



## Using qualitative data to enhance our understanding of the reasons young people decline Structured Diabetes Education programmes

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Review

## Using qualitative data to enhance our understanding of the reasons young people decline Structured Diabetes Education programmes

### Abstract

**Aim:** to explore the reasons young people with type 1 diabetes decline structured diabetes education from the perspectives of the young people themselves, their parents and diabetes educators.

**Background:** structured diabetes education (SDE) programmes that are evidence based and quality assured are a key component to empowering people with diabetes to self-manage effectively. However, research reveals that uptake of structured education programmes is disappointingly low.

**Design:** qualitative cross sectional study involving participants from Northern Ireland and England.

**Methods:** Twenty young people with type 1 diabetes (13 to 22 years) who had declined SDE within the past two years, seventeen parents of a young person with type 1 diabetes and sixteen diabetes educators participated in semi-structured interviews and focus groups.

**Results:** Three main themes emerged from across all three groups: timing, access and communication issues. In addition, a lack of understanding by the referrer was cited by some young people and their parents. Diabetes educators were sympathetic and understood many of the reasons why SDE was declined. Solutions were proposed to overcome expressed barriers.

**Conclusions:** Although the expressed reasons for declining might suggest that the young people simply did not prioritise education, this study adds a more nuanced scenario to the debate. The interviews revealed the tensions that exist between people's daily commitments and their need to self-manage their diabetes. The young people and their parents must be given a much stronger sense of the importance of

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3 SDE and ways to accommodate attendance must be sought. Diabetes educators  
4 must be able to better promote the importance of SDE.  
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8 **Relevance to clinical practice:** As optimal glycaemic control is so vital for long term  
9 health there is an urgent need to understand how to respond more fully to the needs  
10 of young people who have type 1 diabetes.  
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### 13 14 15 16 **Introduction**

17 The landmark Diabetes Control and Complications Study (1993) established beyond  
18 doubt that maintaining blood glucose levels within the normal non-diabetic range was  
19 essential if long-term microvascular complications are to be avoided. Those  
20 diagnosed with diabetes need to know how to monitor blood glucose, to adjust  
21 insulin, to make wise dietary choices and to exercise safely. This is complex and  
22 demanding. Competence and confidence to manage the vicissitudes of daily life plus  
23 resilience and motivation to sustain self-management over time are all vital. This is  
24 especially important for those diagnosed when young as they will live with this  
25 condition for many years and the cumulative effects of hyperglycaemia have longer  
26 to compromise the micro-vascular system. Effective education is therefore crucially  
27 important; yet research reveals that uptake of structured education programmes is  
28 disappointingly low. This paper explores the reasons young people with Type 1  
29 diabetes choose to decline attending education from three perspectives: that of the  
30 young people themselves, their parents and diabetes educators.  
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### 41 42 **Background (literature)**

