A qualitative interview study of people living with well controlled Type 1 diabetes.

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Abstract

Objective: While many people with Type 1 diabetes find it difficult to achieve recommended blood glucose levels, a minority do achieve good control. Our study was conceived by patient and public (PP) partners and sought to learn about experiences of people living with well controlled diabetes.

Design: A collaboration between academic health psychologists and five PP partners with experience of diabetes, who were trained to conduct and analyse semi-structured interviews. Fifteen adults with well-controlled Type 1 diabetes were interviewed about the history of their diabetes and their current self-management practices. Interviews were subjected to inductive thematic analysis.

Results: Eight sub-themes were arranged into two overarching themes, "facing up to diabetes" and "balance leads to freedom." Participants described a process of acceptance and mastery of diabetes, and talked about how they gained a deeper understanding of bodily processes through trial and error.

Conclusion: Based on the experiences of people with well-controlled Type 1 diabetes, interventions for people with this condition should encourage acceptance of the diagnosis and increasing confidence to experiment with behaviours (trial and error) to encourage "mastery" of self-management. The research collaboration described here is an example of best practice for future researchers wanting to actively engage PP partners.

Keywords: Qualitative research, semi-structured interviews, Patient and Public Involvement, thematic analysis, Type 1 diabetes, well-controlled glucose levels.

In people with Type 1 diabetes, maintenance of a blood glucose level as close as possible to the non-diabetic normal reduces the risk of developing complications such as cardiovascular disease, diabetic kidney disease, neuropathy and erectile dysfunction (Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Study Research Group, 2005; Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group et al., 2000). In the UK, guidelines for the management of Type 1 diabetes set target levels for glycated haemoglobin (Hba1c; ≤58 mmol/mol), lipids (cholesterol; <5mmol/L) and blood pressure (≤140/80) (National Institute of Clinical and Health Excellance [NICE], 2015). People living with Type 1 diabetes can reduce their risk of developing complications by meeting these targets (NICE, 2015). This requires them to adhere to a complex self-management regimen. Achieving satisfactory control over blood glucose levels is challenging, as evidenced by the National Diabetes 2015-16 audit data, where only 29.2% of people registered with Type 1 diabetes achieved the NICE glucose control target and 18.1% achieved all three targets (for Hba1c, lipids and blood pressure; NHS Digital, 2017).

While considerable research effort has gone into trying to understand why people do not achieve good control over their diabetes, we know little about the experiences and management practices of the minority who do. In Type 2 diabetes, one study interviewed people with good and poor control and used the data to classify individuals into five patterns of self-management (Savoca, Miller, & Quandt, 2014). Another study, using Leventhal's Common-sense model (Leventhal, Diefenbach and Leventhal, 1992) to inform a qualitative analysis of interview data, illustrated the value of appropriately

supported blood glucose monitoring in achieving understanding of blood glucose levels (Tanenbaum, et al, 2015). To our knowledge, there has been no UK study involving patients with Type 1 diabetes who have good control of their blood glucose levels. This is despite the fact that one of the top 10 James Lind Alliance research priorities for Type 1 diabetes focuses on delineating the characteristics and factors leading to successful self-management (Gadsby, et al., 2012).

We set out to address this research gap by exploring the experiences and self-management practices of people with Type 1 diabetes meeting the National Institute for Clinical and Health Excellence (NICE) targets for HbA1c for the last five years. The aim of the study was to obtain an indication of what people with well-controlled Type 1 diabetes think they are doing to achieve that control.

Background to the study's conception

An important feature of the present study is that the impetus for the research came from a group of people with experience of diabetes. While the value of working with patient and public (PP) partners in research is recognised (Hewlett et al, 2006), to date PP partners have largely been involved in the design of research (Brett et al., 2014; Shippee et al., 2015) and less so as actual researchers. In this study, we trained PP partners to interview participants and then to analyse the interviews in collaboration with academic researchers, reasoning that knowledge and experience held by the PP partners would facilitate both the interview and analysis process.

