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**Young people with diabetes and
their peers - an exploratory study
of peer attitudes, beliefs,
responses and influences**

Final project report to Diabetes UK

May 2014

Principal grant holder: Dr Joanna Brooks

Centre for Applied Psychological and Health
Research, Institute for Research in Citizenship and
Applied Human Sciences

1. Final report to Diabetes UK

2. Appendices

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Final Report

Diabetes UK requires that annual progress reports are provided as part of the Terms and Conditions of award. This report must be received for Diabetes UK to release the final quarter payment. Please take time to complete this form thoroughly and return an electronic copy to research@diabetes.org.uk and a signed hard copy to: The Research Team, Macleod House, 10 Parkway, Camden, London, NW1 7AA.

If you have any queries please contact us on the email address above or on 020 7424 1076.

Part 1: Project Details			
Project BDA number	12/0004515		
Principal grant holder's name	Dr Joanna Brooks		
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Type of project (project, studentship fellowship)	Small grant		
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Part 2: Progress report
<p>Please provide a detailed report describing the progress of the research, the extent to which the original aims and objectives of the research have been achieved and the scientific and/or technological achievements of the research. This should be not more than six pages of A4.</p>
<p>Purpose of the research</p> <p>The United Kingdom has one of the world's highest rates of type 1 diabetes diagnosis amongst children aged up to 14 (Patterson et al., 2014), and the condition is amongst the most common forms of chronic illness affecting young people in the United Kingdom (Murphy et al., 2006). Failure to achieve optimum control in adolescence can lead to poor diabetes outcomes in adulthood, but it is known that managing diabetes can be very difficult for young people. Despite a focus on improving services for young people with diabetes (Department of Health, 2001, 2007), more than 85% of children and young people with the condition did not achieve target HbA_{1c} levels according to a recent audit (NHS Information Centre, 2011). Kime and Carlin (2012) identified large variations in the support currently provided to young people with diabetes, and suggest that a number of aspects of care including psychological support and school involvement need addressing to improve service provision.</p> <p>It is well recognised that peer relations are increasingly important through adolescence generally as young people spend more time outside their home environment and look towards peers for information on behavioural norms (e.g. Collins & Laursen, 2004; Anderson & Wolpert, 2004). For young people with diabetes, peer relations may play an influential role in determining how young people with diabetes think about and manage their condition. Peer group relationships and pressures are likely to impact considerably on young people with diabetes in terms of a variety of outcomes including management and psychosocial well-being (e.g. La Greca et al., 1995). In general, peers are reported to be an important source of both practical and emotional support for young people with diabetes (La Greca et al., 1995; La Greca, 1992; Shroff Pendley et al, 2002; Carroll & Marrero, 2006; Newbould et al, 2007). However, peer lack of understanding and intrusive behaviours (for example, questioning management routines) can be troubling for young people (Carroll & Marrero, 2006; Olsen & Sutton, 1997) and impact on treatment adherence behaviours (Hains et al, 2007). Helgeson et al. (2009) identified peer relations as being related to metabolic control in a four year longitudinal study of adolescents with Type 1 diabetes.</p>

However, there is little known about the beliefs and attitudes of adolescent peers towards those with diabetes. This knowledge is a crucial first step towards elucidating mechanisms by which peer beliefs and subsequent behavioural responses may impact on adolescent diabetes patients. The aim of this research was to explore what the peers of young people with diabetes know about the condition, and their attitudes and responses to it. Specifically, the research objectives of this project were:

- (1) To elicit amongst a small sample of young people with diabetes their experiences with regards to peer responses and attitudes towards the condition using in-depth interviews;
- (2) To elicit amongst a small sample of young people who have friends with diabetes their understandings of, beliefs about and attitudes towards the condition using in-depth interviews;
- (3) To elicit amongst a larger sample of young people in a school setting their understandings of, beliefs about and attitudes towards diabetes using focus group discussions;
- (4) To summarise these findings so that they can be used as an evidence base to design educational interventions aimed at increasing awareness and knowledge of diabetes amongst young people.

Overarching research methods and analysis

Appropriate ethical and research governance approval was obtained. For the interview stage of the study, patient participants were recruited from a NHS diabetes service for children and young people and friend participants were nominated by patients. For the focus group stage of the study, three focus groups were held with secondary school pupils from West Yorkshire. All participants provided informed written consent before participation, written parental consent was also obtained. Interviews and focus group discussions were audio recorded and transcribed. All transcripts were analysed using the template analysis style of thematic analysis (e.g. Brooks & King, 2014). In this, themes are organised in hierarchical clusters, with the broader in scope encompassing the more specific. Final templates for both stages of the research are included in the appendices.

Study part 1: interviews with patients and friends

A total of 10 patients and 10 friends (same sex dyads, 7 female and 3 male and all aged between 13 and 16) participated in the study (full participant details are in table 1 – see appendices).

All participants generally felt that there was limited awareness of diabetes amongst their peers.

Ruby (friend): *I don't think they (peer group) know anything (about diabetes) unless, well like unless they know someone who had it.*

Grace (patient): *They probably wouldn't even know the difference between type one and two and then they wouldn't, they probably wouldn't know that I have to like have injections and stuff*

Lily (patient): *I've been talking to like a few other friends, I mean I don't talk to them about it all the time, but they literally don't know anything about it, which I don't think is very good because it's like they need to know, they need to be aware of it, they need to know about it.*

Patients reported that they tended to discuss their condition only with their closer friends rather than their peers more widely. Close peer knowledge seemed to provide patients with the confidence that, should they need assistance in relation to their diabetes, these close friends would be able to help.