43 Structured Diabetes Education (SDE) programmes are a key component to  
44 empowering people with diabetes to self-manage their condition by maximising their  
45 knowledge, skills and beliefs in order to make the informed decisions that influence  
46 long-term lifestyle behaviour changes and clinical outcomes (Chrvala et al., 2016;  
47 DAFNE Study Group, 2002). [Murphy et al \(2007\) demonstrated that the SDE  
48 programme 'FACTS' could improve parental involvement and glycaemic control in  
49 children and adolescents. While Coates et al., \(2013\) demonstrated that a more  
50 flexible lifestyle and diet can be achieved without any detriment to overall glycaemic  
51 control.](#) However, despite the life-changing gains offered by SDE, many invited to  
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3 attend either decline the invitation or do not attend the programme having agreed to  
4 do so (Harris et al., 2017; Horigan et al., 2016). Kovacs et al (2013) report an  
5 average participation rate as low as 22.1% from an extensive international survey,  
6 but found wide variability according to country (9.4% - 90.3%). They also noted that  
7 those who did participate reported the education to be beneficial. The National  
8 Diabetes Audit in the United Kingdom (UK) reports that although there have been  
9 improvements recently in the numbers of young people referred to SDE (from 17% in  
10 2013/14 to 27% in 2015) the attendance rate remained largely unaltered (Health &  
11 Social Care Information Centre, 2017).  
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19 In the UK there has been a concerted effort to develop quality assured SDE and the  
20 provision of such programmes at the time of diagnosis and thereafter as endorsed by  
21 NICE Guidelines (guidelines NG17, 2015). Nevertheless the House of Commons  
22 Committee of Public Accounts Report (2016) described the existing model for  
23 delivering SDE as 'clunky and antiquated' and suggested it did not work for young  
24 people in its current form. The Committee proposed that to engage young people in  
25 the future, the current system needs modernising by blending peer support and  
26 online resources.  
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34 Most recent studies and reviews on the reasons for non-attendance at SDE have  
35 focused on those with Type 2 diabetes (Winkley et al., 2016; Schwenneson et al.,  
36 2016; Horigan et al., 2016; Schafer et al., (2013). In view of the lack of uptake  
37 amongst young adults with type 1 diabetes, it is timely to focus on the expressed  
38 reasons for not attending in the hope of informing alternative modes of delivery and  
39 to ensure that service provision is aligned more closely with expressed preferences  
40 and needs.  
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47 The study team included two nurses and a clinical psychologist who were advocates  
48 for SDE (xx, yy, zz). However all data were gathered and initially analysed by a  
49 researcher (aa) who had no prior involvement in SDE, who was considered entirely  
50 independent and had no conflicting interests. The composition of the team was not  
51 thought to bias the conduct of the study nor the interpretation of the data.  
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## 56 **Methods**

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3 Following ethical approval, a two-phase study was conducted. In Phase 1 a survey  
4 explored reasons for declining SDE across Northern Ireland and England (*Reference*  
5 *withheld*). To enable the survey results to be better understood we explored the  
6 issue in more detail in Phase 2 with a subset of the young people who participated in  
7 the survey, their parents and diabetes educators.  
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12 From the original cohort (n = 227) of young people with Type 1 diabetes who  
13 completed the survey (*Ref withheld*), 72.3% voluntarily agreed to take part in a follow  
14 up interview if asked to do so. Of these, a purposive sample of twenty young people  
15 aged from 13 to 22 years (n = 10 from Northern Ireland and n = 10 from England)  
16 was selected to achieve diversity across length of time diagnosed, gender and  
17 location.  
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24 To provide context the Diabetes Knowledge Test (Fitzgerald et al 1996), comprising  
25 16 multiple-choice items applicable to this study population were examined. A  
26 maximum score of 16 was achievable. The last two recorded glycosylated  
27 haemoglobin (HbA1c) results obtained from the participants' electronic clinical  
28 records were also documented (Table 1).  
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34 Additionally, 56% of the parents of survey participants consented to be contacted to  
35 take part in a semi-structured interview. Of these, 17 parents (10 from NI and 7 from  
36 England) consented to take part in interviews. All interviews were conducted either  
37 face to face in their own home or via telephone. Some elected to be interviewed at  
38 the same time as the young person but in all cases there were different topic guides  
39 to be followed. In some cases the young person and one of their parents both  
40 consented to the interviews but there were some cases in which the parent was from  
41 a different family. In addition, a convenience sample of 16 diabetes educators  
42 comprising seven diabetes specialist nurses, six diabetes specialist dietitians, two  
43 doctors and one clinical psychologist, from Northern Ireland and England  
44 participated in one of two focus groups, or provided individual interviews that were  
45 conducted in their places of work.  
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54 Each interview lasted 30-40 minutes while the focus group (FG) interviews lasted 45-  
55 60 minutes. Young people and their parents were each remunerated with a £15 gift  
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3 voucher. Diabetes educators did not receive any remuneration. The iterative  
4 development of the semi-structured interview schedule was guided by published  
5 literature, clinical experience and, crucially, from the responses given during the  
6 survey. The semi-structured interview with each young person focused on expressed  
7 reasons for non-attendance, thoughts on the information provided when invited to  
8 attend SDE and how the need for further knowledge, skills or self-management  
9 expertise was judged (Schedules appended).  
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16 Parents' interviews focused on the reasons for their child's non-attendance at SDE,  
17 their feelings about their non-attendance, how important they felt attendance at SDE  
18 was and any advice they would give in relation to referral to SDE.  
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22 The focus group interviews with diabetes educators were conducted after the other  
23 data were gathered. This enabled issues raised by young people and parents to be  
24 explored with the diabetes educators. Opinions on the barriers to SDE and reasons  
25 for non-attendance were explored. We also asked for views on how uptake of SDE  
26 could be improved and when it was thought to be the best time to introduce SDE.  
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### 32 **Data Analysis**