The PP partners approached the research team after identifying this gap in the literature and, in an initial meeting with the academic researchers, the study aims and design were

agreed. The five PP partners either lived with diabetes, or cared for someone living with diabetes. The academic researchers had experience of qualitative research and of research in diabetes. The PP partners were involved in all aspects of the research from inception through to writing up findings. To learn the necessary skills, PP partners participated in five full-day training sessions (Table 1) designed and delivered by the academic researchers. These sessions were central to the success of the project as in addition to providing training on key research skills, they helped maintain communication as a team and offered support to the PP partners throughout the project (INVOLVE, 2012).

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Aims

At present there is no research describing what people with well-controlled Type 1 diabetes perceive to be influential factors in achieving good control, nor their views on important self-management behaviours and practices. Our study represents a starting point in this understanding and may eventually inform structured education programmes. In view of the lack of information about the experiences of people who manage Type 1 diabetes well, we chose an exploratory qualitative approach to gain some insight into participants' experience of controlling their blood glucose levels. In particular, we explored their reported use of self-management methods, techniques or behaviours, and factors supporting them in controlling their blood glucose levels.

Methods

The study was approved by the University of Manchester Research Ethics Committee (reference 15030). This was an exploratory qualitative study, taking a subtle realist approach. This perspective holds that an external reality exists outside of an individual's subjective experience (Duncan & Nicol, 2004), but recognises we perceive the world through our own unique viewpoint (Hammersley, 1992).

Participants and Recruitment

Adults aged 18 and over, able to converse in English, living with well controlled Type 1 diabetes as defined using the NICE targets (NICE 2015 guidelines) were recruited. We excluded those using an insulin pump as we were interested in the experiences of those achieving good control via their self-management techniques alone. No limitation was set for age at diagnosis in order to obtain a wide range of experiences, but participants had to have had a Type 1 diagnosis for at least 10 years and report being well-controlled for the last five years. We set out to recruit 15 participants. An advert was posted in Diabetes UK's magazine 'Balance' (during April-May 2015). Seventy-five participants emailed the research team to volunteer and the first 27 of these were screened by two authors (*** and ***) to ensure they met the study criteria (on the basis of their self-report). Of these, eligible participants were sent further details of the study and on receipt of a signed consent form, the first 15 participants whose availability matched that of a PP partner were allocated to a PP partner for interview.'

Data collection

Demographic details related to the inclusion criteria were gathered; additional demographic information was not collected. A topic guide for the interviews was devised by the researchers and PP partners based on previous literature and personal experience. The topic guide was semi-structured, with opening questions in four sections, each supported with suggested probe questions (see examples in Table 2). Telephone interviews were conducted in April-July 2015 by the PP partners. These were audio recorded and transcribed. The participants were told that the interviewer had 'experience of living with diabetes'. The five PP partners conducted the interviews according to their availability (between 1 and 5 each). After 13 interviews had been conducted analysis was started. To ensure that this was an adequate sample size to summarise the experiences of the sample of people living with well controlled Type 1 diabetes, two more interviews were conducted and analysed in August 2016. No new experiences or ideas were found in these two additional interviews so the authors felt able to cease data collection at this point.

Analysis

Thematic analysis was chosen as a flexible approach capable of summarising the data without losing detail (Braun & Clarke, 2006). The six stages of inductive thematic analysis were followed with themes being identified at a semantic level; *familiarisation, generation of initial codes, searching for themes, reviewing themes, defining and naming themes* and *producing the report*. Stages one to three were conducted on the first thirteen interviews independently by two researchers and four PP partners following training sessions on analysis (Table 1). Themes were agreed at a day-long meeting between the PP partners and researchers (stages four and five) and drafts of a

preliminary analysis were discussed via email (stage six). The final two interviews were then conducted and analysed by three of the authors (two researchers and one PP partner), and it was confirmed that no new ideas had emerged. At this point the analyses were combined and finalised for write up.