Robert (patient): *I've only really told my closest friends, but yeah, I just tell like if I have a hypo, then there's glucose tablets in my bag*

Interviewer: *Do you think your friends are important to you in helping you manage your diabetes?*

Danielle (patient): *Yeah because if anything happens, they'll be there and they'll know what to do.*

However it was apparent from the interviews that whilst all close friend participants knew something about the condition and were aware that the patient had diabetes, they varied quite considerably in the extent of their diabetes knowledge – ranging from the detailed and specific to (more frequently) the rather vague and ambiguous.

Milly (friend): Well I know like how much carbs is in like what food, not like every food, but like more than most people probably, yeah. I know that she has to do a set change every like, like three days or something. I know that if the attachment thing, the pump, like comes off like it did that time, then she has to put another one on. I know about, oh yeah, blood sugars, what's high, what's low, what it should be. I know like what's like her pancreas and stuff, that's why she can't get insulin.

Lola (friend): I think there's two types of it where you like, you've got too much sugar and too little sugar and its basically where they inject summat, I don't know what it is, to increase it or lower it

Amy (friend): I have gone online once, just because when Lily went into hospital, it was a bit like oh my god, so I did go online like once, but that's about it.

Close friends reported providing both practical and emotional support to patients. Obvious emotional support was more evidently prevalent amongst female dyads – six of the seven female friends interviewed highlighted the importance of looking after the patient in this way - but close friends tended to simultaneously emphasise that the patient was no different because of their diabetes.

Beth (friend): Just like don't make a big deal out of it because then they feel like, like they're different, like completely, you know what I mean, like they're not like everyone else and they don't fit in and stuff and that's not really, they are pretty much the same ... I know it would be like nice to know that you've got someone there, but I don't, I don't think that if someone's always there going are you alright, are you alright, then they're like yeah, I can do it myself, do you know what I mean, yeah.

Keira (friend): I do feel a bit more protective of Paige kind of because I don't like want her to get hurt because of her diabetes or anyone to think like differently about her because she's got it because she's still the same person.

Diabetes was recognised as an important part of the patient's life, but given that patients themselves expressed considerable antipathy towards having particular attention drawn towards them or their condition, normalisation and acceptance of the condition by close friends was appreciated. Close friends evidently provided pragmatic support in various ways, including keeping patients company as well as providing reminders of management tasks.

Jade (patient): You don't want to really make a massive deal, because you are the same, it's just you've got one thing else to deal with... it's not like you should always be like 'Oh yeah, I'm diabetic, oh I need all this help' [**Milly (friend):** 'Make way for the diabetic!'], yeah, because other people have different things as well, it's not just you. But then, like when my pump came out, Milly like held it together when I was freaking out [**Milly (friend):** Yeah, if it happens, you get quite worried don't you] so that's like pretty, yeah that's really good.

Lola (friend): At dinner time and stuff, I usually go down with her to the medical room where she does her injection and yeah and remind her, yeah sometimes I do, more independent now, she goes down on her tod and sometimes after she's ate, you have to remind her to go do it because she's slack.

Joe (friend): Before, when he didn't have the pump, I used to go with him when he had to go every lunch, that was meant so he didn't get bored

Beth (friend): She goes very white like [**Ali (patient):** Like a ghost], yeah or she'll, she won't look like, she won't be her usual like really happy bouncy self so then I'll be , 'Ali, are you ok?' and then I'll be like 'What was your blood like?', I'll ask her what was it. So that's just like the really obvious ones, then without even looking, then I'll just be able to say 'Get it Ali, you need to now, it's time'.

Experiences of support offered in the school environment varied enormously, with just over half of participant dyads reporting supportive and informed responses to diabetes by their schools.

Lily (patient): I had, when I first like went back to school, I had a meeting with like my head of year and my PE teachers because of sport and my form tutor and we all had like a chat about it, how like where to keep like all my medication and what to do with it and make sure they're aware if I'm low or high, like what to do and stuff

Alfie (patient): I've got like a card which says if I'm low that I have permission to go out and things.

Ali (patient): It's been useful like, the school like for lunches, this person came at Christmas to like work out, like nutrition in all like the foods in the canteen and that's like on display now. So I know like what carbs are in exactly, so that helped me.

However, there were a number of far less positive experiences of managing diabetes within the school environment reported. The extent to which schools permitted patients to have friends accompany them in matters relating to condition management varied widely. Some schools insisted on the patient being accompanied by a peer whilst others would not allow the patient to have friends with them. There was also inconsistency amongst staff implementing school policies in this regard which could be distressing for patients.

Aaron (patient): The woman in the medical room says if I feel low or if I want to go to the medical room, I'm allowed to take someone with me, but it's just the teachers that don't let them out.

Interviewer: So have you or have other friends ever sort of cut in and said 'Excuse me Miss...'

Aaron: Yeah this happened on Wednesday.

Gary (friend): Yeah, it's not just then though, it's happened loads of times.

Aaron: Last Wednesday the teacher wouldn't let us go, so like two of my friends had a go at the teacher.

Keira (friend): There was like one time when our maths teacher, she didn't let, well she let Paige go, but she wouldn't let me come with Paige.