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35 All the interviews and focus groups were transcribed in full and underwent thematic  
36 analysis, a qualitative method used for 'identifying, analysing and reporting patterns  
37 (themes) within the data collected' (Braun & Clarke, 2006). Analysis was ongoing  
38 throughout the collection of the data, allowing emerging themes to be subsequently  
39 explored in greater detail. Audio recordings were listened to several times to ensure  
40 the accuracy of the transcription (by aa). Three members of the research team (aa,  
41 zz and xx) read and re-read the interview transcripts and extracts were then  
42 organised into categories. This process of repeatedly reading the transcripts and  
43 listening to the recordings ensured the researcher's closeness with the data.  
44 Emerging themes were compared amongst the research team and a coding  
45 framework devised. The following results are structured according to the main  
46 themes that emerged.  
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## Results

Some of the participants had very good diabetes control, others less so (HbA1c ranged from 48.5 – 102 mmol/mol) with the N. Ireland cohort having a slightly lower mean HbA1c of 71.5 mmol/mol compared with 73.8mmol/mol for the English cohort. Some participants had been diagnosed for less than two years whilst others had been living with diabetes for most of their lives. Most had a reasonably good knowledge of diabetes with mean score in diabetes knowledge test being 12.4 in N. Ireland and 14.0 in England. (See Table 1). See Table 2 for the SDE courses offered and declined.

**Interviews with Young People:** The demographic profile of participants is shown in Table 1. Three major themes emerged: timing, access and **communication issues or lack of understanding** by the referrer.

### Timing of courses

The most prominent theme was that courses were offered during school time or the working day for 4 to 6 consecutive weeks. The majority of respondents were either studying towards state examinations or at university and felt they could not afford to take that much time off, especially as they would miss the same subject each week.

*“Amm, it clashed with school times. I think it was either a Thursday or Friday and it was at lunchtime so I was missing about two or three classes in the afternoon and they were really vital” (T1143).*

*“I think the sessions were either once a week for six weeks or they were a whole week and I couldn’t afford... I couldn’t give up a whole week of university time” (T1009).*

For the participants who worked, the problem was getting time off each week for several weeks in addition to routine appointments. Many of these young people said



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3 their employers required them to be flexible or that they would not get paid for taking  
4 the time off.  
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8 *“Work is awkward to get off as I have to be fully flexible” (T1128)*  
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11 Almost all of those who were unable to attend because of school/college or work  
12 said they would go if courses were offered at the right times for them and suggested  
13 having them in the evenings, week-ends or summer time. It was also suggested that  
14 having courses available online, or partially online, would be helpful.  
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19 In addition, timing of the education post diagnosis was also considered to be  
20 important. Four participants felt SDE was offered to them at a time when they had  
21 everything under control and felt it would have been better if it had been offered  
22 within six months of diagnosis.  
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27 *“I have developed a routine now after four years. It would have made more*  
28 *sense to have the education at the start” (T1167).*  
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### 30 31 **Access issues**

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33 Accessing diabetes education was also a problem as many of the programmes were  
34 held at venues requiring participants to make long, expensive or awkward journeys.  
35 **Almost half** of the participants said their parents did not drive. **Most** stated they would  
36 attend if courses were available more locally and several suggested holding classes  
37 in their own GP surgery or online.  
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43 *“Travel, getting in and out ... amm, the venue ... it's not that we live far away*  
44 *but money ... getting in, 'cos it would have been buses or taxis and it just*  
45 *didn't really appeal to me at all” (T1128).*  
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### 48 49 **Communication issues or lack of understanding by the referrer**