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Results

Fifteen people (male = 9 and female = 6), diagnosed with Type 1 diabetes for 10-56 years (mean = 29 years, standard deviation = 15) were interviewed. Interviews lasted for a mean of 35.41 minutes (standard deviation = 14.42, range=13.39-68.17). Two themes, each with four sub-themes, were agreed upon by the research team; illustrative, pseudonymised quotations are provided below to support these themes. Table 3 shows how each sub-theme relates to barriers or facilitators for good control and makes suggestions as to how the analysis may inform future intervention design and the delivery of care.

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Theme 1 – 'Facing up to living with Type 1 diabetes'

Participants discussed their personal journey from being diagnosed with Type 1 diabetes through to their current position of having well controlled diabetes. This emphasised the importance of accepting (facing up to the diagnosis) and viewing Type 1 diabetes as part of their daily life. Four sub-themes contributed to this journey; *i). 'acceptance of condition', ii). 'fear of complications acting as a motivator', iii). 'information leading to knowledge and understanding'* and *iv). 'personal challenge'.*

The first sub-theme *'acceptance of condition'* relates to the time around initial diagnosis, described as a *'grieving'* period by several participants who saw Type 1 diabetes at this timepoint as a medical condition that would control their life. It was only once they accepted they could have control over the condition that they accepted it and moved on to good levels of control. The manner of the diagnosis was important as several participants were originally misdiagnosed with Type 2 diabetes and, thus, found the process of accepting and having control over the final diagnosis to be complex. Likewise, the age at diagnosis was a contributing factor to the process of acceptance as those who had been diagnosed as teenagers and young adults reported finding it hard at first to see how their life as a young adult would not be controlled by Type 1 diabetes.

> *'And it's just, it is a necessary burden of life'* (John)
>
> *'…my GP was of the opinion that it didn't matter what type you were, it was how you treated it that mattered… So I took his word for it but we have battled over quite some time after that'* (Sylvia)
>
> *'Well I was in my 20s…drinking and stuff like that, not really taking good care of myself and my diabetes it was well down on my list of priorities'* (Michelle).

'Fear of complications acting as a motivator' was the second sub-theme. Most participants mentioned at least one complication that can result from poorly managed diabetes as something they personally feared. In all cases, this fear led them to strive to avoid complications by achieving good control. Fear of complications was, in many cases accompanied by a desire to live a healthy life, which acted as a positive motivator. There were different accounts of when and how much information participants were told

about complications by health care professionals. Learning about other people with complications was mentioned as a strong motivating factor with many participants seeking this information. All participants felt that knowledge about possible complications was essential to help people avoid them.

> *'I'm a coward, I do not want to lose my sight, I do not want to lose a limb, I do not want it to affect me anymore that it already has'* (Tom)

> *'I don't think it was ever explained to me what these complications were but you use it as a big, scary word, complications is a bad word, something to avoid'* (Catherine)

> *'…most of the people I see in hospital with diabetes they are just extremely badly controlled … that might be me rationalizing it or trying to say I am controlled so I will therefore not be affected'* (Alex)

Throughout the interviews, the provision and receipt of information was discussed, with examples given and the pathway to knowledge outlined. This relates to the third sub-theme, *'information leading to knowledge and understanding'.* Participants reported the variable quality of information they self-sourced and received from specialist courses (e.g., DAFNE), health professionals, friends and family. In several cases, information from health care professionals was not regarded as useful for various reasons, including timing and advice not being tailored to their personal needs. There were also some examples of incorrect or incomplete information being given and participants not feeling listened to. Many believed they were more expert than some health care professionals, who they felt did not have a good understanding about the complexities of living with Type 1 diabetes. This was also highlighted in relation to

specialist courses, where mixed reports of perceived usefulness were given; some participants felt they knew more than the course leader about Type 1 diabetes and others reported learning new information. Participants tended to be self-taught and to have gained their knowledge of Type 1 diabetes from various sources including the internet. Some explained that they had to ask several times or wait a long time (e.g. Sylvia waited *'12 years'*) to be referred to a specialist course and several were not offered one. Hence, they were often active and assertive in seeking out information and advice that met their needs and helped them to understand how they could live a *'normal'* life in which they controlled diabetes and not the other way around. They favoured learning from their peers and felt that newly diagnosed patients would value meeting others living with well-controlled Type 1 diabetes.