Paige (patient): I have to go with a friend to the medical room.

Keira: And she wouldn't let me go.

Paige: And then I got upset

Patient participants disliked having to leave the classroom setting on their own ('I think everyone thinks I'm weird when I have to leave the classroom early'). Allowing patients to have company was welcomed, with participants seemingly indicating that patients were more likely to adhere to management tasks and behaviours if they were allowed company.

Aaron (patient): I get to go five minutes early for my injection and then I have a little pass saying I'm allowed to go to the front of the queue because I'm a diabetic student but no-one's allowed to come with me so I just like stand in the hall waiting for everyone to come.

Danielle (patient): If I feel low and I want to go and the teachers like say you're not allowed to go out and all that, or they'll go and get your house leader, but then the house leaders already know, but this teacher still doesn't let you go, so I just have to walk out. You don't just go sit back down, if you need to go, you need to go. And the more you're standing there arguing with the teacher, the more lower you get, so you get more weak.

Lily (patient): I get to skip the lunch queue and bring a friend with me, and at lunch, the queue's really long, so it's good.

Paige (patient): I've got like one or two teachers that let me just go out on my own, the rest of them are like why do you need to go, have you got a note.

Several participants felt that their teachers were largely ignorant around diabetes. School nurses were repeatedly identified as advocates, but often participants felt that, despite the efforts of school nurses, teachers were concerned first and foremost with the teaching curriculum rather than pastoral care, including diabetes.

Danielle (patient): She (the school nurse) keeps emailing all the teachers, but none of them really read them. They had a meeting a couple of years ago and like it was alright for like two month and then it just all dropped again.

Paige (patient): The medical woman, she knows everything about it.

Interviewer: Right, ok, and your head of year you said knows as well.

Paige (patient): Yeah, well he doesn't know much about it, but if I don't go to the medical room in time, the medical woman always comes looking for me

Ruby (friend): When the teachers have talked about it, they don't really know that much about it.
Grace (patient): Yeah, they only know what they need to know for the teaching basically

Aaron (patient): Teachers at school, they get emails every week from the woman in the medical room to tell them about us diabetic kids, but they just like delete it, they don't read it at all. They don't know nothing about it. Because they probably don't think it's important, they're more bothered about the work.

Danielle (patient): Diabetic nurses have been to talk to the school loads of times and it just doesn't change nowt.

This could lead to patients being singled out in lessons as an expert in diabetes – a position all patient participants were unenthusiastic about assuming.

Simon (friend): In biology classes, when we do something on diabetes, then Miss will usually just ask Rob about it.
Robert (patient): Yeah, like in biology, it was as Si said, kind of asking me about it and I didn't really want the attention of it really.

Danielle (patient): Teachers, like my science teacher were trying to teach us, but he said he doesn't know much about it, so if I'm telling it wrong, you can just jump in and tell them all.

Paige (patient): People want to learn stuff in science about it (diabetes), they all just turn and ask me what to do.

Participants made a number of recommendations for improving education about diabetes in schools. The misconception that people with diabetes cannot eat foods containing sugar was chief amongst erroneous beliefs held by peers identified by participants. Videos and cartoons were suggested as accessible ways in which to impart information. The transition from primary to high school was identified as an important time for young people with diabetes, and perhaps an appropriate point at which to run education sessions.

Danielle (patient): When you're in high school, it's like you just want to do whatever you want to do. So you just like don't really pay much attention to it at first, but they you like realise you've got to be more sensible with it, with your friends. Because in high school, you don't have like primary school, where it's all like teachers like proper taking care of you. But in high school, you've got loads of different classrooms to go in, so you've got to do it all yourself.

A frequently mentioned suggestion was that sessions with older peers with diabetes (late teens/ early twenties) would be well-received.

Grace (patient): Teachers only know what they need to know for the teaching basically, whereas if it was like someone who had it but not too old, you could ask questions about this and that and they actually know about it personally instead of just being told to teach it.

Simon (friend): Someone that's kind of experienced it or like has like seen someone experience it is probably the best thing. Teachers haven't really like got an, like the understanding of it, but like nurses and people that actually have it, yeah.

Bella (friend): I think like it should be someone who like you'd respect because they properly know about it but like not too old so it's not like they're just lecturing you cos it's like their job and they have to do it. Like in science you might get taught about it but it doesn't make it real, it doesn't really feel like it's Sallv you know

Milly (friend): But I think people maybe not who've studied it or worked with it, but maybe who have had experience with friends or something because they actually know like more about it and what happens like everyday life, it might be easier like that.

Study part 2: focus group sessions

Three focus group sessions with a combined total of 15 participants were held with Year 8 and 9 students from West Yorkshire secondary school establishments (see table 2 for participant details). The focus group sessions were designed with the help and feedback of two young people with experience of diabetes and one parent of a young person with diabetes to ensure accessibility and relevance. The sessions were structured as follows (the materials used are included in the appendices to this report):

(1) What do you know already? Participants were asked to write down three words on separate post-it notes that they associated with the term 'diabetes' – these were then attached to one large (A1) piece of paper in the middle of the group and discussed amongst all group members;

(2) What would you do? Participants were given realistic vignettes of situations involving young people with diabetes (developed from stage 1 of this work) and, as a group, discussed the situations described from the viewpoint of different actors;

(3) Basic information and myth busting. For the myth busting section, statements (identified from stage one of the research as misconceptions encountered by young people with diabetes) were printed out in large font and laminated so that the students were able to group them into 'true' and 'false' prior to discussion. The session concluded with some basic information about diabetes.