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51 Most of the participants felt they were given enough information and said most  
52 referrers were very enthusiastic about diabetes education. However, **a small but**  
53 **significant number** felt they were either not given sufficient detail about what the  
54 course entailed or that the referrer did not relay the benefits of attending.  
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*“They didn’t seem as enthusiastic ... they didn’t talk it up a lot, enough for me ... feel convinced to go, like this will really benefit my diabetes cos they had told me that some people benefited a lot and it didn’t benefit others so basically, it’s a kind of a choice” (T1021).*

*“I just wasn’t interested because she didn’t seem too interested so it rubbed off on me” (T1156).*

*“She asked me once and it seemed like a push really to ask. Am, she didn’t give me no information on what it was, what I would be getting involved in or what benefits I would be getting out of it so I wasn’t really interested” (T1224).*

Those who were in transition from a paediatric to an adult clinic or were diagnosed around 15/16 years of age (n = 3) and automatically assigned to the adult services reported that they did not enjoy the experience and it influenced their decision not to attend diabetes education. **They felt they never saw the same person at clinic and had no relationship with the diabetes team.**

*“It’s not really good to be honest ‘cos every time you go in it’s someone different and you’re not seeing the same person whenever I was at the children’s clinic you always knew who you were going in to ... you were kinda excited but whenever you go in there now I would be really anxious kinda person ... I don’t know who I’m going to see now” (T1224).*

Disenchantment with the hospital service led them to decline education which was hospital based.

**A small number of** participants had some form of learning disability and did not attend the education classes offered as they believed they could not cope in groups as they would feel under pressure. They would like to be taught on a one to one basis.

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3 *“Cos I don’t like being in situations like that groups and I prefer to keep myself*  
4 *to myself basically and I don’t really like, I don’t know ... being put under*  
5 *pressure. I would with just me and the nurse like one to one” (T1 165).*  
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## 10 **Parents and Diabetes Educators**

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13 The themes that emerged from parents and diabetes educators were strikingly  
14 similar.  
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18 All agreed that SDE was a good idea, particularly those who thought their  
19 child/patient was not self-managing effectively. The majority agreed that both young  
20 people and parents alike required extra help. Parents also said they could learn a lot  
21 from the programmes that would help them to better support their children.  
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## 26 **Timing of Courses**

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30 *“The timings weren’t right. I mean I think it’s important that if you are going to*  
31 *have these things that they fit in with the child’s lifestyle you know” (Parent of*  
32 *T1 226).*  
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38 *“... didn’t go because it was bad timing and he didn’t really know much about*  
39 *it at the time...he would need more information. I didn’t know what it was*  
40 *about to tell you the truth...” (Parent of child who did not do interview).*  
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44 Diabetes Educators also recognised that timing was a barrier to attendance and  
45 were open to condensing programmes and running these outside school, college or  
46 work time.  
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51 *“You can see that from both sides, from the patients’ point of view they would*  
52 *maybe not like it during the holidays or evenings... you know, taking time out*  
53 *of school or interfering with their after school clubs and they and their parents*  
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3 *don't want it to eat into their free time but then from staffing point of view how*  
4 *do you get the resources?" (DSN'S NI Focus Group).*  
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## 8 9 **Access**

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12 *"He couldn't go because he was working, but also, it's very out of the way...-it*  
13 *would be six pounds in the taxi there and six pounds back ..."* (Parent of T1  
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221).

19 Many of the educators felt that since most adolescents are computer literate, social  
20 media aware and have instant access to information on their mobile phones, more  
21 web-based information/education should be offered. Likewise many parents felt that  
22 more effort should be put into online courses as almost all young people are  
23 computer literate. Most parents also conceded that adolescents were at an age  
24 where getting them do anything was difficult, so making it fun or appearing to be fun  
25 was a necessity.  
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## 33 **Special Requirements**