> *'I remember talking to my GP about complications, you know once I was diagnosed of course I was on internet straight away almost instantly but then you can get all the horror stories can't you'* (Sylvia)
>
> *'They need to talk to other people that have got it… sharing with the others that's so useful. The discussion times through the course and coffee times and afterwards and so on are so important'* (Tom)

The final sub-theme described the process of facing up to Type 1 diabetes as a *'personal challenge'* and a journey in which they had to accept the diagnosis, living their life with Type 1 diabetes as something under their control. Significant others (e.g., family) were recognised as contributing to this journey in both a positive and negative manner. Participants involved significant others to varying degrees, with some relying on family and friends for emotional and instrumental support (e.g., cooking suitable food), whilst

others did not share such responsibility (e.g., not disclosing their diagnosis). However, relying too much on others and not accepting it as a personal challenge was described as slowing down the process of achieving good control.

> *'…it is just the paraphernalia, carrying stuff around and sometimes having to carry extra stuff around like when you go on holiday. You have to have duplicates and put them in somebody's else's bag'* (Roy)
>
> *'I think it's up to the individual. If you rely too much on other people I don't think you're gonna make it'* (Harry).

Theme 2 – 'Balance leads to freedom'

Theme 1 illustrated that all the participants wanted to lead a 'normal' life in which they controlled Type 1 diabetes, rather than it controlling them. This entailed striving to achieve a good balance in their lives, in relation to diet, physical activity, insulin and blood glucose. Learning to balance their lifestyle behaviours and socio-environmental factors gave participants a sense of freedom from feeling controlled by Type 1 diabetes. Four sub-themes help us to understand how participants achieved balance and thus freedom: i). *'frequent monitoring', ii). 'understanding body through trial and error', iii). 'role of others'* and *iv). 'confidence to be flexible'.*

The first sub-theme of *'frequent monitoring'* was discussed in detail in all interviews. The participants carried out regular personal blood glucose checks and obtained regular HbA1c checks from health professionals. This enabled them to have a clear understanding of their blood glucose levels over time and in relation to lifestyle behaviours and socio-environmental factors. In addition to frequent monitoring of their

blood glucose levels, all participants reported examples of careful record keeping, with many using their records to see patterns in their blood glucose levels and their lifestyle behaviours (e.g., physical activity) and socio-environmental factors (e.g., weather). This furthered their understanding of the relationships between food intake, physical activity, insulin administration and glucose levels. The ways in which participants kept records differed; some had paper versions, whilst others employed technology (e.g., smart phones apps.). The types of blood glucose meters used by participants also varied, with many reporting several instances of changing meters to find one that suited them, and some reporting difficulties in getting certain blood glucose meters or resources (e.g. testing strips).

> *'… I want to continue to live a normal life and I need to be healthy so I make sure that I check my blood sugars five or six times a day'* (Michelle)

> *'…this morning I did my 30 lengths and tried to do a few more but I thought oh I've run out of steam and I got back to the changing room and I thought I do a test now and I was 4.2 and I thought well, that's why'* (Catherine)

> *'For me, the breakthrough, really was when I began testing regularly with small blood glucose meter'* (Roy)

All participants said their ability to balance and thus control their glucose levels was part of an ongoing learning experience that helped them, through processes of *'trial and error'*, to understand their body. This second sub-theme of *'understanding body through trial and error'* relates back to information they received or assessed, which they said was most useful when obtained via a process of self-directed learning. Participants gave examples of when they had experimented (both successfully and unsuccessfully) with

food, physical activity and insulin (timing and doses) to further understanding of their blood glucose levels and how their body worked. At the time of the interview, they all felt they understood their body and could, therefore, balance their blood glucose levels within a 'normal' life. However, they acknowledged that this learning process had taken them many years to achieve and was ongoing as things frequently changed. In relation to this sub-theme, several socio-environmental determinants of blood glucose levels (e.g., infection and mood) were mentioned, and eating and physical activity were the two main lifestyle behaviours discussed.