Participants had all heard of diabetes, and associated it with sugar, but unless they knew someone with the condition they had little other knowledge about the condition. Participants who were more knowledgeable all attributed this to knowing a peer with type 1 diabetes.

- *There's two types, there's type one and type two, I don't know which one is which, but there's like, is there one if you're like, if you get overweight, you can get diabetes and then there's another one.*
- *I don't know what the difference is between type one and type two.*
- *I thought one was like you need sugar and then the other one you need less sugar.*
- *I think they did a bit of that when we did like glucose in science and stuff, but I've learnt more about it from like people that have it than like the lessons*
- *Diabetes might have been mentioned, but not described to us.*
- *But a lot of us like know what it is and why people get it.*
- *We don't really know, but we presume we know, so.*
- *We have an idea of it.*

[FROM FOCUS GROUP 1]

Nonetheless, the groups all engaged well with the focus group discussions. Participants were able to reflect sensitively on the experience of living with diabetes for someone of their own age in discussion based on the vignettes. They reflected on how they thought living with a chronic and incurable condition might well be frustrating, and how adolescents with diabetes might feel embarrassed about being different to their peers – they thought that this might lead to patients potentially failing to manage their condition properly because they did not want to acknowledge it or talk about it.

- *It's like you have to behave yourself really, really well all the time and all you get is normal life*
- *They (person with diabetes) will want to feel independent and if they don't want to talk to anyone about it, maybe they just want other people to forget, pretend like that she hasn't got it and make her feel like she hasn't got it and like she can be as independent as everyone else and stuff.*
- *Yeah, just like skip something you need to do, they'll think oh I'll be alright this time, I'll just skip and do it next time.*

[FROM FOCUS GROUP 2]

Participants empathised especially with how managing diabetes might impact on young people's normal efforts to establish an autonomous and independent identity through adolescence.

- *Oh god, you can just imagine how the parents are always looking over then to make sure they're ok, but they want to be like their own person and have fun and they can't if their parents are watching their every move*
- *Or like teachers, you'd be so put off, I wouldn't even want to go to school*

[FROM FOCUS GROUP 1]

Participants appreciated how being or just feeling conspicuously different to others was unwelcome for people of their age. Being 'different' was seen by all the groups as an enticement to potential bullies, and it was suggested that having diabetes may thus provide an easy target.

- *I think that some people might be a bit horrible about it, like bullies and stuff, like that could pick on them because of they're different like, yeah, so some people are like that and if they're different then someone picks on them*
- *I just think some people in high school can be horrible.*
- *Like if they don't like you, they'll just say anything about you, like they'll pick out anything that they can think of and just use that as something to pull you over.*

[FROM FOCUS GROUP 3]

Participants tended to take one of two approaches to this. Some participants felt that people with diabetes should conceal their condition and management tasks:

- *She could like take her test separately, so like they're not all staring at her in class. Like just don't do that in front of everybody in public. It is a bit like gross. Go to the toilets. We don't need to know.*

[FROM FOCUS GROUP 2]

Others argued that more knowledge and openness regarding the condition would normalise it amongst the peer group.

- *Because like people know about asthma and everything don't they, they just kind of accept it and it's just not a big deal, so I think that people just need to learn more about it to accept diabetes.*
- *Yeah like I think if people learnt more about it, they'd just act as if it was like asthma, you know, just like a normal everyday thing.*

[FROM FOCUS GROUP 3]

One group had a peer in their class with the condition and reflected on this as an example of how, once they knew about diabetes, they quickly became accustomed to this:

- *I think they was at first, you know like when new people came up in year seven, just like wondering what he was doing and then I think everyone's just used to it now.*
 - *You tend just not to like notice him and get on.*
 - *Darren's treated just normally isn't he.*
 - *Yeah because I sometimes forget about Darren's actually got diabetes.*
 - *I do.*
 - *We'll be just in class and I'm like oh yeah, he has got diabetes.*
 - *We see him doing something and oh yeah, I forgot about that.*
- I suppose though if we know people that have actually got diabetes, like I'd never really seen it before, and then when I saw him with it, I was like, I didn't really think of it as any different really, I just thought of it the same, he just needed to do summat.*

[FROM FOCUS GROUP 2]

Whilst some participants felt that it was the responsibility of young people with diabetes themselves to disclose information about their condition, others felt that this information should be provided in school lessons, but again suggested that teachers were not necessarily the preferred source of information.

- *People would be like staring but it would be like 'What's she doing? What's this for?' They're probably wondering what's going on.*
- *Maybe she should just tell them what she's doing.*
- *Explain to them, like what it is.*
- *She definitely needs to tell her friends, she can't just keep it to herself because if she did tell her friends, then her friends would be more aware.*
- *They could help her out.*
- *It's better if you tell them because if they end up finding out, they'd be like why didn't you tell me, then they'll not like you even more.*
- *It's like her choice if she wants to tell people she has it.*
- *Yeah, but she could just tell them about it, like let them know what she's doing and stuff so they're used to it.*
- *I'd feel like people were being nosey if they kept asking me about it.*
- *I think it should just be part of what we learn about like in school, don't like single someone out, that's well unfair*

[FROM FOCUS GROUP 1]

- They could do something like this, like have a lesson about diabetes and stuff
- Someone who has diabetes could like come and tell us about it.
- Because it gives it a change of like just the teacher talking and then it just sort of shows what their point of view is as well.
- Yeah, because maybe it would be good to like hear about what it's actually like rather than a teacher just telling us about what it is.