35 Several parents expressed concern that their children had an educational need that  
36 prevented them from being able to participate in group sessions or the very thought  
37 of being part of a group session resulted in severe anxiety for their child. Most of  
38 these parents reported that they were not offered an alternative. The young people in  
39 question had conditions that ranged from Asperger's syndrome, dyslexia, hearing  
40 and or speech problems.  
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46 *"It's quite a bit of a journey for us to travel and ..... wasn't really confident to*  
47 *go into a group, he would rather one to one"* (Parent of T1 128).  
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51 Some parents felt that their child's interaction with their peers at SDE would be very  
52 beneficial but one parent felt that would be the very reason he would not allow his  
53 child to attend.  
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3 *“To attend an education class at the minute with his peers may jeopardise all*  
4 *our good work... but once he begins to get older and go out with friends, have*  
5 *a drink etc... then I think SDE will be very important. Just not right now”*  
6 *(Parent of child who was not interviewed).*  
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12 Many parents felt the care and support they received from the diabetes nurses,  
13 specifically within the paediatric team, was excellent and there was always someone  
14 available day or night for advice and reassurance. Paradoxically this experience of  
15 responsive healthcare appears to have dissuaded some from attending SDE  
16 because they have access to all the help they need ‘24/7’.  
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22 *“The importance is very high. We had an instance where our child who has*  
23 *been on the pump for six months and his inset didn’t work properly and it was*  
24 *night time and during the night was really, really ill and vomiting but I was in*  
25 *contact with the diabetic nurse every hour on the hour for about six hours.*  
26 *These educational sessions are important but it’s wile hard to take everything*  
27 *in...theory is ok sometimes but you are always learning...Put online ‘cos they*  
28 *are all computer literate” (Parent of T1 223).*  
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### 35 **Improving Attendance**

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38 When asked “As a parent what advice would you give to HCPs to get more young  
39 people to attend diabetes education?” responses were mixed. Many parents  
40 suggested marketing SDE more effectively to make it appealing to teenagers. Some  
41 suggested that the word ‘education’ should be avoided altogether. Those parents  
42 who felt one to one classes would be more appropriate for their children felt very  
43 strongly that this should be an automatic option. Two parents felt that the children  
44 should be given more emotional support.  
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51 *“For me, like I said, I think there were barriers for my child even just going to*  
52 *kind of clinic appointments and when she did actually go there, she would be*  
53 *saying everything’s fine, you know, it’s kind of matter of fact, she’ going to the*  
54 *appointment wanting to get it over and done with and come back out ... em,*  
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3 *but I think kind of more ... if there was more from them kind of appointments, I*  
4 *think that would probably open the floodgates really for them wanting to, em,*  
5 *go to the educational sessions” (Parent of T1 187).*  
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11 A number of educators recognised that a readiness to learn and to self-manage was  
12 very important to attendance and that many of the young people needed to be  
13 psychologically ready to attend. It was felt a barrier could be a fear of being judged  
14 not to be self-managing adequately. A few educators felt the young person’s attitude  
15 to a referral to education was influenced to a great extent by the relationship with  
16 their diabetes team.  
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22 *“I start by finding their interest. If we can click we can start” (Member of*  
23 *multidisciplinary focus group, Leicester).*  
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27 The timing of when to refer young people to SDE was also felt to be crucial, as once  
28 they have coped in their own way for some time without apparent problems there is  
29 an inclination to feel invincible and believe the complications of diabetes will not  
30 happen to them. Hence it was felt that making SDE part of an ongoing treatment  
31 plan upon diagnosis and attending a course within six months of diagnosis was the  
32 way forward. Importantly, it was noted by several educators in N Ireland that, since  
33 referring all newly diagnosed young people to the CHOICE (Carbohydrate and  
34 Insulin Collaborative Education) programme (Coates et al 2013) clinic attendance  
35 increased significantly.  
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43 Several educators felt it was essential that practitioners who refer people to SDE  
44 should themselves be aware of what SDE involves, so they are able to convey  
45 accurately and enthusiastically the benefits of attending.  
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50 A few educators suggested that if persistent non-attenders were doing well, and their  
51 diabetes was under control there may be no need for them to attend.  
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## 56 Discussion