> *'I try to balance my regular exercise with my insulin intake, with my food … after exercise I can quite confidently predict what my body is going to do and the endorphins and helps maintain that control'* (Richard)
>
> *'…once allowed to go low at the hospital to understand what a hypo felt like. I think maybe a few more controlled environments so you can experience to go high, one bar of chocolate to show the impact on you.'*
> (Lee)

The third sub-theme, the *'role of others',* emphasised how significant others often helped participants achieve and maintain the balance in their lives, particularly in relation to healthy eating. Family members, especially the main cook in the family, played a vital role. Those diagnosed as children relied on their parents in terms of food provided and decisions about insulin administration, whereas spouses were essential support sources later in life. On the other hand, the contribution of health professionals was mixed, with many participants discussing less than helpful interactions.

> *'It's a holistic thing, an all-round thing, my family have been incredible, so*
>
> *it is not healthcare professionals'* (Catherine)

In the final sub-theme, *'confidence to be flexible',* several participants said their understanding of how their body worked meant that their daily insulin injection practices often deviated from what they had originally been advised (usually several years ago) or recommended to do by a health professional. However, a level of confidence was required to be flexible and trust their own instincts; this stemmed from participants' belief that they were in a better position to understand their own body than health professionals and that "breaking rules" meant they had better control and could lead a more 'normal' life. The timing of the diagnosis was important here, as some participants had been diagnosed before testing technology allowed them to understand how their bodies worked, and when dietary regimes were stricter.

> *'So I have educated myself so I have just never felt the need to go and ask*
>
> *someone else about it…I understand things far better than my GP does…*
>
> *I've got myself a sort of average amount [of insulin] that I expect to take.*
>
> *If I am going out and wanting to stuff my face then I'll take a bit more'*
>
> (Richard)
>
> *'I can look at something now and work out, sort out in my head, how much*
>
> *to inject from it but I know what I might inject may be different to someone*
>
> *else you need your own personal knowledge…'* (Emma)

Discussion and Conclusion

Discussion

This is the first study to explore the experiences of people who report living with well controlled Type 1 diabetes. It involved a unique collaboration between health psychologists and PP partners. The sample was purposively selected to gain insight into self-management techniques, behaviours and other factors regarded as influential by this sample. We cannot know whether the self-management techniques and views expressed by our participants are unique to this well controlled sample; nevertheless, our findings reveal an interesting journey whereby glucose control was achieved once diabetes was accepted as part of life, and a personal commitment had been made to controlling it. The journey towards good control involved experimentation, support, knowledge seeking and confidence-building, resulting in a sense of confidence in balancing their lifestyle and socio-environmental factors. There are similarities between these accounts and those of people living with well controlled Type 2 diabetes (Tanenbaum, et al 2015). Both samples demonstrated the important role of experimentation in their self-management of blood glucose levels, which led them to develop a deeper understanding of how they could control diabetes and the influence of lifestyle behaviours on it. Our participants shared further characteristics in common with the 'committed' group in Savoca's article about Type 2 diabetes (Savoca, Miller & Quandt, 2004), such as appreciating the risk of complications and viewing control as a personal responsibility. Finally, "strategic non-compliance" was a term coined by Campbell and colleagues (Campbell et al., 2013) to summarise the tendency of people living with diabetes to have selective attention regarding medical advice. This tallies with our finding that participants needed to develop the confidence to be flexible with the use of self-management techniques and lifestyle behaviours to control their diabetes.