[FROM FOCUS GROUP 2]

A number of participants also expressed a worry that, whilst wanting to understand and help a peer with diabetes, they felt that they did not currently know enough about the condition and would be fearful of doing or saying the 'wrong' thing. They felt that more information about the condition would enable them to better support peers with the condition.

- Just because like if it (diabetes) would be like new to them (peers), they wouldn't know what to do.
- I think that they (diabetes patient) probably need to talk about it, I don't know how you'd make them talk about it though.
- Because you might have tried to make the person feel better, but actually made them feel worse. Like if someone's trying to think they know what's best for them and help them. They might get proper angry.
- I can understand where that were coming from though if they respond like that though. I suppose if everyone were looking and pestering, I'd probably do the same after a while.
- I'd probably feel a bit disappointed in myself then, I'd feel a bit guilty that I asked, as if like it offended her or something.

[FROM FOCUS GROUP 1]

Please describe the main conclusions you have reached from the research.

The findings from this research show the important role played by peers in the lived experience of managing Type 1 diabetes for young people with the condition. As far as we are aware, it is the first study of its kind to specifically explore what the peers of young people with diabetes – both close friends and other peers – know and think about the condition, and how they respond to it. An important finding is the reported disparities in support offered in the school environment to young people with diabetes. Our findings are in line with those of Kime and Carlin (2012), and support their suggestion that that greater consistency in school policies and practices is needed for improved diabetes care amongst adolescents with the condition. Some of our patient participants were clearly well supported at school by teaching staff and it was our impression that these patients were both more comfortable and successful in dealing with their condition, and more open with regards to their diabetes and its management with their friends and peers. School nurses were consistently identified as a source of support with regards to diabetes management, but the attitudes and knowledge of teachers were reported to vary considerably. Kime and Carlin (2012) suggest that *'a standardised, formalised protocol in respect of diabetes management within schools needs to be introduced to ensure consistency. This needs to be enforced through a joined up approach between the education authority, health and social care, involving diabetes specialist nurses, dieticians, health psychologists, social workers, school nurses and children, young people and parents'* (page 34). Our research suggests that educating peers about diabetes in the school environment may also help young people with the condition – through both encouraging the school to focus more on the condition and thus hopefully their policies in this context, and through increasing awareness amongst both pupils and teaching staff. A theme repeatedly talked about by all participants in both stages of this research was how increased awareness through education about diabetes and experience of the condition was believed to 'normalise' it, meaning that patients were less likely to be the focus of unwanted attention.

Findings from this study suggest that more education about diabetes amongst young people is needed, but also encouragingly that this would be welcomed by young people themselves. The educational materials we piloted as part of this work were well received and easy to use. An interesting suggestion that was made in both parts of the research was that older expert peers (people with Type 1 diabetes who had recently been through secondary schooling) would be well received as those delivering such sessions. Young people were also positive about the use of video materials in educational sessions. The implications of these findings are explored in the section below ('plans for future research').

<p>Have there been any deviations from the original research plan? If yes, please give details.</p> <p>In the original research plan, we intended to interview diabetes patients and their friends separately. However, after discussion with members of the steering group, it was decided to interview patients and their nominated friend together. This decision was taken as we wished to avoid young people feeling ill at ease about 'being talked about' by the researcher and their friend. We also felt that young people, unused to participating in research interviews, might feel more comfortable taking part with a friend.</p> <p>We originally intended only to run focus group discussions with our school participants rather than piloting any educational information or materials. However, we felt very uncomfortable about potentially encountering misconceptions about diabetes in the school environment and then leaving the group without resolving these. We therefore concluded the focus group discussions with some basic information about diabetes, as well as making sure that any erroneous beliefs that had been expressed in the focus group discussions had been resolved using the 'myth busters' section of the group.</p>
<p>Please describe any problems you have encountered during the project.</p> <p>We under-recruited by two participants in the interview stage of the work in our efforts to recruit an even split in terms of participant gender, but our sample is made up of more girls than boys. Ethnic minority participants are also under-represented amongst our participants. We were not able to access any information with regards to ethnicity in the patient information details we were allowed to access for the purposes of recruitment so were unable to purposively sample on this basis. We made every effort to recruit male participants to the study, but were repeatedly unsuccessful. Adolescent males were less willing to take part in a research interview about their diabetes and their social world than their female counterparts. There were a number of occasions when parents of boys contacted the lead researcher saying how keen they personally were that their son take part on the research, but that he was unwilling to do so. It was the lead researcher's strong impression, especially in conversation with parents, that peer issues are not unimportant to adolescent males, but that they evidently find it more difficult/ less appealing than their female peers to discuss these issues. The issue of how to access this harder to reach group in research of this kind may require some novel and/ or innovative approaches.</p>