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3 At face value, their decision not to attend SDE might simply reflect that diabetes self-  
4 management is not a priority in their busy schedules. However, the results of the  
5 interviews undertaken suggest a much more nuanced scenario. Supplementary  
6 interviews undertaken with parents and diabetes educators illustrated the pressures  
7 and constraints that impede young people from participating in an activity that all  
8 recognise as being valuable.  
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14 Timing and location of courses was a recurrent theme for both young people and  
15 their parents. The main expressed reasons for non-attendance were missing  
16 education or work, compounded by length, time and costs of travel. Overall, the  
17 young people who participated appeared very responsible and interested in  
18 managing their diabetes but felt they did not have much choice as to when or where  
19 they attended SDE. Programmes are mostly held in hospitals and different  
20 approaches to delivery, such as a hub and spoke service, have been considered  
21 (Rogers et al 2009). The need to offer programmes out of hours or on different days  
22 across a programme needs to be explored before assuming that on-line delivery is  
23 the solution. However, it is important to be mindful that to meet the NICE (2011)  
24 criteria for SDE education the resources of a tertiary centre are often required. In  
25 addition, Type 1 diabetes is still relatively uncommon and to provide it to all young  
26 people within six months of diagnosis necessitates some centralisation (Mansell  
27 2012).  
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38 Although timing was a recurring theme we must be mindful that the complexity of  
39 self-managing diabetes, coupled with the fact that aggressive use of insulin is  
40 hazardous, means that the curriculum cannot be too compressed or over-simplified  
41 and must be delivered by trained educators (Heller et al., 2014).  
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46 For people with special needs, learning difficulties, sensory impairment or mental  
47 health difficulties an invitation to attend an educational group causes anxiety and  
48 reinforces the belief that healthcare professional do not understand their needs or  
49 abilities. It should be accepted that these programmes are not suitable for all and  
50 that for some people the complexity of the calculations of carbohydrate counting and  
51 insulin adjustment is beyond their ability. Some parents of children with special  
52 needs explicitly stated that they wanted the option of one-to-one tailored sessions.  
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3 Yet these people had been referred for group education and were judged by  
4 referrers as being suitable candidates. Greater assessment of educational need and  
5 individual circumstances is required prior to referral to SDE. Likewise, people from  
6 financially disadvantaged backgrounds might find the costs of travelling to education  
7 groups prohibitive. Consideration should be given as to how travel expenses might  
8 be reimbursed if that is found to be the only issue that stops someone from  
9 attending. There will never be a 'one-size fits all' approach to SDE and these results  
10 suggest that referrers need to be more aware of specific needs of the individual and  
11 their family.  
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19 Many raised the idea of online education as a feasible option and most educators  
20 agreed that this could work alongside their SDE group provision. This particular  
21 population is computer literate and social media aware therefore online education in  
22 the form of interactive apps, games and quizzes could be an effective and relevant  
23 means of imparting knowledge and encouraging self-management. Significant  
24 moves in this direction are already underway e.g. <https://www.t1resources.uk/home>,  
25 BERTIE online <http://www.bertieonline.org.uk>,  
26 DAFNE online [www.dafneonline.co.uk](http://www.dafneonline.co.uk) and HeLP-Diabetes (Ross et al 2014).  
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33 While the opportunity to avail of SDE on line is likely to increase, it is important to  
34 note that the opportunity to learn with others with Type 1 diabetes and the dynamic  
35 within the group is in itself an important part of its effectiveness (Lawton and Rankin,  
36 2010).  
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41 Health care professionals clearly play a crucial role in ensuring the need to attend  
42 SDE is promoted in an enthusiastic and motivating way. To do this the HCPs need to  
43 explicitly promote the gains to be achieved, especially reduction in future  
44 complications, the contents of the programmes and details about locality and  
45 schedules. The need for better branding and marketing of SDE could enhance  
46 uptake, promotion of SDE has also been advocated by Winkley et al. (2014).  
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53 Education must be integrated into the standard treatment programme and offered  
54 within six months of diagnosis, rather than an optional extra. Hurley et al (2017)  
55 suggest that self-management education is the Cinderella of diabetes care, noting  
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3 that it receives less promotion and marketing than medications and devices but to do  
4 this it requires policy support and sufficient resourcing.  
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8 Diabetes educators felt that SDE may not be absolutely necessary for individuals  
9 who were seen to be managing well with good glucose control. This would of course  
10 refer to young people who not only perceived themselves to be managing well but  
11 where the clinical findings backed that up. Against this backdrop, ongoing monitoring  
12 and self-management support would still be essential to ensure ongoing control.  
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17 The strength of this study is that it used semi-structured interviews to elicit the views  
18 of young people with type 1 diabetes, their parents and HCPs. The group of young  
19 people interviewed varied in terms of age, diabetes control and geography.  
20 Nevertheless, common themes emerged. There was considerable convergence of  
21 views between young people, parents and educators in relation to influences on non-  
22 attendance and how things could be improved by tailored approaches and  
23 development of online education.  
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30 This study helps negate any impression that declining SDE is a sign of disengaging  
31 with self-management but rather that these young people are often trying to deliver  
32 on many fronts and diabetes is only one of many competing priorities. Nevertheless,  
33 the goal of supporting self-management and improving clinical outcomes remains  
34 urgent, particularly in the minds of healthcare professionals with responsibilities to  
35 ensure that changes are made to SDE to enable it to be more appealing and  
36 available to all people within six months of diagnosis.  
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### 43 **Limitations**