Participants expressed a desire to learn from others but emphasised the need to take responsibility for their own actions in order to control their diabetes.

Given the collaborative approach taken in this study there are a few methodological impacts to consider. Interviews were conducted by the PP partners, and there was a strong rapport between the interviewee and interviewer. There was the possibility that the interview direction may, at times, have been influenced by the personal interests and experiences of the interviewer, although the training sessions provided prior to data collection warned against this. The PP partners took part in the data analysis. The academic researchers paid particular attention to ensure that inductive analysis was led by the data and not the PP partners' personal views or experiences. The sample may not be representative of the population of people living with Type 1 diabetes, as it was drawn from responders to our research advert in one magazine who were then selected on the basis of eligibility and availability. We are unsure of the number of people who read the study advert and acknowledge that ours is a self-selected sample and participants may have had a particular story to tell. We are aware that factors other than self-management techniques and practices, such as genetic and physiological factors may contribute to differences in diabetes control. However, this study provides an insight into and an opening for discussion about the experiences reported by people living with well controlled diabetes, allowing suggestions for future research and potential implications for care to be made, thereby addressing a current gap in the literature.

Implications

Findings have implications for the clinical management of Type 1 diabetes and for future research. Table 3 breaks down the themes into perceived barriers and facilitators for achieving control which can be used to inform future care and interventions.

Helping people to accept diabetes as part of their lives and their personal responsibility for control of it seems to be key. Attention needs to be paid to the way in which the diagnosis is conveyed to people; good quality information must be delivered in a timely manner and opportunities provided for patients to integrate that information into their own personal understanding of diabetes through the experience of managing it. Participants in the current study believed that expert patients, who have achieved some mastery over blood glucose control, should be involved in the delivery of information and education. People with Type 1 diabetes need support to 'master' diabetes by developing a deep understanding of a flexible self-management plan that is compatible with their lifestyle choices. Significant others should be included in support plans as the current study identified them as highly influential to the process of mastery of diabetes. However, the emphasis of responsibility must reside with the person living with Type 1 diabetes for them to actively take control. This echoes results from previous research on the importance of social support in the management of long-term conditions (Koch, Wakefield, & Wakefield, 2015). The points referred to above should be included in training packages for diabetes nurses who deliver structured educational programmes (Kar, 2015).

Our findings present the meaning that this sample gave to the role of their self-management techniques, behaviours and influential factors affecting control of

diabetes. Further research is needed to develop and test theory-based interventions.

However, some key constructs were suggested in the current study. In particular, the notion of self-efficacy, or the belief in one's ability to carry out a particular behaviour appeared to be important. Participants developed a sense of personal control and self-efficacy about their diabetes through the mastery of necessary skills and knowledge (Bandura, 1998). They recounted mastery experiences in relation to using their insulin and regulating socio-environmental factors and lifestyle behaviours (e.g., eating and physical activity). Alongside this, vicarious experience is another way that Bandura reports that self-efficacy is enhanced. This can be seen in the interview transcripts in relation to participants viewing others with good control as role models. Also of importance is outcome expectations as a driving force alongside self-efficacy when changing behaviour (Bandura, 1998). Participants in the current study discussed increased motivation to control their Type 1 diabetes due to a fear of complications and referred to the impact of seeing others with such difficulties. Behaviour change interventions that engender self-efficacy (through processes such as mastery and vicarious experience) and consider the role of outcome expectations (Bandura, 1998) should be explored further. The current study also provides some indication of possible effective behaviour change techniques (BCT) for inclusion in these interventions. For example, 'Behavioural Experiments [4.4]' is described in the Behaviour Change Techniques Taxonomy version 1 (BCTT) as 'Advise on how to identify and test hypotheses about the behaviour, its causes and consequences, by collecting and interpreting data' (Michie et al., 2003). This BCT reflects the learning

through trial and error that was reported in our findings. The use of this BCT in care and structured educational programmes should be examined further.