<p>Part 3: Lay language progress report</p>
<p>Please summarise in one sentence the major outcome of the research.</p> <p>In this research, we explored what the peers of young people with diabetes know about the condition and found that responses and attitudes to diabetes in the school environment differ quite considerably.</p>
<p>Please describe the progress of the research in lay language.</p> <p>Peer relations are of increasing importance to young people who spend more time outside their home environment and look towards peers for information on behavioural norms. Achieving optimal self-management of diabetes can be particularly challenging for adolescents, and relationships with others can impact on this. The evidence that other people are important for young people with diabetes in terms of both condition management and other psychosocial outcomes comes largely from studies looking at adolescents in their family setting. Whilst it is recognised that peers are likely to be important in this respect, little research has been undertaken in this area, especially looking at what peers themselves think about the condition and their responses to it. In this research, we used well-established in-depth qualitative research methods (interviews and focus groups) to explore peer beliefs and attitudes towards diabetes from the perspectives of both young people with diabetes and their peers. We interviewed 10 young people with diabetes and a close friend they nominated to take part in the research with them. We also conducted three focus groups with secondary school pupils with no necessary prior knowledge of diabetes. In the focus groups, we used short realistic descriptions (vignettes) of young people with diabetes to facilitate discussion – these vignettes were developed using ideas taken from our interviews with young people with diabetes and their friends and with help from young people on our project steering group. We also piloted some educational materials about diabetes with our focus group participants which we again developed with the help of our steering group and research interview participants as well as useful feedback from a parent of a young person with diabetes.</p> <p>We found that there were significant differences reported in the support offered in schools to young people with diabetes. Those young people with diabetes we spoke to who reported that they were well supported at school by teaching staff seemed to be more comfortable in dealing with their condition, and more open with regards to their condition and its management with their friends and peers. Overall, our</p>

research participants suggested that there was a need for greater awareness of diabetes and for more education about the condition in schools. Participants suggested that this would help normalise the condition and that young people with the condition would thus be less likely to be the focus of unwanted attention. The educational materials we piloted with our focus groups in secondary school settings were well-received and easily graspable by our participants. Findings from this study suggest that more education about diabetes amongst young people is needed, but also encouragingly that this would be welcomed by young people themselves. We hope to use this work to develop a larger scale project to increase awareness of diabetes in school settings amongst both pupils and teaching staff.

Part 4: Future Research
Please describe your future plans based on the outcomes of this research.
<p>We are currently writing up two separate papers based on this research for submission to academic journals in the next three months, and will be making a submission to present the research findings at an international conference in 2015.</p> <p>We are very keen to develop a further grant proposal to advance this work (see section below for more detail).</p> <p>We also plan to reflect further on how we can best develop novel and/ or innovative approaches to recruit harder to reach groups in future research and how we can make these compatible with the requirements of NHS research ethics regulations. Initial ideas include finding ways to approach and make more informal contact with potential participants prior to formal recruitment, and setting up a project recruitment webpage with contributions from other young people who have participated in research (we found the contributions of the young people on our steering group very helpful throughout this work, and would be keen to develop this aspect of our research planning and management further in future research). Providing some sort of recompense for participation in research interviews (we recompensed the young people who participated in our advisory group but did not recompense those who participated in the research) might also assist recruitment in future work and would acknowledge the expertise through experience of the participants more fully and appropriately.</p>
Has the research led (or do you expect the research to lead) to other successful or pending grant applications? If yes, please provide details below.
<p>We hope to now go on to write and submit further grant applications based on this exploratory work. Based on this work, and on other recent research (e.g. Kime and Carlin, 2012), there would seem to be a definite need to improve and standardise school policies in relation to diabetes management. Given the reported importance of teaching staff responses in relation to diabetes management, we envisage a programme which would begin with a stage in which sessions with teaching staff could then feed into a school based programme. We would hope to incorporate those figures identified as key by our participants in such research including diabetes nurses, school nurses and older expert peer educators. Our research suggests that importantly school characteristics and demographics would need to be taken into account in such work. The timing of any programme would also need to be considered – responses from our participants in this research suggest that the first year of high school (a slightly younger age group than our participants) is an important period of transition and might be a good time to consider this.</p>
Has the research led to other academic or industrial collaborations? If yes, please provide details below.
<p>Not as yet.</p>

Part 5: Outputs and outcomes
Please list all publications that have arisen from this grant to date, including any that are currently in press. If possible please send a copy of publications with this report.
None currently. Two academic papers based on the results of this work are currently being written for submission to peer review journals and will be forwarded onto Diabetes UK if accepted for publication.
Please list all oral and poster presentations that have arisen from this grant to date, including any that are currently submitted. If possible please send a copy of the abstracts with this report.
'Young people with diabetes and their peers'. Poster accepted for presentation at the Division of Health Psychology Conference, British Psychological Society, in York – September 2014.
Has the research led to any commercial or potential commercial exploitations to date? If yes, please describe the nature of this and if patents have been filed please give details.
No.