44 It should be noted that while these young people implied that it was mainly external  
45 factors that affected attendance there may have been more internal reasons borne of  
46 their beliefs about attending SDE that may have not been disclosed during the  
47 interviews. If this was the case then other more personal solutions would be  
48 warranted. Cradock (2017) urges diabetes educators to explore the thoughts and  
49 feelings of those with diabetes before attempting to change behaviours and it is  
50 noted that such perspectives were not explicitly probed in these interviews. This  
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3 view indicates that online provision of SDE will not be a panacea to solve all issues  
4 relating to non-attendance.  
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8 The individual interviews were conducted by both telephone and in person. While  
9 this might have led to differences in style the researcher was mindful of this  
10 possibility and aimed to be as consistent in approach as possible. Each interview  
11 commenced with approximately 10 minutes of 'warm up' questions to help put all  
12 participants at ease.  
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17 It was noted during the analysis that accessibility of education was an issue. The  
18 participants' different geographical locations were not probed specifically during the  
19 interviews but in retrospect this may have been of interest.  
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## 23 24 **Conclusion**

25 This qualitative study offered the opportunity to gain direct information from young  
26 people with Type 1 diabetes and showed that they may not take up SDE due to  
27 timing and location of courses that require complicated travel arrangements.  
28 Discussion with those young people, parents and diabetes educators revealed that  
29 online modes of education should be explored alongside consideration being given  
30 to tailored approaches to individuals with specific needs. The use of interviews  
31 provided more depth of understanding to a complex issue than is possible through  
32 survey methodology.  
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## 42 **Relevance to clinical practice**

### 43 **'What does this paper contribute to the wider global clinical community?'**

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45 • Young people with type 1 diabetes frequently decline SDE because doing so  
46 would have a detrimental effect on their studies or because their working lives  
47 do not afford them sufficient flexibility to attend courses.  
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50 • Some people referred for SDE have special needs, learning difficulties,  
51 mental health problems or financial difficulties that make it impossible to  
52 attend. Referrers need to get to know their patients better as they may require  
53 individual provision.  
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- Parents and diabetes educators recognise the value of these courses but also recognise that the responsibility for deciding whether to attend lies with the young people themselves. It was felt that marketing and the use of online technology have the potential to influence the decisions young people make.

For Peer Review

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**Table 1. individual characteristics of those who participated in the interviews**