Our study resulted from a novel collaboration between researchers and PP partners. There were benefits from this approach, such as the constant input from the PP partners improving the quality of the study by acting as a validation method (Guba & Lincoln, 1981). Communicating progress and action plans to the PP group at each stage enabled quality checking of the research, as well as ensuring that the process was fully transparent (Sin, 2010). The involvement of PP partners in grant applications is encouraged by funders (e.g., Research Councils UK, n.d.). Understanding how best to achieve this is something to be encouraged and this paper adds to that knowledge. Actively involving PPI partners can increase transparency of the research process and increased applicability to the target group will improve research quality. However, additional time commitments must be considered when involving PP partners, to develop relationships and to tailor training sessions to meet the needs of the study and individual PP partners. Likewise, the expectations and roles of all the team members must be managed. Table 4 outlines how PP partners were involved at each stage of the research process and summarises challenges and recommendations for future researchers.

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Conclusion

This study provides an insight into self-management techniques used, behaviours and influential factors reported by people living with well controlled Type 1 diabetes. Collaboration between PP partners and academic researchers was successful in developing a novel understanding of this topic. Acceptance of their diagnosis and the ability to 'master' self-management are key components to control and their inclusion in interventions should be examined. Interventions for people with Type 1 diabetes may benefit from the experience of those who have well controlled diabetes. In particular, ways to improve diagnosis acceptance and the ability to 'master' self-management should be explored. This collaboration is an example of best practice for future researchers wanting to actively engage PP partners.'

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Table 1. The five training sessions for the PP partners.

Objectives of session	Resources
Session 1: Study design 1 -Finalise study design – discuss recruitment -Develop study materials (invitation / participant information sheet / consent form / topic guide).	-Powerpoint presentation -Handouts – study materials.
Session 2: Study design 2 -Recap: Study objectives and previous training session -Provide an update on the study progress -Provide an introduction to interviews -Finalise the topic guide for the interviews -Make an action plan to move forward.	-Powerpoint presentation -Handouts – study materials.
Session 3: Interview practice and data analysis overview -Recap: Study objectives and previous two training sessions -Provide an update on the study progress -Agree on the recruitment strategy, data collection and storage process -Opportunity for telephone interview practice -Make an action plan to move forward (e.g., communication via email to arrange interviews).	-Powerpoint presentation -Dictaphones for practice interviews – feedback given by academic researchers -Interview topic guide.
Session 4: Analysis of data.	-Powerpoint presentation

-Recap: Study objectives and previous three training sessions -Provide an update on the study progress -Provide instruction on how to conduct a thematic analysis -Make an action plan to move forward (e.g., thematic analysis stages one-three).	-Thematic analysis research article [13] -Analysed interview examples.
Session 5: Analysis of data and next steps. -Recap: Study objectives and previous four training sessions -Provide an update on the study progress -Agree on the themes: Individual thematic analysis (stages one-three) presented and discussed -Make an action plan to move forward (e.g., thematic analysis stages four-six, dissemination and future work).	-Powerpoint presentation -Interview transcripts -Flipchart paper and post-it notes for displaying themes.

Table 2. *Interview topic guide*

Sections and questions	Prompts
Diabetes history Tell me about your experiences of managing your diabetes.	Diagnosis? History? Any struggles? Feelings about having diabetes?
Participants' experience of controlling their diabetes What are your thoughts about why you achieve good control of your blood sugars? What guides/drives you?	Explore: Knowledge, skills, support sources, electronic devices, time, settings (e.g. eating out), mood etc.
Management practices What are the main things you do to manage your blood sugars? What skills do people need to help them manage their blood sugars?	Explore: Physical activity, diet, monitoring, reminders, education, knowledge, numeracy etc
Advice for others and additional comments What advice would you give to other people with Type 1 diabetes about managing this condition? Is there anything that we haven't covered already about how you manage your diabetes that you would like to talk about before we finish?	