Appendices

- (i) Template from stage 1 (interviews)
- (ii) Template from stage 2 (focus groups)
- (iii) Table 1: participant details from stage 1 (interviews)
- (iv) Table 2: participant details from stage 2 (focus groups)
- (v) Lesson materials
- (vi) Advertising materials – project recruitment
- (vii) References cited in report

(i) Template from stage 1 (interviews)

1. Beliefs about diabetes

1.1 Patient beliefs about diabetes

- 1.1.1 Specific and informed
- 1.1.2 Symptoms associated with diabetes
- 1.1.3 Vagaries
 - 1.1.3.1 *Uninformed about diabetes prior to diagnosis*

1.2 Friends' beliefs about diabetes

- 1.2.1 Specific beliefs/ knowledge around condition
 - 1.2.1.1 *Two types*
 - 1.2.1.2 *Injections*
 - 1.2.1.3 *Glucose/ sugar – needs balancing out*
- 1.2.2 Friends' aware of condition but vague on specifics
 - 1.2.2.1 *Peer knowledge of diabetes provides patient with sense of security*
(Patients seem to assume friends know more than they actually do?)
- 1.2.3 Patient discussion with peers/ friends
 - 1.2.3.1 *Only close friends know*

1.3 Others' beliefs about diabetes

- 1.3.1 Ignorance
- 1.3.2 Misconceptions

2. Responses to diabetes

2.1 Patient responses

- 2.1.1 To diagnosis
 - 2.1.1.2 *Uninformed about diabetes prior to diagnosis*
- 2.1.2 Management
 - 2.1.2.1 *Isolation/ solitude related to necessary management behaviours*
 - 2.1.2.2 *Change in management as get older*
 - 2.1.2.3 *Food*
 - 2.1.2.4 *Pump*
 - 2.1.2.5 *No social impact*
 - 2.1.2.6 *Become routine*
 - 2.1.2.7 *Hypothetical responses – self/ other comparisons*
- 2.1.3 Privileges
 - 2.1.3.1 *Using to own advantage*
- 2.1.4 Openness – extent to which talk about diabetes freely with others
- 2.1.5 Emotional responses

2.2 Friends' responses

- 2.2.1 Responding to negative patient mood attributed to condition
- 2.2.2 Providing company/ support through presence
- 2.2.3 Providing reminders to treat
- 2.2.4 Benefits of supporting patient
- 2.2.5 Defending patient
- 2.2.6 To diagnosis
 - 2.2.6.1 *Fearful initially*
 - 2.2.6.2 *Accepting*
- 2.2.7 Worrying about patient – (over?)protective
 - 2.2.7.1 *Relational issues*
- 2.2.8 Makes no difference
- 2.2.9 Wanting to try out
- 2.2.10 Emergency response
- 2.2.11 Practical management assistance

2.3 Others' responses

- 2.3.1 Standing out (identity as a teen with diabetes)
 - 2.3.1.1 *Staring*
 - 2.3.1.1.1 *People who know about diabetes less likely to stare (which is why more education about condition would be welcomed)*
 - 2.3.1.2 *Squeamish*
 - 2.3.1.3 *Curious*
- 2.3.2 School
 - 2.3.2.1 *Responses of teachers*
 - 2.3.2.1.1 *School nurse*
 - 2.3.2.2 *Patient as expert (rather than teacher)*
- 2.3.3 Pragmatic responses to diabetes

3. Participant recommendations for diabetes education in schools

3.1 Peer educators

- 3.1.1. Examples of peer support

3.2 Diabetes education in schools

- 3.2.1 Part of science curriculum
- 3.2.2 Part of PSHCE curriculum
- 3.2.3 Current standards

(ii) Template from stage 2 (focus groups)

1. Beliefs about/ knowledge of diabetes
 - 1.1 Two types
 - 1.2 Sugar
 - 1.2.1 High/ low
 - 1.3 Management
 - 1.4 Consequences
 - 1.5 Symptoms
 - 1.5.1 Energy
 - 1.6 Personal experiences of diabetes
2. Standing out? Diabetes in classroom settings
 - 2.1 Potential peer reactions
 - 2.1.1 Negative peer responses
 - 2.1.2 Judgements
 - 2.1.2.1 Responsibility of patient to conceal diabetes
 - 2.1.3 Normalisation/ acceptance
 - 2.1.4 Fearful of doing or saying the 'wrong thing'
 - 2.2. Disclosure/ information required
 - 2.2.1 Patient disclosure
 - 2.2.2 School/ teacher information
3. Perceived patient emotional responses to diabetes
 - 3.1 Frustration (due to persisting nature)
 - 3.2 Feeling embarrassed because of being different
 - 3.2.1 Don't want to acknowledge/ talk about it
4. Developing independence with diabetes
 - 3.1 Being watched/ overprotected
 - 3.2 Missing out

(iii) Table 1: participant details from stage 1 (interviews)

[Note: all names are pseudonyms]

	Gender	Patient name	Patient age	Friend name	Friend age
Dyad 1	Female	Grace	13	Ruby	13
Dyad 2	Female	Lily	14	Amy	14
Dyad 3	Female	Jade	15	Milly	14
Dyad 4	Female	Ali	13	Beth	13
Dyad 5	Female	Paige	16	Keira	15
Dyad 6	Female	Danielle	16	Lola	16
Dyad 7	Female	Sally	13	Bella	13
Dyad 8	Male	Robert	16	Simon	15
Dyad 9	Male	Aaron	15	Gary	15
Dyad 10	Male	Alfie	14	Joe	14

(iv) Table 2: participant details from stage 2 (focus groups)

Focus group 1	4 participants – 2 male; 2 female. Year 9 class (all aged 14 years)
Focus group 2	6 participants – 1 male; 5 female. Year 9 class (all aged 14 years)
Focus group 3	5 participants. Mixed group of years 8 and 9. Participant 1: Female, year 8, age 12. Participant 2: Male, year 8, age 12. Participant 3: Male, year 8, age 13. Participant 4: Female, year 9, age 13. Participant 5: Male, year 9, age 13.

