in front of a DVD and is on normal insulinthen 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'ss, if she's just, if she's not physically active, because of her norm is much more active, then it does, does have an affectYou		4.3c	
	don't chase around with a big stick all day.' – mother of a young girl (115P)  'I suppose it's also trying to teach them about knowing sedentary behaviorrather than having to start tennis or whateverthings that they will do rather than putting them off.' – dietitian (107D)		4.3d	
	Getting people to set goals for themselvesso it's things that they can achieve	Set realistic,	4.4a	

rewards	would be good achievable goalsfor children that don't really do anything. You know big charts and things like thatand as they reach each goal they get somea reward.' – mother of an adolescent boy (117P)	achievable targets/goals and provide	
	'So it's not just go outside and do something A target, so each time you go to	incentives/rewards.	4.4b
	the doctor then they saythis is your target for this time.' – young boy (110C)		
Linking behavior 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	Feedback to patients on the efficacy of changing their behavior/s on their	4.5a
	the HbA1c as wellSo that they can see that everything they're putting in is worthwhile.' – mother of an adolescent girl $(103P)$	health outcomes.	4.5b
	'It's quite interesting [gaining feedback]like you find out how healthy or unhealthy you are and I wannae [want to] do more, like, because I'm quite unhealthy.' – adolescent girl (108C)		
Timing			
Near diagnosis	'The things that they tell you in that two weeks [post-diagnosis] you don't ever forgetthere'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 thenI think yesthe earlier you kind of tell them that then the better.' - mother of an adolescent girl (101P)	Intervene as near to diagnosis as possible depending on the severity and experiences of diagnosis.	5.0a

'Well like getting used to like taking insulin and stuff and then you should
introduce [physical activity]so that they're like used to having all that.' -
adolescent boy (117C)

5.0b

'...I think the sooner they understand, the better.' – mother of a young girl (112P)

5.0c

"...I think right away. Yeah I mean there's obviously so much information that you get immediately but that's kind of easier and memorable one with all the kind of stuff that's going on, so yeah I mean any opportunity as soon as possible...I think probably parents feel very motivated at that point as well.'—mother of a young girl (115P)

5.0d

"...When X [son] was diagnosed as much as it was a shock we recognised it and we thought that he was [diabetic]....and [with] X's [husband being] diabetic as well. So as much as it was a shock, we also knew how to deal with it. And we could have probably spoke[n] about it [physical activity] reasonably quickly after diagnosis. But other people that maybe don't have anything, and they're trying to just take in what diabetes is about, it might be a wee [little] bit too, too quick to talk about it straight away...Maybe mentioning it to them, you know, "just because they now have diabetes doesna'e [doesn't] mean to say that they can't have their, their normal childhood," but maybe not make such a big issue about it until...they've accepted the diabetes kind of thing.' – mother of a young

boy (124C)

5.0e

Individualised approach

.t and the.
..s very hard to st.
..tely different to another...
\_s all very dependent on who...yo.
.escent boy (119P) 'Every child's different and their attitudes are different and their environment's

Avoiding a 6.0 homogenous, "cookie cutter approach."

### ID PDI-14-0-0196.R1

Please find enclosed our revised manuscript and responses to the editor's comments. We enclose: 1) clean copies of the manuscript and Tables 1 and 2; 2) copies highlighting the major changes that we have made to the manuscript and Tables 1 and 2 using the track changes 'comments' feature; and 3) a word document with a table providing the editor's comments, our response to the comments and details of changes made to the manuscript, and the track change comment number/s from the manuscript linking our edits to the editor's comments.

We are delighted that the reviewer's were fully satisfied with the changes we made in response to their previous comments and we would like to again thank them for their time in reviewing our manuscript and for their valued feedback. We have now addressed the comments from the editor in regards to reducing the manuscript word count and including suggested citations. We hope that the manuscript has been refined accordingly and that it is now at a stage for publication.