Table 3. A summary of the barriers and facilitators to good control demonstrated in the sub-themes.

Sub-theme	Barriers to good control	Facilitators to good control
i). Acceptance of condition	Misdiagnosis of diabetes and age at diagnosis.	Take responsibility.
ii). Fear of complications acting as a motivator	Wanting to avoid complications and live a healthy life.	Information about complications and seeing others complications.
iii). Information leading to knowledge and understanding	Timing of information, advice not being tailored to their needs and poor quality information.	Meeting other people living with Type 1 diabetes and self-taught learning.
iv). Personal challenge	Reliance on other people and not self.	Significant others and not wanting to give diabetes a bad name.
i). Frequent monitoring	A lack of access to effective meters / resources.	Knowledge of how to look for patterns in data.
ii).Understanding body through trial and error	Role of socio-environmental factors.	Confidence to experiment with lifestyle behaviours.
iii). Role of others	Negative experience with health professionals.	Positive experiences with others.
iv). Confidence to be flexible	Timing of diagnosis.	Knowledge and understanding of one's body.

Table 4. PP partner involvement (adapted from Greenhalgh**,** Snow, Ryan, Rees, &

Salisbury, 2015).

Information	Challenges	Recommendations
1 – Setting the research question and objectives		
-The research started with PP involvement from the outset. -The objectives of the study were agreed upon at the first meeting to ensure the research was an active partnership and everyone's skills were clear.	-PP partners and academic researchers may have differing motivations for wanting to conduct the research and different study objectives.	-Ensure that your research profile is accessible. -Each member must be honest about their desired outputs. -The motivations for involvement must be discussed so everyone can benefit.
2 – Defining roles and responsibilities		
-A training package of five sessions was designed by the academic researchers to ensure PP partners had the necessary skills required for this qualitative study.	-PP partners can have a range of research skills and knowledge which can make it difficult when designing the content and detail of training packages. -Additional administrative time was required to actively involve the PP partners.	-Do not assume that PP partners are skilled in research and provide training sessions that cover all the necessary skills for the specific research methodology. -Be aware of the added tasks which impact on time when developing studies with PP partners and factor this into the

		timeline when preparing grant applications.
3 – Study design		
-All study materials were designed by the academic researchers and PP partners via face-to-face meetings and email. -PP partners are experts in knowing where people living with diabetes seek information, so their input was vital for recruitment. -Pilot interviews were conducted between the PP partners.	-Additional time was required by the academic researchers to actively involve the PP partners at the planning stages. This took the form of several face-to-face meetings and many email discussions.	-Be aware of the added tasks which impact on time when developing studies with PP partners and factor this into the timeline when preparing grant applications. -Remember to include PP partners in the design of the study materials and sample strategy.
3 – Data collection		
-Interviews were conducted by PP partners following their training. -The participants and the PP partners felt a level of familiarity in the interviews (e.g., *'you know'*), suggesting more open accounts were given.	-PP partners had personal views and were keen to probe topics of interest. -The number of interviews was restricted due to PP	-Communicate the study aims at each stage. -Run interview training to make sure questions are used to probe interviewees. -To maintain transparency, make sure you plan a process for

	partner availability. --- Some PP partners conducted more interviews than others.	checking that the sample size is adequate.
4 – Data analysis		
-PP partners are experts in living with diabetes so their involvement during the data analysis process was essential. Each researcher conducted stages one to three independently and then discussed and agreed upon stages four to six.	-The PP partners had no experience of data analysis so a training session supported their skill development.	-Be flexible as more training sessions may be required to support the development of analysis skills. -Communicate the study aims at each stage. -To be transparent, report the data analysis process clearly.
5 – Write up and dissemination		
-PP partners are experts in knowing where people living with diabetes seek information, so their input ensured impact outside of academia.	-There were differing time expectations for finalising the study findings and preparing a manuscript for publication.	-Outline the peer-review process so that PP partners are aware of the time frame. -Factor in the time required to receive and act on feedback.