(v) Lesson materials

Diabetes workshop

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Session plan

- ▶ What do you know already?
- ▶ Some examples and stories – what would you do?
- ▶ Diabetes – some basic information and myth busting

What do you know already?

- ▶ Write down **three** words that come into your mind when you think about diabetes



Mia

- ▶ Mia is 11 years old and was diagnosed with Type 1 diabetes when she was 9. She has just started in her first year at high school. She has noticed that other pupils are staring and whispering when she tests her blood glucose levels in class. It is making her feel really uncomfortable and she is not sure what to do.

Liam

- ▶ Liam is 14 and was diagnosed with type 1 diabetes six months ago. His form are going on a school trip tomorrow and the teacher has told the form that no-one is allowed to bring any sweets because it isn't fair on Liam.

Sam and Joe

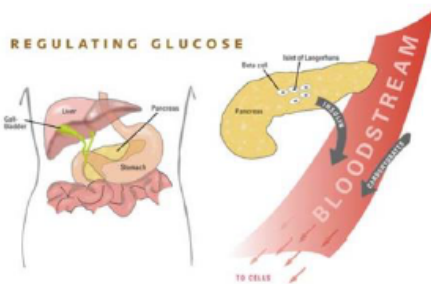
- ▶ Sam is 13 years old and wants to invite his friend Joe for a sleepover. Joe is also 13, and has type 1 diabetes. Sam isn't sure if Joe will be able to be come for a sleepover because of his diabetes.

Susie

- ▶ Susie is 15 and has type 1 diabetes. She was diagnosed with type 1 diabetes in year 7 and at first she had really good control of it, but more recently she's found her diabetes harder to control. Her mum has been talking to her a lot about how important it is to manage her diabetes. Susie just wants to be like the rest of her friends and she doesn't want to talk about her diabetes with anyone.

Some important terms – Glucose, carbs and insulin

Sugars in the food we eat are commonly known as **carbohydrates**. The simplest form of carbohydrate is **glucose**. Our bodies need a particular hormone called **insulin** to turn glucose into energy. Insulin is produced in the **pancreas**.



So – what is diabetes?

- ▶ Diabetes is a lifelong condition where the body cannot regulate glucose levels in the blood.
- ▶ Too much glucose stays in the blood stream and isn't converted to energy.

Type 1 diabetes (T1D)

- ▶ About 20,000 children in the UK have T1D. It is most commonly diagnosed in childhood
- ▶ It can happen to anyone – it's not caused by anything the person with T1D did or didn't do
- ▶ T1D can be controlled and managed, but there is currently no cure. It has a life long impact.

Managing type 1 diabetes (1)

- ▶ A person with T1D will need to test their blood sugar several times a day, keep tabs on what they eat and give themselves insulin.
- ▶ Poor diabetes control can lead to being seriously ill.

Managing type 1 diabetes

- ▶ Blood glucose levels need to be regularly monitored.
- ▶ Insulin can be administered through insulin injections or pump infusions – these are required every day.



Hyperglycaemia

- ▶ **Hypers** (hyperglycaemia) happen when blood glucose levels go too **high**.
- ▶ **Symptoms include:** increased thirst; passing urine more frequently; headaches; lethargy; abdominal pain.

Hypoglycaemia

- ▶ **Hypos** (hypoglycaemia) happen when blood glucose levels go too **low**.
- ▶ **Symptoms include:** feeling shaky; sweating; hunger; tiredness; blurred vision; lack of concentration; headaches; feeling tearful, 'stroppy' or moody; going pale.

Myth busting



True or false?

- ▶ You get type 1 diabetes because you're overweight

True or false?

- ▶ You can develop type 1 diabetes by eating too many sweet and sugary foods

True or false?

- ▶ If you have type 1 diabetes, you can't join in PE lessons or do sports



True or false?

- ▶ Only children get type 1 diabetes



True or false?

- ▶ You can grow out of type 1 diabetes



True or false?

- ▶ With type 1 diabetes, you can't have any sweets, chocolate or anything sugary.



True or false?

- ▶ Taking insulin cures type 1 diabetes



Finally ...

- ▶ A young person with diabetes might feel isolated, alone and different.
- ▶ They may not always want to talk about their diabetes, but if and when they do, you can really help by listening and offering your support.
- ▶ As a friend, your understanding and acceptance is really important. The more you know and understand about diabetes, the less self-conscious and alone your friend is likely to feel – and you could really help them too.



- ▶ If you want to know more, the charity Diabetes UK has a great website which is an excellent source of information – they also have a special section for teenagers:
<https://www.diabetes.org.uk/Guide-to-diabetes/My-life/Teens/>
- ▶ And... THANK YOU VERY MUCH FOR COMING TODAY! I really appreciate your time and your help ☺



Are you aged 13 to 16?
You, your friends, your diabetes.
What's YOUR story?

**What do you think other people
your age think about diabetes?**
Are they supportive?
Do your friends understand?

You have lots of **valuable experience** that it would be really useful for us to know about, and which we hope could **help other young people** with diabetes in the future.

Please **GET IN TOUCH** and tell us your story!

Jo Brooks

CALL: **01484 472546**

TEXT: **07950 836362**

EMAIL: **J.M.Brooks@hud.ac.uk**

The Leeds Teaching Hospitals **NHS**

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Diabetes
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