We feel our manuscript will be important for readers of Pediatric Diabetes as it provides valuable information on physical activity support needs in diabetes care and will be useful for healthcare professionals and researchers involved with young people with Type 1 diabetes.

Thank you for the consideration of our work.

Yours sincerely,

Freya MacMillan

On behalf of the authors

Comments from the editor	Response to the editor	Comments relating to changes made
We would like to see the manuscript shortened by about one-third.	We have worked hard to reduce the word count of the manuscript and have managed to cut the word count by 1188 words (from 4774 to 3586 words). Given the qualitative nature of the study we are struggling to cut the word count down further without losing important points and context. We hope the reduction we have achieved is now sufficient for publication. We have also reduced the text in the Table documents as much as possible (we have avoided removing excerpts based on having added in excerpts in response to previous feedback from reviewers, to highlight perspectives from all stakeholders, and have instead focused on reducing words within excerpts where possible).	Larger deletions are highlighted using the comments feature in track changes (comments 1, 5-15)
Consider adding the following citations to your list of references.  1. Exercise in children and adolescents with diabetes PEDIATRIC DIABETES Volume 15, Issue S20, September 2014, Pages: 203–223, Kenneth Robertson, Michael C Riddell, Benjamin C Guinhouya, Peter Adolfsson and Ragnar Hanas Article first published online: 3 SEP 2014, DOI: 10.1111/pedi.12176	We thank the editor for suggesting that we consider these citations in our manuscript. We have now included citations for the papers by Robertson et al., Nguyen et al., and Short et al. in our introduction section, as we feel the content of these papers fit well with the existing content of our manuscript.	Comments 2-4
2. Impact of regular physical activity on blood glucose control and cardiovascular risk factors in adolescents with type 2 diabetes mellitus – a		

multicenter study of 578 patients from 225 centres

PEDIATRIC DIABETES

A Herbst, T Kapellen, E Schober, C Graf, T Meissner, RW Holl and for the DPV-Science-Initiative

Article first published online: 2 JUN 2014, DOI: 10.1111/pedi.12144

3. Fitness and physical activity in youth with type 1 diabetes mellitus in good or poor glycemic control

PEDIATRIC DIABETES

Thanh Nguyen, Joyce Obeid, Rachel G Walker, Matthew P Krause, Thomas J Hawke, Karen McAssey, John Vandermeulen and Brian W **Timmons** 

Article first published online: 20 JAN 2014, DOI: 10.1111/pedi.12117

4. Postprandial improvement in insulin sensitivity after a single exercise session in adolescents with low aerobic fitness and physical activity PEDIATRIC DIABETES

Volume 14, Issue 2, March 2013, Pages: 129-137, Kevin R Short, Lauren V Pratt, April M Teague, Chiara Dalla Man and Claudio Cobelli

addressed and recommend the manuscript for publication.  Reviewer 2 comments  Thank you for the revised manuscript. You have	Response to the reviewer  Thank you to the reviewer for their time reviewing previous drafts of our	Comments relating to changes made  None applicable
publication.	Response to the reviewer	
publication.		
I have now read the revised manuscript titled 'Patient, parent, and diabetes professional perceptions on building physical activity and sedentary behavior support into care for youth with Type 1 diabetes'. I am satisfied that the points raised in my previous review have been	We thank the reviewer for their time and feedback on previous drafts of the manuscript.	None applicable
Reviewer 1 comments	Response to the reviewer	Comments relating to changes made
5. Physical activity and markers of insulin resistance in adolescents: role of cardiorespiratory fitness levels – the HELENA study PEDIATRIC DIABETES Volume 14, Issue 4, June 2013, Pages: 249–258, David Jiménez-Pavón, Jonatan R Ruiz, Francisco B Ortega, David Martínez-Gómez, Sara Moreno, Alejandro Urzanqui, Frederic Gottrand, Dénes Molnár, Manuel J Castillo, Michael Sjöström, Luis A Moreno and on behalf of the HELENA Study group		