| Participant ID (n = 20) | Gender | Location         | Age(y) | Mean HbA1c % | Mean HbA1c mmol/mol | Years diagnosed | Diabetes Knowledge Score |
|-------------------------|--------|------------------|--------|--------------|---------------------|-----------------|--------------------------|
| T1 009                  | Female | Northern Ireland | 18     | 8.9          | 73.0                | 14              | 14.0                     |
| T1 011                  | Female | Northern Ireland | 17     | 8.3          | 66.5                | 10              | 12.0                     |
| T1 021                  | Male   | Northern Ireland | 14     | 8.1          | 65.0                | 1               | 13.0                     |
| T1 128                  | Female | England          | 18     | 7.5          | 58.0                | 8               | 14.0                     |
| T1 143                  | Male   | Northern Ireland | 15     | 11.0         | 96.7                | 1               | 11.0                     |
| T1 146                  | Female | England          | 21     | 9.3          | 77.5                | 8               | 15.0                     |
| T1 150                  | Female | England          | 20     | 11.5         | 102.0               | 3               | 13.0                     |
| T1 152                  | Male   | England          | 13     | 11           | 97.0                | 12              | 14.0                     |
| T1 156                  | Female | England          | 20     | 10.7         | 93.0                | 3               | 13.0                     |
| T1 165                  | Female | England          | 15     | 7.4          | 57.5                | 2               | 15.0                     |
| T1 166                  | Female | England          | 16     | 7.1          | 54.5                | 2               | 15.0                     |
| T1 167                  | Male   | England          | 22     | 9.4          | 79.0                | 1               | 15.0                     |
| T1 173                  | Male   | England          | 16     | 9.0          | 74.9                | 8               | 16.0                     |
| T1 187                  | Female | England          | 17     | 6.6          | 48.5                | 2               | 12.0                     |
| T1 200                  | Female | Northern Ireland | 22     | 6.8          | 50.5                | 2               | 15.0                     |
| T1 221                  | Male   | Northern Ireland | 17     | 7.8          | 61.7                | 3               | 12.0                     |
| T1 223                  | Male   | Northern Ireland | 16     | 8.7          | 71.5                | 8               | 14.0                     |
| T1 224                  | Female | Northern Ireland | 20     | 7.6          | 59.6                | 19              | 14.0                     |
| T1 225                  | Male   | Northern Ireland | 13     | 9.3          | 78.0                | 9               | 7.0                      |
| T1 226                  | Female | Northern Ireland | 16     | 10.0         | 86.0                | 1               | 12.0                     |



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**Table 2. SDE Courses that were offered and were declined in both N. Ireland and England**

| <b>SDE course offered and declined</b>                           |  |
|--|--|
| <b>N. Ireland<br/>(n = 10)</b>                                   | <b>England<br/>(n = 10)</b>  |
| <b>Carbohydrate and Insulin Collaborative Education (CHOICE)</b> | <b>Year 10 Structured</b>  |
|  | <b>Dose Adjustment For Normal Eating (DAFNE)</b>   |
| <b>Bournemouth Type 1 Diabetes Education Programme (BERTIE)</b>  | <b>Child and Adolescent Structured Competencies Approach to Diabetes Education (CASCADE)</b> |
| <b>Southern Health adjusting insulin round eating (SHAIRE)</b>   | <b>Structured diabetes education for type 1 diabetes (SELECT)</b>                            |
| <b>Dose Adjustment For Normal Eating (DAFNE)</b>                 | <b>Dose Adjustment For Normal Eating (DAFNE)</b>   |
|  | <b>Flexible Adjustment of Basal Bolus (FABB)</b>   |

## Appendix 1 – Interview Schedule

### Exploring engagement with structured diabetes education amongst young people with Type 1 diabetes in order to enhance future service provision.

#### *Interview topic guide for phase 2*

Note: The contents of this topic guide may be revised in light of issues identified during interview.

**1) Can you begin by telling me about yourself from when you were diagnosed with Type 1 diabetes?**

-How did you feel when you were diagnosed?

How others around reacted e.g. parents, siblings, peers?

**2) How have you managed with your diabetes up to now?**

Tell me about all the things you have to do to manage your diabetes?

Has that changed over time?

Does anybody help/support you to live with diabetes?

Would you welcome more, or a different kind of help/support?

What has been the hardest thing about having diabetes?

What is the easiest thing about having diabetes i.e. has it brought any positive aspects to your life?

Has that changed with time?

**3) What is it like for you at school/college/work, socialising with your peers?**

What is it like for you to balance diabetes with all your other everyday activities?

**4) How often do you see Health Care Professionals for you diabetes?**

Who would you see the most frequently?

How would you describe your relationship with your HCP?

What is your view on the advice and support you have received to date?

**5) Do you remember being invited to SDE?**

-What did you think diabetes education would entail i.e. what is its goal?

-Why did you decide not to attend SDE?

-Where you given enough information to make an informed decision?

-Did whoever invited you seem enthusiastic about SDE?

-What was your first thought when you were invited?

-Do you think it was the right time for you?

**6) What is your blood sugar control like at the minute: what was your last HbA1c result?**

-Is that something you would like to change?

-In terms of your diabetes control what is your goal?

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